

# If You Could See Her Through My Eyes ~ A Journey of Love and Dying in the Fall of 2007

By Bill Zirinsky

## November 1st

If you could see Juliana through my eyes, she wouldn't look like a dying child. But she is. From the outside, she looks like a tiny, 9 year old girl, disabled, non-verbal, with a nasogastric tube for her feedings, hearing-impaired, and unable to use her hands. But to me she is the most exquisite little faerie sprite this side of Paradise.

Juliana is dying of the same ultra-rare, neuro-metabolic, degenerative disorder that her brother, Sam, died of four years ago. (So rare that the precise nature or "etiology" of the biochemical defect which they both have suffered from, is as yet unknown.)

Sam was just short of his tenth birthday when he died. We didn't know he was dying, we just knew he was losing steam. This time, we are all too aware that Juliana is dying, right before our eyes. We can remember the path of Sam's illness, and we watch as Juliana follows in her big brother's footsteps. Of course, Sam never walked, so following in his footsteps is a tricky thing to do.

Yet one senses that Juliana is not entirely discontent about her path. She is frustrated at times, as she loses motor functions and skills, and she cries sometimes when she feels sorry for herself, for her situation. Yet there has descended upon her a certain wisdom and meditative resignation, which is very becoming. Meanwhile, she does suffer physically, and that is painful for her and us.

Most people think this must be an awful time for our family. I do not see it that way. As Juliana fades, I find that life is intensely rich, and that my love for her deepens beyond words. My time with Juliana is sweet, and I'm savoring each of her smiles.

From the outside, one sees what is hard. But I'm living in the moment with Juliana, and the good moments are wonderful.

Juliana is a rare bird, a butterfly, a snow fountain cherry blossom. She is, to me, all that is tender and innocent and light-filled. How do you say goodbye to that which is the most cherished? How do you say goodbye to the one who is most cherished?

It's a beautiful fall day, the day after Halloween. The sun is shining brightly, and the fall leaves are turning. Juliana is at school, as I write, and each day that she is well enough to be in school feels like a blessing.

Last evening, Juliana and our family went trick-or-treating on Granger Avenue, which is the Burns Park neighborhood's designated Halloween Candy Central. Juliana was so animated, excited to be out at night, proud of her fairy princess costume. She conked out on the early side, and so she went home early with Maka, while we stayed out with her sister, Leela. Sitting in her car seat, ready to go home for her bath and bedtime, Juliana looked at me as if to say, "Dad, I really partook this year --- been here, done that, take notice."

And as I kissed her five, six, seven times before parting with her, I just felt it was her last Halloween. We've had years of pushing Sam, and now Juliana, around in their wheelchairs, amidst all the healthy kid in costumes, and it's never been easy, but we've made a pagan night of it.

A few days ago, Juliana's physical therapist came over to work with her. Juliana looked weak and less-than-alert. But Karen has been working with JJ (as we call her) for her whole life, and slowly she roused her. Once roused, Juliana was so delighted and pleased with herself to be using her body, and to be standing (supported). We've always called these physical therapy sessions "the JJ Show" and the audience (my wife, our other daughter, our child care provider, and any other house visitors) applauds her readily.

Juliana beamed for about 25 straight minutes as she did all that Karen asked of her. It was hard work. Rolling over a physio ball, stretching, assisted walking, bending, torso turning. When JJ makes progress in physical therapy, I see

an unfettered hope in her eyes --- "Hey, I'm walking again". When JJ's smile is infused with that light and hope, I'm content with the world. There's always a letdown after Karen leaves, for all of us.

It is less than two years ago that Juliana began to have somewhat regular seizures. At the time of her 8th birthday party, in May of 2006, she was still walking around, and I remember her standing on her own as we helped her to bat the birthday piñata. Soon thereafter, she stopped walking. Then, last winter, she slowly lost the ability to stand unassisted. In the spring, she began to lose the ability to sit unsupported, and grasping everyday objects became harder and harder.

On the days that Juliana is relatively well, we breathe more easily. But over the last few months, her health has been tenuous. She's dodged quite a few bullets these past few months... to use the expression our pediatrician used. She came home from the summer with pneumonia, and she dodged that bullet. She had a urinary tract infection that sent her to the ER, and she dodged that bullet. And she's had an ongoing, unexplained low-grade fever even when otherwise well. She takes 4 seizure medicines twice a day, and other medicines, and she's been getting Motrin or Tylenol around the clock most days. Overall, her decline is noticeable, and irreversible.

