



BY RACHEL MORTON

extraordinary measures

FOR AN ORDINARY LIFE

Lilly Grossman, daughter of Gay Johnson Grossman '84 and her husband Steve, is in many ways a typical 11-year-old girl. She likes baby dolls and ballet. She is passionate about pink. She adores Hannah Montana and Abercrombie and is beginning to find boys interesting. She sometimes thinks her parents are clueless, and she likes to tease her dad. With her long wavy blonde hair, big smile, and a twinkle in her eye, Lilly is her parents' pride and joy.

She was in the Honors Choir, and last year when the choir trooped over to a television studio to film its holiday concert, Lilly was part of the action. This was an exciting afternoon for most of the kids, but for Lilly Grossman the drama extended beyond the musical score and the thrill of being on television.

Lilly has mitochondrial disease, a rare and often disabling illness that can make summoning the energy to do something like stand and sing nearly impossible. That day her mother watched in dread as the hot television lights blared down on the children. Heat affects Lilly immediately and drastically, sapping her strength and muscular control. As Gay feared, Lilly keeled over sideways into a bank of poinsettias. Gay rushed up to lift her daughter offstage and cool her down, glad that Lilly had seized her chance in the limelight even if it didn't start well.

Being an advocate for Lilly is now Gay's primary job. Every day, all day and sometimes long into the night, she takes extraordinary measures so her daughter can have an ordinary life. A child with a chronic debilitating illness would be a huge challenge to any parent, but Gay and Steve Grossman have met this challenge with determination and grace. Gay herself is surprised at how her priorities changed when the extent of Lilly's needs became evident. But rather than plunge into a depression or become paralyzed with the weight of her responsibilities, Gay found that caring for Lilly has given her life purpose and meaning and strengthened the bonds in her marriage.

This is a busy family. In addition to supporting Lilly's participation in school and extra-curricular activities, Gay also works full-time designing high-end writing paper for her company, Letters From Lilly, Ltd. Her

"All of us who are parents wonder how we would do, when presented with a situation like that. You never know until you are there."

husband Steve sells document-management software for the pharmacy industry. And they are both active in school and community and very involved with the United Mitochondrial Disease Foundation, giving support and advice to parents of children who have been diagnosed with this immunological disease that

can severely affect a child's body and mind. Some kids can't walk or talk. Some need to use feeding tubes or oxygen. Some, Gay says grimly, "are severely compromised in all their critical body systems. We're lucky. Lilly's bright, she's funny. She can tell me she loves me."

Gay and Steve are now veterans, having been inexperienced parents themselves 11 years ago, when they first noticed that Lilly was not progressing in the same way other children her age were. They began taking her to doctors and hospitals in what seemed like a never-ending process of trying to find out what was wrong. One day, Gay's best friend arrived at the hospital to keep her company. "It is so heartbreaking," this friend told Gay, "to walk through these hallways and see these parents and the sick children." Then she looked at Gay and said, "Oh my god, you're one of them."

"It's a new club," says Gay. "The club of parents with sick children. Sometimes you're in clubs you don't want to be in."

MEMBERSHIP IN THIS CLUB has changed their lives totally. Gay and Steve moved from Cleveland to San Diego, away from all their family and friends, to be in a place that is better for Lilly. Cleveland's temperatures were too extreme, the icy sidewalks unnavigable for a little girl with a walker. And the hospital at UCSD in San Diego is one of the world centers for mitochondrial disease research. They have changed jobs—both Gay and Steve developed home-based businesses. And they've both turned their acute intellects toward understanding this rare disease and learning how they can best help their little girl participate in life to the fullest.

This has involved a fair amount of advocacy, educating themselves and others, and a stubborn insistence

that opportunity not be denied Lilly because of her disability.

Gay developed this determination during the years it took her to get a diagnosis for Lilly, years when no one in the medical establishment could find anything wrong with her daughter.

The disease began slowly for Lilly. Gay did not begin to get concerned about her daughter's progress until she was nine months old. Doctors thought

she was just slow at reaching those physical milestones—pulling herself up, sitting, walking. But a mother knows, and as the months wore on, Gay became more and more convinced that Lilly had a serious health problem.

