

## Elizabeth Hoff chosen for 8-month advocacy program

By Jenny Kirk

Having two daughters who have a rare genetic disorder can be a lot for one family to handle. There are different kinds of challenges that come along with varying levels of uncertainty as well. But for Balaton native Elizabeth Hoff, it's all about meeting those challenges head on in the effort to be the best mom she can be.

Having been chose from a statewide pool of applicants, Hoff recently started an 8-month Minnesota Partners in Policymaking advocacy skills and leadership training program for parents raising children with developmental disabilities and for adults with disabilities.

"When we go to see the doctors, I encourage them to have their own questions," Hoff said. "So, they will go through and ask their questions, or they will tell the doctor what they need. As a mom, it's good to train them for their future. And by taking this class, it's my way of teaching my kids because they see by my example."

Participants in the nationally-recognized program include 35 men and women.

"There's a lot of information that gets thrown at you, but it's been great," Hoff said of the intensive program. "There are parents who are there for advocacy for their kids with disabilities and then individuals that have a disability themselves and they are there to learn about their advocacy, so there's a nice mix."

Chris and Elizabeth Hoff's world changed shortly after their oldest daughter, Willow, turned 3 years old. Daughter Bella was between 9-10 months old at the time.

"It was just after Willow's



Elizabeth Hoff

third birthday when we learned she had a rare genetic disorder," Elizabeth said. "Then once we knew, we had Bella tested, too. It's hard. It's like having the wind knocked out of you."

Hoff explained that it took time to process all the information.

"While you're processing it, you go through the grieving process, where you go through all the things you thought your kids would experience and realize that now, all of that looks different," she said.

The Hoff's reached out to the National MPS Society, a non-profit organization dedicated to acting as a support group for families affected by mucopolysaccharidoses (MPS), mucopolipidoses (ML) and other related disorders, along with increasing

professional and public awareness and raising funds to further research of the many disorders.

"They were able to give us some guidance on finding a very knowledgeable geneticist at the University of Minnesota," Elizabeth Hoff said. "Primarily, all the specialists the kids see are there. The girls do go to Gillette (Children's Specialty Healthcare) in St. Paul for orthopedic. Their ortho department is top notch. They're amazing."

The **mucopolysaccharidoses** are a group of inherited metabolic diseases caused by the absence or malfunctioning of certain enzymes needed to break down molecules called glycosaminoglycans — long chains of sugar carbohydrates in a person's cells that help build bone, cartilage, tendons, corneas, skin and connective tissue.

"The girls (Willow is now 12 and Bella is 9) have had a lot of surgeries for correcting issues within the skeletal system," Hoff said. "We've gone through 14 surgeries and we do weekly home infusions, which are enzyme replacements."

Willow and Bella have a progressive disorder, primarily affecting their skeletal system, vision and heart. It is a rare form of dwarfism.

"They were both in an under-5 clinical study for (enzyme replacement)," Hoff said. "Then they moved into an extension study. That's the leg between the clinical trials to the FDA (U.S. Food and Drug) approved phase."



Hoff explained that other than doing surgeries, there was no other treatment options at the time.

"Thankfully my kids got into the under-5 study and got the medicine into their system early on," she said. "We've seen the benefits of that, including increased endurance and energy level, as well as some of the visual ones, like their hair was better."

Although her daughters have an FDA treatment, this isn't where Hoff wants the regimen to stop.

"There always has to be something better," she said. "That's why further research is so important."

The Hoff's youngest daughter, 3-year-old Lillie, does not have the rare genetic disorder that her older sisters do.

"It was nerve-racking after she was born, until she was tested," Elizabeth said. "Lillie has been an awesome addition to our family. What I love with Lillie is that she thinks nothing different of her sisters. All the things we do medically in our house is just the normal for her."

Hoff shared that her children bring her great joy and that they are very kindhearted, loving and show great compassion to others.

"I wouldn't trade my kids for the world," she said. "They're amazing kids. Willow has a smile that'll light up the world, and Bella is so kindhearted. I'm thankful that my kids have friends who don't look at them differently for the things they can't do. They're blessed with really great friends."

Hoff said she and her husband have always been

open with their daughters, even at a young age.

"They are very involved in the decisions," Hoff said. "If they aren't, they won't be able to make those decisions when they're older."

The Hoff's have also tried to instill confidence in their daughters by focusing on their abilities rather than their disabilities.

"I always tell my kids that there are things maybe they can't do, but even then, there's something you can do," Elizabeth said. "That's true with anyone. Each of us has our strong suit and each of us has our weaknesses, but there's always something you can do."

With a positive attitude and plenty of support from the family and community, Hoff said she's not worried for the teen years.

