sustain™

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

Sustain Newsline

Volume 1, Issue 1 **January 2012**

Update on Sustain

Sustain offers 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, 25 medical centers, hospitals, and home infusion agencies have enrolled; eight are approved, trained and entering data, with more than 210 patients entered thus far. We have dozens of other sites including national home infusion companies with a large number of branches that are interested in participating. To learn more or to get your organization involved, please visit the Sustain website. Also come see us at CNW12! Feel free to send us your comments and questions.

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Clinical
Nutrition
Week2012

Sustain Featured at Clinical Nutrition Week 2012

Join us at Clinical Nutrition Week 2012 (CNW12) in Orlando and participate in the following events to learn more about Sustain!

Sustain Users and Prospective Users Interactive Session
Monday, January 23, 3:00 – 4:00 pm.
Representative from both the pediatric and adult HPN centers will speak on their experiences with Sustain including processes and challenges and answer your questions.

Sustain: The Why, How and the Data
Tuesday, January 24, 10:00 – 11:30 am.
Speakers Alan Parver, Marion Winkler, Ezra Steiger and Peggi Guenter will discuss HPN and Public Policy, Sustain Development and Operations, and the first Sustain HPN Data.

Live Demo Sessions:
There will be demonstration area near registration where you can have a hands-on opportunity to try out the Sustain database system. Dates and times:

Sunday, January 22
    9:30 - 10:30 am
    5:00 - 6:00 pm
Monday, January 23
    9:30 - 10:30 am
    5:30 - 6:30 pm
Tuesday, January 24
    12:00 - 1:00 pm
    3:30 - 4:30 pm

JPEN Paper on Sustain

Look for the **Sustain** development article coming out in the March 2012 issue of the Journal *of Parenteral and Enteral Nutrition* (*JPEN*), which was written by members of the original Sustain Task Force.

JPEN
Journal of Parenteral & Enteral Nutrition

Sustain from the Consumer's Perspective

Former HPN Consumer's Perspective, written by Michael Medwar *(consumer representative on Sustain Executive Council)*

We live in an information age, a time when people understand more than any other period in history that information is power. Thanks to technology, that information is more readily available and easier to gather than ever.

And that's great news for HPN consumers.

HPN consumers do not live life in a vacuum. Everything that happens to them regarding their therapy, every course of action their clinicians take, will affect another consumer somewhere down the road. ASPEN's Sustain, its online patient registry for those on nutrition support therapy, is a cutting-edge effort to gather data on 100 percent of the HPN population. This effort will ultimately improve quality of life for consumers by helping clinicians to help them.

On HPN? Get Your Provider Involved with a Valuable Database! (from *LifelineLetter*, Oley Foundation www.oley.org)

A little data on home parenteral nutrition (HPN) can go a long way. That's why the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) is encouraging HPN consumers to tell their providers about Sustain™, LLC, its online patient registry for nutrition support therapy in the United States.

Sustain offers an unprecedented opportunity for HPN providers to help A.S.P.E.N. collect valuable data about consumers who are on HPN. The information entered into the registry will ultimately help organizations make better-informed patient treatment decisions, support the appropriate use of nutrition support therapy, and help improve patient outcomes.

Please note that patient privacy is a priority. The registry constitutes a Limited Data Set under HIPAA requirements and all patient identifiers under those requirements are not entered into the dataset. All persons using or receiving access to the data must sign a data use agreement through which he or she agrees to protect the privacy of the information received.

Currently, in the United States little is known about the annual use of HPN. Sustain will help generate data about therapy utilization, outcomes, and patient demographics, which will help all consumers, present and future.

A.S.P.E.N. needs your HPN providers to get involved with Sustain. Institutions, home infusion company providers, and U.S.-based clinicians who discharge patients from the hospital or care for them at home can join this patient registry program. Get your providers involved.

User's Corner

Congratulations to all of the users! You are entering great data and getting Sustain off to a terrific start. Just a few tips:

Be sure to complete, sign, and close your baseline forms within one month of starting a patient record.
Check the help section on each page if you have questions.
You will begin receiving email reminder messages to close and lock your patient forms.
Be sure to complete the critical elements and please fill out the insurance information.
Go to the user manual or training videos for further questions or just send us an email or call if you need an answer.

