



Meet Lainey

The Pulse

pediatric home service

Summer 2013

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Support through input and resources

How PHS partners with families

A lot goes into creating and implementing a safe care plan for keeping medically-complex kids healthy at home. In the last few issues, we've talked about what PHS does to hire the right people, how we train them, and how we use technology to make our care better.

Here's one more critical piece of a safe care plan — attentive, loving and constant care from family caregivers. Part of our job is to do all we can to support our PHS families. Here are some of the ways we do that.

We ask for input, and we listen.

We want to know what's working and what isn't so we can continually improve our services. We send satisfaction surveys to our families when they start with PHS, at six months, and one year into service, and annually after that. They can also fill out an online survey any time they have something to say, or better yet, call and speak with someone at PHS.



PHS families indicated they were **97.7 PERCENT SATISFIED** or **VERY SATISFIED** with the overall quality of care and services.

When it's clear something needs to happen, we'll take action. For example, we added private duty nursing service because so many of you asked for it. You've indicated an interest in online ordering, so we are working on that now. With a new system, you'll be able to log into your account, see past orders, confirm shipping and insurance information, and place an order for delivery. Stay tuned to hear more about that.

Families need information; we are a resource.

- **Homecare tips:** Printed homecare tips on a wide range of topics go to families every month with their supply deliveries.

PHS Homecare Tip

Contacting PHS

When You Can Reach Us

You can reach us 24 hours a day, every day of the year by calling 651-642-1825 or 800-225-7477.

Business Hours

Our office, located at 2800 Cleveland Avenue North in Roseville, is open Monday through Friday, 8am to 5pm for

- Scheduling visits with a clinician
- Supply questions, ordering and pick-up
- Billing or insurance questions
- Equipment questions or concerns



After Business Hours or on Weekends & Holidays

Our on-call staff is available to support services provided by PHS. After-hours answering service helps to identify the correct on-call staff to return your call for the following issues:

► Infusion (IV) Nurse (RN)

- Signs of bloodstream infection including fever, shivering, upset stomach, throwing up, dizziness, sickness after IV flushing, temperature greater than 100.5°F (38°C)
- Catheter site tender to touch; drainage, pus, excess blood; swollen, red, rash-like; clear bandage wet or loose
- Catheter partially or fully blocked; starting to come out
- Admission to hospital or other cause for appointment cancellation
- Discharge from hospital with need for medicine or IV supplies to go home with child
- Lab draw scheduling or lab results, questions
- Late or missed dose of medicine
- Questions about IV pump, food pump, blood pressure monitor

Turn over →



July 2013 Homecare Tip
#PHS 03-12-04-26-30-06-2013
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PHS families get helpful tips along with their monthly supplies.

You'll also find them on our website, along with extensive health information and community resources.

- **Multimedia resources:** The PHS website has tips, troubleshooting, how-to videos, and presentations on everything from cleaning a food pump to blending formula for tube feeding to organizing your medical supplies.
- **Education:** PHS provides family caregivers with education, training and easy-to-understand materials translated into the most common languages spoken in the Twin Cities. Parents with no medical background are able to take on intricate daily care responsibilities for their children.

For more on partnering with PHS, look on page 2.



PHS Services

- Respiratory Therapy
- Infusion Nursing and Pharmacy
- Private Duty Nursing
- Clinical Support Services

Pediatric Home Service (PHS)

is an independent pediatric homecare company that provides specialized health care services to medically-complex, 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:

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Follow us:



• **Thrive blog:** Our blog provides a wealth of useful information. Learn how to optimize your insurance dollars or navigate the MN State Fair with a medically-complex child. Meet our amazing patients. See what the PHS staff is up to. Add your comments or suggest topics. You'll find it on the PHS website.

Parents are an amazing resource — we simply facilitate conversation.

Our PHS Facebook page is a place for families to ask questions, give advice, discuss topics, share stories, news and information. See what people are talking about and join in.

