Dietary Recommendations for Patients with Intestinal Failure  

K.N. Jeejeebhoy, MD, St. Michael's Hospital, Toronto, Ontario

Intestinal failure occurs when gastrointestinal function is inadequate to maintain the nutrition and hydration of the individual without supplements given via a tube into the upper bowel or via an intravenous catheter.

In order to formulate dietary recommendations based on scientific considerations, it is necessary to understand how intestinal resection alters the physiology of the intestine. The gastrointestinal tract is designed to act as a single unit from the stomach to the colon. Therefore, in order to understand the factors that contribute to intestinal failure, it is necessary to identify the role of each of the components in aiding the digestion and absorption of food and in the maintenance of the fluid and electrolyte status of the host.

PHYSIOLOGICAL CONSIDERATIONS

Stomach

The rate of gastric emptying regulates the progress of the meal through the small bowel. In turn, the rate of gastric emptying is dependent upon the consistency of the meal. Gastric emptying of liquids depends upon osmolarity and that of digestible solids on the particle size. Furthermore, intestinal contents entering the distal intestine inhibit gastric emptying.

Small bowel

Small bowel motility is three times slower in the ileum than in the jejunum. In addition, the ileocecal valve may slow transit, especially when part of the ileum has been resected. The normal adult small bowel receives about 5-6 liters of endogenous secretions (digestive juices) and 2-3 liters of exogenous fluids (oral fluids or fluids delivered via a tube) per day. It reabsorbs most of this volume in the small bowel. The amount reabsorbed in the small intestine depends upon the nature of the meal. With a meat and salad meal, most of the fluid is absorbed in the jejunum whereas with a milk and doughnut meal, less is absorbed proximally and more flows distally. In
Dietary Recommendations, from pg. 1 addition, the absorptive processes are different in the jejunum as compared with the ileum. These differences depend partly on the nature of the electrolyte transport processes and partly on the permeability of the intercellular junctions. In general, water absorption is a passive process following the active transport of nutrients and electrolytes. The transport of sodium creates an electrochemical gradient and this drives the uptake of carbohydrates and amino acids across the intestinal mucosa. Additionally, in the ileum there is neutral sodium chloride absorption. However, the net absorption depends not only upon these processes but upon the extent of back diffusion of the transported material back into the intestinal lumen through “leaky” intercellular junctions. In the jejunum these junctions are very leaky and thus jejunal contents are always isotonic (same tonicity as blood) as illustrated in Figure 1. Fluid absorption in this region of the bowel is very inefficient when compared with the ileum. Hence the ileum is important in the conservation of fluid and electrolytes, as shown in Figure 2. It has been estimated that the efficiency of water absorption is 44% and 70% of the ingested load in the jejunum and ileum respectively. For sodium, the corresponding estimates are 13% and 72% (See table below).

**Figure 1**

**Figure 2**

Colon

The colon has the slowest transit varying between 24-150 hours. The intercellular junctions are the tightest in this part of the bowel and the efficiency of water and salt absorption in the colon exceeds 90%5. In addition, carbohydrate is fermented in the colon to short-chain fatty acids (SCFAs), which in turn have two important actions. First, SCFAs enhance salt and water absorption. Second, the energy content of malabsorbed carbohydrates is salvaged by being absorbed as SCFAs. Recent data suggest that in short bowel patients this salvage may be greater than in normals. Thus, the colon becomes an important organ for fluid and electrolyte conservation and for the salvage of malabsorbed energy substrates in patients with a short bowel.

**Unique functions of the ileum**

The ileum uniquely absorbs vitamin B₁₂ and bile salts. Bile salts are essential for the efficient absorption of fats and fat-soluble vitamins. Normally the demand for bile salts imposed by fat absorption cannot be met by synthesis alone. The need for bile salts is only met by ileal resorption of bile salts which are then recycled into the intestine about six times per day. With ileal resection, the loss of bile salts increases and is not met by an increase in synthesis. The bile salt pool is depleted and fat absorption is reduced. In addition, loss of bile salts into the colon affects the colonocytes and reduces the ability of the colon to reabsorb salt and water resulting in increased diarrhea. In the colon, bile salts are also dehydroxylated to deoxy bile salts which induce colonic water secretion.

