Oley Conference: It’s All About Connecting

Another Oley Foundation Consumer/Clinician Conference is behind us. It was a wonderful meeting in San Diego, marked by blue skies and friendly faces. At the welcome reception Thursday evening, where we joined to celebrate Oley’s twenty-fifth anniversary, many of us were meeting for the first time. By Sunday afternoon, when we gathered for the walk-a-thon and picnic by the pool, we were like old friends, having spent the previous days sharing ideas, experiences, and stories.

Nichole Loewen and her family attended the conference from Manitoba, Canada. Nichole keeps an online journal, where she wrote about her experiences at the conference. Here is her entry from Sunday, June 29.

It’s been a very full weekend. The Oley Conference has been a fantastic time and the whole family has enjoyed themselves. There is so much to say about it, and I’m sad to see it come to an end, but I am so glad we have gotten the opportunity to be here.

Friday and Saturday were spent in sessions with topics ranging from advocating, to preventing line complications, depression, pain management, transplants, and so much more. Lots of fascinating new ideas and we have some questions to go ask back home, and a few new things to hopefully try out.

Be Counted in Major Quality of Life Study

Darlene Kelly, MD, PhD, FACP

At the annual Oley Conference in San Diego, Dr. Darlene Kelly announced Oley’s participation in a large international study on home parenteral nutrition (HPN) and quality of life. Read on to see how you, if you are an adult HPN consumer, can be part of this valuable and exciting research.

“Quality of life” has become a buzz term in the medical literature. Many people think they know what it is or why it is significant, but there really is no official, widely accepted definition. According to a World Health Organization description from the 1940s, quality of life (QoL) is “a state of complete physical, mental and social well-being, and not merely the absence of disease.”

Many individuals indicate that people in the Western "Quality of Life, cont. pg. 2"
Quality of Life, from pg. 1

world have an intuitive understanding of what an individual’s QoL is. However, the only person who can really understand a given person’s QoL is that person.

One of my colleagues, who is a world’s expert on inflammatory bowel disease, judged a young woman’s QoL as being terrible because she was on home parenteral nutrition (HPN). He overlooked the fact that her Crohn’s disease was a major complicating factor and that she often developed dehydration because of disabling diarrhea. The diarrhea also interrupted her ability to leave her home. When I talked to the woman about her life, she judged the inability to go on outings with her family (because of the need to find “facilities”) and the inability to enjoy a meal with them as the issues that made life most difficult.

Measuring QoL

How can we determine how a specific disease or treatment alters an individual’s QoL? Different questionnaires have been developed over the years as tools to measure QoL. These include generalized questionnaires that have met the test of time and have been applied to a variety of different disease states.

The SF 36 (a 36-item short-form health survey) is an example of a general questionnaire that has been extensively tested and accepted as a tool to compare individuals with a disease to those without disease. There are also specialized tools (questionnaires) that apply to individuals with certain diseases and treatments, such as cancer and treatments applied to cancers.

QoL and HPN

In the past, there have been some important QoL studies of HPNers. But each of these studies has been a relatively small study that may be biased and may not reflect the experience of consumers in general. Many of these small studies have been done with consumers who were identified through a specific infusion company or with handpicked individuals (sometimes through Oley). These studies have measured QoL in a variety of ways.

Until recently, there were no life assessment tools designed specifically for widespread use with individuals receiving HPN. However, Janet Baxter, a Scottish dietitian who is working on her doctorate, has been developing such a questionnaire, and it is now ready for use. Baxter has been working in conjunction with her advisor, Peter Fayers, who is a world expert on QoL. and who (literally) wrote the book on QoL. (Quality of Life: The Assessment, Analysis and Interpretation of Patient-Reported Outcomes, one of the major textbooks on QoL).

Baxter’s tool has been tested extensively for validity over the last few years. The tool has been validated in several European languages and countries, and to some extent in America through Oley. It is now “ready for prime time,” and Oley is privileged to be able to cooperate with the Home Artificial Nutrition workgroup of the European Society for Parenteral and Enteral Nutrition (ESPEN) in participating in this very large international study.

Some issues of concern to American HPN consumers do differ somewhat from the issues of concern to European consumers. For example, in European countries the governments pay the cost of HPN. Therefore Oley board members have developed an additional brief questionnaire that will be distributed with the Scottish tool and will consider some of the financial issues that affect consumers in the United States.

Why?

Why do we (the Oley Foundation) have an interest in these QoL measurements? There are several benefits to understanding what factors most affect consumers. While the physicians, nurses, pharmacists, and dietitians who work with you may think they understand what issues affect you, only you, the consumer, can communicate what issues the health professionals may be overlooking, and what is truly most important to you as the consumer. Developing this understanding further could result in Oley being of greater benefit to you.

Further, as intestinal transplantation becomes more widespread and has better outcomes, comparisons of QoL between transplantation and HPN may become more important to transplant centers, insurance companies, and consumers. Lastly, comparisons between the practice in North America and Europe and QoL in both may help clinicians do a more effective job of improving QoL by learning more effective practices. For example, sealed, partitioned TPN bags that are manufactured commercially and do not require refrigeration are commonly used in some European countries, especially when consumers travel.

You may wonder if the questionnaire can help your doctor gain any understanding of what affects you and your QoL specifically. If you wish your physician or homecare company to review or even copy your questionnaire, you can be sent to the Editor at the address above.

Oley is privileged to be able to participate in this very large international study.
Tube Talk

Thank you to everyone who sent material for the "Tube Talk" column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or E-mail Metzgel@mail.amc.edu. Information shared in this column represents the experience of that individual and should not imply endorsement by the Oley Foundation. The Foundation strongly encourages readers to discuss any suggestions with their physician and/or wound care nurse before making any changes in their care.

Dining Out

One of the major concerns of enteral feeders is the social problem of eating in a public restaurant. We need to develop a wall of invisibility around our person. Here’s the way I do it.

I look around the restaurant and think, does that man over there know anything about tube feeding? It’s unlikely. Does that woman in the next booth have any interest in watching me? Probably not. What would she think if I pulled up my shirt a couple of inches and exposed my cute stomach skin? Again, it wouldn’t occur to her to peer out of her shell and cast her interest in my direction.