Whenever she is not well, we feel her vulnerability. It wouldn't take much more than a blustery breeze to knock JJ down and out. Her resources are limited; she is, after all, only 25 pounds at the age of nine! And, at a certain point, Sam's body just gave out. JJ is not so far off from that point of no return for Sam.

I've been loving giving Juliana her evening bath. She has a special bath seat for handicapped kids, and in it she can lie back. She and I spend time soulfully looking at each other while I shampoo her lustrous brown hair and soap her up. With her hair wet, she is so beautiful. She has the most gorgeous eyelashes, and big brown eyes. She really loves having her Daddy give her a bath. I love giving it to her.

A child who is as disabled as JJ is, who can not much move her own limbs at will anymore, is particularly dependent --- there is a very fine tactile dance that Juliana and I navigate during her baths. She has to cooperate, and I have to be respectful and careful. And when the dance works, she is gleeful, and I'm satisfied with my part.

Never have I known such tenderness as I do when I am taking a washcloth to her skin near the tape that holds her

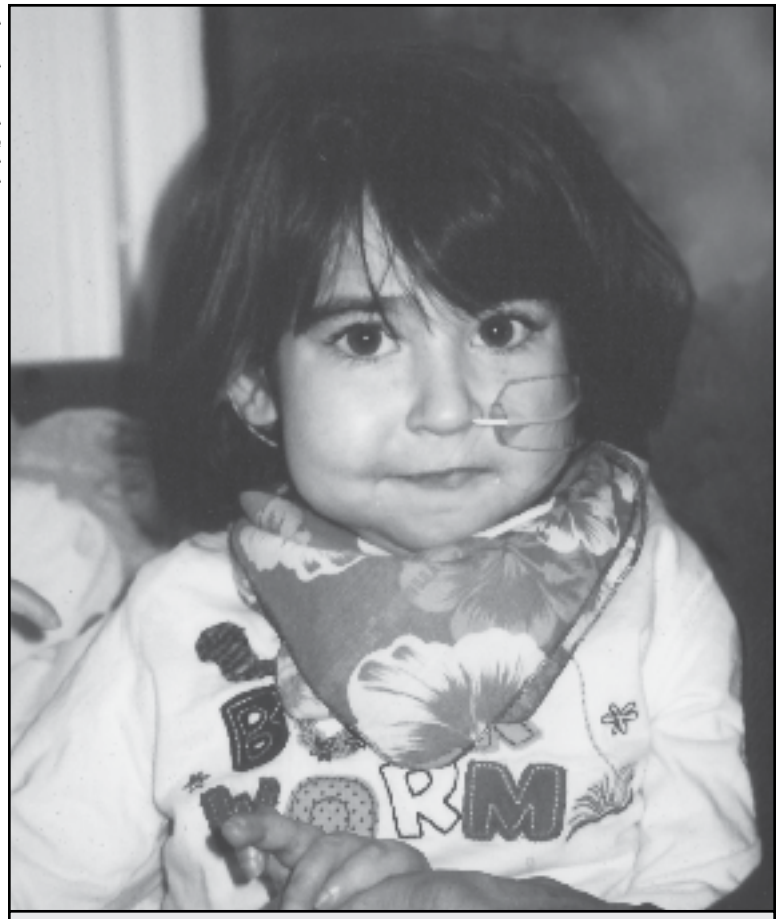
I found myself crying along with her, holding her hand, looking in her eyes, she looking in my eyes. My daughter, my beloved daughter, my flesh and blood, my little girl, and she was crying because she completely understood, and hadn't really known this truth before.

nose tube. It must be an irritant to have tape stuck to her body 24-7, and so I think she really loves me when I do a good job of cleaning around that area without suffocating her. She always looks particularly relieved, and yet grateful, when I'm done with that chore.

And then the "dry off period". She watches me, so dependently, and with such curiosity, as I towel dry her hair, and take special care to make sure she's warm and dry all over.

After she's dressed, I take great pleasure from holding her in her rocking chair, all clean and pajama'd and smelling lovely, and slowly administering her syringes of bedtime medicines. It takes about 30 minutes for her to

Photo by Ruth Schekter



Juliana Zirinsky, age 9

get all her medicines, and she needs to stay calm to digest them properly. She likes to complain and fuss when being dried off, but once she is in her pajamas and in my arms, she is feeling better, and so am I.

What adds poignancy to that activity, and all our activities together, is that our days together on this earth are limited. I know that she can get sick again at anytime. I know that there came a day that Sam got sick, and he had to go to the hospital, and he never returned. I remember standing at the door, as the emergency medics took Sam away, with my wife, Ruth, accompanying him to the hospital. And Juliana and I watched them drive off as they went. And when Sam left, he departed our family life, forever.

