# The Life and Times of CE

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The first entry is at the end, so start there.

### **April 28, 2006**

# About raising "different" children

Over the years I have read a number of books about the state of life, society, and personal awareness today. And often times the pictures are very grim. That those quieter days of the past are gone, and we live in a world today that is full of fear and uncertainty, distrust, and lack of honor and principals. And I must admit I am often transported in my mind to see and focus on what is wrong with our society today, not what is right~

But as you have said one only has to look at the sea, mountains, sky, flowers, seasons, and our children to know all that God put on this earth is still there. In place, ready for the taking to lift ourselves up and see, taste, touch and feel, the goodness in life around us.

And we especially should know that miracles are still there for the making and the taking, when we look at our children. Even our most difficult children. Why? Perhaps because after millineum of ignorance our eyes are finally able to see the good in our children with differences. Our minds are searching and finding answers to help these children, because there are answers today. Children who only 20 years ago were considered to be "throw away" kids. Children, teens, and adults that to most of the world had not future, would never fit in, would never be understood. And so they were relegated to institutions, or prisons or jails, or worse the streets. Because no one understood them, no one chose to care for them, and no one cared, because no one knew~

For every negative in this world there is a positive, the world is always finding a balance, if it werent, humankind would not have flourished.

We are perhaps some of the luckiest in this world that we were given the opportunity to turn a life around with our children. Shape, mould and save a human life, that before might have been given up on.

We often feel very overwhelmed and unsure that we are perhaps not the right choice for such and incredible task. To see the good in a child so contrary to everything we were taught. To wrest the conscience, the heart, mind and soul of a child who seemingly has none of these at times.

And yet we do, and we survive lifes challenges, we accept the unpredictability, the unfaireness, the pain, but do not let it stop us, or change our direction. Our hearts, our deep love, our unbending devotion to our kids rises us up and carries us along on a different plain.

I like so many of you, did not sign up for the war that came into my home, the tearing down of my illusions, the cessation of my life and stability that I had clung to, built up, depended on. And I have seen so many people misunerstand how and why I believe in what I am doing, what are my motivations are to hang on so desparately to a child who to the outside eye of opinion, is "wrecking my life".

But once I stepped onto that not so popular, not dependable, not predictable, not safe path, I did not run, I did not turn around, I did not quit.

And in my surprise, I found a revelation, that I was not the "finished" person I thought I was. That I had so many new unexplored parts of myself of who I am, and who I am going to be. And had I not been given the gift of my "different" child, I would never have grown, stretched, expanded as I have.

Thanks for reminding me of how far I have come, what miracles I have been privvy too, and where I find my daily solace. Solace that comes from around the world, from people, Moms, Dads, and family members I have never met, but I treasure, appreciate and love. Because they are there when I needed them. And they amongst few, understand who I am, what I am going through~

## **April 17, 2006**

Mia Well if you like the puking story this one will really make you laugh!! Hope everyone is getting their humor on this morning because I have had quite a laughable few days!! First off, like Leslie, I have felt like crap warmed over! I have had a huge stomach ache that has kept me mostly bent over or in bed in a fetal position. I finally got some meds but they don't work if I try to eat something. So for now, no food!

Yesterday I had a flash to call Mia's job (she just started working at Babies R Us, about one month ago). She had been leaving at 9PM and coming home around 2 PM. She said it was all nightime stocking, and training sessions. So I bought it for a while. She was also going to school, and was getting ready to go to a formal (\$300 dress, \$60 shoes, \$90 earrings!) and I was OK with all of that. I had just been thinking these late night sessions were a bit weird for an 18 year old, but she was being very responsible about everything else and other than fighting off bronchitis was doing alright. But something just didn't sit well with me about this graveyard shift job. So I call information, and get the store number and ask for personelle. I get this guy Mike on the phone and tell him I am Mia Echternach's Mom, and I was wondering how long the graveyard work was going to be going on. He asks me how I was feeling, and I thought that was weird, but said "good, and you?". He told me that I had had a car accident several weeks ago, and apparently had been in a coma for 2 weeks. (ROFLOL)!

He said Mia told him I had just woken up yesterday~ After I laughed my head off I asked him about the "graveyard shift" and he said they had never had one!! Her hours were 10am - 8 or 9PM depending on the day. So I said thanks and hung up. Boy I was really glad I got out of that coma by then!!! I call Mia on her cell phone, and asked her about my car accident and the coma thing, and she was speechless. Then I told her to come home ASAP!!

First of all, all the formal wear is going back! Next she lost her cell phone, and third I was going to take her car away, but Dad overrode that because I havent been feeling well, and she does have to go to school. Found out she has been working for an all night "teen" dance club. No booze or anything just cokes and dancing, but an all night club. She has been doing their PR work for the last month, making \$12 an hour, which is \$6.00 an hour more than Babies R US.

So she thought that was a good idea!! Don't tell parents, lie, twist everything around, get sick because she is up all night, and then suck \$500.00 out of me for a dance. NOT!!! So the old "needs an external brain" thing came into my memory (I was so sad because I thought she was really doing well~) and I thought we really had not been checking up on her enough, keeping track of her and what she was doing, and giving her too long of a leash. She is not ready to be responsible yet. In her own little upside down thinking she thought working the club at night was a good idea because she was getting paid better, but all the other crucial cognitive thinking about the lying, the playing, the using, the manipulating, was right out the window. She of course in her inventive FASD way of thinking managed to turn everything around on us, that we were not good parents, that we didn't trust her, that all of her cousins had done stupid stuff when they were 18, she tried valiantly to turn all of her responsibility over all of this on us. But niether Dad nor I were up for discussion!!!

So here I am, 2 of my little angels that I thought were doing so well, have had the ugly head of FASD raised up again. Impulsivity rules, what comes to mind is what they do, and they have no compunctions about doing really stupid stuff. They just do it, and when they get caught, it is usually our fault.

On a softer note, Lana did apologize in the ER, and she knew immediately when she became coherent enough to talk, that she would lose all of her privileges at the facility. She begged me not to tell them, but with a maturity level of a 9 year old, I knew she would try to hide all of this from them. I called the facility and told them all the gory details (puke and all) and they said bring her back.

So hear we are all with our little wonders, I guess my lesson in all of this is to not be so stupid to not be vigilant, not to expect too much out of them, because they are going to screw up if you are not watching!!!

Oh, and yeah I feel much better after have survived the come!!!! LOLOLOLOL!! You have to give her a little credit though, that was pretty creative lying, sounds like a good episode for a soap opera!!

February 25, 2006

### Some metaphores for dealing with a child with disabiliteis

I again have read everything you ladies wrote to me. Sorry I did not reply earlier. I seem to be having more difficulty 'comming to terms' with the RAD FASD in Jewel then would seem logical. Of course was it Elain that said there is no right way to emotions.

I am not sure if you ever come to terms~ you never in your deepest heart of hearts want to let go of the hopes, wishes and desires. You don't want to let go of the lifeline that was keeping you attached to that boat which personified all the best qualities you saw in Jewel. It's a bit terrifying to let go, to let "all that might have been" float away, to know that you can't save her, you can't make her that perfect person you saw~ So you are left still hanging on, while she tugs, and pitches, and pulls every time she has a meltdown, every time she rages, everytime she doesn't understand even the simplest of things.

I dont want this... ok you can check that one off the stages "of comming to terms," I went through it. If I get a badge saying I went through the "I

dont want this" stage will it be over? "I don't want this" "I never signed up for this" "I never expected this" "I want this to go away" "I want my old life back" are all badges, steps, stages that we go through. And while she seems to be getting worse, going down, you are reluctantly walking up those steps, collecting your unwanted badges, your unfortunate trophies, your undesired awards. And as time goes by and you look behind yourself you realize you are coping, you are learning and you are making progress. Much faster than her progress though. Because you are OK, you are normal, you are wired to be successful, she is not~ What do i want?

I want a clean and orderly house, beautiful happy children, that make the world a better place through their own good choices.... Guesss I can still

have all this. You want to go backwards and recapture what you had before. You want to be in one of those movies where everything turns backwards, and all that was broken is fixed, and all that had fallen down is righted, and everything swirls and swoops and is sucked back up into that perfect time that you were comfortable in. You want that, and yet you are a realist, and so you are stuck. You don't want to go forward because that would mean acceptance of what you don't want, and you can't go backwards, you can't make things the way they were, and you don't know how to make things better now, so you stay stuck, in a molten emotional morass, where nothing will be solid, eveything keeps melting away~ Who says that the world cannot be a better place just because there is chaos. All of history reveals times of chaos before stability. You, we, she are all human, we are all capable of making changes, making things better, organizing that which is disorganized. And truth be told our damaged children are the banners. the beacons, the public announcements that you cannot treat a human being with anger, violence, neglect, abuse, and expect them to blossom and bloom like all the other well tended flowers in the garden. Our hurt children are that one straggly, wiry, wormy, mishappen plant that we spend a little extra time in nurturing it, wondering how to make it perfect. What do we do? It doesn't respond to the extra fertilizer, the watchful watering, the endless pruning. And yet we don't give up on it. Some would pull it up and throw it away, and explain to ourselves it is better to spend our time on those that are doing well, bearing fruit, blooming wildly. And yet, we keep going back to that straggely little life and choose to give it a little extra of our time, with no guarantees that it will survive, and no guarantees that it will be as beautiful, or as verdant, or as breathtaking as the rest in our garden. But as time does, it eventually rewards you. And your efforts, your attention, your care will bear fruit. Perhaps not as lush, as colorful, as abundant, but because of your attention, that sweet, mopey, seemingly worthless little life will branch out, and bud, and then blossom. In it's own way, the little runt of the garden, the one that took the most time, the one you told yourself you should of let it go will grow, and there will be a flowering that you never expected, you never expected to care, you never thought you would care. But you did, and you do, and you realize later that you saved that little scrubby little mite.

As I go through the 'commming to terms' I have a hard time dealing with the mundane everydaystuff of keeping a 'clean and orderly home'. Someone outside looking in would say "why all the trouble. you knew she had 'special needs' when you started this, there is nothing new here." Or they would say "special needs what special needs?" I guess I realise now that one can never really know what another person struggles with in daily life. This part of "coming to terms" is a transforming experience, it is a priorities shift, an emotional paradigm that is passing from one form, state or level to another. Some of those things that were priorities before become not as important. In the life of a damaged child, love, nurturing, support, attention are what they will remember, not the orderliness of the house, the cleanliness of the floors. Why all the trouble? Who knew what she would be like? Who could have guessed the open drain of attention she would be. No one saw it coming, no one~ Raising these children is a challenge few would take, and even fewer would understand. In everyones lifetime at one time or the other we cross paths with someone with a disabled child, someone challenged, or someone

incapacitated. We look, but we look right through them, over them, pass them. We don't really know or care what a completely different life they have than our own. We try to be empathetic, or compassionate, but it is rather shallow because we really don't want to know what their lives are. It is too confusing, too frightening to know. Anyone who has not had a "special needs" child cannot even come close to

understanding their difficulty. Jewel looks, acts, like any other child at the playground. But everything is backwards and upside down in raising this child.

When we bring these children into our lives, these children so difficult, so damaged, so unrelenting in their behaviors, we are somewhat cheated. Our reality is misrepresented, distorted, falsified, because they "look normal". "What could be wrong with this beautiful child". "They don't look like they have a problem in the world". "How could they, they are perfect?" And yet we soon find their disability is "hidden", it lurks beneath that adorable face, that false charm, that adorable personality. Perhaps their disability is the most incidious because no one can see it, so to them it doesn't exist. And we are left looking like liars, or whiners, or pity mongers and yet only we know the truth. We live it, we deal with it, we understand it, we know it, even if the world outside of our lives does not.

Do you think the Lord placed these children with us because he knew we had "special abilities" to help these children with their "special needs".

Because, I can not see how even wonder woman could hold up to the difficulties this causes and I can forsee it causing in the future. Some say God only gives us what we can stand. God knows what you do not. God knows that you are frightened with the prospects of your life with this child, God knows your mixed emotions, your confusion, and even your worst hiddne secret, your hate. God understands that we hate what we can't understand. God sees we cannot relate, that we are angry at our own inability to accept. God knows when we hate ourselves for feeling out of control, robbed of our "other" life, hate a child. Who? We? hate a child, that could never happen and yet it leaches itself out of our thoughts, and strangles us with self hate and self loathing for thinking those thoughts. God knows and understands this is a human condition, and he knows it will pass, and you will find your center, you will begin to find your way.

When I am over whelmed and "just need a break" from it all. I dont care that Jewel needs attention. But if I forget it then she is causing trouble. If she cannot go 5 min without attention, how will I stay sane? May the Lord grant me with these abilities... You know how to find your own balance, and if and when that means walking away from Jewel when you are overwhelmed, you will learn to do it. And do it without self doubt, or guilt. She will still be there when you have found respite, when you feel like you can go back to her with a restfullness that is what you need to keep your sanity, your equalibrium.

Where would I be without you ladies who know and have gone through this. I want to cheat and skim through the chapters of 'comming to terms'. Cant you just tell me the stages I will go through and I take 30 mins out and experience each stage, and get it over with, and get back to a clean house? Jeanine You can cheat~ You can just jump and make the leap, and pass over all the inertia, and hanging on. It's up to you to make that choice, to know when you are there. A lot of the "cheating" comes from our inner self, that says I am a compassionate person who will strive to understand this child, I am empathetic person who will make an effort to appreciate the good in this child, a person who will realize what I need to know. I don't understand now, but I will let the understanding come. We all makes those leaps, sometimes we leap and sometimes we crawl, but we all eventually make it. And a new order will come from your dedication, your tolerance, and your intuition~

### November 29, 2005

# Quick 5 year update to DeDe

Hey Dede, Yeah, I guess FASD is as good a place as any to start on my novelette. I suspected alcohol exposure with Lana pretty early on. The papers we have with the girls state the mother was an alcoholic, was always gone, sometimes for months, would come home pop a kid out and then leave again. Lana and Mia have very similar features. Anya is a total opposite. The social services papers we have on the girls has a couple short reports on the conditions of the house when they would go to check on this family (the neighbors would watch and call them). The father worked about 18 hours a day, there was 7 kids, with 3 older boys all mentally retarded to some degree, a middle daughter (at the time my girls were taken she, Vera, was only 10 years old) and my 3 girls all in a one room house. There were always booze bottles laying around, and on report stated said the "children were drinking from the liquor bottles". When the girls were taken they were 4, 2, and 9 months. Many of you may remember we were adopting Mia and Anya, we knew nothing of Lana, until we made a trip over there. When we found out there was a 12 year old sister living in an orphanage for children with mental retardation (oligrephenia) and mental illnesses, we knew she would not survive to adulthood, so we just said we didn't care what was wrong with her, we would bring her home with her sisters. Getting Lana out of the Hellhole she was in, was part of why our adoption became so difficult. Russia didn't want "mentally defective" children adopted if they had spent long periods of time in the "c" orphanages, they are the worse orphanages, and they don't want people to know what it is like. In any case, I fought, and won and got her out of there. She was a handful from the beginning, tried to run away from us in Moscow, was very aggressive at times, but then the rest of the time she was a sweetheart. When they got here our school district did a psycho assessment on all of my girls with a Russian interpreter, and Lana was IQ' d at 72, Mia and Anya at normal IQ's. Lana was put into special ed, and she did pretty well, she really did and still does love school. I don't think she had more than a couple months of school all total when she was in the bad orphanage, she was there for 7 years. We mostly had problems with her at home. She has always had this split personality. Quite cute and sweet on one side, and then aggressive, assaultive, mouthy (profane) on the other side. But I just dug in and researched my brains out trying understand what was the matter with her. Over the first 2 years she hit me, pushed me, rammed me, so many times she hurt my back and my shoulder. I ended up going into the hospital for a spinal fusion and got e-coli, almost died from that, was there for 4 months, had 6 debridments where they open you up and scrape and hose all of the infection out of you. But I digress. When I finally got home, my business was going down the tubes. I was the owner, head designer, I oversaw everything, the majority of our clients were mine. By the time I got back, everyone had left, and my sister (who did not work for me) had been left holding the bag. nothing had been kept up not even our business insurance. In a twist of fate and irony, God intervened and my Gateway computer monitor caught fire, and burned my store down, also took two other stores with it. With no insurance they went after our house and everything we had. Fortunately all the lab work on the computer came back that it was the computer that caught fire, so everyone went after Gateway. During all of this Lana raged on. And Mia also began showing signs that something was just not right with her. By the time Mia was in the 7th grade she had begun running away, getting involved with the prurient types, becoming extremely hard to handle, we had to lock her in her room at night. She eventually got an FAE/ODD/ADD/bipolar dx. But the good news on her is she is now in the 11th grade, and doing fantastically. So there is hope for some of these kids. By this time the stress was taking it's toll on dh, and he came down in flames when he got fired and was put on un-employment. So here we were living in the OC, on unemployment, with 3 special needs kids, one who was by all accounts dangerous at times. We had to go through 3 different attorneys groups before we finally got one that was

capable of handling our BK, and not getting us evicted. So we managed by the hair of our chinny chin chins to hang on to the house. By then Lana was now raging, melting down, mood swinging, and be assaultive up and down on a daily basis, always with the intermittent little pumpkin face sweetheart munchkin. The first hospitalization they did all the MRI', CAT scans, genetic testing's, blah blah, and they came up with nothing other than the standard bipolar, possible scizo affects, ODD. I told them outright she is alcohol exposed and was probably RAD, and they were so stupid, naive, ignorant, they really didn't' know that much about FASD or attachment disorders. But I was able to get a "possible FAS" on her AXIS diagnosis before she got out. The did the behavioral therapies, group sessions, titrated her meds, saw a psychologist, psychiatrist, behaviorist, and then let her out. That was the beginning of the past 4 years, and it has been about the same ever since with her. I have fought with every placement she has had, getting them up to speed on FASD, RAD, post institutionalization, and got the ball rolling here in our county about these subjects. I also was made director of California Fetal Alcohol Spectrum Organization. We met in Washington DC, this past summer and I met with Diane Feinstein, Barbara Boxer, Duke Cunningham, The Dashchles, Sam Donaldson, and many other senators and legislators about the subject of FASD, to begin legislation's for advocacy, awareness and prevention. FASD is now on the national agenda, the surgeon general made a statement earlier this year that "no alcohol" is safe during pregnancy. Also the terms FAS/FAE/ ARND/ARBD were all synopsized by the surgeon general to be FASD (Fetal Alcohol Spectrum Disorders) So the word is not legitimate. FASD is also now under review for submission to the next DSM. The biggest prevalancy in the US and Canada for FASD is in and around the native communities where alcoholism is multi-generational. On many reservations you have grandparents, parents, and children all with FASD caring for each other. Since alcohol exposed brains and nervous systems are damaged, it stands to reason there is huge problems in family dynamics with these families. Most of the research over the past 35 years that surrounds FASD has been in Universities, clinics and colleges that are in areas where there are also native populations. In the American foster care and adoption community, unless the child is of native heritage there has been systematic denial that kids coming from abusive, neglectful, dysfunctional, alcoholic/drug taking families would have FASD or attachment issues. It's the old head in the sand thing. So parents adopting domestically do not get much support yet, when it comes to the possibility that the child they are adopting might be alcohol exposed. Black children, mixed race, and kids from very poor demographics are becoming the second most likely to be diagnosed and admitted by social services that the child might be alcohol exposed. It's not much different for domestic adoptive parents than it is for international parents, you have to get your child and then begin the process of untangling what all of their issues are. But you can almost bet if the birth mother was an alcoholic or used drugs the child was probably exposed.