In other words, the people in the restaurant are notably ignorant of tube feeding. So, I look around to see everyone engrossed in his or her own meal and not caring one little bit about what I might be doing. Although I don’t use a syringe and a bowl any more, I’m certain that if you are comfortable with your feeding technique, you could ingest at a restaurant table and nobody would notice.

Sit next to the wall so your table buddies’ bodies shield you, and pump away. The wait staff is usually so hurried and hassled, they won’t notice either. Do your feeding duty after the order is taken, and relax. The general public won’t know to look at you, because you’re not standing on your chair, waving your arms in the air and screaming.

— Robert Flute Snyder, DMA
fluteduo@aol.com

Equipment/Supply Exchange

Are you looking for formula, pumps, or tubing? Do you have items that you no longer need? Try Oley’s Exchange!

Items are available free of charge and are posted at www.oley.org. The listing is updated every week (usually on Mondays), so check frequently. When you see something you can use, or have supplies to donate, contact Oley toll-free at 866-454-7351, from 9 a.m. to 4 p.m. EST, or harrinc@mail.amc.edu. This is the same number to call if you want to participate but don't have access to the Internet, or you want to be notified when a particular item becomes available.

After we refer you to someone offering supplies, please follow up with the Oley office. If you do not take the supplies, we need to know they are still available; if you do take the supplies, we will remove them from the list.

We ask that those receiving goods offer to pay the shipping costs. Oley cannot guarantee the quality of the supplies donated or be responsible for their condition.
Congratulations 2008 Oley Award Winners!

Jenny lives to the fullest, and it’s because of this that he was honored with the Oley Foundation Celebration of Life Award at the Oley annual conference.

Sharon Woods, MSN, RN, CNSN, who serves as one of Jerry’s homecare nurses, says, “Jerry started on HPN in the days when consumers had to go to the hospital pharmacy and pick up all their supplies themselves—a daunting task. This included the glass bottles of amino acids, dextrose, and lipids. It was an incredible time for the first HPN consumers. Jerry took to this problem with perseverance and a positive outlook.” Of course, not only did early consumers like Jerry have to pick up their own supplies, they had to learn to mix them as well. At that time, Jerry was working full time, teaching physical education in elementary schools, and infusing at night.

Jerry is now retired, which gives him more time to devote to being a Purdue fan. During football season you are likely to find Jerry and his wife Dotty at a Purdue game, occupying some of the best seats in the stadium. In the off-season, Jerry and Dotty are likely to be traveling. In late June of this year, Jerry and Dotty went on a cruise to celebrate their fortieth wedding anniversary.

“Jerry is an inspiration to any one of us,” says Sharon. “His chronic health problems/challenges have not consumed his life or prevented him from living life to the fullest even though he infuses his HPN six times a week.”

Nominees:
Esther Ann Adler
June Bodden
Susan Gale Hall
Loretta Need
Theresa M. Norris
Lyle Reder
E. Carol Rosheck
Charlene Rottler
Shirley Stubblefield

Jerry Fickle, New Haven, IN

Jerry Fickle has been on parenteral nutrition (PN) since 1981, and in that time PN hasn’t stopped him from doing the things he loves.

Nina Marie Marino, Clearwater, FL

At the conference, nine-year-old Nina Marino was presented with this award for her positive attitude in dealing with her illness and therapy, and for the inspiration and encouragement her attitude offers others. “Nina does not let anything get in her way of enjoying life,” says her mom, Lesley. When she received the award, Nina commented that one of her goals was to make people laugh. Another, more long-term goal, was to be a Montessori teacher.

Nina has had a G-tube since she was four days old, and has been on and off parenteral nutrition several times. Nina is missing most of her esophagus, one lung, and several centimeters of intestines, and has three heart defects. She has undergone seventy-three surgeries. Yet in February, she participated in her first national ice-skating competition. She won second-, fourth-, and fifth-place medals. One day, Lesley says, Nina wants to skate with the Disney on Ice company.

A Marino family friend, whose son, like Nina, has extensive medical issues, says Nina has helped them to see the positive side of life. “Nina is a compassionate, happy, and energetic young lady,” she says. “Nina has taught us that in spite of all the challenges she has been faced with, the most important part of life is living it to the fullest. She has also taught us acceptance. She seems to thoroughly understand all her medical issues and accepts them with no self-pity.”

Nina and Lesley visited the Oley–Tampa Bay Area support group this spring as the group celebrated its twentieth anniversary. “Nina’s winsome personality had our hearts in just a few minutes,” says Oley Regional Coordinator June Bodden. “Everyone was very impressed with the knowledge this pint-size child possesses and what an energetic, full-of-life example she is.”

Nominees:
Bonnie Burch
Olivia DeKold
Mason Lindley
Angel Perrenoud
Charles Michael Rolfe
Reese D. Tower
Tim Weaver
Rowan Jameson Windham
LifelineLetter Annual Award

In Honor of Nutrishare, Inc., Oley Platinum Partner

June Bodden, Clearwater, FL

At our annual conference in San Diego, the Oley Foundation was pleased to present June Bodden with the LifelineLetter Annual Award, which is given to recognize a homePEN consumer or caregiver for his or her courage, perseverance, positive attitude, and generosity in helping others in their struggle with homePEN issues.

June, who has been PN dependent for twenty-three years, has been an Oley Regional Coordinator volunteer since the early 1990s. In that capacity she has reached out to many who were looking for support and answers. Beyond that, on Tuesdays June is active with her church Bible study group; on Wednesdays she volunteers with Meals on Wheels (and has for eighteen years!); and on Fridays she helps at her local food pantry.

June has been very active with the Oley–Tampa Bay Area support group since it began in 1988. She stepped up to lead the group about ten years ago, and since then has carefully planned meetings and located materials that might be of interest to the group or other PN consumers. Twenty-seven people, including consumers, caregivers, and clinicians, gathered in March to celebrate the group’s twentieth anniversary.

