



Meet Josie

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Two decades of home makeovers

PHS adapts equipment and supplies to get and keep kids home



Bruce Estrem, BA, RRT-NPS, LRT

“But that’s a ventilator that only works in a hospital.” That statement was made 23 years ago, and it may be the last time Bruce Estrem protested a plan to bring a child home on PHS services. At the time, Bruce was working alongside

PHS Founder and President Susan Wingert as she explained her plan to bring a little boy home on a Sechrist IV 100B ventilator.

They did successfully bring that boy home.

During the past two decades, Bruce, a respiratory therapist who is now the Education Coordinator at PHS, has worked with PHS colleagues to adapt countless setups for thousands of homes. He teaches all PHS respiratory therapy classes and continues seeing some long-term patients.

“In the beginning, health care equipment was designed for hospitals. It wasn’t portable or meant for home use,” Bruce recalls.

“But our goal then was the same as today: bring kids home where they belong. We would arrive with a vanload of equipment at the same time as the contractors with their hammers and saws. We often had to work with carpenters and electricians figuring out how to fit air compressors in garages and basements, and thread high-pressure tubing and electrical wiring through the walls and into the child’s living areas. We wanted children to be mobile — not confined to one room.”

Smooth moves

As technologies advanced and evolved, Bruce and his team continually investigated new offerings, embracing technologies such as smaller equipment with longer battery life. “We have more compact, portable models so our kids can go to school, camp, activities and family vacations,” Bruce explains. “A

ventilator setup that once required a large red wagon to haul it is now the size of a small laptop computer. Now, an IV system fits in a backpack.”

Two decades ago, it was also challenging to find medical equipment designed for pediatric patients. “Equipment and supplies were designed for adults in hospitals,” Bruce explains. “Since then, the technology has improved. We are very demanding with our manufacturers and suppliers. We work with more than 200 companies, and we have a good working relationship that allows us to be proactive and diversify our products in case of recalls, custom orders or necessary changes.”

TLC for equipment

PHS has a Biomedical Department with specialists (including two technicians with Biomedical Certification) who disinfect, adapt, and prepare every nuance of every piece of equipment before it is used with patients. “Each of these people understands where that piece of equipment will go and its critical role in keeping a child at home,” Bruce says.

Bruce and his team also provide in-depth training for PHS employees, children’s families, and any in-home nurses the child may have on all equipment and are readily available for support and assistance.

“Our challenges now include our growing, wide range of patients, from those in the city where we may need to accommodate crowded apartment configurations, to patients in very rural areas, where homeowners have to make detailed plans for long stretches of bad weather,” Bruce says. “I’m continually amazed at the commitment of families to rearrange their homes and their lives to keep their children at home, getting the care they need.”

He continues: “Whatever our children and their families need, I’m certain our team can accommodate.” ■

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:

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Empowering parents in the fight against infection

It can be as simple as 123

Anyone with a central line can get a serious or even deadly infection. For medically-fragile children, the risk of a catheter-related bloodstream infection (CRBSI) is even greater.

Fortunately, research has shown that a little knowledge, some simple steps, and good hygiene practices go a long way in keeping central line infections at bay. With that in mind, PHS developed a program — 123 Infection Free! — to help parents ensure consistent “best practices” in keeping their children infection free.

Empower caregivers to be advocates
Caregivers who participate in PHS’s 123 Infection Free! program receive tools and training that gives them an understanding of **WHAT** needs to be done to prevent infection each time a central line is accessed, and also **WHY** that *care needs to be done every single time*.

“One of our primary goals is to empower caregivers to be advocates for their children by knowing how to prevent infection each and every time a central line is accessed,” said Jean Stumpf, BSN, CRNI, Nursing Manager.

“This means they may be asking nurses and doctors in clinics and hospitals to follow infection prevention practices, such as washing hands and cleaning valves before accessing.”

Families love the program, according to Stumpf. “They tell us they have a clearer understanding of what they need to be doing,” she explained, “and they also feel as though they have ‘permission’ if they need to ask health care professionals who may not be following protocol to do so. This is hard for a parent/caregiver. We are seen as the experts and clinical settings can be very intimidating to non-professionals.”

Safe and simple tips

PHS works hard to make the tools and training easy to understand and follow. “We need to make sure all parents and patients can understand the materials,” said Stumpf, “so we use illustrations and very clear layman’s language. We are also having the poster translated into Spanish.”



The 123 Infection Free! kit.