So, when I give JJ a bath, or hold her in my arms in her pajamas, or when I take her to school, I just don't know how many days are left.

I don't dwell on that in a maudlin way. No, not at all. Instead, I relish these days.

Juliana was in a therapeutic horseback riding program this fall. There are two "side-riders" on each side of her, and one person leading the horse by the reins. No matter how lousy JJ felt this fall, and she had some days that she felt pretty weak and nauseous, she always got on her horse, Star, and she took pride and pleasure in being on that horse. My spirits would soar watching her come back around the ring, and then her looking over towards me to see my reactions. If I used some sign language to tell her, "great job, JJ, nice work on the horse," she would acknowledge me with a satisfied nod, and "walk on".

Juliana is so small and fragile. Her body is uncomfortable often. She throws up often, and she's had ongoing diarrhea. The diarrhea is scary, because it could lead to dehydration, which was the trigger for Sam's final hospitalization. We worry that the ongoing fevers will get worse, and there will be nothing much more we can do to keep her home, and alive.

It is weird to be preparing to say goodbye to the favorite person in my life, and that person to be younger, and my child. I remember the morning that Sam died. The Pediatric Intensive Care Unit had turned off the dialysis machine because he was in his last hours. And their turning it off was a jolt --- that meant his life was really going to be over, and soon. Those were the saddest, most grief-filled hours of my life.

When I look at Juliana, I see this beautiful, very special, extraordinary and magical little being. I feel such deep gratitude to have been her father these years. I know I won't ever again have anyone as extraordinary as her in my life, so close.



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So, then, these days are filled with love and wonder, gratitude and laughter, sadness and worry. Ruth and I delight in Juliana's very existence, in her vulnerability and her lovely skin, in her daily participation in her not-so-easy life, in her appreciation and jealousy of her sister, in the great comfort she finds in the arms of her nanny, Maka, and in her continuing joy in being alive.

Gazing at her as she sleeps, reading a book to her, entwining my fingers with hers, zipping up her jacket, stretching her contracted arms, combing her hair, kissing her on her porcelain cheek, rocking her to sleep --- it is all suffused with deep love and a taste of the finite.

### November 22nd

Juliana has another infection, and she's at the ER with her mom. She looked so terrible today --- dehydrated, pale, peaked, eyes sunken, and she was so weak.

This was Thanksgiving Day. And Ruth stayed home with Juliana while I went to a dinner, with our four-year-old, at the home of close friends. It was painful for all of us to have JJ be quite sick on yet another holiday weekend. How many times over the years have we, as a family, felt isolated and alone on a day others are enjoying. Many. And today we felt especially desperate and sad.

Now, we wait to hear the results of the lab work being done in the ER. If Juliana's sodium count is off, well, that will be very scary, since an infection followed by diarrhea and dehydration and then a high sodium count were the precipitating factors that led to our Sam's final hospitalization and subsequent death.

It feels like we have just days with Juliana. That's how it feels whenever she has gotten quite sick the last months, but it feels even worse now.

It's been easy to intellectualize her dying, and her eventual death. But, tonight, it feels closer, more inevitable than ever.

I don't know why I couldn't see the truth staring me in the face. Ruth and I keep thinking about various eventualities, such as difficulties breathing, or her heart racing or ... but now I can see it. She will probably die just as Sam did. At a certain point, he could no longer digest his food. It just went right through him. And there was nothing the doctors could do about it, nothing the best specialists at Mott Hospital could do for him, nothing which showed up in his autopsy. Basically, his undiagnosable (currently undiagnosable, that is) neuro-metabolic disorder, whatever the underlying biochemical defect is, caused his digestive system to just fail, to no longer be able to metabolize any more food.

The same thing is about to happen to Juliana, if not yet tonight (and we'll know soon) then in the next days or weeks, or maybe, if we are very lucky, months.

And how do I feel about this? Lousy, terrible. When she is well, I have been able to savor these weeks with her, knowing her time is limited, and my time with her.

But, now, looking into the heart of it, I feel desolate. JJ's absence will no longer be conceptual. She will be gone, gone for good, gone forever, gone from my life

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always. No more holding her close, no more bathing her, no more building our family life around her. No more light coming from her eyes towards me. No more will this profound delicacy of a child inhabit my home. The magic that is Juliana will be gone from my earthly life.



Juliana, at age 3, with her father, Bill Zirinsky.

