



Meet Lexi

# The Pulse

pediatric home service

Spring 2011

## Inside this issue:



Area summer camps for  
medically-fragile kids  
page 2



Message from our  
Medical Director  
page 3



News and Notes  
page 4



Hot Topics  
page 5



Staff Spotlight  
page 6



Kids Being Kids  
page 6



Thriving at Home  
page 7

## We'd like you to us

PHS adds a Facebook page

**Pediatric Home Service**

Local Business · Roseville, Minnesota

click

**Meet the miracles. Hear from parents. Prove it to yourself.**

Like PHS and you'll love the tips, tools and support we'll send you:

- Blogs from care to coping and anything that relates to your child's condition
- Tips, techniques and technologies that will help your child thrive
- Sharing Care information and support from parents like you
- Kids' stories of success, so you can meet the miracles themselves

As parents know, the key to keeping track of their kids is communication — and there are so many more ways to communicate these days. At PHS, we're always looking for effective new communication tools that will help us interact with patients, families, physicians, and community organizations. And as any kid can tell you, social media offers some excellent tools to keep everyone informed and share ideas.

So, PHS now has a Facebook page and we want to be friends with you.

As you are probably already well aware, Facebook is a widespread communication tool for individuals and organizations. According to Facebook, there are more than 500 million active users; the average user is connected to 80 community pages, groups and events, and more than 200 million people actively use Facebook on their mobile devices.

Each Facebooker uses the tool very differently. PHS's Facebook page is updated regularly and serves as a hub of information on news and events related to PHS kids, families and pediatric home healthcare.

The page includes:

- New videos, photos, and blog posts
- Resources for families with medically-fragile children
- Conferences and events that PHS clinicians attend
- New presentations with links back to PHS and other relevant websites
- Interaction with other PHS fans to share ideas, converse, plus get and give support

We look forward to chatting with you so please take a minute to 'like' PHS on Facebook at [facebook.com/PediatricHomeService](http://facebook.com/PediatricHomeService). We also encourage you to post comments and information that will help other PHS families and caregivers. We'll all benefit from the interaction as we share our journey *taking care of the child.*

## PHS Services

- Respiratory Therapy
- Infusion Therapy
- Pharmacy
- Private Duty Nursing
- In-Home Asthma Management
- Clinical Support Services

**Pediatric Home Service (PHS)** is an independent pediatric homecare company that provides specialized health care services to technology-supported 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:

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Follow us:    



## Let's go camping!

Fresh air, new friends, crafts, and of course campfire skits: Even medically-fragile kids can be happy campers at summer camps designed for their specific needs

PHS encourages families to consider summer camp for their kids. Counselors, staff members, cooks, guides, therapists, and 24-hour on-call health care professionals bring unique training, expertise, and enthusiasm for working with medically-fragile kids. Most of all, kids learn they're not at all alone.

Check out these summer camps for medically-fragile kids in the Twin Cities and surrounding areas. For further details such as dates, ages and registration information, please visit the Resource Library on the PHS website at: [www.pediatrichomeservice.com/health-library-documents.php](http://www.pediatrichomeservice.com/health-library-documents.php)

If you don't see a camp that fits the need of you or your child and you are a PHS patient, please contact Social Worker Monica Handlos at 651-789-9215 or email her [mhhandlos@pediatrichomeservice.com](mailto:mhhandlos@pediatrichomeservice.com). You may also contact United Way First Call for Help for additional camps at 651-291-0211 or 1-800-543-7709.



**Asthma Camp** for kids with asthma.

- Camp SuperKids in Loretto (just west of Minneapolis)

**AuSM Summer Camps** for children and young adults with autism.

Sessions include:

- **Camp Hand in Hand** near Brainerd
- **Wahode Day Camps** in Eagan
- **Camp Discovery**, for kids with Asperger's Syndrome, near Maple Lake

**Camp Needle Point** for children with diabetes.

- Sessions at Camp St. Croix in Hudson, Wis.

