



Meet Braylin

The Pulse

pediatric home service

Summer 2012

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The best is yet to be

As she says "I'll see you around" — Susan's remarkable legacy will live on

Most people have a retirement party. Susan Wingert had a Succession Celebration.

On a Sunday afternoon in June, hundreds of family, friends, staff, colleagues, and of course, PHS patients and their families, gathered at International Market Square in Minneapolis to acknowledge Susan's accomplishments.

True to her nature, Susan wanted this occasion to be about the future of PHS as well as its past. The event was not simply a retirement party celebrating Susan's successful contribution to the pediatric home health care community, but also a celebration of Mark's future contributions.

Longtime friend and colleague Dr. William Wheeler, who acknowledged Susan's status as a trendsetter, good-naturedly teased, "Now, I suppose everybody's going to want one of these parties." It was a fitting tribute to a woman who never hesitated to challenge the status quo to achieve a single-minded purpose: *taking care of the child.*

Susan built PHS from the ground up, recruiting a staff that shared her vision and gutsy way of getting things done. Together, they revolutionized pediatric home health care. Today, hundreds of medically-fragile, technology-dependent children live safely and successfully at home rather than in a hospital — something unheard of 25 years ago.

And now that Susan has handed the PHS reins to her son, Mark Hamman, she's confident he will do the same, "dreaming dreams and making things happen that would never have occurred to me."

Mark comes to the role very well prepared, having been in a formal succession plan for the past six years. He's earned his stripes and the respect of the staff, having worked in every department and done nearly every job in the organization.



Mark Hamman

See what some guests had to say.

"Susan knows the value of a dollar and what it costs to deliver a service. Yet she never turned down a case because of a family's inability to pay. She has lived a life of consequence and I don't think she's done yet. She's just going to a different playground."

— *Dr. William Wheeler*



Dr. William Wheeler

For more on the Succession Celebration, take a look at pages 5-6



PHS Services

- Respiratory Therapy
- Infusion Therapy
- Pharmacy
- Hourly Nursing
- Clinical Support Services

Pediatric Home Service (PHS) is an independent pediatric homecare company that provides specialized health care services to medically-fragile, technology-dependent children — in their homes, with their families. We recognize and understand the different needs of infants, children, and adolescents. We ensure continuity of care by working together with health care professionals, payers, and family caregivers.

The Pulse is published quarterly by Pediatric Home Service for clients, professional partners, the health care community and other friends of PHS. We welcome your suggestions and story ideas. If you have comments or questions or would like to be placed on the mailing list, please contact:

Lori Murray
2800 Cleveland Avenue North
Roseville, MN 55113
Phone: 651-642-1825
Toll-free: 800-225-7477
Fax: 651-638-0680

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PHS again one of Twin Cities' Top 100 Workplaces

Recognized with Ethics and Values Award

For the second consecutive year, PHS was recognized as one of *Minnesota's Top 100 Workplaces*. In addition to making the Star Tribune's third annual list of top workplaces, PHS was one of 12 companies to receive additional recognition — earning this year's ethics and values award.

“Ethics has been the foundation of our work since our doors opened in 1990, and it will continue to guide decisions we make operating our business in the years to come. When you operate based on morals, you feel good about your accomplishments. At PHS, we all rest easy at night knowing we did the right thing to take care of the child,” said Mark Hamman, PHS President.

Top Workplace winners were chosen based solely on employee responses to surveys focused on leadership, communication, career opportunities, workplace environment, managerial skills, pay and benefits. PHS was recognized at startribune.com and in a Star Tribune special print section. ■



PHS partners to help reduce hospital readmissions

Helping keep kids at home

PHS is a Community Partner in Minnesota's RARE Campaign, an effort to reduce hospital readmissions. While many readmissions are necessary, a lot are avoidable. The RARE Campaign is engaging Minnesota hospitals and care providers to prevent 4,000 avoidable hospital readmissions by Dec. 31, 2012. A broad-based, concerted effort to coordinate patient care after discharge across the continuum of care, the coalition aims to help these patients enjoy peaceful sleep — and better health — in their own beds rather than in the hospital.

