



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

Sustain Newsline

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Update on Sustain

Sustain™ continues to offer an unprecedented opportunity for organizations to help collect valuable data about consumers who are on HPN. The information entered into the registry will ultimately improve patient outcomes. Thus far, **43** medical centers, hospitals, and home infusion agencies have enrolled; 13 are approved, trained and entering data, with more than **375** patients entered thus far in just 10 months. We have dozens of other sites including national home infusion companies with a large number of branches that are interested in participating.

In April 2012, the first Sustain reports were distributed to all sites actively entering patient information. These sites gained valuable information about their patient population compared to the aggregate patient group.

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

Peggi Guenter, PhD, RN
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Sustain Announces Sites Participating in Sustain

We would like to thank all of our active sites for their participation in Sustain.

- Children's Hospital of Boston
- Children's Hospital of Michigan
- Cleveland Clinic
- Equinox Healthcare, Inc.
- Mayo Clinic - Jacksonville
- Pediatric Home Service
- Sharp Home Infusion
- Spectrum Health – Butterworth
- Swedish American Hospital
- Texas Children's Hospital
- Thrive Rx
- University of Michigan
- University of Pennsylvania

[Watch the Sustain Demonstration](#)

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

Success at CNW



Sustain education and informational sessions held at Clinical Nutrition Week 2012 in Orlando, Florida, were a huge success. Not only were these sessions well attended, but generated lots of enthusiasm and interest in participating. As a result, eight new sites enrolled in

Sustain at CNW12. On-site live demonstrations allowed attendees to see the type of information that is being collected.

During the Users Group Informational session, Mandy Corrigan from Cleveland Clinic and Dr. Beth Carter from Texas Children's, Baylor College of Medicine, spoke about their organization's experiences with Sustain. Mandy emphasized the importance of participation and how easy the registry is to use. "The Sustain data collection sheets from the website with orange bullets helped us prioritize which data to collect and enter. We adapted these data sheets from the website into our existing form."

Dr. Carter spoke about the ease of enrolling to become a participating site, and how Sustain will help improve outcomes across the nation.

Mandy Corrigan, featured in above photo with Dr. Larry Robinson, was awarded the 2012 Sustain Distinguished Service Award for her overwhelming dedication and efforts with Sustain.

During the [CNW12 Educational Session, Sustain: The Why, The How and The Data](#), Erza Steiger, Alan Parver, Peggi Guenter and Marion Winkler spoke on the value of Sustain.

Alan Parver interpreted the public policy factors that are influenced by registry data, while emphasizing that the health care industry is moving towards evidence based medicine to improve quality of care. The Sustain data will be useful, and probably necessary, in integrated care systems and similar health delivery models.

Peggi Guenter described the development and logistics of Sustain, by explaining what a registry is and the type of data that is being collected. She gave several examples of the information that is being captured and what questions will be asked, such as, what percentage of patients on HPN have cancer and what is the catheter infection rate for patients with short bowel syndrome?

Marion Winkler evaluated the data presented from the Sustain registry and explained the different type of Sustain reports; cross-sectional and longitudinal reports that active sites will receive. These reports give us valuable insight in to the HPN population.

JPEN Paper on Sustain

Look for the **Sustain** development article now out in the July 2012 issue of the *Journal of Parenteral and Enteral Nutrition (JPEN)*, which was written by members of the original Sustain Task Force. [Development of Sustain™: A.S.P.E.N.'s National Patient Registry for Nutrition Care](#) *JPEN J Parenter Enteral Nutr* 2012;36 399-406.



User's Corner

A big thanks to all our Sustain Users for their data contributions and helping us make a difference!

In August 2012, the Sustain reports will be distributed to all sites actively entering patient data. Please remember to close and lock all your patient forms by July 12th so that all your patient data and hard work can be captured in your quarterly report.