### November 15, 2005

### I swallowed a battery

"Ok, Mom, I am changing my behaviors. I won't swallow anything ever again." This she says over the phone, with her little adolescent voice, and her impassioned plea that she finally has control over her behavior. This as she currently has a battery making its way through her digestive tract, that she took out of the facilities TV remote control device, and swallowed it. She who has a pathological problem with swallowing even the smallest of pills without, juice, or ice cream or something to help her get it down. Herein is the rub of a person with two distinct power mongering personalities, and one little weak barely audible personality who tries so hard to keep the other two at bay. One part of her arguing with the other constantly, one trying so hard to survive the personality grinding so hard to end her own life. And little Lana Svetlana

Echternach, caught in the middle really unware of why she does what she does, but always trying to make sense of it, and always making promises she can't keep and always being the victim of her own *self*. I feel so much for her, and yet I wilt with exhaustion knowing every promise from her is one she can't keep, every willing time frame to keep, every pleading promise to be good, to "manage her behavior", to "help herself", to "be better", is only the fragile commentary of a *self* not under control. A *self* with it's own ambitions to destroy, a *self* weak and unable to control it's own directions. A split *self*, a fragmented *self*, a weak *self*. Lana, oh Lana, will you ever be able to put all of your pieces together? I love you so~

### November 8, 2005

### "2 days pass" ~ what really happened

Well the day pass started out pretty wonderful, with promise of having a fun weekend with Lana. We were going to Paris lake, taking Grandpa's speed boat, staying overnight at a hotel, eating out at restraunts. It was going to be fun. Lana hadnt been on a boat in a few years, she was excited and in good spirits, and in a very sweet and loving mood. The weekend started out great, we had to launch the boat ourselves, first time for the family with "12 left thumbs!!" It was fun, funny and hilarious, as the boat came sliding off of the trailer sideways and splashing into the water with a mind and life of its own. Of course we were the show of the moment with all the lake onlookers watching the harried father, and the bevy of incompetent, giggling teen girls all trying to take orders, be serious and laugh at the same time. Lana, usually upended by this kind of stress hung in their like a trouper and bucked up everytime Dad yelled orders to push the boat this way, or pull the pulley that way. As the day blossomed into a warm blue sunny lake day, everyone was actually getting along, Dad, Mom, Lana, Anya and Kelley, Anya's good buddy from soccer. Kelly's dad lives on a small boat in Long Beach, so she was very comfortable with all the splash and splatter, and quick maneuvers around the lake speeding along as fast as we could ducking and driving around skiers, little Seadoos, and all kinds and sizes of other boats. Lana did well, but I felt the slight tension between her and Anya and her friend Kelley. Lana doesnt share her sisters well, its either them or nothing, no sharing. But Anya can't tolerate Lana without a buffer, so Kelley was it. Anya was kneeboarding and the water was getting very choppy when out accross the horizon all we could see was a 180 degree panorama of black that was moving very quickly toward the lake, slowly overtaking the lake top and moving towards us like a black wall. At first we thought it was a fire, but as the water began to smack up against the boat, and it began to rain we realized the rain was full of sand, it was raining mud. We were in the middle of a rare desert storm that was careening right over the lake. As the black began to move towards us we got Anya in the boat and began moving towards a small island in the middle of the lake. Lana was showing signs of stress, fear, anxiety. but also resolve. She said she was scared, but she kept herself very much under control. As we arrived at the island we all jumped off the boat and slogged our way through the waist high water to the shore. The boat was ramping bow to starboard and port side to port side. I guess the stress of the "desert storm" as Lana has now and forever named it in her memory, was her first real trigger for the day. We waited the storm out on the island, and after it passed we had a long wait to get our boat up the ramp and out of the water, everyone on the lake decided to leave at the same time, so it was very slow going waiting out about 300 yards from shore, to get in the long line of boats approaching the docking area and pulling their boats in and leaving. When we got back to the hotel, Lana was stressed. She immediately snapped at me and said she was mad at Anya and Kelley, she refused to go into the room, so she sat outside in the parking lot, at the front entrance to the hotel. Of course no one knew what to do. Can't leave her sitting there by herself all steamed up! Can't get her to budge without a fight! So I told everyone to go ahead in and go up to the rooms. This began a long night of fighting, she argued and

stormed outside and inside the lobby. Of course everyone in the lobby was looking, very odd to see a kid having a major fit with a harried mother in the front of a chandeliered elegantly appointed hotel lobby. But there we were. We all tried to downplay her behavior and coaxed her up into the room. The girls had the adjoining room and Lana was in our room on a rollout bed. She didnt like that one bit!! She wanted her own room! "Not realistic Lana!" but when was Lana ever realistic?! We all decided to go to a quaint little traditional Italian restraunt that was accross the street from the hotel. It looked small sweet and promising for a large plate of steaming good old fashioned pasta and a red and white checkered table clothe, and maybe a nice red cabernet to help soothe the burgeoning migraine. Lana did not want to go to the restraunt, it became a showdown either her or us, she demanded we all stay with her in the room, or we go alone. Feeling manipulated and stonewalled we left her in the room, hoping she would settle down and be calmed by the cool dark quiet of the room and the slow din of the TV in the background. Just as I stuck my fork into my bouillibaise, I got a cel phone call. Lana is at the front desk of the hotel and is ordering an ambulance. I ran accross the street leaving everyone at the table behind me. As I came into the glass doors of the hotel I could see Lana standing at the front desk. The concierge is all engrossed in Lana's latest drama. To her, this unaware hotel night clerk, she could be dealing with a child newly in emotional teen turmoil and conflict, and she the newly appointed hotel angel of mercy, might be able to make a difference in this childs imagined angst ridden life. As I approached Lana she was in full panic mode. "I want to go to the hospital!!" I want an ambulance!!" I'm going to die!!" I managed to talk Lana down and get her to agree to go up to our room, to at least discuss why she needed to go to the hospital. Once we got up to the room, she admitted the minute we left the room, her "voices" told her to go to my overnight bag and take some pills I had in there for my back pain. The pills were Darvocette, mostly just Tylenol but with a small amount of narcotic. I went and looked at my bottle. Living with Lana has taught me to always count my pills, I have had to for safety and defense sake. I could see she had only taken 4 pills, although she was allegating 40! I told her "no ambulance! no hospitals! no paramedics! no drama!" I told her I know how many pills she had taken and it was not enough to kill her, make her drowsy and out of it maybe but she would live. She stormed, and cried, and flailed all around the room, but I was firm. "go to bed" "sleep it off, you will be fine, I am right here I will watch you all night". Dad and the girls were holed up in the other room waiting and hoping I could get Lana to settle down. Thankfully she did get drowsy, enough to get her to lay down. I watched her like a hawk throughout the evening, but her breathing was stable and easy and I knew she would make it to the morning. Sadly our weekend trip ended the next morning, we split up and I took Lana back to her facility, where they checked her in and she began a long diatribe to the facility staff about how she had taken 40 pills, and I would not take her to the hospital. Of course as usual, it looked like I was an uncaring, unemotional bitch mother who did not care about her daughters welfare. Dad and the girls took the boat back to grandpa's and went home. Lana got to spend the morning with her emergency team and all she needed to finish out her day pass with lots of drama, tension and attention~

#### September 8, 2005

### How have I changed so?

I cried today. Long hard, breathtaking sobs. Sobs from my inner self, my heart my soul, my life. I cried when as I sat, the impact of how much I love my family overwhelmed me, smothered me emotionally, as if I could not breath between each memory of my children, our lives together, what they have brought to my life.

Almost as if drowning, the waves of feelings overtook me, feelings from deep inside me that who I am today, is only *because* of my children. That all the years of self development, self

analysis, self awareness, self seeking was only scratching the surface of a self not yet bloomed, not yet fully formed, not yet really functioning until my children came into my life.

I wondered when exactly my gestalt began to slide from the world that revolved around me, because of me, to the world that I live in now. The world that is for them, about them, and because of them.

Somewhere along the line, my "self" was not the center of me anymore but they were.

That what I wanted didn't really matter unless it was important for them.

That there was nothing I needed or desired before what was necessary for their happiness and their existence.

How have I changed so?
I am in wonder, in awe, in love.
When did the "I" in "me" move on?

### August 7, 2005

### Two days pass

We took Lana out for the weekend Friday night. It was the first time she had been away overnight for nearly a year. We didn't take her because she "earned it" or had "progressed behaviorally" as she never has for more than a day or two ever. And there are no immediate expectations that she will anytime soon, Lana is Lana, she does what she does, she doesnt learn, or get better, so take her or leave her, it's who she is.

I stood waiting for her in the facility common area, the front reception room. The room with the big metal door to the right of the sign in desk. The door with a worn metal handle mounted on a big block of wood and rows of locks beside it. The door with the small window, where patients vagrantly walk on the other side, and peak out and smile, or wave a fingery scratchy little wave on the wired glass. I signed several documents for her medications, and instructions lists on how, when, what time, how many, what doses for what. And at the bottom of pages to be signed was a typed single paragragh contract that stated that I understood she had been physically agressive and assaultive with staff only one day before, and that normally overnight passses would not be approved. So I signed that page too.

She came into the front waiting room of the care facility with bags enough for 2 weeks rather than 2 days. Clothes, shoes, purses, sheets, bed clothes, radio's, cd's, as if she were moving away not going to a hotel for the weekend. Circling around her, behind her, hovering within inches of her were her facility guardians. Staff members, behavioral managers, program managers, bag carriers. All assigned to the chubby little potentate with the quirky smile, and the mismatched outfits, who always seems to be running the show as if they were the patients and she were the boss. Each one always anxiously smiling, with a look of veiled perplexity and faint fear about her.

Lana's a lot like a wild little animal, she looks so cute and cuddly, so approachable, so huggable, but she's unpredictable. Make the wrong move, say the wrong thing, blink the wrong way, and she might go off like a caged cat and everyone around her goes flying to the wall or to the ground with her. She'll bite, she'll scratch, she'll fling her arms and flail her body, and take 3 men down to the floor with her, everyone in a ball of mangling muscles, sweat, bruises, gashes and abrasions.

With full knowledge and an odd mixture of nauseous anxiety and protective love, I signed all the waivers, and agreed to all the terms from the keepers, and took my curly little fireball out the front door into the sunshine. And the first thing she does is run straight for the street curb. Lana, Stop! Lana, come take my hand! Lana lets go to the car, come on sweetie.

"I just want to say goodbye to all of my friends Mommy" as she runs up to the van with the side opening door, pouring out fellow inmates coming back from a morning outing.

### July 26, 2005

# I can't take it anymore Mom~

"the staff is hurting me, a cabinet fell on me yesterday"

"Fatim told me you don't love me anymore"

"why do they say those things to me?"

"Fatim keeps telling me to hit myself with the cabinet"

"Fatim said "keep bleeding as much as you want, we are not going to help you anymore"

"I can't sleep at night, everyone is yelling, everyone is screaming"

"when I wake up in my sleep and I am crying "mom help me" they tell me my Mom doesnt love me anymore, they won't come to help you, they don't care for you"

"Randy, he's Mexican, he told me to hit myself on the head with the cabinet, I told them to leave me alone, and to stop hurting me, but they won't leave me alone. They took my CD's they help me relax"

"my head hurts, I am so confused, they told me to hit myelf on my head, and I did, and now my head hurts on the top"

"I tried to call you last night and they turned the phone off and they wouldnt let me talk to you" they took my fan, I think they broke it, they even took my pillows, I don't have anything left Mom"

"I told them to leave my TV, that it helps me relax, and they took it anyway"

"I scream for my Mom, and they tell me "your Mom won't help me anymore"

"Tracy, pulls my hair, when she restrains me, she hits me and makes fun of me. She has given me a lot of bruises. My foot has bruises on it"

"They are abusing me Mom~" "I tried to call you yesterday, and they turned the phone off Mom" "I don't know what to do Mom, I don't want them to come and scare me again" "I am tired of all of this Mom"

"Caroline hurts me too Mom"

"I was crying and they tried to trick me, they told me my parents don't want me"

"they sleep a lot when they are watching me, they talk on the phone when they are supposed to be helping me"

"the PM shift are all mean, they all try to hurt me, there are a lot of girls that hurt me" "Can you help"

"they took everything out of my room, my TV, my music, my blanket, my pillow, my chairs, my clothes. Last night, Fatim, Randy, Tracy, they came in my room, and they took everything, they took everything from me. Now I can't do anything to relax myself, my CD's are gone, my new headphones are gone. They hurt me really bad last night Mom"

Who help you baby? who do you trust there? " no one on the night shift. Yolanda, Marissa, Evaline, June and Larry are always nice to me, they have always been nice to me" How about Clarrisa isnt she nice? "no not really, not always, she likes to shut windows on people"

"Tracy hits me on my face" "Fatim pushed me back onto the cabinet" "she tells me she doesnt care if I got hurt" "I try to scream Mom I need help, and she says "your Mom is not coming, she is not going to help you"

"the guys jump on my back when they are restraining me" "my back is really hurting"

"my behavior was good, until they started confusing me, then my behavior gets bad" "I hope my brain isnt damaged worse Mom"

### July 24, 2005

### Took her to the dress shop, can't hide the scars~

We just took Lana out yesterday for an all day pass, she did very well, but she was dressed top to bottom in long sleeves, and long pants and a jacket. I took her to a dress shop to get her some cooler clothes (it was almost 100 degrees out), and her arms, legs, belly are covered with scars, up, down, and sideways.

All self inflicted over the past 4 years, when she began the self injuring behaviors. Lately she also started head banging. She picked this up in the facility this year. They told her they were going to order her a helmet if she didnt cut it out. So far that has stopped her. But she has plenty of other things in her self injuring repetoire~

Lately its been nose picking, she gets her nose bleeding so bad they have to take her to the ER to get it stopped.

And once again~ she is supposed to be on "one-on-one/line-of-sight" supervision, within 36" of her at all times.......NOT! They leave her to go to the bathroom, or go out of the room, or some lame thing, and she just goes after herself. She says she hears voices, I think it is perseverative, and attention seeking. In any case I just wish she would stop, she will never get out of the RTC, until she stops this stuff~

### June 30, 2005

### If it isnt working.....change it!

"If what you're doing doesn't work, CHANGE what you're doing!" (Deedee)

I have to admit I was reading your tagline the other day and it sent me on a day dream about when our girls first got here. We had already raised one ADHD son, and half raised (6 years) a bipolar nephew, and an ADHD niece. We lived in a very educated area near a university known for it's work in neurological behaviors, we had pretty much everything at our fingertips. We had all the parenting, school IEP plans, behavioral plans and charts, you name it we thought we knew it! In fact that was one of our stand up arguments in court when the judge asked us if we thought we were capable of handling children who had been raised in orphanages and were from an "alcoholic family". Boy did we look down our noses at her! What could she know? She was just a back woods Russian "country" judge~ We told her we had it all wired! No problem! Uh huh! yeah~ well......we didn't know anything~ and that was a big big surprise to both of us.

It took about 2 years of fighting and arguing, and chest beating and brow beating, between my husband and I before we realized we had to completely go to the bottom of the class and relearn everything we ever knew about parenting when it came to these kids, especially Lana. I can remember the exact evening when we came to a roaring, screaming conclusion that "nothing is working here, we apparently don't have any idea how to parent these kids! so that means we have to change everything!!" And that was what we had to do. We literally had to go back to "parenting difficult children 101" and start over again, and then we had to take "parenting kids with mental illnesses 101" and "parenting children with neurological behaviors 101" and then "parenting difficult children 102"! LOL Everything in our repertoire of "raising good kids" had to be scuttled because these kids just did not respond to the old order of "do this, do that, do your chores, be quiet, do your homework, eat what is on your plate, don't talk back to your mother, be consistent, brush your teeth, take a shower".

So we indeed did have to change what we were doing! It was a big major change in our lives, we actually had to come down off our high horses and accept these kids needed specialized, extremely specialized parenting, and if we didn't change, we were going to lose them. Literally. Although change is not so good for these kids sometimes, change is good when it is necessary,

it is what makes us grow, and learn, and learn how to do things differently and even better. It also creates an incredible thing, mental flexibility. This is not a trait I would say my past military man husband was that good at, but he learned. And he has become a much better Dad for it! So, thanks Dee Dee for reminding us, if it isnt working, no matter how tried and true, you think it is, change it~

First of all Lana is a sweetie pie, anyone who meets her falls in love with her. She just has this

### June 28, 2005

### Borderline Personality? or alcohol and abuse.....hmmm

little adorable angel side. But she also has the out of control, impulsive, mean, panicky, fearful, tortured, devious side too. Over the years of diagnosis, it has been suggested that she is probably also borderline personality. Which unfortunately means she has two definite active personalities. She has the sweet adorable cuddly determined to achieve and succeed Lana, and the self harming aggressive impulsive seems to have no conscience no cause and effect thinking no getting to the next level Lana. If you were to look at all of these attributes you would see both FASD and RAD in them. She is also a bit low on the IQ level which doesn't help her ability to rationalize things well. Most people who meet her never suspect how critical her disability is, they are just taken in by her sweet disposition and her willingness to succeed. But as time goes by reality sets in that she cannot be trusted for even a second because she will not/cannot do what she says, and she does not ever get it and move to the next level. Or if she does she inevitably slides right back to the bottom rung. Token reward systems, reward systems, progressive teaching systems, all do not work, she never actually succeeds at staying at the level she progressed to. Except in academics, she did grow quite rapidly when she first got here academically but then she plateaued and that is where she is stuck, in about 2-3 grade. Who knows about borderline personality that much? even in the DSM it is not that well defined. It was added as most DSM mental illnesses are, when there becomes an overwhelming body of cases that have similarities that then are agreed to a the highest level of the American Psychiatrists Association for acceptance into the DSM. That is where FASD is right now, RAD is already accepted as a DSM diagnosis. It has always been accepted that borderline personality comes from acute emotional abuse in early infancy and childhood, and that the emotional personality sort of splits off and creates distinct personality types, usually bipolar i.e., one good side, one bad side, one protective side, one destructive side. But what if it is also an affect of attachment disorder and other nuerologically based brain dysfunction's such as alcohol/drug exposure in combination with other mental illnesses such as bipolar, RAD. Lana's behaviors are so typically FASD and RAD, but to most of the psychiatric community they only see the borderline IQ, the bipolar tendencies, and the scizo affects. I had a long long talk with the program coordinator at the facility yesterday, now that I am conservator I have that right (that is such crap, but that is another whole story)! To go over all of her behaviors, behavioral plans, medications, incidences, patterns of behavior, behavioral cycles, triggers, etc. As the conversation progressed she was very apologetic, she was also aware that Lana looked like she had been in a train wreck, and she had brought this up several times with the chief psychiatrist before they moved her to the acute care hospital. She said the combination of Lana's explosive behaviors, aggression, self harming, head banging, assaultive behaviors towards staff, plus their need to restrain her behaviors and stabilize her had just ended up in on bruise after another. As Erin had stated on many occasions staff would get all tangled up with her, and they were all sliding down the walls and then down on the floor with her. Everytime some on was getting hurt, not just Lana. I tried to explain to her the nature of FASD and SID and how when they are neurologically amped up, and firing, talking to them, yelling at them, trying to restrain them, getting through to them, talkng them down, just doesn't work. They are

not reachable at that time, it is best to just stay close but stay quiet and stay calm, stay soothing, and let them come down a bit. She asked me about the fact that this is when Lana will try to self harm herself when she is all worked up in an emotional lather, she attacks herself, and that is when they try to restrain her. I asked her why then if she is on one on one, line of sight at all times would she have anything in her hand she could hurt herself with? Like broken coat hangers, staples, broken CD case boxes, these are all things Lana will ferret away if you are not watching her, and use if she is all fired up and panicky. She explained that they have been trying to wean her off of the one on one, that even at their facility (at \$10,000.00 a month) they do not have provisions for anyone to be on one on one/ line of sight permanently. I told her I have been telling everyone for the past 4 years you cannot let her out of your sight EVER!. I think that is finally sinking in with her. She said she will need to request for more funds for this, so they can provide this. Anyway alot of stuff was covered, and the fact that Lana is unpredictable, unstable, untrustable, at all times even though she has you snowed and you believe she can and will do what she says she will is finally understood. The FASD was really sinking in with this woman, she also says that their chief psychiatrist is a professor at UCLA. where they have a great diagnostic research clinic for FASD, so perhaps Lana could be transferred there if they need to. No one really knows what will be the short term/long term with her yet, other than she is going back to the facility today. They are going to be initiating a completely different program with her, and they are going to begin communicating with me, and trying to understand her behaviors as being different from their expectations. Sometimes I wonder why I stay on this day after day, week after week, morning after morning, like a broken record, Lana is FASD. She is also RAD. It's like chipping away at a big stone mountain of doctors and therapies, and belief systems, but they do begin to see an emerging picture after a while. And they do begin to put the puzzle pieces together, and they do become willing to step out of their little bipolar, scizo affective boxes and realize there are other reasons and other combinations of reasons for these behaviors that they don't understand, and are unwilling to diagnose because they just don't know enough yet. Anyway, off of my soapbox, today, there are mounds of incident reports of Lana, every bruise, scrape and abrasion is noted, so they are not trying to cover things up. They just really don't know how to handle her. So that is the next step......how to handle Lana~ Only time will tell. I will be here, and they will be listening. Hopefully we will have some converts and some new ways of looking at things, and some new approaches that will be helpful to all, and save Lana from so much daily trauma. She is the victim here. Even though she looks like the perpetrator, she is the victim.....that is so RAD and FASD.