**EFFECTS OF INTESTINAL RESECTION**

**Gastric and Intestinal Secretion and Motility**

Gastric hypersecretion occurs after small bowel resection in response to increased gastrin output. This hormone may stimulate growth and adaption at the proximal bowel. On the other hand, hypersecretion of acid may reduce nutrient absorption by inactivating pancreatic enzymes. Reducing acid secretion improves absorption in patients with a short bowel. Furthermore, hypersecretion can cause nausea, reflux and hemorrhage from severe esophageal ulceration which may require proton pump inhibitors for control.

Gastric motility is enhanced following small bowel resection. While proximal small bowel...
Dear Readers,

We often receive inquiries about specific issues and requests for ideas or solutions to unique challenges. Just prior to the annual conference in San Francisco, we received a request for information about dressings for a mic-key on a 17 month-old boy with multiple medical issues who was starting to belly crawl. The movement the child was attempting was causing his mic-key stoma area to become irritated. Additionally, the child was sensitive to adhesives, and tape had to be avoided. Working with a home care team, they came up with trying a product called “Pro-Net”, a tube of stretchy netting fabric that is often used when casts are put on limbs. Their success was only partial, but they continued to experiment with wrapping multiple times and were satisfied with the result. She cautioned leaving the netting on for too long, as they encountered some skin breakdown. I posed this question at the Enteral Nutrition Workshop conference session, and some other ideas emerged, including:

- Cutting loops of panty hose (queen size) that could be put on the baby, (similar to an elasticized head band), but obviously around the abdomen to secure the dressing.
- Attaching velcro to a neoprene pad or thin foam pad, and wrapping the velcro around the baby, securing it behind his back.
- Also helpful was getting the “mini button” rather than the Mic key button as it is a little flatter. Parents can put Tegaderm around the stoma to prevent irritation when it’s sore and this allows for healing, parents just have to keep child upright more often to help with this process.

A helpful tip on cleaning and unplugging tubes:

I have two sons who are g-tube fed and I have found a way to clean and unplug connector tubes for buttons. Pinch the tube between your thumb and the dull side of a table knife, and run the knife down the tube exactly as if you were curling a ribbon. This will unplug most plugs, it will completely clean the crud out of the tube, and it only takes 5 seconds. I had tried using just fingers or fingernails, but it takes longer, is less effective, leaves a lot of crud behind, and can hurt your fingers. The knife works beautifully. Try it.

Sincerely,
Donna Miller

A reader’s recommendation followed by a question:

My son is a TPN patient. He is six years old and uses the CADD pump. He was having a hard time with the backpack the home care had given us to use. It was very big and bulky also very heavy for him to carry. Luckily, he would be hooked up at night. His nutrients run for 12 hours. We ride quads and looking at a catalog for apparel I came across a pack. It’s a hydration pack, it’s reservoir holds 70 oz. of water. It is designed to be worn on long rides. It is light weight and designed to distribute weight evenly. With many adjustments you can make fit comfortably. I took out the reservoir and I put the bag in its place. I then ran the line through a whole in the bottom. The pump was then placed upside down in the pouch at the front of the bag. I didn’t need to modify it in any way and it works perfectly. Maybe another child could benefit from this information. It’s called a Camelbak this particular bag in called “lobo”. Here is a link to their web site http://www.camelbak.com/rec/recreation.cfm. They carry many different styles. I hope this can help someone else.

Additionally...

My son has Intestinal Lymphangiectasia, this is a rare disease that affects children. I have started a web site to give parents support. Littleleakers.com. Can you tell me if there is anyone with this disease that you know of?

Thank You for your time.