Diane Wagner, a consumer who has also been part of the group since 1988, says, “June is in contact with me and others by e-mail, snail mail, or phone. She makes an extra effort whenever someone she knows is in the hospital or sick at home. She spends hours planning our group meetings, contacting new patients on PN, and keeping us informed of new advancements in Oley and PN-related areas.”

Through the years, June has frequently given of her time to answer calls to one of the consumer/caregiver toll-free phone lines Oley offers. In fact, she’s “(wo)manning” a line in September. Don’t hesitate to call her.

As Oley Consumer Advocate Don Young says, “June is a hard worker who gets the job done. If she were a baseball pitcher,” he adds, “we would say, ‘She still has her fastball.’”

Nominees:
- Gabriela Bahena
- James Cowan
- Margorzata Lewandowska-Fared
- Philip Lindensmith
- Sheila Messina
- Holly Owens
- Robert M. Smithers, Jr.
- Karyn Thomas
- Elizabeth Tucker
- Tony Zawalski

Lenore Heaphey Grassroots Education Award

Sponsored by Kimberly-Clark, Oley Blue Ribbon Partner

Ann Weaver, Naperville, IL

Ann Weaver is always available to reach out and educate others about Oley, and about what it means to be dependent on enteral or parenteral nutrition or to care for a child on homePEN. She was chosen to receive the Lenore Heaphey Grassroots Education Award this year for her work organizing and participating in several education programs.

Ann has had direct experience with homePEN since her son was born with Hirschsprung’s disease in 1994. She has served as an Oley Regional Coordinator volunteer since 2001, and as such has generously offered support and information to other consumers and caregivers. In February, Ann, her son Tim, and Oley Trustee and HPN consumer Sheila Messina, RN, MA, spoke as part of an Oley panel at Clinical Nutrition Week in Chicago. Organized by the American Society for Parenteral and Enteral Nutrition, Clinical Nutrition Week brings researchers and clinicians from around the world who specialize in the field of homePEN together to share ideas. Ann, Tim, and Sheila spoke on what it means to be a homePEN consumer and/or caregiver, offering clinicians a glimpse into consumers’ and caregivers’ day-to-day routines and concerns.

For several years Ann has also helped educate pharmacy students by sharing with them the consumer’s and caregiver’s points of view on homePEN. Anna Nowobilski-Vasilios, PharmD, BCNSP, writes that Ann has helped her teach a Home Infusion Therapy elective at Midwestern University’s Chicago College of Pharmacy. “Her insight and candor,” says Dr. Nowobilski-Vasilios, “have contributed significantly to the education of future pharmacists and to their development of compassion for the individuals whom they will serve once they graduate and begin practicing.”

Nominee:
Ann Weaver
Nan Couts Award for the Ultimate Volunteer

Coordinated by Judy Peterson, RN, MS
Mark DeLegge, MD, Charleston, SC

Mark DeLegge, MD, has demonstrated a willingness to give of himself—above and beyond his regular work hours—to educate and empower homePEN consumers and to improve their quality of life. For this, Dr. DeLegge was presented with the Nan Couts Award for the Ultimate Volunteer at the Oley annual conference.

“Mark DeLegge is a gastroenterologist with a huge heart,” says Dr. DeLegge’s friend and colleague Carol Ireton-Jones, PhD, RD. “He takes care of patients on home parenteral and enteral nutrition clinically, but also personally and with TLC.” Dr. DeLegge is open to speaking with homePEN consumers one on one, and listens and offers support. He is an active member of the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) and serves on many A.S.P.E.N. committees. Earlier this year, Dr. DeLegge received the 2008 Outstanding Contribution Nutrition Physician Award from A.S.P.E.N. and was elected to A.S.P.E.N.’s research foundation board.

A nomination for Dr. DeLegge cites how he “makes tough medical jargon easy to understand” and, in speaking to consumers at Oley conferences, how he “takes time with each individual as needed to make sure their questions are answered.” Dr. DeLegge also trains new physicians, nurses, dietitians, and pharmacists in nutrition support. Hopefully he instills in them respect for the qualities that are regarded so highly in Dr. DeLegge.

Nominees:
Gwen Cole, RN, CRNI
Darlene Kelly, MD, PhD
Patricia Perez, PharmD
Gail Sansivero, MS, ANP
Kerry Stone, MS, RD, CNSD

Kyle R. Noble Scholarship

Coordinated by Donna & Richard Noble
Mariah Abercrombie, Henderson, NV

Kyle R. Noble’s enthusiasm for life affected many positively, and he is remembered widely with affection and admiration. Kyle passed away in 2006 at the age of eight. In 2007, the Noble family established the Kyle R. Noble Scholarship to recognize others who share the admirable qualities for which he will be remembered. In 2007, the scholarship was awarded to Alicia Hoelle. This year’s recipient, announced at the Oley Conference in San Diego, is Mariah Abercrombie.

“Living with and battling a chronic illness has made my life more fulfilling,” says Mariah. “It has pushed me to strive to accomplish more, although maybe not at the pace I would have imagined for myself or preferred. I’ve learned more about my strengths and weaknesses than many my age. I’ve been able to meet others who may not have entered my life otherwise and learned a great deal from them. Simply, I’ve become a better person because of my illness.”

Mariah was diagnosed with pseudo-obstruction syndrome and put on parenteral nutrition (PN) at the age of two and a half. At that time she also received a gastrostomy tube (G-tube) and a jejunostomy tube (J-tube). “Despite all my health problems and the struggles my family faced,” Mariah relates, “I enjoyed a normal childhood... Is hooking up to IVs every night and taking a twenty-five pound IMED machine on family vacations normal? For my family it was. We learned how to accommodate my medical needs and live as ordinary a life as possible.”

Since then, Mariah has undergone additional surgeries and faced complications. Yet, as a nurse involved with Mariah’s care states, “Despite a severe and chronic medical condition, which requires a tremendous amount of day-to-day management, Mariah has persisted in pursuing her educational goals at the college level.”

Mariah would like to pursue a bachelor’s degree in psychology or social work. She plans to use the scholarship as she continues her studies at the University of Las Vegas. “Everyone has their struggles,” says Mariah. “It only makes sense to use our struggles to help others and better ourselves. I only hope that I am able to keep helping others, as I have been so graciously helped by so many in my life.”

