



Meet Emily

Inside this issue:



PAC: Parental Advisory Council
page 3



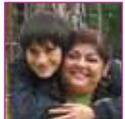
Message from our Medical Director
page 3



News and Notes
page 4



Hot Topics
page 5



Staff Spotlight
page 6



Kids Being Kids
page 6



Thriving at Home
page 7

Get organized

Suggestions from parents and PHS on how to manage your child's medical supplies

Bringing home a technology-dependent child can be overwhelming. Coming home to boxes filled with unfamiliar products that you don't know what to do with adds to the anxiety.

That's why PHS staff and other professional in-home caregivers are available to help you set up equipment and organize your home and supplies to ensure a safe and efficient environment for your child and best accommodate you, your family, and other caregivers.

"Things are chaotic as it is when you've got a special needs child."
- Diana Johnson

Why should you organize?

A good system for organizing your equipment and supplies:

- Helps you manage your inventory. You know what supplies you have on hand and when you need to reorder.
- Is cost effective. You save insurance dollars by not over ordering supplies and by being efficient with those you have.
- Makes your home safer for your child. You save precious time by finding supplies quickly in emergency situations.

Watch and Learn

Becki Nielsen, BA, RRT-NPS, LRT, Respiratory Therapist and PHS Director of Ancillary Services, and two PHS families share tips for organizing and managing medical supplies and equipment in a series of videos posted on the PHS Thrive blog (<http://www.pediatrichomeservice.com/blog/>) and the PHS YouTube channel (<http://www.youtube.com/user/pediatrichomeservice>). Each video features a narrated tour that shows you how supplies can be organized and managed to simplify life, ensure the safety of the child, and optimize health care dollars.



The closet in Tana's room holds the most often-needed supplies. "We try to hide most of the medical supplies in her room," says Jill, "so it looks more like a kid's room than a hospital room, but it's also very efficient. Other closets are utilized for supplies not routinely used every day."

How to organize

- Assess your current storage system, decide what's working and what's not, what you need and what you don't need.
- Inventory your supplies and group them by category, for example, emergency supplies, daily supplies and supplies not used daily, supplies used with water, supplies that need cleaning, medications, etc.
- Label drawers, storage bins, and containers to indicate what each one holds. Include order number for easy ordering with PHS.
- Put items used most often in storage space first and place everything according to need and ease of use. Check items frequently for expiration dates and replace if need be. Rotate supplies so oldest are used first.

Tips from PHS

PHS encourages parents to be involved with supply ordering and management. Get a firm grip on the exact supplies you are using, particularly in emergency situations. While every child has different needs and some require more supplies than others, PHS suggests setting up a three-tiered system that can be adapted to the needs of most families with technology-dependent children.

Continued on page 2



pediatric home service®
taking care of the child®

PHS Services

- Respiratory Therapy
- Infusion Therapy
- In-Home Asthma Management
- Pharmacy
- Support Services
- Other services are available upon request.

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:

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

Visit www.pediatrichomeservice.com to view an electronic copy of *The Pulse* or if you wish to receive this newsletter electronically, please send your email address with request to lamurray@pediatrichomeservice.com

No portion of this newsletter may be reprinted without permission from PHS. To make a request to reprint, please contact *The Pulse* at the provided address.

1. **A central supply area:** this is where most supplies are categorized, stored and organized to be readily and easily accessible, according to need. A PHS supply sheet helps you determine what you have, what you need, and when and how much you should reorder.

"You don't have to spend a lot of money to organize. For example, we use a lot of wipes, so I clean the containers and use them to store smaller supplies."
- Jill Wall

2. **Bedside supplies:** these are the supplies used by your child on a daily basis
3. **Emergency back-ups:** this is an emergency set of supplies available as a back-up or for use when you leave the home and don't have emergency supplies available to you. You might also want to consider putting emergency supplies in a shower or cleaning caddy. It's light and easy to carry around the house or to the back yard, so can be close at hand if you need supplies immediately.

Two PHS families, two systems

Diagnosed with dravet syndrome, Sarah Johnson has been a PHS patient since June of 2006. Because Sarah doesn't require as

many supplies as some other PHS patients, the Johnsons were able to dedicate a large closet to her supplies. They use one main central closet for storage.

Tana Wall, who has spina bifida and multiple other illnesses, requires many more supplies, so mom Jill Wall has categorized them and stores them in four separate closets.