JUST A FEW TIPS:

- *Be sure to complete, sign, and close your baseline and follow-up forms within one month of starting a patient record.*
- *Complete as many critical elements as possible including the insurance information on the data collection forms.*
- *Go to the user manual or training videos for further questions or just send us an email or call if you need an answer. Sustain@aspen.nutr.org*

FOLLOW-UP GUIDELINES:


Use these Follow-up Guidelines for entering your patients' follow-up visits; however, if there is a significant event, such as hospitalization or PN Restart, please document that as well.

FOLLOW-UP INTERVAL GUIDELINES

Type of Patient	Suggested Intervals	At a Minimum
New Patient - On HPN for the first time	Monthly	Quarterly
Existing Patient - has been receiving HPN	Quarterly	Semi-annually

Insurance Coverage – Critical

The field, *Insurance Coverage*, in the Patient Information Form is now a critical field in our data collection. Help us capture this important information by selecting the insurance coverage as you enter your patients into the registry.

 Insurance Coverage (check all that apply)

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

No Time To Enter Patient Info?



We know that your time is precious....Here are some creative ways to deal with entering patient information when staff time is limited.

Some sites have printed out the data collection forms, completed the paper forms and then enlist the help of clerical staff to do the data entry.

Some sites have tapped into other resources to help enter the patient data, such as:

- *Medical Students*
- *Fellows*
- *Pharmacy Students*
- *Dietetic Interns*

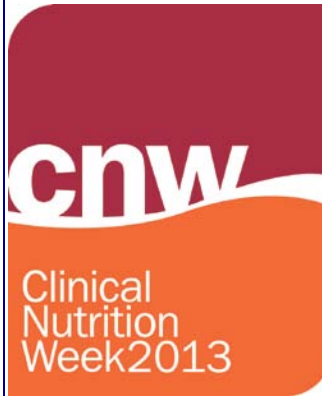
Another Time Saver!

Look for the orange dots on the data collection forms which represent critical fields. These critical fields are the questions that we have identified as most important. So if time is limited, and you are unable answer all questions on the patient forms, just complete the questions with the orange dot!

Not an Official Sustain Site?



CNW13 in Phoenix, Arizona



Plan on attending Clinical Nutrition Week 2013, held February 9 – 12, 2013, in Phoenix, Arizona. There will be a session on HPN registries.

CNW13 is the premier conference on clinical nutrition and metabolism! Gain vast insight into evidence-based research and practical applications that will impact how you care for your patients every day. [Register today!](#)

Sustain Councils

Sustain Advisory Councils as of June 15, 2012. Thank you to the councils for their continued support, expertise and guidance.

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Beth Lyman
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Funding Sustain

A.S.P.E.N. would like to express our sincere thanks to Baxter Healthcare Corporation for their unrestricted scientific grant in sponsorship of Sustain.



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

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. Also look for the new information in oral presentation and posters coming out of CNW12. Take a look at [all CNW12 Abstracts](#) (large .pdf file, please be patient)

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* 0148607112441800, first published on March 27, 2012 as doi:10.1177/0148607112441800.

[Prevalence of Vitamin D Deficiency and Response to Oral Vitamin D Supplementation in Patients Receiving Home Parenteral Nutrition](#) Puja R. Kumar, Tanis R. Fenton, Abdel A. Shaheen, and Maitreyi Raman *JPEN J Parenter Enteral Nutr.* 2012;36: 463-469.

HPN Registries:

[Canadian Home Parenteral Nutrition \(HPN\) Registry: Validation and Patient Outcomes](#) G. Fernandes, B. Kaila, K. N. Jeejeebhoy, L. Gramlich, D. Armstrong, and J. P. Allard *JPEN J Parenter Enteral Nutr* 2012;36 407-414.

[Development of Sustain™: A.S.P.E.N.'s National Patient Registry for Nutrition Care](#) Peggi Guenter, Lawrence Robinson, Rose Ann DiMaria-Ghalili, Beth Lyman, Ezra Steiger, and Marion F. Winkler *JPEN J Parenter Enteral Nutr* 2012;36 399-406.

[The Canadian Home Total Parenteral Nutrition \(HTPN\) Registry: Vitamin K Supplementation and Bone Mineral Density](#) Badr Aljarallah, Gail Fernandes, Khursheed N. Jeejeebhoy, Leah M. Gramlich, J. S. Whittaker, David Armstrong, Don R. Duerksen, and Johane P. Allard *JPEN J Parenter Enteral Nutr* 2012;36 415-420.

