

The Oley Foundation and Consumer Support Groups



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KEYWORDS

- The Oley Foundation • Support groups • Intestinal failure • Parenteral nutrition
- Enteral nutrition • Home nutrition support • HPN • HEN

KEY POINTS

- Because of the complexity of home parenteral and enteral nutrition (HPEN) therapy and treatment of intestinal failure (IF), HPEN consumers often face depression, isolation, fatigue, anxiety, financial stress, and so on, in addition to the physical effects of IF and HPEN. These stressors affect the families of HPEN consumers as well as the consumers (patients) themselves.
- Research shows HPEN consumers benefit in many ways from participating in Oley Foundation programs.
- Other organizations also offer support, programs, and educational opportunities for HPEN consumers and IF patients.

INTRODUCTION

When someone is diagnosed with a life-altering illness or condition, there is an unmistakable hierarchy assigned to the resulting problems and changes. At first, life for the patient and their family is all about survival and recovery. Time, money, and sometimes comfort are thrown to the wind to ensure that the patient will live to see another day. Family dynamics change; hospital visits take priority over work, school, hobbies, and sometimes other family members. Survival is the top priority. When it comes to chronic illnesses, however, what happens when survival is not a pressing question?

When a chronic medical condition is no longer an imminent threat to the patient's life, everyone feels, of course, a moment of overwhelming relief. However, as time goes on, that relief fades and is replaced by anxiety and uncertainty about the future as the patient and their loved ones learn to manage the condition and the changes it has wrought in their lives. Suddenly, the patient is asked to thrive when he or she has been focused on merely surviving.

Disclosure: Authors are all Oley Foundation staff.

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Gastroenterol Clin N Am 48 (2019) 625–635

<https://doi.org/10.1016/j.gtc.2019.08.006>

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As someone who suffers from short bowel syndrome resulting from a congenital diaphragmatic hernia, I (Julie) am in a unique position to comment on the physical as well as the psychological effects of intestinal failure and the use of home nutrition support.

INTESTINAL FAILURE AND MANAGEMENT

Looking at data it had collected, in 2016 the European Society for Clinical Nutrition and Metabolism (ESPEN) ruled intestinal failure (IF) the rarest form of organ failure.¹ ESPEN defines IF as “the reduction of gut function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation is required to maintain health and/or growth.” IF may occur suddenly and abruptly (eg, as the result of an accident), or it “may be the slow, progressive evolution of a chronic illness.” It may be short term or long lasting (chronic intestinal failure).²

Common treatments for IF include parenteral nutrition (PN) and enteral nutrition (EN), often administered long term and at home (HPN and HEN).^{3,4} The use of these life-saving treatments comes with many complications, such as the threat of infection, intolerance, and metabolic deviations. Both IF and HPEN come with the often less well-considered or acknowledged psychosocial effects of depression, isolation, fatigue, anxiety, loss of independence, and reliance on technology and caregivers, the inability to eat, interference with friendly, romantic, and sexual relationships, and, in many cases, severe financial stress.^{3,5,6}

The source of the IF, whether it is sudden onset or the progressive evolution of a chronic illness; the chosen treatment options, including nutrition support, medical or surgical options; the ongoing effects of the IF, including pain, diarrhea, food intolerance; family support; support of a knowledgeable medical team, or a lack thereof; and other factors, have tremendous effect on how well a patient is able to manage their IF.

PREVALENCE OF HOME PARENTERAL NUTRITION AND HOME ENTERAL NUTRITION

Based on a review of Medicare beneficiary data for 2013 and data provided by 3 of the largest home infusion providers in the United States, Mundi and colleagues⁴ estimate that in 2013, 25,011 US inhabitants were sustaining themselves on HPN and 437,882 were dependent on HEN. Of the 25,011 HPN users, approximately 83% were adults, and 17% were pediatric. Comparatively, of the estimated 437,882 HEN users, 57% were adults and 43% were pediatric.