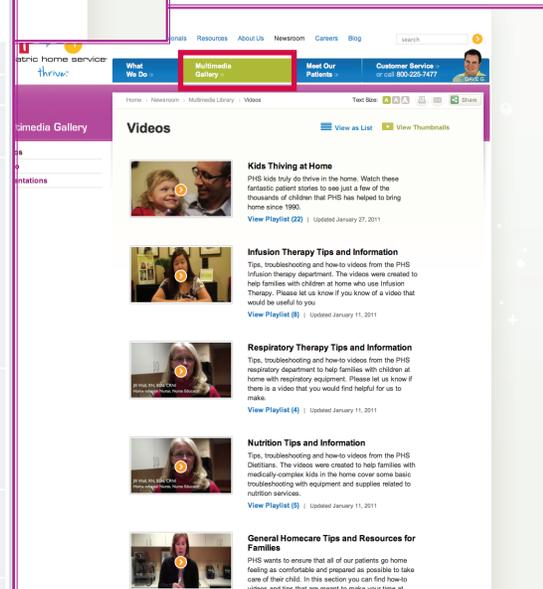
With a wide array of resources, knowledge and personal experience, the caregivers and staff at PHS know how important each parent is in the care of the child. Ultimately, each family is one of the strongest advocates for their child and a crucial part of a safe care plan. ■



PHS's Thrive Blog



The PHS Facebook page creates a space for conversation between families, caregivers and health care professionals.



PHS's online Multimedia Gallery gives families information and opportunities to read about and interact with others in similar situations.



Message from our Medical Director

Dr. Roy C. Maynard

An ideal partner for medical homes

Medical advances have allowed for increased survival of children with extreme prematurity, chromosomal abnormalities, congenital anomalies, cardiac defects, inborn errors of metabolism and neuromuscular disorders. Recent estimates suggest up to 15 percent of children have special health care needs. The more fragile or medically complex of these pediatric patients often see multiple specialists, and optimization of care can be challenging for both providers and families. Medical homes can help meet these challenges.

What is a medical home?

The medical home is not an office or a clinic, but rather an enhanced model of primary care that revolves around the patient and their family. Although all children may benefit from a medical home, the more complex the patient, the greater the potential for patient satisfaction, improve patient health and decrease costs with this concept of healthcare delivery. The cornerstones of the medical home outlined by the American Academy of Pediatrics include "health care delivery that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate and culturally effective."

How does it work?

Several principles differentiate the medical home from other care models in order

to meet the medical, developmental, emotional, social and educational needs of the pediatric patient. To avoid fragmented care, the medical home uses a comprehensive care team. Generally, the team includes a designated primary doctor working with nurse practitioners, homecare nurses, occupational and physical therapists, social workers, and, ideally, a care coordinator. The care coordinator is a liaison between medical providers and other services/community resources caring for the patient. Mental-health practitioners, educators, pharmacists and medical subspecialists may also be team members.

How does a medical home promote better outcomes?

Coordinated care depends on better sharing of information and communication among the care team, patient and family. Ultimately, this shared knowledge builds trust when partnering with families in the care of their child. In the U.S., roughly 30 percent or 700 billion of the 2.5 trillion dollars spent annually on health care is estimated to be unnecessary. Comprehensive use of information technology may prevent duplication of costly tests and services. Round-the-clock access to care provided by the medical home may decrease emergency room visits, hospitalizations and costs. The latter is accomplished by establishing open scheduling or expanded hours in a

physician's/nurse practitioner's schedule to see an acutely ill child or to increase the number of well visits, in lieu of more costly sick visits. Cost sharing, with money saved from the use of hospital-based services (emergency room and admissions), may support the payment structure of the medical home.

How can PHS help?

PHS is an ideal partner for the medical-home model for caring for medically-complex children. Accessibility to clinical staff is just a phone call away 24 hours a day. Infusion nurses, respiratory therapists, pharmacists, dietitians, a clinical social worker and homecare nursing case managers attend joint clinical meetings to share information and coordinate comprehensive care for our patients. In many ways, our nurse case managers function as care coordinators and help decrease family stress. PHS is also culturally effective by using language translators on a regular basis for phone calls and the translation of education materials. Lastly, by providing an enhanced level of compassionate care in the home, PHS decreases health care costs associated with taking care of the child. ■



Kids Being Kids

PHS patients go to prom

Sebastian, Sophia and Thomas's fun days



We love to see our patients out and about, and prom is no exception! This spring, three PHS patients attended the dance in their area and we got to hear all about it - learn more about Sebastian and Sophia's day and Thomas's grand march on the PHS blog at www.pediatrichomeservice.com/blog/patients-go-to-prom.