But though she might have been developing slowly, Lilly was a pretty little girl with cognitive acuity and



Lilly loves a trip to the mall as much as any other pre-teen girl. It just takes more time and effort to get her there safely. And though she adores new clothes, trying on clothing is physically draining.

no obvious illness, so doctor after doctor told Gay there was nothing wrong. One doctor suggested that perhaps the problem was Gay's, and he requested that the next time she came to see him, she should bring her husband. Gay and Steve eventually got a diagnosis when Lilly was three years old at the internationally renowned Cleveland Clinic. Though Gay still harbors bitterness toward some of the doctors and hospitals she took Lilly to before the Cleveland Clinic, she has moved on. She has more important things to do. If there's one thing she's learned, it's that in her life there is no time for complaining.

She has a role model here. It's her delightful, funny, intelligent daughter Lilly. If Lilly isn't complaining, stuck in a wheelchair, unable to join her friends in the simplest physical activities, then Gay feels she certainly has nothing to complain about.

Gay and Steve's attitude as parents is remarkable, even humbling, to their family and friends. "The most overwhelming thing is just how incredibly they have risen to the task that was placed in front of them," says sister-in-law Dana Grossman, who is married to

Steve's brother, Dan. "They grew up far, far faster than anyone ought to, or usually has to. All of us who are parents wonder how we would do, when presented with a situation like that. And I suppose there may be more challenging situations, but this is right up there. You never know until you are there."

Gay has also been surprised and grateful at the generosity and goodness that people have shown her and Lilly. Just when she thinks she is going to have to "strangle someone" who might be about to prevent Lilly from participating in some activity, that person shows an open heart and includes Lilly with warmth and love.

That afternoon when the choir was being filmed, Gay assumed that Lilly's performance was over, but the music director surprised Gay by declaring that until Lilly recovered and returned, the show would not go on.

Or, take the American Girl Fashion Show. Even though fashion shows are not exactly what Gay might have dreamed of as an activity for her daughter, when Lilly said she wanted to participate, Gay made sure she got the chance to try out. The officials declared

that if Lilly could walk and smile, she was in, even if walking entailed a pink walker. Officials placed themselves strategically along the stage in case Lilly faltered, and Gay watched from backstage and thought she'd throw up from anxiety, imagining her daughter pitching forward off the stage into the audience. But everything went well and Lilly had her day in the sun.

Though Gay experiences numerous stomach-churning moments, she certainly doesn't appear to be an overanxious mother. Quite the contrary. Dana observes: "Lilly falls down, and instead of pity and rushing to help her, it's, 'Hop up, dust yourself off. You're tough.' They have done such a fabulous job with her."

"We're pretty strict," says Gay. "I don't want her to think she's getting special treatment. So there's a fine line. Sometimes she's being a preteen, a pain, not wanting to do homework. Other times I know she's hit the wall and she's had enough."

MITOCHONDRIAL DISEASE is a genetically transmitted illness that can have a wide variety of symptoms. It affects the mitochondria, which function in every cell in our body and affect how energy is created and used. It can manifest itself in numerous ways—it can be mild and treatable, or cause serious physical and mental disabilities. It is a progressive disease, and there is no

cure, though for some people treatments can be helpful. Most children seriously affected by the disease won't live beyond adolescence.

In Lilly's case, she tires easily and has little muscle strength or stamina. Walking, talking, eating, even breathing and sitting take a lot out of her. She has tremors at night that leave her screaming with pain from muscle cramps. She can't hold a pencil, so she uses a computer to do her schoolwork. She uses a walker to get around and increasingly needs a wheelchair. Temperature affects her drastically. She overheats easily and her body just "wilts," like a flower out of water. When Lilly is depleted, she can't hold her head up, and she can't speak without superhuman effort. She needs immediate attention to replenish her energy and restore her equilibrium.