Candidates:
John Hudson
Rebecca Thompson

Mariah Abercrombie, Henderson, NV

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Candidates:
John Hudson
Rebecca Thompson
Nutrishare Home TPN Research Prize
Sponsored by Nutrishare, Inc., Oley Platinum Partner

The Nutrishare Home TPN Research Prize, sponsored by Nutrishare, Inc., was established in 2007 to encourage clinical studies focused on improving the quality of life for homePN consumers. In 2008, prizes were awarded to the following individuals:

Cindy Hamilton, MS, RD, LD, CNSD
Cleveland Clinic, Cleveland, Ohio
“Identification of Factors that Lead to Complications in New Home Parenteral Nutrition Patients”

This study was designed to determine what factors might predispose patients to HPN-associated complications. The study concluded that complications may be reduced by either changing the process of care or by providing additional training to healthcare professionals, patients, and caregivers. The data provides a benchmark to test these strategies.

Marianne T. Opilla, RN, BSN, CNSC
Nutrishare, Inc., Midlothian, Virginia
“Self-Administered Alteplase in a Home Total Parenteral Nutrition Population”

Thrombotic catheter dysfunction is a commonly reported complication for central venous access devices. Alteplase, a fibrinolytic agent, has been shown to be safe and effective in restoring catheter patency; it may be administered therapeutically for occlusion or routinely as a prophylactic measure. The aim of this study was to compare methods of usage, as well as determining safety, efficacy, and incidence of catheter salvage in HPN patients using self-administered alteplase.

Geert Wanten, MD
Radboud University Medical Centre, Nijmegen, The Netherlands
“The Arteriovenous Fistula: A Feasible Alternative to Deliver Home Parenteral Nutrition”

Radboud University Medical Centre has had ongoing experience with HPN for 37 years and has remained unique in the world by using arteriovenous fistulae (AVF) for vascular access in HPN. The goal of this research was to evaluate complications related to AVF-use in comparison with central venous catheter (CVC) use. The study concluded that AVFs have a higher rate of initial failure, but once functional, the bloodstream infection rate is much lower than during CVC use whereas the occlusion rate is not increased. Considering the very low rate of infections, the study concluded that AVFs are a valuable alternative to CVCs in the administration of HPN.

Contact the Oley office for more information on these studies.
On Your Behalf

Each year, Oley Executive Director Joan Bishop attends the annual meeting of the National Digestive Diseases Information Clearinghouse (NDDIC). The Clearinghouse meets to discuss programs, provide guidance for projects, share news about panel member organizations, and allow representatives from these digestive disease organizations to showcase their efforts/activities and to network.

At this meeting, Joan learns more about other organizations (both consumer and professional groups with a focus on digestive diseases)—their efforts, trends, challenges, and so on—and shares information about Oley. She found this year’s meeting very enlightening. The National Institutes of Health’s Webmaster discussed his efforts and challenges in maintaining an accurate, effective site. It is likely that you will notice some of the ideas shared at this meeting implemented on www.oley.org. Joan also learned more about diagnosing colon polyps, their removal (the graphics are still floating through her mind!), and advances in this field.

Joan has also been invited to serve another three-year term on the National Board of Nutrition Support Certification (NBNSC). As the public member, she participates in monthly teleconferences and contributes toward NBNSC’s mission: “To promote the enhanced delivery of safe and effective nutritional care through the certification of qualified clinicians practicing nutrition support.”

Oley Presents

From September 11–14, Joan and Oley Founding Trustee and Past President Don Young will join attendees, faculty, and exhibitors at the Association for Vascular Access (AVA) annual meeting in Savannah, Georgia. On Thursday, Don will join Oley Trustee Gail Sansiviero, MS, ANP, to present “Partnerships in Access: Consumers and Clinicians Working Together.” Gail is an interventional radiologist and Don is a thirty-three-year HPN veteran.

The program will showcase the advantages of consumers/patients and clinicians working together toward optimal care. Everyone participating in this event has a serious interest in vascular access and after this session will have a much better understanding of the ins and outs of educating consumers as to catheter options, placement, and so on.

Oley Exhibits

As part of its outreach efforts, Oley regularly exhibits at homePEN-related meetings and conferences across the country. From June 2007 through May 2008, former Oley Outreach Coordinator Kate Swensen arranged for Oley to exhibit at over twenty-five meetings.

We’ve attended and exhibited at big conferences, such as the annual meetings for the American Society for Parenteral and Enteral Nutrition (A.S.P.E.N.) and for AVA (coming up in September), and at smaller events, such as chapter or regional meetings of A.S.P.E.N., AVA, and other organizations.

Oley volunteers are always needed to staff exhibits. In fact, Joan and Don would like to invite you to join them in staffing the Oley exhibit at the AVA conference in Savannah (see above) for as much of the meeting as your calendar will allow!

There are many benefits to volunteering in this way. Certainly you will be serving the homePEN community by spreading the word about Oley to someone who may really needs it. You’ll also have the unique opportunity to learn from experts in the HPEN field and wander through the exhibit hall and talk to other vendors.

Other exhibits currently on the Oley calendar include:

- Pediatric Intestinal Failure and Rehabilitation Symposium, 9/11–9/13/08, Pittsburgh, PA
- European Gastroenterology Week, 10/18–10/22/08, Vienna, Austria
- ASPEN’s NY/Long Island Chapter, 11/6/08
- ASPEN’s Clinical Nutrition Week, 2/1–2/4/09 in New Orleans

If you are interested in volunteering to help staff an exhibit at these or other meetings, please contact Joan at bishopj@mail.amc.edu or call (800) 776-6539. We can also send you Oley materials if you would like to represent Oley at other appropriate meetings in your region.

Give us a call to talk about possibilities!

2009 Oley Conference Travels to St. Petersburg, Florida

The dates are set for the 24th Annual Oley Consumer/Clinician Conference. Plan to join us June 29–July 2, 2009, at the Trade Winds Island Resorts (www.justletgo.com) on St. Pete Beach in Florida. The attractive rate of $139/night at this outstanding venue and our commitment to plan a meeting that will further your understanding of the therapy that sustains you, along with the opportunity to meet others who survive similarly, should inspire you to begin planning now. Stay tuned to the LifelineLetter and www.oley.org for updates.

