

FINfacts



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Parent Engagement: Parent Pays It Forward

By David Whitehurst, Editor

The medical journey of a child with special needs is often a very confusing and frustrating one. Mark and Denise Greenblatt of Toledo know this truth well. Their son Cayden has had such a journey.

The Greenblatts were heartbroken when their first child, Jonah, was born very prematurely in September of 2005 and lived only seven minutes. They were excited when Denise became pregnant with their second child, due March 1, 2007. But Cayden also was born very early-- on November 11, 2006. And he was small, one pound, 14 ounces and only 13 ½ inches long. Mark remembers, "My wedding band fit over his hand, over his wrist, over his elbow, up to his shoulder. We couldn't get it around the trunk of his body, but he was pretty tiny." On January 30, 2007, after 81 days in the NICU and relatively steady progress, Cayden came home for the first time.

A few months later, when their worried sitter told them that Cayden often tilted his head to his left side when interacting with her, the Greenblatts consulted with their doctor who ordered a CT scan for him. Enter confusion and frustration. Because the scan was performed late in the day, the results were interpreted remotely (in Australia!) and the report indicated a skull fracture and a subdural hematoma (brain bleed). Cayden was admitted to the hospital, and the new parents had to defend themselves against an unfamiliar doctor's assumption that their child had been mistreated.

"Cayden's two days in the hospital were a really traumatic time for us. I don't want any other parent to have such an experience," Mark says. "That situation motivated me to get involved in ad-

vocating for parents."

After their own doctor, knowing Cayden's medical history, determined that the "fracture" was a benign line on the skull and the "bleed" was enlarged ventricles due to prematurity, the Greenblatts were relieved—and vindicated. But, back home, they noticed that Cayden had trouble hearing from the right side. Tests soon confirmed profound hearing loss in his right ear, and the family contacted Project REACH, the Regional Infant Hearing Program (RIHP) of



Max, Denise, Cayden, and Mark Greenblatt

Lucas County, for help.

After more sickness, tests, hospital stays and medication, Cayden was finally diagnosed with Mondini dysplasia—a condition in which an incomplete cochlea (the "snail shell" part) often causes hearing loss. In Cayden's case, the cochlea allowed cerebrospinal fluid (CSF) to leak into his inner ear and bacteria to develop there causing Cayden's recurrent meningitis. Two surgeries and two long hospital stays later, Cayden's meningitis was finally stopped, but he had lost the hearing in his right ear.

Since this surgery, Cayden has been relatively "hospital-free" and living the life of a carefree four-year old. Mark acknowledges that Cayden has some bal-

ance problems and gross motor delays due to his medical issues. (Cayden didn't walk until July 8, 2008, at 20-months old.) One day in the spring of 2009 when he picked up his son from the sitter, she was apologetic because Cayden had scrapes on his knees from falling. Mark, recalling the incident, wells up with tears. "I told her, 'No, this is perfect. It's a beautiful day. He was playing. There's dirt on his knees. He's a typical kid.' ... Because of his medical history, if Cayden falls, other parents run over, but we say, 'He's OK. He's not crying. He got up, let him play.' We don't sweat the small stuff."

Mark, a proud father, recalls another emotional event. "Cayden and his mommy had baked the night before and, on November 11, his second birthday, walked into the NICU with brownies for the nurses, and Cayden asked, 'Is Dr. Stein here?' He wasn't, but the nurses let him know that Cayden had **walked** in to deliver the goodies."

Mark and Denise have transformed concern for their sick child into advocacy for all children with special needs. As a result of their experiences with Cayden, the vice president of Toledo Children's Hospital recommended that Mark and Denise serve on the Family Advisory Council (FAC), a group with representatives from the pediatric unit, the neonatology unit, and families of children who have had multiple hospital stays. The FAC encourages a patient- and family-centered approach to care that is a significant culture shift in medical practice. Through the FAC Mark learned about Project DOCC and Project SPEAK and became a parent-teacher (see page 3). Denise advocates for children as a member of both Project DOCC and the local

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A Mothers' Journey from Denial to Advocacy

By David Whitehurst, Editor

Sherri Rogers, president of the Down Syndrome Association of Greater Toledo and parent coordinator of Toledo Children's Hospital's Project DOCC (see page 3), has a passion for helping children with special needs and their parents. But she wasn't always so enthusiastic. In fact, at one time she was really down.