Alecia Johnson
Simi Valley, CA

To communicate with Alecia about Lymphangiectasia, drop her a note through the “comments and suggestions” option on her website, www.littleleakers.com.

A word to the wise:

Dear Editor,

Please print this in your "LLL" as I think others should be aware that this practice goes on and they should protect themselves.

Last Fall, I spent 54 hours in the hospital for a line infection. I had a peripheral line placed and then a PICC placed for TPN and antibiotics. One morning, after my infusion was complete, the IV pump beeped incessantly. After ten minutes waiting for a nurse, I disconnected the tubing and then went looking for a nurse and flushing supplies. I found a cart outside my room and approached a nurse, I disconnected the tubing and then went looking for a nurse and flushing supplies. I found a cart outside my room with some supplies but no saline. A nurse came a moment later and pointed to a communal 1 Liter bag of sodium. “We use this for flushing lines,” she said. I had no choice but to allow her to administer it. I phoned my sister and said, “If the doctor is not going to discharge me today, please come and bring my single dose sodium chloride vials so I can flush my own lines.”

After discharge I spoke with the infectious disease doctor and he said he was aware of this problem but there was little he could do.

In the future, I will carry my own supplies. Just the thought of sharing a 1 Liter bag with several nurses and patients gave me the creeps. Not all nurses use the BEST technique. This practice has probably led to other BSI. I feel very fortunate that I did not contract another germ.

Sincerely,

Robin Lang-TPN consumer
2004 Oley Award Winners

The Annual Oley Awards Program recognizes homePEN consumers and family members who exhibit courage and perseverance in overcoming the challenges of long-term homebased medical care.

LifelineLetter Annual Award Winner
Malisa Matheny, Doylestown, Pennsylvania

Diagnosed as a young teen with pseudo-obstruction, Malisa has been on HPN, and sometimes HEN, for 11 years. Almost from the start she’s been involved at Oley. She was one of the first teenagers to volunteer as a Regional Coordinator, she’s helped with numerous conference youth activities, and she’s been a tremendous advocate for summer camp experiences for homePEN youth.

Watching her blossom into an capable, caring adult has been a pleasure. Her choice to pursue a career in pediatric nursing comes as no surprise. She is always giving generously of her time. In addition to working in the hospital, Malisa volunteers for many health-related organizations like CHOP, REACH and others. She also continues to coordinate special experiences for chronically ill youth, like trips to Canyon Ranch and wellness days for friends in a local support group.

Over the years she has helped hundreds of Oley members. She is a great listener and always has something positive to say to the teens, the younger kids, and the parents who care for them. She goes above and beyond to stay in touch with a large network of consumers, writes many cheerful messages, sends care packages and visits them.

She’s built a wonderful support network for herself as well, which has been especially critical this year to help her as they investigate the possibility of her having a second, new diagnosis: a mitochondrial disorder. True to her spirit, she is researching the disease, and adjusting to her lower energy level one day at a time. It is a privilege to honor Malisa today with this award and to share her shining example with everyone in the homePEN community.

Nominees:
Stephanie Harlow, Matthew VanBrunt

Oley Foundation Young Adult of the Year
Korey Harlow, Fredericksburg, Virginia

Oley member Korey Harlow, 12, has Inflammatory Bowel Disease (IBD), and Eosinophilic Gastro Enteritis Disease (EOG) He’s had a G-tube since he began middle school, was the first recipient of the new GJ button at his hospital and modeled the device for anyone wishing to see it. Korey has faced some uncomfortable issues such as changing for gym in a locker room full of pre-adolescent boys and having to explain the plastic button on his abdomen, and having tube feedings for lunch while his friends eat “real food”. He has always faced these challenges with poise and dignity.

In fact, Korey actively works toward raising awareness of IBD and how it affects the lives of those who have been diagnosed with this unforgiving disease. Korey has testified to the Virginia State Commission on Health Insurance, where he wrote his own statement about how his life is impacted by his illness. He’s also made a documentary for C.U.R.E.D. describing life with EOG and how his family has coped, and will participate in the Crohn’s and Colitis Foundation Hill Day.