**Camp Odayin** for children with heart disease.

- **Residential Camp**
- **Day Camp**
- **Family Camp**

**Kamp Kace** for children in all stages of cancer treatment.

**Camp M.A.S.H** Make. Arthritis. Stop. Hurting. This camp is for children ages who have arthritis or a related illness.

**Courage Center** has many camp sessions for many interests. It also offers camps for independent and active adults ages 18 and family camps.

- **Literacy Camp** for campers who are struggling readers
- **Camp for kids with physical disabilities or visual impairments**
- **For campers with communication disorders**
- **Leadership for teens with physical disabilities or sensory impairments**
- **Hemophilia** This session is geared for children who have hemophilia and other related bleeding disorders.
- **Oncology/Blood Disorder session** This session is geared for children who have or had leukemia or other blood disorders, brain tumors and other forms of cancer.



# Message from our Medical Director

## Dr. Roy C. Maynard A peek back and a look ahead

We just passed my one-year anniversary as PHS's on-site medical director. The scope of my responsibilities continues to expand. Along with it, PHS's success in taking care of the child also continues to expand. Here's a view of some accomplishments during my first year here:

### Controlling infection

Since I have an undergraduate degree in microbiology, it was logical for me to lead the PHS infection control committee, and our activities include:

- Monthly reviews of policies and procedures.
- Implementing and updating guidelines for hand washing, equipment cleaning and sterilization to comply with Joint Commission standards.
- Examining CDC recommendations for health care workers' immunizations and passing those on to PHS staff members.
- Reviewing central line bloodstream infections in PHS home infusion patients; our infection rates are much lower than reported hospital infection rates.
- Launching a pilot study last fall to look at the incidence and management of tracheobronchitis in trach-dependent patients; the study will be completed this year, and we'll use the information to establish the standard of care in managing this recurrent problem in tracheostomized patients.

"Already this year, our work reviewing new equipment, sharing current topic information, working on infection control, and offering Private Duty Nursing services has helped us enhance our services in effectively, efficiently taking care of the child. And that's what PHS is really all about."

### Reviewing new equipment

Working with the committee that reviews all PHS new equipment acquisitions has helped me learn more about the actual equipment, logistics, insurance and other issues. Our focus is on getting the right equipment to each individual patient, and we're always looking for safe, high-quality new equipment such as:

This past year, a novel new ventilator series made by Resironics (Trilogy Series) made significant inroads with our ventilator dependent infants. The Trilogy ventilator offers a replacement for a previous and aging infant ventilator no longer in production. PHS respiratory therapists have adapted this ventilator to "sip and puff" mode for neuromuscular patients with respiratory involvement.

### Sharing information

I provided quarterly lectures for our clinical staff members on the following topics: cystic fibrosis, enzyme replacement therapy, bronchopulmonary dysplasia (BPD), and pediatric neuromuscular diseases. Staff members get CME credits and reinforce their knowledge of specific topics to better care for patients with these diseases.

You can view the PowerPoint presentations on the PHS website (click News/Media on the homepage, then choose Presentations under Multimedia).

### Adding Private Duty Nursing

We recently added Private Duty Nursing for our patients, along with other educational offerings. We address the importance of communication between health care providers, our homecare nurses, and on-call physicians. We discuss different diagnoses and associated challenges with the private duty nurses to help them troubleshoot potential clinical scenarios. ■

### 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

*In keeping with our mission to take care of the child, PHS supports the efforts of many like-minded organizations. Since our last issue, Sharing Care has supported the following:*

### Gutter Bowl

Bowling may not be what we do best, but helping kids is right up our alley. On Feb. 18, two PHS bowling teams joined in the fun at The Brunswick Zone in Brooklyn Park to help raise money for the University of Minnesota Amplatz Children's Hospital. This was the 5th annual Gutter Bowl hosted by WCCO and morning announcer, Dave Lee, and PHS has participated in every one.



