

It looks as if I'll always have more QUESTIONS than answers.

THE LIGHT OF HIS

He wanted a boy. In the summer of 1984 his wife, Cathy, gave birth to Sharon. It took the new

father about three hours to fall hopelessly in love. But something was wrong with their beautiful baby, and the Polishborn photographer and his American wife could not get doctors to agree on a diagnosis. As years went by, they learned that Sharon has a seizure disorder, speech delay, perhaps a bit of autism. She has severely impaired vision and

below grade level. Still, as the following excerpts from her father's journal make heartbreakingly clear, once in love with a child, in love for a lifetime.



ALAMEDA, CALIFORNIA

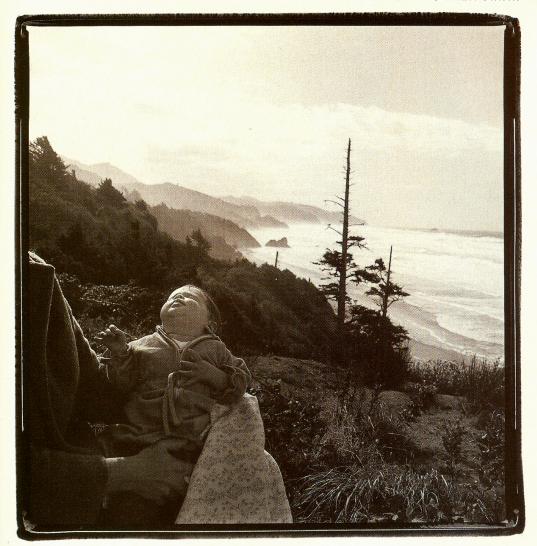
IN HIS OWN
WORDS AND
PHOTOGRAPHS.

LEON BORENSZTEIN

ILLUMINATES
HIS DAUGHTER'S
JOURNEY

DARKNESS.

THROUGH



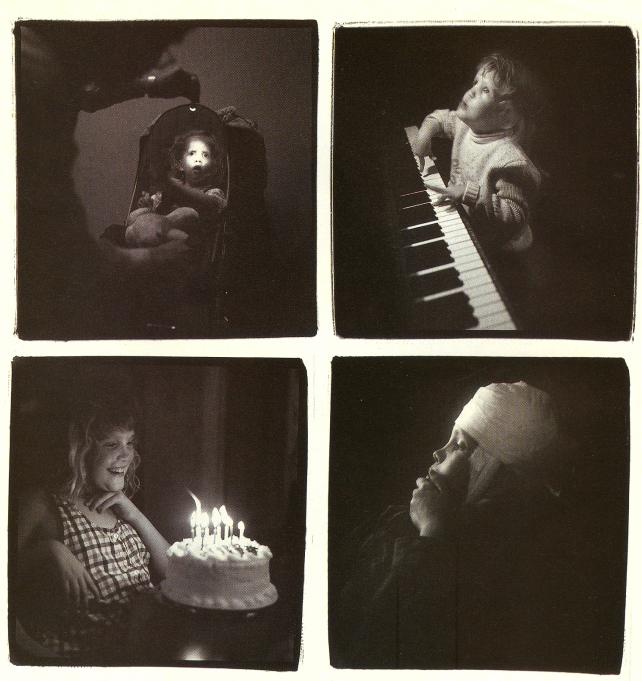
IT WAS FOUR O'CLOCK in the morning when I saw the head. I was trying to concentrate on photographing the miracle, when the doctor said, "It's a girl!!!!" I was ready for a boy—with strong arms and muscular legs. I had a name for him and clothes that were blue. With a boy you can go out, play soccer, go on trips. Just be a

fearful and I don't know of what.

buddy. But actually, why can't I do it with a girl? I think all this is a myth. I'm sure you can do all this with a girl. Suddenly, in a matter of seconds, I was a FATHER. I started to fall in love with her. What kind of father will I be? How will it change my life?

AFTER CHECKING HER, the pediatrician said that Sharon looks fine. Because I was still insisting that she is not like other little kids, the doctor sent us to a neurologist. He checked Sharon thoroughly and he also found that my daughter is okay. Then [the ophthalmologist] checked Sharon. His diagnosis was simple. Sharon has a blond fundus in her eyes, a condition that many little girls have, and like everybody else, she will outgrow it too. Don't worry, he said.

WHEN I put her to sleep, she puts her small sweet hands on my shoulders, so trustful, and her soft hand embracing me, my heart melts for her. But I have frightful feelings. Am I going to lose her? Or maybe she will be severely handicapped? I don't know.