The 123 Infection Free! kit includes supplies, an educational poster, emergency information, and a care log for parents to use every day to inspect the IV site. Understanding proper protocol includes knowing:

- The difference between clean and sterile,
- The importance of securing the catheter,
- When to call PHS or the doctor, and
- How to advocate for the patient when other people are accessing the catheter. ■

Efforts to keep children infection free at home are working.

1 2 3
INFECTION FREE!

Informed families have the right to ask for proper care of their child’s IV catheter, whether it’s at home or in the hospital. The success of 123 Infection Free!™ depends on its consistent use by our PHS families and caregivers, and they are doing a terrific job. In 2009, PHS had its lowest rate ever with only 0.68 central line infections per 1,000 catheter days, compared to the national average of anywhere from 2 to 5. The goal: to get catheter-related infections down to zero.



Message from our Medical Director

Dr. Roy C. Maynard

An update on the latest in ventilator technology

My transition from a clinical and predominantly hospital-based physician to medical director at PHS has been made easy by the excellent staff employed here.

Their knowledge base, attention to detail and service, and compassion for the children and the families they serve is unparalleled in my experience. Undoubtedly, these factors have contributed to the success and growth of PHS in the homecare arena.

I hope to add to that success by using this column to bring you up-to-date information to help you meet the challenges of caring for children with complex medical conditions.

Today, I'll talk about some upcoming changes regarding ventilators.

First, a little ventilator history

My experience in caring for technology-dependent children started during my fellowship training in neonatal and pediatric pulmonary medicine. Many of these infants and children remained hospitalized for extended periods of time until the tools could be provided for the skilled nursing agencies to manage these patients safely in a home environment. These tools included monitors, oximeters, feeding pumps, and home ventilators.

Dramatic improvements

The evolution of ventilator technology has progressed dramatically in the past two to three decades. Children with significant lung disease can now be managed at home in a nurturing environment that only a

family can provide. Initially patients were discharged on nonsynchronized, time-cycled, pressure-limited ventilators like the Sechrist or the Puritan Bennett® LP-10® with continuous flow circuits.

As technology improved so did the sophistication of neonatal hospital ventilators that can now easily be triggered by premature infants as small as 500 grams. The advent of this patient-triggered technology has been passed on to the new generation of turbine powered home ventilators like the Pulmonetic LTV® Series and T-Bird ventilators.

Phasing out equipment

Unfortunately for medical device manufacturers, the market for sophisticated homecare devices is relatively small with little financial incentive to continue to improve and upgrade home ventilators. In the recent past, T-Bird ventilators seem to have matched the respiratory mechanics of some of our more fragile vent-dependent infants best. Regrettably, the T-Bird will be phased out at the end of 2010 as parts and service will no longer be supported by the manufacturer.

Finding successful replacements

Currently, we are attempting, with some success, to transition these smaller infants and children to the Respironics Trilogy vent. This small, quiet ventilator provides "Direct View" technology to study breath-

If you have any concerns or questions about ventilators or any other equipment or supplies, don't hesitate to contact PHS at 651-642-1825.

by-breath waveforms and it may provide information to best match the ventilator to the patient's pulmonary mechanics.

We will continue utilizing the Pulmonetic LTV Series ventilators: excellent performance that also meets the needs of our patients.

Ultimately, the Trilogy ventilator will be a timely replacement for the T-bird ventilator in a select population of home ventilator dependent children.



T-Bird® ventilator



Respironics® Trilogy ventilator

Dr. Maynard is board-certified by the American Academy of Pediatrics in general pediatrics, pediatric pulmonology, and neonatology. ■



During this season of recognizing moms and dads with their own days, we wanted to take a moment to say **THANK YOU** to all of our PHS moms, dads and family caregivers for all you do to make a difference in your children's lives. **HAPPY DAY** from PHS.

On the home health care beat

Helpful reminders, PHS recognition and education

PHS recognized for first-rate respiratory care

PHS has been named a Quality Respiratory Care Provider by the American Association for Respiratory Care (AARC). PHS received the recognition under a new AARC national recognition program aimed at making sure patients cared for by homecare organizations have access to respiratory care services provided by qualified respiratory therapists.

For more information, please visit <http://www.pediatrichomeservice.com/news.php>

PHS staff attend conference

Clinicians Bryan Freisinger and Mary Wightman attended sessions on pandemic H1N1 influenza, percutaneous trachs, how to talk to doctors, and pediatric ventilation at the Minnesota Society for Respiratory Care Winter Workshop in St. Paul.

On the Sharing Care beat

PHS making a difference

Worthy causes

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 organizations:

The Arthritis Walk: PHS patient and second-grader Charles Dias has arthritis. Charles' team raised more than \$2,500 at the March event held at the Mall of America. Learn more at <http://www.arthritis.org/>.

