



A.S.P.E.N.'s National Patient
Registry for Nutrition Care

Sustain Newsline

Volume 2, Issue 2

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Update on Sustain

Sustain™, A.S.P.E.N.'s national patient registry for nutrition care, continues to offer an unprecedented opportunity to help collect valuable data about consumers who are on home parenteral nutrition (HPN). Ultimately, the information entered into the Sustain registry will improve patient outcomes and help guide practice.

See what we have accomplished in less than 3 years!

- Over 1500 patients entered into the Sustain database
- 69 medical centers, hospitals, home infusion agencies enrolled
- 31 sites approved, trained, and entering data (active sites)
- 7 sites close to becoming active
- Provide benchmarking reports to active sites
- 6 publications on Sustain data

On February 15, 2014, Sustain rolled out an improved data collection process; these system changes were intended to:

- Reduce time users spent on data entry by reducing the number of data fields, and auto-populating significantly more fields
- Improve the quality of the Sustain data by adding "quality controls"

More specifically, the data collection forms were streamlined and the number of data fields have been reduced, more auto-population on follow-up forms, and more detail on the follow-up form. Additional quality controls were added to improve the quality of the data and

reduce user error with system checks. All sites were provided the opportunity to attend re-training sessions on the improved system. After close to six months, Sustain has received positive feedback from users who comment that these changes have improved their efficiency and have made it easier to complete follow-up data.

Make a Difference—Join Today!

So your institution still is not participating in Sustain. Why not? It just takes **four simple steps** to begin contributing valuable information out patients on Home PN.

1. Complete a short enrollment form and tell us about your institution.
2. Obtain IRB approval. No worries if your site does not have an IRB, we have you covered with our independent IRB.
3. Sign the Sustain Data Use and Participation Agreement.
4. Attend a web-based training session.



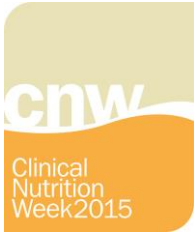
[Learn more about the approval process!](#)

Contact us if you have questions about Sustain!

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Clinical Nutrition Week 2015



Join us in sunny California! CNW, the premier scientific conference that will equip you with knowledge you can take back to your institution to implement necessary changes immediately. Your attendance will positively impact you, your patients, your fellow nutrition support team members, and your institution. While at CNW, we invite you to attend the Sustain Site Users session or attend a live demo to see just how simple Sustain is to use.

Long Beach, CA ~ February 14-17, 2014.

[Register now and save!](#)

HPN Awareness Week

The [Oley Foundation](#) has designated **August 3-9** as HPN Awareness Week. Help them spread the word that people can survive and live a full life at home with parenteral nutrition, and help create understanding for some of the challenges HPN consumers face.

Here is how you can [help promote HPN Awareness Week](#) in your community!

Scientific Research

Interested in conducting scientific analysis on the Sustain data? Sustain encourages widespread use of its data resources to address policy-related issues and to improve the care of people on home parenteral nutrition. To promote research in these areas, Sustain will soon release data sets that are available for public use.

What is included in Sustain's public-use data sets?

- Analysis-ready data sets that contain both cross-sectional and longitudinal data describing Sustain participants, their health profiles, and outcomes
- The first 2.5 years of data collection in the Sustain Registry

What other documentation is available to support use of Sustain's public-use data sets?

- A data dictionary that describes variables in the data sets
- A study binder that contains information about Sustain, including the Registry's rationale, operations, protocols, and regulatory considerations

What can Sustain's public-use data sets be used for?

- Hypothesis generation and hypothesis testing in the area of HPN
- Research training for students
- Manuscript preparation

[More information on accessing Sustain's data use sets.](#)

Sites Participating in Sustain™

Sustain™ is proud to announce that the following institutions have completed the approval process and are now official sites!

- Arnold Palmer Medical Center for Children
- CarePoint Partners – Dallas
- CarePoint Partners – Providence
- CarePoint Partners - Tampa
- Children's Hospital Boston
- Children's Hospital of Michigan
- Children's Hospital of Orange County (CHOC)
- Children's Mercy Hospital
- Cleveland Clinic
- Columbia University Medical Center
- Connecticut Children's Medical Center
- Cook Children's Medical Center
- Equinox Healthcare, Inc.
- Fairview Home Infusion
- Geisinger Medical Center
- Indiana University Health Home Care
- Intermountain Medical Center
- Le Bonheur Medical Center
- Nation's Home Infusion, LLC
- Nationwide Children's Hospital
- Pediatric Home Service
- Rady Children's Hospital
- Rhode Island Hospital & Hasbro Children's
- Riley Hospital for Children at IU Health
- Sharp HealthCare
- Spectrum Health
- The George Washington University Hospital
- Thrive-Rx
- Truman Medical Center
- University of Michigan, Mott Children's Hospital
- University of Pennsylvania

Keep the Feedback Coming

Your feedback is valuable information and is very much appreciated. Your insight was a key factor in improving the data collection process of Sustain. Thank you, thank you!