This study was compared with a similar one conducted in 1992 by Howard and colleagues⁷ in which the number of HPN and HEN consumers was estimated to be approximately 40,000 and 152,000, respectively. In the 21 years between these studies, the prevalence of HPN has actually decreased, whereas the prevalence of HEN has increased (**Fig. 1**). (A note on terminology: Over the years, Oley Foundation members have expressed a preference for the term “consumer” over “patient.” They acknowledge they are “patients” when they are in the hospital, but when they are home, living their lives on HPEN, they prefer to be called “consumers.” This term is used from here on.)

When compared with the total population of the United States, these are not large numbers, amounting to 21 Medicare HPN consumers per 1 million US inhabitants and 361 Medicare HEN consumers per million.⁴ It is uncommon for a person on HEN or HPN, especially, to know of anyone else on the therapy, and a sense of isolation prevails in this population (**Fig. 2**).

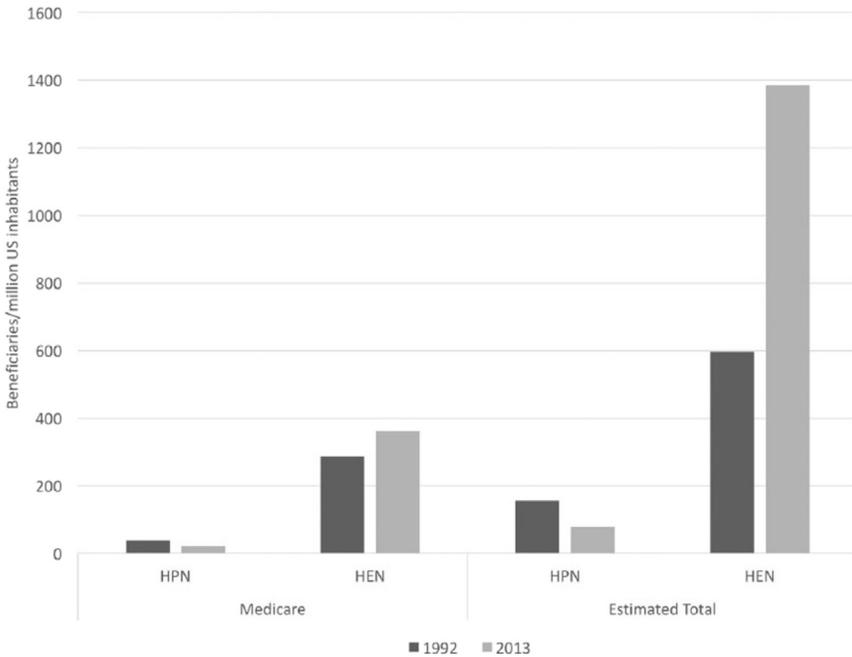


Fig. 1. Prevalence of HPN and HEN for Medicare and estimated total beneficiaries per million US inhabitants for 1992 and 2013. (From Mundi MS, Pattinson A, McMahon MT et al. Prevalence of home parenteral and enteral nutrition in the United States. *Nutrition in Clinical Practice* 2017 Dec;32(6):802; with permission.)

THE EFFECT OF SUPPORT GROUPS ON HOME PARENTERAL NUTRITION AND HOME ENTERAL NUTRITION CONSUMERS

Merriam-Webster defines “support group” as “a group of people with common experiences and concerns who provide emotional and moral support for one another.”⁸ Metzger and colleagues⁶ note that support groups give people “opportunities to talk to others who share a common experience; give and receive emotional support; share problems, concerns, and coping skills; and gather information and learn.” Studies have shown that participating in support groups can positively affect patient outcomes in multiple areas for those who suffer from chronic illnesses.⁹ There are many different types of health-related support groups in the United States, varying in size, professionalism, meeting regularity, and form of interaction (face to face, over the phone, over video, and so on).^{3,6}

Support groups allow people the chance to learn by sharing experiences, problems, concerns, coping skills, and valuable information that can reduce the feeling of isolation or “otherness.”⁶ In 2002, Carol Smith and others¹⁰ conducted a study to determine how association with the Oley Foundation affected HPN consumers. They concluded that patients affiliated with this support organization had a higher quality of life, less reactive depression, and fewer encounters with catheter-related sepsis than patients who were not affiliated with the organization.