ALL: OAKLAND, CALIFORNIA

THIS LITTLE GIRL has seen many doctors in her life. Three times she has had general anesthesia. This time the operation will be the most serious. I can almost see the fingers holding the scalpel, cutting slowly around her eye, all the six muscles that make the eye move. After that, he sews it all up with a needle and thread. Then he uses his scalpel again on her other eye. Yet Sharon will be happy to go to the hospital. She likes doctors and usually they don't hurt her. But she is very used to pain and can endure it. Part of her disorder is low muscle tone and slow reactions. Therefore, when Sharon falls down she doesn't extend her hands in front of herself for protection, but simply falls down on her face. She's never complained about it.



WE ARE SITTING in a French restaurant in Aix les Bains. At the next table, a large French family is sitting, with a small boy about three years old. I let Sharon stroll between the tables. I believe she needs this exercise after spending the whole day in the car. The French boy started to follow her. When I

Where is God?
Somebody young,
innocent and
helpless
needs Him.

saw the boy walking, I felt a deep sympathy for him. He had a problem. He couldn't walk straight. Something was wrong with him, but I couldn't figure it out. Then to my horror, I realized. I looked at Cathy. Do you see? Yes, she saw it too. Cathy begged me to take Sharon out of the restaurant immediately. The nightmare came sooner than we expected. It was the first time I saw somebody make fun of my baby.

WHEN I PUT SHARON TO SLEEP, I sing a Polish lullaby. If I stop singing before she is in a deep sleep, I will soon hear "moore, mooore" in a sweet, soft voice. I am resting my head on her back, hugging her gently and sobbing. What can I do for her? How can I help her? I can't help repeating my old cliché: Where is God?

Sharon likes to imitate lions and tigers. I hear her roaring, trying to scare me. I am ready for a pact. With God or the devil. Either one, and they can set the terms. I am ready for any conditions for the sake of this little puppy. The roaring lion puppy.



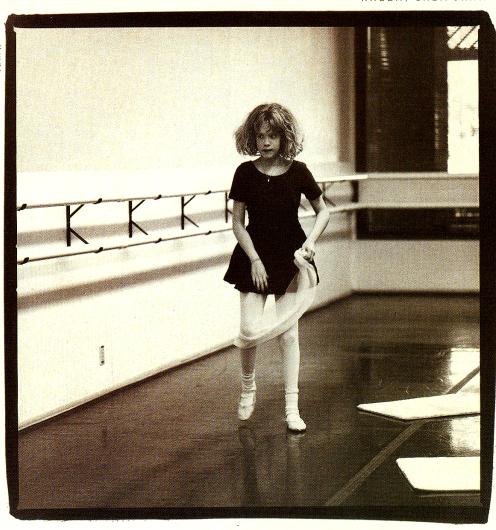
Will my darling remember all the good times we had together?

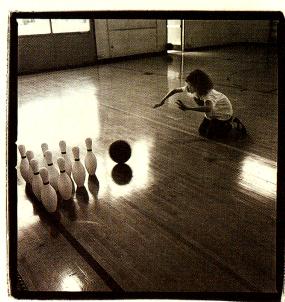
I take nothing for granted with her.

I WAS HOLDING HER sweet little hand with its long fingers in my big palm. During the hour of our walk I tell her "I love you" more than I ever heard in my own entire life. I show her flowers, we smell them together. We touch cars and she has to tell me their colors. We get stuck to every phone or electric pole. She always gets a big healthy laugh. Today as always I was looking

for dandelions so she could blow them out. Now she is really doing a good job: She holds the plant in close to her mouth and blows very strong. It gives her a lot of satisfaction.

WHAT SHOULD I DO about this puppy? Ignoring the obvious for many years, I was living day by day. But it is impossible anymore to live hiding one's head in the sand. The differences between Sharon and her classmates are growing rapidly. I can imagine how she feels when the teacher explains the material to the whole class and my puppy sits there without understanding. It is so painful to me. Parents take it for granted that their children will walk and talk and take care of themselves. I know that she will not have a normal life. How long can I kid myself by telling myself that the most important thing is to give her a lot of love now and not worry about later?





FREMONT, CALIFORNIA



SHARON'S TEACHERS and Cathy have been recommending that Sharon start to use a white cane. They think that people would be more aware of her disability and would be more sensitive. I am against that because it will focus everybody's attention on Sharon. Poor cute blonde blind girl. I want people to take her for what she is. I have to start looking at what is better for her, in spite of my own emotions.

Today she brought her psychological evaluation home from school. She is almost twelve years old but on the average she scored much younger. Yet I always considered myself lucky. I don't have it easy, but I also don't have it so difficult. Sharon can feed herself, she can walk, even communicate. She doesn't have any life-threatening sicknesses. Slowly but surely she is progressing. Could I ask for more? Can I?

WHAT WILL HAPPEN to her later in life? Will she work? What kind of job can she hold? If she is good-looking, but limited in her ability to comprehend, she will be a target for a lot of men to take advantage of her. If she's not very pretty and has some limitations, will somebody give her any attention? What kind of man will date my daughter? Who will she get married to? Can she have children? If so, how will they be?

Years from now, what kind of person will you be?