Korey has three brothers with EOG who all have G-tubes. He helps his mother care for his siblings and fully cares for himself. He’s an expert on pump maintenance and function, he mixes formula, makes his own bags for school and troubleshoots errors with his pump. He’s also a leader of a group of students with IBD at Freedom Middle School, and provides them with motivation and inspiration on a daily basis.

Korey manages to have excellent attendance and maintains high academic standards, despite struggling with pain and the effects of large doses of steroids and 6MP. He’s a member of the Art Club and Science Club, and plays trombone in the school band. He has also been awarded numerous blue ribbons for his horse riding skills.

For his unwavering perseverance, his inspirational role-modeling for others and his work to raise national awareness, we are proud to present Korey with Oley’s Young Adult of the Year Award.

Nominees:
Emily Koprucki, Amherst, NY
Rachel Schten, Novato, CA
Samantha Fallacara, Cheektowaga, NY
Devin Barss, Regina, SK
Kyle Noble, Grove City, OH

Where Wishes Come True

Do you know what the face of magic looks like? It is the smile on the face of a child who learns that his or her dearest, most heartfelt wish is about to come true. If you know a child with a life-threatening medical condition, consider referring them to the Make-A-Wish Foundation.

Children between the ages of 2-1/2 and 18, who are living with life-threatening medical conditions, are potentially eligible for a wish. Several Oley members have had their wishes granted, for things like family vacations and playground equipment.

Making a referral is simple. Visit www.wish.org and click on “wish referral.” You can also call (800) 722-9474. For special children, like ours on homePEN, there is nothing like the power of a wish. Make a difference in a child’s life by helping to make their wish come true!
the adversity of illness and are generous in the effort of helping others. Congratulations to all winners and nominees!

Celebration of Life Award
Megan Gravenstein, Huntsville, Texas

At 22, Megan’s lived with intestinal failure for almost all of her life, and in recent years Hepatitis C as well. She’s faced these trials with tenacity and vigor—embracing her community, her education and her independence.

Despite spending most of her high school junior and senior years in the hospital, she graduated on time, and received the Senior Merit Award from her Drama Department and the Human Spirit Scholarship. She walked across the stage for her diploma to a standing ovation. Megan now lives fully independently, attending Sam Houston State University full-time while also caring for older relatives and her three feline roommates. She’s studying criminal justice and plans on a career in child-advocacy.

While most patients would not be able to attend school full-time and participate in community outreach programs, Megan has showed motivation that surprises her doctors, family and friends. On days when she’s experiencing severe pain or exhaustion from being up all night, she’s managed to get out, accomplish her tasks and get through a full school day. She’s treasured her time in school, has directed a play for her Drama Department and has even traveled to England to study Shakespeare with her theater class. Additionally, Megan has committed herself to visiting a nursing home during the holidays with gifts and flowers for the residents. Even when Hepatitis took away her ability to walk, she retaught herself and managed to visit her elderly friends; her smile never wavered.

We are proud of Megan’s perseverance and growth into an independent, caring and capable woman. Her attitude is “can do” and her focus is on the positive, but it’s her zest for life that makes her truly deserving of the Celebration of Life Award.

Nominees:
Samantha Fallacara, Cheektowaga, NY
Todd Friedman, San Pedro, CA
Jake Ryan, Alexandria, VA
Albee Ginger Bolinger, Rio Rancho, NM
Diana P. Rhodes, Powys, UK
Dawn Dewien, East Amherst, NY

Nan Couts Award for the Ultimate Volunteer
Richard Patt, MD, Houston, Texas

Dr. Patt’s dedication to patients is evident through his home-based private practice where patients can relax in his garden or discuss their cases in his living room. He has cared for Oley member and HomePEN consumer Megan Gravenstein (winner of the Celebration of Life Award) for many years and was a guest speaker at this year’s conference.