To be a RARE Community Partner, an organization must provide service or support that helps improve care transitions and patient care following hospital discharge. As a Community Partner, PHS has endorsed the campaign and will be actively supporting it in a variety of ways. ■



Help us GO GREEN

Small actions can make a big difference when it comes to protecting our environment. If you'd like to help PHS GO GREEN, visit the PHS website home page and check the corresponding box, to indicate you would like to receive product alerts, *The Pulse* newsletter, or PHS satisfaction surveys via email rather than in the mail.



Message from our Medical Director

Dr. Roy C. Maynard

PHS helps enhance quality of life for kids with rare diseases

Uncommon diseases find common ground under the PHS umbrella of services. In pediatric medicine, one such disease is spinal muscular atrophy (SMA), a rare genetic neuromuscular condition that is the leading genetic cause of death for children younger than two years of age.

An inherited disease affecting the large motor neurons in the ventral (anterior) spinal cord, it is characterized by muscle atrophy and weakness and often presents in infancy and early childhood. Multidisciplinary care can improve the quality and length of life for SMA children, and PHS has been providing these services for nearly two decades.

There are four primary clinical types of inherited SMA with types 1, 2 and 3 presenting in childhood. A defect in the SMN1 (survival motor neuron 1) gene on chromosome 5 accounts for the disease. This gene encodes a protein essential for survival of motor neurons, with differing mutations of the protein accounting for the variable expression of the disease.

Inheritance is autosomal recessive: each parent must have one defective gene and the affected child inherits both bad genes.

When both parents are carriers of a gene mutation, there's a one in four chance for each pregnancy of having another child with SMA. Incidence of SMA is believed to be one per every 6,000 to 10,000 births.

Type 1 SMA, also known as Werdnig-Hoffman disease, usually presents at birth or shortly after. Infants with SMA Type 2 typically present with symptoms after six months of age. Clinical presentation includes low muscle tone and floppiness. Without intervention to support respiratory muscle function, patients will eventually succumb to respiratory failure. Type 3 SMA is known as Kugelberg-Welander disease. Children with this form of SMA usually present with symptoms after 18 months of age, and because they have much less involvement of respiratory muscle function, generally have a normal life expectancy.

Weakness of skeletal muscles that help with breathing and stabilization of the chest wall contributes to the respiratory complications associated with SMA. An ineffective cough results in poor clearance of airway secretions and increased risk for recurrent pneumonia. Shallow breathing, particularly when asleep, may cause low oxygen and elevated carbon dioxide levels. Partial or

total lung collapse can occur, especially after respiratory viral infections resulting in respiratory distress or failure.

Treatment of SMA is supportive, not curative. Outside of nutritional issues, managing these patients' respiratory systems is paramount to enhance quality of life. Early intervention includes cough assist devices to facilitate clearance of airway secretions. Disease progression often results in the need for respiratory support. Initially, noninvasive ventilation by mask and bilevel positive airway pressure (Bipap) are often utilized and improve pulmonary status. Some families will choose tracheostomy and mechanical ventilation for patients failing noninvasive respiratory support. Many of these families with SMA children will qualify for in-home skilled nursing care to provide safe treatment in the nurturing environment of the home.

Research has the potential to alter treatment from supportive to curative for some of these rare diseases in the future. Until those dreams come to fruition, PHS will continue to provide comprehensive services that help children – including those with obscure diagnoses – thrive at home. ■

C'mon online!

Join the PHS online community. Post pictures, share stories, give tips, comment on our blog and connect with other families facing similar challenges. Lend support and help celebrate the achievements of children who overcome tremendous medical challenges to live full and happy lives at home.

