



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

Sustain Newsline

Volume 1, Issue 4

June 2013

Update on Sustain

Sustain™, A.S.P.E.N.'s national patient registry for nutrition care, continues to offer an unprecedented opportunity for organizations to help collect valuable data about consumers who are on home parenteral nutrition (HPN). The information entered into the registry will ultimately improve patient outcomes. So far, **60** medical centers, hospitals, and home infusion agencies have enrolled; **30** are approved, trained, and entering data, with more than **900** patients entered. We have dozens of other sites, including national home infusion companies with a large number of branches, that are interested in participating.

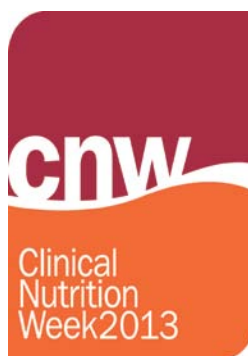
In April 2013, participating sites received a cross-sectional report along with their longitudinal report. The Sustain™ reports were distributed to all sites actively entering patient information. These sites gained valuable information about their patient population compared with the aggregate patient group. Information such as patient demographics, catheter infection rates, and re-hospitalization rates are just some of the comparisons made between sites and the aggregate group.

Sustain™ is now listed in the Agency for Healthcare Research and Quality's (AHRQ) ClinicalTrials.gov under the new program AHRQ's *Registry of Patient Registries*. The study is listed as the Sustain Home Parenteral Nutrition Registry and can be accessed through the new [Registry of Patient Registries website](#).

To learn more or to get your organization involved, please visit the [Sustain™ website](#).

Peggi Guenter, PhD, RN
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Affairs, A.S.P.E.N., peggig@aspen.nutr.org

Sustain Sessions at CNW13



Sustain™ educational and informational sessions were held at Clinical Nutrition Week 2013 in Phoenix, Arizona, and were a huge success. Not only were these sessions well attended, they generated lots of enthusiasm and interest in participating. On-site live demonstrations allowed attendees to see just how easy the online database is to use and familiarized people with the type of information that is being collected.

Prior to the users group's informational session, active Sustain™ users were surveyed by the Sustain™ administrators to gain insight and feedback on the Sustain™ registry and the reports they received. A majority of the active site users responded to the ten open-ended survey questions, and Mandy Corrigan, formerly with the Cleveland Clinic, shared the compiled feedback with attendees and Sustain™ Advisory Council members. Users' feedback will be incorporated in future modifications to the system. Suggestions included carrying over more data from baseline and follow-up forms to autopopulate in new follow-up visits whenever possible, and more clarification to the medication section was suggested.

During the educational session, "Home Parenteral Nutrition Patient Registries: An International Perspective", Dr. Ezra Steiger presented the U.S. demographics for HPN-dependent patients, as well as some patient outcomes. Dr. Marion Winkler presented the findings from the first year of Sustain Registry data at the Nutrition and Metabolism Research Paper Session. Access the audio and handouts from the [Sustain educational session at CNW13](#).

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.
- Geisinger Medical Center
- Indiana University Health Home Care
- Intermountain Medical Center
- Mayo Clinic - Jacksonville
- 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
- SwedishAmerican Hospital
- Texas Children's, Baylor College of Medicine
- Thrive-Rx
- University of Michigan, Mott Children's Hospital
- University of Pennsylvania
- University of Virginia Health System

User's Corner

In an effort to assist users and to have patient data entered more consistently, below is a highlight of several areas that should be reviewed by your team. **Help Screens**, located in the Registry, have been updated to provide additional clarification and information.

Central Line–Associated Bloodstream Infection (CLABSI)



For Sustain™, we are using Central line–associated bloodstream infection (CLABSI) as our central line infection definition. CLABSI is a primary BSI in a patient that had a central line within the 48-hour period before the development of the BSI

and is not related to a bloodstream infection at another site. However, since some BSIs are secondary to other sources other than the central line (e.g., pancreatitis, mucositis) that may not be easily recognized, the CLABSI surveillance definition may overestimate the true incidence of CRBSI. For example, CLABSI is a term used by CDC's National Healthcare Safety Network (NHSN). For more information and to view the reference for this definition, go to:

Guidelines for the Prevention of Intravascular Catheter-Related Infections, 2011. O'Grady N, et al. Centers for Disease Control and Prevention, U.S. Department of Health and Human Services.
<http://www.cdc.gov/hicpac/pdf/guidelines/bsi-guidelines-2011.pdf>.

