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LifelineLetter

Living with home parenteral and/or enteral nutrition (HPN)

Getting Ready for a Natural Disaster *One Center's Experience with Pediatric HPN Patients*

Russell J. Merritt, MD, PhD, and Catherine J. Goodhue, MN

From the Division of Pediatric Gastroenterology, Hepatology and Nutrition, and the Division of Pediatric Surgery at Children's Hospital Los Angeles

A few years ago, one of our pediatric gastroenterology fellows, new to California but not earthquakes (she was from Pakistan), became interested in the question of whether or not our patients are prepared to deal with a potential earthquake in Southern California. As an initial step, Dr. Toor evaluated how prepared our families were, and how comfortable they were with their degree of readiness. She found that most of our families were unprepared, except for having extra batteries for infusion pumps, and unsatisfied with their degree of preparation.

Dr. Toor then set about to develop a program to improve their readiness and to assess their comfort with their readiness after completing the preparation program. What she learned was that providing disaster preparedness information and instructing parents to complete

the preparedness process led to a much-improved level of preparation and confidence in that preparation. This article reviews what we learned from the program she developed and since the project was completed.

The Vulnerability of Children in Time of Disaster

Children are particularly vulnerable in the time of a disaster, especially when they have chronic health issues or are separated from their families. There have been studies of households of children with special needs in regards to disaster preparedness. These vulnerable households have been shown to have an even lower level of preparation than the general public.

In addition to the risk this presents for each of these children, it also represents a substantial public health challenge, and especially for those involved with Oley,

Natural Disaster, cont. pg. 11 ➤

HPN Awareness Week: October 14–18

A picture is worth a thousand words. Express yourself by submitting a photo for our annual "Alive with HPN" video to kickoff HPN Awareness Week! Send us a photo of you or your child, doing what you/they like to do (action photos welcome), along with a sentence or two saying what you would like people to know about home parenteral nutrition (HPN).

If you are comfortable sharing your story, reach out to your local media. Share an event in your life (an HPN anniversary, a graduation or wedding, etc.) around which they can build a story. Someone in your community may be encouraged by learning about your experiences.

Request your free HPN Awareness pin now! Share them with friends, family, clinicians.

Submit photos to Lisa at metzgel@amc.edu (or mail to the office, street address on page 2) by October 1—the sooner, the better! For free pins, go to www.oley.org/HPN_Awareness_Week, e-mail Lisa, or call Oley at (518) 262-5079. Give us a call if you'd like help with a press release. Thanks to Baxter Healthcare for underwriting the pins and promotional materials for HPN Awareness Week.

One Mom's Experience Tube Feeding in Uganda

Moreen Nakalinzi

Eunice was born in a remote area in the eastern part of Uganda to rural parents. Her mother never attended prenatal care and she delivered Eunice at home by herself. She had a difficult labor that lasted for three days.

Because she never received any prenatal care at all, she did not know that her baby had hydrocephalus. The mother was finally able to deliver the baby, but she unfortunately died due to postpartum hemorrhage.



Moreen and Eunice

Tube Feeding in Uganda, cont. pg. 9 ➤

LifelineLetter

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Subscriptions:

The *LifelineLetter* is a bi-monthly newsletter sent free of charge to those on home parenteral or enteral nutrition. There is no charge for others as well if they receive the newsletter electronically. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed with your health care provider prior to actual use. Correspondence can be sent to the Editor at the address above.

Our Mission

...is to enrich the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking.

The Oley Foundation provides its 20,000+ members with critical information on topics such as medical advances, research, and health insurance. The Foundation is also a source of support, helping consumers on home IV nutrition and tube feeding overcome challenges, such as their inability to eat and altered body image. All Oley programs are offered **FREE of CHARGE** to consumers and their families.

Oley Foundation Programs

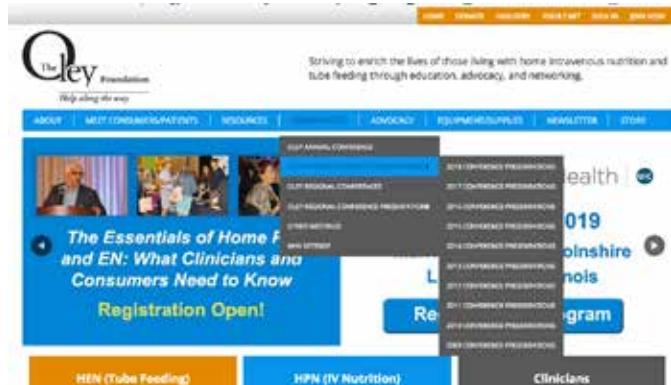
- *LifelineLetter*
- Peer to Peer Support
- Conferences and Webinars
- Resources to Promote Living Well on Tube Feeding and IV Nutrition
- Equipment Supply Exchange
- Advocacy and Awareness

Check Out This Resource:

Live Streaming and Videos on YouTube

Can't make the 2019 Oley/UI Health Combined Conference? Many of the sessions will be streamed live and recorded. Details will be posted at www.oley.org/AnnualConference. Clinicians: You will need to register for the live streaming if you're looking to earn CEs.