West Metro Miracle League: A Minnetonka based non-profit organization, West Metro Miracle gives children with challenges the chance to play baseball. PHS also allows employees to volunteer time as team buddies. Learn more at <http://www.westmetromiracleleague.org>.

Spare Key: Spare Key provides assistance to Minnesota homeowners with critically

Stop by the PHS exhibit

We'll have booths at the following events:

- Sixth Annual North Regional Respiratory Care Conference Minnesota & Wisconsin, May 2-6, Rochester, Minn.
- MINNIVAN, May 6, Brooklyn Center, Minn.
- Gillette Children's Conference, May 20-22, Minneapolis, Minn. (topic: treatment of pediatric neurological disorders)
- University of Minnesota: Topics and Advances in Pediatrics, June 10-11, Minneapolis, Minn.

PHS monthly alerts

Look for these helpful reminders in your shipments and each issue of The Pulse.

- **March tip:** *What you need to know about changes in maintenance stickers.*
 - The gray sticker is going away; it will be either white or yellow.
 - A white sticker means the manufacturer (MFG) says the equipment **does not** need routine skilled maintenance.

- A yellow sticker means the MFG says the equipment **does** need routine skilled maintenance. When maintenance is due, equipment will have one of the following to alert you: 1) sticker with calendar date; 2) sticker with hours of equipment use (ask us if you can't find the meter); 3) sticker with both date and hours of use (maintenance is due on whichever occurs first).

Contact PHS Customer Service at 651-642-1825 well ahead of when maintenance is due. We'll arrange to pick up equipment and talk about short-term replacements if needed. Read the info from PHS and the manufacturer about what to do for routine equipment cleaning and upkeep.

- **April tip:** *Make shipping easier by using our PHS call-out service.* You can request that one of our customer service reps call you or a person designated by you, at a time, day and interval of your choosing, to remind you to check your supplies and place an order if needed.

ill or seriously injured children by making a mortgage payment on the family's behalf. Learn more at <http://www.sparekey.org/index.html>.

Burundi African Orphanage:

Civil war and the HIV-AIDS crisis have left hundreds of thousands of orphans in Burundi, Africa. The Burundi Orphanage is one of the few that takes infants and has the staff to care for very young children. PHS helps with payroll to ensure children are safe and well cared for.

Congratulations

to the winners of a weekend stay at Faith's Lodge

Faith's Lodge, a retreat for families with medically-fragile children or families who have lost a child, is the perfect setting to unwind and recollect.

- Beth B. and sons, Alex and Levi S., age 16 and 15 respectively and both PHS patients
- Jim and Rebecca R. and their daughter and PHS patient Anna, age 3
- Sara B. and her son and PHS patient Trevor, age 2
- Jodi and Jason B. and daughter and PHS patient Ashlyn, age 5

Volunteer events

Sharing Care and PHS volunteers lend a hand



Sharing Care participated in the 4th Annual WCCO Dave Lee Gutter Bowl to raise money for the University of Minnesota Children's Amplatz Hospital.

PHS will be holding a **blood drive** in April in conjunction with memorial blood centers. For more information on donating life-saving blood or on how to set up your own blood drive, visit <http://www.memorialbloodcenters.org/MBC/DesktopDefault.aspx>.

SHARING care

PHS employees donated time to help assemble materials for families in need at the Roseville branch of **Bridging**, a program that “bridges the gap” by providing furniture and household goods to help community members get back on their feet.

Hot Topics

It's good for you

Some foods may boost immunity

Drawing on her own expertise and that of others, PHS Clinical Dietitian Gwen Pritchard, RD, LD, offers tips on eating to stay healthy.



Gwen Pritchard, RD, LD

Cold and flu season is still with us, even though there are signs of spring. The escalation of nasty viruses makes the ongoing battles our young PHS patients fight all year long more challenging.

Researchers are finding links between foods and immune function. So, if you and your family catch every cold or flu making the rounds, consider adding more immunity-building foods to your table. Some examples include:

- **Yogurt** and other cultured milk products contain probiotics — live microorganisms thought to have immune-boosting benefits — as well as vitamin D. Look for a “live active culture” seal on the packaging.



- **Fruits and veggies** such as berries, citrus fruits, kiwi, apples, red grapes, kale, spinach, sweet potatoes, and carrots are packed with antioxidant vitamins

known to boost resistance to infection. Pack a real punch by consuming a daily multivitamin too. Supplements can be a healthy addition to one's diet, however, eating foods rich in antioxidants and vitamins is most beneficial in resisting infection.