Length of Hospital Stay

If patient is hospitalized for less than a week...

- Complete the Patient Hospitalized Follow-Up visit making sure to do the following...
- Enter the morbidity information under the Patient Hospitalized Follow-Up and complete as much information as possible on all forms.

If patient is hospitalized for a week or more...

- Complete the Patient Hospitalized Follow-Up visit making sure to do the following...
- Enter a **discontinue date** under the Current PN Section of the Patient Hospitalized Follow-Up because the patient is no longer receiving the PN at **home**.
- Enter as much information as possible, including in the morbidity section.
- Once the patient is discharged home, you must enter a **PN Restart Follow-Up and update the Date Began HPN on the Patient Information Section with the new restart date.**

Patient Discontinues Therapy

Current PN Formula

If a patient discontinues therapy for more than a few days, please select the follow-up form type – **Patient Discontinues PN Therapy**.

- Make sure to enter date of discontinuation and reason for the discontinuation on the Current PN Formula section.
- Add information in the Food and Diet section, such as type of diet and percent of calories. Please also add patient's height and current weight in the Current Nutritional Status section.
- Then, if the patient is put back on HPN at a later date, a follow-up visit – Follow Up **Patient Restart** needs to be entered. Please go into the Patient Information Form within the Follow-Up Patient Restart and **update the date HPN began with the restart date.**

Medications – Multiple Usages

If a drug has multiple effects (e.g., erythromycin can be a prokinetic and an anti-infective) indicate the drug in the category that it is being used to treat the patient.

Sustain Resources

[Sustain Publication Guidelines](#)

[Sustain Registry Scientific Query Protocol](#)

[Sustain Help Screens](#)

New HPN Research

In order to keep you current on HPN research, this newsletter section will provide citations on the latest selected research in A.S.P.E.N. journals.




HPN:

- [Vitamin Serum Level Variations Between Cycles of Intermittent Parenteral Nutrition in Adult Patients With Short Bowel Syndrome.](#) Iahel Manon de Lima Ferreira, Camila Bitu Moreno Braga, Nathalie de Lourdes Souza Dewulf, Julio Sérgio Marchini, and Selma Freire de Carvalho da Cunha *JPEN J Parenter Enteral Nutr.* January 2013; vol. 37, 1: pp. 75-80.
- [Anemia and Leukopenia in a Long-Term Parenteral Nutrition Patient During a Shortage of Parenteral Trace Element Products in the United States.](#) Pornpoj Pramyothin, Dong Wook Kim, Lorraine S. Young, Sanit Wichansawakun, Caroline M. Apovian *JPEN J Parenter Enteral Nutr* May 2013; vol. 37, 3: pp. 425-429.
- [Reversal of Parenteral Nutrition-Associated Liver Disease With a Fish Oil-Based Lipid Emulsion \(Omegaven\) in an Adult Dependent on Home Parenteral Nutrition](#) David L. Burns and Brian M. Gill *JPEN J Parenter Enteral Nutr* March 2013; vol. 37, 2: pp. 274-280.
- [Fat Overload Syndrome After the Rapid Infusion of SMOFlipid Emulsion.](#) Iva Hojsak and Sanja Kolaček *JPEN J Parenter Enteral Nutr*, 0148607113482001, first published on March 21, 2013.
- [The Association Between Home Parenteral Nutrition and Patients With FAP-Associated Intra-abdominal Desmoids: A Retrospective Study.](#) Abdullah Shatnawei, Monica Habib, et al. *JPEN J Parenter Enteral Nutr*, 0148607112471860, first published on January 14, 2013.
- [Identification and Early Treatment of Dehydration in Home Parenteral Nutrition and Home Intravenous Fluid Patients Prevents Hospital Admissions](#) Denise Konrad, Mandy L. Corrigan, et al. *Nutr Clin Pract*, December 2012; vol. 27, 6: pp. 802-807.