Both families have emergency systems. ■



Sarah's meds are stored in plastic bins **out of the reach of children**. Tiffany, Sarah's personal care assistant, uses the PHS supply sheet and a notebook to keep track of them. "Everyone has a system that helps them see patterns," says mom Diana, "also, if Tiffany weren't here and I had a question about what she had ordered, I could look and know it would be coming in a couple of days."

Enter to win these storage supplies from PHS



pediatrichomeservice.com/blog/): share your best medical supply organization tip or ask your most burning organization question. We'll add you to our drawing and announce the winner on the PHS Thrive blog on November 15. Check back to see if you are the lucky winner who will receive:

- one wide three-drawer plastic rolling cart
- two medium-sized, three-drawer rolling carts
- three medium bins with snap-on lids
- three small bins with snap-on lids
- two plastic caddies for emergency equipment

Can you add to the conversation about organizing homecare medical supplies? We'd love to hear from you.

To enter, all you need to do is comment on the medical supply organization topics on the PHS website Thrive blog (<http://www>

PAC talks, we listen

Parent Advisory Council provides PHS with valuable insight

Parents are the real experts.

At PHS, we have more than twenty years of experience in working with medically-fragile children, but we also know there is much we can learn from the families we serve. PHS has always been committed to customer-centered service and care, and we have always considered our patients and families as partners. In 2010 we added another component to that partnership — a Parent Advisory Council.

What Is PAC?

The Parent Advisory Council (PAC) is a group of parents/guardians who meet twice a year to discuss policies, procedures, new service opportunities, and other business objectives. The group:

- Allows families to provide input on PHS policy and program development, materials, and tools
- Gives them an opportunity to review recommendations made by PHS

- Provides a channel for them to relay information, needs, and concerns to PHS, and
- Provides PHS with the opportunity to listen to our families

By forming the PAC, we gain valuable insight from families who have medically-fragile children. The group helps ensure that our processes, policies, and procedures work for our families. PAC is one more tool that helps us improve the way we do business and fulfill our ultimate mission — to better take care of the child.

What do PAC members talk about?

Examples of discussion topics from the last PAC meeting:

How to disseminate information to families? What works? What doesn't? Families said:

- PHS does not communicate too often; in fact, members said they would rather hear something three times than not at all

- Families would like a forum to talk with other families in similar situations (there is a place to do that; consider using our new PHS blog to get tips from others and offer your own insight and advice).

Families would like more information on managing inventory and health care dollars.

- Read about the PHS videos on organization of medical supplies on pages 1–2 of this edition of *The Pulse*, in the blog, and on YouTube — directly as a result of suggestions from PAC members.

Families are concerned about the cost of equipment and conserving health care dollars

- PHS plans to include an article addressing this topic in an upcoming issue of *The Pulse*. ■



Message from our Medical Director

Dr. Roy C. Maynard

New PHS website is a great resource for patients, caregivers, and health care professionals

PHS is committed to providing high quality, safe and nurturing care for its young technology-dependent patients, regardless of their medical needs and fragility. To meet that objective, PHS remains at the forefront of in-home medical technology and continually expands its capabilities.

The new redesigned website is one recent example of how PHS is constantly evolving to better serve homebound children and young adults, as well as the families and professionals who care for them.

Learn what PHS can do for you

On first review of the website, potential patients, payers, and health care providers will find information about the many services offered by PHS. These services include, but are not limited to, in-home asthma management, nutrition consultation, respiratory, and continued escalation of in-home infusion therapy.

The latter provides the same high-quality administration of antibiotics,

gammaglobulin, and enzyme replacement therapy as well as other therapies in the home as in a hospital or outpatient clinic, but at a fraction of the cost.

Using technology to improve care

Continuing medical education for physicians and other health care practitioners largely relies on evidence-based medicine. Evidence-based medicine has become a valuable and essential tool, providing guidelines for patient care gained from well-designed clinical trials on a certain test or treatment. Information and outcomes from these research studies is accessible on the Internet and in medical literature to help professionals improve the quality of care for their patients. In accessing online information, however, it's important to seek out reliable sources.

Reliable resources and links

Many of the physician-prescribed treatments offered by PHS are based on outcomes from evidence-based medicine. Web technology has surfaced that allows health care consumers to enhance their own education regarding a disease and

its management.

The PHS website includes a wealth of information, including links to reliable resources and an expanding health library. This is a public interface to valid and credible health information online accessible through the PHS website. You will also find links to the more common medical conditions affecting PHS patients.