Conference, from pg. 1

While we were at sessions, Kailyn and Joshua spent an afternoon on a private trolley tour of San Diego and an afternoon at SeaWorld. They were thrilled! Yesterday evening was the silent auction where the kids went a little nuts at the kids’ auction table and ended up with a bunch of Disney loot. And today was the picnic by the pool with face painting, rock painting (not sure how we will lug those home!), and just socializing. Once again, the kids were spoiled rotten with freebies. Good thing we have extra room going home after using up all Noah’s supplies!

But the best part of the conference was the people we met. Other parents with kids on TPN, and adults who’ve been doing this for twenty or thirty years. A few of them I have been corresponding with on my Internet TPN support group, so it was wonderful to put faces to names. But to just—for a few days—feel like the “normal” ones, when everyone is walking around with tubes and pumps, was such a great experience. A few times Kailyn mentioned how neat it was to see kids like Noah, especially kids her age. “To just be around families that “get it,” without having to explain yourself...they’ve been there, done that...that was priceless. We will miss them and are already talking about how we will get to next year’s conference. (See above for details on the 2009 Oley conference.)

Thanks for sharing this, Nichole! You can read more about Nichole’s family at http://noahgrantjohn.blogspot.com.
2008 Walk-a-Thon

The fourth annual Oley Walk-a-Thon, held June 29 as part of the Oley conference in San Diego, was a great success. Walkers raised just under $4,000 to support Oley programs, and the group—walking with bright, sunny, yellow T-shirts—generated a lot of interest in Oley. Thank you to everyone who was a part of the walk-a-thon, whether it was by walking with us in San Diego, by gathering sponsorships, or by sponsoring a walker. Our apologies to anyone we may have missed in this listing.

Walkers:
Nikki Albrecht, Antonucci family, Jameson & Leah Atkinson, Balli family, Carlotta Bentley, Joan Bishop, Bette Marie & Elizabeth Bond, Brown family, Cleberg family, Faye Clements, Zachary Colton, Team Coram/Apria, Barbara Crouse, Roz Dahl, DeKold family, Enzro Digennaro, Beth Dinett, Terry & Anne Edwards, Melissa Fedell, Andrea Hirschbrunner, Lynn Howard, Toly Kuzushin, Mark Lopez, Noreen Luszcz, Nina Marino, Michael Medwar, Metzger family, David Minoggio, Heather Nichols, Noble family, Lynn Patton, Liz Pazos, Joseph Reza, Stacey Sanders, Sandy & Yvonne Schwarz, Shearrow family, Colleen Steadman, Kate Swensen, Monica Szabo, Dana Thornley, Cathy Tokarz, Billy & Carla Truman, Marrissa VanAlstine, Pam Wagner, Brian Windham, Kelly Zeller, Lou Zeller

Sponsors:

NutriThrive
Improving life on nutrition support…one consumer at a time.

NutriThrive is proud to announce
Nina Marino
As the recipient of the Oley 2008 Child of the Year Award

Thanks, Nina for all you do!

For more information about our Free Educational Clinics in Cincinnati on September 20th and in Boston on October 18th email us at info@nutrithrive.com or call us at 888-684-7483.

1-888-N-THRIVE (888-684-7483)
or info@nutrithrive.com
gwww.nutrithrive.com
Scenes from San Diego —
Site of the 2008 Oley Conference
2008 Conference Support

Many thanks to the following companies and individuals for their generous contributions of time and/or money to the 2008 Oley Conference.

25-Year Oley T-shirts:
Nutrishare, Inc.

Child Care:
NutriThrive (both days). Volunteers: Marjorie Quinn, Audrey Yadrich, & Peter Yadrich; Helpers: Danielle Cox, Tim Cox, & Tiffany Crocker

Conference Badges:
Apria Healthcare / Coram Inc., Specialty Infusion Services

Conference Bags:
Nutrishare, Inc.

Conference Co-chair:
Laurie Reyen, RN, MN

Conference Program Books:
Hospira Worldwide

Exhibitors:
Abbott Nutrition, Abbott Laboratories; American Society for Parenteral & Enteral Nutrition; Applied Medical Technology; Apria HealthCare; Calmoseptine, Inc.; Coram, Inc., an Apria Healthcare Company; Covidien; Crescent Healthcare; Critical Care Systems; Curlin/Zevex, Inc.; Emmaus Medical, Inc.; First Call Pharmacy; Green Pasture Products; Hospira Worldwide, Inc.; InfuScience; Kimberly-Clark; Mealtine Notions, LLC; Nestlé HealthCare Nutrition, Inc.; Nutrishare, Inc.; NutriThrive; PromptCare Home Infusion, LLC; Walgreens-OptionCare

Faculty:
Marcia Boatwright, RN, CRNI; Faye Clements, RNC, BS; Rick Davis; Mark DeLegge, MD; Thomas Diamantidis, PharmD; Douglas Farmer, MD; Joan Gordon, MSW; Cindy Hamilton, MS, RD, LD, CNSD; Brenda Hansen, MS, RD, CNSD; Lyn Howard, MB, FRCP; FACP; Carol Ireton-Jones, PhD, RD, LD, CNSD; Michael Joseph, MD; Darlene Kelly, MD, PhD; Marsha Dunn Klein, OTR; Diane Machincinski, MEd, RD; Laura Matarese, PhD, RD, LDN, FADA, CNSD; Sheila Messina, RN, MA, CLNC; Melissa Miller, RN, BSN; Reid Nishikawa, PharmD, BCNSP, FCSHP; Laurie Reyen, RN, MN; Christopher Russell; Gail Sansivero, MS, ANP; Douglas Seidner, MD, FACP; Kerry Stone, MS, RD, CNSD; Janet Toney, OTR; Anne van Dijk; Jorge Vargas, MD; Renate Vissers

Focus Groups:
Apria Healthcare / Coram Inc., Specialty Infusions Services; Nutrishare, Inc.