HPN Registries:

- [Prescription of Trace Elements in Adults on Home Parenteral Nutrition: Current Practice Based on the Canadian Home Parenteral Nutrition Registry](#) R. Abdalian, G. Fernandes, D. Duerksen, K. N. Jeejeebhoy, S. Whittaker, L. Gramlich, and J. P. Allard *JPEN J Parenter Enteral Nutr* May 2013; vol. 37, 3: pp. 410-415

Catheter-Related Research:

- [Hospital Readmissions for Catheter-Related Bloodstream Infection and Use of Ethanol Lock Therapy: Comparison of Patients Receiving Parenteral Nutrition or Intravenous Fluids in the Home vs a Skilled Nursing Facility](#) Mandy L. Corrigan, Cassandra Pogatschnik, Denise Konrad, and Donald F. Kirby *JPEN J Parenter Enteral Nutr* January 2013 vol. 37 no. 1 81-84.
- [Role of Peripherally Inserted Central Catheters in Home Parenteral Nutrition: A 5-Year Prospective Study](#) Jose I. Botella-Carretero, Carmen Carrero, Eva Guerra, Beatriz Valbuena, Francisco Arrieta, Alfonso Calañas, Isabel Zamarrón, Jose A. Balsa, and Clotilde Vázquez *JPEN J Parenter Enteral Nutr* 0148607112457422, first published on August 16, 2012 as doi:10.1177/0148607112457422 [Full Text \(PDF\)](#) 
- [Catheter-Related Complications in Cancer Patients on Home Parenteral Nutrition: A Prospective Study of Over 51,000 Catheter Days.](#) Paolo Cotogni, Mauro Pittiruti, Cristina Barbero, Taira Monge, Augusta Palmo, and Daniela Boggio Bertinet *JPEN J Parenter Enteral Nutr* May 2013 vol. 37 no. 3 375-383.

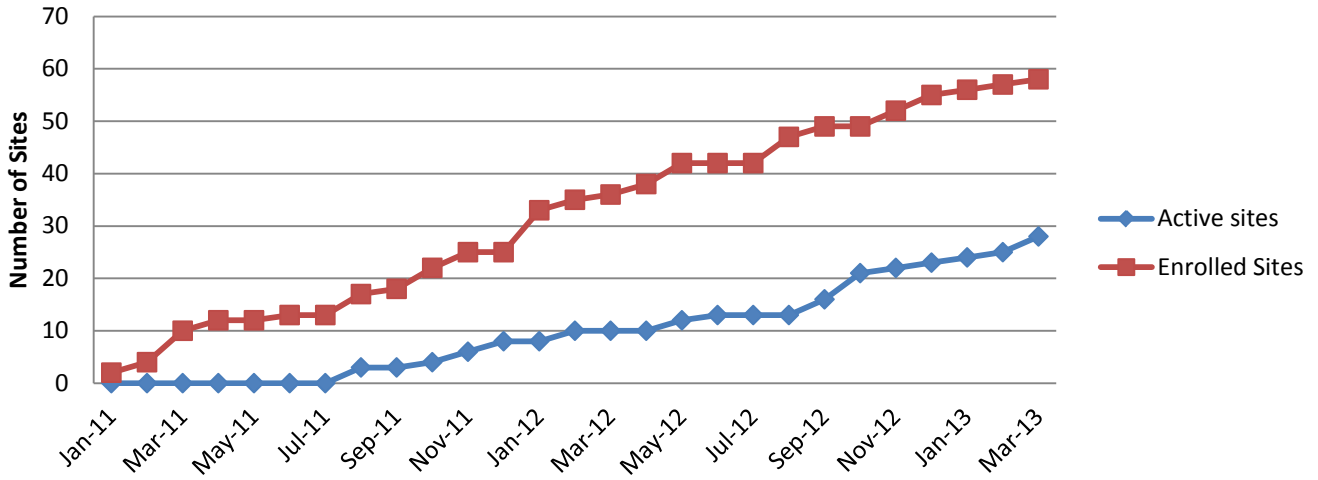


"This registry will be transformative for our Society. Sustain will allow A.S.P.E.N. to become an outcomes research- generating association."