### Civil rights for the body but not for the mind~

Lana has been sexually assualted several times as well. Unfortunately since she is over the age of 18, she has civil rights that protect her ability to have sex. And since she is so impulsive, suggestable, and hormonal, she apparently feigns an interest in sex and then it goes to the next level very quickly. What starts out as a little flirting ends up as a full on sexual encounter, where she has no control over the boy, and he has no control either, but both of them think they are exerting their adult rights to have sex. It's a terrible catch 22, they have the mind of a 5 year old and the body of a 19 year old and the laws respect the 19 year old body not the 5 year old mind. There is nothing they (the facilities) can do to tell them actively they cannot have sex. They are bound by the law to allow them to have sex if they want to. Unfortunately with the young cognitive age, suggestability factor, and impulsivity it just invites sexual encounters, that end up being molestations, and assaults~ Been there, dealing with it, not sure how to fight it, but I am trying~

#### The beautiful Bubble

Hi Theresa! Thanks of much for the encouragement. I often wish I had the organizational skills to put a book together. I fear I am just a paper collector, and not a book builder <sigh>. I was so empowered and yet at the same time overwhelmed and somewhat defeated when I read Bonnie Buxtons book. When I was reading it, I was going "now this is how you write a book!! This is how it is done!" I was very impressed. I zoomed through the whole book in less than 2 days. I unfortunately have no idea how to write in congruent structural linear thought. I just have stories. and episodes and remembrances. I have no idea how that all comes together as a book~ Maybe someday. You are welcome to use this piece on your site. I have been writing quite a bit lately, but it has been fairly dreary, sad, stuff. We are not progressing much with Lana, and life just never seems like it will get better. She just stays in that little 5 year old wild child mind, acting up when she doesn't get her way, and melting down everyday. Since she has been in the care center where she has been lately, she has lost her virginity, amongst other things <sigh>, so much of her innocence that we had been able to protect is just getting lost to pure mental illness, violence and aggression. She gets restrained a lot, and is into head banging now (totally new for her, I'm sure she learned it at one of the facilities). So she is always checkered with bruises, and abrasions. I wish so much for this mixed up little curly headed pumpkin, but she is like a bubble, no one can hold on to her, she just floats around her iridescent outside shell always changing colors, swirling and twirling with fresh new unrealistic ideas, and unattainable hopes and fantasy dreams, but there is nothing inside of her to sustain her willingness, her promises, her desires, and she always bounces and floats around in the air for a while and everyone smiles and claps their hands at how wonderful she is, how bright, how sweet, how cute, and then she inevitably pops. And the beautiful bubble pops and is gone, and that sweet hopeful glow is just air, and she falls to the floor, a wet, miserable fluid that has no boundaries, no shape, no momentum, no energy to project itself against the inertia and gravity of her mind.

# June 22, 2005

#### **American Gold**

What is the life of an American born in the 1950's but an amalgum of human "mettles"? Mental steel, emotional coal, visceral will, blood and determination, religion, immigrant culture, God, TV, the old ways and the new ways. The emerging culture of psychology, social welfare and awareness, medicine, economics, an agrarian society moving to the cities. Mom, Pop, Grandma, merging with Mother, Father, and Aunty Sue. We grew up partially in the country, with the scent of the grass and the wonder of God and his creations, and the other part, TV, and radio, and Washington DC, wars, and politics. Amercians became the gold standard for the world, what we did, said, created, become the nucleus for change internationally, and yet our own sense of what was reality Gold and what was fools gold became inextricably fused. We became the Amercian Societal Gold generation, an amagulm of gold mixed with steel, iron, alluminium, nickel, copper, sweat, fear and blended urban and suburban confusion. Cultures clashing, genders screaming look at "me" " I am one" " I am two", "I am the same." Races, racing to seek equality, only to find that equality comes not with uniqueness and individuatlity but with blending and crossing the lines. Who were we? What were we? Where did we come from? Where were we going? What was our legacy to the earths traditions of cultural transitions? Peoples changing people. West mixing with East, Populations merging, thoughts becoming one, then something new, something origional, then something questionable.

What makes American Gold? is it soft and yellow and full of fear and too much pride and naive fearlessness, nothing to harden it, to help it keeps it shape, its luster? Is it white, European, Western, pure thought, pure with no confusing alloys, to cloud its color, its rigidity. Is it rose colored, mixed, soft and hard, resistant to change, will take the extreme temperature changes, is not sure of what it wants to be, it's a blend, but it polishes well, and it survives under intense use and pressure. American Societal Gold, it's a blend, it's flexible, it grows, it reinvents itself, it can be stretched, it can be broken, it can be welded, it can be resized. It is a chain, a circle, a diadem, a bracelet, a pendant with a picture of hope, of love, of struggle, of heart and willpower. It is an amalgum. American Gold, that is what I am, we are. That is our worth. It is how we became powerful when we had no value. We are all American Gold. Are we white, are we black, yellow, Asian, Indian, islanders, Yukoners? Are we immigrants, or first, second, their generationers? When do we pass the Golden seal of approval, is it mental, is is an act, is it the right to vote, the right to drive, the right to say my parents came here on a boat. We are Americans, it was our blood, our sweat, our semen, our babies, our new ways of thinking that made us the new Gold. We are part steel, part iron, part wood, part cement, part paper, all dreams, ambition, losses and successes, quite martyrs, silent partners, loud an bawdy, ruleing with our fists, our guns, our balls, our brains and our hearts, we have all become American Gold, no matter where we began, were we started from, in the end we are amalgumated, united in our differences, our idisynchrasies, our willingness to befriend, trust, and fold everything into ourselves to become one and to become strong.

#### June 19, 2005

# Just another day of rape, bruises, shots and restraints~

No this is not the 19th century England, this is good old sunny Southern California, and life on the loony ward. Every day everything is fine (or so staff says) and Lana has another bruise, or cut, or incident report. And they all said alcohol doesnt really hurt a developing fetus. The Hell it don't!! I called the police into the facility yesterday. First time I have had to do that. Lana called me and said she had been raped, the facility (they always sound like they are on trangulizers themselves) said everything was OK. Or they refuse to talk to me, or they disconnected the outside phone (they have a button to disconnect it when they need to), or they won't pick up the desk phone, they must know it is me. Lana says she has been raped in her room this time by her "boyfriend", and this time it was not consensual. She says he came in her room (no supervision) (where is her caregiver??!!) asked to look at her breasts when she said no, and he off on her. He then tore her pants off of her and they had sex on the bed. He then ran around the room screaming he wanted to kill her and her parents, tore up her stuff, and smashed some of her things. This is the 5th time in roughly 3 months she has had sex. Up until going into this facility she was still a virgin. But as they say there at the facility "sex is normal, everyone does it, she is over 18 and she does have reproductive rights!!. What a bunch of Eslan loving, still living in the 60's, psycho sexual babbled bunch of idiotic babboons. Lana is mentally retarded, and mentally ill, she is impulsive, suggestable, and very well developed. They have had her and "all the boys and girls" in sex ed classes, passed out condoms to the boys, and the let them all run around in each others rooms unattended.

For a \$10,0000 a month nursing facility, this is not college. But that's what they say is therapy. Oh and she also has bruises all over her body from restraining her when she is out of control and a big cut on her head from bashing her head into a wall. But that seems to be an OK thing in mental facilities. Especially OK, if you don't have a conservator. We shall see about that, when she goes to court this week.

Hopefully, the consevatorship will finally go through, and I can get on the phone and kick some psychiatric ass around there. Today, she was all compliant, would not tell me what the police did or said, did tell me she was given a shot for birth control and that her boyfriend was sorry. Oh, and that he wanted to kill me......I forgot about that part~

### June 5, 2005

### I really dont need you mom

Our discussion this evening was more about she has no control over her checking account and her ATM card, which she can't handle and has no money in, but seems to be in her mind, "her ticket to independance" .She wants her cards, her bank account number and her money. So "Chris and her can "leave this place and get an apartment". Now this is so far out from reality it is not worth getting into the argument with her, but at this time she is all angry with me for not being there for her, and not understanding her, and "paying all of your attention and love to my sisters instead of me" .

She just doesnt get the part that she has been in the hospital for the past 3 years for aggressive, violent and suicidal behavior, and she has never had more than 3 days where she could be trusted on her own. She doesnt see it that way. It is all my bad parenting, and my trying to keep her from her ability to be independent that has been constantly drilled into her by the staff and her public defender. They keep telling her she doesnt need to finish school, that she doesnt need parents. That she is an "adult" and she just needs to go off and get her money from the state, and start a new life with Chris her equally suicidal, equally violent, mentally ill, developmentally disabled boyfriend. I know this is an unrealistic disaster in the making, but no one there at the facility will back me. Or be realistic with her and help her understand her inablities to support herself. So we just have to listen to her bagging and droning on us about how we are trying to keep her money and her independance from her. What they are nurturing and setting up in her mind is the forumla for her to end up on the streets. They are turning her against me. This will not set well in court and she will end up being her own consevator, God forbid!~ and God save us all if that happens~

### June 3, 2005

# They're going to kill me Mom

Lana called last night, and begged me, pleaded with me to call the police for her. She said she was hurting all over, her nose and mouth was bleeding, and no one at the facility would listen to her. I have to always listen to Lana with a filter, she somaticizes and focuses so much on her own pain, that she makes herself think she is really dieing. It is such a complicated life listening to the words and then knowing that what she says is partially hysteria, partially fabrication, partially crying for attention, and partially reality. That is always the case. She begged me, to call the police for her, or to talk to someone on her behalf at the facility. I explained to her as I have many times before "I am not your conservator" "I can't help you" " they won't listen to me". I asked for her one-on-one to talk to me on the phone, and as usual they refused to talk to me. The public guardians office will not talk to her either, so even though she has a temporary guardian, they will not respond to her everday, every minute needs. So she calls home~ crying, pleading. She told me had climbed the tree again, and they pulled her down, then they restrained her and pulled her hair.

Last Sunday she was full of bruises from being restrained. I look at her arms and I know she is being strong armed, but there is nothing I can do. At this point since the sexcapade, no one at the facility will talk to me. They just say, "you are not her guardian.".

I know this is not the way our government meant for things to be when they established rights for citizens with mental illnesses. I know they did not mean for children with mental illnesses to be separated from their parents protection when they were in need, but that is the way the laws work. Her rights as an "individual" supercede my rights as a parent to help her. Her civil rights to be "independant" supercede my rights as a parent to help her make right choices since she cannot do so for herself. So far that is the way the law is working. I called her a little later in the evening, and she was very calmed down, her voice was low and shaky, she told me she did not want to die, she said, they were going to kill her. She said the had given her a shot, I knew it was probably a shot of benadryl and ativan, that is what she has written for PRN when she is out of control. I told her the shot was to help her calm down. All she could say was "they want to kill me Mom".

My poor Lana, my poor poor sweetbaby, what all has been done to you my love? I know so much of her fear is from her past, and it comes up and smothers her, and she cannot escape it. It makes her everyday life unreal. Her daily reality is living with her tragic past~

### May 30, 2005

# From cutting to swallowing

Lana's self harming behaviors have taken quite a turn over the past year. After her first psychiatric admission 4 years ago, she learned the lovely act of "cutting" from some of the girls in her room. She is developmentally disabled, mildly mentally retarded, peseverative, and easily lead, and yet this facility put her in a room of 18 year old girls who were fine cognitively, but were having mental/behavioral issues. Lana like the baby that she is, thought cutting was "what all the girls are doing" so she started cutting herself when she was raging, melting down, explosive, or angry, or even when she wanted to get attention. The first couple cutting episodes were very hysterical she grabbed knives (big knives) in the kitchen and just started stabbing herself, when she realized the actual gravity and possible danger of using such dangerous knives she began useing smaller things, steak knives, peices of glass, staples (she learned staples in the hospital too). At first she always attacked her lower forearmns. Just slashing them not too deep, just enough to leave a red welt or slight bloody gash. Then she began cutting her stomache. Her stomach has rows and rows of horizontal scars now back and forth over her belly area. She stopped cutting pretty much though when she discovered swallowing. Somehow in my own mind, always trying to intellecutalize what would be the reason for the change of behavior, I figured it had to do with, less pain more gain. If she swallows they have to x-ray her. She loves x-ray machines, she loves all the medical attention, and she loves all the extra meds that come with trying to get whatever she swallowed out of her stomach. She has swallowed staples, change, coins, plastics, berries, leaves, buttons, but she has had a penchant for staples. She like the fact that they can be watched in the x-ray machine I think. She has also told me on many occassions with that serious tone of hers "they will have to cut them out of my stomache". I have told her many times, they won't do this, but she is adamant. She is hopeful, she really wants to have surgery. This is the ultimate goal for her, to have surgery. This is one of the reasons I think she keeps swallowing things, she is hopeing eventually she will get them to open her up, and do the whole surgery drama. That is one of her deepest fantasies~

#### Post sexual encouter

Lana's week was very busy last week, the facility bussed her to UCI, to have her genitals all checked out. Apparently she had a full OB/GYN work up. Of course they don't/wont' tell me anything. Because I am her Mom, not her conservator. She also got to go sit at the police station, for 5 hours (she says) and answer a lot of questions about the whole incident. I am sure it will reflect something like "it was consensual sex, they are both over the age of 18". But won't say too much about the fact that Lana is impulsive, has no judgment, and is mentally about 6. Because she is FASD, she can be very charming and precocious and can talk a good story. You never know who hears what from her, or what their translation is, many times they just think she is so cute, and can't imagine that she is totally out of her mind, and has the mind of a young adolescent.

So because this facility has no rules that protect her from being sexually used (can't say abused) even when she is supposed to be watched with a "one -on -one, line of sight" caretaker at all times, she is now having to go through all the post sex trauma. Tests, observations, meds, questions, interogations. But who knows, for Lana maybe this is just great. She loves the attention, and she has no idea of ramifications of what she has done or what happend to her. She has been in a semi fantasy lately of what it would be like to have a baby (her and Chris), and they can get an apartment, and live happily ever after. She keeps telling me she is pregnant, and I quietly and softly say "no Lana, they gave you the morning after pill remember?" But then I don't know if they really did or not either, since they won't really talk to me. So if my mentally retarded/mentally ill daughter gets pregnant at this facility, who is responsible? who takes care of the baby? what happens to the baby when the mother is a child/ baby? Is this when my rights automatically get kicked back in?? Do I then become the grandmother? Or does this baby end up in foster care with all the other children in America who have parents who can't take care of them?? As usual what a mess. She was much better off in the hospital, it was the only place she was safe, they treated her with understanding and compassion, and knew how to deal with her expolosions. They also did not have any weird socially pc rules about her reproductice rights. They were clear that she was mentally retarded/ and mentally ill.

### All bruised up

I saw Lana yesterday, she was in her usual good/weird mood. Happy to see me and very bubbly about everything. She had bruises all over both upper and under arms. She told me they were from staff, then she said "they just appear out of nowhere! I don't know where they come from". She is really getting institutionalized over there quickly. When she goes off they just hammer her down to the ground or hold her against the wall. This morning she said she climbed a tree (this is not the first time) but this time they pulled her down out of the tree by her hair.

As usual she is sad, happy, bubbly, subversive and totally in her own world. She acts like she is with it, but the longer you talk to her the more you realize she is not. She lives in an adolescent world, where everyone is supposed to be her friend, she always has new things to do (which she never completes), and she is the perfect princess in the world she exists in. She shows me her workbooks, they are the same things she has been working on for 4 years, over and over, different books, different teachers, different places. She never moves ahead, or if it seems she has, she always slides back to the same place. She wants me to help her, but I can't. On the temporary conservatorship, she is conserved by the public quardians office, they are all a happy an bright bunch, who when I told them she was sexually attacked in the facility, they said "that

happens all the time" she is over 18! Oh geez, silly me. I am her mother, but I have no rights, I can't help her and I can't do anything. I am not allowed to talk to the people at the facility now, since I got all worked up over the free sex in her bedroom thing. Supposedly (Lana tells me) all the rules have changed, the clients are not allowed to go into each others rooms for sex now. Well, no duh! These are 30 individuals who are for the most part mentally adolescents, they are also sucididal and aggressive, and yet, the facility seemed to believe that they had "reproductive rights" that superceded their safety, and I guess the life of the potential baby who might occurr from these laisons. Oh well, life in a mental facility, I guess you shouldnt expect, rational thinking.

### May 25, 2005

# Life in a Residential Facility

So far Lana has done fairly well in the facility, her behaviors, moods, impulsive actions (self harming), have been a lot more well regulated. When I talk to her at times her maturity seems a lot less babyish and more mature. But as expected she has not had any incredible breakthroughs, or has not become a normal person. She is still Lana, babyish, child like, cute, doesnt think thinks through, has not concept of reality, talks a lot about how well she is doing, but really isnt. She remains the same person who always sees a new coping strategy, a new companion, a new idea, a new behavioral chart as if it were the first time she has ever encountered this. Every day is a new idea, one she never thought of before, every new caregiver is her new best freind, and is teaching her new things she never heard of before. Lana lives in a perpetual "new day", and no one before ever seems to have taught her a thing. It's hard being the Mom to a child who never remembers all the years of struggle, all the learning modules, behavioral charts, behaviorists, schools, special classes, new doctors and therapists with new ideas. Because for Lana, it is only the current person she is working with that has the solution. To her nothing has ever been done in the past. It is forever a new learning experience.

The one thing I did manage to protect, and keep safe was her virginity. That was something we drilled into her, no sex, she is too young for sex. Sex is for marriage, sex is not something you do for fun. In her limited capacity it is hard to tell her she would not be a good candidate to be a mother, in her little mind, she would love to be a mother. The idea of taking care of babies is very powerful and compelling to her. But apparently in her facility, a facility which takes care of individuals with limited mental abilities, impulsivities, lower IQ's and mental illnesses combined, they thought it was a good idea to teach them about sex. "Sex is normal, everyone does it" " it is your right as an adult to have sex". And they passed out condoms to all of the males, and told them to go engage in their "reproductive rights" as per the United States of America. So....last Friday night, Lana calls me and tells me she has had sex with her new "boyfriend". She related to me how long they were left alone (30 minutes) with her 1:1 "line of sight" caregiver standing outside her bedroom door, while they were getting it on. This is two mentally incompentent individuals who areboth suicidal, and he just recently tried to kill himself with the lamp cord. They were "left alone" to have sex! She then told me "it was really big~(his penis)" I asked her if he penetrated her, and she said yes he did. So, score one for these two spencial needs individuals, who according to the facility were exercising their reproductive rights. Now she has had to have a full gynecological exam, with speculums and everything looking and gouging inside of her, and a visit to the police department for 5 hours. Was this necessary??? No!! Stupid facility!!