General Conference Support:
Ann & Paul DeBarbieri; Charlie Freeny; Hospira Worldwide; Jane Lindsay; David & Theresa Mathiasmeier; Sheila Messina; Susan & Jeffrey Schesnol; Donna Yadrich

Hotel Room Subsidies:
Apria Healthcare / Coram Inc., Specialty Infusion Services; Critical Care Systems; Nutrishare, Inc.

Jammin’ Jammies:
Abbott Nutrition—PediaSure. Volunteers: Sheila DeKold, Rose Hoelle, Marjorie Quinn, & Patty Woods

Lunch (Friday):
NutriThrive

Medical Support:
Apria Healthcare / Coram Inc., Specialty Infusion Services

Regional Coordinator Workshop:
Apria Healthcare / Coram Inc., Specialty Infusion Services; Faye Clements

Silent Auction:
A big “Thank You!” to volunteers who helped orchestrate the event, and to those who donated, brought, and/or purchased items!

Speaker Support:
Angiodynamics; Albany Medical Ctr.; Apria Healthcare / Coram Inc., Specialty Infusion Services; C.R. Bard, Inc.; Cleveland Clinic; Community Care Physicians; Crescent Healthcare, Inc.; Digestive Disease Ctr., Medical University of South Carolina; Dumont-UCLA Transplant Center, UCLA Medical Center; EMD Serono; I-Flow Corp.; Intestinal Rehabilitation and Transplantation Ctr., Thomas E. Starzl Transplantation Institute, University of Pittsburgh Medical Ctr.; Mayo Clinic Rochester; Mealtine Notions, LLC & Mealtine Connections, LLC; Nationwide Children’s Hospital; Nutrishare, Inc.; NutriThrive; University of Kansas School of Nursing; University Nijmegen Medical Ctr. St. Radboud, The Netherlands; Vanderbilt University Medical Ctr.

Travel Scholarships for Consumers:
Anonymous; Jarol Boan, MD; Melissa Chaney Memorial Fund; Bruce Groeber Memorial Fund; Janet Platt & Christopher Hlatky

Walk-a-Thon:
Apria Healthcare / Coram Inc., Specialty Infusion Services; Critical Care Systems; Nutrishare, Inc.; NutriThrive…and thank you to everyone who walked or otherwise supported the effort (see list page 14).

Youth Activity (Friday):
Old Town Trolley Tours of San Diego. Chaperones: Bea Close, Sheila DeKold, Rose Hoelle, Roni Kanumari, & Kishore Kanumari

Youth Activity (Saturday):
Admission courtesy of SeaWorld San Diego. Chaperones: Joe Antonucci, Jameson Atkinson, Bettemarie Bond, Bea Close, Sheila DeKold, Michael Medwar, Ron Metzger, Susan Metzger, & Cathy Tokarz
HPN Centers of Experience

Because of the complicated nature of home parenteral nutrition (HPN), the potential for serious complications is always a concern. This column is meant to highlight institutions that specialize in caring for HPN consumers. At least one study has shown that consumers who are treated by programs specializing in HPN have better outcomes. Oley does not endorse any center but brings this to our consumers strictly as an informational tool. For a listing of other experienced centers visit www.oley.org.

The Intestinal Rehabilitation Center at James Whitcomb Riley Hospital for Children/Indiana University

The Intestinal Rehabilitation Center at James Whitcomb Riley Hospital for Children/Indiana University was conceived a year ago to provide comprehensive treatment of children with short bowel syndrome in Indiana and surrounding states. It is a collaboration between the Department of Pediatrics, division of Pediatric Gastroenterology, and the Department of Surgery, division of Pediatric Surgery and Organ Transplant.

The multi-specialty group is headed by Joel Lim, MD, a pediatric gastroenterologist whose special interest is short gut. The team also includes Alan Ladd, MD, of Pediatric Surgery who shares the same interest, and Rodrigo Vianna, MD, who specializes in intestinal/multivisceral transplant. The team is also supplemented by dietitians, pharmacists, nurses, and a social worker.

The goal of the center is to provide excellent care to pediatric patients dependent on parenteral nutrition (patients with necrotizing enterocolitis, volvulus, atresias, and gastroschisis). This includes helping them transition to enteral feeding through a multidisciplinary approach that maximizes their potential to adapt and decreases complications. The center also evaluates patients who might benefit from intestinal/multivisceral transplant.

You may contact Dr. Lim at (317) 274-3774 or jdlim@iupui.edu.
Individual Donors—Thank You!

The following list represents everyone who contributed between May 29 and July 16, 2008. We also want to thank all of those who are not listed below, who gave earlier this year or who have supported the Foundation by volunteering their time and talents.

**Ambassadors ($2,000+)**
Darlene Kelly, MD

**President’s Circle ($1,000–$1,999)**
Cheryl Thompson
Jane Balint, MD*

**Benefactors ($500–$999)**
Marcus & Sallie Simpson, in memory of Bruce Grefrath

**Sponsors ($250–$499)**
Alyson Giles & Samuel Bondi, from a local fundraising effort

**Patrons ($100–$249)**
Milton Abercrombie
Robert Hydorn, in memory of Joyce Hydorn
GE Matching Gifts Program, via Joan & Francis Scheib
Pamela Katz
Jack Kordash
Helen Pizzuti
Jeffrey & Susan Schesnol

**Supporters ($50–$99)**
John & Anne Beaman
Sharon Cottrill, in memory of Bruce Grefrath
Richard & Faith Dillon
Charles Freeny
Todd & Julie Freier, in honor of Darold Hauer
Linda Gravenstein, in honor of Mark DeLegge, MD
Richard Hermansen
Ellen Lead & Quinn & Dylan Biter, in honor of Marion Winkler’s PhD
Melissa & Christopher Miller
Anna Sarkisova
Rex & Karen Speerhas
Charles & Rochelle Zeigler, in honor of Marion Winkler’s PhD

**Contributors ($30–$49)**
Mr. & Mrs. G. Camp, honoring memory of Florence Bye, family of Kirk & Ruth Bye, and Allen & LeeAnne Bye**
Jane Linday
Ms. Mercedes Marson
Mary Probus, in memory of Bob Klenke, 28 yrs of TPN