What People Are Saying about Sustain?

How will Sustain benefit the field of clinical nutrition and patient care?



Dr. Robinson: Data collection efforts for HPN patients in the US have been very limited over the last 20 years. Consequently, attempting to determine the long-term outcomes for these patients is very difficult.

It is hoped that Sustain will be able to fill this gap with useful knowledge about the HPN patient population so that many key questions can be answered. It is only with useful data that best practices can be determined and useful benchmarks can be established to provide the best possible care for these patients.

Larry Robinson, BS, MS, PharmD, Director, Strategic Support Services, MedCommunications, Inc., Memphis, TN, Sustain Executive Council Chair

How does your involvement in Sustain benefit your research?



Ms. Konrad: Sustain benefits our institution in so many ways. It provides us with important patient characteristic data, allows us to measure patient outcomes (e.g., CRBSI rates, hospital admissions), and creates quarterly reports that show cross-sectional and longitudinal data. Perhaps more

importantly, it allows us to evaluate how our institution and patients are doing compared to the rest of the country – and internationally, soon.

Denise Konrad, RD, LD, CNSC, Home Nutrition Support Clinician, Cleveland Clinic, Cleveland, OH and Sustain Site Coordinator

How does your involvement in Sustain benefit your research?



Ms. Bennett: Being involved in Sustain has brought more attention to our HPN patients from not only RDs but also GI physicians and homecare pharmacies. Although HPN patients make up a small percentage of our population, they are a high acuity patient population. Sustain is helping us learn more

about our HPN patients and improve the care we provide to them. For example, we are streamlining the transition for our HPN patients to/from inpatient/outpatient settings and improving communication so that PN orders are correctly transcribed. We are also in the final stages of developing a HPN clinic for our patients. Our HPN patients were routinely followed by only a GI Physician and have limited or no access to a Registered Dietitian, Case Manager, and other disciplines. The PN Clinic will provide a "home base" for our HPN patients and families and allow us to individualize care. We will also implement much needed patient care guidelines, such as routine care checking/monitoring of labs and provide education for line methods (our Sustain data indicated that our hospital admit rate for line infections was higher than other pediatric institutions).

Katherine Bennett RD, MPH, CLE, Clinical Dietitian III, CHOC, Children's Hospital, Orange County, CA, and Sustain Advisory Council member, and CHOC's Primary Sustain Investigator

Why should a new site consider joining Sustain?

Ms. Bennett: Three reasons:

- 1) Learn more about your HPN patients
- 2) Benchmark your institution with others, learn from others, teach others.
- 3) Provide even better care for your HPN patients!

Why should a new site consider joining Sustain?



Dr. Ross: HPN is a high cost therapy. Like many other areas of patient care, third party payers will begin to require providers to benchmark their care against standards. Sustain participants now have a benchmarking option for their care.

Vicki M. Ross, RN, PhD, CNSC, Nutrition Support Nurse Scientist, Truman Medical Center, Kansas City, MO, Sustain Advisory Council member and Sustain Site Coordinator

[LEARN MORE ABOUT WHAT ARE LEADERS AND SITE COORDINATORS ARE SAYING ABOUT SUSTAIN!](#)

Benchmarking Reports

Sustain reports, including cross-sectional and longitudinal information, provide insight to each site about its patient population, as well as benchmarking information about the site compared to the nation's aggregate data. Re-hospitalization, thrombosis and CLABSI rates are just a few of the interesting details the reports provide. Due to the transition to the new data collection process, benchmarking reports have been delayed for the recent quarter, but are expected to be delivered in August 2014.

Tell Us Your Sustain Story



Have a story to tell about your experiences with Sustain™? You could be featured in the next issue of *Sustain Newslines*.

New HPN Research

To keep current on HPN research, check out the latest!