Medical information obtained online improves patient knowledge and allows better communication with health care providers. By providing links to reliable health information, PHS hopes to promote utilizing online information as an effective learning strategy. Of course, ongoing consultation with a patient's doctor or health care team is still vital to understand the pros and cons of any potential treatment identified online. ■

On the Sharing Care beat

PHS reaches out

Helping to make a difference

- PHS made a donation to the Northeast YMCA to help with children's programs and the renovation of the new teen center.
- PHS donated asthma supplies to the South Washington County School District to be used by students who do not have or use a holding chamber to take inhaler medications.
- For the third year in a row PHS supported the Maisie Dhenicke scholarship walk, which raises money for a scholarship given to a high school graduate going into a career in nursing. The walk was started after Mr. and Mrs. Dhenicke lost their daughter Maisie weeks after she was born. The scholarship is meant to ensure future families have the same quality health care they received from nurses before Maisie passed away.
- PHS has collected:
 - Canned vegetables and fruit for the Emergency Food Shelf Network
 - Arts and crafts supplies for Faith's Lodge
 - Noodles for Groveland Food Shelf
 - Pasta sauces for Second Harvest Heartland

Want to donate to Toys for Tots?

Throughout the month of December, PHS will be collecting Toys for Tots. Readers who would like to make a donation to be added to the PHS toy bag are invited to drop off donations at the PHS building or to send them with any PHS driver or clinician.

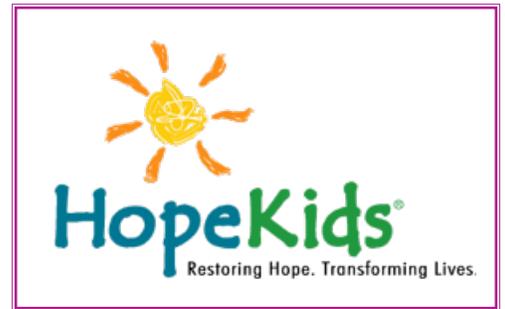
SHARING care



PHS employees put together care packages filled with camp necessities like sunscreen, snacks, and activity books. The packages are given to children attending Camp Odayin, a summer camp for kids with heart disease. See <http://campodayin.com/> to learn more.



In July PHS staff prepared and served breakfast and lunch to the children staying at the Greater Minneapolis Crisis Nursery. Learn more about this wonderful facility where kids stay while their parents attend to family emergencies at <http://www.crisisnursery.org/>.



Each year, HopeKids sponsors a year-end festival for the kids and families who participate in their events throughout the year. PHS was excited to be a sponsor for this year's very successful event, held Sept. 12.



Inside the PHS Pharmacy Department

Visit (<http://www.youtube.com/user/pediatrichomeservice>) and take a quick video tour of the PHS Pharmacy Department, meet some staff, learn about what they do, and see how meds are prepared, stored, and shipped. The pharmacy has:

- The ability to compound medications onsite
- Individualized medication/nutrition dosage for each patient
- A certified clean room
- On-site pharmacists to troubleshoot, monitor, and work with physicians to ensure children stay healthy and improve in the home



Hot Topics

PHS to conduct tracheobronchitis study

Identifying risk factors aims to help reduce infection

Beginning this fall, families and caregivers of PHS patients with tracheostomy tubes will be asked to take part in a study being conducted by PHS clinical staff. Participation is voluntary and confidential, and consists of providing information on a monthly basis to the PHS respiratory therapy clinical staff, via a questionnaire or phone call.

Patients will be followed for one year to determine how often tracheobronchitis occurs in this population and to identify interventions prescribed by their health care providers.

Tracheobronchitis (inflammation of the lining of the trachea and bronchi) is one of the most common medical conditions occurring in pediatric patients with artificial airways, yet very little is known

about its frequency in pediatric homecare patients with tracheostomy tubes.

Why do research?

Monitoring clinical outcomes validates that a minimal standard of care is being met and helps identify interventions that may be beneficial and cost effective for patient care. For some time now, PHS has been monitoring central line and bloodstream infections in its homecare patients with central lines. These central lines are utilized by IV infusion nurses for medication administration and pose a potential risk for bacterial contamination and systemic illness. The incidence of line infections in PHS infusion patients continues to be extremely low, thanks to the diligence and skill of the infusion nurses in their handling of these central lines.

The information from the tracheobronchitis study will be used to establish a benchmark for the incidence of the disease and the standard of care for its treatment. Other potential benefits include identifying risk factors predisposing patients to the disease, and effective strategies in mitigating its recurrence.

Want to know more?

If you are interested or want more information about the study, contact the PHS Respiratory Therapy Department or Roy Maynard, M.D., PHS on-site Medical Director at 651-642-1825. PHS has distributed information to tracheostomy-dependent families and patients prior to the initiation of the study.