Catheter Related Research:

[Central Venous Catheter Thrombosis Associated With 70% Ethanol Locks in Pediatric Intestinal Failure Patients on Home Parenteral Nutrition: A Case Series](#) Theodor Wong, Vanessa Clifford, Zoë McCallum, et al. *JPEN J Parenter Enteral Nutr*, May 2012;36: 358-360.

[Prophylactic Anticoagulation Decreases Catheter-Related Thrombosis and Occlusion in Children With Home Parenteral Nutrition](#) I. L. Vegting, M. M. Tabbers, M. A. Benninga, J. C. Wilde, M. J. Serlie, T. A. Tas, C. F. Jonkers, and C. H. van Ommen *JPEN J Parenter Enteral Nutr* 2012;36:456-462.

[Impact of a National Shortage of Sterile Ethanol on a Home Parenteral Nutrition Practice: A Case Series](#) Mandy Corrigan and Donald F. Kirby *JPEN J Parenter Enteral Nutr* 2012;36 476-480.

[Ethanol Lock Therapy in Reducing Catheter-Related Bloodstream Infections in Adult Home Parenteral Nutrition Patients: Results of a Retrospective Study.](#) Bijo K. John, Maqsood A. Khan, Rex Speerhas, Kristen Rhoda, Cindy Hamilton, Robert DeChicco, Rocio Lopez, Ezra Steiger, and Donald F. Kirby *JPEN J Parenter Enteral Nutr* 0148607111428452, first published on December 28, 2011 as doi:10.1177/0148607111428452.



Feedback and Suggestions

Have any suggestions or comments? Send it our way; we value your feedback and insight to help improve Sustain.

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

Send your suggestions, comments and feedback to sustain@aspen.nutr.org.



SUSTAIN QUESTIONS AND ANSWERS

Is there a fee to participate in Sustain? No. Unlike most studies and registries who charge organizations to participate, Sustain does not charge organizations to participate or to receive their quarterly data.

Do we have to obtain IRB approval, or is this optional/only need it 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 those organizations that do not have an IRB, Sustain has been approved by an Independent Review Board and your organization can use this IRB approval.

What is this difference between the Informed Consent Document and the Waiver of Informed Consent Document? Are they both given or just one, how do we decide?

If your IRB specifies that you must get consent, then the Informed Consent document must be signed by each patient or guardian authorizing their participation in Sustain. If your IRB allows for a waiver of consent, the Waiver of Informed Consent document is an information sheet that must be provided to each patient or guardian prior to their participation in Sustain; no signature is required with the Waiver of Informed Consent document. Visit our website for [Consent template documents](#).

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 name, date of birth and Sustain patient number assigned by Sustain database either locked in an office or password protected. Sustain only tracks patients by their Sustain patient number.

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 will be accessed via the web and data stored by Sustain will be on a secure web server with access limited to those with a user ID and password.

How many people from one site can enter patient data into Sustain's on-line database?

Sustain allows 10 users from each site to enter patient data.

With regard to the collection of follow-up information on the patients, for how long, and over what time intervals, will this be done?

We suggest that for new patients, follow-up visits should be entered monthly, or at a minimum, quarterly. Existing patients' follow up visits should be entered quarterly, or at a minimum, semi-annually, or when there is a significant clinician encounter or event.

How much time is involved in enrolling a patient and then subsequently adding data?

It takes approximately 15 minutes per patient to enter baseline info, possibly less. Follow-up visits should take less time since you are basically updating information and some information is auto-populated. We have identified critical elements to cut down on data entry time. View [Blank Data collection forms](#).

How long the data will be kept by the registry?

Indefinitely

Any data collected on co-morbidities/other diagnoses?

There is a lot of data collected on multiple diagnostic categories and co-morbidities – again please feel free to review the data collection sheets which have all of the diagnoses listed.



[Complete List of Frequently Asked Questions](#)