PHS bowlers had a blast while supporting the University of Minnesota Amplatz Children's Hospital that takes such good care of kids.

## SHARING *Care*

### Blood Drive

The annual PHS blood drive will be held May 5, 2011. Each year, PHS gives its employees and others the opportunity to give a life-saving donation of blood by hosting the Memorial Blood Centers at the PHS building in Roseville. This year's drive will be from 8 a.m. to noon.

Anyone interested in coming to PHS to donate blood should contact Dana Akerson at 651-789-3270.

### Faith's Lodge

For the past two years, PHS has taken a weekend trip to Danbury, Wis., to help Faith's Lodge prepare its facility for the spring season. A retreat for families facing serious illness or death, the rural setting provides a peaceful escape for those who need time to reflect and refresh. On April 1 and 2, PHS employees cleaned and cooked, preparing trays of lasagna and cookie dough to keep in the freezer for the families who come to stay at the lodge.



A group of 27 Sharing Care volunteers including PHS employees, their family and friends spent the day cooking and cleaning Faith's Lodge in preparation for new guests.



PHS volunteers (left to right) Michael, Karen, Nick, Lisa, Dana, Janelle and her three sons were proud to support the event and a great organization: the Arthritis Foundation of the Upper Midwest. Charles is the one with the snazzy red ribbon and medal; his mother, Louise, is in the black t-shirt.

### JAM Event

PHS patient and this year's honoree Charles Dias kicked off the 2011 JAM (Juvenile Arthritis March) held at the Mall of America Saturday, March 5. He was joined by teams dressed as doctors, Thing 1 and Thing 2 from Dr. Seuss, clowns, and teams dressed in camouflage, hunting for a cure. Motivating cheers from "Charlie's Angels," including Charlie's family, candy, and music from the Minnesota music group KooKooKangaroo ensured fun for everybody.

### Seals of approval Assurances you are getting the best possible care

- In 2009, PHS earned its sixth consecutive accreditation Gold Seal of Approval from the Joint Commission (first accreditation in 1994). The award marked 16 consecutive years of accreditation.
- PHS licensed respiratory therapists are also neonatal/pediatric specialists and 2 therapists are certified asthma educators whose capabilities are verified annually through extensive skills testing.
- PHS is the only pediatric disease-specific independent homecare program in the country certified by The Joint Commission, received the Gold Seal of Approval for Pediatric Asthma, a distinction first awarded to PHS in 2003.
- PHS has been named a Quality Respiratory Care provider by the American Association for Respiratory Care.
- PHS respiratory therapists are certified by the National Board of Respiratory Care and licensed in both Minnesota and Wisconsin.

- PHS has two employees with the title of Certified Biomedical Equipment Technician (BMET). They are two of 62 in Minnesota and only 2,500 people worldwide to receive the title from The International Certification Commission and The United States Certification Commission for Clinical Engineering and Biomedical Technology. BMET certification guarantees PHS is up-to-date on the latest technology in medical equipment.



## Hot Topics

### Rules were made to be followed

PHS goes above and beyond to meet and exceed quality standards and ensure regulatory compliance

It's scary enough having to bring a sick child home, explains Cameo Zehnder, Managing Director of Regulatory Affairs at PHS. "We want our customers and referral sources to feel 100 percent confident PHS is providing the safest and best possible care. Creating the accreditation and patient safety position is one of many ways PHS ensures that happens."

#### What does accreditation mean?

Think of it as a stamp of approval by an independent third party that verifies the authenticity and quality of an organization and its services.

#### Why the industry needs standards

Accountability is becoming increasingly important, especially in health care, says Zehnder. As the nation struggles with rapidly rising medical costs, stories about medical fraud, abuse, and waste are making headlines in newspapers across the country.

