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The Cleveland Clinic’s Experience with Home Parenteral Nutrition Associated Liver Disease
Therese Austin, MS, RD, LD, CNSD; Douglas L. Seidner, MD, FACP, CNSP

Parenteral nutrition (PN) is a lifesaving treatment for patients with intestinal failure who are unable to ingest or absorb an adequate amount of nutrition, fluid and electrolytes from their diet. While the benefits of this therapy are obvious, the complex nature of providing intravenous nutrition is accompanied by a variety of problems, the most common being infections and mechanical complications associated with the vascular access device used to receive this therapy. Metabolic complications include fluid and electrolyte abnormalities which are usually associated with the underlying disease. One of the more serious metabolic complications is the development of liver disease. In this article, we will discuss the experience of the Home Parenteral Nutrition Service at the Cleveland Clinic. These results were recently published in the Journal of Parenteral and Enteral Nutrition, a professional publication of the American Society of Parenteral and Enteral Nutrition.

How Common Is Liver Disease?
Numerous studies have been conducted to investigate how many patients on long-term PN (usually defined as 6 months or more) develop liver test abnormalities and significant liver disease to help determine the cause of this problem. Some of these studies have shown an incidence of liver test abnormalities ranging from 25 to 100 percent and that advanced liver disease may occur in 15 to 40 percent of these patients.

The Home Parenteral Nutrition (HPN) program at the Cleveland Clinic is one of the largest HPN programs in the country. A computerized medical record has been used to help us manage consumers who require long-term PN. We conducted a study to investigate the prevalence of abnormal liver enzymes and advanced liver disease in an attempt to identify risk factors that might be associated with these abnormalities. The study was done by querying our medical records.

Annual Conference ‘07
Plan to join us June 27 to July 1, 2007 at the Cape Codder Resort and Spa (www.capecodderresort.com) in Hyannis, MA, on Cape Cod. Offering crisp ocean air and rolling sand dunes, scenic back roads and quintessential charm, endless attractions and great shopping — Cape Cod is the perfect setting. Your days are crammed with opportunities to learn more about the therapy that sustains you, and your evenings filled with great fellowship and plenty of opportunities to relax and enjoy!

The conference rate at the Cape Codder is $129 for single or double occupancy and is being offered to attendees three days pre and post conference. Hurry! A limited number of rooms have been reserved at this reduced rate. Book now by calling (508) 771-3000.

Parenthood and TPN
Liz Tucker, HPN Consumer and Parent
Over the last six months or so, we have had several requests from young women on TPN with questions about pregnancy, parenting and TPN. This article is a compilation of the questions, concerns and experiences of the following TPN consumers: Bettemarie Bond, Dannene Bone, Malisa Matheny, Sally Moore, Candace Verner, David Young and myself. Obviously we won’t have all the potential questions and answers, but we hope we will give you something to think about.

Start Thinking Ahead
Everyone agreed that parenting is not a decision to be made lightly or quickly. Give yourself plenty of...
Liver Disease, from pg. 1

For the purpose of our study we classified liver tests into two main categories; either liver associated enzymes (LAEs) or liver function tests (LFTs). LAEs include aspartate aminotransferase (AST), which reflects inflammation or injury to hepatocytes (one of the major cells within the liver) and alkaline phosphatase (AP), which reflects inflammation or obstruction of the biliary system of the liver. We categorized the degree of abnormality for these labs as mild, moderate or severe depending on the degree of elevation (see table 1). LFTs were defined as blood tests that reflect the metabolic capacity of the liver and include bilirubin, albumin and prothrombin time. These labs were combined to determine overall liver function. This measure was only felt to be important when the bilirubin was over 3 mg/dL, the albumin was less than 3.2 mg/dL and the prothrombin time was more than 3 seconds prolonged. Patients with these results were defined as having severe liver dysfunction. (Note: these values vary slightly from table 1 because they are based on a Childs-Turcotte-Pugh score.) Patients with a known liver disease, drug induced liver injury, alcoholism and cancer, all of which can cause an elevation in LAEs, were excluded from the study. Patients with a transient elevation in LAEs were excluded by only studying patients who had lab abnormalities on more than one occasion over a period of at least 6 months. In addition to these laboratory results we gathered information on the patient’s age, gender, underlying disease, indication for PN and PN formula.