THE OLEY FOUNDATION: MISSION AND HISTORY

The Oley Foundation is a national, independent, not-for-profit organization located in Albany, New York.¹¹ It is one of several nonprofit organizations that offers support to

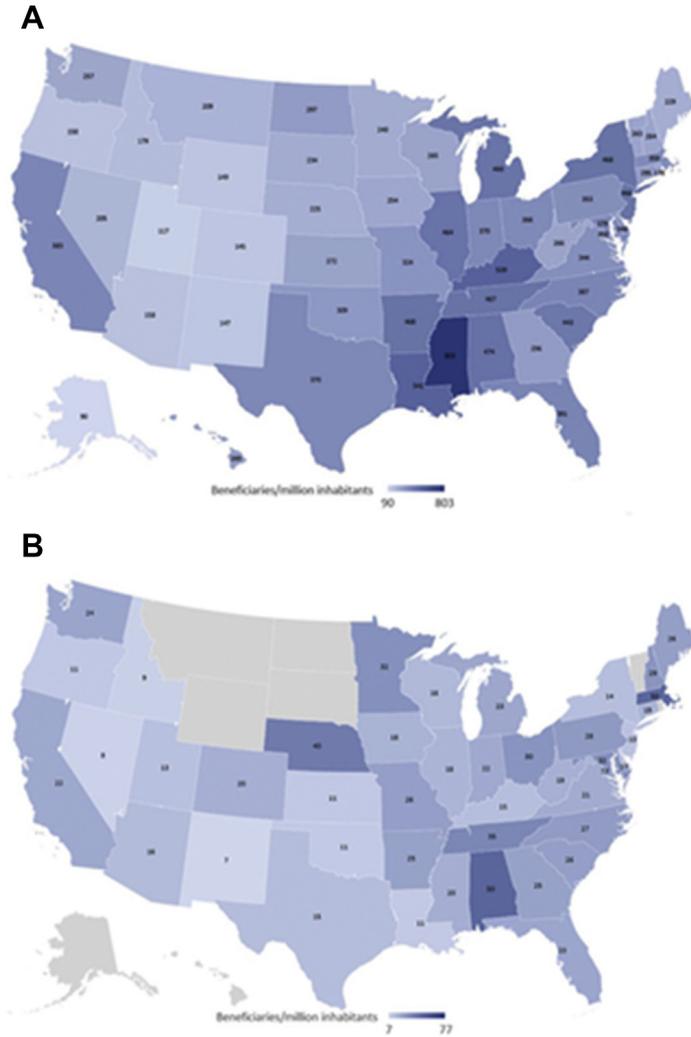


Fig. 2. Number of Medicare beneficiaries per million inhabitants per state for (A) HEN and (B) HPN. States in gray did not have information available. (From Mundi MS, Pattinson A, McMahon MT et al. Prevalence of home parenteral and enteral nutrition in the United States. *Nutrition in Clinical Practice* 2017 Dec;32(6):803; with permission.)

people with IF and/or on HPEN (see others listed later). The Oley Foundation was founded in 1983 by then Director of the Clinical Nutrition HPEN program at Albany Medical Center in Albany, New York, Dr Lyn Howard, and her long-time patient Clarence “Oley” Oldenburg, and the mission of the Oley Foundation is “to enrich the lives of those living on home intravenous nutrition and tube feeding through education, advocacy, and networking” (Dahl R, Oley Foundation FY 2018 and FY Q1 2019 reports, unpublished).⁶

In 1975, when he was 46 years old, Clarence suffered intestinal ischemia that cut off blood circulation to his intestines. He spent 5 years in the hospital, where he underwent several emergency surgeries and eventually lost most of his small intestine.