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1-800-727-4567, ext. 133.

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.

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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.

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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)

Dosing and Monitoring of Trace Elements in Long-Term Home Parenteral Nutrition Patients Imad F. Btaiche, Peggy L. Carver, and Kathleen B. Welch *JPEN J Parenter Enteral Nutr,* November 2011; vol. 35, 6: pp. 736-747, first published on August 8, 2011.

Growth Hormone to Improve Short Bowel Syndrome Intestinal Autonomy: A Pediatric Randomized Open-Label Clinical Trial Noel Peretti, Irene Loras-Duclaux, Behrouz Kassai, et al. *JPEN J Parenter Enteral Nutr,* November 2011; vol. 35, 6: pp. 723-731., first published on October 5, 2011

Central Venous Catheter Thrombosis Associated With 70% Ethanol Locks in Pediatric Intestinal Failure Patients on Home Parenteral Nutrition: A Case Series Theodoric Wong, Vanessa Clifford, Zoë McCallum, et al. *JPEN J Parenter Enteral Nutr,* 0148607111414713, first published on October 5, 2011

Characterization of Posthospital Bloodstream Infections in Children Requiring Home Parenteral Nutrition Aminu Mohammed, Frederick K. Grant, Vivian M. Zhao, et al. *JPEN J Parenter Enteral Nutr,* September 2011; vol. 35, 5: pp. 581-587., first published on July 28, 2011

Psychosocial Complaints Are Associated With Venous Access–Device Related Complications in Patients on Home Parenteral Nutrition Getty Huisman-de Waal, Michelle Versleijen, Theo van Achterberg, et al. *JPEN J Parenter Enteral Nutr*, September 2011; vol. 35, 5: pp. 588-596.

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SUSTAIN QUESTIONS AND ANSWERS

How will Sustain complement your current quality improvement efforts?

Participation in Sustain provides sites and clinicians with quality measures of their Home PN program to share with key stakeholders including administration, payers, and the community.

Who supports Sustain?

Sustain™, LLC is a subsidiary corporation owned by the American Society for Parenteral and Enteral Nutrition. The Sustain Registry has been sponsored by an unrestricted scientific grant from Baxter Healthcare Corporation.

Who maintains the database and who owns the data?

Sustain and our database vendor maintain the database, while Sustain owns the data. However, you will receive quarterly reports on how your organization compares to the aggregate group.

Who can participate in Sustain?

Whether you are from a large academic medical center or a small home infusion company, we want you to participate. Individuals must successfully complete the enrollment process which includes Institutional Review Board (IRB) approval and signing of a Participant Agreement. Even if you have never done this before, we can help walk you though the process. Sustain has been approved by an independent IRB, so if you don't have access to an IRB, we can help. Feel free to set up a time to talk with us about your participation, no question is too small.

What kind of patients can be entered into Sustain?

Patients on Home Parenteral Nutrition, either newly discharged or existing on HPN can be entered into Sustain. We will include adult and pediatric patients. We will not include HPN patients in long-term care or rehabilitation facilities, nor will we accept patients on IDPN. Patients in the U.S. are now eligible and international sites will be accepted on a case by case basis.

Is IRB approval required to participate?

Participating sites will have full responsibility for obtaining any internal approvals necessary for participation in the program including IRB approval or waiver.

Is informed consent required on each patient? If not, is the waiver intended for our institutional use stating we decline to have each client sign informed consent?

The decision about whether informed consent is necessary is up to the local IRB. If the IRB says it is not necessary (as many of them are), then you need to provide each enrolled patient with the waiver of informed consent information sheet that we have in our site participation materials.

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 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 are asking that new patients have follow-up a minimum of quarterly, hopefully monthly and existing patients when there is a clinician encounter or minimum of six months.

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 info is auto populated. We have identified critical elements to cut down on data entry time. Blank Data collection forms can be found at http://www.nutritioncare.org/ASPEN_Sustain/Participation_Materials_Intro .