### May 3, 2005

### **Mothers Day Gifts**

We too were asked (told by my Mom~) why we didn't just get rid of Lana. In fact when things were the worst and we had many body slamming squirmishes in house (between the girls, usually provoked by Lana) that resulted in cuts, bruises and bites <sigh>. Mia and Anya begged me to get rid of their sister. They had never lived with her before this experience (adoption) and the more they got to know her the more they didn't like her, were scared of her, and just wanted her out of the house. I had it coming from all directions believe me, and I had plenty of my own moments of "this is it! she's out'a here, I can't take it any more!". And every time as everything calmed down and life got back to somewhat normal, and the stress of the incident was over, I knew I couldn't do that. I kept telling my girls "you don't just get rid of family just because they are hard to live with" " you have to stick with your family" " they are all you have, and you are all she has" "no matter how bad it gets, we will not ever get rid of her, we will stick by her and figure out how to help her." And as time marched on, that is what we did. And my love for this child did not wax or wane, or diminish, I just became more resolved to help her. I had to get over the perfect bubble I had had of a life, and the perfect family I had envisioned, and the perfect children I had dreamed of. I had read a lot of novels in my life, maybe too many where people had scores of children and everything was wonderful and noble, or where orphans always made it up from the streets to become intelligent, caring, thinking human beings, who were so thankful for their lives......<a in sigh >. I was not prepared, not equipped, not educated, not emotionally ready, not strong enough to strip myself bare and start all over, as a new kind of Mom, and person. After 10 years of looking into adoption, the one thing we knew was we did not want was to adopt children with disabilities, handicaps, or special needs. We believed we were not the right kind of people for that job. I had all the respect and admiration in the world for people who could work with children with special needs, but that was not me~ And then wham! There I was, learning about IEP's and special Ed, and developmental delays, and brain damage. I have written that it were not for Lana, I would never have become the person I am today. I would have just gone on my merry little suburban soccer Mom way, not ever stessing over to much, not ever worrying too much about things like violence in the home. aggression, abuse, neglect, alcohol and drug abuse, children born with brain damage, children so neglected they were just not normal. I have wondered if this has made me a better person. more dedicated, more committed, more able to understand children, more aware of emotions, of people with disabilities. Or has it made me a worse person, tired, exhausted, stressed out, confused, baffled sometimes, hitting my head against a wall all the time. The bottom line is I have always been" tired, exhausted, stressed out, confused, baffled" sometimes, even when life was good. Weekends were for down time to complain about all of these things and just lay around and be lazy, watch TV, go out. It's just now the context is very different, and the words come from a different experience, and I am a much stronger, bigger, more flexible, more intuitive, more sayvy person than I was before. And when I am tired it is for very different reasons~ What made me stick it out? I think it is the same for all of us, we are people of commitment, of discipline, of integrity, of human decency. We take on our life's challenges with fervor and a never ending need to understand, and then to help, and hopefully to fix. We are flexible individuals, who can bend, but not break, but can also stand firm in the wind but allow the wind to go through, us, go past us, not break us. And we are people who love, with such deep conviction, an empathetic love, that goes beyond reciprocal love, that can give love out, and survive when it does not come back to us. Am I seeing rewards for my efforts? I can say that I am. I am seeing my 3 children growing up into remarkable young ladies all in their own rights. Even my most severely affected child who lives in a facility where she cannot be left alone, where she needs constant supervision. She is there, but even in this context she is

growing, and she is doing better. She called me several times yesterday, to tell me she is working on something for me for Mother's day. She said "I am making it with my own hands Mom......remember how you always said that a gift made with your own hands was better than a gift that was bought?" I said I remembered. She was very proud. And she always finished her phone call with "I love you Mom" "I miss you Mom". For me that is a big reward, to some a small one. To me the fact that she has come this far, is a reward only I could know, could be proud of, could treasure. I'm hanging on to my little rewards, as if they were golden Oscars. And as she grows we will rebuild our broken mantel and put them up there. Sitting proudly amongst the certificates of achievements, the special Olympics medals, and the pictures. Lots of pictures. The most provocative and prescient of all the pictures of her and her sisters standing at the orphanage, smiling and looking into the lens that day, with no idea who I was, that lady holding the camera, or what their future would be~

### March 19, 2005

#### **Brief window cont**

Last evening the phone rings and it is Lana. She moved effortlessly into the conversation as if there were no emotional conflicts left over from the evening before. "Hi Mommy~" "Hi Sweetheart, what's up?" "Well I have been thinking about the DVD's Mommy, and I think it is Ok if you just bring me one." I was interested in hearing how she was going to work her way through the puddle she had created with demanding 3 DVDs, now whittling it down to just one. "Mom, I have been thinking how much I love you" "I miss you" "I was scared after you left, that you were mad at me" "I don't want you to be mad at me" "I know I get mad at you and it is bad" "I don't really need 3 DVD's Mom I only need one". I was so taken aback by her stream of reasoning that included regret, responsibility, and renewal. Not Lana's usual fragmented way of seeing things. I told her I was impressed, in fact I was very proud of her, for working this through in her mind. She told me she had talked to her nursing staff and they had helped her to know how to say it properly, how to realize that she had been wrong and that she needed to recant and talk to me. I knew that for Lana, every experience is like a new experience, that every time she has a new nurse, a new staff member, a new therapist, guardian, caseworker, that they are like a brand new teacher, new book, a new revalation. I let her tell me how she listened to everything they said, and how she couldn't sleep with worry that I was mad at her, and how they had helped her know what to do, what to say. I was very proud of her because in spite of the fact that she had gone through this a million times before she sounded like she had really reasoned this one through and had come to an end result of action. She acted, she thought about it, she talked to someone, she synthesized, and she projected a way to resolve. All very appropriately. Homerun for Lana! I told her how very proud I was of her, how impressed I was with her way of talking to me about this, and how well she handled it. I told her how much I love her, and how much I miss her. And for the first time Lana told me "don't say that Mom you are making me cry". I sat there for a while after I hung up with her and wondered is Lana actually able to connect with a reciprocal emotion such as that? Can she feel a sympathetic emotion? an emotion that says "I know you love me, and I love you back, so much so that your disppointment in me or your pride in me is going to make make me cry". I could not help think maybe she did, maybe for an instant there Lana connected directly to her heart, not through the faulty wiring, not through the broken glass of emotions, not through the foggy intelligence, but right to her heart where love sits in all of us. Where we feel love, and we know we don't want to hurt those who love us. I thought to myself, perhaps a window to Lana's inner self had just opened, a brief whisp of clear, crisp, Russian air had crossed over me. It felt good, it felt soft, nothing like the ending of most conversations with Lana. Conversations that end with

tension, regret, or the feeling of futility. It was a nice ending, one I will treasure for a while, one I can hang on to when the next storm begins to brew, and the window is shut again.

# A brief window of cognitive reasoning

Lately Lana has been on a behavioral see saw, up one minute, sweet and adorable, down the next, mean, argumentative, demanding, and self abusive. She has been residing in the neurosphysicatirc ward since the first week of January this year, it is now the end of March. Not even the acute care hospital, have been able to control her behaviors, emotional storms, and mood swings. She has become their little Curley Sue with a bad attitude and a dangerous proclivity for swallowing staples. Even the hospital with psych doctors, and qualified behavioral nurses on staff 24 hours a day have all thrown their hand up and said "nothing works" "she is stuck" "she doesnt respond to behavioral strategies, therapies". Yes well, we already knew that, but that is not the story here. Over the months, she has gone through days of rages and meltdowns, and then days of calm, and somewhat control. Usually on a 3 day cycle. Cognitively she swings from 2 year old behavior, to 5 year old thinking to 12 year old manipulating. Mostly she stays in a state of babyishness, making many demands, getting angry when she doesnt get her way, and not having any idea why everyone is always pissed off with her. Her ability to understand her responsibilty to all of her behaviors is little to nil, and most times she just seems to be oblivious that the aftermath of her turmoils leaves everyone around her tired, exhausted, hurt, with veiled anger and frustration. But unpredictably there are days when Lana will rally, and will act almost like a normal person, and everyone raises their hands and claps and says "aha!! she is getting it!! she is going to be OK!! See there, the strategies are working, she is catching on!". Last night, Friday night, March 16th, was one of her moments of clarity. A stream of consciousness that held together in a linear line of thinking and expression as if she had control of her thoughts, her emotions, her cogntive state. After several weeks of her hourly calling me and telling me not to come see her one minute, and then calling me back and asking me to come see her the next, my patience was wearing thin. The daily drip of Lana's calls keeps my mind whirling, part of me reminding myself she is like a little child who doesnt know from one minute to the next what she wants. The other side of me paranoically saying she is manipulating me just to punish me in some way, or show me who is in charge. She had been arbitrarily demanding things, one day spelling out a long list of items, CDs, DVD's, candy, clothes, then the next day changing her mind and retracting and revising her list. usually as it grew bigger, and more expensive. Each time I responded with attempts to keep the demands structured and measured. So that she recieves things in a limited, rewards oriented fashion. Not too much, not too many, and not just because she is demanding so. Several nights ago she demanded that I bring her 3 new DVD's instead of the one DVD, Titannic, that we had agreed to. It had taken me a week of daily reinforcement with her, that at the end of the week, she would get the Tittannic DVD. "On Saturday" " next Saturday" "on the weekend." It really doenst matter how you project the timing because in Lana's reality of space and time she really never gets it. Sometimes she understands if you use a calendar and make her plot it out, so she can see the relationships of days and weeks, but she usually doenst get it if you just say "next week" or "next Saturday". She broke down into arguing with me about getting the 3 DVD's. Battering me with how I am not a good mother, how I try to keep her money, don't let her have her own things, don't let her buy what she wants when she wants it. I got up and walked out, and as I turned to leave said "don't expect me to be here on Saturday now, not with 3 DVDs! don't even expect me to come with the Tittannic". And that was that, she didnt call me that evening, and I just waited to see how she would respond. Usually she would just let a few days go by, and call as if nothing had happened, sometimes asking if I was angry, sometimes just moving to a new subject. Letting all the behavioral participles dangle as they may.

### Cutting, swallowing, self punshment, what are the rewards?

Lana's life and our lives have been chaotic at best, Hellish is more like it. Since the onset of her mental illness several years ago, she has been in and out of hospitals, emergency rooms, police departments, and our home. Lana was always mildly retarded and a bit explosive. But her behavior was at least tolerable. When she became violent and self destructive we could not contain it anymore. Eventually last August we placed her in a group home, that seemed to me to be the best case scneario for her. It was small, only six individuals with disabilties, there were staff that were easy going, kind, and careing. Lana was able to go to special Ed school, at the local high school and she had an active schedule which included, vocational training, outings to the stores, parks, and beaches. Special olympics, music, and lots of attention from the staff. It seemed like the dream place for her to be. She had her own little room, with matched linens and window treatments, a TV, VCR, DVD player, lots of closet space, a desk, and she was allowed to hang her own pictures and school awards around the room. It was very sweet and personal. Lana, though, could not handle the stimulation. Too much to do, too much free time, too many people attending to her every demand. She began to spiral in October, and the group home ended up admitting her to ER's over and over (as we had for years) for raging behaviors that became violent, and her constant self harming behaviors. When she is angry, bored, overwhelmed, not getting her way, she hurts herself. Her repetoire for these behaviors include cutting, hitting herself, and swallowing things. When she is totally out of control these behaviors are incessant, she will use anything to hurt herself, anything plastic can be crushed or broken to be used as a knife or sharp object. Pills, small caps, lids, coins, staples can be swallowed, as can cosmetic products. She also can strip a staple from a magazine, or a paper and open it to create a sharp edge to cut herself or to swallow. When at school if she was not watched every minute she would find broken glass on the ground and squirrel it away under her shirt, only to cut herself with it on the bus or in the bathroom. Eventually the school had to provide a one -on one so she was not ever left alone or unattended on the school grounds. Why does she do this? It is not the characteristic "self harmer". She does not cut to relieve tension, she does not hit herself in a bipolarrage. She is not premeditated, she does not think about it, plan it, nor does she experience relief. It's as if she is a victim of her own self. Her superego victimizes her ego. At first it was diagnosed as being attention seeking behavior, because yes, she does recieve attention, and it is always dramatic attention. Plenty of running around, doctors, nurses. x-rays, scopes, people worried about her and emotionally charged atmospheres. But the paradox is she never does these things in front of anyone. So wheres the drama? the immediate gratification of attention? It is always alone, secretive, by herself. It is confusing. Its as if she has a destructive side of her that wants to harm herself, punish herself, and will not come out or do so if anyone is looking. Borderline personality? Perhaps. Arrested cognitive and emotional developement? definately. The affects of years of abuse, punishement, neglected or inappropriate attention for sure. It's as if she has two distinct sides. One is an adorable little 5 year old and the other is an older angry, tempestous side who wants.....no, demands, everything go her way, or she will blow up and then ultimately hurt herself, harm herself, punish herself. But not when anyone is looking, always behind closed doors. Always preying on herself.

#### October 28, 2004

#### Mia's confession

Today my daughter Mia came into my room and laid next to me in bed. We were cuddling and crying about how much we loved each no matter what. That we accept each other for who we

are. That nothing stands between our love. Not adoption, not the years lost between us, she in Russia, and I here in America. She growing up for 10 long years, hoping and knowing in her heart that she would find her one true Mom someday, and I knowing that my children were out there waiting for me somewhere.

Mia told me that she loves me beyond adoption, that I was the mother she always hoped for. That she could never love anyone more than me, her mother.

"Write it down Mom, I don't want you to forget this night, these things we are saying. That I cant remember having any other mother than you. My life began when you found me and my sisters. When I think about my love for you I think in my heart and mind that I came from your tummy. That there is no other time that I remember that didnt include you..... you are my real Mom. I can't imagine my life with out you Mom".

A languid moment later, Mia quietly and embarrassedly admits the times she had been violated by young boys in the orphanage. They would press her behind the door of a cold standing cabinet and force their penis on her. Or the time she was held in a dark cold room and touched by a man, the husband of a caregiver "his hands were cold and rough Mom, and I was terrified, and he touched me Mom and put his finger in there. His fingers were rough. I was scared, I woke up and saw him sittiing over me. I pretended to be asleep. After that I have always been afraid to be in the dark and all the doors need to be locked on my room".

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"I had always wondered why she was so adament about locked doors" I thought to myself, earnestly listening to her whispered confession.

I mourn for my precious sweet daughter who "would be punched in the face and my nose would bleed" because she said something someone did not like.

I mourn for the innocence lost as the constant brutality taught her to be tough, and callous and angry. She said she would put the young children up in a row against the wall and slap them all, even her beloved little Natasha. "I don't even know why I slapped her Mom....I don't know why I would hurt her, but it just seemed normal to be like that, until she cried and then I couldnt take itanymore, and I would hold her and tell her not to cry. That I didnt mean to hurt her~

### July 24, 2004

# The ending to many years of struggles......

The ending to many years of struggles with Lana at home and a transition to a new life in a group home happened last week on Thursday. I have had many emotional struggles with actually talking about this and am having a difficult time letting go mentally ever since. No matter what, she is my child, my baby. Children are supposed to grow up, learn, and be safe at home, with their parents, and their siblings. That is what we all know and believe. That is true for all children.....but not for some Our life the past two years has been a daily roller coaster of social services, police, emergency room, school, county and hospital interventions. She was admitted 9 times in 16months to psychiatric hospitals in our area. Each time she would come home, do well for a while and then descend into weeks of psychotic behaviors, often self harming or harming family members. I've often thought living with Lana was what it must be like

living with an abusive spouse. You love them, you don't want to leave them, they are your world. but you just can't live like that forever. It's not a life most people could tolerate or understand and you hang on as long as you can, but there does come a time when you know you can't help them anymore, and they don't even understand how much they hurt everyone around them. Lana is somewhat of an enigma in that she is sweet, loving, caring, darling when she's not yelling, screaming, throwing, slamming, crying or swearing. Yes, the darling Lana, cusses like a dock worker when she's manic and out of control. Who would ever know meeting her? She is cute, adorable, beautiful, fine white flawless skin with rosy pink cheeks and silky brown curly hair. She has the voice of an angelic little muppet, that is when she's not screaming at you and calling you a bi\*\*\*, or other lovely gritty terms that we were taught never to say. When we brought Lana into our lives, everything was hopeful, we knew we could help her, fix her, teach her, love her through it all. We believed we could erase the years of abuse and neglect with our determination and will, and resources, we could give her everything and that would make it all better. That was when I knew she was born of an alcoholic mother and had lived 9 years institutionalized away from anyone by herself, alone......and I thought nothing of it, "oh poo. that's no big deal we can overcome that......". That was beforel knew anything about mental retardation, and mental illnesses, attachment disorders, and fetal alcohol syndrome. Perhaps if I knew, I wouldn't have thought with a mothers detachment from reality when it comes to her children, that everything could be better. Everything would be better just because I loved her. Oh well for "love conquers all", it does in novels and love stories and tear jerker movies, but it doesn't for people who have been abused, neglected and brain damaged from the ravages of alcohol and drugs. And the children who never had a chance or a choice in the matter before they were even born. At least for us and for Lana, we know she is in the best place we could give her. I would not let go of her until I knew it would be a place that would be good to her, care for her, nurture her. Surprisingly those places do exist. She is in a very small group home, only 6 clients, there are 4 staff members there 24 hours a day. She has her own room with all her own things from home, her own TV and her own stereo. It is bright and sunny and she has a garden with flowers outside her window. If I had to let go of my baby, I wouldn't let her go unless I knew she would be as happy as she can be. For Lana she only lives in the moment anyway. as long as she is getting attention, and being attended to, and everything is good and not stressful she is OK. I think she misses us, but in a lot of ways she really doesn't. She is somewhat oblivious most of the time. Love and loyalty, respect and responsibility are most of the time out of her mental reach, she has her moments but they are rare. We love her, and we miss her, and I can't imagine not being able to hug her and kiss her everynight after she is asleep and the waking monster is at slumber. Right now and for the first month we cannot see her and she cannot see us. Life is actually taking on an amazing transformation here, it is guiet, peaceful and almost normal. Lana has been a great teacher to me and to my husband. Through her we learned we had an enormous reserve of patience, that we could change our behavior, our habits. Things we never would have changed until the day we died, had it not been for her. Her demands were so great on us she made us grow to be able to appease her, to nurture her, to teach her. She opened up to me an awareness of what can happen to a persons brainand life if it is damaged through alcohol and neglect. Hopefully now I will be able to use what I have learned, and pass on what I know, and help others understand what I have been taught by her.

### May 7, 2004

# Do you know how precious you are to me?

I am sorry my darling that life has been chosen to be so difficult for you.

I wish that I could take all your pain, and confusion and frustration away.

I wish I could help you when your mind gets the better of you and you don't know what you do, or what you say.

Life has not been easy for you my dear one, your mood can be stomy, your words can be mean. Your thoughts get ahead of you, and you *do* before you *know*.

To some who don't know you, they would judge, they would talk, they may stare.

They might say you are wilful, your aim is to disregard.

I know you don't mean it my love, I know you wish you wouldnt.

And when you are storming, and when you are mean, and when you are throwing and when you are crying, and when you are hitting, and when you are not there in your mind so that I can talk to you,

work with you,
reason with you,
do you know how procious

do you know how precious you are to me?

## **April 7, 2004**

### You say you are adopted

You say you are adopted and you are *not* complete, And yet for me and my life with you I am complete. You say you always wanted a mother, and a family, and yet you are not sure if I am the right one if I am the best fit if I am to be yours. To me you are my dream child, the one I have always yearned. To me you are my world for this my heart has earned. I hope when you know inside your heart that we were meant to be that being adopted will set your mind free~

# **April 1, 2004**

#### Alcohols children

They are the the children of alcohol...

Alcohol became their mothers sustenance, after work or on the weekend, chilled, neat, or on the rocks and quickly brought to their unborn childs brain and nervous system through the placental cord.

When their mother got a buzz, the fetus had one too.

When their mother felt queazy, or weak kneed, or nauseous they did too.

They were not yet born, but she drank anyway. Their brains became hardwired for anger, anxiety, fear and agitation.

As they grow up their behavior and their actions resemble the angry drunk, who when asked to be reasonable can only rage. Who when asked to remember can't grasp a thought. Who when asked to do a task can't organize or collect their abilities.

It has been said "the children of alcohol" are born drunk, and their hangover will last them forever

this is true~

### March 9, 2004

#### Like an Untamed River

There comes a time when it is understood this person will never be in control of themselves. Will never say

- " I won't do this again"
- "I promise I have changed"
- " this will never happen again"

and mean it, and be able to stick by their words, be able to do what they say.

It's such a waste, such a sad reality, that you can look into a persons eyes and know and understand beyond a shadow of a doubt, that this person cannot control their impulses. Will never be able to say no to themselves and stick with it, learn from it. Will not be able to stop themselves before they do something damaging, destructive, debilitating.

This is contrary to the concept of positive anticipation, that everyone deserves a chance, that there is always hope.

And yet for some there is little hope, there are few possibilities, there are no maybe's. There are only degrees of probability, but no assumptions of a healing, beliefs for a cure, presumptions of a permanant correction.

For some will not walk, and some will not hear, and some will not see, and some......will not ever think.

Will not think in an organized fashion, will not be able to construct their mind, set boundaries for their actions. Their mind will not let them, their mind is not able. Their mind is like an untamed river it flows and takes over and expands and rambles and has no curb, no dam, no channel, no regulation, no control~

### March 3, 2004

#### You dont think!

"You don't think!" the angry father demanded

"You don't think!" the concerned teacher remanded

"You don't think" the frustrated mother cried

"You don't think" the aggravated friend reacted

"You don't think" the crazed sister screamed

"I know...... I don't think"

I react, I don't think, I am impulsive, I don't have good judgement, I don't plan what I do, I don't get the consequences, I don't work on it, I don't learn from my experiences, I do the same thing over and over again.