He started to get his life back in the early 1980s, when he was referred to Dr Howard at Albany Medical Center, who discharged him on HPN. Dr Howard arranged for her patients who were on HPN, including Clarence, to meet in both formal and informal settings, such as at clinic and at picnics. After realizing how Clarence's quality of life had improved on HPN, and how little was understood about this as an option for home use, his brother, Bill, provided the seed money to get the Oley Foundation started.¹²

Five years before the founding of the Oley Foundation, Lee Koonin, a new HPN user, and her husband, Marshall, started the Lifeline Foundation: a support group for HPN users in Sharon, Massachusetts, striving to reduce feelings of isolation and spread knowledge of the life-saving therapy. In 1977, when Lee was put on HPN, it was still an experimental therapy that was not being used in many hospitals. Lee felt very alone and became determined to connect with others in a similar position. Together, Lee and Marshall published a newsletter, organized picnics, and brought together a network of consumers who were willing to share their knowledge and experiences with other people on HPN. By 1984, the Lifeline Foundation had acquired about 600 members, and it had begun to put a strain on the Koonins in terms of both time and money. After confirming the commitment and dedication of the newly created Oley Foundation, Lee and Marshall put their Lifeline Foundation into the hands of the Oley Foundation staff, giving thanks to Clarence and Dr Howard.¹²

Today, the Oley Foundation continues to provide education, advocacy, and support to its now 21,975 members, made up of HPEN consumers, family members, clinicians, and members of industry.

THE OLEY FOUNDATION: A TYPICAL SUPPORT GROUP?

The Oley Foundation is often referred to as a support group, but it goes well above and beyond that label. In a study of the value of membership in the Oley Foundation to HPN- and/or HEN-dependent people, there arose 4 main themes that membership with Oley provided: competency, inspiration, normalcy, and advocacy⁵ (Fig. 3).

Competency

Consumers involved in the study stated that they felt more competent in managing their lives on HPEN when they received education and materials from Oley. Because the foundation is made up of consumers and clinicians, new members are able to receive information based on years of personal experience that their specialist or primary care physician may not be able to provide.⁵ One mother of an HPEN-dependent child attended an Oley conference and claims to have learned information that saved her son's life. After having his first central line placed at age 3 because of short bowel syndrome that resulted from an intestinal infarction, the woman explains how her son suffered from continuous fevers, a sign of infection, and was in and out of the hospital for 4 months.

In the midst of yet another hospitalization due to a bacterial line infection, this mother took the opportunity to attend the annual Oley conference, which happened to be going on locally. She gathered family and friends to attend and help her learn as much as possible:

"On the first day we split up to cover as many presentations as possible. Later we met in 'headquarters' upstairs in the hotel room, and everybody starts looking at each other saying, 'You know what? You can live on HPN. Our doctor and nurses said you die on HPN! They said he'd never eat. He can eat. You know what? We're not being sterile with the line, and you're not supposed to have a cap with lipid crud coming out the top.'"⁶