His formation of the National Chronic Pain Society and his volunteerism of time and money to this cause further illustrate his devotion to patients, regardless of their diagnosis.

The first conference for chronic pain sufferers was spearheaded by Dr. Patt and the national Chronic Pain Society would not exist without his efforts, money and time. Instead of working with a large organization or group of doctors, Dr. Patt has opened his home and his heart to his patients, as demonstrated by one grateful woman who delivered a banana pudding to thank him for caring for her dying husband, despite the fact that he was not a privately insured, wealthy man.

Last year, Dr. Patt opened his home for a fundraiser dinner where he was able to arrange for Dr. Patch Adams to be the special guest speaker. Although Dr. Adams was the special guest, the evening’s stories, told by family members of current patients and those that have died, revolved around Dr. Patt’s dedication to those in his care and the fact that in his case, care is not profit-driven but instead driven by compassion and old-fashioned, hands-on caring.

Dr. Patt’s dedication to sufferers of chronic pain and homePEN consumers is what makes him so deserving of the Nan Couts Award for Ultimate Volunteerism.

Nominees:
Anne Julmann, RN, Waukesha, WI
Melinda Parker, MS, RD, San Francisco, CA
Kerry Stone, RD, San Diego, CA

Lenore Heaphey Grassroots Education Award
Ruthann Engle, Streetsboro, Ohio

A TPN consumer for 14 years due to Short Bowel Syndrome, Ruthann has taken an active role in developing the northeastern Ohio Oley support group in the past few years. With help from Jim Cowan and Bert Gelle she has increased the initial membership of four to the current membership of 20.

Ruthann provides members of her group with current clinical articles, insurance updates and information on national Oley meetings and publications. She also arranges for a speaker at each of these regional meetings who brings fresh, innovative and valuable information to the group. She makes regional Oley information available through e-mail to those individuals who are unable to attend those meetings. She’s also been a valuable contributor to the LifelineLetter.

Ruthann is an integral and invaluable asset to the Oley Foundation, and has illustrated true dedication to the education of parenteral and enteral nutrition consumers. Her volunteerism has earned her this year’s Lenore Heaphey Award for Grassroots Education.

Nominees:
Robin Lang, York, ME
June Bodden, Clearwater, FL
Silent Auction bidding with mom and dad’s money!

Snapshots...

A consumer receives information and a smile at a vendor’s exhibition booth.

Nader El Samaloty and Regional Coordinator Rose Hoelle celebrate together.

Regional Coordinator Robin Lang with Jeff Hoelle and former Oley Publicity Director Roz Dahl.

Josie Dietel, sister of Jackson Dietel, models her balloon chapeau next to her mother, Kathleen Jackson, MD.

Dr. Howard shares information with Madalyn George-Thiemann and her husband Dale, parents of consumer Ray George.

Newcomers Tom and Jane Parker.

Eric and Rachel Schten


Silent Auction bidding with mom and dad’s money!
Dear Joan,

I can’t begin to tell you how gratifying it was to again be a part of your recent Foundation Conference. As always, there was much to learn and do, as well as getting to personally know some of the members and families. The attendees clearly come away with an increased sense of community and support, and the bonding among the participants was palpable.

As promised in my e-mail, enclosed are two CDs with photo images I took at the Oley Conference in San Francisco. I’m sure you’ll recognize most of the individuals in the photos. As you can probably tell from the pictures, trying to keep up with those Jammin’ Jammies was no small feat!

Please enjoy the photo memories and share them with your colleagues and membership as desired. It was a terrific conference and we look forward to continuing to grow our relationship with Oley and its members in the years to come!

Sincerely,

Frank A. Murawski

Jammin’ Jammies Festivities.
Thank You for Making the 2004 Conference a Success!

A huge thank you to everyone who volunteered their time and resources so generously.