A recording of this conference, past conferences, and Oley awareness videos are available at www.youtube.com/theoleyfoundation. You can also access the list of conference presentations by selecting the "Conferences" tab at www.oley.org, and awareness videos are under "Advocacy."

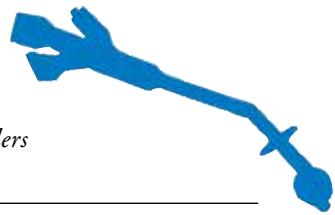


How to Support Oley

Donations are tax deductible and are accepted at www.oley.org/donations or at the street address on left.

Tube Talk

Send your tips, questions, and thoughts about tube feeding (enteral nutrition) to metzgel@amc.edu. Information shared in this column represents the experience of the individual and, while medical information is reviewed by an advisor, should not imply endorsement by Oley. The Foundation strongly encourages readers to discuss any suggestions with their clinician before making any changes in their care.



Cell Phone Stand Holds Syringe

Greyson is a 7 1/2-year-old boy, full of life. He has eosinophilic esophagitis, also known as EOE. He was diagnosed when he was 1 1/2 years old. We learned he is allergic to a long list of foods. Until recently, we have been able to manage his EOE with diet and an occasional stint with oral steroids (called a slurry).

As he got older, Greyson remained small for his age, but not too alarming. He would get tired easily and he started going on strike from some of his regular special foods. We tried many different feeding therapists over the years to help him eat other foods, but he just wouldn't. Eventually he was eating just chips, tapioca bread, waffles that we made from a special mix, and hemp milk.

He stopped growing. His thyroid stopped working and he wasn't getting the nutrients he needed to grow. Even if he had started eating the foods that he could eat, it wouldn't be enough to give him the nutrients he needed to grow. He was 7 but had stayed the size of a small 5-year-old for at least two years.

We received a feeding tube in February 2019 and he just got the button [a low-profile feeding tube] last week. He has grown 1.5 inches

and has more energy than before. He likes to do everything himself, which makes me nervous and results in lots of spills.

We met a friend in the feeding tube community, David, who told us about the cell phone holder and how helpful it could be. We found one at the store fIVE and Below for just \$5 and thought it was worth a try. The holder has allowed me to give Greyson his afternoon gravity feeds while he does his homework, and it allows him to participate in his feeds when he feels the need to be independent. I can see where this would be helpful with much younger kids who can't sit still and/or when a parent needs a third hand, too.



Greyson, showing how he helps with his gravity feeds.

—Staci P.



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Thank You for Your Support in Fiscal Year 2018!

The following list represents everyone who contributed toward Oley's efforts in our 2018 fiscal year: October 1, 2017, to September 30, 2018. Donations are given in honor of, or in memory of, an individual or special event, we've created a separate list, which can be found on page 7.

Generous Gifts Without Bounds**(\$5,000+)**

Anonymous

Steven and Leah Atkinson

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Lillian Harvey Banchik, MD, FACS, CNSC, FASPEP,* in honor of the birth of her first grandchild, Cameron Walter Banchik Morpeth

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Dale and Martha Delano, includes matching gift from the GE Foundation

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ThriveRx, Inc., in memory of Miles Agnew, Marsha Brent, Tony Forte, Karen Keener, Brittney Salinas, and Joshua Willis

Enhancing the Lives of Those We Care for Each Day.

Patrons (\$100–\$249)

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Anonymous, includes matching gift from the GE Foundation

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Gabriel and Nancy Bitton, in honor of Natalie Rosenthal's birthday

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Proud supporter of the **Oley Foundation**, home nutrition support consumers, and their caregivers.

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We also want to thank those who are not listed below, yet have supported Oley by volunteering their time and talents. Note: when three gifts received October 1, 2018, or later will be acknowledged in next year's listing.

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 Chet and Kay Kent
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 Michele Tanner
 Mary Susan Thomas, RN, MSN
 T. Bryan Tims
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 Brian McCall
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 Janet and Kevin Miller, in honor of Jonathan Miller, "26 years on HPN and now 9 years off!"
 Leah Mitteer
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 William and Thelma Pierce, in honor of Dr. Ellen Pierce and Mr. Chris Erickson's 21st wedding anniversary
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Karen Hamilton, MS, RD, LD, CNSC
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Pauline Kubizne
Sandra Lynn, in honor of Mike Sherels—"Sherels strong!"
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Peggy Roth
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Devang Patel
Helen Pizzuti
Judith Rabiner, in memory of Liz Wolfson
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Jim and Sarah Rausch
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Becky Richardson
Denise Richardson, RN
Doris Rios, in memory of Roberto Sanchez-Guzman
Tom Rush, to Oley, "a continuous holiday to people everywhere"
Susan Schesnol, in honor of Jeffrey Schesnol
Alan Segal, in memory of Robin "Peaches the Clown" Lang
Amy Shearow, in honor of Dr. and Mrs. Breaux

Gattex Approved for Peds with SBS

Adapted from a press release by Takeda Pharmaceuticals USA.

This May, the U.S. Food and Drug Administration (FDA) approved extending the indication of Gattex® (teduglutide) for injection to pediatric patients 1 year of age and older with short bowel syndrome (SBS) who need additional nutrition or fluids from intravenous feeding (parenteral support).

