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LifelineLetter

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

ECHO Intestinal Failure Network:

Introducing an Innovative Model for Education and Patient Care

Marion Winkler, PhD, RD; Kelly Tappenden, PhD, RD; Kishore Iyer, MD

Intestinal failure (IF) is a rare, chronic, debilitating disease defined as the reduction of intestinal function below the minimum necessary for the absorption of nutrients and water. Management of IF often involves parenteral nutrition (PN), with the ability to provide IV nutrients, calories, vitamins, trace elements, and minerals to maintain health and/or support growth. Although considered a life-saving therapy, PN may be associated with life-threatening complications of liver disease or recurrent central line-associated bloodstream infections.

Intestinal rehabilitation programs offer multidisciplinary management of IF with the goal of restoring enteral autonomy and reducing the need for PN support, and, sometimes, liver and/or intestinal transplantation or referral for such transplant. Access to specialized intestinal care and expert PN management may be challenging for patients who do not live close to intestinal rehabilitation programs. Novel approaches to provide specialized care for IF are necessary. The Expanding Community Healthcare Outcomes (ECHO®) model may be an innovative way to expand and support such expertise.

Project ECHO

Project ECHO® is a movement started by Dr. Sanjeev Arora from University of New Mexico to improve the lives of people all over the world. Simply, ECHO aims to provide the “right knowledge at the right place and the right time.” The ECHO model has four key pillars:

1. move knowledge by using technology to leverage scarce resources
2. share best medical and health practices
3. apply case-based learning to master complex care
4. evaluate and monitor health-care outcomes

Dr. Kishore Iyer, Director of the Intestinal Rehabilitation and Transplant Program at Mount Sinai Hospital (New York, New York), is organizing the LIFT-ECHO (“Learn Intestinal Failure Tele-ECHO”). This intestinal failure ECHO is a collaboration among experts in nutrition, gastroenterology, surgery/transplant, patient advocacy, and insurers (see table 1); and the ECHO Institute (University of New Mexico, Albuquerque); with the American Society for

Parenteral and Enteral Nutrition (ASPEN) as a continuing medical education (CME) provider.

LIFT-ECHO aims to provide a virtual multidisciplinary “consult” service to physicians and other health-care providers who manage and care for IF patients. A virtual, multidisciplinary hub of experts will provide education and support to non-specialist clinicians caring for patients with IF, through case-based tele-learning in regularly scheduled tele-ECHO clinics.

Target “learners” will be nutritionists, nurses, pharmacists, physician assistants, primary care physicians, gastroenterologists, surgeons, and any other clinician having to care for a complicated IF patient, far removed

from a multidisciplinary specialty center.

Clinicians may present anonymous patient cases, covering a broad range of topics in IF, short bowel syndrome, dysmotility syndromes, PN, and so on, utilizing a structured template with moderated case discussions. A summary of recommendations by the experts will be provided to clinicians regarding the cases they present.

A separate but complementary research project is planned to evaluate patient-reported quality of life



ECHO trains non-specialists to provide specialty care services, so more people can get the care they need.



ACTION ITEMS

Consumers/Caregivers: Share the information about the LIFT-ECHO clinic with your clinicians and encourage their participation.

Clinicians: Share your difficult cases, and gain expertise and help while getting continuing medical education (CME) credits for free. Get your colleagues involved, too.

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among IF patients receiving standard of care at major specialty centers compared to patients receiving care from non-specialists participating in LIFT-ECHO clinics.

Role for the Patient/Consumer

Patients are not directly involved in the LIFT-ECHO clinic, because this is treated as a confidential, academic setting; however, Oley consumers are invited to share the information about the LIFT-ECHO clinic with their clinicians and encourage their participation. By participating, clinicians may receive expert consultation and continuing education that may benefit the clinicians themselves, but it will also benefit individual patient care. The establishment of a LIFT-ECHO network, based on the ECHO model of care to share “right knowledge at the right place and right time,” is expected to improve management of complex IF in the United States.

The anticipated launch date for LIFT-ECHO is May 1, 2019. Watch for more information on the Oley website. More information about the ECHO model is available at <https://echo.unm.edu>.

Table 1. ECHO Intestinal Failure Network Advisory Board

LIFT-ECHO's board reflects the collaboration among experts in nutrition, gastroenterology, surgery/transplant, patient advocacy, and insurers.

- Joan Bishop, The Oley Foundation, Albany, NY
- Anthony Bonagura, MD, Optum Health, Minneapolis, MN
- John K. DiBaise, MD, Mayo Clinic, Scottsdale, AZ
- David Gutierrez, Mount Sinai Medical Center, New York, NY
- Kishore Iyer, MD, Mount Sinai Medical Center, New York, NY
- Lisa Metzger, The Oley Foundation, Albany, NY
- Marjorie Nisenholtz, Mount Sinai Medical Center, NY
- Ron Potts, MD, Kaiser Permanente National Transplant Services, Portland, OR
- Douglas Seidner, MD, Vanderbilt University Medical Center, Nashville, TN
- Michelle Spangenburg, MS, RD, American Society for Parenteral and Enteral Nutrition, Silver Spring, MD
- Kelly A. Tappenden, PhD, RD, University of Illinois, Chicago, IL
- Marion Winkler, PhD, RD, Rhode Island Hospital/Brown University, Providence, RI



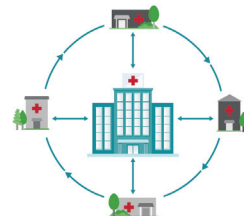
In the U.S. and around the world, people are not getting the care they need, when they need it, for complex but treatable conditions.

What is project ECHO?

Extension for Community Healthcare Outcomes

Moving Knowledge, Not Patients

Through technology-enabled collaborative learning, ECHO creates access to high-quality specialty care in local communities.



Hub and spoke knowledge-sharing networks create a learning loop:

Community providers learn from specialists.
Community providers learn from each other.
Specialists learn from community providers as best practices emerge.

Project ECHO (Extension for Community Healthcare Outcomes) is a movement to demonopolize knowledge and amplify local capacity to provide best practice care for underserved people all over the world.