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@pediatrichomeservice.com.



On the Sharing Care beat
PHS making a difference



A PHS buddy rounds the bases with a player from the West Metro Miracle League Pirates.

PHS plays ball with Miracle League

Every child deserves a chance to play baseball — and that’s why there’s Miracle League. A nonprofit organization run by volunteers, it gives children between the ages of 3 and 19 with cognitive and/or physical challenges the great opportunity to play baseball. The Miracle League of Minnesota is growing each season, with leagues established throughout the metro area, as well as in Brainerd, Rochester, St. Cloud, Duluth, Mankato, the Hibbing area and Fargo-Moorhead.

PHS teamed up with the Pirates from West Metro Miracle League for a fun game of baseball on May 7, and the PHS Pirates from South Metro Miracle League on July 9. We’ve got one more round of buddies coming up on July 24, and have loved each evening’s game as much as the last!

Everyone is a winner in Miracle League, and the energy that the players bring to the field is enough to remind every buddy, coach and spectator why programs like this are so important. With the simple involvement of a buddy, players can run, hit and catch with the best of them, and the smiles on their faces shows just how much joy it brings.

If you’d like to get more information about being a buddy or getting involved in Miracle League, visit www.miracleleaguemn.com.

More
SHARING :
care

April 14 - iCANhoop – West Metro Miracle Athletics

May 8 - PHS Blood Drive – Memorial Blood Center

May 10-11- Spring Clean Up – Faith’s Lodge

June 1 - Baby Step 3k – Children’s Hospital

June 8 - Suburban Adventure – HopeKidsMN!



Hot Topics

Did you know...

Infusions can be done safely at home?

PHS has been providing safe and effective infusion therapies in the home for 17 years. Administering intravenous immunoglobulin (IVIG) at home not only reduces the risk of infection, it also improves the quality of life for patients and their families.

Those who receive IVIG are immunocompromised, so staying home is a beneficial alternative to going to a clinic or hospital where they’re exposed to more germs and potential illness. Plus, most families prefer receiving IV therapy in the privacy and comfort of their own homes. It’s easier to accommodate their schedules and gives them more freedom to go about their daily activities.

PHS infusion nurses administer infusion therapies in the home every day. Here’s how it works and how to get started.

IVIG at home



step 1

If your child is receiving IVIG in a clinic, ask the doctor who does the therapy to write an order for IVIG to be done at home. If you are new to IVIG therapy, it is likely the first few treatments in a clinic setting, to see how your child reacts to therapy in a controlled setting.



step 2

When you’re ready for IVIG in the home, a PHS nurse will call to schedule a time for administration that works with your schedule between 8 a.m. and 5 p.m.



step 3

A PHS nurse will do a full assessment and monitor vitals throughout. The nurse will access a central line if the patient has one or administer the infusion peripherally. This can take anywhere from two and a half to eight hours, depending on the patient's dose. Pre-medications can be given to prevent side effects, if ordered by a doctor. The IV nurse can also draw IGG levels and other labs as ordered by your doctor.



step 4

Each PHS patient is assigned a case manager who works to provide continuity of care, which means we’ll make sure the same IV nurse administers the IVIG as consistently as possible.



You can learn more about our wide range of pediatric and infusion-related services at PediatricHomeService.com/services-infusion-therapy.php.



Hot Topics

2013 MN Legislature

What you should know

The 2013 session of the Minnesota Legislature began with plenty of “change” being handed out by the voters of Minnesota in the November 2012 elections. Republicans lost majority control of the House and Senate so the Legislature and Governor’s Office were controlled by one party for the first time since 1990.

PHS worked to bring about these changes: removal of the Durable Medical Equipment Sales Tax; clearly defined categories for all DME companies, and reimbursement parity for homecare private duty nurses.