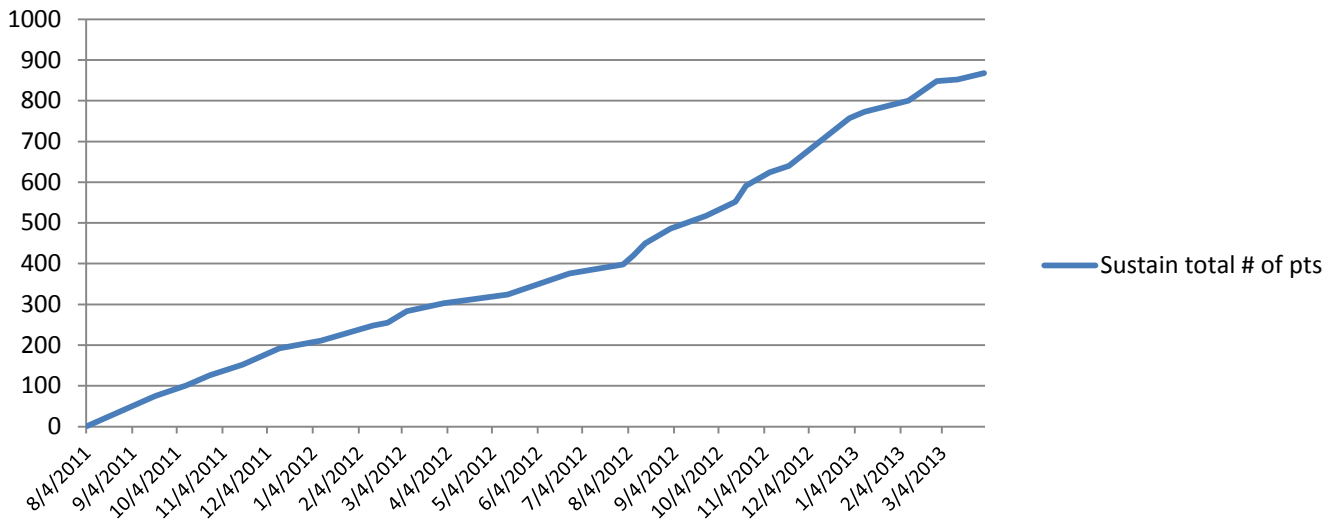
Tom Jaksic, MD, Ph.D

Growth of Sustain

Number of Active Sites and Enrolled Sites



Sustain Total Number of Patients



ENROLLMENT AND APPROVAL TIPS:

Participation in Sustain™ is easy! Follow these simple steps:

Steps to Become an Official Site:

1. **Enroll:** Complete and submit the [enrollment form](#).
2. **Obtain approval to participate from your IRB.** Submit the IRB protocol and informed consent or waiver of informed consent to your IRB. Once you receive IRB approval, please send us a copy of your approval letter.
 - Participation Agreement ([pdf](#)) ([word](#))
 - IRB Protocol ([pdf](#)) ([word](#))
 - Patient Informed Consent ([pdf](#)) ([word](#))
 - Waiver of Informed Consent ([pdf](#)) ([word](#))

Blank Data Collection Forms can be used in conjunction with the IRB submission.

- Baseline ([adult-.pdf](#)) ([pediatric-.pdf](#))
- Follow-up ([adult-.pdf](#)) ([pediatric-.pdf](#))

3. **Complete and submit your Participation Agreement**
 - Participation Agreement ([pdf](#)) ([word](#))
4. **Send all forms to:** Katy Hanley, Sustain Registry Coordinator, A.S.P.E.N., 8630 Fenton St., Suite 412, Silver Spring, MD 20910 katyh@aspen.nutr.org

Watch the Sustain Demonstration



Just 4 minutes long. See how user-friendly the system is!

Feedback and Suggestions



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

Sustain™ Councils

Thank you to the Sustain Advisory Councils for your continued support, expertise, and guidance. Councils as of May 1, 2013.

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Funding Sustain™

A.S.P.E.N. would like to express our sincere thanks to the following organizations for their support of Sustain™.



We are continually seeking additional sponsorship for this important project, so please contact Cheretta Clerkley at A.S.P.E.N. at cherettac@aspen.nutr.org if your organization would like to support Sustain™.

SUSTAIN QUESTIONS AND ANSWERS

Do we have to obtain IRB approval, or is this optional/only needed if our organization requires it? If there is an Institutional Review Board (IRB) at your organization, you must get approval from them to participate. However, if you do not have an IRB, your organization would be covered by our independent IRB.