- **Fish** is rich in minerals that help keep the immune system working properly. Shellfish, such as oysters, lobsters, crabs, and clams contain selenium, which may help white blood produce proteins that fight viruses in the body. Salmon, mackerel, and herring are rich in omega-3 fats thought to reduce inflammation, increase airflow, and protect lungs from colds and respiratory infections.
- **Zinc**, found in meat, chicken, peanuts, and peanut butter, is thought to be effective in fighting colds. Even minor zinc deficiency can affect a person's immune function. Enjoy chicken with Thai peanut sauce and you'll get a double dose of immune-boosting zinc.
- **Sunflower seeds** have vitamin E, which can help you resist the flu and upper respiratory infections. Two tablespoons provides more than a third of the daily requirement. Nuts, seeds, soybean oil, canola oil, corn oil, leafy green veggies, and fortified cereals can also be added to your daily diet for a dose of vitamin E.

If you do catch that dreaded cold, try a teaspoon or two of honey. It exerts antimicrobial activity that can help suppress your cough.

Other reminders to prevent illness:

- Most importantly, **WASH YOUR HANDS**.
- Don't share silverware, dishes, cups, or glasses.
- Clean doorknobs, faucets, and phones.
- Use the antibacterial soap typically now available in high-contact places, such as grocery stores, schools, etc. ■

Contact PHS for your free copy of our hand washing guide and keep it handy.

Call 651-642-1825 and ask for a customer service representative.



Sources for the above information include:

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Staff Spotlight

Meet Anthony

Behind-the-scenes magician

When PHS patients are ready to go from a hospital to their homes, they each need a specific equipment setup. And it's Anthony Scandariato who performs a little magic — sometimes a lot of magic — to secure the exact products and supplies to fit each child's situation. Anthony is Senior Warehouse/Purchasing Specialist, and began his sixteenth year with PHS on April 2.

He began his health care career with the Veterans Administration in supply management, and was referred to PHS by a recruiter. "After my first interview here, I knew this is where I wanted to work," Anthony recalls. "I truly continue to feel that way every day here.

"We make sure we have the products needed to take care of children. I work well under pressure and love the challenge of making things happen so our families have the proper supplies and equipment to make a smooth transition from hospital to home," he says.

Born and raised in upstate New York, Anthony is the fourth of five children in a proud Italian family. He's a U.S. Navy Veteran, and moved to Minnesota in 1994. "I have become a Minnesota Twins fan,

but I still bleed blue for my New York Giants," Anthony says.

He's married to Summer Scandariato, a PHS Respiratory Therapist, and he has four children: Robert, age 19, who is now serving in the U.S. Marine Corps; eight-year-old Jagger; and twin daughters, Ava and Liliana, who are 1 1/2 years old.

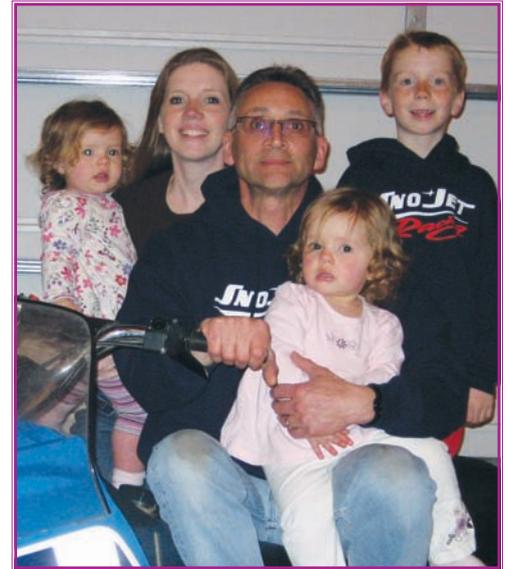
Away from work, Anthony races, restores, shows, and rides vintage 1970s snowmobiles, particularly Sno*Jets. He also savors Italian fare ("go figure!" he says with a smile) and his wife's chocolate chip cookies, preferably in his favorite spot to relax, his recliner.

"Right now I'm reading a couple different books on the United States Marine Corps, trying to stay in tune with my oldest son's world. As summer approaches, our family is excited about camping with other family members and friends. It does not matter where, as long as we are camping," he says.

Anthony most admires his parents for raising their children with love and respect, and his wife for everything she does for him and the kids — at home and with her PHS patients. Professionally, he most admires Chris Geraghty, retired PHS Vice

President of Regulatory Affairs, "for all that he instilled in me and mentored to me. A day does not go by that I don't use something Chris taught me," he explains.