What you need to know about insurance

PHS helps make a smooth transition with insurance

If you're switching from Medicaid to Medicare

PHS is not a Medicare supplier. Should your child become eligible for Medicare coverage, PHS will help you transfer to a new supplier of your choice. Please be aware of some common changes you might experience with your new medical equipment supplier:

- Medicare requires special documentation from your doctor for some equipment and supplies. Your doctor or new supplier may ask for your help.

- Medicare may require additional tests for some equipment or services, such as oxygen. Your new supplier may instruct you to have these tests completed.
- Medicare limits how much and how often a supplier can dispense many supplies. Your new supplier may use a different process to take your supply order.
- Due to limited Medicare coverage or reimbursement, your new provider may not offer the same products. Your new supplier may suggest an alternate product to the one you received from PHS.

- Medical equipment suppliers choose various ordering and delivery methods to best meet the needs of their patients. We suggest starting this conversation about ordering and delivery early so you know what to expect.

You are likely to encounter other changes that will reflect each medical equipment supplier's unique way of providing care to patients. If you have any concerns, please contact your new supplier. We are confident that any supplier will welcome your feedback to improve the service provided to your child.

Ensure you will be covered in 2011

Open enrollment for many employer-sponsored health plans is just around the corner. Don't forget to double check your proposed coverage for any updates that could affect your family's care. If your coverage is going to change, please call a PHS billing specialist or patient service representative at 651-642-1825 to help ensure a seamless transition to 2011.



Staff Spotlight

Meet Claudia

Easing families' financial concerns

Families with medically-fragile children face many pressures — including the financial costs of care. Claudia Alcalá-Rodríguez tells these families exactly what they need to hear, and helps them navigate the system. She explains: “I tell our families, ‘this should be your last concern. You focus on your child. We’ll help resolve your billing issues.’” And as lead IV billing specialist, Claudia does just that, using her industry expertise and diplomacy to ease families’ complications.

Claudia just celebrated 12 years with PHS. Prior to her time here, she worked at Rehabicare, an electrostimulation device manufacturer, as a billing specialist. Before that, she lived in Colorado, working as a full-time mom and part-time receptionist for a chiropractic office.

Alias, Mrs. Claus

“I especially enjoy meeting our patients and their parents at company functions, being able to put a face to the names I see on paper,” Claudia continues. “My absolute favorite moment was the first PHS holiday party in 2001. Mrs. Claus allowed me to play her role at that party. It meant so much to connect with the children and I started a great friendship with one PHS

family in particular. I still hold that friendship very dearly.”

California, Colorado

Originally from Santa Ana in Orange County, California, Claudia most admires her uncle Tony and aunt Sylvia. “I lived with them in Colorado for two years while I was in junior high school. They helped me see the importance of education and being involved in important causes,” Claudia says. “They also taught me to always passionately defend your family.”

She has one son, Alex, and two step-children, Jeremy and Julia. She also has two dogs: Blu, an Alaskan husky and Bailey, a bichon frise.

On the move

Away from work, Claudia likes dancing to country music, romance novels, Zumba dance workouts on DVDs at home, and a glass of wine at the end of a long day. Claudia admits a fondness for “all kinds of food.”



Claudia and son Alex participate as 'buddies' at PHS Sharing Care volunteer event for the West Metro Miracle League (<http://www.westmetromiracleleague.org/>) with PHS patient Lucas.

Look out, Greece

“I’m particularly compulsive about making sure work is done and done correctly,” Claudia admits. Her colleagues say she takes a lot of pride in her work. For a while, she was so meticulous, she avoided vacations so others wouldn’t have to do her work. She does go on vacation now, and for her 50th birthday, she plans to visit Greece. “I’ve never been there, but I want to do the whole Mamma Mia movie tour,” Claudia says with a laugh. ■



Kids Being Kids

Meet Cody

Giving smiles to more than just pumpkins



Something to smile about. Cody helped carve this big, grinning pumpkin for Halloween last year, using his mobile arms to get inside and dig out the “goop” as he calls it. He puts on gloves because he doesn’t like to touch the messy orange pulp (we’re with you, Cody!). Diagnosed with spinal muscular atrophy (SMA), Cody has been a PHS patient since March 2004. He is 14-years-old and doing well, thriving at home, and looking forward to carving more pumpkins this year.

Picture this: We’re on the lookout for photos of “kids being kids” to consider for use in future issues *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@pediatrixhomeservice.com. We’ll contact you if your photo is chosen.