Accreditation, certification, and compliance are all very important for not only the health care consumer but also the health care professional," said Zehnder. Reputable credentials mean that patients and health care professionals can be reasonably sure a provider adheres to standards and ethics:

1. To ensure safe care
2. To ensure quality care
3. To contain costs by avoiding waste and ensuring health care dollars are spent appropriately

As the liaison between PHS and its various accrediting and regulatory agencies, Suzie Clifton, Accreditation and Patient Safety Coordinator, ensures PHS is always in compliance with the standards they set. She does that by acting as a "third set of eyes," assuming the role of an independent outsider who objectively scrutinizes the organization by applying the same standards as do outside agencies when evaluating PHS.

#### How we ensure safety, efficiency, and quality

**Regulatory affairs:** oversees and directs quality assurance and ensures compliance with all rules and regulations, federal and state, laws for fraud, antikickback statutes, accreditation, civil rights, billing, and licensure. "You name it," says Zehnder, "and we make sure we comply with it. We check everything, audit everything, electronically, manually, and more than once."

**Health information:** Health Information Manager, Josh Larson, leads the health information function in Regulatory Affairs, analyzing and improving information process and flow, leveraging technology infrastructure, and working with patient records and documents to ensure billing and HIPAA compliance, and improve quality of care. (Read more about Josh in the Employee Profile on page 6)

**Billing and claims:** coordinates patient account and reimbursement services. Says Billing Manager Laurie Finch, "We make sure our computer files are up-to-date, that every claim that goes to an insurance company is accurate, that we are pricing products and services correctly, monitoring quantities correctly, and that all claims are paid in a timely manner."

#### Avoiding waste with appropriate care:

"We go to great lengths to avoid waste," says Clifton. "One way to do that is to make sure our patients receive appropriate and necessary care, not more or less than they need. This makes for better quality care, but it also goes a long way to help keep health care dollars down." For example, a comprehensive client assessment tool is used to determine the number of hours a child really needs a private duty nurse. "A child may need 24 hours to begin with, but then we reassess and may adjust hours."

PHS also works closely with manufacturers, she added. "If something fails, we make sure they replace it. We also educate families on the appropriate reuse of supplies and are careful to correctly interpret quantity limits to make sure the patient gets what is needed, which, at times, may be less than what is allowed. And we work closely with physicians to make sure we are following orders. The patient specific PHS supply sheet — a list of all disposable supplies with the recommended quantity — is a very effective tool in helping patients make sure they aren't over or under ordering supplies."

**Patient safety:** PHS focuses on patient advocacy and safety issues, such as recalls or concerns with any medical devices or products. "We identify the product and patients who have received it," says Clifton, "and work in accordance with instructions from the FDA and manufacturer. Our Patient Advocate, Cathleen Urbain, also makes sure our patients and families understand what is happening by using appropriate language and photos where health literacy may be an issue." ■

## 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 homepage and check the corresponding box, to indicate that you would to receive product alerts, *The Pulse* newsletter, or PHS satisfaction surveys via email rather than in the mail.



# Staff Spotlight

## Meet Josh

### Following in the family footsteps

Health care has been a family affair for the Larsons. When Josh began working as a respiratory therapist in 1993, he was following in his parents' footsteps. His mom was a radiology technician and his dad owned a Medical Imaging repair company, contracting with hospitals in Northern Virginia where the family lived.

"It wasn't uncommon for me to tag along with them on weekends or after school," says Josh. "I grew up in a hospital environment." When he was 18, his interest in health care deepened after his father was diagnosed with pulmonary fibrosis. "He was in and out of hospitals and on ventilators," he recalls. "I saw what the respiratory therapists were able to do for him and it opened a career door for me."

Josh graduated in 1994 with an RT degree and began working as a respiratory therapist at Arlington Hospital. Later, he moved to upstate New York, where he had his first experience working with kids, as a respiratory therapist in neonatal and pediatric intensive care units.

#### From hospital to homecare

Born in Minneapolis, he moved back to Minnesota in the mid-90s. "My grandparents were having health issues,"

he said, "and I wanted to be closer and help support them."