Medical Support:
Coram Healthcare

Conference Registration Bags:
Nutrishare, Inc.

Conference Videotaping Services:
Abbott Laboratories/Creative Network

Lunch (both days):
Sponsored in part by Coram Healthcare

Conference Program Books:
Ross Products

Travel Scholarships for Consumers:
Anonymous; Bruce Groeber Memorial Fund; Sunshine Scholarship Fund; Walgreen’s Health Initiatives

Support for Speakers:
Boston Scientific; Cleveland Clinic; Coram Healthcare; Crescent Healthcare; Janssen Pharmaceuticals; Mayo Clinic, Rochester; Medtronic; Mediflex; Nutrishare, Inc.; Option Care

General Conference Support:
NPS Pharmaceuticals; Anonymous; Pat Brown; Joseph & Kathryn Cleberg, RN; Mary Friel; Todd Friedman; Linda Hopwo; Jane Lindsay; Elias & Joan Medwar; Sheila Messina, MS, RN

Gifts/Flowers for Award Winners:
Zevex, Inc.

Journaling for Youth:
Nutrishare, Inc

Sharps Containers
Sharps Compliance, Inc.

Photographs:
Pat Brown, RN; Jim Wittmann; Frank Murawski of Ross Products

Oley T-shirts, Hats, etc.:
Party and Darryl Woods

Registration:
Jeff Hoelle (Mr. Oley!)

Silent Auction:
A big “Thank You!” to all that donated and purchased items!!

Sunshine Scholarship Fund:
Robin Lang and all who contributed

Audio/Visual Equipment Support:
Abbott Laboratories/Creative Network; Stephanie Pelham

Child Care:
Marjorie Quinn

Jammin’ Jammies:
Ross Products

Youth Activity (both days):
Ross Products

Awards:
Pediatric Services of America; Judy Peterson, RN, MS

Exhibitors:
Baxter Healthcare Corp.; BD Medical Systems; Boston Scientific Corp.; Coram Healthcare; Crescent Healthcare; Mayne Pharma; Nestlé Clinical Nutrition; Novartis Medical Nutrition; Nutrishare, Inc.; Option Care, Inc.; Patient Support Services, Inc.; Ross Products division of Abbott Labs, Inc.; Serono, Inc.; Shield Healthcare; Thomas Crown Publishing; Tyco Healthcare/Kendall; VIASYS MedSystems; Zevex, Inc.

Faculty:
Mariah Abercrombic; James C. Andrews, MD; Jane Balint, MD; William Berquist, MD; Marcia Boatwright, RN, CRNI; Patricia Brown, RN, CNSN, OCN; Mica Coffin; Gordon Eckerling, MD; Marti Fledderman, MS, RN, CS, PNP, CNS; Pamela Fogle, MS, RD; Roy George; Megan Gravenstein; Megan Hoelle; Lyn Howard, MB, FRCP, FACP; Carol Ireton-Jones, RD, PHD, LD, CNSD, FACN; Darlene Kelly, MD, PHD, FACP; Kristy Kuhl; Vanessa J. Kumpf, PharmD, BCNSP; Sheila Messina, RN, MA; Nadine Nakazawa, BS, RN, OCN; Anthony Nichols, PHD; Melinda Parker, MS, RD; Richard Patt, MD; Stephanie Pelham, RD; Craig Peterson, RD, CNSD; Susan Poole, RN; Michael Rigas, PharmD; Marcia Ryder, PHDC, MS, RN; Rex Speerhas, PharmD; Ezra Steiger, MD; Marc Stranz, PharmD; Darryl Strickler; Stephen Swensen; Elizabeth Tucker; Marcia Wise, RN; Darrell Woods.

Keeping It Simple
Realizing that the holiday giving season may not be the best time for everyone to write a check, we are implementing a policy to include a donor envelope in each issue of the LifelineLetter...simply to make it easy for you to consider supporting Oley programs.

Thank you so much!