Thriving at Home

Feliz en su casa

A team solution helps Emily be happy at home

Three days after she was born, Emily was diagnosed with cystic fibrosis (CF) — a chronic disease that can lead to serious breathing problems, lung disease, infections and problems with nutrition, digestion, growth, and development. Adding to the challenges facing little Emily: only 82 centimeters of small intestine, rather than the normal 240, an abnormally small colon, and esophageal reflux.

Had she been born twenty years ago, Emily would be living her life in a hospital. Even in 2007, her original prognosis was grim.

Yet three-and-a-half years, six surgeries and countless infusions and feedings later, Emily is doing far better than anyone expected. At home with her family, she lives life much like any other toddler. “I’ve got a happy child,” says Emily’s mom, Edith Rodriguez, who speaks Spanish and occasionally relies on a translator, “and that’s the most important thing. When I hear her playing in the other room, she sounds just like a normal child.”

Two backpacks provide the only visual clue that Emily is different from other children. One holds a food pump for the enteral

“I’ve got a happy child,” says mom Edith. Sweet words in any language.

feedings and the other carries her Total Parenteral Nutrition formula. Says Doreen Carson, RN, Emily’s PHS nurse, “She’s just like everybody else. She’s just got a few extra things to carry.”

Life has been difficult, says Edith, but they manage with the help of a lot of people. “PHS has trained me to be able to take care of her so that she can improve,” said Edith, “and thanks to them, we can be here today.”

“We’ve established a good working relationship,” said Doreen, “and Edith knows what she needs to do at home to troubleshoot before she calls us. And if she does call us, we work through it on the phone, figuring out what we can do to fix the problem. If not, then we come out — even if it’s the middle of the night. We do whatever needs to be done to make sure Emily continues to get the care she needs to stay at home.”

Adding pounds

The biggest challenge is helping Emily gain weight, enough so she can be taken off the TPN before it damages her liver. Emily currently gets two kinds of feedings, explains Doreen, “the pump with the TPN and lipids, which are referred to as the ‘steak and eggs’ in the nursing world.” Mom has been trained to change the IV dressings and run the pumps, but all of Emily’s feedings need continual monitoring and adjustment. PHS clinicians make in-home visits weekly. The PHS pharmacy mixes the TPN and, along with PHS dietitians, monitors the formula.



Emily’s PHS Infusion Nurse, Doreen Carson, RN, at the Rodriguez home with mom, Edith.

Medical care and more

A PHS social worker also helped Edith secure the support she needed to keep her daughter at home: helping find an in-home agency, assisting with housing issues, and securing a translator when needed to keep the lines of communication open among all Emily’s caregivers.

“Without PHS, life would be much more complicated,” said Edith, “and Emily is so much happier at home.” ■

Get a weekly dose of PHS in our new blog

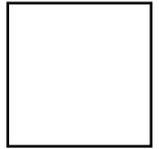
Need advice from other parents with medically-fragile kids? Check out the PHS blog.

As part of its new website, PHS has ramped up its social media presence with a blog and Twitter account. Blog posts, added at least once a week,

highlight timely information from and for PHS kids, families, and others. For instance, recent posts provided tips for a trip to the Minnesota State Fair with medically-fragile kids, a back-to-school checklist for kids with asthma, and suggestions on protecting home medical equipment from storm-related power outages.

We’re always looking for blog topic ideas from our PHS families. See what blog topics can help you and your family and join the conversation at PediatricHomeService.com

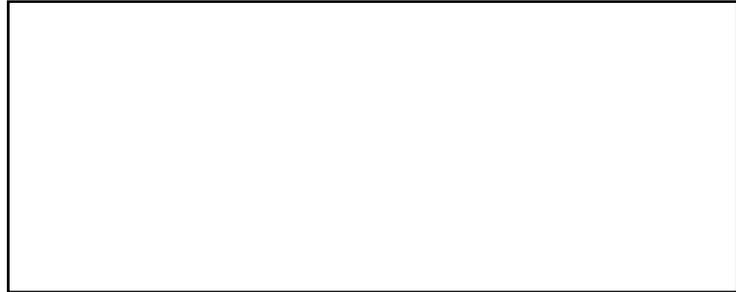
We’re also tweeting! Follow PHS on Twitter @PHSKidsThrive



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



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



The Pulse

news for our health care partners

PHS helps you get organized

Smoothing insurance transitions

Cody carves his pumpkin

Parents have something to say

Claudia calms billing