When she was told in the delivery room that her first child Kaiden had Down syndrome, Sherri was upset and afraid. "At the hospital, they gave me information about the Down Syndrome Association. But I clearly was not ready for that. I was in denial, and it was a whirl of emotions for a few months. 'Why me?' and 'I don't understand why.' And then I was hit with everything else. 'You have to do early intervention. He's low tone so you have to do physical therapy.' He was going back and forth between pediatricians, cardiologists, and pulmonologists weekly... It was very overwhelming at that time."

Rogers learned later that her grieving process was natural. "It's grieving not for the loss of a child but for the loss of your expectations," she explains. "When you hear Down syndrome you expect the worst, but things have changed so much...Kaiden is more of a typical child than I ever would have expected."

Although Kaiden is delayed in gross motor development, with low muscle tone, Sherri notes with pride, "His speech is good. He speaks very clearly for a child with Down syndrome. And he converses well with others, which is not typical of a child with Down syndrome at age four."

Sherri illustrates her son's skill. "Kaiden started preschool when he turned three. His classroom was at the very end of the building, so he had to walk down the entire hall. Every day when he got

there, right away from the first day, he would wave and say, 'Hi,' to everybody, all the way down the hall. Within the first week, his teacher said, everybody in the building had nicknamed him 'The Ambassador.' He was so charming."

As she watched her son grow and develop, Sherri grew as well. "Once I accepted the diagnosis, I embraced it and said, 'OK, I'm going to do everything I can to help him reach his potential.'"

When she went to a Down Syndrome Association of Greater Toledo (DSAGT)



Kaiden Rogers

Buddy Walk, an event designed to raise public awareness and understanding of people with Down syndrome, she heard the Association was looking for a secretary. Rogers, who has a bachelor's degree in Computer Programming and Web Design, decided to offer her services.

As secretary, one of her first tasks was to build a web page for them, www.dsagt.org. [Check it out. It's really good!] She

started answering the phone and reading e-mails and meeting people, and that's how she was directed to Project DOCC. "Some of the parents involved in it told me, 'You would be a great asset in the program. You're so eager'. So I took it on...To be honest I hated public speaking, even through college. All that changed with Kaiden. Now that's what I do because it is something I am very passionate about."

Rogers served as secretary of DSAGT for two years and as a Project DOCC parent-teacher for two years. Now she works as parent coordinator of Project DOCC, and in January of 2010, she was elected president of the DSAGT.

"The Down Syndrome Association serves 430 families, with close to 200 active families. It's really nice to network with other parents. We share information and advice to help the next parent. When I branched into Project DOCC, I became

interested in other diagnoses... Now I want to learn about other special needs and what they require... We all have medical problems and school issues in common."

Sherri feels that sharing her experiences with new parents is the most rewarding part of her job. She observes that the parents of a typical child have at least an idea of what to expect from their newborn. "But a child with Down syndrome or other special needs is different. The new parent thinks, 'Holy cow! I have no idea what I am facing. Is he ever going to talk?'... I can put the parents at ease by sharing my personal experience. 'Hey, everything is going to be OK. My son does everything that everybody else does. It may just take him a little bit longer.'... Parents need this to push them through that grieving stage."

Unlike helpful family members, other parents of children with special needs really do understand the daily challenges and anxieties new parents face, and they can share suggestions. "I can tell other parents what I did when Kaiden went through the biting stage...And now for me it's potty training. My mom can give me ideas of what she did with me, but that probably is not going to work with Kaiden. But to talk with another mother of a child with Down syndrome is much easier and more helpful. Nothing can top personal experience."

Rogers enjoys life with her family, husband Justin, sons Kaiden, 4, and Keegan, 1 1/2, and daughter Kayleigh, seven months. Her experiences have given her purpose. "My main goal is to educate others to see individuals as people rather than their disabilities. That's hard sometimes. Before I had Kaiden, I probably was one of those who saw the disability before the person. For me, to explain that to other people can change things dramatically, even if it's one person at a time. We love our kids for who they are, and now it's our job to help others to love our kids for who they are."