He adds: "I really enjoy all aspects of my purchasing role. Making magic happen for PHS families is fun and very rewarding." ■



Anthony and his wife Summer, along with their children Jagger, Ava, and Liliana. Not pictured is Anthony's oldest son Robert. The family is in the shop where Anthony can often be found repairing and restoring his Sno*Jets.



Kids Being Kids

Meet Blake

Doing what he loves



Ride 'em cowboy. Blake's rodeo career took root when his uncle bought him a horse. But as you can see in this picture, he also rides sheep, or as they say in the business, he does "mutton bustin'." This photo of the daring young contestant was taken at a competition in 2006. Blake, who has dermatomyositis and extrinsic asthma, receives IV services from PHS, but clearly, he doesn't let that stop him from doing the things he loves to do.

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. We'll contact you if your photo is chosen.



Thriving at Home

Bouncing back — again and again

Meet Josie

At PHS, we believe every one of our children is special. Some kids, like little Josie, have complicated conditions that require ever-changing care. We feel privileged every day to help these children live full, happy lives. Here's how Josie and her family are thriving at home.

Getting sick on vacation is no fun — yet usually not serious. So when Deborah Adams noticed her two-year-old daughter's rash and sore muscles during their family vacation, she chalked it up to sunburn and exhaustion. Then the rash and muscle weakness got worse. After a month of medical appointments to various specialists, little Josie was diagnosed with a rare, incurable disease, dermatomyositis, a muscle disease with inflammation, rashes, and weakness; it also leads to calcinosis, or calcium deposits under her skin.

Facing a stubborn case of an incurable disease

That was four years ago, which began “an odyssey,” explains Josie's father, Jay. Jay and his wife Deborah also have three other young children, Josie's older siblings: Trip, Henry, and Evie. Jay continues: “At first, we figured we'd just apply a salve and move on. Not so.”

We also want Josie to continue getting stronger, thriving at school, and bringing joy to our family.

One step forward, two back

Josie's initial treatment included intravenous medications, injections, and various therapies. Pediatric Home Service provided at-home intravenous immune globulin (IVIG) as well as many other services and supplies, including a food pump, formula, suction machine, and two infusion pumps. She improved the first year then dramatically regressed. Treatments grew in intensity as her

condition worsened. At age 4, after a debilitating few days, Josie was diagnosed with duodenal perforation. “Basically her intestines fell apart,” her dad recalls. “We were back in the hospital.”

Overnight hospital stay turns into seven months

“Our hospital stay was supposed to be overnight, but turned into one more day, then a week, and before we knew it, we'd been there seven months, through four surgeries. At one point, Josie was a whisker away from not being alive,” Jay says.

Amidst all this, Pediatric Home Service provided assistance for a memorable weekend at home. Deborah explains: “Josie was scheduled for one last life-saving, risky procedure. We all wanted her home for a long weekend.”

“Pediatric Home Service spent hours training Deborah and me to care for Josie,” Jay says. “It looked like an ICU in our home, yet we had the equipment, supplies, and trained skills to take care of her.”

That care continued when Josie came home after the successful surgery. Jay recalls: “Pediatric Home Service was part of an amazing support system that included our family, friends, neighbors, and people from our church. Josie required an extraordinary level of medical care when we first brought her back home, yet Pediatric Home Service eased the transition.”

PHS goes to Kindergarten

Josie continues receiving infusion therapy — at home. “Without Pediatric Home Service, Josie would be at the hospital every other week. That's not where she wants or needs to be,” Deborah says. “Josie attended afternoon Kindergarten. That entire school year, PHS came to our home in the morning,



Josie enjoying time out in her backyard on the family trampoline.

started her IV, then accompanied Josie to school to finish the infusion, monitor her vital signs, and other details. Josie didn't have to miss school every other week, she got her medications, and she even participated in music class and yoga,” Deborah says with a smile.

Promising potential

Considering her poor initial prognosis, Josie's future is promising. She has no neurological delays. She now visits her primary pediatrician once a month and has physical therapy once a month — all other medical care is at home. “Our goal is to get a handle on this calcinosis,” Deborah says. “We also want Josie to continue getting stronger, thriving at school, and bringing joy to our family.”

Jay adds: “Thanks to Pediatric Home Service, we can be at home together, which is exactly where we belong.” ■

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



The Pulse

news for our health care partners

The fight against infection
is as simple as 123

At the rodeo with Blake

Anthony the magician

Foods that can boost
your immunity

Two decades of
home makeovers