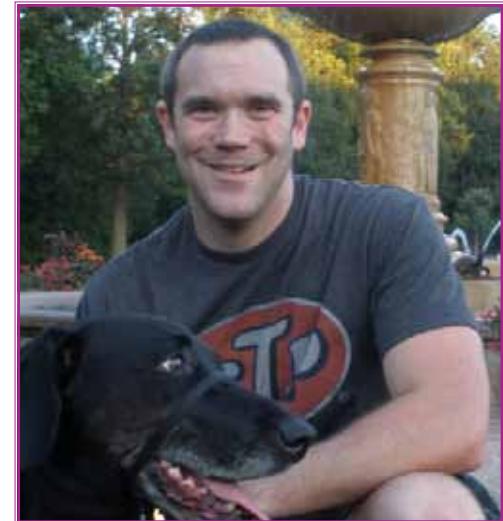
Josh took a job as a respiratory therapist at PHS, although he initially had some misgivings about making the transition from hospital to homecare. "In school, I didn't think I'd be working in a homecare setting," he admits. "I thought it would involve sitting by a bedside. Until I came to PHS, I had no idea homecare could be so challenging. We take on kids with such complex conditions and who have such a high level of need. Plus, PHS is unique in that it really engages clinicians to be part of a team."

#### From the field to management

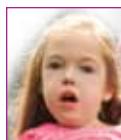
In 2006, Josh took on another challenge, filling a newly created position as Accreditation Coordinator for PHS. It was a natural step for this lifelong learner who has long combined additional schooling with work, earning a master's degree along the way.

After four years, he moved into another new position as Health Information Manager, responsible for anything and everything having to do with health information.

"All our private duty nurses chart real time in the home," says Josh. "We track infections in patients and self-reported infections in employees to identify possible trends. No one has to create a rule for us to do something that is advantageous to our patients or the health care community. If we see something that will help, we just do it." ■



When he's not on the job, Josh likes being active, running, biking and playing with his black lab, Chloe. He also likes to travel and doing what he came back to Minnesota for: spending time with his grandparents, family, and friends.



# Kids Being Kids

## Meet Mary Kate

### Blooming at home



*Gardening with Grandma.* Mary Kate and her grandmother were enjoying the sunshine as they planted this blooming beauty. And with tender, loving care, it will grow — just like Mary Kate. Born with a damaging type of spinal muscular atrophy, Mary Kate can't walk, sit up by herself or even clear her own airway. Yet, with the support of her family and PHS, she thrives with treatments and technology that allow her to exceed expectations and stay healthy and at home where she enjoys a good quality of life planted right in the middle of people who love her.

**Picture this:** We're on the lookout for photos of "kids being kids" to consider for use in future issues of The Pulse. Photos can be of any kid activity, from drawing a picture to trick-or-treating to playing with pets. Submit photos via email to [dmakerson@pediatrichomeservice.com](mailto:dmakerson@pediatrichomeservice.com). We'll contact you if your photo is chosen.



# Thriving at Home

## Finishing dialysis, beginning childhood

From frightened baby to willing patient

"She had no symptoms. No fever, no complaints of anything."

That's Lexi's mom, Maria, explaining the start of an unexpected chapter in their lives. Maria and her husband Travis received a call from Lexi's daycare provider about a "large bump on her tummy." At the time, Lexi was 17 months old.

Just two days after detecting the "bump," Lexi was diagnosed with Wilms' tumor, a rare kidney cancer that primarily affects children. Wilms' tumor can be hard to detect, since as in Lexi's case, one of the only signs is a mass in the abdomen. Most Wilms' tumors affect only one kidney, yet about five percent of children — including Lexi — are affected with cancer in both kidneys.

"Her physicians determined they needed to remove the kidneys as soon as possible," Maria explains. "That's also when she was re-diagnosed with Rhabdomyomatous Nephroblastoma, a more aggressive Wilms' tumor. At the time, only 14 kids in the world had this condition.