I am not stupid~

I just don't think

I just can't

### February 29, 2004

### My mind screamed with paniced rebuttles

Our daughter Lana sat there, in the clean round room with glass windows overlooking the wide green vistas of the hospital complex. She was dressed in her soft pink sweat clothes, with still visible food stains from lunch on her chest and too long pants legs, worn and crumpled under her heels. Seven doctors, therapists, and social workers were in attendance, sitting with their notepads, listening and ready to report everything she had to say about us, our family, the way she has been raised, the way she had been treated.

How could she ever know the cascade of events that were put into place when she came into our lives? We were not ready, we did not know. We thought we could save her, help her, fix her. We thought love could conquer all, that everything would be all better. That she would be our baby and we would heal her broken mind.

In *her* mind she stated she was hurt and lost and misunderstood, and we did not try hard enough to understand her, work with her, help her. We did not give her enough, we did not listen, we did not make things go the right way, so *she* could have a chance at a normal life. My stomach felt tense and nauseated, for with every one of her statements my mind screamed with paniced rebuttles. "Wait let me answer.... let me explain..... let me tell you what really happened......"

But we could only sit tensely, renounced and dejected, and hold our breath and cry internally, and know in our hearts and memory we had loved her beyond reason and had tried everything we knew, and she would not, could not, ever see it that way.

## February 29, 2004

### **UCI Neuropsychiatric**, the round room

The view through the sleek contemporary glass windows overlooked the steaming frenetic California freeway. She was sitting in a circle of specialist, psychologists, psychiatrists, nuerobehaviral specialists, social workers, case managers at UCI Nueropsychiatric Hospital, one of the finest resarch and treatment facilities for psychiatric treatment in southern California. This round room filled with MDs, and phds, and MA's had become her stage, she was the star dramatists, star actress, star patient. Sitting there amongst the best psychiatric minds we could summons on her behalf she wove a tale of abandonement, neglect and abuse.

The questions asked of her were simpley stated, easily projected and non-threatening. They struck memories of intermingled pain and beauty she could never escape. Thoughts she lived everyday, that never left her, that interupted her thinking and took her on unannounced journeys into the past without her bidding.

What do remember about where you came from?

"I remember the snow, white and bright, I could walk in the snow and no one would come after me. I remember rainbows in the rain, and flowers I could pick when I was alone. I remember someone hit me, they hit me on the head with a brick I was bleeding,. I could'nt think. They broke my head. I was little. I didnt know why"

Her train of thinking raced from her memories as a child in waves of fear and anger and worry of why no one wanted her, no one loved her.

"I miss my sister Vera, she loved me, she took care of me, she was good to me, she helped me, she wants me, I want to live with her"

She did not know her sister Vera, who she had been sent to the orphanage with, never had a chance either. She too had been abandoned and abused by her family, by her society, by men.....many men. She had turned to drugs and alcohol much the same as her mother. She

lived on the streets as a prostitute and was homeless the last time we heard about her in the courts.

What do you think about your parents, who adopted you?

"I know they love me......but sometimes they are mad at me, they punish me. I remember they made me sleep in the garage.........I remember they yelled at me.......I remember they got angry with me"

# February 27, 2004

#### Court decision

Miss. Yanna Besplova, a timid and apprehensive nurse who worked at the tiny local hospital in Yazicka, smoothed the wrinkles from her white apron with cracked red chill blaned hands. She reported that she came to see the baby Anya several times "to make sure she look OK" "everytime I come, I never see mother" "in most cases the children are alone and do not know where their mother is" "when the children were admitted to the hospital for care in dead of winter, they were dirty, hungry and were dressed in thin summer clothes, they were covered with dirty blankets".

In compliance with Titles 59, 64 and Title 191 and 197, the laws and regulations of the Russian Federation the mother, Tatyanna Guseva's, rights were terminated. The children were removed from their father, Gusev Nikolai Viktoriavich, and his care. They were then placed in the care of the Ulyanovsk regional Court and orphanages.

With this final and swift decree, my three daughters, Svetlana, Ludmilla, and Anya were moved from their home and remanded to the care of the Ulyanvsk regional orphanage system. First the babies (Ludmilla 20mo and 9mo Anya) were sent to the baby dom < home> and the older children (Vyash 12, Vera 10 and Svetlana 4) were cleaned up, fed and moved to cottages at the Ulyanovsk regional dietzky dom <childrens home>.

The fathers parental rights were never severed, the children remained in orphanages for the next 8 years, no one ever looked at their papers again. It was unquestioned common knowledge these children were there for life, they would never be separated from this fatal error in their social system. No one knew or dreamed they could have a different life. No one realized they would have choices. They were not free to be adopted, Russians do not adopt older children, only babies. They were not free to go to a new home, they had no relatives who could afford to take them. They had no family who would take on the reponsibility of 3 girls with enormous needs. They were in the system, with no way out, and no one to help them.

### On behalf of the Russian Socialists Federal Republic

April 17th, 1991, In the town of Yazikova, in the district of Karsun, the honorable judge of the Peoples court S.A. Ibraeva signed and sealed the court decision to remove the 6 minor Nikolaivna-Guseva children from their one room home.

The prosecutor of the Karsun district and juvenile crime commission submitted the application to the court to terminate the parental right of Guseva Tatyanna Aleksandrovna, birthdate 1956. Her children Vyacheslav, Evgeny, Vera, Svetlana, Ludmilla and Anya were removed from the house by social services. The court document read "due to the reasons that the mother is not responsible in raising her children, and on taking away the children from their father, because it is becoming dangerous for the children" According to Section 103 Title 59 "parents can be terminated the parental rights if it is proved that they don't cope and don't want to be responsible in raising their children and influence them negatively". Title 52 of the Regulations on Family and Marriage, "parents must take care of children and teach them different usedful skills". The facts were collected during the investigation from the neighbors and witnesses of the Nikoliavna-Guseva household. Several witnesses E. Khorkov and S. Bylinina the neighbors stated "we have known this family for two years, The mothers behavior became simply

impossible, the older children took care of the smaller children. The children were locked in house, they should be in school". " the mother spent all of her time with different men" " the children were always dirty, hungry and had no clothes. The mother is never home, and completey ignore the family"

The assistant director of the school in Yazikova, stated in court, the children could not learn when they did attend school, and they "could not cope with the programme". " the mother had never been to school" "during one year, none of the 5 children attended school at all". A member of the juvenile commission a Mr. Kulagian, stated that " this family was the most dangerous in our small community" " the children did not understand or have contact with their parents" the oldest boy Shirkanov had already become a criminal". "the main reason this boy has come to this is because these children have had no parental care since they were born".

# February 26, 2004

### Mommy I have learned a new thing~

And Lana sitting there at the small round formica table with her pudgy little hand wrapped around her newly made artwork struck me as interestingly happy. Content in this environment with locked doors, and people in white coats and uniforms, and daily schedules and hourly rounds and spot checks. She sat there with her fine brown hair loose and touseled. Little Goldielocks, the red blush roses back in her fair cheeks two weeks after her most recent admission to the hospital. The admission that nearly killed her, robbed her of her ability to stand. to think, to speak. This time she had taken a handful of Tegretol, to her it was "white pills". I found her laying in her bed in her own vomit, she couldnt even respond to my voice. Her face was ashen green, her eves looked out but did not not focus or respond to light. She sat there perched on the edge of her chair and smiled her sweet smile, a guirky little toothy smile, that makes you want to pinch her cheeks and kiss her forehead. She showed me her artwork, cutout pictures from a magazine, with ragged edges pasted onto colored construction paper. "what are you learning sweetheart" "about Africa Mom" "what else baby?" "I learned how to use a fork to cut myself too.....the girl in my room taught me" "and now I can use staples too" my stomache sank and turned as I asked her slowly " Staples for what Lana? what would you do with a staple?"

She studiously showed me in great detail how to take a staple out of the top left hand corner of her behavioral chart and pull it free unbending the clamped corners of the stapled wire. She pretended to hold a small staple between her thumb and forefinger as she intently proceeded to open the staple up and force it accross the skin of her forearm.

"you can make it bleed Mommy"

"they have taught me even more things now"

"but I am not thinking bad things Mommy, because now my thoughts are good, they are not going to be bad anymore"

"I learn bad things when I am in the hospital.....but I won't do these things anymore....."

She cocked her head to the side and put her finger to her dimple just like Shirley Temple. I looked at her and thought this is what Shirley Temple would have looked like if she had of been completely mad~

### February 26, 2004

# "every human being is fixable"

He never even shifted his weight as he stood there transfixed both hands down on the table, fingertips touching the wood top the whole time he spoke.

We were one in that moment, we thought together, what I knew and believed he said. He told them what we wanted to say, that we would move the world to help these children. That what they did not have for the first 12 years of their lives they would have forever from that point on. That everything they had been deprived of would now be theirs for the asking, and more. That we did not believe human beings were unretrievable, uncurable, unfixable. That we knew in our heart of hearts we had all that it took to save them and we could and would do that.

# February 26, 2004

#### "we have the resources"

The whole courtroom looked to my husband and I, and I was asked to be quiet and not speak. I had not learned to keep my tongue and stay my anxiousness in a society where a womans word is not wanted. I was not comfortable with my husbands ability to speak for me and for our children to be. The children we have fought for 2 years for, have spent much of our savings for, had fought Moscow and the National Registry and Ministry of Education for. The children we waited together through infertility, and surrogates leaving and county foster social workers insulting us. It had been 10 long years of trying it all, and now here we were face to face again with the biggest impediment of all to stare us down. Our children, our adopted children to be, the children of our dreams were branded in a society that did not care for them, want them, and now they were attempting to brand us too. They wanted to make us unfit to parent, incapable of doing what they couldnt do.

My husband stood up and faced the judge, and with his deep resonant booming voice said everything I would have, could have, wanted to.....

"We have the resources to help these children. We have the medicine and research and science to help them with whatever is wrong with their minds and bodies. We have the schools to teach them, the doctors to care for them. We have the psychological specialists, the learning specialists, the speech and motor specialists. My wife works with children with learning disabilities, we have raised a good and strong son with many of these same behavioral difficulties. He is now in the United States Air Force. He has taught us many things about how to work with children with behavioral and learning differences. We live in a city near a teaching university that specializes in neurobehavioral research and training. We have access to everything we need to raise a child with difficulties. We have availability to the best doctors, hospitals, therapists. We live in America. We live in a country where everyone has a second chance, and no one is left behind. We have laws to protect every child with all disabilties". My husbands ardent impassioned breathless diabtribe began, lasted and ended in 5 long and short minutes.

### "What makes you think you can save them?"

I remember standing in the small Russian courtroom, we and our fleet of coordinators and facilitators and translators were on one side of the room. The prosecutor, the state appointed attorneys, the local social workers, the Ministery of Education representatives accross the room. 1950's style mass produced dark wood and tubular steel ables and chairs lined up against adjacent walls. The floors were time worn wood that clicked when you walked on them. The walls were tongue and groove wood paneling. Thick painted wallboard completed the wall above the paneling rising to the canopy where miles of exposed plumbing and electrical snaked perpendicular to the ceiling. Everyone in the room appeared to have stiff,

stoic, passionless expressions on their faces and in their body language. There were a few, the ardent translator, the impassioned coordinator, who still believed a life could have a new beginning but most were concrete in their thinking these children could not be saved. This was not a contemporary *Law and Order* courtroom. This was a *Perry Mason* courtroom. If it were not for the leggy looking green plant stretching for light in the corner of the room there would have been no color at all. Everything, everybody was black, white, gray and brown. The palette of daily life in the former soviet union. It were as if the monochroamatic settings were fixed on our mental camera lenses, the aperture was diffused, the speed slowed down and low visibility was the way it seemed in this days cold reality.

The judges simple podium and chair was on a raised platform and at right angles to our line of tables. She asked us in Russian, our translator translated "how will you take care of children with the serious problems of these children" "do you know their mother was an alcoholic?" " do you understand their sister is a prostitute" " their father is uneducated". " Do you think you will do better than the Russian government has to feed and care for. and educate these children" " these children will never be normal, they have lived for 9 years in orphanages" " they will never be able to read normally, or learn, or act without the insanity of their mother and the indolence of their father" " this is a crazy family" "what makes you able when Russia cannot?"

## February 23, 2004

### She invades my sleep

I had a dream last night that my daughter was OK, that somehow I had misunderstood her and had misread her. She looked at me with a quizzical look and asked me "what is wrong Mom? I am fine" "I don't know why everyone keeps holding me back Mom......like I am some kind of baby or something" "why am I in special school Mom?" "I can read like everyone else, I'm not so bad, I'm getting it".

I looked at her hard and wondered how I had made so many mistakes in judging her, reading her. How had I thought that she could not make decisions for herself, that she could not think through anything without losing her train of thought? I looked at her and her sweet smile and lovely face, and thought I have made so many huge mistakes.....there is nothing wrong......she is fine.

yes that was her......I could feel that little butterfly in my stomache that is always there when I first see her, my heart quickens, my breath is still. That is her......that is *my* baby. How did I not know that she was alright? this child who is with me all the time, she invades my sleep, my inner most thoughts.

Oh yes... that is right.....my sleep.

She invades my sleep.

Now I am awake~

### February 15, 2004

#### Watercolors

I study her soft watercolors, washed pigments of blue sky and yellow sun. And I know the loving touch, the sweet hand grasping the chipped black school brush, the twist of the wrist it took to transform this now dried and puckered paper. A soft picture of an apple tree, watery and blended. The greens of the leaves, red of the apples and browns of the trunk once sharp and crisp now an intermingled fog of tints and hues.

I remember her first art set, the excited look in her eyes, her face her composure. She had never had her own paints, never had a doll, never owned anything that was completely hers. And then in that chrystal moment she was handed the magic box, an open portal to her mind and her unexpressed abilities. At first she was not sure the art box was all hers. I was never certain if she was confused or if this look was just part of her normal blunted way of perception. She made no eye contact, she always looked away or down, but never at me or to me, she was never really with me.

I handed her the white birch dovetailed and brass hinged box with the words Prang hotbranded accross the flat front. Inside were rows of pastels, and watercolores, oil crayons, and markers, and pencils of every shade. She took the box tentatively from my hand, at first not sure of the weight nor the handle, then she lifted squarely with both hands and it was hers. This unbelievable gift that to her had never even been hoped for. For her life had not been allowed posessions of luxury, of education, of knowledge.

She had been culled from her sisters when she was only 5years old. "she can not keep up" " she is not capable to learn" " she will not be allowed to stay". And for her, this breif year and moments of normalcy at Cherdakly orphanage were ended. She was transported to Krasmabor, an orphanage so far away, so far out in the country, so distant few had been there, and even fewer were allowed there. She was labeled *oligrephenic*, mentally retarded, and sent to a place where only the worst children were sent. The "bad" children, the "children who did not want to learn" " the children who deserve to be there for they are lazy".

The vaspatatia were unflagging in their insults and criticism of the children who were sent to Krasmabor. "They go there because they don't want to help themselves!".

### February 14, 2004

### Toxic children

There is the now classic "toxic personality" pop psych theorum that everyone subscribes to......stay away from people with toxic personalities, keep them out of your circle of freinds, don't marry one, try to limit your relationships with them as they can bring you down, poison your emotional well being, thwart your daily balance efforts.

But what do you do with a toxic child? A child who rants and rails, and yells and storms, and screams and threatens. A child who snappishly triggers with the slightest comment and flays you emotionally without any thought to your feelings. A child who has no barometer for your susceptabilities. A child who is an abusive loud speaker, a word warrior, an expressive genius with the turn of an insult, a cut, a bludgening phrase.

A child who has no verbal boundaries, no idiomatic parameters, a child who shoots with oral bullets and aims to kill. A crazy mad, insane kind of murder, that of your immediate consciousness, your transitory ruminations, your momentary mental peace. An annihilation of your pure train of thoughts. A child whose words are nuclear, immediately poisonous. Toxic venting meltdowns.

What do you do? it is a child..... it is your child.

### February 13, 2004

# It must be Terrifying to be That child

And she cries. Sad, wet, closed mouthed cries. Cries of unrelenting anguish always trapped there just under the airy ice of her momentary existence, pushing against that thin veneer of newly constructed happiness the "who I am right now" because I can't think backwards and there is no forward.

It must be terrifying.....

To live in a place where children are wharehoused. So many children, so many kids without mothers or fathers or families. Without homes to go to, grandmothers to dote with uncelebrated gifts and folded bills pressed into your palm. No seemingly stern aunties to admonish with a wink and a loving perjorative. To exist with careless caregivers who stay detached from you, keep their emotions from you. Who are instructed not to get close to you, are not allowed to touch you, sense your pain, express their concern. It must be terrifying.......

To wake up in the morning and see so many children like you, who have no home. Who were "saved" from their own families. Saved from the dirt and filth and abandonement that was a daily existence until they were spirited away. Picked up and removed, like so much baggage. Children without choices. Children who made the mistake of being born to the wrong parents. It must be terrifying to hold back those thoughts, those feelings as you stand in the long line wide awake and waiting to have your tonsils sliced from your throat by a cold steel knife. Alone in your own fears with nothing on but a crisp white shirt to capture the frothing steaming blood as it pours from your lips onto your shoulders and chest.

It must be terrifying to stand in line for your meager meal and know other children can sit down to a table in their own home, with their own plate, and knife, and spoon, and fork and they can oh so casually say "no more Mom I'm full" " no thanks I've had enough".

It must be terrifying to lay there at night and know you will never have a chance beyond those windows, outside of this room, beyond these grounds.

It must be terrifying to be branded an orphan. A silent brand, a quiet unspoken brand, a brand no one sees but everyone percieves. A brand you carry to school, that sits with you at your desk, that seems to be on your dress your shirt, everyone seems to see it, but its not really there.

#### Who am I?

"Why did you adopt me?" "Who am I?" "Why didnt you leave me there?" "No one loves me.......No one wants me.......No one cares for me"

The visceral gut wrenchingness of these questions hit me like a burlap bag of sand square in the chest every time she cries them.

They are the age old adoption questions. The unspoken.. unsaid...

" Hope my child doesnt think them"

"Hope my child is spared these" questions.

These are the questions every adoptive parent never wants to hear, cannot seem to erase, cannot seem to escape, cannot seem to get away from.

How could a little girl so damaged, so hurt, so cognitivley unable to worry about such existential things understand these abstract questions? And yet she does.

She does.

And she brings these questions out like they were her banner, her poster, her advertisement. She wears them and announces that she is the unhappy adopted child. The one that everyone

theorizes about. The adopted child who wants to be birthed again. Who cannot picture herself in her own shoes. Who cannot put the two mirror images together in her own mind.

Can she extrude abstractions through the concreteness of her perceptions? Can she wonder about what might have been? What...? who..... she could have been if her world had been perfect?

She does.

When her life is bottomless, and the dark damp heavy fog of depressed thinking has taken her over she cannot see the new lightness of her existence. She is unable to see the bigger picture, the picture with hope and love and reason. Her life with a family who cares for her, wants her, needs her, will go to the end of the earth for her. She cannot see these things for she only knows she *was* unwanted. She only feels the tears in her psyche which will never be mended, scars that will never be smooth. Angry red ripped scars of her memory that will never have a happy ending, no cosmetic uplift, no artificial disappearing. They will forever be there, waiting for her depression, her anger her pain to resurrect them.

Does she know she is loved now? that her adoptive mother and father are the ones she was supposed to have?

She does.

But when she is lost......she doesnt care.

### February 12, 2004

#### **Ludmilla and Anna**

Two little girls, one little report, one little video and both sides of the world changed. Ludmila: DOB 1/12/87

Weight at birth 3.7 kilos, apgar 7/8, head circumference 36m, was the 7th pregnancy, 5th delivery, was exposed to TB, has bad posture. Is reported to have a cheerful nature, is hardworking, and is a good leader. Ludmila is good at reciting poetry and folkdancing.

Anna: DOB 1/30/90

No birth info, is communicative, hardworking (she irons and washes her own underwear), quiet and shy.

The girls were sent to the orphanage in 1991, we don't know why. *Tree Adoptions*And for these two little girls so simple, so neatly packaged, so uncomplicatedly notated, their lives were to veer. Into and onto a path no one could have dreamed of, expected or described. These somewhat careless descriptions would be the progenator of their future, the naive and unsophistocated threads that would carry them and their amazing story across the globe.