There were a total of 162 patients that constituted the study group. The clinical characteristics of these patients are shown in table 2. The average duration of PN in these patients was 2.14 years. While this may seem relatively brief, this reflects the fact that many patients are able to discontinue PN within one year. Many patients were on PN for more than two years and one patient was on therapy for more than 10 years. We found that 92 (57%) patients had chronically abnormal LAEs.

Table 1: Categorization of Liver Test Levels

<table>
<thead>
<tr>
<th>Liver-Associated Enzyme (LAEs)</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>aspartate aminotransferase</td>
<td>upper normal to</td>
<td>2-5 times</td>
<td>&gt;5 times</td>
</tr>
<tr>
<td>alkaline phosphatase</td>
<td>&lt;2 times normal</td>
<td>normal</td>
<td>normal</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Liver Function Tests (LFTs)</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>total bilirubin</td>
<td>1.5-1.9 mg/dL</td>
<td>2-3 mg/dL</td>
<td>&gt;3 mg/dL</td>
</tr>
<tr>
<td>albumin</td>
<td>3.6-3.9 mg/dL</td>
<td>2.8-3.5 mg/dL</td>
<td>&lt;2.8 mg/dL</td>
</tr>
<tr>
<td>prothrombin time</td>
<td>13-16.9 sec.</td>
<td>17-19 sec.</td>
<td>&gt;19 sec.</td>
</tr>
</tbody>
</table>

Note: these levels were used for the purpose of this study and are not used for general medical care.

Table 2: Clinical Characteristics of 162 Cleveland Clinic Patients Receiving Long-term PN

<table>
<thead>
<tr>
<th>Demographics</th>
<th>53 years +/- 14 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Male</td>
<td>60</td>
</tr>
<tr>
<td>Age Female</td>
<td>102</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Underlying Diagnosis</th>
<th>56</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inflammatory bowel disease</td>
<td>56</td>
</tr>
<tr>
<td>Mesenteric ischemia</td>
<td>15</td>
</tr>
<tr>
<td>Radiation enteritis</td>
<td>9</td>
</tr>
<tr>
<td>Other gastrointestinal disorders</td>
<td>32</td>
</tr>
<tr>
<td>Other medical disorders</td>
<td>43</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Indication for parenteral nutrition</th>
<th>79</th>
</tr>
</thead>
<tbody>
<tr>
<td>Malabsorption</td>
<td>79</td>
</tr>
<tr>
<td>Fistula</td>
<td>35</td>
</tr>
<tr>
<td>Bowel obstruction</td>
<td>20</td>
</tr>
<tr>
<td>Other</td>
<td>18</td>
</tr>
</tbody>
</table>

*Diagnosis was only available for 155 patients and indication for parenteral nutrition was only available for 152 patients.
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 DablR@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.

Clothes Hold Tubes, IV Lines, Bags

The BundieBaby is a onesie-like outfit designed for children with G/J-tubes, ostomy bags, bile bags, central lines, and/or other medical devices attached to the torso. Jody Williams designed the outfit to overcome some of the challenges she faced as a foster parent of medically fragile infants; namely, keeping active infants/toddlers safe from tugging on necessary tubes, lines and bags, and comfortable during frequent changes due to leaks or doctor exams.

The front panel is equipped with two special pockets. A smaller front pocket on the left stores gastrostomy tubing, and can hold a standard nursing pad as well to absorb leaks. A larger pocket behind the G-tube pocket accommodates ostomy bags, bile bags or other medical devices attached to the torso. The inside side seams have ties to secure a central line or apnea monitor leads.

The Bundie’s front panel can be removed and replaced with a clean panel without lifting or disrobing the wearer. The armholes open completely for ease in dressing, especially those with IV lines attached to the arms. The snaps are plastic so the outfit can be worn during MRI testing. For more information or to order, visit www.BundieBaby.com or call (410) 884-0982.