In a 24-week pediatric study, Gattex helped reduce the volume of daily parenteral support (PS) required and time spent administering PS. Some children even achieved complete freedom from PS. Fifty-nine pediatric patients with SBS aged 1 year through 17 years chose whether to receive Gattex or standard of care (SOC). Patients who chose to receive Gattex treatment were subsequently randomized in a double-blind manner to 0.025 mg/kg/day ($n=24$) or 0.05 mg/kg/day ($n=26$), while 9 patients enrolled in the SOC arm. The recommended dosage of Gattex is 0.05 mg/kg/day. Randomization to the Gattex dose groups was stratified by age.

At the end of the 24-week study, 69% of patients (18/26) who took Gattex 0.05

mg/kg each day reduced PS volume by 20% or more. Based on patient-diary data, patients who received Gattex 0.05 mg/kg/day experienced a 42% mean reduction in PS volume (mL/kg/day) from baseline (-23 mL/kg/day from baseline). At week 24, 38% of patients (10/26) were able to reduce PS infusion by at least 1 day per week. Patients reduced their PS infusion time by 3 hours per day on average compared to baseline. In addition, during this study 3 out of 26 (12%) children who received Gattex 0.05 mg/kg/day completely weaned off PS.

Gattex has a demonstrated safety profile that is similar overall in pediatric and adult patients. The most common adverse reactions ($\geq 10\%$) seen in adult patients treated with Gattex in clinical trials were abdominal pain, nausea, upper respiratory tract infection, abdominal distension, injection site reaction, vomiting, fluid overload, and hypersensitivity. For more information go to www.gattex.com.

Gattex has been shown to reduce parenteral support volume and to help some children with SBS wean off of intravenous nutrition over time during clinical studies.

Philip Sortino, in memory of Donna Sortino
 Robert and Tammi** Stillion
 Jean and Asa Talbot
 Enrica Thure, in memory of Greg Tongol
 Emma Tillman, PharmD, PhD, BCNSP
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 Jason Valenzano
 Bev Walgrave
 Carol Walsh, in honor of Mary Ellen Costa
 Watkins Family
 Michael Wenz
 Carolyn Wijnholds

In Honor of Lyn Howard, MB, FRCP***
 Sharon Alger-Mayer, MD
 Paul DeBarbieri, in honor of Lyn and Jack's birthdays
 Carl and Jeanne Ferrentino
 Olwen Giddings, RN, in honor of Dr. Lyn Howard, "a wonderful doctor whom I had the great opportunity to serve with and had learned a great lot, enhancing my job as a nurse"
 Michael Medwar
 Ron and Lisa*** Metzger
 Erik Schten, in honor of Dr. Lyn Howard, "a giant in her field and a wonderful human being"

In Honor of Swapna Kakani
 Andrea Bolton
 Bhavani Kakani
 Michael Medwar

In Honor of Phil Kellerman***
 Harry and Ruth Forgan
 Janet and Frank Ivory-May
 Karen Kellerman
 Fred Levine
 Scott and Kim Young

In Honor of Bob and Mary Smithers*, ** and their 50th wedding anniversary
 Maria and Zenaida Sciaino
 Gail, Charles, and Chad Smithers

John Smithers
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 Pauline Kubizne

In Memory of Clifton Dodge, Sr.
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In Memory of Robin Lang
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 Timothy Lang
 Alan Segal

In Memory of Bruce Wolf
 Louise Brandt
 Donald Brennan
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Fund-raisers
 BriovaRx Infusion Services fund-raiser at ASPEN annual conference
 Bharath Surapaneni's Chicago Marathon run, in honor of Swapna Kakani
 Phil Kellerman's eBay sales
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Remembering Kay Oldenburg

The Oley Foundation sadly announces the passing of Kay Oldenburg, from Baldwinsville, New York, on May 5, 2019. Kay and her husband, Clarence "Oley" Oldenburg, who co-founded the Oley Foundation with Dr. Lyn Howard in 1983, were great supporters of the foundation.

Kay and Clarence served as Oley Foundation Regional Coordinators (now our Ambassador program) for many years. They held their first support group get-together in the Syracuse, New York, area in 1989. Their objectives were "to relieve the feeling of isolation for PEN people; to exchange ideas and experiences; to answer questions about living on a PEN program; to make new friends who understand the PEN lifestyle." These remain core to Oley's goals today.

Learning of Kay's passing, Dr. Howard notes, "This feels like the end of an era with both Oley and Kay gone. I have terrific memories of how the Oldenburg family got us started, and frequently made the long drive from Syracuse to Albany to cheer us on. The Oley Foundation has steadily grown to over 20,000 participants so the Oldenburg family has made an enormous contribution and we will always be incredibly grateful for the Oldenburg startup funds from [Clarence's brother] Bill."

Joan Bishop, Oley Executive Director, writes, "Kay and Clarence always represented the 'voice' of the consumer dependent upon home nutrition support with class and dignity and will be remembered as such. We will always do our best to keep the Oldenburg family's wishes moving forward."

Celebrating Oley's Roots

Clarence, born in 1929, led a normal and healthy life until 1975, when a blood clot cut off circulation to his intestines. Over the course



Kay Oldenburg

of several emergency surgeries, most of Clarence's small intestine was removed. He spent the next five years in the hospital, "in a demoralized state of starvation" (*LifelineLetter*, Jan/Feb 1998).