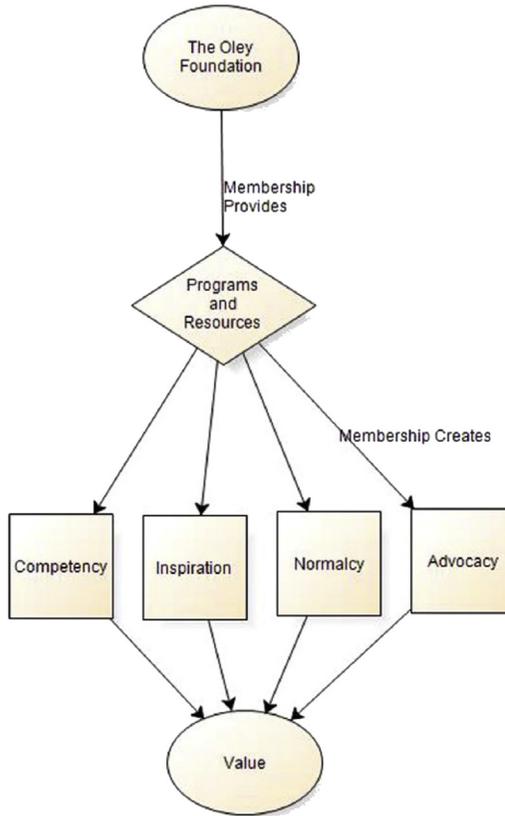


Fig. 3. A conceptual model of value of membership in the Oley Foundation. (From Chopy K, Winkler M, Schwartz-Barcott, D et al. A qualitative study of perceived value of membership in the Oley Foundation by home parenteral and enteral nutrition consumers. *Journal of Parenteral and Enteral Nutrition* 2015 May;39(4):431; with permission.)

Because of the information she received at the conference, this woman's son was not only able to survive, but thrive on HPN, going from spending 70 days of the first 7 months in the hospital, to a total of 7 in-patient days in 8 years. She concludes, "The Oley conference saved his life, there is no question."⁶

Inspiration

Both HPN- and HEN-dependent participants in this study felt a sense of inspiration from being connected to the members of Oley. They expressed that "seeing other people living their life" despite using these therapies was encouraging and helped them to accept their own need for HPN and/or HEN. After seeing images of children living their lives with feeding tubes, backpacks, and pumps, one man said, "[S]urely a grown man who was in the army could tackle it too."⁵

From listening to the stories of others, many participants who had previously viewed their dependence on HPN or HEN as life ending conceded that it was actually a means for people of all ages to "carry on a decent life as long as their disability allows."⁵

Normalcy

By being a part of Oley, consumers felt that they were a part of a community of HPN and HEN users, which significantly decreased feelings of isolation. Participants made

note of the strong support system, and the opportunity to see other people with similar conditions thriving in their everyday lives. Contrary to the common assumption, many people affiliated with Oley stated that they felt they could live a completely normal life with their feeding tubes and central lines.⁵

Advocacy

On the topic of advocacy, participants in this study made note of 2 distinct types: the Oley Foundation advocating for HPEN consumers and membership with Oley generating a desire to self-advocate. In regard to the former, participants reported feeling that Oley was there and standing up for consumers; regarding the latter, stories were told of consumers who took it upon themselves to lobby and write letters to congressional leaders, arguing for expanding health care coverage to include HPEN supplies and additives.⁵

OLEY PROGRAMS AND SERVICES

The Oley Foundation provides several valuable programs and services to its members.

Newsletter

Oley publishes 6 bimonthly newsletters a year that are received by approximately 17,000 HPEN consumers, home care providers, and health care professionals in a total of 49 countries. The newsletter, called the *LifelineLetter*, a homage to the Koonins' support group, is published both electronically and physically and includes a wide range of information for consumers. Articles are peer reviewed. Newsletter readers praise its connectivity and valued information. One HPEN consumer said "I LOVE, LOVE, LOVE getting the newsletter. It makes me feel connected, and not so alone!"¹³

Dr Darlene Kelly, Oley's Advisor for Science and Medicine, referring to 1 article published in the *LifelineLetter*, said, "[The article] gives pointers on how patient/consumers and others should critically read healthcare-related websites. It is important to consider the source by observing the address: if it ends in .org, it is a not-for-profit organization, while .gov comes from the government, .edu is from an education/academic institution, and .com is a commercial company. The HONcode, sponsored by the Health on the Network Foundation, is an additional assurance that the not-for-profit websites have continual oversight to assure that they provide trustworthy medical information."¹¹

I, myself, have gotten a lot of use out of the *LifelineLetter*, reading the stories of other HPEN consumers during times when I felt abnormal or uncomfortable with my condition. The newsletter certainly does provide a sense of connection and reassurance that you are not alone.