Ambassador Kaiden has taught his mother well. ☺

Parent Power in Lucas County

By David Whitehurst, Editor

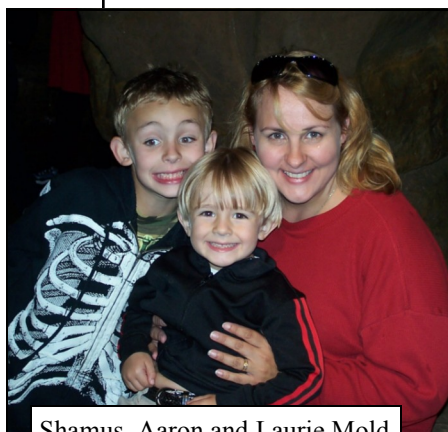
In 1994 in New York City, three determined parents of children with chronic health-care needs met to solve a problem. They were frustrated because their doctors, from a variety of disciplines, often were unaware of the daily health-care challenges faced by their children and their families. These concerned parents wanted to do something to promote better understanding of their exceptional family needs and thereby to improve the quality of their health care. From their ideas and efforts, an effective family-centered education program, **Project DOCC (Delivery of Chronic Care)** was born.

Laurie Mold had been a very engaged parent in Lucas County, Ohio, even before she became active in Project DOCC. She was a parent mentor for the Arc of Lucas County, an information assistant with The Autism Society of Northwest Ohio (her nine-year-old son, Shamus, has autism) and an information and assistance specialist at the United Way of Greater Toledo, a position she still holds. Laurie clearly enjoys her work, and one of her work goals is clear. "I want to help empower parents by giving them the tools and means they need to be effective advocates for their children with disabilities."

In June of 2007 Laurie became parent coordinator of Project DOCC, a new program in the Community Outreach Department of Toledo Children's Hospital. The purpose of the medical education project is to improve the quality of life for children who are chronically ill and/or disabled and their families by using **parents as teachers of health care workers**. The parent-faculty, by sharing their real life experiences and their children's special health care needs, help to educate doctors-in-training (residents from the W.W. Knight Family Practice and the University of Toledo Residency

Program), other health care professionals, and community partners. The project is funded by a five-year grant from the Ohio Developmental Disabilities Council (ODDC) and matching funds.

Ms. Mold, now the project coordinator, describes the process. "To be selected for training as parent-faculty, parent volunteers must have two years working with their child's disability. We look for parents who are committed to making a positive contribution, and we involve parents of children with a wide variety of chronic care needs, whether it is asthma, ADHD, muscular dystrophy, autism, allergies, seizure disorders, cerebral palsy, or Down syndrome. The needs we share allow us to speak with one voice no matter the disability."



Shamus, Aaron and Laurie Mold

Project DOCC's "family-centered care" model of treatment has three main components. 1) In the **Home Visit**, each medical

resident visits the home of chronically ill child for a two-hour parent-guided tour which illustrates a typical day in the life of the family and the child. 2) In addition, the resident arranges and conducts a doctor-generated, two-hour, one-on-one **Parent Interview** based on the parents' answers to Project DOCC's Chronic Illness History Questionnaire, an instrument which explores issues not identified by traditional medical histories. 3) Lastly, health professionals attend a **Panel Presentation** at which four or five parents tell their stories, from their children's birth to the present, in a scripted program using PowerPoint, slides, and video to describe the chronic care process families and providers undergo.

"Since 2007, we have trained 8-10 residents each year. Each meets with at

least three parents. And over 40 parents participate each year... We give the parents many opportunities to teach. We want to keep them busy," Laurie explains. 75 parents have been active in Project DOCC at Toledo Children's Hospital (TCH) since 2007.

Mold's work with Project DOCC also inspired another parent-engagement program, **Project SPEAK (Supporting Parents through Empowerment, Advocacy, and Knowledge)**, a grant partnership between TCH and Bowling Green State University (BGSU). Project SPEAK utilized **parents as teachers of teachers-in-training**. In this program, parent panels have educated general education majors at BGSU about ways to help students with disabilities and chronic illnesses in their general education classrooms. Project DOCC parent panels also have spoken at the University of Toledo, at Lourdes College, at Owens Community College, in nursing and occupational therapy classes, and at a nurses' conference.