Here's where you'll find us:

 PHS Thrive blog at <http://www.pediatrichomeservice.com/blog/>

 Facebook at <http://www.facebook.com/PediatricHomeService>

 Twitter at <http://twitter.com/PHSKidsThrive>

 YouTube at <http://www.youtube.com/user/pediatrichomeservice>

On the Sharing Care beat PHS making a difference



Faith's Lodge crew

Helping out at Faith's Lodge

The annual trek to Faith's Lodge is a sign of spring at PHS. One weekend each year, PHS volunteers cook and spring clean at the Wisconsin retreat for parents and families facing a serious illness or the loss of a child. It's always special, but last April PHS volunteers arrived in time for Tree Planting Day. They purchased and planted eight trees to help replenish the forest which had been left barren after a storm the previous summer, and cooked a meal to serve the hungry crew. Read more about this event, Faith's Lodge, and the families who find hope and healing there on our PHS blog at <http://www.pediatrichomeservice.com/blog/faiths-lodge-family-shares-their-phs-experience>

PHS supports Children's Hospital

PHS was excited to participate as sponsors and volunteers for the Children's Hospitals and Clinics Baby Steps 3K. The event, which took place on a beautiful day in June at the Minnesota State Fairgrounds, is a way for families with children who have graduated from the Children's NICU to get together, raise money and have A LOT of fun!



PHS volunteers and family at the Children's Hospital Baby Steps 3K

Memorial Blood Centers Blood Drive

PHS hosts two annual blood drives in coordination with Memorial Blood Centers. Lately, we've added a bit of competition – and we're proud to say we have 'The Quick Draw' traveling trophy that goes to the donor with the fastest donation time (SAFELY, of course!). Thank you to Memorial Blood Centers for making sure our competition is fun and safe. PHS blood drives are typically held in May and November and open to the public. Keep an eye out on our Facebook page for sign up information and join us.



Blood Draw winner Laura shows off her trophy

Fun with a purpose: Hope Kids MN Suburban Adventure 5K Run/Walk

Face painting, clowns, crawly reptiles, swimming and beach volleyball: they all take place at the HopeKids Suburban Adventure Run/Walk and it's fun with a purpose. For the past four years, PHS has partnered with HopeKids MN to support this event that helps raise so much of the money needed to provide all the other events enjoyed by families who have a child with cancer or some other life-threatening medical condition.



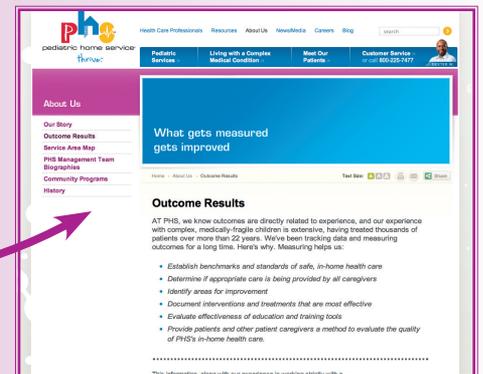
Volunteers had fun walking the 5K for HopeKids MN!



See what's new on our website - Outcomes page

Measuring outcomes improves care, that's why PHS has been doing it for a long time. By measuring key outcomes, PHS ensures we're delivering the best possible care for our pediatric patients and providing caregivers with the tools and resources they need.

New data have recently been added to the Outcomes page on the PHS website, and we've worked to make all the information even easier to find and understand. Visit <http://www.pediatrichomeservice.com/about-us-outcome-results.php> to see the latest outcomes data.



The best is yet to be

As she says "I'll see you around" — Susan's remarkable legacy will live on

"PHS has had a monumental impact on my family. Our son, Nick, is a testament to Susan's visionary thinking. We moved to Roseville in 1994 with a 7-year-old medically-fragile, technology-dependent child and a healthy 2-year-old, and we were blessed to be referred to PHS. Our wish was that our son would always live at home with us and be as happy and healthy as possible. Today, Nick at 25, has that quality of life. Susan, I salute you. You give children an opportunity to be at home in their own beds with everything they love and need around them. God bless you." — **Bernadette Torretto Bernardini**



Left to right, Lorraine O'Malley, Nick and Bernadette Bernardini, each of whom helped inspire PHS to become the kind of company it is today