HPN:

- [Fat Overload Syndrome After the Rapid Infusion of SMOFlipid Emulsion](#). *JPEN J Parenter Enteral Nutr*, 2014; 38(1): 119-121.
- [Identifying Patient-Centered Quality Indicators for the Care of Adult Home Parenteral Nutrition \(HPN\) Patients](#) *JPEN J Parenter Enteral Nutr* first published on July 26, 2013 as doi:10.1177/0148607113495891
- [Excessive Aluminum Accumulation in the Bones of Patients on Long-Term Parenteral Nutrition: Postmortem Analysis by Electrothermal Atomic Absorption Spectrometry](#) *JPEN J Parenter Enteral Nutr*. 2014; 38(6): 728-735.
- [Decreased Bone Turnover Markers in Children on Long-Term Parenteral Nutrition \(PN\) for Intestinal Failure \(IF\)](#) *JPEN J Parenter Enteral Nutr*, 0148607113500695, first published on August 23, 2013
- [Pediatric Intestinal Failure-Associated Liver Disease Is Reversed With 6 Months of Intravenous Fish Oil](#) *JPEN J Parenter Enteral Nutr*, 2014; 38(6):682-692.
- [A.S.P.E.N. Standards for Nutrition Support: Home and Alternate Site Care](#) *Nutr Clin Pract*, 2014; 29 (4):542-555.
- [Prevalence and Predictors of Vitamin D Deficiency and Response to Oral Supplementation in Patients Receiving Long-Term Home Parenteral Nutrition](#). *Nutr Clin Pract*, 0884533614539178, first published on July 18, 2014
- [How Hyperalimentation May Be Necessary to Reverse Severe Malnutrition in Selected Patients Receiving Home Parenteral Nutrition](#) *Nutr Clin Pract*, 2014; 29 (2):229-233.
- [Quality of Life Analysis During Transition From Stationary to Portable Infusion Pump in Home Parenteral Nutrition Patients: A Canadian Experience](#) *Nutr Clin Pract*, 2014;29(1):131-141.
- [Expert Beliefs Regarding Novel Lipid-Based Approaches to Pediatric Intestinal Failure-Associated Liver Disease](#) *JPEN J Parenter Enteral Nutr*, 2014; 38(6):702-710.
- [Outcome Indicators for Home Parenteral Nutrition \(HPN\) Care: Point of View From Adult Patients With Benign Disease](#) *JPEN J Parenter Enteral Nutr*, 0148607114536926, first published on June 10, 201
- [A Qualitative Study of the Perceived Value of Membership in The Oley Foundation by Home Parenteral and Enteral Nutrition Consumers](#) *JPEN J Parenter Enteral Nutr*, 0148607114527134, first published on March 17, 2014.
- [Vitamin D Deficiency in Children With Intestinal Failure Receiving Home Parenteral Nutrition](#) *JPEN J Parenter Enteral Nutr*, 0148607114527135, first published on March 14, 2014

Catheter Related Research:

- [Peripherally Inserted Central Catheter for Use in Home Parenteral Nutrition: A 4-Year Follow-up Study](#) *JPEN J Parenter Enteral Nutr* first published on November 13, 2013 as doi:10.1177/0148607113512508

- [Epidemiology and Risk Factors for Bloodstream Infections in a Home Parenteral Nutrition Program](#). *JPEN J Parenter Enteral Nutr* first published on September 26, 2013 as doi:10.1177/0148607113502361
- [Risk Factors for the Development of Catheter-Related Bloodstream Infections in Patients Receiving Home Parenteral Nutrition](#) *JPEN J Parenter Enteral Nutr* 2014; 38(6): 744-749
- [A.S.P.E.N. Clinical Guidelines: Support of Pediatric Patients With Intestinal Failure at Risk of Parenteral Nutrition-Associated Liver Disease](#) *JPEN J Parenter Enteral Nutr*, 2014; 38,(5):538-557.
- [Peripherally Inserted Central Catheter \(PICC\) Complications During Pregnancy](#) *JPEN J Parenter Enteral Nutr*, 2014;38 (5):595-601.
- [No Light at the End of the Tunneled Central Line](#) *JPEN J Parenter Enteral Nutr*, 2014;38(5): 534-537.
- [Prospective Cohort Study of the Outcome of and Risk Factors for Intravascular Catheter-Related Bloodstream Infections in Children With Intestinal Failure](#) *JPEN J Parenter Enteral Nutr*, 2014;38 (5):625-630

Short Bowel Syndrome:

- [Short Bowel Syndrome: Highlights of Patient Management, Quality of Life, and Survival](#) Darlene G. Kelly, Kelly A. Tappenden, and Marion F. Winkler *JPEN J Parenter Enteral Nutr*. 2014; 38(4): 427-437.
- [Overview of Short Bowel Syndrome: Clinical Features, Pathophysiology, Impact, and Management](#) *JPEN J Parenter Enteral Nutr*, 2014; 38(1) suppl: 5S-7S.
- [Spectrum of Short Bowel Syndrome in Adults: Intestinal Insufficiency to Intestinal Failure](#) *JPEN J Parenter Enteral Nutr*, 2014; 38, 1 suppl: 8S-13S
- [Intestinal Adaptation Following Resection](#) *JPEN J Parenter Enteral Nutr*, 2014; 38, 1 suppl: 23S-31S.
- [Clinical, Social, and Economic Impacts of Home Parenteral Nutrition Dependence in Short Bowel Syndrome](#) *JPEN J Parenter Enteral Nutr*, 2014; 38(1) suppl:32S-37S.
- [Pharmacologic Options for Intestinal Rehabilitation in Patients With Short Bowel Syndrome](#) *JPEN J Parenter Enteral Nutr*, 2014; 38(1) suppl: 45S-52S.
- [Short Bowel Syndrome in Adults: The Need for an Interdisciplinary Approach and Coordinated Care](#) *JPEN J Parenter Enteral Nutr*, 2014; 38, 1 suppl: 60S-64S.

PN Shortages:

- [Zinc Deficiency in a Parenteral Nutrition-Dependent Patient During a Parenteral Trace Element Product Shortage](#) *JPEN J Parenter Enteral Nutr*, 2014; 38(5): 637-639.
- [Selenium Deficiency in Pediatric Patients With Intestinal Failure as a Consequence of Drug Shortage](#) *JPEN J Parenter Enteral Nutr*, 2014; 38 (1): 115-11

Sustain™ Councils

Thank you to the Sustain Advisory Councils for your continued support, expertise, and guidance. Councils as of May 1, 2014.

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Funding Sustain™

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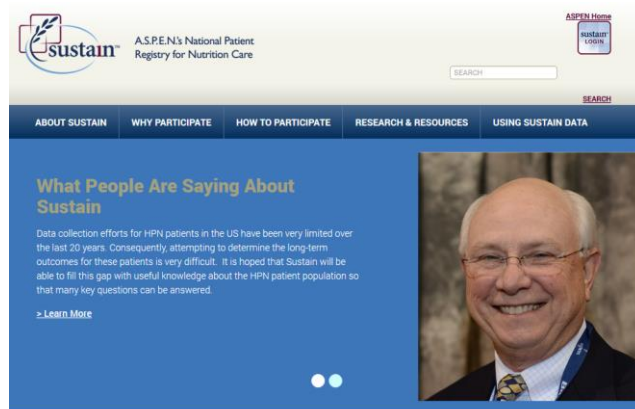
We are continually seeking additional sponsorship for this important project, so please contact Dr. Peggí Guenter at A.S.P.E.N. at peggig@nutritioncare.org if your organization would like to support Sustain™.

Sustain User Tips

While the improved data collection process has incorporated many new quality control measures to enhance the value of the data, we still need your help! Tips for site users to keep in mind:

- ✓ Enter baseline and follow-up forms in a timely manner.
- ✓ When entering follow-up forms, make sure to review and update the information that is automatically populated.
- ✓ Patients change over time, and these changes are important for Sustain. Please be sure to update all changes in a patient's profile each time you do a follow-up.
- ✓ Pay close attention to ensure patient discontinuation and restart information is being captured.
- ✓ The main outcomes for Sustain-hospitalizations, infections, and various morbidities will help us understand the relationship between HPN and these outcomes. Be sure to fill out the follow-up form so that all of this information is captured!
- ✓ Lock forms as soon as records are complete. To lock a form, enter your user password and select save.

Check Out Our New Look!



About Sustain

Sustain™, LLC: A.S.P.E.N.'s National Patient Registry for Nutrition Care is a comprehensive, web-based tool that allows clinicians to enter patient data, measure and analyze results, benchmark outcomes against the aggregate data, and publish findings. The purpose of Sustain is to maintain a prospective, longitudinal nutrition therapy patient registry in order to improve patient outcomes. In its initial phase, Sustain is collecting data on patients receiving home parenteral nutrition (HPN). Subsequent phases will allow expansion to other populations and therapies.

The A.S.P.E.N. and Sustain websites have fresh new appearance designed to make finding important information and resources easier for you!
www.nutritioncare.org/sustain