In 1980, Clarence met a nutrition support specialist and started parenteral nutrition (PN). He was able to go home on the therapy and leave the hospital for good. He was one of Dr. Howard's patients at Albany Medical Center, Albany, New York, in the early 1980s. Clarence's brother, Bill, convinced of the great value in bringing home nutrition support consumers—and their families—together, provided the funding to start the Oley Foundation.

Meanwhile, in nearby Sharon, Massachusetts, Lee and Marshall Koonin had started the Lifeline Foundation, a support group for people on homePN, in 1978. Lee had begun homePN in 1977, and Marshall was committed to finding others on homePN, both to reduce the isolation Lee and others felt, and to help others learn about the therapy.

They published a newsletter, organized picnics, and established a network of patients who were willing to talk to others. By 1984, membership had grown to about six hundred and it had become a huge commitment for the Koonins, both in terms of time and money. When they were confident that the Oley Foundation would continue the work they had begun, they turned the Lifeline Foundation over to the Oley Foundation.

What began with Kay and Clarence and Lee and Marshall in the 1980s has, as Dr. Howard notes, grown to a community of over 20,000. This community and all of the information and support shared, are a beautiful legacy that we will continue to celebrate and for which we will always be grateful. ¶

Where Was Oley This Spring?



Tube Feeding in Uganda, from pg. 1

Baby Eunice

The baby was purposely neglected by relatives. When she was two weeks old, she ended up in a children's home, where I later fostered her. Given the difficult birth, Eunice ended up with severe brain damage. She was diagnosed with spastic quadriplegia cerebral palsy (CP) at the age of one and dysphagia (difficulty swallowing) at the age of three.

For the first few months, Eunice gained a little weight but I noticed she could not take fluids very well. For the most part, I had to tilt her and pour the fluids in, which most times resulted in her choking, and numerous stays at hospital for pneumonia. I shared my concerns with the nurses during hospital visits, but they did not seem to pay much attention to my concerns.

When Eunice made six months, I introduced solids like porridge, but she again had difficulties chewing and swallowing the solids. Eventually she started losing weight.

Because Eunice always scored low on the growth chart, we were immediately taken to the nutrition unit every time we went to the hospital. On numerous occasions I was accused of purposely starving my child. I on many occasions tried explaining that the child was having difficulties feeding, but none of the medical staff paid attention to me.

We always ended up staying weeks in the nutrition unit for severe malnutrition and pneumonia and were always discharged with ready-to-eat therapeutic feeds called Plumpy'nut. (These feeds are given in hospital freely to children who score low on the MUAC tape and are suffering from severe malnutrition.) But by the next visit, nothing much had changed with Eunice and the same process would begin all over again.

Finding Help

In 2017, Eunice started attending occupational therapy and for the first time, I met someone who understood the challenges I was going through. She not only gave a name to the condition my child had, but she also referred me to see a speech therapist. I was happy that I had gotten a name for this condition and also a referral.

I took Eunice to see the speech therapist and tests revealed she couldn't take fluids but could try taking feeds with a thickened consistency. I was advised on what food to feed her and we tried it. She still wasn't doing very well. She was still choking, feeding her took around forty-five minutes to one hour, and she still wasn't gaining weight.

Her pediatrician later recommended a feeding tube, which she got on August 4, 2018. I immediately started seeing change after the tube was placed. Eunice's stomach did not have creases, her hair wasn't brown, and her skin was no longer glassy. She also started gaining weight real quick, and feeding her wasn't taking forty-five minutes.

The Challenge of Finding Supplies, Blending Foods

Pediatric tube feeding due to congenital complications like CP is not very common in Uganda, so finding feeding supplies, let alone a surgeon who will do a PEG procedure to place a tube, is very challenging. Medical insurance companies do not cover the procedure, meaning that you have to pay out of pocket, which is very expensive. Similarly, pharmacies do not stock any feeding tube supplies, like split gauze, feeding syringes, extensions, PEG tubes, or buttons.

In my daughter's case, we solely rely on supplies donated from organizations or from friends in the USA. I am also a member of various online special needs supply exchange groups, which gives me an opportunity to not only meet other parents but also to get supplies for the cost of shipping.

Enteral formulas are near to nonexistent in Uganda. We automatically exclusively feed our kids on a home blended diet, which has been

I immediately started seeing change after the tube was placed....She started gaining weight.

a blessing for us. This being a tropical climate, fresh organic food and fruits are readily available throughout the year. However, there are also a few challenges that we face with a blended diet, ranging from no power supply—which makes it hard to use a fridge to store the food—to finding a good blender and access to clean water for food preparation.

We live in a rural remote area, with no piped water and no power grid. Though I have a solar system, it cannot power a fridge. I have to take Eunice's food overnight to a house nearby that has a solar system strong enough to power a small fridge, and pick it up in the morning. I use a cooler with icepacks throughout the day at my house to keep the food cold, and I boil all water to prepare her food.