Tube Feeding Workshops

A series of workshops designed to teach professionals and parents about the medical and social aspects of tube feeding will be held in several cities in 2007: January 20-21 in San Diego, CA; March 9-10 in Birmingham, AL; and October 25-26 in Cincinnati, OH. Entitled “Tube Feeding with Love,” the workshops feature Marsha Dunn Klein, MEd, OTR/L, a pediatric occupational therapist who specializes in feeding infants and young children. Attendance costs $350 for professionals and $200 for family members. CEUs are available. For more information call (520) 323-3348 or visit www.mealtimenotions.com.
Lending a Helping Hand

Oley has many volunteers who generously give of their time and talents to support Foundation programs. Some take the toll-free line each month, Regional Coordinators offer education and support, while others write articles for the newsletter or help organize conference events. Here we’d like to offer a special thanks to our “behind the scenes” volunteers who help at the Oley office.

Nancy Linsley has come to the Oley office every Wednesday, since Ellie Wilson (former Outreach Coordinator) first introduced her to us four years ago. She helps the Oley staff by addressing the hundreds of information requests we receive each month. Nancy is also instrumental in getting out large mailings, and preparing staff materials for special events. She is loads of fun and raises our spirits tremendously.

Blanche Hoffman is another terrific helper who volunteers at the office regularly, doing mailings and the like. In addition to her sense of humor, Blanche offers the understanding that comes with living with a husband who has been on tube or IV therapy for more than ten years. We are so happy to have her on board!

A third volunteer, who helps out in the office whenever we have special projects, is Joyce Hydorn. Joyce and her husband Bob have also been a big help at locally-held events and conferences. Joyce is a long-term TPN patient, and began volunteering after her health prevented her from working full-time.

A good friend of Joan Bishop, (Oley’s Executive Director,) Marjorie Quinn has a warm personality that’s endeared her to the rest of the staff and many Oley members. Marjorie has worked on a number of projects in the office, and helps out at the annual conference and local events too. She attended her first conference in 2003 and has helped at every conference since – donating her time as well as paying her own travel expenses! She is very dedicated to Oley.

We are grateful to all of our volunteers for their many contributions. Truly we could not run Oley without you.
**Summaries of Conference Sessions Available**

Summaries of the 2006 Oley Conference sessions that were filmed for DVD are available. Sessions include: What Is Rational Management?, Being All That You Can Be, Reducing HPN Dependency, What Are Probiotics, MicroNutrients, and the History and Future of HPN. The summaries can help you decide which DVD you’d like to borrow from the Oley Library.

Summaries of other Oley DVDs/videos are coming later in 2007. To read the summaries or order the DVDs, visit www.oley.org or contact Cathy Harrington at (800) 776-OLEY.

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**Equipment Exchange**

Newly available items offered free of charge include:

**Formula:**
- 3 cases Complete, exp. 4/07
- 6-7 cases Elecare Pediatric Formula (powder), exp. 8/07
- 3 cases Jevity 1.2, exp. 7/07
- 5+ cases Jevity 1.5, exp. 8/07
- 3 cases Fibersource HN, exp. 11/07
- 4 cases Glucerna, exp. 1/07 & 4/07*
- 2 cases Osmolite 1 Cal, exp. 7/07
- 9 cases Osmolite 1.2 Cal, exp. 4/07*
- 5+ cases Pediasure, vanilla, exp. 7/07 & 8/07*
- 14 cases Peptamen, exp. 7/07 & 8/07
- 4 cans powder, Portagen, exp. 8/07 & 1/08
- 6.5 cases Promote with fiber, exp. 3/07
- 2 cases Promote, exp. 1/07
- 3 cases Pulmocare, exp. 3/07
- 4.5 cases Traumacal, exp. 2/07 & 9/07

**Bags/Tubes:**
- 17 Kangaroo 1000 ml bags
- 30 Kangaroo gravity feed sets, 1000 ml, #8884702500
- 30 Ross Easy Feed Enteral Bag, 1000 ml, #56
- 1 Viasys enteral feeding tube w/o stylet, 8 Fr., 36”, #20-1368
- 56 Zevex Infinity 1200 ml bags, #INF1200*

*multiple donors

**MORE SUPPLIES** are available! Visit www.oley.org, or contact our volunteer, Ben Hawkins (benhawkins@fuse.net; toll free 866-454-7351). This number reaches Ben’s home, so PLEASE, CALL BEFORE 9 P.M. EST! (Not CST as incorrectly printed last issue.)