Hiking through the Redwood Forest.
Foundation Offers Assistance to Children

The First Hand Foundation is a philanthropic, nonprofit foundation established by the associates of Cerner Corporation. First Hand helps the families of children with health problems address the financial aspects of their child’s health care.

Generally, requests for grants and cases that receive funding fall into one of three broad categories of assistance. (1) Clinical expenses: Expenses associated with clinical procedures and treatment, such as prescriptions, therapy, prostheses, specialized infant formula, organ transplants, craniofacial reconstruction, or dental work clinically relevant to the child’s well-being and health. (2) Durable medical goods: Expenses such as wheelchairs, assistive technology equipment, specialized transportation, van lifts, and other forms of physical equipment that are clinically relevant to the child’s well-being and health. (3) Displacement Expenses: Expenses associated with families of seriously ill children who must relocate during treatment. Displacement costs may be for either a member, or members, of the family or the child. First Hand considers covering costs that allow the child to be with a family member(s) during treatment to be clinically relevant.

In order to be considered for funding, the following criteria must be met. The child must be under the care of a pediatrician. (First Hand provides funding for individuals up to 20 years of age. Any child over the age of 17 must be in a childlike mental state to be eligible for funding.) The case must involve a specific child with a specific need. The request must be clinically relevant to the health of the child. There must be no existing financial net, such as Medicaid or private insurance, to cover the requested expenses. The case must be in a proactive stage. Requests for debt reduction of expenses already incurred will not be considered.

For more information about the First Hand Foundation, visit their website at www.firsthandfoundation.org.

Equipment Exchange

The following supplies are offered free of charge to readers:

**Enteral Formula**
- 1 case Fibersource HN, exp. 2/05
- 10+ cases Osmolite 1 cal (formally HN), exp. 1/05
- 3 cases RCF formula, exp. 3/05
- 3 cases Glucerna w/ fiber, exp. 3/05
- 1 case Jevity 1.2, exp. 2/05

**Tubes/Administration Sets**
- Kangaroo 1000 ml pump sets
- 20 Kangaroo 1000 ml bags
- Ross EZ feed 1000 ml bags
- Ross Companion Bags
- 1 case Ross Gravity Bags, 1000 ml
- 21 Baxter ext. sets 16", 0.22 micron filter, # 2C5671
- 2 Baxter ext. sets 21", 1.2 micron filter, # 2C1103
- 1 Baxter ext. sets 8”, 0.22 micron filter, # 1C8363
- 6 Baxter Continu-Flo Solution sets, # 2C7595
- 8 Sabratec 6060 sets, .22 micron filter, # 567122-L
- 12 Sabraset Sets with spike/cassette, # 560100

**Miscellaneous**
- 2 TPN Backpacks
- 1 box Bio Dressing (Johnson & Johnson)
- 20+ 4” x 4” Sterile drainage sponges
- 50 Kendall Rayon Tip Applicators
- 12 cases Large pull-up diapers
- 4-2 oz Bolus catheter tip feeding syringes
- 100+ 12 cc syringes
- 2-60 ml syringes
- 6 Clave needle free injection site (luer lock)
- 2 Gripper Port-a-cath needle 0.7 mm (22G) x 19 mm (3/4 in)
- 1 Gripper Port-a-cath needle 0.7 mm (22G) x 25 mm (1 in)

MORE SUPPLIES are available! For a complete listing, visit our website at www.oley.org or contact Cathy at HarrinC@mail.amc.edu, (800) 776-OLEY. Oley cannot guarantee the quality of the supplies donated or be responsible for their condition. In the spirit of Oley, we ask that those receiving goods, especially heavy items like enteral formula or infusion pumps, offer to pay for shipping.

Mom Needs Support!

*Alicia Enriquez, mother of a nonverbal, 25 year-old writes:*

My daughter Andrea has a muscle disease called Retts Syndrome. Due to the muscles not working properly in her stomach, she cannot eat very much. She has a G-tube for feeding. It’s a struggle to get 750 calories in her in a 24-hour period. She infuses Peptamen Jr. and Peptamen 1.5. She’s very thin (under 50 pounds).