**Friends (Up to $30)**
Anonymous, in honor of Daniel DeHart’s 10 yrs on HPN!
Gretchen DeKalb, in honor of Mary Kunz’s birthday
Dale & Kevin Kronau, in memory of Joyce Hydorn
Lois Moran
Carmen Tullius

**In Memory of Florence D. Bye**
Mr. & Mrs. Robert Adamo
Joseph & Kimberly Ailes
Atlantic Coast Alarm Inc.
Carmen & Gertrude Barone
Paul & Elizabeth Bryant
The Victor Dosch Family
Mr. & Mrs. James Gehringer
Rose**, & Jeff Hoelle
Nicholas & Lisa Latarola
Karen Kindle
Dr. & Mrs. Kramer
Stephen & Jeanie McKeone
James Portock
Emily Reynolds

**Donna Stempin, in memory of Marlana Curry, Evdie Kirby, & Bob Sweet**

**Freihofers Community Walk**
Sharon Alger-Mayer, MD
Bill Berglas
Bert Crosby
Linda Dalton
Robert & Joseph Harrington
Robert & Cynthia Johnson
Dorothy Juda
Lawrence & Karen Juda
The Juda Family
Ronald and Bernice Lamont
Delores & Ron Metzger
Eleanor Orkis
Susan & Dan Staver
Antoinette Toczykowski
*Oley Trustee
** Oley Regional Coordinator
*** Oley Staff

Confidentiality

How do you know that the information reported on the QoL questionnaires will remain confidential? Oley will not be identifying individual’s questionnaires. Once a questionnaire is received at Oley it will be assigned a number. The list associating an individual with a number will only be seen by one designated person (the Oley administrative assistant). The names will be separated from the questionnaires and put into a locked box in order to keep the questionnaires anonymous.

The only time the list would be retrieved would be if follow-up questionnaires were done. In that case, the administrative assistant would assign the identifying number linked to the initial set to the repeat questionnaire from an individual, so that comparisons over time can be made. Once again, only the administrative assistant will have knowledge of who the consumer is.

HEN and QoL

What about Oley members who are enteral (HEN) consumers? Oley is interested in you as well, but we have not been able to acquire a similar QoL tool specifically developed for HEN consumers. At the Oley annual conference, I encouraged enteral consumers and clinicians to form a group to start developing such a tool. This is a time-consuming and rather daunting project. Certainly individuals who take on such a project could benefit from the model presented by the HPN QoL tool. The research committee can act as advisor to a subgroup identified to develop an HEN tool. Please contact the Oley office if this is something you are interested in.

Quality of Life, from pg. 2

are certainly free to share your questionnaire with them. If Oley does further questionnaires in the future, a comparison may be useful in identifying new or changing issues in your care.

How to Participate

If you are an adult HPN consumer, we encourage your participation! You may participate by contacting the Oley office through the Oley Web site (www.oley.org) or at 800-776-Oley. You will be sent three questionnaires (the general SF 36, the Scottish tool, and the Oley supplemental questionnaire), a medical information form, and a stamped envelope to use for returning the questionnaires.

We ask that consumers fill the questionnaires out personally. It is your responses that are important to us, not those of your caregiver, spouse, parent, or child. You do not have to complete the questionnaires at one sitting, but we suggest that you answer the questionnaires within two days if possible.

Do you have to be an Oley member to participate in this? Absolutely not! We would really like to have everyone who is on long-term PN included in the study. Some of the home infusion companies will have a link to the Oley Web site that will allow their consumers to participate. Word of mouth, between consumers and consumers to homecare companies, will help extend the study a great deal (hint). All questionnaires should be returned directly to Oley.

Tools are not available at this time for pediatric consumers of HPN. Such a tool may be developed in the near future for children and youth, also as a result of working with the Europeans. Stay tuned for this development.

Contributor News
Thanks for Supporting Oley Programs!

Please join us in thanking our corporate partners. This issue we highlight:

**Walgreens-OptionCare**

Walgreens-OptionCare is a single-source provider of total parenteral nutrition and/or enteral therapy with individualized care based on the patient’s therapy needs. The company's services provide care to those of any age and at any condition stage. Walgreens-OptionCare proactively manages the consumer's nutritional requirements with a thorough medical assessment, therapy monitoring, and 24-hour access to healthcare staff.

Walgreens-OptionCare is committed to outstanding clinical programs and quality care. “Our dietitians and home care professionals,” the company writes, “balance patient needs with those of the healthcare team to achieve successful results.” Walgreens-OptionCare offers accredited home infusion, respiratory therapy/oxygen, nutrition support, and home medical equipment in thirty-six states.

**B. Braun Medical Inc.**

A recipient of the 2007 Frost & Sullivan Medical Technology Global Excellence Award, B. Braun Medical Inc. has built a large store of knowledge and expertise in delivering innovative health care products, medical devices, and programs that enhance working processes in hospitals, alternate care settings, and medical practices—increasing safety for patients, doctors, and nurses.

The company writes, “Our 35,000 employees worldwide are proud of their commitment to translating customer needs into products with unmatched quality, superior technology, cost-effectiveness, and environmental responsibility.” Today, B. Braun offers a complete line of basic nutrition products for parenteral administration, including 3%, 8.5%, and 10% FreAmine® III (Amino Acid Injections), and concentrated Dextrose Injections. B. Braun states, “We are more than a reliable supplier of parenteral nutrition products—the company is a partner, too, providing customers with assistance on product decisions, technical support, and more.”

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**Oley Horizon Society**

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. To learn how you can make a difference contact Joan Bishop or Roslyn Dahl at 800-776-OLEY.