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

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**Don’t Miss Us in Phoenix!**

Start the new year out right by joining Oley on January 27, 2007 in Phoenix, Arizona! This one-day regional conference will show you what’s new in homePEN therapy for 2007. Topics include the emergent therapies, Pre/Probiotics, as discussed by Kelly Tappenden, RD, PhD and Growth Factors: GLP2 and Teduglutide, covered by Palle Jeppesen, MD, as well as Complications Associated with Vascular Access, by Sheila Messina, RN. Roundtable sessions will be hosted by Lyn Howard, MD and Jane Balint, MD, on Pediatric Issues; Kishore Iyer, MD, on Intestinal Failure; Doug Seidner, MD, on Avoiding Complications; and Sheila Messina, RN, on Sharing from the Consumer Perspective. Registration begins at 9:00 a.m. and the program will run from 10:00-4:30 p.m. Walk-ins are welcome. Stay tuned to www.oley.org for the exact location of the conference and for program updates.

Oley’s conference has been developed in conjunction with the annual meeting of the American Society for Enteral and Parenteral Nutrition (A.S.P.E.N.). A.S.P.E.N.’s “Clinical Nutrition Week” runs from January 28-31 at the Phoenix Civic Plaza. We invite you to join us there too by volunteering at Oley’s booth in A.S.P.E.N.’s exhibit hall. Don’t miss this rare opportunity to be among hundreds of exhibitors showcasing their newest products. Volunteers are needed January 28, 29 and 30 to work one or more shifts at the Oley booth from 9:30 a.m. to 11:15 a.m., 12:15 p.m. to 2:45 p.m. and/or 3:00 p.m. to 4:15 p.m. each day. For more information or to volunteer, contact Kate Swensen at (800) 776-OLEY or email Swensek@mail.amc.edu.

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Volume XXVII, No. 6 (800) 776-OLEY • LifelineLetter — 5
Regional News

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 the institutions around the country 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.

University of California, Los Angeles Medical Center

The Home Parenteral Nutrition (HPN) program at the UCLA Medical Center was founded in 1974 by Dr. Marvin Ament. The program was the first of its kind in California and serves both pediatric and adult patients. Consumers are seen in a designated PN clinic, where besides receiving care from an expert multidisciplinary team of physicians, RN specialists, a social worker, dietitian and pharmacist, there are opportunities for meeting other HPN consumers.

The team at UCLA cares on average for 70 to 75 HPN consumers, as well as individuals who are supported on enteral nutrition or who have successfully been weaned from PN. The team has a strong commitment to consumer and caregiver education, advocacy and support. Quality of life issues for consumers and caregivers are a strong team focus.

The UCLA Medical Center provides a full range of experienced medical and surgical specialists to support the special needs of the HPN population. The UCLA Homecare Pharmacy was one of the first homecare pharmacies in Southern California and continues as an experienced provider of HPN and other home infusion therapies.

In 1991, the UCLA Intestinal Transplant program was founded under the direction of Dr. Douglas Farmer, completing the full scope of services available to individuals with intestinal failure. For more information regarding the HPN program at UCLA contact Laurie Reyen, RN, MN (310) 825-4823 or nsler@mednet.ucla.edu.

Welcome Aboard!

Please join us in welcoming our two newest Regional Coordinators:

Shannon Curran (HEN) — Ontario, Canada

Shannon began using her first j-tube at the age of 16. Now 27, she still uses a j-tube but is currently waiting for a MIC-KEY. Shannon feels she is a very good troubleshooter. She also has been surprised that so few Canadians really know anything about HEN and Oley. Shannon is hoping to educate Canadians and enhance OLEY’s presence in Canada through a variety of seminars and meetings. She is available to talk and offer her insights to new users as well. Shannon can be reached at (705) 728-6123 or shannon122122@hotmail.com.

Joseph Rodgers (HEN) — New Bedford, MA

As a teenager, Joseph was diagnosed with Achalasia, a rare and degenerative disorder of the esophagus. Joseph experienced progressive difficulty swallowing, until the year 2000 when his esophagus finally had to be removed. He temporarily relied on a j-tube immediately following the surgery, but was unable to thrive once it was removed. His j-tube was reinserted permanently in 2005. Joseph is a consumer who does “not miss eating at all.” Joseph goes to work as an RN while hooked up to a portable pump. He and his wife, Robyn, are raising 3-year old autistic twins and he tries to spend as much time as possible with his family. He is a motivational resource for consumers. Joseph can reached at (508) 999-7363, or JMR12667@aol.com.