If anybody has any suggestions, please contact me at (760) 726-7861.
In Memory of Elsie Roesch
Contributions from Kay Oldenburg, Robin Lang and Joan Bishop

Elsie Roesch entered the world of home nutrition support a little unstable psychologically. One of her physicians had told her that people don’t live long on TPN. Thankfully, she found the Oley Foundation and discovered just how untrue that information was.

Her involvement with the Oley Foundation began shortly after a discussion Elsie initiated with her physician regarding her struggle adjusting to life on TPN. Regional Coordinators, Kay and Clarence “Oley” Oldenburg were called and quickly reached out providing information and assistance. Kay recalls watching the Yankees play in the World Series on the television during their first visit and how this common bond helped them connect. Shortly after this visit, with a long period of feeling secluded behind her, Elsie moved forward, living her life...attending the Oley conferences, becoming an Oley volunteer herself and surrounding herself with “Lifeliners” from across the country. It seems that the Oley Foundation contributed to improving her quality of life, which is the very goal of Oley.

In return, Elsie inspired her physicians, homecare company representatives, Oley staff and fellow Oley members ten-fold. She was a delightful woman with a huge heart and a quiet demeanor.

Early in June 2004, Elsie moved into the Francis House (a Hospice Inn) where she ended her long journey with TPN, passing away peacefully on June 24th at the age of 75.

Kay Oldenburg attended her memorial services and had an opportunity to speak with Elsie’s brother who reflected on how proud his sister was to be involved with the Oley Foundation. We’re grateful for the chance to know her. She’ll be missed!

From the Desk of Joan Bishop, Executive Director...

With summer drawing to a close and the holidays on the horizon, it seems natural to reflect on recent activities and glance at upcoming efforts. In June our energies were focused on our annual program in San Francisco - the 19th Annual Oley Consumer/Clinician Conference. What a wonderful gathering of Oley members: the extraordinary professionals who so generously give of their time and expertise to support this educational endeavor; the consumers who crossed the country to bring their perspective and to learn more about the therapies that sustain them; and the representatives of industry who showcase their products and services and end up walking away much more enlightened about the needs of those they serve. It is a thrill to be a part of this connecting!

Witnessing the value of bringing everyone together makes it easy to swing into gear planning for the 20th Annual Conference. Mark your calendars! Returning to where it all began, next year’s activities will be held from June 27 to July 1 at the Holiday Inn in Saratoga Springs, NY. We appeal to you for ideas/suggestions for next year’s program and related activities. Please send them to bishopj@mail.amc.edu or call (800) 776-6539.

I continue to be deeply moved by how much time and effort Oley members are willing to give in assisting each other. Not a day passes that I am not reminded of the “above and beyond” efforts being made to bring comfort, information and support to others in the Oley family. The result is a stronger community. The sacrifice and sharing that is exhibited can be humbling and overwhelming. It fuels those working on your behalf with passion. We push harder to achieve our goals - personal and professional.

At the most recent Board Meeting I was pleased to report that Oley will be ending the 2004 fiscal year in the black. This is very exciting. Despite the poor economy, increased unemployment and a strong prediction that nonprofits will struggle financially, Oley Foundation members keep us on solid ground. Thank you for allowing me the privilege of standing behind this “good health” ($$).

I look forward to the exciting Regional Conference being held in Chicago on November 13th. Plans are also underway for a Regional Conference in Orlando on January 29, 2005 (being held in conjunction with Nutrition Week activities at Gaylord Palms from January 30-Feb 2, 2005). These are wonderful educational opportunities as well as occasions to meet other consumers. Plan to join us for either or both if you can.

I conclude by wishing you all a happy healthy fall season and remind you that we always look to improve on what we do. We thrive on new ideas! This is your organization - keep them coming!