



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

Sustain Newsline

Volume 2, Issue 1

January 2014

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. So far, **63** medical centers, hospitals, and home infusion agencies have enrolled; **29** of these are approved, trained, and entering data, with more than **1184** patients entered. We have dozens of other sites, including national home infusion companies with a large number of branches, that are interested in participating.

Participating sites received their Sustain Quarterly Report in November, 2013. Each quarter, cross-sectional, cumulative, and longitudinal reports provide insight to each site about its patient population as well as benchmarking information about the site compared to the aggregate. Re-hospitalization, thrombosis and CLABSI rates are just a few of the interesting details the reports provide.

In addition to the quarterly reports, Sustain will provide more in depth reports twice a year. These will include detailed statistical analyses. It is anticipated that the first of these reports will be available in March, 2014.

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

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Sustain Sessions at CNW14

Join us at Clinical Nutrition Week 2014 (CNW14) in Savannah and participate in the following events to learn more about Sustain!

Focused Learning Session: Sustain Sunday, January 19, 4:30 – 6:00 pm.

Speakers Katy Hanley, A.S.P.E.N.'s Sustain Registry Coordinator, and Betty Hagen, RN, CNSC from Rhode Island Hospital will discuss the how to get involved with Sustain, the benefits of becoming a participating site, and the upcoming changes to the registry.

Sustain Users and Prospective Users Session Monday, January 20, 9:30 – 10:30 am.

Sustain representatives will speak about new Sustain developments, results of the first two years of the data collection, and answer your questions.

Live Demo Sessions:

A demonstration area, located near registration in the River Concourse, will provide a hands-on opportunity to try out the Sustain database system.

Have questions related to patients or entering data? Stop by the Sustain demo area so we can personally answer your questions.

Sunday, January 19
9:45 - 10:15 am
12:30 - 1:30 pm

Monday, January 20
3:30 - 4:30 pm

Tuesday, January 21
7:00 – 8:00 am



January 18-21
Savannah, GA

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
- 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
- University of Michigan, Mott Children's Hospital
- University of Pennsylvania

Not an Official Sustain Site?



You Spoke, We Listened!

In response to feedback received from you, our participating and potential sites, the data collection forms have been streamlined, with February 15, 2014 as the anticipated roll out date. These changes include a reduction in the number of fields, various clarifications, auto-population, more detail on the follow-up form, and built-in pop-ups to answer common questions.

What does this mean to for the users?

YOU SAVE TIME! The data collection forms will reduce the amount of time spent on data entry. All sites will receive training on the new data collection forms in the upcoming months.

Highlighted Changes:

- Psychosocial and Functional Status sections have been removed from both baseline and follow-up forms.
- We will have just one follow-up form type, instead of the multiple types currently in use.
- The Baseline Form has been consolidated so you only have to sign off and save one time!
- The Follow-up Form has been consolidated, so only have to sign off and save one time!
- Considerably more fields will auto-populate on the follow-up form.
- More user-friendly forms.

What you need to do?

- CHECK WITH YOUR IRB!
- These changes may require sites to file an amendment with their institutional review board (IRB). While it is anticipated February 15, 2014 is the approximate switch over date, it is encouraged that sites contact their IRB as soon as possible to prevent any disruption in data collection.
- Submit these revised data collection forms to your IRB
[Revised Baseline Data Collection Sheet](#)
[Revised Follow-Up Data Collection Sheet](#)

THANK YOU!

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

Keep the feedback coming!



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:

- [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*, September 2013 37: 683-688
- [Effects of Manganese From a Commercial Multi-Trace Element Supplement in a Population Sample of Canadian Patients on Long-Term Parenteral Nutrition](#). R. Abdalian, O. Saqui, G. Fernandes, and J. P. Allard *JPEN J Parenter Enteral Nutr* July 2013 37: 538-543.
- [Identifying Patient-Centered Quality Indicators for the Care of Adult Home Parenteral Nutrition \(HPN\) Patients](#) Mira Dreesen, Veerle Foulon, Kris Vanhaecht, Lutgart De Pourcq, Martin Hiele, and Ludo Willems *JPEN J Parenter Enteral Nutr* 0148607113495891, 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](#) Pamela C. Kruger, Patrick J. Parsons, Aubrey L. Galusha, Michelle Morrissette, Robert R. Recker, and Lyn J. Howard *JPEN J Parenter Enteral Nutr* 0148607113491981, first published on June 13, 2013 as doi:10.1177/0148607113491981

Catheter-Related Research:

- [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* July 2013 37: 538-543.
- [Peripherally Inserted Central Catheter for Use in Home Parenteral Nutrition: A 4-Year Follow-up Study](#) Line Dahlstrøm Christensen, Henrik Højgaard Rasmussen, and Lars Vinter-Jensen *JPEN J Parenter Enteral Nutr* 0148607113512508, first published on November 13, 2013 as doi:10.1177/0148607113512508
- [Epidemiology and Risk Factors for Bloodstream Infections in a Home Parenteral Nutrition Program](#). Sam Elfassy, Zain Kassam, Faizan Amin, Khurram J. Khan, Shariq Haider, and David Armstrong *JPEN J Parenter Enteral Nutr* 0148607113502361, 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](#) Alan L. Buchman, Marianne Opilla, Mary Kwasny, Thomas G. Diamantidis, and Rodney Okamoto *JPEN J Parenter Enteral Nutr* 0148607113491783, first published on June 6, 2013 as doi:10.1177/0148607113491783

Short Bowel Syndrome Review:

- [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* 0148607113512678, first published on November 18, 2013 as doi:10.1177/0148607113512678

Personnel Changes



When personnel changes occur at your site, please notify [Katy Hanley](#) of your Sustain user changes. Immediate notification is imperative when employees are no longer employed by your

Institution, or are no longer involved with Sustain. Since the Sustain Registry is a web-based database, these users must be deleted from the system as soon as possible, so they no longer have access to your patient data.

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.

- Current Baseline ([adult-.pdf](#)) ([pediatric-.pdf](#))
- Current Follow-up ([adult-.pdf](#)) ([pediatric-.pdf](#))
- February 2014 Baseline ([pdf](#))
- February 2014 Follow-up ([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@nutritioncare.org

Watch the Sustain Demonstration



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

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 Newsline*.

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 Dr. Peggi Guenter at A.S.P.E.N. at peggig@nutritioncare.org if your organization would like to support Sustain™.

SUSTAIN QUESTIONS AND ANSWERS

For the field “Patient Type”, what do the fields “New PN Patient” or “Existing PN Patient” really mean?

“New PN Patient” is a patient who began Home PN no more than 90 days prior to being enrolled in the registry (Baseline Date). An “Existing PN Patient” is one who began Home PN more than 90 days prior to being enrolled in the registry (Baseline Date)

Is there an age limit for the registry?

No. Patients of all ages can be enrolled in the registry.

What happens if another participating site is entering patient data for the same patient?

Even when two or more participating sites are treating the same patient, only one site can enter patient data for the patient. However, if you would like to see those patients that you treat but for whom you don't enter data, you may be able to have these patients included in your aggregated site data in your quarterly reports. By reaching an agreement with the site that is entering the patient data, your reports could reflect your entire patient population. Contact [Katy Hanley](#) for more details.

Can the system detect duplicate patients?

Yes, the system cross-checks three 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 is hospitalized and discontinues their Home PN while they are in the hospital, should two follow-up forms be completed? Which follow-up forms should be completed?

No, it is only necessary to complete one follow-up form. Please complete the Patient Hospitalized Follow-Up form. In the Current PN section of this follow-up, the Home PN discontinuation information can be captured. Just remember to enter a Restart Follow-Up form if the patient goes back on Home PN.

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, 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.

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.

When trying to enter another follow-up visit for a patient who was previously hospitalized, an error message occurs saying a PN Restart needs to be entered; however, a PN Restart had already been entered, why am I getting this error message?

Make sure when adding the PN Restart visit, to update the

field “Date began Home PN” with the most recent date that Home PN began (restart date) on the Patient Information Form. If this form has been locked, please contact Katy Hanley so she can unlock the form so the field can be updated.

sustain™ A.S.P.E.N.'s National Pa

[Help with this page](#) | [Spellcheck this page](#)

Followup Patient Information (00010003)

This record is locked. As part of the administration group, you can unlock the record.

Patient Information

Note: ● indicates a critical field

● Followup Date 11/24/2012

Patient Number (As designated by study) 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

Who does patient live with? (please select)

● Insurance Coverage (check all that apply)

- Private Insurance
- Medicare
- Medicaid
- Personal Payment
- Medicare Supplement
- Other

What type of information does my site receive on our patients?

Sustain™ quarterly cross-sectional and longitudinal reports compare 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 sites' 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.

TIPS FOR IMPROVING DATA

Here is how **YOU** can help improve the quality of the Sustain data.

- Use correct units of measure for height, weight, length fields.
- When a patient restarts Home PN, complete a Restart Follow-Up form and remember to update the field “Date began home PN” on the Patient Information Form with the new restart date.
- For the field, “Who Does the Patient Live With”, remember if you select “Alone”, this can be your only choice. Multiple selections are not permitted when “Alone” is selected for this field.

QUALITY DATA = QUALITY REPORTS 