Susan Wingert and Judy Giel

"Susan literally revolutionized pediatric home health care over the last three decades through her vision, resolve and integrity. Working in homecare 27 years ago, medical professionals asked her to help them transition Patrick, a medically-complex, 3-year-old boy, out of the hospital where he had spent most of life, to his home. Patrick turns 30 this month. Susan's effort to achieve Patrick's independence propelled an overwhelming response from the pediatric community to begin building the framework of a health care system capable of safely delivering and supporting complex medical care in the home." — **Judy Giel, Senior VP, PHS Clinical Services**



Bruce Estrem (left)



pediatric home service®
thrive.™



Kay Kufahl

T = Technology
H = Honesty
R = Respect
I = Integrity
V = Vision
E = Expectation

"THRIVE. This word describes all we have done over the years. The letters are a reminder of where we came from and where we are going to go in the future." — **Bruce, Sandi and Kay, three of the six PHS founding members.**



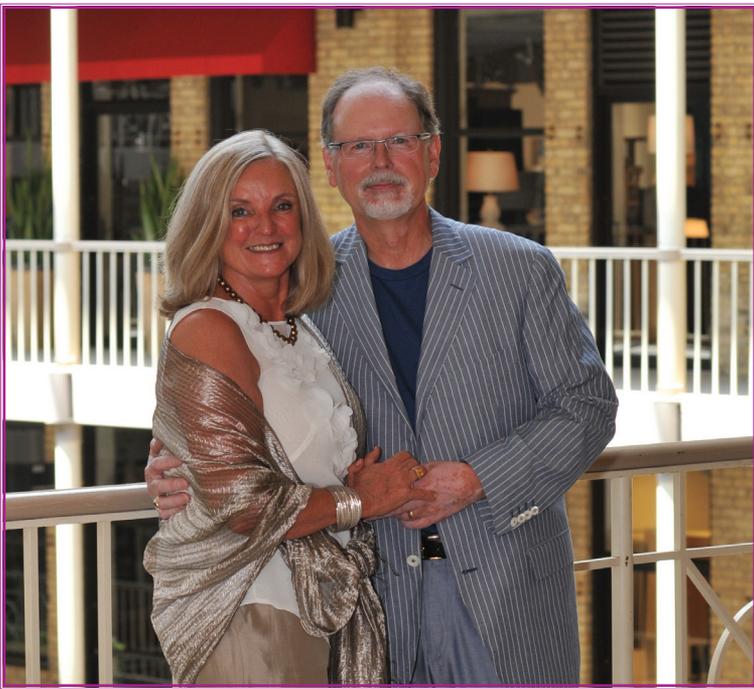
Sandi Maguire



PHS patient Claire

Little Claire attended the party with her family. A 1-year-old with spina bifida, she receives hourly nursing and respiratory therapy from PHS.

Continued on page 6



Susan Wingert and husband, Jan Mattson

“I would like raise a glass to Susan and to British Oxygen. There would be no PHS without British Oxygen. Susan said to me one day, ‘I know I can do this better.’ So we borrowed some money and we ate peanut butter for a couple of years and it all began. How many lives has PHS touched – and all for the better. If the hard way is the right way, we did it the hard way. I’m proud of my wife. She can truly look back and say, ‘I made a difference.’” – **Jan Mattson**

“How can I succeed my mom who did so much? I take confidence in her belief that I can do this. No one out there does the kind of work we do at PHS, not anywhere in Minnesota, in the country, in the world. Everyone who surrounds me is 100 percent dedicated to this vision to take care of the child. Thank you, mom. With all the tools you have given me, I have no question that we will continue the legacy.” – **Mark Hamman**



Susan Wingert and Mark Hamman



Susan Wingert gave praise to all during the event

In true Susan fashion, she gave as many accolades as she received during the Succession Celebration, thanking the medical community, vendors, partners, the folks who pay the bills, legislators, patients and their families: “I am absolutely overwhelmed. But as many tributes as come this way, I have to say they have more to do with what the PHS people did, not what I did. The people I work with are the best people on the face of the earth. I got lucky. This isn’t a job for them; it’s their calling.”

– **Susan Wingert**



Mark's promise to PHS families:

“Every day we do the best we can for your children and we will continue to do that.”