Here’s what happened:

No increase in HHS spending, but fewer reductions

After much negotiation, Gov. Dayton and Legislature agreed to a \$50 million decrease to Health and Human Services (HHS) spending. While disappointing to patients and health care providers, this was the smallest level of reductions seen in a decade. Highlights from the bill:

- DME providers will receive a 3 percent increase in DME rates for Minnesota Medical Assistance and MinnesotaCare, effective in September of 2014.
- Repeal of the 1.67% Minnesota Medical Assistance (MA) provider rate decrease that was passed in 2011, impacting hundreds of thousands of MA patients and their care providers.

- An increase to MA rates for Private Duty Nursing providers of 1 percent, effective April 1, 2014.

- Elimination of asset testing for MA and MNCare. Previously, to qualify for MA/MNCare Minnesotans would have to show that in addition to being below a certain income level, they also did not have substantial assets.

- Many changes were made to homecare licensing, including changes to the Minnesota “patients’ bill of rights” and the manner in which homecare providers are licensed and report to DHS.

- The Legislature appropriated \$12.7 million in new spending for intensive services for children with Autism Spectrum Disorder.

- Funding and policy changes to help implement MNSure, the new health insurance exchange mandated by the federal Affordable Care Act (ACA). The exchange will be open for business in October.

Competitive bidding rates for DME delayed

Working with other health care providers like Mayo, Corner Medical, Key Medical, and Allina, PHS was able to include an amendment in the HHS Finance bill that prevents DHS from implementing competitive bidding rates for DME in the metro area until July 1, 2014. As a result,

PHS can maintain access to continue providing services and equipment to our families. We’ll keep working to find a long-term solution.

Durable medical equipment sales tax goes away

After five years of hard work by PHS and others in the DME provider community, the 2013 Legislature finally eliminated the uncollectable sales tax on DME products. The tax was implemented with good intentions, but way down in the weeds of the agreement was an option for states to apply sales tax to some DME items — those that were “for single patient use” and “not worn on the body.” The problem was that the tax was largely uncollectable — Medicare and Medicaid do not pay sales tax, and health plans were not reimbursing for sales tax.

For more about legislative impact on MN health care, contact Bill Amberg at wjamberg@pediatrichomeservice.com. ■



Staff Spotlight

Meet Beth

We knew she was special, MN thinks so, too

Beth Reisdorf always knew she wanted to work with kids.

So when she was hired temporarily at PHS while another dietitian was on maternity leave and stayed through a second dietitian's maternity leave, she knew this was a company where she could see herself working. She spent nine months at PHS in this temporary role and was hired soon after when a permanent dietitian position opened.



Beth visits Tikal in Guatemala

Beth, who received her master's degree in public health with a nutrition emphasis and also recently became Board Certified as a Specialist in Pediatric Nutrition, was named one of Minnesota's Registered Young Dietitians of the Year by the Minnesota Academy of Nutrition and Dietetics (MAND) in April — an honor that came as no surprise to those who see the work she does.

In her role as a clinical dietitian, Beth provides nutrition assessments and works with children receiving tube feeds and TPN, while also serving as a resource for other PHS clinicians and teaching feeding-tube classes for our PHS private duty nurses.

“Every day, I am able to support the family in achieving goals for their child, whether that may be changing the feeding schedule to match the family's or ensuring appropriate growth. I try to make their lives a little easier by providing resources, being an advocate and collaborating with other members of their care team,” Beth says.

Patient see, patient do

Beth remembers a day recently when she was in a patient's home taking measurements to chart growth. Soon after she had finished, the patient insisted on measuring Beth. “She knew every detail of the process — each exact step I take, how to take each measurement, and the lines I often say word for word. She was so methodical in her process, and the fact that she observed so closely was completely unknown to me. It was incredible to see.”



The Reisdorf family

All in the family

Growing up in St. Paul, Beth moved away when she pursued her undergraduate degree at the College of St. Benedict in St. Joseph MN. Now back in St. Paul, she still has her parents nearby — and a sibling even closer. Her brother, Joe, is a service specialist for PHS. “I always tell my patients that if a man named Joe delivers their supplies, that's my brother. They think it's pretty funny.”