"Challenges and pain come in many different ways," she said. "We all have to go through it one way or another. For us, we've just had to prepare for challenges a little earlier than a lot of other people. Willow and Bella have had life experiences that most adults haven't even had. It's given them such insight and wisdom beyond their years."

With the medical challenges involved, Hoff said she began homeschooling her children for the past year and a half.

"It is probably one of the most challenging things I have done in my life, but I love it," Hoff said. "It has been a very good fit."

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The girls are active with two homeschool co-ops, which Hoff praised for their efforts to make appropriate

accommodations for all of the kids' physical levels.

"They've been great," she said. "It has given my kids opportunities to participate and do things they otherwise couldn't do based on that, by the end of the day, they'd be physically exhausted," she said.

Recalling the time when the family was tasked with fitting a mobility scooter, walker, wheelchair, stroller and crutches all in the minivan for a trip, Hoff said having a good sense of humor also helps.

"We got it all in there, but it was quite the chore," she said. "We really had to be creative on the spot. Willow often uses crutches because of chronic foot pain, and Bella is still recovering from some orthopedic surgeries she's had. She has a walker for physical therapy, but for something with a long distance, Bella still has the wheelchair she is using."

When times get tough, Hoff said she's grateful for the outside support.

"Our family has been amazing," she said. "There were years that were really, really tough, and I'm very thankful for the support we've gotten from our church (Victory Christian) and our community, too. It's not something I take lightly or for granted. I am so appreciative."

Hoff is likely to inspire others with her desire and effort to improve the quality of life for her children in the way of advocacy and leadership above and beyond typical parenting duties. September marked the first class she attended through the program. A typical class runs from 11 a.m. to 9 p.m. on Fridays and until 3 p.m. on Saturdays.

"Classes are held in a meeting room of a hotel in Bloomington," Hoff said. "All of our meals are there, too, so that's nice. Last month, it was all about the history of disabilities. We went back into the Egyptian period and learned how people with disabilities were treated. We looked at how some time periods have improved while others have regressed." Hoff said there was a lot of discussion about the Parent Movement and how that affected perceptions over several decades up to the 1970s and beyond.

"You become very thankful for the people who have gone before you and paved the way," she said. "They've helped open the doors of opportunities."

This past weekend, Hoff said the focus was all about inclusive education.

"We had people from the Board of Education that came in during the evening for a round table discussion," Hoff said. "Every month, there's a different topic of things covered. It's been amazing. And in between the (monthly) meetings, we have our homework assignments we do. We take what we learn and build on it for the next month we meet."

One of the scheduled

activities Hoff is most looking forward to is having the opportunity to go to the State Capitol in March.

"We get to advocate there," she said. "I have some things I want to ask for, so I'm excited to get that component of knowledge through this class."

Hoff related the benefits of advocacy for people with disabilities to an iconic cartoon strip where you see a bunch of kids who are waiting for the snow to be removed on the stairs outside the school. Then you see a picture of a child in a wheelchair who asks if the ramp can be cleared so that everyone could benefit.

"Oftentimes things that can benefit someone with a disability can benefit so many people," Hoff said. "Sometimes we can pave the way that opens up opportunities for everyone."

Hoff is expected to graduate from the Partners in Policymaking program in May.

"What is terrific about this program is that it is open to any Minnesota parent raising children with disabilities and also individual adults who have disabilities," Sheri Wallace said. "They learn to feel confident in speaking up for their children and themselves. The program is paid for by the Federal

government because the benefits are so powerful."

Wallace has been part of The Wallace Group, which is hired to promote the program, for more than 10 years and says she has seen so many positive outcomes.

"It is such a well-designed program and it makes a life-changing difference for all involved, that it is a pleasure to promote," she said.

Partners in Policymaking was created by the Minnesota Governor's Council on Developmental Disabilities.

"The goal is to develop leaders statewide to partner with school systems, medical and business communities so all individuals with disabilities are supported as they become self-confident, independent and contributing citizens across the state," Executive Director of the Governor's Council Dr. Colleen Wieck said in a news release.

The program was introduced in 1987, and through expansion to other states and countries, Partners has trained more than 27,000 people worldwide.

"I'd encourage other people to seek out the program," Hoff said. "It is really helpful to apply for something like this, to gain knowledge and advocacy skills for themselves or for their kids."



**As a loud plane flies overhead during the Lyon County Fair in August, (clockwise from left) Elizabeth Hoff, her mom, Karen Larson, and Hoff's daughters, Lillie, Willow and Bella, react to the noise. *File photo by Jenny Kirk***



Bella Hoff enjoys a pony ride with her dad, Chris Hoff, alongside of her during Balaton's Fun Fest celebration in July. Bella and her sister, Willow, have a rare genetic disorder that primarily affects their skeletal system. *File photo by Jenny Kirk*