Mark Hamman, new PHS President, interacts with current PHS patient Shelby.



What's new in health care reform

Access to care is a key issue

Much of the debate surrounding health care reform has focused on the need to improve access to health care – in other words – a person's ability to get needed care. That ability to get care is affected by many things, including:

- the availability of health insurance or coverage,
- the cost of care,
- the geographic location or availability of health care clinicians,
- the number of clinicians working under contract with a health plan.

Without access to care, patients, rural and urban, aren't able to maintain or improve their health. And even with access to a health care provider, there can be additional barriers – language, literacy and cultural differences – that make it harder to utilize health care resources to achieve successful outcomes.

That's where patient advocacy comes into play.

Cathleen Urbain works alongside PHS clinicians to help improve their access to health care.

"PHS is constantly trying to ensure and improve access to health care for everyone," says Urbain, "regardless of language, health literacy or cultural beliefs."

Here are some examples:

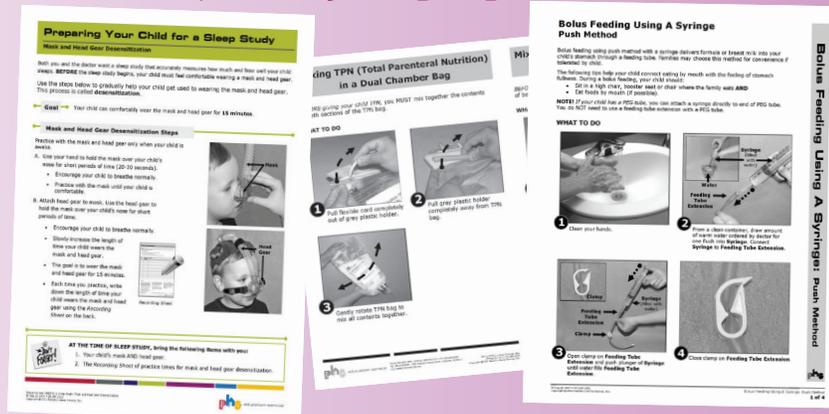
- PHS completes some or all of a communication and cultural assessment with the patient's family. This assessment includes *the learning style and language they prefer as well as any cultural or religious beliefs that may affect patient care*. PHS uses that information as they try to tailor care to unique patient needs. If there is a change in staff, the information remains in PHS medical records to ensure consistent care.
- PHS *provides an interpreter*, regardless of reimbursement. There's an in-person interpreter available for clinical visits and hourly nurses, as well as a phone interpreter available for phone calls. All PHS employees are trained to know that this is a patient right and that patients are to be notified of this. To expand access to care, PHS is also currently considering video remote interpretation as a possible additional resource.
- Following U.S. Health & Human Services guidelines, PHS provides *translation of vital communications for caregivers such as letters, educational documents and forms in the most prevalent languages*. Additionally, all patients are notified that they have the right to a free interpreter and someone available to help them understand a document they receive.

PHS currently provides translations in Spanish and Hmong, and has made some documents available in additional languages. Urbain explains there is a threshold for determining when languages should be added, "Although we provide services throughout Minnesota, we use the seven-county metro area as the basis for determining which languages reach the threshold, which is that at least five percent of the population identifies that language as the one they prefer to speak in relation to healthcare."

- PHS hourly nurses are provided extensive training in the areas of cultural competency, interpretation and translation, and health literacy. This includes tips for patient-centered communication, e.g., asking "What questions do you have?" rather than "Do you have any questions?" or "What about infusion medications make you uncomfortable?" rather than "Are you comfortable with infusion medications?" ■

What does PHS do when someone's preferred learning style isn't reading, or when English is not the primary language?

PHS uses pictures to provide education documents to patients and caregivers who prefer to learn in ways other than reading, or whose primary language isn't English. When written communications and product alerts are necessary, we aim to provide them in plain language.





Staff Spotlight

Meet Miguel

Helping people in need, just like his granddad

Miguel Schultz admires people who go out of their way to help other people. “My grandfather, for example, would just stop to help people by the side of the road, even when they were strangers. He was able to have an impact on that person’s day by helping out in a time of need,” says Miguel.