Our organization does not have an IRB. Can we still participate in Sustain? Yes. For organizations that do not have an IRB, Sustain™ has been approved by an Independent Review Board and your organization can use this IRB approval.

Who will have access to the data? Site participants will have access to the data through system-generated reports. The site and all data will be protected through a secure password-protected system. Site participants will receive benchmarking reports to compare their own results against aggregate results of all sites participating in the program.

How is confidentiality maintained? Patient information is de-identified. The site will keep a log of patient names, dates of birth, and Sustain™ patient number assigned by the database either locked in an office or password protected. Sustain™ only tracks patients by the patient number assigned by the system.

What are the registry requirements? Do we need to purchase any special software? Sustain is web-based. Users only need to have access to an Internet connection and a current browser (Internet Explorer 7, Firefox, or Safari). No additional software is necessary. A password-protected system is accessible online and data stored by Sustain™ will be on a secure Web server with access limited to those with a user ID and password.

Is there a target accrual goal for the Sustain registry? Our goal is to capture data on 100% of the HPN population; however, there is no current data that exists documenting the number of HPN patients.

Applying to your IRB, but having difficulty? What should I do? Reach out to the Sustain™ Registry Coordinator with your questions. Also, Sustain™ can match you up with another site that has successfully gone through the IRB approval process and can provide their mentoring and insight.

What type of training is available to new site users? All new site users go through a training session via an online meeting format with the Sustain Registry Coordinator. Help screens within the registry and a training video are also available to supplement the training process. Training is scheduled once the site has completed the approval process.

What type of information does my site receive on our patients? Sustain™ provides quarterly cross-sectional and longitudinal reports to all sites actively entering patient data. This information compares your site to the whole aggregate of patients as a group and can be used for benchmarking purposes. Sites do not have access to other site's patient information or report information. Patient demographics, nutrition, medications, catheter infection rates,

thrombosis/occlusion rates, and death rates are just some of the information in the site reports. Your site's data is available if you would like to do further analysis.

Can the system detect duplicate patients? Yes, the system cross checks four critical fields for all patients. If two or more of these fields match, the system generates a possible duplication notice to the Sustain Registry Coordinator who contacts the appropriate site users.

If a patient starts their therapy at home, what should be entered for the Discharging Institution field on the Patient Information Form? If a patient starts their therapy at home, you can enter "Home Start" in the Discharging Institution field.

What should be done if a patient is no longer under the care of your institution? If a patient is no longer under your institution's care (i.e., patient transfer care), you should enter a No Follow-up Needed Follow-up.

When a patient is hospitalized for more than a week, do I complete a Patient Discontinuation Follow-Up? While it is very important to capture the discontinuation information, it is not necessary to complete the Patient Discontinues Therapy Follow-Up. However, please enter a Patient Hospitalization Follow-Up, and make sure to capture the PN discontinuation data on the Current PN Formula form and answer as many critical fields as possible on all forms. When discharged, add a PN Restart Follow-Up, making sure to change the date Home PN began to the restart date, which is on the Patient Information Form. Please see the graphic below on the restart date. See the PN Restart Follow-Up below.

The screenshot shows the 'Followup Patient Information (00010003)' form. At the top, it says 'This record is locked. As part of the administration group, you can unlock the record.' Below this is a 'Patient Information' section with a note: 'Note: ● indicates a critical field'. The form contains several fields, each with a red circle icon indicating it is a critical field. The fields and their values are: Followup Date (11/24/2012), Patient Number (00010003), Attending Physician's Name (Dr. Test), Discharging Institution Name (Test Hospital), PN Home Infusion Care Provider Name (NEW CENTER), Patient Birth Date (11/27/2006), Gender (Male), Date began Home PN (11/24/2012), and Who does patient live with? (please select). There is also an 'Insurance Coverage' section with checkboxes for Private Insurance (checked), Medicare, Medicaid, Personal Payment, Medicare Supplement, and Other. A callout box with a red border and the text 'Enter the new restart date here!' has an arrow pointing to the 'Date began Home PN' field.

[Complete List of Frequently Asked Questions](#)