Some of Beth's delicious homemade desserts

Beth most admires her mom, who is a parent to five children. “She finds a good balance between volunteering, her family and her professional life — she sets a good example of helping others, something I really admire in her,” Beth says. When Beth isn't coordinating feeding schedules, she can be found baking desserts in the kitchen (her pen name when doing restaurant reviews for her college newspaper was Betty Crocker), reading for book club, or cross-country skiing in the winter. She also recently finished her role as education chair for the Twin Cities district of MAND and is currently the president elect for the association.

If she's able to escape the city life (and the latest yard project at her house), the family cabin up north is her favorite destination. “Nothing beats sitting outside at the lake in northern Minnesota,” Beth says. With all the amazing work she does for her patients, Beth deserves to kick up her feet and relax. ■



Thriving at Home

Meet Lainey

Milestones and magical days



Lainey lives life to the fullest, with help from PHS, her family, and organizations like HopeKids.

She dances in her wheelchair. She brightens a room when she enters. She goes to Twins games, movies and all kinds of events with the organization HopeKids MN. Doctors love to see her coming.

Lainey is a happy kid — even though she's faced more challenges in her six years than most people face in a lifetime. She was born with campomelic dysplasia (CD), a severe disorder that affects the development of the skeleton and reproductive system and is often life-threatening — 95 percent of children with CD don't live to age two. Lainey, who just turned 6, has been with PHS almost from birth. She is on a vent and CPAP/BiLevel.

"She was in the hospital for six or seven weeks and diagnosed with a 'failure to thrive,'" recalls her dad, Chris. "A lot of campomelic kids don't make it because of upper airway issues. When she got home, she really started thriving. Kids need their family. And we're very fortunate to be here."

Chris says when they brought Lainey home, they had nurses in the home for a week. "That just didn't work for our family. I stopped working and stayed home with her. At that time, she needed to be bagged 10 to 20 times a day because every time she went to the bathroom, she'd destat. It was a rough first year."

None of that prevents her from living a full life with her parents and sister, Bani.

"We are lucky to live in Minnesota where we have excellent health care options and support like PHS. We view all the little things as milestones for Lainey. Every little bit she grows usually makes her a little more stable. We are fortunate she is still with us."

— Lainey's dad, Chris

"Lainey's really into play and has a great imagination," says Heather. "We do a lot of gardening. She loves to ride her trike. She's pretty mobile: she has a walker and is really good at driving her power wheelchair around, getting in and out to play. She's proficient in sign language, but when she got her voice, she was much more excited to talk and is vocalizing a lot now." Lainey is in school five days a week, where she socializes and works with a team of physical and speech therapists.

Thanks to HopeKids MN, Lainey is able to get out in the community and do things alongside other medically-complex children. HopeKids provides ongoing events, activities and a strong support community for families who have a child with a life-threatening medical condition. Through this organization, children and their families attend activities like Wild games, plays, rock climbing and much more — all while restoring excitement and hope back into their lives during what is likely a difficult time.

"It's such a great organization, because she's able to do what any kid can do, but on a smaller scale. With HopeKids, we can get out of the house and do things without worrying about being exposed to as many germs since they're so good at limiting exposure to those concerns," said Heather. "It is the only place Lainey can regularly see kids that are in wheelchairs and/or have a vent/trach like her. HopeKids is awesome!"

"We know we've beaten the odds so far," say her parents. "It's never far from our minds how quickly things could turn. That's why we try to make the most of every day we have with her."

And there have been many good days. Chris said, "Our first milestone was coming home. I don't know how we'd do it if we weren't at home. Another was making the decision to have me stay at home to care for Lainey. Our family needed to do that. It helped us come to terms with, and make the best of, our situation. Another big milestone was when she had a growth spurt at 10 months. Before that, she'd have a dozen or so blue spells every day and need to be ambu bagged. That growth spurt meant no more blue spells."

"We are letting Lainey lead us on this journey. She tells us when she's ready to do something. We are along for the ride, wherever she takes us, and it's always an adventure." ■

Recently, you may have seen PHS talking about HopeKids MN on the Facebook page — during the month of June, we donated \$1 to HopeKids MN for each 'like' we received. The success was outstanding! We donated \$1,721 dollars, helping increase our contributions to this organization that we see as such an important resource and asset for our families. Thanks for helping spread the word!