### February 11, 2004

#### **Loves Selection**

Adopting is about hopes and dreams.
Hopes of a family
Dreams of a mother
Dreams of a child
Dreams of a daughter
Dreams of a father
Dreams of a son
Adoption is a marriage
a blending
a weave
of love
from hopes and dreams

a family marries
A child of another and a mother become one
It is a choosing
This is not natural selection this is not random selection. it is
Loves Selection

## **February 5, 2004**

#### Her Wars are Hardwired

I remember wondering if this would be my last day as the chandelier glass began raining from the ceiling. All it took was one moment, a book unleashed from her hand, and jagged chrystaline precipitation was crashing down on my head. I could hear the crackling of glass and and crystals shattering above me but I was riveted to the ground below the fragmenting shards. She had been screaming for an hour. Loud disjointed, irrelevant, ranting that went on and on and had no subject or story. Riotous earsplitting howling that came from her confused emotions and unfounded fears. Mental panic that often overtook her tenuous grasp on logic, drowning her in an ancient horror programmed in her nervous system.

I was not the hated one, the tormentor, the angry caregiver, her enemy. But to her, caught in a nueronal maelstrom, fighting her way through her miswired senses I was the one to kill. She stood there at the end of the long room, the office, our beloved project room. The very same room we sat in daily. A safe room, a working room, a learning room. A room we lovingly pour over science books and struggle through English assignements. Today this room for solace and knowledge was a feirce battle ground, books and papers hateful anger grenades, pencils and pens dangerous bullets.

She lunged stooped and grabbed anything within her reach, and everything she touched became part of her library Gattling gun.

But I stood my ground, I did not move to her advances, I knew I must show a gentle defense for her threatening intentions were not willfull. She was not my adored child in this split second in fear, she was a lost and fearsome hurt child. A child who does not know or feel or think. Her war is hardwired within her brain, in those frenzied agitated moments she has no conscience, no regrets, no remorse. For these are the distilled qualities of forethought and planning and remembrance, and to her in these moments of her insanity these attributes do not exist.

### January 31, 2004

### Now this is what You have to do~

Lana was flipping out about something (doesnt really matter what~) this morning and stormed into her room, whined a little, cried a little, slammed around a little, and then came back to me with a book in her hand. It was the "Teaching Social Skills to Youths" book by Boystown USA. She has had it for about a week ,and took it to school with her. Her teachers loved it~ She brought the book out to me and flopped it down on the desk beside me and pointed to a page "Accepting decisions of authority" she pointed to this particular page and read me the instructions:

- 1 -Look at the person
- 2- Remain calm and monitor your feelings and behavior
- 3 -Use a pleasant or nuetral tone of voice
- 4 Acknowledge the decision by saying "OK" or "yes I understand"

She fumbled a bit on the big words, but that was OK, she looked me straight in the eye afterwards and said

" Now this is what y o u have to do!"

## January 26, 2004

## Who said, Why me?

What's Up? Who said? Why me?
That I should raise a child with F A S D
That I could have a child who cannot love me?
A child who will not understand me?
Will never know me?
A child who will live inside her mind, caught in time
Will never grow up
Will never mature
Will never be mine.
No way, who said, Why me?
I will never know
Will she?

## January 13, 2004

#### Untitled

She who gave birth to my precious dreamed for daughters, also gave birth and life to 7 other children, ten all total. She behind the impenitrable wall of political concrete and cold tension, without care or desire had the 10 children I had always dreamed of. I have often wondered what she thought about as she carried my children in her belly, or if she thought about them at all. One child so permanatly destroyed by the effects of alchohol on her developing fetal brain, another bright and inquisitive but still forever damaged, and then one child with no effects at all. How does this happen? When she was carrying Anya was she happier? When she found herself pregnant with Lana was she more depressed? Was the man she was with different? did he like her more, did she like him more? What was her life like? Did she care? I sometimes finding myself asking her "Tatianna, what were you thinking?, was your life that horrible? did you know you were going to have a child? a person who would come out of your womb, wet and new and wailing ready to begin their life? Did you forget between each pregnancy?

## January 4, 2004

## 3 Daughters of Russia

Well I have been journalizing for 7 years, and I have been considering writing my own American novel all of this time.

I guess I need to get on the stick.

If you go back and read some of the diaries and blogs in these journals you will get a picture that I have 3 very different girls.

One seriously wounded by the effects of alchohol and mental illness, one defiant and oppositional and yet still unbelievably adorable, and one sporty, ambitious and level headed. And I? ...... well I have a rather colorful history myself. So the journey begins. How to weave all of us together, as we have in life, can we do it on paper~

### **December 24, 2003**

#### That FAS moment~

And in those fractuous moments, their life long inebriation is apparent.

They will never be completely free, they will never know the stability of sobriety.

For them stress is the forbidden injection, it is a switch, it is a snap, it will upend them, it will throw them off, throw them over, throw them down, it is the ubiquitous mental cocktail and it is always there....

waiting for them around the corner of everyday daily life.

### **December 23, 2003**

### The conundrum ends

And so as time passes as it always does, and life goes on, and somehow right reveals itself, our lives have a measure of temporary peace. We have had time to think and heal, and rejuvenate. Lana's respite has worked well and we are all better for it. My Medical has been restored so I can see a doctor once again. And Christmas is upon us. My mother and father got over the stealing, and gifted us with a nice check to help buy presents for the children. Lana is not forgiven but her actions are in a small way forgotten, at least for now~

## **December 21, 2003**

## The legacy of Respite

I woke up this morning and heard the birds singing outside my door.

These were not the same birds from everyday. The birds that twitter and become part of the busy sounds of the impending day. Their broadcasts a vibrant part of the cacophonic mileau of the morning sounds.

These were the musical birds I heard as a child, walking to school in the brisk morning air. Stepping over the threshhold of my door, rallied and refreshed from a good nights rest. At first one small voice, then I would hear them all. They twirped, and chattered in mass and I could smell the crispness of the atmosphere they flew in. I did not need to see them then, I do not need to see them today, for they are always there in my memory waiting for a day of rest and clarity to crystallize their voices. The open aperture of my memory pictures them winging their way from tree to tree chirping and fluting to each other, today is a new day, a day of teeming life and promise. They fill the air with their sound, they fill my mind with a rush of youthful beginnings and innocent expression and mental clairvoyance.

Why do these birdsongs come to me this morning clear and resonant? Why can I breathe and feel the air that touches my senses, my face, my skin, my lungs today? The birds have been there, the air has been the same, the pale blueness of the sky all in place. But I have not heard them, seen them, felt them.

I have heard the argument that *Respite* is not measurable, it does not have the value to condone its cost. There is no mathematical factors to calculate its return. There are no research based evidences, no labs, no scientific studies, no laws or acts or bills in place to support the benefits.

*Respite* is a soothing vacation, it is a life rendering medicine, it is a therapy, it is rest. *Respite* is mental and physical peace, it is a chance to breath, it is a gift with no comparison.

And so, for one benevolent moment I have received the largess of deep sleep, and I have rested sweetly. I can think and feel and smell the air once again. My heart is not quick, and my fears are at rest.

I can once again go outside my door, and I can hear those beautiful and precious birds I had forgotten were there all along.

## **December 10, 2003**

## Limiting life~

So far in home respite has turned out to be an incredible solution, Lana has one on one attention, someone to care for her and attend to her needs every minute. There have been moments though, Thanksgiving broke down her pattern of daily routine and structure. And so she went on the warpath and looked for pills. She found some in her Dads' cabinet out in the garage (old stuff) and took a couple of handfulls. Once this happens it takes her days to recoup. Then on another day she was perseverating about cutting, couldnt find anthing so she cut herself with some foilwrap from the Christmas stuff. Duh!!

Oh well, lots of lessons learned.

Structure, pattern, predicatability, not many choices, not too much stuff around, daily routine, not too many changes. And she does well. Not real life. But for her it works best.

## **December 9, 2003**

# Forgeing love through Tears

Like the molten meld and making of metal, the mix of mental mass and the burning off of psychic impurties a uniquely dense love can be forged.

Not a love light as air, or fantastically free
But a love with weight with a solid core.

This love cannot be shaken, will not dissolve, will never break. This love has been molded through pain, and tragedy and fears

This love creates its own balance, its own center

A molten memory of love

### December 2, 2003

forged from tears.

### Nice Break but knew it couldnt last~

Three and a half whole weeks of luxury, no screaming, no yelling, no threats, no crying, banging, throwing. All the powers that be, child protective services, child youth services, social services, childrens systems of care, county department of education and the courts all came together in a last ditch offer to keep our abandonement case out of the courts sytsem and agreed to my request

" a caregiver, in our house, whenever she is awake!".

So we have had someone here from when she arrives home from school to when she goes to bed, and on weekends, every day 8am to 8pm.

Has it worked? Like a charm, did it last? As long as everything stayed structured and predicatable. The Thanksgiving Holidays were the rub. Nothing happened really, we had a good time, everyone came here, and she had a caregiver too. But her daily routine was broken, and then the holiday decorations anxiety began. All of the boxes in the garage to be put back from Halloween and Thanksgiving, all the new boxes to come down for Christmas. Seems an exciting benign thing, but for Lana, too too much.

So the other night, while we were working upstairs in the bathroom, fixing up the shower, her Dad left the lock on the cabinet in the garage hanging on the latch. The cabinet where he had

stored some of her old medications. And she just happened to be sitting there on the floor patting the dog, and she looked in and spotted them and...

the "thoughts in my head told me to take some pills " "what did you do so you would not listen to the thoughts Lana?" "I hit myself on the head" "I hit my self with a pillow on my head" "but you still took the pills sweetie??" "yes I couldnt make the thoughts go a away"......So she overdosed herself again, and the last two days has been watching her go through a total stoner, and the drugs she took are pschotropic drugs, so her face went all limp and lame and swole all up. And she couldnt walk, and she just kept sleeping.

## November 8, 2003

## We cannot take her home part 2

Lost children, children with no connections to their own self, who look at themselves in the mirror for hours and are surprised that that image is their own. Children who were not loved when they were but fetuses, not yet breathing air, wrapped in their mothers womb, growing in a bath of salt water and ethonal and the sounds of hysteria outside their warm room. Children who recieved no blankets, or nipples or tippe cups. Who cryed with no answers or touch. Who's wet tears were not blotted, whose cold feet were not warmed. Children who laid alone, agitated and forgotten. Children who grow up not trusting or knowing who wants them, loves them, cares for them.

### Children of no awareness

How do we understand these children? Children who have no awareness of their past present or future when they are living in their "moment". Perplexing and persistant explosive moments, that appear like a slice in time and isolate and insulate and cocoons them from their own conscience.

Moments that only they exist in, although you are standing right there. They look at you, but they do not see you. They scream at you but they do not hear you. For they are living in their rage, and their internal time frame, time bomb, time warp.

These children who will reach out to touch and love anyone, anytime, anywhere, who will become "best freinds" in an instant, without fear of consequences. They who have no naturual bonds, no real emotional attachments, but they can magnetize to a complete stranger as if they had known them their whole lives.

Children who take their fabricated pain, internal terrors, and allegations of abuse to strangers, and have no cognition that this will hurt the ones that truly love them, who truly care for them. They lie, they steal, they twist what's real. These children who I have come to know so well, and yet do not understand my own.

My own darling child. My beloved girl. My sweet kitten. Who I have hidden, have protected, have taken the blame for, endured the shame for. She who has taken my soul, and still it is not enough for her. For she has too many chaotic moods, too many contradicting selves, too many fractuous moments, and I have only this one bludgeoned life to give her. She depletes me, she exhausts me, she uses me, she abuses me, and yet she tells me I am not there for her. She can be the willing avid learner, the determined reader, the sweet devoted friend, the caring nurturer. She can be the cuddly bear who loves to take a shower and be all squeaky clean for Mommy, who loves to decorate her room, or clean the house in a sweep of dusting and floor mopping and bathroom cleansing energy.

And yet it is also she who steals and skulks and knows where to find the knives and pills around the house. Who slides out of view to slip a \$20.00 bill from my wallet and run to the corner market to buy pockets full of candy. It is she who hides tools from the garage under her

mattress, steel tools to poke, to slice and prod her soft unwilling skin when she is angry and her temper is flaring and she cannot get her way.

Who is this complicated child who can keep herself in check all day at school and yet comes home ready to charge, and burst, and meltdown and rage. Who in her rages manifests the vocabulary of a longshoreman and the cunning of a temptress. Who throws, who slams, who bangs who hits, who spits and vomits, who shakes and shivers, who is restless, and twitchy, sleepless and witchy.

Who can arbitrarely manipulate the fears and tensions of the whole household in a moment of rage. Who can clear the room of every breathing inhabitant she is wrathrul of, and then in a split microsecond call 911 and draw the rapt attention, compassion and empathy of everyone who is willing to listen to her tales of abuse and neglect.

How do we live with these children with no awareness of themselves? Who live in their moments as if each day is a new day, and everything they have done in the past does not exist. Who have no sense of consequences, of personal responsibility, of logic, and honor. How do you deal with someone who has no awareness of their impact on everyone around them?

### "We cannot take her home"

And so 5 years later, it seemed inconcievable that I could stand there in the emergency room, once again, after many visits, visits for so many reasons my head was exploding with the too tightly packed memories. Memories that seethed with anxiousness, and nausea, and fear, and panic. Memories that overwhelmed me so that I felt I would faint, or fall down, or throw up, and sweat. Sweat that seemed to erupt from every pore of my body, as I stood there for I knew the consequences of my words. That I could not, would not, was not capable of mothering this child. That her needs exceeded my abilities, that her pain was not within my nurturing, that her mind and love was not mine. I stood there amongst the stainless steel tables, and polished linoleum floors, the abhorant nurses and the slack jawed child protective agent, and said I could not, would not, take her home. She asked me slowly and willfully "do you understand the ramifications of what you are saying?", I looked at my husband, and over Lana, curled up amongst the sterile sheets and blankets, crying "they don't want me" they hate me" and said once again "I cannot take her home". I knew what that meant to me, and my husband and my family. But they did not understand. They could never know of the chilling terrors of living with a child who could take a knife and slice herself willfully, climb on the roof of the house and threaten to jump, hoard and take pills for the slightest infraction of her constant demands. Who wails, and screams, blood curdling ferocious gut wrenching screaming, that never stops until the neighbors call the police, and they all come in droves to constantly remind me, how to be a parent. Who can, in an instant, change from a sweet loving affectionate child, to a red faced bloated sweating monster who takes captive the whole house, the family, as she rants and rails, and threatens to do harm, to herself, or to me, her mother, who loves her beyond reason. I who have spent countless hours, reading, researching, have lost my job, my passions, my interests, to focus willingly, intensly, passionately, on anything and everything spoken, written, or taught about children such as her.

### The album

For Lana and I, somehow we both imagined each other as maleable lumps of clay. From the beginning, she in her world of fantasy and fog thought all Moms were princesses and families were people who had no faults or discontents.

I in my mind of art, architecture and design saw this damaged child as another unconstructed space, a line that needed a point of reference, some slip that needed a vessel to mold. She never really even thought about having a *new* Mom, it would never have occurred to her. I still remember her eyes, as we sat there together on the edge of the little wooden orphanage bed. She looked up at me as I pointed to the pictures on the album page, a picture of our home.

our elaboratly decorated living room, and a picture of Anya and Ludmilla her sisters already smiling there on the pate. I held her cut out photograph in my fingers as I opened the plastic sheet and added her to the black paper page beside here sisters already there in the album.

At first she didnt understand, she didnt recognize, that this meant she too would be part of our family. She didnt even really know that Anya and Ludmilla, her sisters, were being adopted. No one explained to her about such things, that a child could get a new family, a Mom and Dad that were not *her* Mom and Dad she had always dreamed would come and get her and take her home, to the little cottage she had always remembered in her dreams.

She never conceived that a child could live in a far away place, in a far away house, with people she didnt know, and they would be called Mom and Dad, and they would be called her family. She looked up at me with her fragile oval face turned just a little sideways, my first clue that for her the world always was a little sideways. Nothing was ever really straight up, as it should be, not even the way she thought, or felt.

She looked down at the album, and up into my eyes, and once again down, and once again up into my eyes, and then she shook her head in acceptance and awareness and a sweet gentle smile spread accross her face. She knew, and I knew that she would be part of her family. But to her it was a book, with cutout pictures, cutout pictures of her and her sisters, and they were glued on a page of a place she did not know.

One day many years later, as we talked about this day and this moment and I askedher if she understood that she would be our daughter, that she would someday live in this house, this picture,

and she said "no"~

## **November 2, 2003**

# What's her problem?

What's her problem?

Why is she crying, why is she upset? Why is she angry? Why is she confused?

Everyone wants an answer.....

Doctors, teachers, therapists, policeman constantly ask these questions as if the answer to the moments trigger will make up for a lifes root cause.

They probe and interrogate, dissecting every instant, contemplating each second before the psychological scism, the eruption, the volcanic event

Such idealism

From proffesionals who would normally expect empirecal evidence, solid confirmation, or concrete proof

But not to the explosive origins of the behavior of a mentally ill child

No for this they just want to know

"what happened!!"

As if knowing that moment of that day made any difference at all

### October 15, 2003

## Will I like it there Mommy?

I'm so sorry for you my precious one, so confused, so hurt, so unaware and disconnected from your own impulses. So disabled from your own thoughts, your own imaginings, your own treacherous ruminations.

I feel the warm down of your hair against my cheek as you wrap around me. " I love you Mommy"

I, knowing underneath your fresh white t-shirt are long fresh blood stained tracks accross that sweet skin, that soft pudgy little tummy, from too many chocolate chip cookies, and candy your favorite thing in the world.

"what will it be like Mommy?" " will I have freinds there" " will it be like my house, Mommy?" "It will be a place where there are other children like you sweetie, kids who have problems like you do my darling...who have anger they cant stop, and do things they cant stop, and do things they dont' want to"

"will I get to go have a job there Mommy" " will they let me have my clothes? " " I think I need new clothes to go there Mommy"

They wont have things there that you can hurt yourself with baby, you wont be able to get things when you are angry, it will be better there, and when you need help, there will be someone to help you with your brain, they will help you remember to take your medicine, and help you when you don't want to take it.

She looks up at me, with those eyes. Those eyes that look mad and needy and loveing all at the same time, and she nods yes, and feels secure. And is good and happy, that she will be somewhere where they know her and what she will do, and knows she has no control, and she knows that too.

## October 13, 2003

## Manipulation

Very interesting part of manipulation, the child who is the best manipulator becomes the child everyone listens to the most. But she is also the most needy, the most sad, the most wanting. She will take her tales to anybody when she wants to get back at the other person, sister to sister, sister to mother, and carry a tale to anyone anytime when she wants attention, or sympathy or stuff. Watch out for the manipulative child for they are very wanting, and they are able to pit one person against the other and get what they want. Don't be afraid of this person, and don't judge them as morally incapable, they are just doing what comes easy to a person who needs to survive. They get what they want and need, in those moments they are not thinking about feelings or respect or dignity, they are just getting. And getting it must be. Be careful, be watchful, and be not afraid, but be watchful and cautious and do not be lead.

## October. 3, 2003

### Mental Health Services, a conundrum

They say in our perfect society where there is a department for everything, a station, an organization, a policy, a law, an officer, a specialist, a teacher, a leader, an advocate, a senator, a congressman, that if you are a good citizen there is someone there to protect you. They say in our idealized, copied, sought after system that everything is set in place, organized, alloted, well designed

But what about social services what a morass Mental health services, a conundrum School services a joke Law enforcement services are part of the circle An unbending, unbreakable, inaccessable ring That only circulates within themselves And your unique set of circumstances Will not allow you to navigate their territory You will not be allowed within their boundaries And there will be no help And no one will be there for you No one will really be there.

# October 2, 2003

#### Confabulations

Stories

Lies

**Fabrications** 

Threads of thoughts that come from nowhere, have no reality, no truth...

For them it is reality, it sounds real, they believe it, they project it.

And everyone believes them, they are witty, they are charming, they are sweet, they are believable.

Everyone listens and everyone believes, the teacher, the school nurse, the lady at the drug store, the librarian, the kids at church, the youth group, the lady at the amusement park, the nice policeman, the fireman, the neighbor, the bus driver, the shop owner, the coaches, the parents.....

And so they go on never stopping, never feeling any remorse or guilt, or shame, or regret for what they say, what they convey, what they relay.