<table>
<thead>
<tr>
<th>John Balint, MD</th>
<th>Valerie Gyrko, RN</th>
<th>Nancy Nicholson</th>
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<tr>
<td>Joan Bishop</td>
<td>Alfred Haas</td>
<td>Rodney &amp; Paula Okamoto, RPh</td>
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<td>Ginger Bolinger</td>
<td>Shirley Heller</td>
<td>Kay Oldenburg</td>
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<td>Pat Brown, RN, CNSN</td>
<td>Alicia Hoelle</td>
<td>Judy Peterson, MS, RN</td>
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<td>Katherine Cotter</td>
<td>Jeff &amp; Rose Hoelle</td>
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<td>Jim Cowan</td>
<td>Lyn Howard, MD</td>
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<td>William Hoy</td>
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<td>Tom Diamantidis, PharmD</td>
<td>Darlene Kelly, MD</td>
<td>Roslyn &amp; Eric Scheib Dabl</td>
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<td>Hubert Maiden</td>
<td>Eleanor &amp; Walter Wilson</td>
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<td>Linda Gravenstein</td>
<td>Kathleen McInnes</td>
<td>Patty &amp; Darrell Woods</td>
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<td>The Groeber Family</td>
<td>Meredith Nelson</td>
<td>Rosaline Ann &amp; William Wu</td>
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**Oley Corporate Partners**

The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. We are grateful for their continued interest and strong commitment.

**PLATINUM LEVEL PARTNERS**

($70,000+)

- Apria Healthcare / Coram Inc., Specialty Infusion Services
- Nutrishare, Inc.

**GOLDEN MEDALLION PARTNERS**

($50,000–$69,999)

- NutriThrive

**SILVER CIRCLE PARTNERS**

($30,000–$49,999)

**BRONZE STAR PARTNERS**

($20,000–$29,999)

- Abbott Nutrition
- Nestlé Nutrition

**BENEFACTOR LEVEL PARTNERS**

($10,000–$19,999)

- Critical Care Systems, Inc.
- EMD Serono, Inc.
- Hospira, Inc.
- InfuScience, Inc.
- Walgreens-OptionCare

**PATRON LEVEL PARTNERS**

($5,000–$9,999)

- B. Braun Medical
- Kimberly-Clark
- Sherwood Clinical
- Sigma International

**CONTRIBUTORS**

($1,000–$2,499)

- Baxa Corporation
- Zevex, Inc.
### Toll-Free Numbers Available to US and Canadian Consumers!

The Oley Foundation is able to offer its toll-free lines to consumers in the United States and Canada. Two toll-free numbers are circulated to experienced homePEN consumers on a monthly basis. The goal is to make speaking with fellow lifeliners more affordable, and to provide Oley’s Regional Coordinators with a better grasp of their region’s needs.

Advice given by volunteer coordinators represents the experience of that individual and should not imply endorsement by the Oley Foundation.

Due to the expense, a per-minute fee charged to Oley, we ask that you limit your conversations to 30 minutes.

The schedule of toll-free numbers and volunteer coordinators is updated in each Lifeline Letter, and posted at www.oley.org. Comments? Call (800) 776-OLEY.

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<th>SEP. ‘08</th>
<th>OCT. ‘08</th>
<th>NOV. ‘08</th>
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<td><strong>Felice Austin/ Mariah Abercrombie</strong>&lt;br&gt;Henderson, NV&lt;br&gt;(888) 610-3008 PST</td>
<td><strong>Mariah</strong> is a 26-year-old college student; she’s been on PN since 1985 due to pseudo-obstruction and now short bowel. She also has a G-tube and ileostomy. She works as a nanny and enjoys many activities and hobbies. She is comfortable talking to young adults and parents. <strong>Felice</strong> is a single mother and former social worker. She was Mariah’s caregiver and has been an Oley RC since the late 1980s. June has had Crohn’s disease since age 15, an ileostomy since age 21, and has been on PN since age 39 (over 23 yrs., 14 hrs. every day). An Oley RC and an active support group member, June believes networking with others is important. A strong faith, volunteer work, and help from family and friends keep June upbeat.</td>
<td><strong>Lou Pacilio</strong>&lt;br&gt;Leeds, MA&lt;br&gt;(888) 610-3008 EST</td>
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<td><strong>June Bodden</strong>&lt;br&gt;Clearwater, FL&lt;br&gt;(888) 650-3290 EST</td>
<td>June had Crohn’s disease since age 15, an ileostomy since age 21, and has been on PN since age 39 (over 23 yrs., 14 hrs. every day). An Oley RC and an active support group member, June believes networking with others is important. A strong faith, volunteer work, and help from family and friends keep June upbeat.</td>
<td><strong>Anna Cyr</strong>&lt;br&gt;Sabattus, ME&lt;br&gt;(888) 650-3290 EST</td>
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<td><strong>Don Young</strong>&lt;br&gt;Porter Corners, NY&lt;br&gt;(888) 610-3008 EST</td>
<td>Lou was diagnosed with sarcoidosis and developed a swallowing disorder (a rare side effect). He was on HPN briefly, then weaned to tube feeding 9 years ago. He has a J-tube and an ostomy, and works PT as a radiologist. He is experienced with changing feeding tubes, caring for ostomy sites, and coping with not being able to swallow even saliva. Anna’s daughters, Mallory (aged 23) and Maisy (aged 15), were born with microvillous inclusion disease and have been on HPN almost since birth. She has experience with Hickman catheters, pumps, and G-tubes, as well as in child development. Anna works as a consultant with families of children with special health needs, and is an Oley RC.</td>
<td><strong>Sheila DeKold</strong>&lt;br&gt;Floyds Knobs, IN&lt;br&gt;(888) 650-3290 EST</td>
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<td><strong>Sheila DeKold</strong>&lt;br&gt;Floyds Knobs, IN&lt;br&gt;(888) 650-3290 EST</td>
<td>Don has been on HPN for 33 years due to short gut and Crohn’s disease. He also has an ostomy. Call him to learn more about central venous catheters, PICC lines, and reimbursement issues (i.e., Social Security, Medicare, private insurance, etc.) or for a great chat with someone who has a healthy perspective on living with HPN. Olivia has a G- and a separate J-tube for venting as well as an ileostomy, and requires catheterization overnight.</td>
<td><strong>Don Young</strong>&lt;br&gt;Porter Corners, NY&lt;br&gt;(888) 610-3008 EST</td>
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**Lifeline Letter**

The Oley Foundation  
214 Hun Memorial  
Albany Medical Center, MC-28  
Albany, NY 12208

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**Thanks for a Great Conference!**