Prior to tube feeding, I had never given a thought to food calories. All of a sudden, it became necessary for me to pay attention to that. I have downloaded an app that was recommended by other parents in the online groups, but I have realized that some foods common in a Ugandan diet are not present on the app or they are called by different names. Also, on the app most foods are weighed in pounds and ounces instead of kilograms and milliliters. It's definitely been a learning process for me, but I think I have slowly gotten better at understanding how calories work with the help of other parents and her nutritionist, who has been a huge help.

Tube Feeding in Uganda, cont. pg. 16

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In Memoriam: Dr. Hickman

Fred Hutchinson Cancer Research Center*

Dr. Robert Hickman, a pediatric nephrologist and inventor of a catheter that revolutionized care for cancer and parenteral nutrition patients, died on April 4. He was 92.

In the 1970s, Hickman was a founding member of the team at Fred Hutchinson Cancer Research Center that pioneered the Nobel Prize-winning bone marrow transplant treatment. His contribution to that effort: The lifesaving device that bears his name and is still used worldwide to deliver IV nutrition, draw blood, and deliver chemotherapy.

The Hickman catheter “was a gift to the world,” said Dr. Fred Appelbaum, executive vice president and deputy director of Fred Hutch, who worked with Hickman.

That invention transformed doctors’ ability to access a patient’s bloodstream. And it was born out of desperate need. Among the many hardships early bone marrow transplant patients faced was an endless nightmare of needle sticks, Appelbaum recalled.

“Patients were starving to death nutritionally,” he said. “They couldn’t eat because of chemotherapy and radiation therapy. They were losing enormous amounts of weight that made them much more susceptible to infections.”

That meant they had to be fed intravenously. But nurses and physicians often struggled to find a vein to do so.

“These were very sick patients,” Hickman recalled in 2002. “They had come to the Hutch as a last resort, and after all the other treatments they’d been through, the vast majority of their veins had been used. You’d stand in awe of the nurses who could find usable veins.”

At the time, he was conducting kidney consults for patients in the Hutch transplant program. One day in 1973, nurses repeatedly tried and failed to find a usable vein in a patient with advanced leukemia. Hickman offered to try to place a device called a Broviac catheter.

Invented by a colleague of Hickman’s at the University of Washington, the Broviac catheter passed through a vein in the chest into the right atrium of the heart and allowed for successful delivery of intravenous nutrition. The device worked well, but it hadn’t been tried in bone marrow transplant patients.

Until Hickman did. Although the patient ultimately succumbed to her disease, her positive response to the IV nutrition was dramatic enough to open the transplant team’s eyes to the potential.

Gradually, Hickman placed more Broviac catheters in transplant patients. He credited Fred Hutch nurses who played a critical role in the evolution of the device.

“The nurses said, ‘Well, this is nice, but we need a bigger line,’ he said. “So we had the engineers design new catheters. The Broviac line was sacred, for nutrition and nothing else. But the nurses said, ‘We need to draw blood.’ We developed a new catheter with additional lumens, the portals through which fluids can pass.”

The Hickman catheter, as it came to be known, instantly transformed care, said Dr. Rainer Storb, who was on that pioneering transplant team and is one of the founding scientists of Fred Hutch. The [invention of the Hickman] catheter was an incredible event,” Storb said. “We were able to leave all the pain and tension of constant punctures behind us.”

Hickman’s skills at placing the devices—he was very gentle with his patients—became legendary. “The patients just fell in love with him, and for good reason,” Appelbaum said. “Bob was a saint.”

His colleagues felt the same, Storb added. Hickman would respond day or night to put in the catheters. And his personality would brighten any room, operating or otherwise, he entered.

“He was always smiling, always in a good mood,” Storb said. “That says something about the man. There aren’t that many people who are kind and nice and willing. Working with him was a joy.”

Hickman retired in 2009, shortly after turning 82. He credited a deep devotion to his patients as the reason why he continued to scrub in.

“We treated hundreds of patients every year, and I kept working well beyond the age of retirement,” Hickman said. “But that’s because I enjoyed working with them so much. They were wonderful people, and they contributed a great deal to my life.” ¶

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Natural Disaster, from pg. 1

as it is estimated that there are 16,000 children receiving home parenteral nutrition (HPN) in the United States.* Previous studies in Los Angeles found that only 17 percent to 28 percent of families had any form of emergency preparedness. Our Los Angeles area population is heavily Latino in origin, and levels of preparation may be still lower in that population, and especially in Latino households with children with special needs.

Assessing Preparedness

In order to proceed with this project in our community, Dr. Toor and her collaborators developed a questionnaire to assess the readiness of the parents of our patients to deal with a possible natural disaster emergency (figure 1). This questionnaire was adapted from previous work on assessing disaster preparedness of families of children with special needs. An opportunity presented itself to administer this questionnaire when our hospital sponsored an "Intestinal Rehabilitation Day" for education and mutual support of our HPN and intestinal rehabilitation (IR) patients. In addition, we held focus groups that day to get a more in-depth sense of the issues our families saw as interfering with disaster preparedness.

After the conference we analyzed the data from both the questionnaire and the recorded focus groups. We found that our HPN and IR

patients had a low level of disaster preparedness and felt a corresponding lack of confidence in their ability to respond in the event of a disaster.

