

# Different as Night and Day – Life with My Two Little Girls

By Bill Zirinsky

It's the Friday after Thanksgiving. Snow is on the ground. The sun warms the living room. My two little girls are gone from the house this afternoon, along with my wife, Ruth, visiting family friends in Howell. I'm reading the most recent issue of *The New Yorker*, the "Cartoon" issue.



Juliana Zirinsky, age 7

I love Michigan's cold winters, particularly snowy ones. I love my wife's blue eyes, particularly after she's had a good cry about something. I love my dear friend Jon's silly epistles to nothingness – nothing, that is, except his desire to communicate. I love my bookstore (Crazy Wisdom) when it's busy, and I love its place in the commu-

nity. I love reading a Crazy Wisdom staff log note which expresses that staff person's love affair with the store. Sometimes, new applicants write, "I love this store" on their applications. It's music to my ears.

But what I love most these days is being the father of two small girls, Juliana and Leela. Juliana is 7. JJ (her nickname) is very sensitive and adorable. She is a beautiful and delicate little girl, with dark brown hair, big brown eyes, and long eye-lashes. Her skin is like porcelain, and to us she is like a miniature Audrey Hepburn, all neck and slenderness. JJ's bright eyes sparkle with delight in the world.

Juliana breaks my heart ten times a day, she is such a treasure. Her smile, her giggle, her love for me, her delicacy, her trust. Juliana is all about love, plain and simple. Fam-

ilions are unlike 99.99% of the rest of the population when it comes to food. She does not have an appetite, and the smell of food does not appeal to her.

On the other hand, Juliana is in a therapeutic horseback riding program, and she loves being on her favorite horse, **Fable**. There is nothing quite like the sight of a pint-sized, disabled little girl, with a tube in her nose, on a big horse, giggling and laughing, to make my heart soar.

It's an interesting dance between the two girls. One is older, but already smaller. One is younger, but already more world-wise. Juliana is slow moving, hardly growing physically at all, slow to change. Leela is fast moving, growing quickly, changing every week. Leela is of the world. Juliana lives in a quiet, pixilated fairie world.

I love reading to Juliana. She studies the pictures. She gets excited and waves her hands. I like just snuggling with her. I take pleasure in her small accomplishments, her happiness in simple things. Just walking around with a coveted crayon in her hand can turn her on for oodles of time. The dog's presence can wow her. A good kids' TV show engages her. A cozy atmosphere enralls her. At

I laugh uproariously, all to myself but out loud. I surprise myself with my laughter, how deep it feels.

I get such pleasure from so many aspects of my life. Is that normal? I have no idea, but it's the truth, nonetheless.

I love the ocean. I spend many weeks by the ocean, each summer. And I'm devoted to the waves. On rough days, I am often the only person over 40 splashing around with the 12 year olds. Diving into the waves. Running away from them. Getting tumbled by them. Feeling the delicious jolt of crashing white waves awakening my every sense.

I love the daily *New York Times*. I don't know what I'd do without it. I've been absorbing the world through the "frame" (the word of the year, perhaps) of *The Times* since

Juliana is as fine as fine can be – sensitive, subtle, complex and full of feeling... There is nothing quite like the sight of my Juliana, a pint-sized, disabled little girl, on a big horse, giggling and laughing, to make my heart soar.

ily love.

JJ is tiny. At the age of 7, she is the size of a 2-year-old. She has a serious and degenerative metabolic disorder. She is hearing-impaired, fed by a nasal gastric tube, and she is retarded. I know that it's not politically correct to use the word 'retarded' but as the father of two 'retarded' children, I've come to like the word. The revelation for me was when I realized that being 'retarded' did not mean being scary or thick or cruel or gross. To the contrary, my daughter, Juliana, is as fine as fine can be – sensitive, subtle, complex and full of feeling.

(When I was a child, I associated being 'retarded' with the character, Boo Radley (played by Robert Duvall), in *To Kill A Mockingbird*; in fact, Boo was the quiet hero of the story.)

Juliana attends a wonderful special education classroom at High Point School. Her teachers and aides, Deb and Merri and Dean, love her, and treat her accordingly. The classroom she is in is labeled "SXI", for the severely multiply impaired. But the labels mean almost nothing to us, on a day to day basis. To us, Juliana is the most delightful human being, our faerie sprite, our family jewel.