Conferences

At Oley national and regional conferences, HPEN consumers, their families, clinicians, Oley sponsors, and volunteers come together to share research and experiences. In a discussion about Oley, the executive director, Joan Bishop, said about the conferences, "There are education sessions, which are presented by well-known clinicians from the US, Canada, and on occasion from abroad. Breakout sessions give attendees an opportunity to ask questions and to learn more about specific topics. Exhibits introduce attendees to new technology and there are opportunities for networking among those who are on these therapies. Friendships develop, and many become lifelong."¹¹

In 2018 to 2019, regional conferences were held in Massachusetts, Ohio, Texas, California, Florida, and Nevada (Dahl R, Oley Foundation FY 2018 and FY Q1 2019 reports, unpublished).

Oley's 2019 annual national conference took place in Chicago, Illinois. It was a collaborative effort with the University of Illinois at Chicago, with exciting presentations and an opportunity for clinicians to earn continuing education credits. A recording of the presentations is available on Oley YouTube channel.

I (Julie) attended for the first time since I was a child. Meeting other HPEN consumers and networking with the faculty gave me a new outlook on my life as a consumer.

Webinars

This online source of education is provided free of charge to everyone. Recorded and later available on Oley's YouTube channel, the Webinars can be viewed by consumers, caregivers, family members, and clinicians in the comfort of their own home.¹⁰ The Webinars cover a wide range of topics, from new technology to coping strategies, and are presented by both clinicians and consumers alike.¹⁴

Oley Web Site and Information Clearinghouse

Oley responds to hundreds of queries from patients and family members each year, including direct requests for information about managing IF, clogged or leaking tubes, finding a nutrition support clinician, and much more. In fiscal year 2018 (October 1, 2017–September 31, 2018), they had 619,000 page views on the Oley Web site. Resources on the Web site (some also available in print) include complication charts for HEN and HPN (HPN currently under revision); a glossary; links to meet other patients and inspiring patient stories; tips for daily living, such as travel, swimming, bathing; links to other organizations and information sources (such as insurance resources and tips on writing appeal letters, Oley's travel and hospitalization packet); a clinician directory (yet to come); and much more.¹⁵

Learn Intestinal Failure Tele-ECHO

The Oley Foundation is on the advisory board of the newly launched (2019) Learn Intestinal Failure Tele-ECHO (*LIFT-ECHO*). *LIFT-ECHO* is a collaborative program that allows clinicians to present their patients' symptoms to a board of specialists, who then suggest to the clinician tests they could run and steps they could take during treatment. It allows clinicians to treat their patients locally, so the patient does not have to spend time and money traveling or uprooting to find a specialist. *LIFT-ECHO* holds virtual clinics twice monthly, where clinicians present cases related to IF (Dahl R, Oley Foundation FY 2018 and FY Q1 2019 reports, unpublished).

Awareness and Advocacy

Oley spreads their mission by exhibiting at and attending meetings nationwide, held by professional associations, home care companies, other not-for-profit organizations, and hospital programs. In 2019, Oley exhibited at the American Society for Parenteral and Enteral Nutrition (ASPEN) Science and Practice Conference in Phoenix, Arizona; the National Home Infusion Association conference in Orlando, Florida; the 6th International Pediatric Feeding Disorder Conference in Glendale, Arizona; the United Ostomy Associations of America conference in Philadelphia, Pennsylvania; the Association for Vascular Access conference in Las Vegas, Nevada; the Infusion Nurses Society conference in San Diego, California; and several ASPEN chapter meetings (Dahl R, Oley Foundation FY 2018 and FY Q1 2019 reports, unpublished).