What she eats has a huge effect on Lilly's condition. Over years of trial and error, Gay and Steve have found foods that Lilly can tolerate. They include organic fruits and vegetables, bison meat, goat milk, oat flour, and organic honey. Minor variations from these specific foods can cause a severe reaction. Even changing the brand of a specific product can affect Lilly for hours or even days.

And she has to eat an enormous amount of food just to have enough energy for daily living. At 65 pounds,

Lilly dances with her dad at the wedding of her cousin in September. She was a flower girl at the ceremony.



Laura DeCapua, Gay Grossman

Lilly is “a little slip of a girl,” says Dana, who describes a recent dinner she had with the family, where Lilly ate a heaping plateful of several bison burgers, a big portion of potatoes, and a pile of green beans. “She wolfed it down,” says Dana. “Then she said she was still hungry, so Steve made her some scrambled eggs, which she finished, then wanted more. So her father made her a big bowl of oatmeal.

“It’s just incredible to see her eating these massive quantities of the most healthy stuff. And then seeing how hard it is for her to summon energy to do the things the rest of us take for granted.”

Yet in most ways she is a normal pre-adolescent girl. She has a cell phone and texts her friends. She likes to go to the beach, where her dad helps her ride the waves on a boogie board with him. Lilly is smart and does well in the public school, where she is in a regular classroom, though Gay says, “The adjustments we make to make that happen are huge.”

Because she can’t use a pencil or pen, Lilly uses a computer with special software. An aide meets her at the curb every day and helps her set up her computer and papers at her desk, then steps to the side of room, ready if Lilly needs her again. The aide scans in her homework so Lilly can keep up with the class, doing exactly what they are doing, but in a different medium.

Once a month her life comes to a screeching halt, when Lilly has to go to the hospital for a two-day intravenous procedure. She gets an infusion of human immunoglobulin, or IVIg, which helps her marshal enough energy to keep living that ordinary life. Lilly hates these infusions. What 11-year-old could bear sitting in a hospital for two days being hooked to a machine?

“These are not happy days,” Gay says simply. “She cries, she’s a puddle. But if she doesn’t have the infusion, I am carrying her everywhere. I have to feed her and bathe her. She gets very stiff. If she has her infusion, she helps me move her around, and she can get her legs in the car.” At a recent infusion, Lilly, depressed and exhausted from the procedure, turned to her mother and said, “I quit.”

“You can’t quit!” Gay told her daughter. “There is no quitting.”

Gay understands and is humbled by her daughter’s spirit. “I don’t know if I could do what Lilly does. Have the smile, the energy, the gumption. She has this unbelievable sense of humor, this desire to be a part of the world, even though it’s so hard for her. I can go out with my girlfriends and get away from it all. But Lilly has to deal with this all the time. Everything is hard.”

“Sometimes those kinds of things, when they land on you, they tear relationships apart. I think it has absolutely made theirs.”

WHEN YOU ASK HER HOW SHE MANAGES,

Gay will say it’s just her life. It’s all she knows.

“I go to the infusion center and think, ‘This is my world. This is normal for me.’ And that’s when it scares you. But it’s not like I have a healthy kid so I know it any other way.

“This is going to be our life forever. So the question is, what can we do to make our life better? We can work on our marriage. We’re a team,” she says. “I couldn’t do this without Steve.”

When she was a student, Gay says, there was a prevailing philosophy that a woman could do it all, by herself, in the face of any challenge or danger.

“I’m not just this extraordinary woman doing this by myself,” says Gay. “Emma tries to teach you you can do anything, but I couldn’t do this by myself. My husband is part of my team. We need to rely on other people for help.”

Though Gay has found support in unexpected places, she’s been saddened by some of her friends’ and sometimes even her family’s inability to understand the constraints of their life. They often don’t realize how hard it is for Lilly to do something without serious effort or accommodation on their parts.

“I guess it just happens when you cannot participate in the same family activities—skiing, sports, camping—you kind of fall off their radar screen and lose touch. Having a kid with special needs often magnifies the distance that evolves.

“That’s the biggest disappointment from the whole experience,” she says. “We often don’t quite fit into the pretty picture of what is supposed to be going on.”