Be a Star!

Your face could be the new face of Oley! Send us pictures of YOU doing what you like best: hanging with friends and family; biking, hiking or another activity; with or without your tubes/IV lines showing. You can also shape Oley materials by telling us how Oley has helped you and more importantly, how oley can help you better. Let us know what is working and what needs fixing or creating. We want to hear from you! Send your photos and ideas to DahlR@mail.amc.edu, or The Oley Foundation, 214 Hun Memorial, MC-28, Albany Medical Center, Albany, NY 12208. Be sure to include your name, daytime phone or email address, permission to print / post them on the web, and your home address if you want prints returned.

Conference, from pg. 1

To secure this reduced rate be sure to let the reservationist know that you are attending the Oley conference and be sure to indicate whether you will need a refrigerator and/or handicap accessibility, or if stairs present a problem. Questions? Need additional information? Call us at (800) 776-6539.

As always we invite you to send along suggestions regarding topics you’d like to see covered and/or recommendations for speakers.
Spotlight on Neal Samara, a Jordanian TPN Consumer

Liz Tucker

This past July during an appointment at the Mayo Clinic, my physician, Darlene Kelly, MD, asked if I would talk to a new TPN patient at St. Mary’s Hospital. I agreed, and so she introduced me to Neal Samara, the TPN patient, and her father, Dr. Mohammad Samara from Amman, Jordan.

We spent almost two hours together. Neal and her father asking questions about different aspects of living with TPN; while I asked questions about Neal’s history and how she came to be on TPN. She is married and her husband is an engineer for a major company in Amman. They have five children, two girls and three boys, ranging in age from nine to sixteen. It was obvious she was very proud of her family.

Differences in Care

Neal had a thrombosis in the mesenteric vein that resulted in gangrene in her small bowel. Surgery removed all but one foot of her small intestine. Luckily her large intestine was not affected. The original surgery occurred ten months previous to her trip to the US. When she went home she wasn’t able to maintain her weight and had to be hospitalized again. They inserted a catheter and put her on TPN. She told me a number of things about TPN in Jordan are very different from here in the U.S. They don’t mix all the components together in one bag but instead give a number of small bags with different components over the course of the night. For example, dextrose would be in one bag, lipids in another, potassium in a third, etc. Because of that, TPN is not done at home, only in the hospital.

The second big difference has to do with the catheter. Neal told me that the care given her Hickman catheter was much different than what she was taught to do at the Mayo Clinic. The emphasis is not on sterility. Consequently Neal got a blood infection and had a fever over 104 degrees for two weeks while they gave her intravenous antibiotics. Her fever did not go down until they pulled the catheter. Neal had spent four of the last ten months in the hospital and she was still very underweight. It was at that point that her father decided she should come to the Mayo Clinic in Rochester, Minnesota.

Forging a Friendship

Dr. Samara is a highly regarded pediatrician in Amman, but getting a visa from the United States to bring Neal to Rochester was difficult. Once at Mayo, Neal was hospitalized because she was so emaciated. Tests were done and once she was stabilized a new catheter was placed. I met her and her father a week or so after she started her training to take care of her catheter and do TPN at home.

Neal and Dr. Samara’s questions for me ranged from how long I had been on TPN, to whether had I traveled, to what were the problems with doing TPN at home. They were in awe at how healthy I looked. As luck would have it, three days later I ended up at St. Mary’s with a blood infection of my own. Our rooms were across the hall from each other and we spent a great deal of time together walking the halls, sitting outside and just talking. I was more and more impressed with her positive attitude and hard work to make sure she could do TPN once she got home, as well as her father’s unwavering support and help whenever she needed it.

Long-term Solutions

Dr. Kelly did a tremendous amount of work finding a source for a premixed TPN solution that would work for Neal, and then a doctor in her region who would be able to carefully monitor her condition. Because the thrombosis was caused by a hereditary blood problem, Neal has the added complication of having to take significant doses of cumadin.

Neal and her father stayed an additional month in Rochester so she could take human growth hormone (HGH) shots. The hope is that the HGH will help her one foot of small bowel absorb better so she won’t need quite as much TPN.