Developing a Disaster Preparedness Plan

The focus groups were particularly helpful in identifying perceived barriers to disaster preparedness. These included developing a list of specific extra supplies that might be needed; knowing how to obtain those extra supplies in the current insurance environment; the families' lack of a general disaster plan; and their lack of understanding about how their physician and hospital might be able to help them prepare. From this starting point, we concluded that most families with a child on HPN were not prepared to meet their child's special needs (or the rest of the family's needs) in the event of a disaster. From dealing with these families, we know how committed they are to assuring their child's welfare, and we thought this might provide sufficient motivation for them to better prepare for a natural disaster, given support from their medical support team.

The American Red Cross (www.redcross.org/get-help/how-to-prepare-for-emergencies/make-a-plan.html and, for earthquakes, www.redcross.org/get-help/how-to-prepare-for-emergencies/types-of-disasters/quakes.html)

Natural Disaster, cont. pg. 12 ➤

Figure 1. Survey to assess the readiness of patients' families to deal with a possible natural disaster emergency

1. Does your family have a written Family Emergency Communication Plan in case you are separated during a disaster? YES/NO
2. Does your family have a designated meeting place outside of your home? YES/NO
3. Does your family have a designated meeting place outside of your neighborhood? YES/NO
4. Does your family have an emergency supply kit that can last you for 3 days? YES/NO
5. Does your family have a fire escape plan for your home? YES/NO
6. Does your family keep emergency supplies in each of your vehicles (e.g., blankets, flashlights)? YES/NO
7. Does your family have 3 gallons of water stored for each person in the household (3-day supply)? YES/NO
8. Does your family have enough stored food that does not need refrigeration or preparation that can sustain your family for 3 days? YES/NO
9. Is the food separated from your regular food supply? YES/NO
10. Do you have a working flashlight with an extra set of batteries in your home? YES/NO
11. Do you have a packaged first aid kit in your home? YES/NO
12. Do you have a container that is both fireproof and waterproof for storing important papers in your home? YES/NO
13. All family members over 14 years old know how to turn off the gas, power, and water to our household in case of an emergency. YES/NO
14. I have a copy of my child's Medical Emergency Plan (Emergency Information Form) completed by his/her doctor. YES/NO
15. All children over 5 years old in our house are able to state their full name, address, and phone number. YES/NO
16. How many extra days of medication do you have on hand at all times for each family member with a chronic medical condition? _____ days
17. Do you have a back-up source of electricity for your child's infusion pump? YES/NO
18. Do you have additional supplies necessary for your child's infusion system? YES/NO
19. Do you have "back-up" nutrition for your child? YES/NO
20. On a scale of 1–10 with 10 being the best, how confident are you that you are ready for a disaster?
1 2 3 4 5 6 7 8 9 10
21. Demographics
 - a. Gender/age/marital status of respondent
 - i. MALE/FEMALE
 - ii. Your age: _____ years
 - iii. MARRIED / SINGLE / DIVORCED / WIDOW
 - b. Gender/age of child with special health care needs
 - i. MALE/FEMALE
 - ii. Child's age: _____ years/months

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Natural Disaster, from pg. 11

of-emergencies/earthquake.html), the Department of Homeland Security (www.ready.gov), the American Academy of Pediatrics (www.emergencycareforyou.org/globalassets/ecy/media/pdf/eif-form.pdf), and other organizations provide online and hard-copy directions for general disaster preparedness, and specifically for earthquake preparedness. These documents are an excellent starting point for families beginning to prepare for a possible disaster.

In general, it is recommended that families plan to have sufficient water, food, power sources, and supplies to be able to cope in place for three days ("shelter in place") following a natural disaster. Hospitals may have insufficient beds and supplies to meet the needs of patients in a disaster situation. Being prepared for at least three days at home reduces the pressure on hospitals and allows some time for infrastructure recovery before patients may need to seek additional assistance. For families dependent upon the delivery of medical supplies, infrastructure recovery [clearing roads, for example] is especially important.

If we look at the experience from Hurricane Katrina and from the recent Japanese tsunami, we see that lack of an alternative source of electricity was a huge determinant as to whether children with special health-care needs were brought to the hospital following the natural disaster. Other issues that were important to this population under those circumstances were accessibility of medical records, communication with their medical support team, separation of children from their caretakers, and the level of household preparedness.

Since a disaster may occur at a time when there are few bags of PN remaining in the home, advice was provided to our families about obtaining and using 10% dextrose as a temporizing measure until a supply of PN could be re-established.

We are fortunate at our children's hospital in having a number of national leaders in disaster preparedness. Since we also have a great deal of experience in supporting families on HPN, we united these capabilities. Dr. Toor and our disaster planning experts developed a plan to help our HPN patients achieve disaster preparedness and confidence in their preparedness. The education took place in our HPN clinic. At the beginning of the project, thirty-one families were asked six questions about their disaster preparedness.