### December 4th

Now, it's twelve days later, in early December. The news was bad that night. Juliana's sodium was high, and her kidneys were failing. (Reminders of Sam.) And then, she bounced back! Re-hydration worked quickly, and her kidneys started doing their job. We caught it soon enough. Juliana has come home tonight, having survived the ordeal of her hospitalization.

The days of her being in the hospital were unbelievably hard and exhausting. We can't leave her there on her own for a minute.

We received excellent care there, but the doctors don't, in some fundamental way, "get" Juliana. Because only 1 in every 5,000 kids has a rare metabolic disorder such as hers, they have consistently made mistakes related to her nutritional and digestive capacity. So we have to watch them like hawks.

Just yesterday, I had to explain to one of the gastroenterologists why it was so critical to not overburden Juliana's capacity to handle her intravenous feedings. I've been down this route with her doctors so many times before. As part of the conversation, I said to the doctor that I know Juliana is dying, that we are realistic about that, but that we are trying to get her home for some weeks or months. Then right after he left the hospital room, I started to hold JJ's hand, and she started crying. I immediately knew that she was crying because she had absorbed the conversation, the first conversation in front of her in which I had talked about the inevitability of her dying.

Yet here she was, my non-verbal, profoundly retarded daughter. She had felt and absorbed and understood what I had said. And she began to cry. Not the cry she cries if something physical hurts, or if she is tired or cranky or irritable. No, this was Juliana's emotional cry. With big tears, and heartbreaking sobs.

I found myself crying along with her, holding her hand, looking in her eyes, she looking in my eyes. My daughter, my beloved daughter, my flesh and blood, my little girl, and she was crying because she completely understood, and hadn't really known this truth before.

The crying helped us both.

Coming home tonight was so filled with sadness and sweetness. She is coming home with an intravenous line into one of the main arteries in her chest. She is weak. Her health is deeply compromised. She is closer to dying now.

Photo by Ruth Schekter

We have come home, and said goodbye to the hospital, hopefully for the last time. Though we're not ready yet to bring in hospice, we know that it wouldn't take much now to push JJ "over the cliff", to use a phrase from one of her doctors.

I wish I could convey how meaningful it was to us to return JJ to her home tonight, to steal her from the grips of the medical world. To bring her to her own room and her own pajamas and her own bed and her own stuffed animals and the home she was born in. She was so excited to get into the car tonight, realizing she was finished at the hospital.

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We never did get Sam home. Now we've gotten Juliana to a place we had never reached with Sam. Home, after her digestive system has collapsed, home with an intravenous feeding system that will buy her some days or weeks or months. Tonight, I don't actually believe we'll be buying her much time, yet I'm still hopeful.

I am not so afraid of Juliana dying. I was afraid of her dying in the hospital. Now that she is protected, and in her family's womb, I feel much less anxious, much less terrorized.

### December 13th

The first week at home was difficult, but also satisfying. It was a relief to have our family together again, and very challenging to learn how to properly care for a small and fragile child who is now exclusively being fed intravenously. There are issues of kidney function, and vulnerability to infections, which seemed initially daunting.

A few days ago, Juliana seemed "logy" -- sluggish and a bit foggy. We became concerned that possibly she was getting overloaded with fluid, or that her kidneys weren't doing their job. We are acutely aware of how small she is, and that if her kidneys began to fail, that she might go quickly. We felt scared.

I haven't wanted to be very far away from our house this past week. I have had a sense that I could miss something important, and a sense that the only interactions I really care about right now are with my family.

How do I get enough of her? How do I get my fill of

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her? Being in our home together with Ruth, Leela and Maka, I feel that JJ is very safe. We have lit Chanukah candles together. We read stories together. We huddle around Juliana, who is sitting in her rocking chair -- she is the hearth of our family life.

The last two days she has been good. Her blood work looked okay, and she appears to be stable, for now. So, today, for the first time in three weeks, JJ went back to school. Just for 2 hours. But, still. The teachers and aides doted on her. And she was glad to be out and about, glad to be alive, glad to be dressed in her winter coat looking out the window.

I think we're all surprised -- Juliana included --- that she made it through her hospitalization, and that she has lived to see another day, and hopefully another Christmas.

We took some black-and-white photos of Juliana a few days ago. One of them in particular stands out for me, and I love it. It is a photo of me looking at the camera, seated beside Juliana, who is also facing the camera. Her eyes happen to be shut, as if she is blushing, and your eyes are drawn to her incredibly long and beautiful eyelashes. And the smile on my face is her smile. Her delicate, pure and pixilated smile is on my face. I am channeling my daughter's Harpo Marxian smile.

That photo reminds me of why I can't bear to lose her. And it also reassures me that the light in her eyes is within me.

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