That is not only a characteristic Miguel admires, it’s one he is able to put into practice every day on the job as Admissions Supervisor at PHS. “What we do in the admission process,” he explains, “is to make sure the transition from hospital to

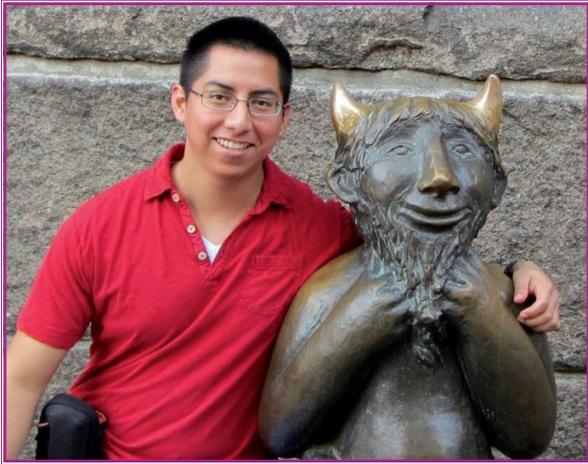
home goes smoothly. We make sure that insurance coverage is there and help to keep the family at ease throughout the whole process, from intake to going home. That is invaluable in *taking care of the child.*”

The best part of his job, he says, is seeing the kids and connecting with the families. When he is an on-call driver, he gets that chance. When a family is really concerned about a situation and Miguel can reassure them that PHS is doing everything possible to care for them from start to finish – those are his best moments on the job.

three boys. Someday, he says, he would love to add a dog to the mix. In the meantime, he watches football, eats his favorite ethnic meal of lentils and rice – doing the cooking once in a while – and indulging in his chocolate obsession. “I can’t live without chocolate, especially M&M’s and plain Hershey bars.” He also likes to travel, and has just returned from Germany where he says you can just feel the history. “It’s cool to walk down cobblestone roads and know that people have been there so long before you.”

Born in Ecuador where he was adopted by a missionary couple, Miguel and his family lived there for eight years before moving back to Minnesota. He attended high school at Rivers Christian Academy and went to Bethel, Century College and St. Paul College. He had been working toward a degree in kinesiology and computer science, and says Miguel, he would like to go back and finish in a year or two.

But for now, he loves doing just what his grandfather did – helping people in their time of need and making a difference in their lives. ■



Miguel visits a famous landmark on his trip to Germany.

Miguel has been with PHS for four-and-half years. Previously employed by a delivery company that works with PHS, he got to know some of the guys in the PHS warehouse and when they told him about a job opening at PHS, he applied. He was promoted to Admissions Supervisor in May and says it is a great opportunity.

Miguel’s family includes his parents, a brother, Marc, who is five years older, Marc’s wife, Laren, and their



Kids Being Kids

This PHS kid isn’t a kid anymore, and PHS couldn’t be prouder!



PHS started caring for Anastasia when she was five years old, after she had been diagnosed with Spinal Muscular Atrophy (SMA). Led by PHS Respiratory Therapist Dan Cleve, PHS provided Anastasia with respiratory therapy and equipment and supplies, including a BiPAP machine to help her breathe at night, a food pump and suction machine. Today, Anastasia lives independently in a Twin Cities apartment with 24-hour nursing care. She just turned 19 and she’s writing a book (look for it later this summer). And she’s preparing for college, where she will study creative writing. Anastasia and her friend, Brielle, pictured at left, like to attend a street dance/festival every year. At this particular one, they were attending a baseball game for Brielle’s brother.

We’re on the lookout for photos of “kids being kids” to consider using in future issues of *The Pulse*. Photos can be of any kid activity, from drawing a picture to skiing to playing with pets. Submit photos via email to kkhalena@pediatrighomeservice.com. If we choose your photo, we will contact you.