"I can't tell you how overwhelmingly positive the evaluations of our parent-teachers are. They say, 'Wow! I had no idea about these issues. It was really moving.' And these comments come from both the medical and educational professionals."

Laurie adds, "These programs help parents to flex their advocacy muscles... They have stories which are unique and powerful... Twenty or thirty years ago parents were not even allowed in the hospital room with their child. There has been a real shift in the mindset at hospitals to work toward a family-centered care model of treatment... Doctors come and go, but the family is consistent. They stay in that child's life forever. The family is the real case manager."

Mold believes that parent engagement is both healthy and helpful. "Many families who have been lost and alone in the beginning have found support, strength and friendship through the program... These parents just want to make a

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Ohio's Family Engagement Committee

In 2009, the Ohio Family and Children First (OFCF) Cabinet Council created a cross-system Family Engagement Committee with the goal of aligning, coordinating, and consolidating parent/family engagement resources, policies, services, and efforts among OFCF Cabinet agencies.

The committee held a meeting with parent associations, parent groups and parent representatives in March

2010. The group's honest feedback and helpful input was used in the Family Engagement Strategic Planning Report. A key message shared at the meeting was to have "less talk and more action."

In response to this message, the Family Engagement Committee is now implementing the strategic plan with an initial focus on developing a universal Family Engagement Website to serve as a network for parents and professionals. This website will promote family engage-

ment and align parent and professional trainings, education resources, supports, and events.

The most recent Family Engagement Strategic Plan and future updates can be viewed at <http://www.fcf.ohio.gov/initiatives/family-engagement.dot> If you are interested in getting involved in this effort, please contact Tammy Payton at 614-752-4044 or tammy.Payton@governor.ohio.gov &

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March of Dimes board.

"There was a year when we were seeing six different specialists on a quarterly basis. We had to adjust work schedules constantly. Some families can wait to see a doctor and burn their entire afternoon. Our families don't have that same flexibility. Doctors need to understand the special challenges facing them. That was our message in Project DOCC."

In addition, Diane Frazee, director of the United Way Family Information Network of Northwest Ohio, informed Mark that the Ohio Developmental Disabilities Council was looking for parents to advocate in a variety of ways. Mark, a financial representative, reflects, "Before our visit to Israel, we made some plans to be safe and not to leave a potential financial problem for Cayden." He felt he could be helpful working with the ODDC as a parent advocate and bringing additional expertise to the Council based on his professional background. He applied for a position on the Council and was appointed by Governor Strickland.

After six years of marriage, Mark and Denise are enjoying their two great children, four-year old Cayden, an active and intelligent boy, and Max, a healthy and happy 8-month old. They have learned how to react positively to setbacks. Mark believes, "You have to play the hand you're dealt." He also firmly believes in reaching out to other parents. He is "paying it forward," doing good work for others to repay the good that has happened to him.

"In my work with the FAC, Project DOCC, Project SPEAK, and the ODDC, I try to make the system easier, better, more patient- and family-friendly, whatever you want to call it, for those who come after us. Now we have integration and inclusion where before we had separation and isolation. That's progress." &

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difference because they've had a hard journey. They just want to see other families have an easier way of it."

What does Laurie find most rewarding about her own work in Project DOCC? "I think the doors we are opening for future families and the friends I have made through the programs have

been the greatest gifts to me personally."

From an idea shared by three engaged parents 16 years ago, Project DOCC has grown into a vital program which has trained thousands as parent faculty and over 800 medical residents at 24 hospitals in the U.S. and Australia. And new programs are beginning each year.

That's how parent power works! &

"In our PowerPoint presentation to health professionals, we highlight a line from the song 'Colors of the Wind' from Disney's film Pocohantas, 'If you walk the footsteps of a stranger, you'll learn things you never knew you never knew.'"

Free Webinar for Families in HMG

Special Topic Webinar Repeat: On Thursday, November 4, 2010 from 1:00-2:30 pm and 7:30-9:00 pm, "How to Encourage Language in Young Children." Go to www.akronchildrens.org/fin to register.

Educational Webinars for HMG families

Steps Toward Tomorrow Educational Session Webinars – for a list of sessions, dates and times, go to FIN's website at www.akronchildrens.org/fin

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