Confabulation.....

big word for lieing~

## **September 30, 2003**

#### Moments to remember

Teaching Lana to do the air wave with her hand out of the car window

Lana getting her tent, then going to the beach to find a tent ground to camp out in Lana and the dance at school, the picture of the dancing couple on the school paper, the overstimulation, the rage, the fight over the dress

The evening of the chocolate icing and the glass mixing bowls, all the girls fighing in the computer room, Lana's bite on her back

The evening of the restraint by Pop, and the ER visit later

Amy the behaviroal coach, and the "trained seal"

Mia, her freinds, Lysette, going to the dance club, the meth lab, the Four Seasons Hotel, and the guy who stole the computer, Mia sitting in the backseat of the police car

Mia going to school with her gangster prison outfit on

Meeting officer Wolf in the school parking lot, the discussion about how the school's admin believes the problems with the girls is "the parenting"~

Mia hanging with Shelley and Shelley's brother, Mia and Shelleys dad

Mia and the 4 kids invitation to our house for a pool party which turned into 150 kids, the police, and a drunken brawl outside

The evening of the party at our house, and all the things that got stolen

The boy Chris who took my wallet and ended up on the streets of CM with my wallet in his backpack

## **September 27, 2003**

## Being in Love with your child~

And after the storm has passed and she is in the calm, I softly kiss her precious face, placing my lips on still wet and warm, closed eyelids. I feel the tickle and curl of her eyelashes against my lips, and that sweet depression that I love to touch with my cheek and my fingertips. I kiss the cashmere skin of her cheek, fleshen velvet, delicate and cherished. I kiss the ridge of her nose, her gently padded forehead and the pungent oiled-sugar aroma of her skin overwhelms my senses. The tip of my nose and nostrils finds their way into the first strands of hair that rise from her forehead, ascending in waves, gradual tendrils of silken fibers with the mysterious still present scent of newborn baby and fragrant rose scented shampoo. I am at once quickend and overwhelmed, my head is rushed with my own senses of nurture and parental passion. Instincts of hormones rush through me brought on by her bodies prescient pheromones. They flood me like morphine. I am taken into a place where only mothers go. That existential awareness, that of a child and its mother. That which dips deep below consicisousness, beyond cognition, past rational thinking. Into a place that only a mother can smell..... feel..... be.~

And from this mothering place, I draw my strength, my resilient resolution, my willing forgiveness. This well of cherubic fragrances, child born sensorial drugs, that soothes my ardent anger, frees my constant frustration, clears my confusion. From here I dip in the well of my resolve, and I can let go and be calm, and know I will always love this child~ September 25, 2003

### 3 Horses

Svetlana, Ludmilla, and Anya~

Driving into the Lomborsky orphanage was a total surprise. It looked more like driving up to an estate than a dietzky dom (childrens home). An Italian estate blended with a lushly landscaped stately soviet appearance. I couldnt see any buildings as we were lead onto the grounds through several long convergent country lanes that all met in the middle, then at once leading towards a massive monument of bronze on an angulare concrete plinth. Tall, lean and handsome, three youths with arms held skyward they all raised a winged dove to the tips of their fingers at once leaving their hands to ascend to the clouds. There were matched collumned Italian cypress lining both sides of the road as you were directed towards the statue and then in circular form around an into the orphanage acreage. And acreage it was as this orphanage was a collective farm, with miles of orchards, and a working farm with livestock. As the road widened the view of the multiple buildings put one in mind of mountain architecture, rough sawn heavy beam construction, with alpine features and high gabled rooftops. The roads were unpaved but neatly kept and maintained with loose rock and gravel broadcastment.

## Suspicion

bring trouble into your house,

cause trouble,

get you in trouble.

Trouble is attached to them like a leech. They are symbiotic the host and the parasite. And like a leech, trouble drains everything from the host. They reach out to gain strength, and sustanance from everyone and everything around them and they take it and move on without

appreciation for what they took or how they recieved it. They feed themselves and the trouble within in them.

And you are always left drained, tired, and waiting for the next wave, because they will get in trouble again. And you will be involved, called on to help, to bail them out, to assist, to support. And when the outside looks in on you, and your trouble, it is you who will be blamed. You are the suspect.

### **September 23, 2003**

### Orphanage 3

These beautiful children, my children, the children of my heart. That I had hoped for my entire life. The children of my dreams, of my losses, of my parental urges, my primal screams, my instincts to survive and carry on my lifes heritage. My children but someone elses children too. The children of their birth family, the children of the orphanage, the children of their homeland. The fresh air wafting briskly across the inside of the car seemed flat for a moment, as my emotions and feelings, memories and thoughts collided. A collision of what if's, what has been, what will be's and fearful fragile what might be.

## Orphanage 2

I wondered, how these blissful sensorial memories of the crisp Pennsylvania air would affect my experience when I reached the home. Would these nostalgic aromatic remembrances affect me as I arrived at this days destination. This far away place, the land of my children, the end and beginning of my lifes journeys. These frosted visions and scents and fragrances of the Russian winter, how would they impact with the reality of what I would see and experience when I finally got there. To this mysterious place, these unidentified people which held my hopes, my future, my children in their hapless and unknowing hands. I wondered in my solstice reverie what would I do if things were not as I wanted them to be. That my children would not want me. refuse me, not like me, not love me. And this nostalgic land would not be as I thought I remembered it in my childlike memories warm and hospitable, but instead harsh, cold and unforgiving. Because this was not Pennsylvania, and it was not my grandparents farm, and there would be no warm fragrant kitchen filled with freshly baked apple pies and prune cakes. I was not 5, this was not a book, it was real. And these children, my children, did not know me. They who had spent their entire lives living with strangers, prescribed parents, caregivers, state allocated families. Distant unattached family who arrived on schedule in white institutional coats worn over their day clothes, who came in shifts, in rotations throughout the day and evenings. Family who lived in the buildings behind the orphanage with their own families in their own state allocated flats and apartments won by career vocation and kept by stolid social allowances.

### Cherdakly orphanage

Driving up the winding flint gravel strewn lane to Cherdakly orphanage reminded me of my German grandparents Pennsylvania dutch farm in the 1950's. Spartan but verdant landscape, rustic and rural with quaint village farms all around. Dappled and brown horses whinnying and neighing, nostrils flaring as they pressed themselves up to the craggy guard rail of the rough hewn fence constructed the same way as they had been for countless centuries.

I could hear the crunch of the snow beneath the tires and the rocks being loosened as the car made its way through the time worn wells carved into the ancient path. The fragrant earthy smell of cold snowy mud and crystalized slush mixed with the brisk sweet Russian winter air aroused my memories and senses. At once in my memory I was 5 again, excited and anxious arriving at the place I loved the best in the world my Grandma and Grandpaps farm. I felt the layers of years of adulthood melt away as my heart quickened with the view ahead of me. Trees of birch

and ash and slovakian spruce lined both sides of the road draping their thinning multi colored leaves, white bark trunks, and profuse green pine branches framing the entry of the only way onto the dietzky dom grounds. The sky was gray and dense with dark clouds. The weather this morning was a gentle harbinger to the cold day, and the too soon evening, when snow would begin to fall softly and quietly on the rusty orphanage roof tops. I felt as if I was reliving every Charles Dickens drama, every Charlotte Bronte' novel, every Shakepearean sonnet that I had ever read. Stories interlaced and layered in my memory about bygone eras where homeless children grew up in grim, dark and damp orphanages.

A fearful chill ran through me not knowing, not wanting to know if this orphanage would be the same as in my voracious readings. Would I find the children here begging for the smallest of lifes necessities, unwashed and ill fed, not cared for, their fragile health and precious lives not attended to

## A moment of FASt tears~

A miserable moment, where she is confused and cannot find her way out of the dark vortex of her thoughts, except through her tears, millions of opal tears, forever flowing tears.

Tears that come quickly

have a will of their own,

every salty rivulate,

formed from an ancient emotional chemistry

fermenting

in her daily dose of fear, startled reactions, mistrust, and pain.

# Pushing a mentally crippled child~

Would you push a child who was unsteady? a small child who has not learned to walk, someone who was crippled, could not speak, could not talk?

Would you cause to fall down someone you knew who was in pain, could not stand, with no aim?

To a child whose frailties are behavioral their handicap is their moods, their thoughts, their reactions.

Their mind is their maim

their handicap their brain

Don't push with your words, for they cannot catch their balance. To them they are falling, their response will be emotions calling.

Words out of balance, with no rhyme and not reason.

For these children words are their treason.

### **September 19, 2003**

#### The Words of Mental illness

Psychopathic, Pathologic, Sociopathic, Oppositional,

Unstable, Out of control, Uncontrollable, Unreachable, Unteachable,

Dangerous.

Brain injured, emotional trauma, brain damaged.

Damaged,

Not curable, not healable, perhaps not fixable......

Very scary words full of pain......

horrible unthinkable words,

Words we are not used to hearing or thinking about when it comes to our children, our family.

Words we are not programmed to accept,

nor supposed to relate to.

Certainly not about someone we love, someone we care for, someone we have high hopes for. How does one make peace with these words? Where do you find normalcy, obtain balance or resolution?

How do we believe there is good, there is a future, there might be harmony?

How does one understand these states of mind?

Can you see through or past these illnesses?

Over and above all the diagnoses?

Accept these predisposition's?

Endure these behaviors?

To you my friend, my parent, my teacher, my doctor, my nurse.....

it takes

*Time...*to see them struggle through the bad times and the good

**Understanding....**to have sympathy and tolerance that they are people in enormous pain **Knowledge....**to be familiar with that which is common to their life's struggles

*Faith.....*to have a firm conviction in them and the innate goodness and abilities that are born into all of us

**Patience.....**in bearing the pain or trials calmly without complaint and manifesting forbearance under the provocation or strain they bring into your life

**Willingness.....**to accept by choice without reluctance that their lives are worthwhile and have meaning

## **September 17, 2003**

### The slide

Out on the playground it stands erect, straight and straightforward or curved and convoluted the slide sits planted amongst the childrens playthings.

So many steps to the top... one two three, a foot slipping off the step for a moment but it is caught and the toe takes hold, the incline begins a again...four five six, balance wavers and the head feels dizzy but look up the top is getting near... seven eight nine, it feels too high.....tighten up the grip, hold close to the steps.... ten eleven twelve. Wow, the air, the sky, the crisp wind blowing, up and over both legs tightly together, hold close, tight, straight, let go~

And down.......fast, sometimes spiraling through the descending sleuce, sometimes sliding straight down blindingly breakneck to the bottom, crash, thump, bump, in the pit of sand. The physical feeling of iron inertia. No motion. Everthing stops. It is over, and the top is no more. And ahead, all those steps once more, one two three...... over and over again an infinite circle of ascendance, descendance.

For my child life is like the slide, everyday progress marked by dogged steps, sometimes tenuous, always tenacious. But the top is always teasingly taunting, for it is there reachable and dizzying, full of accomplishments and rewards and successes. And each time as it is attained and the seat is firmly seated, and the heady atmosphere is full of pride and satisfaction the descent is primed.

Ready to pull them down, the furious force will be swift and speedy, their lifes unique gravity always decided.

# **September 15, 2003**

# Don't give in to her moods~

I tried desparately to do this thing which everyone says I must....." don't give into her demands" "don't jump everytime she says jump" "make her delay satisfaction"

I know I should but she is so needy, so sad, so hurt, I want to help, to heal, to assist.

"don't give into her every request" "she is terrrorizing the whole house" " she is manipulating evervone"

I try to see her wiley ways, her sneaky maniputlaions, her plans to decieve, to run things, but all I see is a pathetic child with no control over her own impulses, her own actions.

"aive her consequences"

"put her in time out"

"make her draw, paint, squeeze and squish her anger pillow, play relaxing music, give her CD's, charts, systems, be methodical, be more structured......cool down her room, get rid of stimulation, get rid of the light, get rid of the stuff, make sure she takes her meds on time, make sure you don't react in a way that is confusing to her, stay calm around her" Ok, all done~

#### Now what?

And she is still stuck in that same place, where she is alone, and no one will be her friend, where nothing is ever fun or satisfying, or is what she had hoped it would be. And she has no idea who she is, or why she does what she does. And she doesnt know who's to blame, and everything is in the moment.

## Little Prisoners in the making

Lock up the house, the cabinets, the drawers, put all dangerous items in safety latched places. Do not leave anything out that might harm, like medications, pointy objects, knives, blades, or anything that would clean.

Harness them, leash them, pen them in, lock their rooms, lock the windows~ Sounds like a toddler or a criminal.....no its my teen.

### Why is my house a prison?

Life with these children can be so isolating.......But it is necessary. For too much too soon, too anything can send them right over the edge. So we stay in the house, before school, to help get everyone ready and get them out the door without any meltdowns or episodes, during school by the phone, to catch any call from any school teacher, advisor, principal, or parent who has had to run interferance or placate, or ameliorate, after school, so they can be helped home, relaxed, calmed down, unstressed, and during and after dinner to stand between them and any altercation or depression, or outburst.....and your sweet home, that you lovingly saved for, that was your coccoon, your space, now becomes your prison.....

### **September 14, 2003**

### I don't know who I am

"Mommy, I don't know who I am....."

I look into her slightly slanted thick lashed eyes and I do not see intellectual vacancy, or emtional vapidness, but total aloneness. A person unfortunately locked inside themself and helpless as to who they are, where they are, or where they came from, or why. Her crys bite me, eat at me, bruise me, move me, for I wish I could help her find herself, her gestalt. Her beginning. Her center.

I want to sit beside her all snuggled up, warm and comfy in our green velvet easy chair and say "Lana, my love, Mommy can help you with this. We can do this. Together we can sort out all your feelings, your questions, your aloneness, your lostness, your fears" "We can take away your demons babe, clear your head of your monsters, take away all the scary stuff.....and you will feel so much better"

But the center of Lana's earth is unstable, angry, explosive, like molten lava, waiting to escape, vent upward, pushing and savaging as it makes its way out into her daily words and thoughts and moods and feelings. And she is forever scorched by her own emotions, burning through her rages, red hot rages, that explode like a volcano, raining pith and pain on everyone around her. And after the heat has cooled, and everyone has left her, ran away from her, doesnt want to be with her, near her, understand her, listen to her, or talk to her, she is left alone. Wondering why she did that, why does everyone leave her, who she is~

## Holding back the anger

Holding back your anger is so difficult.

Especially when it is so reasonable, so righteous. You deserve to be angry, you have every right. It makes sense, it is intelligent, it is not invalid.

Yet holding it back is what you must do, for wasting it is what it would be. A total waste of energy, of time, of breath, of your incredibly important words. Anger that holds weight, that everyone else responds to with respect and understanding.

Your anger, your angst, so bewildered. Your ability to vent and clear you mind of what you know to be right and wrong. Your unameliorated avenue to clear consciousness. Your conscience cleanser. Stuffed... with no outlet. You need it for your own peace of mind, your mental health. Yet you cannot let it out, not to her, not this time, not ever, for to her your anger is a trigger, not a comment of frustration, an emotional discipline.

To them it is a catalyst for explosion.

For them you must hold your anger, to them it cannot be justified, it is never understood~

## **September 11, 2003**

## **Child Abuse the Living Legacy**

Interesting combination of words, child abuse. In todays society these words immediately gets everyones attention. As well they should, and thank God we live in a day that the laws are written to uphold the care, safety and protection of each and every child in our country. Thank God when you say Child Abuse people listen, pay attention, wake up, consider the meaning, and how it affects them, or others around them.

For child abuse fosters child abuse. And the behaviors of the parent are passed down to the child. As behaviors are learned and experienced, they are imprinted in the brain, neural networks of memory. Those imprints become an impulse map, an emotional compass a behavioral navigational instrument. And for abused kids their natural logistics for anger is using these maps to their emotions on the people around them. Their families, there parents, their siblings.

If abusive behaviors are learned, imprinted on the memory then can they be unlearned? Can any abused damaged person, whos intellections, will, ego and memories have been quashed by abuse manage this feat of accomplishment?

And to what flawed brain is this possible? Does this take a certain amount of intelligence? a combination of performance IQ? a mixture of verbal skills? an ability of temperment? of will? What is the combination.....

To unlearn abuse, after the fact of irreparable damage engraved upon a childs brain, a living indelible memory, seems to me impossible.

But they say it can be done. That behaviors are learned and they can all be unlearned and managed, and massaged, manipulated and reversed.

So I wait, I work, I hope, I will, I chart, I reward, I ignore, I long to see the reversal of child abuse in my child. The legacy of pain in her reactive instincts that seems so very much a part of her, who she is, and who she might always be.

## **Desensitization (work in progress)**

There was a time when I was extremely sensitive — I would get hot and angry when I got a parking ticket, sob and cry if a police stopped me for a moving violation, and pull my hair out if my child dared get a C on his report card. The sight of police cars and uniforms never failed to make my stomach tight and queazy, and full of anxious butterflies. I hated doctors offices and hospitals. Who had stolen my favorite pen, or advertising pages in magazines, were some of my worst pet peeves. I often blanched when I knew people didnt recylce their glass and aluminum cans, or only read the paper on Sundays. You couldnt call me sweetie, and my husband was required to call me sweetheart. Mommy would do for my children, and Auntie for all the neices and nephews. Being embarrassed was an actual emotion that I felt, it was a physical happening, I knew what it meant.

It's funny how all that changes when you have a mentally ill person in your life. How doctors, and hospitals, and medications and police men become your freinds. How you overlook most grades, or messes around the house. How broken windows and doors, and chipped tile and cracked glass becomes your norm. It's sad when you find your only vacations seem to be when your loved one is in the hospital or in therapy. How the word violence does not have that scary spine tingling tone to it anymore, its just a word that somehow relates to you.

Maybe desensitization is a learning experience, a learned behavior. I am sure it is. I had to learn to not be embarrassed, shocked, scared, terrified, depressed, squeemish.

So maybe it is a good thing~ For all the minor, trivial, silly little things that used to send me over the edge, don't bother me anymore. I have a higher calling, I must stay strong for the ones I love. Who so need me and my resolve to be there for them, care for them, and do whatever it takes to keep them safe and protected. So desensitized is what I am.

And sometimes I am glad for it~ Mother Theresa must have been desensitized too.......

### **September 10, 2003**

## Changing your way of thinking Part 2

You must change your ways of thinking, you must hear things that you would not necessarily listen for, words with no context in your normal way of thought. Expressions of worry or fear, over nothing to you, but to them, are grave portents of a storm brewing in their mind, their body, their spirit.

If you think you can raise a child like this, with your old fashioned ways, the ways the Bible teaches, the ways the church demands, the ways your conscience tells you, you may have to change your mind.

It will not come easy, it will not come quickly, you will not go willingly, but it you love this child, and you want this child to survive in this world, you will change.

### FAS and paradoxical reactions~

Paradoxical reactions to medications paradoxical reactions to Dignity paradoxical reactions to stimulation paradoxical reactions to love paradoxical reactions to sleep paradoxical reactions to learning

paradoxical reactions to morals paradoxical reactions to depression paradoxical reactions to mother.....

### School storm part 3

And in her usual bravado Lana screams she is going to kill herself, over and over, it is her anthem, it is her battle cry, it is her attention getter and her broken record soul soother. She leaps to the kitchen drawer, where cooking knives and gourmet utensils no longer reside, for they have all been replaced by safe non-lethal plastic. So in her frenzy of fear, and hate and anger and pain, she grabs a pancake turner, a spatula, not what she intended, but just the same sticks it in her stomach. As the handle breaks in her hand, she drops to the floor, as if dead, as if in silent seizure, not breathing, not thinking, not living......for that stolen moment she has killed herself. She lays there then waiting for attention, waiting for love, for caring, for warmth, for validation. Validation that she is hurt beyond repair, that she cannot live in a n y moment without confusion, validation that we all know and acknowledge this, acknowledge her reality. And, in the length of a few counted minutes, as many times before, the drama ends, and the moment is over, and the passion has breathed its last breath, she gets up and goes about her day. As if nothing has happened, as if this does not affect anyone. As if this were normal daily fare, in the calm and balmy suburbs. Breakfast toast, tea, and torment. And she swiftly leaves from the front door with her mismatched clothes to catch her waiting yellow school bus, and Anya in reverse, out the back, fuming, red with anger, wanting Lana to go away and not infect her life anymore.

And I sit here with my morning beverage, noticing everyone forgot their lunches, they are still sitting on the table, all scrunched and forlorn, silent witnesses~

# School storm part 2

When I try to dissect exactly what word, what sentence, what comment, what noun, verb, adjective it was that sets her off I can never totally reconstruct it. I am told, watch for the triggers, be cautious of things that upset her. Life upsets her. To Lana a glance upsets her. It is not the trigger it is the gun.....