Juliana walks okay, not great, but okay. You might call her gait "unsteady but cute". She doesn't talk, but she does use her hands a lot. She doesn't have the motor skills to communicate in sign language, but she tries. She eats nothing, and receives her Pediasure nutrition through her nasal tube, which runs directly to her tummy. Foods have no interest for her, and they make her gag. These kids with rare metabolic condi-



Leela Zirinsky will be 3 in February.

dinner time, just having unilateral possession of a fork can make the whole experience inclusive for JJ.

JJ's older brother, Sam, had the same medical condition. And he died two years ago, at the age of 10. His death cast everything in a different light.

the fourth grade. My sixth grade teacher used to read *Times* columnists Russell Baker and James Reston and C.L. Sulzberger out loud to our class, an early tutorial in self-expression. I lived without *The Times* a few times, during trips to rural China and the mountains of Nepal. I was fine going cold turkey for some weeks, but in daily life I derive great pleasure from it. Another man's pleasure in a game of football is akin to my excitement each and every morning in jumping out of bed and retrieving *The Times*, and then skimming the paper quickly to choose the stories I most want to read.



Photo by Ruth Schekter

Sorrow, laughter, loss, love, grace. The adventure of life keeps unfolding.

Since their condition is undiagnosable by current diagnostic capabilities, we never knew how long Sam would live, and by extension, we still don't know how long Juliana will live. We were surprised and deeply disheartened when Sam's health declined steeply in the last year of his life. It became increasingly hard for Sam to grasp anything at all in his hands. His seizures increased in duration and frequency. His digestive system gave out.

Right up to the last days of his life, we hoped and believed he might stick around longer. And if that meant Sam would have come home from the hospital on dialysis, we would have adjusted to that, as we had adjusted to the onset of his seizures at age 5, and to his being in a wheelchair, and to his severe, ongoing discomfort from reflux.

Juliana's health has been better than Sam's. The manifestations of her illness have been much milder than Sam's. Not only does she walk, but also she has had much less tummy pain (reflux), and no seizures, so far. And while Sam was deaf, Juliana does have some residual hearing, and she wears hearing aids. Last winter, Juliana began to have some mild tremoring. We watch that closely. There is a foreboding quality to her tremors; Sam's seizure disorder also began incrementally.

Juliana's younger sister, Leela, is almost 3. She does **not** have a metabolic disorder. God bless her. She was born in Guatemala, and adopted by us, at birth. It took 11 long months for the Guatemalan adoption bureaucracy to approve the adoption, and my wife, Ruth, went to pick up Leela and bring her home on the week that Sam died. We hadn't designed it that way, but it certainly did *feel* like Intelligent Design. (One can believe in Darwinian evolution, and still believe in Intelligent Design!)

Leela is a real character. She is a passionate, dark-haired Mayan toddler Goddess. She wants in on *everything*. She is fun loving, fully in her body, curious, and bursting with personality.

Leela is coming up with new words, and new questions, and new reactions, all the time. I'm having the time of my life. My first healthy child. And I couldn't have asked for a healthy child more to my liking than Leela. She is no shrinking violet. She is already giving me a run for my money. I love my outings with her. She's fun to go with to Jefferson Street Market, and to the Fleetwood. She's fun to shop with. I love taking her to a parent/child swim class. In the summer, we like driving around in my old red 1972 Skylark convertible. I love watching her mind at work, and I love playing with her.

When I watch the two of them together, I'm reminded of the theme song from the Patty Duke show. Some of you baby boomers may remember the show: two cousins, who look like identical twins, end up living together in Brooklyn during their high school years. Patty Duke plays both cousins. "Patty" is the Brooklynite, popular in school, not very studious, with a goofy boyfriend; "Cathy" has been

brought up in England, has an English accent, and is very studious and cultivated. Part of the song goes like this:

**Where Cathy adores a minuet,  
The Ballet Russes, and crepe suzette,  
Our Patty loves to rock and roll,  
A hot dog makes her lose control —  
What a wild duet!**

**But they're cousins,  
Identical cousins all the way.  
One pair of matching bookends,  
Different as night and day.**

I have my own stanzas for Juliana and Leela:

**Where JJ adores a pen to hold,  
A fork to wave, a brush to shake,  
Our Leela loves to rock and roll,  
A kitten makes her lose control —  
What a wild duet!**

**But they're sisters,  
Not-identical sisters all the way.  
One pair of unmatched bookends,  
Different as night and day.**

It's an interesting dance between the two girls. One is older, but already smaller. One is younger, but already more world-wise. Juliana is slow moving, hardly growing physically at all, slow to change. Leela is fast moving, growing quickly, changing every week. Leela is of the world. JJ lives in a quiet, pixilated fairie world. One may live a long time. One will most likely not.