A disaster survival toolkit was developed for each family. It included:

- Four D-cell batteries for use in HPN pumps
- Power inverter for charging laptops and phones from a car battery source
- Waterproof flash drive with the child's medical information and instructions for a local emergency department or provider, should the child present for care (e.g., for fever, low blood sugar, dehydration, a need for alternate fluid sources, or central line damage)
- Paper copies of the same medical information, as some hospitals do not allow external information to be uploaded on their electronic medical record (EMR) systems
- Supply list (figure 2)
- Emergency Information Form (EIF, available at www.redcross.org/get-help/how-to-prepare-for-emergencies/make-a-plan.html)
- Power and water discount forms (obtained from local utilities)
- Handouts from FEMA and the Red Cross specific to earthquakes.

After the first steps, Dr. Toor then followed up with the families by phone at two- and four-month intervals and re-asked the same six questions that had been posed at the initial study clinic visit. In this way, she documented any improvement over time in the disaster preparedness of our families.

What we learned was highly encouraging. By four months after the start of the project, 90 percent of the families had an emergency plan, 93 percent had an emergency supply kit, and all of the families had an alternative power source for the PN pump (they all had this at the beginning as well!). Because of the expense, few families had invested in a generator. Their confidence in their disaster preparedness had gone from less than 10 percent to greater than 90 percent. That last result is seen in figure 3.

What we learned from this educational project was that it is possible to apply the principles of disaster preparedness available for the general population and families of children with special needs to help families of HPN-dependent children be prepared and feel more prepared for a possible natural disaster. At the time of the conclusion of the project, both we and the families felt good about what had been accomplished.

Staying Prepared

Since completing the initial disaster preparedness project, we have learned how difficult it is to maintain this level of preparedness. New patients come into our clinic. Medical information changes over time. Supplies become outdated. Batteries need to be replaced. Without an individual with sufficient time and commitment to continuing assessment and education for disaster preparedness who can update the relevant materials and supplies, we have not been able to maintain a high and appropriate level of disaster preparedness.

We see many opportunities for improving this situation. Perhaps the most important is creating the expectation that we achieve a high and ongoing level of disaster preparedness. There may be ways of using the electronic medical record (EMR) to our advantage. For example, after hospitalizations or clinic visits, the medical information sheets

and the thumb drive could be routinely updated. The EMR could be programmed to pull the relevant medical information. Similar things are done for other patient populations, such as those in our cancer program.

We can also work with insurance companies to assure that supplies held in reserve for a disaster are replenished as necessary, for example on an annual basis. The recent availability of pre-prepackaged PN in special IV bags has also broadened the choice of alternative fluids that can be kept for use in an emergency.

We also think families can and should play an important role in achieving this goal. Families working in groups or as individuals can develop a plan for updating their preparedness on at least an annual basis. They can insist that they have information available at all times that would assist them in an encounter with a new hospital or provider in the event they require care after a natural disaster (or on other occasions).

The Oley Foundation might also be a great resource for developing information resources and guidance to families for achieving these goals. In addition, they could be instrumental in urging national standards for disaster preparedness for children with special needs, particularly those on home parenteral and enteral nutrition.

There is a lot to be done to achieve the desired level of preparedness of HPN families. Our preliminary experience suggests that it is possible to do this work. There remain significant challenges we will need to overcome together to keep PN-dependent children from needing hospitalization after a natural disaster. ¶

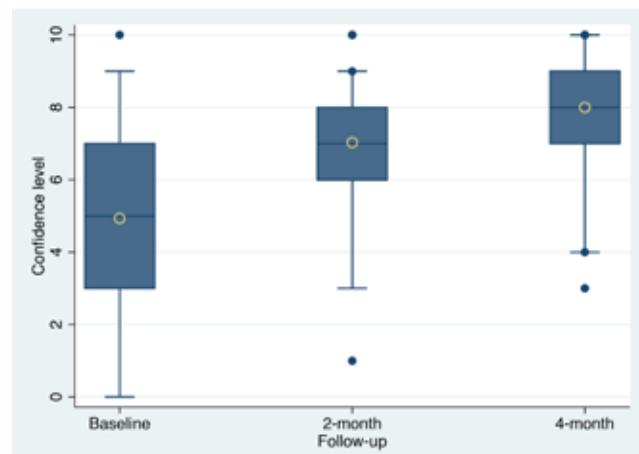
* ASPEN Pediatric Nutrition Support Core Curriculum. 2nd ed. Silver Spring, MD: American Society for Parenteral and Enteral Nutrition; 2015.

Figure 2. Sample emergency supply list

Checklist of Supplies	Quantity/ Expiration date
1. PN bag	_____
2. Pump	_____
3. Tubing for PN pump	_____
4. Battery	_____
5. Normal saline flush	_____
6. Heparin flush	_____
7. Water flush	_____
8. D10 fluid bags	_____
9. TPA/Alteplase	_____
10. Ethanol lock	_____
11. Alcohol wipes	_____
12. Central line caps	_____
13. Central line care bundle (mask, gloves, alcohol wipes, Biopatch)	_____

Figure 3. Family confidence of disaster readiness (10 is best)

On a scale of 1-10 with 10 being the best, how confident are you that you are ready for a disaster?



Reprinted with permission from Toor K, Burke R, Demeter N, et al. Improving disaster preparedness of families with a parenteral nutrition-dependent child. JPGN. 2018;67(2):237–241. www.jpgn.org

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Takeda is a global, values-based, R&D-driven biopharmaceutical leader headquartered in Japan, committed to bringing better health and a brighter future to patients by translating science into highly innovative medicines.