But she has friends—very good friends, including a handful of dear friends from Emma. And there’s Steve’s family. And there’s her marriage—she and Steve will celebrate their 20th wedding anniversary in June.

“They have a great marriage,” Dana Grossman observes. “One zigs and the other zags. They both have a lovely relationship with Lilly and with each other. Sometimes those kinds of things, when they land on you, they tear relationships apart. I think it has absolutely made theirs.”

“I don’t have time to squabble with Steve about things,” says Gay. “No time for being selfish. When our friends get divorced and they have three healthy children, we say, ‘What was so tough for them? They don’t even know what tough is.’”

TWO DAYS AFTER Lilly’s September infusion, the Grossmans traveled to Vermont. Traveling, which takes them far from their food sources and support system, is not something Gay and Steve do frequently. The few times they’ve tried to fly with Lilly have resulted in exhaustion and sometimes illness for Lilly, and damage to both the walker and the wheelchair. So it would take a very special circumstance to get this family back on a plane.

The circumstance this fall was a wedding. And Lilly was intent on going because she had been invited to be a flower girl, something she’d wanted to do, like forever!

Whenever Lilly really wants to do something, Gay does everything within her power to make it happen.

Every night when Lilly can go to sleep thinking happy thoughts is a night that Gay and Steve Grossman go to bed happy themselves.

She and Steve are determined to give Lilly as normal a life as possible. “We don’t want to look back and say, ‘If only we had done this.’ Having her do these things, it’s more important than that she could get sick.”

The wedding was important not only because Lilly wanted to be a flower girl. She and the bride-to-be, her cousin Joanna, had something in common. Both were battling immune system diseases. Joanna’s was much less severe, and with treatments she was living an ordinary life. But it was a bond between them, and Lilly was determined to be present.

When Gay arrived at the wedding site in Vermont, the first thing she noticed wasn’t beautiful Lake Fairlee, or the mountain views, or the fields of September asters and goldenrod.

“Honestly, the first thing I noticed was the lawn sloping down to where the ceremony would take place. How would Lilly maneuver that? Grass is tricky enough, let alone on a slope.”

They did a number of trial runs, and on all but one, Lilly fell. They came up with a plan that Steve would sit in the last row, Gay in the first row, and they would place other people along the aisle who would jump up and pull Lilly to her feet if she fell.

Gay and Steve fed Lilly her special food (driven in from Boston by the bride’s sister) so she’d be full of energy when it was her turn to walk down the aisle. On her pink walker was a bouquet of mums and pink Gerbera daisies—a special request by the bride, who knows how much Lilly loves pink.

Though they’d prepared for weeks for this trip, and had practiced and planned for any eventuality, Gay was still anxious. “Yes, I was nervous. I got nervous because I wanted Lilly to succeed. I wanted her to walk down the aisle and smile and have fun. I wanted her to remember doing it just as she would want to—on her feet.

“I couldn’t see her from the front row. I watched the expressions on the faces across the aisle and I knew she was doing okay because they were all smiling.

Then I saw her come down the last few rows, beaming. She did it. Of course she did it.”

That night, after the cake was cut and Lilly had a few dances with her dad, Gay and Steve untied the bouquet from Lilly’s walker and put it on her nightstand in the cabin.

“Lilly went to sleep knowing that she had been a flower girl.”

Gay’s life is a far cry from what she imagined for herself as a girl at Emma, or even at 30, when she had Lilly. “My life was planned. We knew we’d have two or three kids. My house was decorated. My china pattern was complete. Everything was just the way it should be. And then I got pregnant, and what I thought was my perfect world came shattering down.”

Would she have been happier than she is now, in this mythical perfect life? She can’t even imagine it. “Was I ever that shallow,” she wonders, to think that a nice home and healthy children are the necessary prerequisites to a happy life?

Because she is happy every day that she helps create a happy day for Lilly. Every night when Lilly can go to sleep thinking happy thoughts is a night that Gay and Steve Grossman go to bed happy themselves. It’s as simple as that. **e**