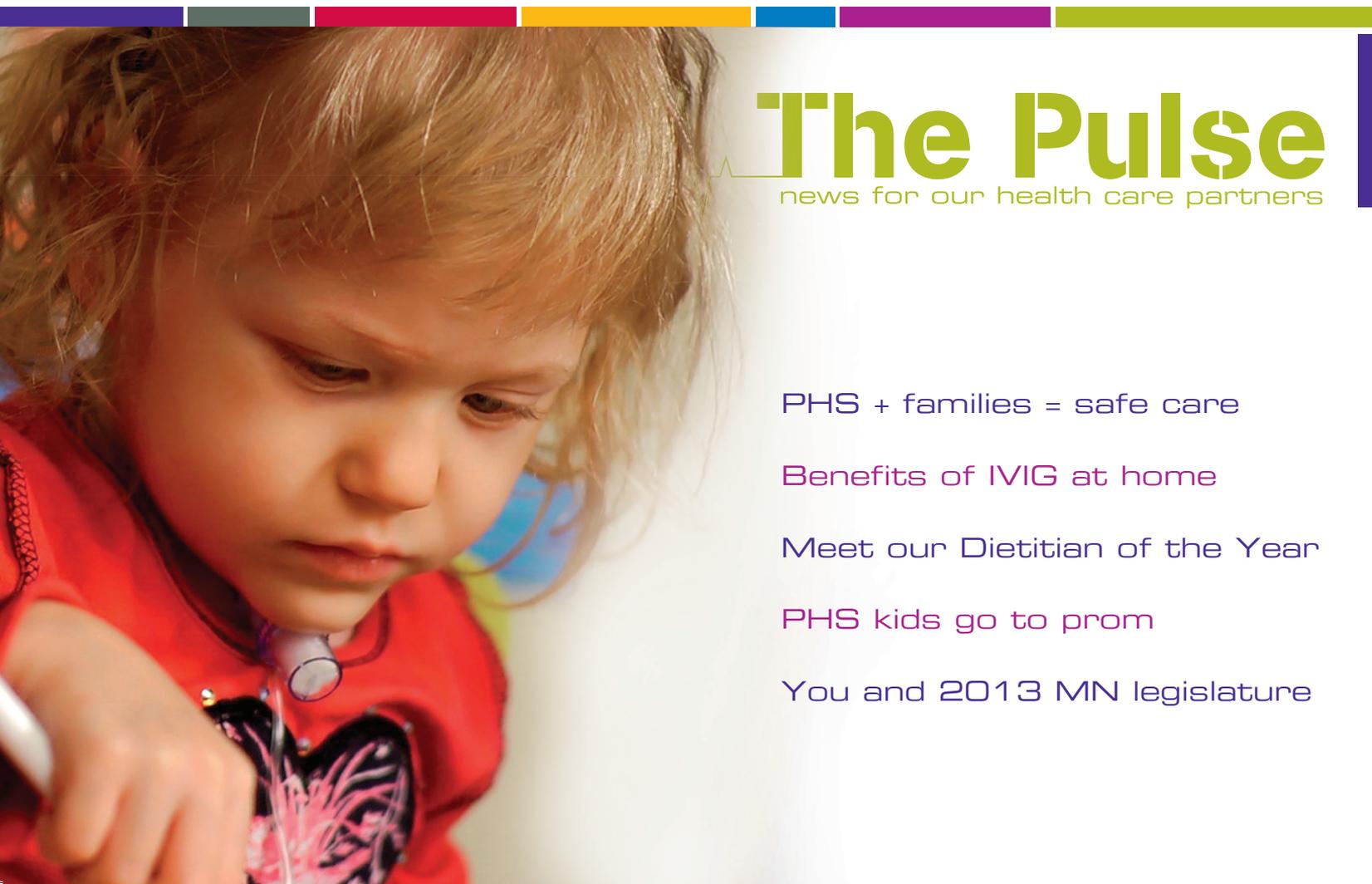


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PHS has earned the Joint Commission's
Gold Seal of Approval™



The Pulse

news for our health care partners

PHS + families = safe care

Benefits of IVIG at home

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You and 2013 MN legislature