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Nutrishare continues to be the only TPN pharmacy that is dedicated exclusively to the home TPN consumer. One hundred percent of its consumers are HPN consumers.

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BioScrip is a leading national provider of comprehensive, cost-effective pharmaceutical and home care solutions. Their goal is to partner with patients, physicians, health care payors, government agencies, and pharmaceutical manufacturers to provide access to infusible medications and management solutions that optimize outcomes for chronic and other complex health care conditions.

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Born from a mom and dad's love for their tube-fed son, Real Food Blends makes 100 percent real food meals for people with feeding tubes. No corn syrup or preservatives; just real ingredients to nourish your body and soul. The meals are covered by many insurance plans and available through RealFoodBlends.com or DMEs nationwide.

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Notable Individual Gifts

Among the contributions we receive, there are always several dedicated to those who have inspired the donor. We share this list of honorees below. We are grateful for the following gifts received from March 9 through May 3, 2019.



Tributes: In honor of all the Oley Foundation does to support those with feeding needs, especially the Equipment Supply program; Bettemarie Bond and her family, and all of their work on behalf of Oley; Barbara Bray; Dodie Carmichael; Phil Kellerman; Aidan Koncious; Dashiell Lyon; Alan Taxman, for making Forbes list of Best Wealth Managers in Missouri for 2019

Memorials: In memory of Kathy Bucher; William Fitzpatrick, Sr.; Paul Gosnell, Lt. Colonel, USAF (ret.); Monsignor Daniel Hamilton; Alisha Hoelle; David Markowitz; Laura Matarese's mother, Rosina; Ruth and Roland Milow; "my Dad, because I miss him"; Mary Patnode; Elizabeth Tucker

Matching Gifts: FM Global Foundation; GE Foundation; Johnson & Johnson; Lexis Nexis; National Grid; ThermoFisher Scientific; United Services Automobile Association (USAA)

Fund-raisers: Al Mackay's long trail hike; funds raised at a Painting with a Twist event, donations for Oley's annual silent auction

Thank you for all gifts and the kind comments we receive throughout the year. Your support overwhelms us and continues to be a source of inspiration.

FY 2018 Corporate and Foundation Program Support

Thanks to the following corporations, foundations, and organizations for their generous gifts (\$500+) for specific Oley programs. These gifts extend support beyond the corporate partner pledges.

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Oley Horizon Society

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. Learn how you can make a difference by calling (518) 262-5079 or visiting www.oley.org/plannedgifts.

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Lifeline Letter

The Oley Foundation

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Delmar, NY 12054

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Oley/UI Health Conference

June 21–24, 2019

Lincolnshire, Illinois

See You There!

Tube Feeding in Uganda, from pg. 9

Even with all the adjustments we have had to make at home to accommodate my daughter's needs, I think a feeding tube was the best thing that ever happened to us. I wish I had known about it early and that the medical people in the hospital had extensive knowledge about it. I would have made a decision to get her one when she was a few weeks old.

I have started sharing my experience with everyone in a bid to demystify tube feeding because most people here do not know about feeding tubes and at times judge a parent who has a child with one because they think that they don't want to feed their children. I also meet with special needs parents who have children with feeding difficulties to educate them about dysphagia and about the tube alternative.

For most of these parents, it's like candy on Christmas day when they realize for the first time that they are not horrible parents who have failed to feed their kids but that their child has a disorder. This is information I would have gladly appreciated in the first three years of my daughter's life.

Editor's note: Moreen sent us photos of Eunice for Feeding Tube Awareness Week with a note about how much tube feeding had helped Eunice and how long it had taken for Moreen to learn about it as an option. We were pleased she was willing to share her story with us for the newsletter. We were also pleased to be able to send her some supplies through our Equipment Supply Exchange Program, thanks to Oley members' donations and the lucky coincidence that Moreen had a friend traveling to Uganda from the US, so we were able to send the supplies to the friend to carry with her. We were also able to contact a supplier of medical products in Uganda, who hopes to be able to help Moreen and others obtain supplies more easily in the future. ♣

Oley Calendar

Ongoing: Applications being accepted for Oley Tim Weaver Camp Scholarship

June 21–24: Oley Annual Conference, Lincolnshire, IL

August 6–10: Oley attending and exhibiting at United Ostomy Associations of America (UOAA) meeting, Philadelphia, PA

September: Oley Regional Conference, Miami/Fort Lauderdale area

October 4: Oley/Association for Vascular Access collaborative education day, Las Vegas, NV

October 4–7: Oley exhibiting and participating in Association for Vascular Access (AVA) Annual Scientific Meeting, Las Vegas, NV

October 14–18: HPN Awareness Week

For updates or if you are able to help at one of the Oley exhibits listed above, please email harrinc@amc.edu or call (518) 262-5079.

Additional Meetings of Interest

June 21–23: National Organization of Rare Disorders (NORD) Patient and Family Forum, Houston, TX

June 26–29: United Mitochondrial Disease Foundation (UMDF) meeting, Washington, DC

October 15–16: National Organization of Rare Disorders (NORD) Rare Summit, Washington, DC

October 25–30: American College of Gastroenterology (ACG), San Antonio, TX