Oley collaborates with multiple groups, such as the Digestive Disease National Coalition (DDNC), National Board of Nutrition Support Certification, Patients and Providers for Medical Nutrition Equity Coalition, and the Food and Drug Administration, to advocate on behalf of patients in need of nutritional supplements, like HPEN, and their families. With DDNC and other groups, Oley members and staff visit elected officials to represent Oley members' needs and circumstances and to put a face to HPEN therapy (Dahl R, Oley Foundation FY 2018 and FY Q1 2019 reports, unpublished).

Ambassadors

Oley Ambassadors are volunteers who have experience receiving or caring for a receiver of HPEN.¹⁶ One Oley member said about the Oley Ambassadors:

“When I needed support the most, Oley paired me with someone who would become a lifelong friend. My ambassador not only helped me stay sane while navigating the g-tube world and all its ups and downs, she instilled hope and courage in me when our other child ended up on TPN, suddenly. The positive ripples of the support Oley provided to me still resonate today. Friendships like these are one in a million. So is Oley!(Stacie P to Lisa Metzger, Personal communication, May 28, 2019)”

Online Forum

The Oley-Inspire Forum is an online resource that connects HPEN consumers with one another through instant messaging. Available through the Oley Web site (www.oley.org/Forum), the forum allows consumers and caregivers to ask and answer questions and give and receive advice in a wide range of topics, including “Family and friends,” “Home IV feeding,” “Home tube feeding,” and a “Spouses only” page. Clinicians are asked not to comment on posts, and consumers/caregivers are asked not to offer medical advice.¹⁷

Equipment and Supply Exchange Program

The cost of HEN can add up, even when insurance does cover it. In many instances, it is not covered, or the copays are significant. For this reason, Oley coordinates the exchange of new, nonprescription supplies (eg, syringes, feeding bags, extension tubing, and so on) from consumers who no longer need them to those who do, but may not be able to afford them under their insurance. The person receiving the supplies is responsible for paying for shipping, but the recipient incurs no other expenses associated with the program (Dahl R, Oley Foundation FY 2018 and FY Q1 2019 reports, unpublished).

FINDING RESOURCES

The organizations listed (including the Oley Foundation) represent a few of the many that offer programs and resources for people with IF. Professional and consumer groups are included here:

- Oley Foundation (www.oley.org)
- American Society for Parenteral and Enteral Nutrition (ASPEN) (www.nutritioncare.org)
- Association of Gastrointestinal Motility Disorders (AGMD) (www.agmdhope.org)
- AuSPEN (www.auspen.org.au)
- Caregiver Action Network (caregiveraction.org)
- Crohn's and Colitis Foundation (CCF) (www.crohnscolitisfoundation.org)
- European Society for Clinical Nutrition and Metabolism (www.ESPEN.org)

- Gastroparesis Patient Association for Cures and Treatment (G-PACT) (www.g-pact.org)
- Global Genes (www.globalgenes.org)
- International Alliance of Patient Organisations for Chronic Intestinal Failure and Home Artificial Nutrition (PACIFHAN) (pacifhan.org)
- International Foundation for Gastrointestinal Disorders (IFFGD) (www.iffgd.org)
- MitoAction (www.mitoaction.org)
- National Organization for Rare Disorders (NORD) (www.rarediseases.org)
- Parent to Parent USA (www.p2pusa.org)
- Parenteral Nutrition Down Under (PNDU) (pndu.org)
- PINNT (organization for HPEN consumers in the UK) (www.pinnt.org)
- United Ostomy Associations of America (www.ostomy.org)

(See www.oley.org/general/recommended_links.asp for the most up-to-date listing of Web sites that may be of interest to the HPEN community.)

SUMMARY

Understanding the psychosocial needs of HPEN consumers can be difficult for clinicians, which is why I (Julie) jumped at the opportunity to write this. As someone formerly on HPN and still on HEN, it is easier for me to explain and relay the value of being part of a support group, specifically the Oley Foundation, to others like me.

One could fill a book with all of the benefits the Oley Foundation provides to its members, as many people have testified. With the information provided, I will leave it up to the reader to decide: Is the Oley Foundation “just” a typical support group?

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