Juliana was wary of Leela for a long time. Who is this little sister who has come into my home, and at the same time that my brother disappeared? Not easy to explain all that happened to a child with no language. Instead, Juliana has had to just observe, absorb, and feel.

And Leela, being a typical toddler, runs circles around Juliana. And takes her toys. And tussles with her. And Juliana doesn't quite have the social skills to fend her off, though she does possess her own skillful means, tactically employed. Now, as Leela's language skills are more developed, she can be encouraged, through example, to treat Juliana tenderly, and respectfully. And Leela, being a good kid, is coming around.

Ever so slowly, Juliana is coming around, also, to like her sister. Very slowly. Which is how Juliana does everything.

As for me, I feel that I inhabit a magic kingdom. These two little girls, so very different. Juliana has very little ego. Her love suffuses me. With JJ, each day matters. I have already lost one child. I may lose JJ, too. All we have are the moments together. Moments of love, moments of laughter. Moments of deep non-verbal connection. Moments of snuggling. Moments of resting my cheek against hers. Moments of slowly poring over each beautiful illustration in a book on fairies. Moments of combing her hair. Moments of tickling her. Moments of watching her excitedly wander off on her own at the beach. Moments of pouring warm bath water over her head as she watches me expectantly. Moments of drying her off, wrapped in towels, as she gazes adoringly at me, kicking her feet deliriously. Moments of looking into her eyes and feeling her love.

With Leela, I am having an experience I have wanted for my whole life. A connection to a small child, to her hopes and questions and needs and complex feelings. Leela feels everything with such a passion. She reminds me, each day, of what it means to be fully human. I see that my answers don't stack up when measured against the emotional integrity of a small child, pure of heart.

For Leela, stuffed animals have personalities. Objects are alive for her. Even combs. When told to leave her comb in the car when we are getting out of the car to shop at Office Max, she insists on putting her comb in her car seat and making sure the comb has its seat belt on.

Food is to be really tasted. Smells are to be experienced. Her tears are real, her mouth quivers. Her feelings are strong, undiluted by life's conventions and constraints. The night is full of the unknown. Each day counts. Each hour. Each minute. She is all about saying 'yes' to the adventure of life.

Leela's love is whole-hearted. She runs up to me when I come home, and she hugs me with gusto. The challenge for me in loving Leela at this age of my life is to remember my tenderness. I'm not an old man yet, hardly. But it's not always easy to be tender enough to meet Leela where she lives. To be good to Leela is to be soft enough, to remember that the world still is fully alive, for her. She hurts easily, and often. And she lives in a world that is more magnificent and more authentic than anything I can remember. And I don't live in that world anymore. I can just hope to join her in her world for brief fragments of time.

Leela's love is different than Juliana's. More ego. More 'me' and 'I' and 'I want'. Yet, I recognize her. Leela is more like you and me.

Leela feels everything with such a passion. She reminds me, each day, of what it means to be fully human. I see that my answers don't stack up when measured against the emotional integrity of a small child, pure of heart.

So, then, Thanksgiving 2005. What a blessing it is to get to inhabit this planet. What a blessing good health is.

I have a dear friend whose wife just died, of cancer. A few weeks ago, he wrote an email to people in his world, and I found myself sobbing as I read and re-read his carefully chosen words, saying that her time was short, that the final chemotherapy had failed, that her breathing was becoming harder, that their family was beginning to gather around. And in a subsequent email he sang out to God, with anguish, "please don't take my wife from me".

I loved my friend for writing those emails, and for the feelings he evoked in me. I treasured those emails because of how they spoke to the world that I live in, of my friends struggling valiantly to make sense of their lives and their deaths. A world in which people are now open about death, and a world in which one family's death experience is shared with a wider community, so we can all learn from it, we can all grieve together, we can share in the mystery of saying goodbye.

I love my wife, Ruth. I love my little girls. I love this community of Ann Arbor. Sorrow, laughter, loss, love, grace. The adventure of life keeps unfolding.

###