*"Lexi has gone from a frightened baby who cried 'all done, all done!' the moment a nurse entered the home to an interested and willing participant in her care. Now she even 'draws blood' on her nurse with pretend needles."*

"That's also when PHS became part of our family," Maria says. And that's when Maria began preparing to donate one of her kidneys to her daughter.



All grown up, Lexi spent the first two and a half years of her life inside by 7 p.m. on dialysis. Now, she's experiencing the joys of childhood just as she should be.

Lexi underwent two separate surgeries to remove her kidneys and chemotherapy to treat residual cancer cells and help prevent spreading. As she prepared for her kidney transplant, PHS helped allow Lexi to remain at home and receive the care she needed.

PHS worked with the family to arrange convenient times for lab draws, IV therapy and enteral feeding when necessary. She was set up to receive daily peritoneal dialysis at home to replace the blood-cleansing function of her lost kidneys.

### At ease at home

"The PHS nurses worked with us to set up times for Lexi's lab work. Both my husband and I work outside the home, so from the beginning, our PHS Infusion Nurse has come early in the morning so we are able to live the rest of our lives as normally as possible," Maria says. "Working with PHS helped us feel like we were more in control of managing all aspects of Lexi's care, and we're all more at ease at home."

In January 2009, Lexi received a kidney from Maria, ending her body's dependence on dialysis. The days and weeks following Lexi's transplant were also crucial to the success of the procedure. When Lexi went home, PHS continued providing care, saving the family the task of transporting a medically-fragile child to a hospital or clinic.

"It has been such a pleasure to watch this family adapt to a life-changing diagnosis of cancer," says Jean Stumpf, Clinical Nurse Consultant and former case manager for Lexi. "Lexi has gone from a frightened baby who cried 'all done, all done!' the moment a nurse entered the home to an interested and willing participant in her care. She even 'draws blood' on her nurse with pretend needles now."

### First fireworks

Maria says, "You look at Lexi today, and you have no idea what's she's been through. For example, during the first 2½ years of her life, she wasn't able to be outside at night, as her dialysis began each evening at 7 p.m. After her transplant, she could go out. On summer evenings, you see her awe, just looking at the stars."

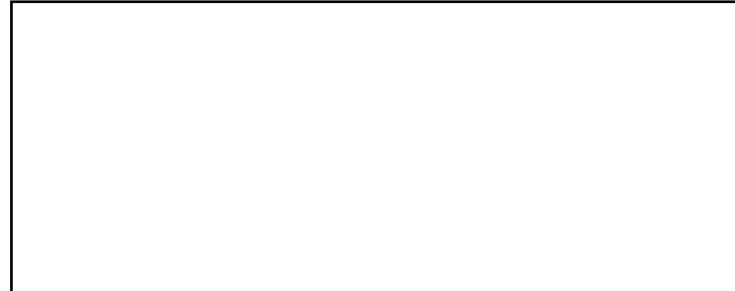
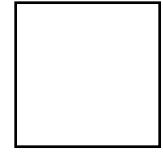
Travis adds: "She saw the 4th of July fireworks for the first time, and she absolutely loved it all."

PHS continues providing homecare for Lexi, who continues thriving, eager for each new chapter in her life and very much looking forward to her next 4th of July fireworks display. ■



Spring 2011

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PHS has earned the Joint Commission's  
Gold Seal of Approval™

A photograph of a smiling baby wearing a white polo shirt with a small blue dolphin logo on the chest. A clear plastic tube from a nebulizer or similar medical device is attached to the baby's nose. A thin, light-colored line representing a pulse or ECG trace runs from the bottom left across the baby's head towards the right side of the page.

The Pulse  
news for our health care partners

Let's be Facebook friends

PHS kids can be Happy Campers

Josh, the RT, HIM guy

Growing with Mary Kate

Passing inspection: PHS goes above and beyond to comply with standards