She is a colt 45 cocked and ready, just don't cross her when she is wound up.

This morning was too much for her, I should have known, I should have sat beside her every minute, stood beside, walked beside her guided her, thought for her, breathed for her. But I let her get ready on her own.

And when the two of them came into my sweet country kitchen, pickled pine and Waverly linen, porcelain tile and washed wooden floors, it was like a match to a roman candle, a flame to a firecracker, fire and fireworks.

One word, one sentence, something about a lunch food, and bodies were flying accross the room. Lana lunging at Anya, screaming and wailing. Anya swinging her fists as if she were Tyson, going for the face, the head the upper body. And as usual, I am in the middle taking the blows from both sides, grabbing a hank of hair, the back of a shirt, anything I can hang on to to separate them. And Mia hearing the clamor from the other room, ever the ready defender, comes in "dont' hurt mom" "Anya stop it" Anya get away from her" and everyone screaming "Lana, Lana, Lana".

The backyard sliding glass doors are open and the neighbor calls accross the yard to stop it or she is calling the police.

#### School storm

Steaming hot tea laced with milk and sweetner sitting beside me I am looking at the lunchbags lovingly packed the night before on the table, labeled one for Anya and one for Lana.

Anya my picky eater, not too much sugar, spice, anything nice. It must be simple and plain, and nothing touching. Anya has one plain bagel and cream cheese, a plum and water. Pure Anya~ Lana my carnivore, herbivore, omnivore a bulging bag with a chocolate lunchable cookie and cream icing, a banana and a plum, a juice, cottage cheese and fruit, and a bubble gum yogurt. Both bags still sitting, lumpy and leaning, brown paper scrunched at the top and silently waiting to be picked up and swept away on another day of school. A school day, a regular day, like a million other days of showers, and clothes arranging, and bookbag stuffing and teeth brushing. But for these two girls, and these two lunches it will be different. For their lives are different, as different as their lunches. Their personalities, their looks, their preferences, their abilities, as contrasting as night and day.

Lana, short and chubby, with frizzy bushy hair, thick Russian eyebrows and the queer temperment of one living daily on the edge of their own sanity.

Anya, thin, slim, silky blonde hair, icey blue eyes, full passionate lips on an angular Slavic face that whispers a Norse origin. Bright and inquisitive, sometimes selfish, sometimes caring, always calculating.

There was too much pressure for this particular morning, too many things to do think about, worry over, work out. Picture day, first day of school, sign up and registration papers, checks for school fees and dues, checks written from an empty account. Checks written with hopes the money will be there when it passes through the doors of the bank on Friday.

Lana stands there with her soft wiry hair pulled straight back from her short forehead, too tight, too severe, unkempt but freshly done. "do I look pretty mom?" with her choice of too tight clothes, bright colors of red and mixed patterns, pulled over her plump frame. A slinky skirt, a zippered velour pullover jacket, white bobbi sox and duck toed sneakers.

"You look beautiful sweetheart..." I say, wishing I could have helped her with her clothes but she will not allow it and keeping Lana from having a tantrum is well worth looking the other way on her wardrobe choices.

## September 9, 2003

## Their internal stress meter

These children of fear, and anger, of wasted emotions, of hate and aloneness They have an internal meter, that is always ticking, you can't see it, or hear it, there is no arm that points to tilt, or lights that begin flashing. There is no mercury, or red lines in a glass tube, but the rising level is still there.

Every negative that they encounter in a day fills up their vessel of frustration, every "no", every look they do not understand, every comment that does not register, begins to fill their daily intake levels. It can be explained as easily as that, for that's what it is, a level of anxiety that is filling from the moment they wake, slowely filling, level by level, line by line, while you do not see, you are not aware.

And sometime during the day or evening, this vessel will fill, a waward glance, a "no please dont' do that", a click of the remote, a sandwich that broke, cereal that spilled, a sister who provoked, a brother who taunts....

And then the tank is full, and they blow. They explode and the heated tension emerges like a volcanic eruption. Hot, angry, loud, shrill, explosive. They are over the edge, over the top, strung up, strung out, detonated.

It will be unexpected and irrational, you will not see it coming, it will take you by surprise, but it will happen none the less.

For they have reached their maximum, it will be mental critical mass, thermo nuclear emotional reaction, the nuerotansmissions chemistry set has exploded and it must and will be released......on you~

## Changing your way of thinking

It is difficult raising a child with mental illness, who does not think the way you do, the way your mother taught you, the way you know works with everyone else

"my way of thinking" "my way of doing things" "what's good for the goose....."

A child who cannot react to an everyday event with an understandable reaction. Who cannot understand your humor sometimes, or your famous sarcasm, or your understandable frustration

Who does not understand you when you are angry on that *everyday* level..... those degrees of anger that we all go through, "I'm just a little angry but I will get over it" "I am angry now, just give me some space" "I love you but I am angry now".

A child who reads your face by your lips, not your expressions, not your whole face, not your softness, your warm love, your soft eyes, your enduring caring.

These very different children..... you cannot correct them, admonish them, set limits and boundaries, not in an *everyday* 

"this is how we do it" " this is what I want you to do" " these are the rules" fashion.

You cannot "lay down the law" "set the parameters".

For to them your rules are perceived as anger. They do not see the subtleties of emotions. They do not understand sliding scales of behavior, boundaries that are changing. The ebb and flow of a day, of a household. They will not understand if the rules get stretched, or laxened, or changed.

To them the world needs to be concrete, no changes, no emotions, no quick thinking no rules changing, no sliding scales of behavior, to them there is only one way, the limited, unruffled way. The slow tone, no anger, no frustration, no confusion, measured way. A predictable way, a bordered day.

For them your rules of character, of discipline, of parenting may not apply. Your ways of thinking, that you have earned, that you have nurtured, that you thought was brilliant, will probably not work. For them, all your work means means little. In their storms of thinking they do not see it, they cannot appreciate.

You must change your way of thinking, you must hear things that you would not necessarily listen for, words with no context to your normal contemplations. Expressions of worry or fear, over nothing to you but to them, are grave portents of a storm brewing in their mind.

## September 8, 2003

## Saying No~

Saying no to this child is not saying a word, it is a wall, a black hole, she is harmed by it, it makes her nauseus, sick to her stomach.

Saying no creates a storm of anxiety, a concrete force they cannot move through. It is the opposite of yes, and that is all they see, yes is their expectation, in their limited reasoning and fantasy world everything will be as they dream it, expect it, will it, want it. No, is like pulling the rug out from under the feet. Its a punch in the face. It is not what they had percieved would happen and it hurts.

Remember when you say No to a child with FAS it is not a word, it is an act. It is a motion, it moves them. They may not accept this from you. This word, this simple tool to teach, to regulate, to keep things in order and perspective.

So be cautious and tread lightly when you say no, don't use it lightly, without thought, without judgment for it can harm. It can be harsh. It may hurt.....it will be unexpected.

## School starting....

Phone rang this morning, Dr. Shappel from the hospital.

"Lana will be released later today, she has done really well here the last few days, I think the main thing that upset her this time was the stress of school starting last week" We increased her Rispardal, kept her on the Zoloft and the Trazadone.....I don't think she will be having any more problems...at least for a while anyway"

School starting, what 200,000,000 children around the world would consider to be exciting, new clothes, new shoes, new notebook, pencils, paper. To my child was so overwhelming she tried to kill herself~

When they say these children are easily overwhelmed, overstimulated, easy to set off, easy to blow up, this is not an overstatement. The mere thought of new kids, new classes, new teachers, decisions, questionnaires to fill out, forms to fill in, lines to stand in, what to wear, who to talk to, who's my freind, who's my enemy sends a jetstream of fear and panic through their minds and nervous systems like electric shockwaves. To them it is sheer panic, raw and unleashed.

To Lana it was easier to get a knife and slice her arm then to bear the thought~

## September 7, 2003

### Isn't she sweet

"He is the best little child......"

"Isnt she sweet, cute, adorable, darling....."

"So well behaved, so good, so mannerly......"

"She is such a joy, so wonderful to have around...."

"He is welcome here anytime, so helpful and kind....."

Who's child are they talking about anyway? not mine...

not this child of the major meltdowns, smart mouth, sassy mouth, tired, cranky, crabby, picky, messy

Who is it they are talking to, who is it that they see?

When will I get this elusive child to be here for me?

### A Moments peace~

Sitting here in my quiet and peace......

no kids

no screaming, no crying, no whining, no yelling, no fighting, no questioning, no arguing, no slamming, no throwing, no hitting, no badgering, no emotions, no explosions.

I wonder if I should feel guilty that I enjoy this moment of respit.....

NOT

## September 6, 2003

### Is it learned behavior? prt 2

It is not just *good behavior - bad behavior*, this is not just a learned problem. She will not get the concept of consequences......not when she is raging, and in pain and panic, and lost in her head, where she can't reach you, where she can't feel anything except soaring humming tissue insulated electricity, surging through her nervous system, her arms, her legs, her brain. This is not bad behavior, this is a brainstorm. It is not feasable to say please when you are in the midst of an existential explosion, a neuronal a-bomb. A flesh fusion, sinew surging, brain fuser. This is not a teaching moment, this is not a behavioral faux pas. This is evolutions lessons for survival gone tragically awry...... in a childs precious head.

### Is it learned behavior?

I have 3 other children, other than my Lana, 1 boy, 2 girls. If irrational, illogical, impenetrable behavior is learned and not visceral than none of them should have learned a thing. My oldest is an attention deficit and hyperactive child, he didnt listen, never sat still, couldnt concentrate, couldn't relax, never slept well. My middle child is hypo-manic biploar, she is restless, hypersexual, can be mouthy, will be snotty, profane, loud and irrascible. My youngest has a mild form of bipolar and she will be paranoid, confused, headachy, sleepless, hyperactive. All of these children, with all of their problems, still have good manners, and understand behavior. They know how to say please and thank you, and how to react and not react. They know how to cover their mouths when they sneeze, and how to use a napkin when they eat. They close the door when they come in, and shut the windows when it rains. How to match their clothes, and look for crumbs on their face and shirts. They know how to wash their hair when it is dirty, take a shower when they are grungy, and brush their teeth when they are fuzzy. They wipe their feet at the door, and wear pajamas not their day clothes to bed. Why can't my Lana? she lives here too.... she listens to my diatribes on cleanliness, on neatness, on behavior. She has had the charts, the lessons, the tools. She has been told over and over and over, the same things, the same ways......and it doesnt sink in. So... to you our teachers, our therapists, our doctors, our observers, who think a behavioral coach will get through to her, a visit to the hospital will be the trick, a new system will be the answer, I say good luck. I hope your ideas and plans and prescriptions work, for her sake, for our sake, for science's sake.....but I doubt it.

### September 5, 2003

# A Hurt Childs Spirit

If a child could be 17 in body and 7 in mind, how old would they be in spirit? Would their spirit be wise?

Could they be thoughtful, perceptive?

In their unfortunate confusion of gestalt would they know dignity, peace, hopefullness. As she lay in the hospital this lonely and pensive evening, I found in her room a scribbled writing, so precious in her cramped and childish pencil style, the notebook paper turned backwards so the holes were on the wrong side, crumpled, and erased many times over, a passage from one of her favorite movies.... Spirit~

### I will Always Return

I hear the wind call your name It calls me back home again It sparks up the fire - a flame that still burns Oh, it's to you I'll fly away.......

## Don't bring her here again

What is the feeling that comes over you when you realize you are completely on your own? A feeling of sick density, a heaviness, a weight, a fear, convoluted inertia. Peril and aloneness. That your decision has forevever altered your relationships with everyone you even knew. No one sees you that same way from this point on. The perception that you were in control of your life, that you knew what you were doing, that you were on top, managing, is now replaced by perceptions that you are failing, you have made a big mistake, you will never be the same person, your life is over, you have no where to go, no one understands what you are doing. When you are told by those who love you, who want to protect you, want to see only whats best for you, that you are being hurt beyond repair and it is them or her. What do you say? how do you feel? what do you do?

Don't feel bad for me, I am doing what I was taught, I am loving, nurturing, caring for, being responsible. I am putting into action all the commandments from Moses, all the volumes of Dr.Spock, MD, all the books on behavioral health and psychology, parenting magazines, everything anyone told me on how to be a good parent, a good person, and more. Much more. So much more.

For where I go, I must break all the rules, ignore all the commandments, exclude the parenting magazines, refute the precepts of discipline and structure.

My child does not fit these molds, for everything written that is bad, she does. Without will, without judgment, without premediation, without conscience.

But then in a moment of lucidity, a stolen moment of reality, she is good, and loving and caring, and logical, and smart, and willing to be better. And cognizant of her misguided actions and thoughts. And wants to be the child she knows you want.

But you are alone in this, not many will walk this walk with you. It is your 40 days and 40 nights. Alone.

## September 5, 2003

#### All the meds

Zyprexa, geodone, topomax, prozac, neruontin, rispardal, strattera, trazadone, rittalin, concerta.....and the beat goes on~

Drugs..... can't live with them can't live without them.

60's 70's 80's 90's message was always the same, just say no! Drugs kill, drugs fry your brain, drugs are bad for you, drugs hurt your unborn fetus.

Then enter your very sick child, who was damaged as a fetus, when she had no choice of her own, who's own brain is a chemistry experiment gone terribly wrong. And what is the remedy for this biological miasma.....drugs.

Drugs, no one knows much about, not sure of the dose, have no idea what will work, when or how. So once again your childs brain becomes a chemistry experiment, with no probable antedote, except experimenting with the experiment. No scientists in white coats, no double blind studies, no control measures. No dose response methods.

So you go willfully and willingly into this abyss, doing what you have been told is wrong and bad, but in "this case" is good, but know one really knows really how or why~

Weight gain, hair growth, organ damage, aggression, depression, sleeplessness, aloneness, aches and pains, can't hear, can't breath, panic attacks, can't eat,

"Mommy why do I have to take this stuff?"...... " Just take your meds baby~"

OK, just handcuff me now, blindfold me and shoot me, hang me, cut my tongue out. Might as well, I know I am guilty in this somehow, someway~

## September 4, 2003

## They took her away ~part 2

And my other girls watch once again, peering in from the distance of the living room, clothed in their blue jeans and t-shirts, braces and tennis shoes, poney tails and scrungies, disbelieving, stunned, shocked, embarrassed, humiliated, and angry.

I am once again reminded of the sound as they roll the clicking clanking gurney out the double front doors to the waiting ambulance, sirens blaring, lights scrolling, Lana perched like a Roman diety atop the squarely tucked hospital linens. She with that oddly morose look of pain and contentment, fearful joy, failure and success all seamlessly blended upon her fragile complexion. On her way, once again, with all the loud fanfare, personal attendants in waiting, instant delivery to her own personal land of Oz, where she always hopes to find her heart, her brain, her courage.

### September 3, 2003

# They took her away today~

My kitchen never looks like my kichen when all the police are here. Various sizes and shapes of uniformed people whom I don't know, stoicly planted, unstructured community soldeirs, standing around my beige procelain counters where I make lunch meat sandwiches with Mayo for Lana and mustard for Anya. Black-blue uniforms in darkened contrast to my pickeled pine breakfast table where I serve pancakes and eggs in the mornings on Saturdays. Silver badges and polished name sheilds, pinned on their shirts as they lean into my old worn tapestry barstools. Ones I bought from an estate sale years ago, threadbare from all the kids sliding down off the seats without picking up their butts like Pop has told them to over and over. But nobody listens to Pop when he's being bossy about the furniture....... All these people with their dark spit and polish outfits, that make the women look like men, and the men look all alike. Belts bulging with weapons, and tools, and radios all neatly snapped into their individual webbed leather pouches. Stiffly standing there, with their note pads, top page drawn back, pencils poised, and grim expressions of suspicion tinged with curiousity on their faces as the subject of abuse is very delicately and professionally brought into the conversation, here in this sunny suburban house, so neatly decorated and well cared for. My husband and I....loving parents of Jonathon, Lana, Mia, and Anya, adoring Uncle and Auntie of Jason, Holly, Heather and Hillary. We who have rarely been stopped for a moving violation or a parking ticket. Who pay our taxes religously, and go to city council meetings, and volunteer with the Ronald McDonald House, and Orangewood Home, and Cerebal Palsy. We who recycle our cans, and faithfully cut every plastic container holder so not one wild bird will get caught and choke accidently as a result of our carelessness. Who donate to the church, and to Childrens Hospital, and to the Police Department every year for their annual fundraisers. But then, they don't know these things, they don't know us, they only know our name which shows up on their computer screens, another call to the E's house, another 911 call, their daughter again..... her mother says she has a knife.....

## September 2, 2003

### This Moment on Tuesday

My Dad just called....someone stole \$300.00 out of his wallet yesterday, he left it out in plain view on his desk when the family was over for Labor Day. It was probably Lana~ Anya's upstairs playing dress up with her freind Kelsey

Mia's in her bathroom taking a shower

Lana's in her bedroom with a carving knife.. screaming, cutting, more cuts on her arm now, new fresh tracks to add to the old ones that were just beginning to fade. I hear her screams, crys of emotional pain, her tortured mental state, and I can't help~ I can't....she has a conscience but it is so weak, so small, so slippery, so hard for her to hold onto~

I'm numb now, I want to move off my chair, to run in her direction, to help her, to hold her, to love her, to save her from her own relentless hands. But the chills are running the length of my spine and I know she will hurt me if I go in her room. So she cries and pounds the walls, the desk, her bed, she wails, her life is over, no one wants her, no one loves her. She flips through the radio stations, rap, hip hop, the incessant bass beating.....and I wonder where the knife is, and how I will find her

when I go on the other side of the wall.... only 8 short feet away...but I'm numb~

### September 1, 2003

### Fu\*\* You

I love you my sweet and innocent one, *you* with your pouting pink rosebud lips and transparent skin as soft as chamois silk. Damaged beyond repair by neglect, abuse, abandonement and the affects of alcohol on your developing brain.

Precious face, and fragrant hair on a head much too small for your frame, they call it microcephaly. Short, stocky and bosomy....my dear little shorty~ Your body announces "I am 17" but your mind and emotions admit 6......

She says she wants to know who she is this warm summer evening. She is proud to read Dr. Suess with no mistakes and her math skills seem to be forever frozen in the mid 3's of her multiplication tables......,

And yet she sincerely fretts and wonders in her endearing dialogue, an adolescents voice, clothed in her innocent English, a contrast of maturities sometimes raw and outspoken, sometimes a mere child............" why am I only in the 10th grade? "

"I'm 17 1/2, Mom, I think I should be in college... Why am I in only 10th grade!? Is it because I am short? Is it because they hit me in the head with a brick when I was only 5? They broke my head Mom, I almost died, I was bleeding and bleeding and they never took me to the hospital~" "Why am I so confused Mom? "..........." I am so confused Mom."

And in her moments of confusion, the only one to blame is me "I hate you...

it's your fault, you never do anything right for me Mom, you are confusing me Mom......
Fu\*\* you Mom, it's all your fault~"

I am so sorry for you my dear sweet one, your pain, your hurt,

but as always

I love you still...

# September 1, 2003

# My girls ~ Summer is ending

September 1

We made it through the summer. The girls fourth here in America. They are all in their teens now and each one is becoming a young woman in her own way.

Lana is 171/2 now. She is my teacher. Through her I have learned patience. I have learned how to subvert my feelings, my desires, my needs, my interests, for a greater good. Through her anger, pain and hurt I have found my own resolution and a peace with myself. I have learned to not dwell on what I have or who I am, for to a person who is in pain it means nothing. I have learned to sometimes walk small, not tall. To find brilliance in confusion and to wrest love from anger~

Mia is 15 1/2, she is my freind. She tells me that I am not so great after all, that I am getting fat and old, and my hair is not as beautiful as it used to be. She would only say that to her freind. Someone she can bear her soul to, be honest with, be frank, be candid. Mia likes to talk, to share, be freinds and be loyal. She would "have my back"anywhere, anytime. Mia is moody, sometimes vulgar, sometimes crass, but always with an underlying compassion for people. She is my little Russian.

Anya is 13 1/2, she is my soul. She thinks, she advocates, she analyzes, she cooperates. She is beautiful and smart and witty and knows it, and is just learning that this can be a vicious weapon or a gentle tool. Anya loves sports and will gain entry to the world through her physical self first, her thoughts and actions second. We play together Anya and I. She is the link to my own wandering child, that child who is quickly going away. Being taken over by this middle aged woman, who often forgets to be fun.