Thriving at Home

The eyes have it

Braylin sweetens up precious time at home



The family enjoy precious moments – evenings, they say, are the best time of day

“We are blessed to have her. She’s taught us a lot about life and happiness and what matters.” If that sounds like any new parent, it is – and it isn’t. Shannon and Matt, parents to Braylin, now 18 months old, have the gratefulness and renewed perspective of new parents. But their fondness for Braylin and precious time with their little girl is made more priceless, since Braylin was diagnosed with Type 1 Spinal Muscular Atrophy (SMA).

“The general diagnosis is that babies with Type 1 SMA do not live past their first birthdays. It’s the number one genetic killer of children under age 2 in the world,” Matt says. “But, there are also thriving 12-year-olds with Type 1 SMA. Our early diagnosis was critical, along with finding the right caregivers, including PHS.”

Peace of mind from PHS

After her diagnosis last year, Braylin and her parents spent five days at the University of Wisconsin Madison Children’s Hospital. She had a g-tube placed and has been at home since then. Her care is overseen by a PHS Case Manager, PHS nurses covering four night shifts each week and some day shifts and a PHS respiratory therapist.

Matt explains: “Our house is basically a Pediatric Intensive Care Unit with everything an SMA patient needs. Hospitals have SMA specialists, but they also have more germs. Germ-wise, she’s safer at home than in a hospital. Cognitively, it’s a better environment. For a family, home is the best place for all of us.”

Sweet moments

“We absolutely love evenings with Braylin,” Shannon says. “We turn on some music, lay her on the floor and stretch her and talk with her. She talks with her eyes, and it’s very clear to us what she is saying. It’s the sweetest, most precious time.”

Shannon explains: “Braylin uses bi-pap to mask vent for 10 hours at night. Also at night, she gets a constant drip of formula with Vivonex to help her energy and respiration. She gets feedings every three hours to slow

down muscle atrophy. We do at least two respiratory therapy treatments each day.”

Cognitive awareness

“Braylin isn’t able to sit independently, but she really likes to look out the window at the trees,” Shannon says. “Cognitively, she is completely here. She laughs and responds like other kids her age, and loves when we read to her. Since she says everything with her eyes, we are currently working on different eye-communicating techniques, with guidance from a specialized teacher.

“Our goals are to get Braylin in a powerchair so she can scoot around the house and get her an eye-gaze machine so she can communicate better.”

PHS re-energizes

“Besides the great care for Braylin, PHS has given us emotional strength,” Shannon continues. “At first, I didn’t trust anyone with Braylin. But PHS nurses and clinicians as well as other caregivers allow me to take much needed little respites, which re-energize me so I can be the best mom possible. My husband is able to continue working to support our family.”

How to handle initial diagnosis

Shannon recalls: “Like other expectant parents, I knew the unpleasant parts of pregnancy would be worth it because we would see our child grow, get married and have a life. When we learned Braylin had medical issues, I realized she will not be a ballerina or volleyball player like me. To come to terms with this disease and deal



S-t-r-e-t-c-h those arms! Mom turns the music on for exercise time with Braylin

with it is very, very challenging. When you get news like that, you don’t know how to process it. Your body shuts down. I stopped living; I stopped eating. My motherly instinct said, ‘take care of your child.’ But it wasn’t what we envisioned. Today, I encourage parents of medically-fragile children to see a grief counselor or other professional. That really helped me.”

Powerful resources

Matt and Shannon offer some guidance to parents of medically-fragile kids: “Have hope: there are many trials and research programs underway. Get support: there is a private Facebook page for SMA families, SMASpace.com (a website started by a SMA father that provides excellent information from other families), plus many great blogs for information, discussion and advice.”

While they give and get support from other parents, Matt and Shannon also treasure precious moments with their child at home. Just like other new parents. ■



Braylin says everything with her eyes, says mom, and the family is working on eye-communicating techniques with help from a specialized teacher

2800 Cleveland Avenue North
Roseville, MN 55113
Phone: 651-642-1825
Fax: 651-638-0680
www.pediatrichomeservice.com



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The Pulse

news for our health care partners

Celebrating our past and
future

Little Braylin gives lessons on
life

Partnering to reduce hospital
admissions

Annastasia all grown up

Working to improve your
access to care