Building Bridges

After my hospitalization I drove down at least once or twice a week to take Neal and her father shopping, to take pictures of the Mayo Clinic and just talk about our lives and the world in general. They told me several times that their impression of the United States was changed dramatically by coming to this country and their experiences with the people here. They both said that without exception everyone they met here or who had taken care of Neal in the hospital was kind, generous and helpful. They were also amazed by the fact that so many people here smile. People in Jordan don’t smile nearly as often; particularly not at other people when they are out in public. Before the end of their stay, Dr. Kelly and her mother, Dorothy, brought Neal and Dr. Samara to my house for a visit. Neal and Dr. Samara brought all the ingredients needed to make a real Arab meal. It was wonderful.

Neal and her father have returned to Amman, but we plan to keep in touch. They are wonderful human beings and it is a privilege to call them friends.
Parenting, from pg. 1

time to make your decisions. There is a great deal to think about. One of the first questions is whether you can carry the baby yourself. TPN should not, in and of itself, be a barrier. The medications you take for your underlying condition, however, could be a problem. This is one of those very important questions for your doctor. It may be possible to change to another medication, lower the dose or even go off the medication during the pregnancy/nursing period.

Similarly your underlying disease or energy level may present a significant obstacle. One participant spent the entire nine months she was pregnant with nausea and abdominal pain and it didn’t go away until right after her baby was born. One of the others, not only didn’t have any nausea; she actually felt her underlying disease was much better while she was pregnant. Another of our participants talked about how helpful her homecare company was during her pregnancy. They worked closely with the doctor to make sure both she and the baby were getting enough nutrition. The result was a healthy baby. As with a person who is not on TPN, everyone’s pregnancy experience can be different.

Another consideration if you want to carry the baby yourself, is whether your underlying diagnosis is hereditary. This has been a very difficult issue for some patients and their families. Genetic counseling should be done before you make any decisions. One of our participant’s and her husband believe that is a good idea and are already working with a geneticist to determine any possible impact should they decide to try pregnancy.

What are the chances that your disease or being on TPN will affect the pregnancy or your long-term life expectancy? If the answer is significant, you need to face the possibility of losing the baby or, after the baby’s birth, the baby losing you. Because she had lost a child due to her underlying condition, one participant gave up on ever having any children. At age 44 she became pregnant and one of her concerns was how would it affect her child if she were to die before she became an adult. After very serious thought she decided she would just be the best mother she could be and if something unforeseen happened she would have faith that her child would be okay with one parent. After all, there have been many children in this world who have lost a parent and grown up to be healthy, happy and productive human beings.

Other Options

If you are not able to carry your own pregnancy to term, or have a hereditary disease, surrogate birth mothers, adoption and foster care are options, though they each come with a different set of issues

Surrogate Mother

Do you have a person you know and trust to be a surrogate birth mother for you? One of our participants has a sister who has offered to carry the baby. Other people have needed to go outside of their
families. There are hefty financial costs to consider as well: fertility treatments, harvesting of your eggs, invitro-fertilization, implantation of the eggs and medical care for the surrogate mother, to name a few. Don’t forget the physical considerations of these actions as well. They can be very taxing on the body. Finally, there are significant legal and psychological issues regarding having someone else carry your child that should be looked into and dealt with before you start the process. In addition to your physician and family support, you will likely need to retain a lawyer and possibly a counselor as well.

Adoption
Adoption gets around many of the physical obstacles; however, with the exception of minority and disabled children, adoption in the US can be a long and expensive process. There just are not enough healthy babies to go around. Because of that, many couples have looked to countries in Eastern Europe, the Far East or Africa for babies to adopt. There can be many regulations and a significant amount of money involved to adopt children from these areas. In addition, in some cases parents have adopted supposedly healthy children only to bring them home and find they have very serious health issues. Can your support system handle a second chronically ill person?

Foster Parent
Becoming a foster parent also gets around the physical issues associated with pregnancy, but comes with other risks. Because many children in the foster care system come from problem or dysfunctional homes, being mentally and physically equipped to care for one of these children is essential. You also have to be prepared to give the child back to their biological family if there is a positive change in their home situation. One of our participants is looking at the possibility of taking on a school-age foster child to overcome the energy issues of pregnancy and caring for a small child, as well as the expense of all-day childcare (she works). She will still need a solid support system for those times when the child may be ill, she may be ill or hospitalized or, as a single parent, those times when she feels the total weight and responsibility for bringing this child up and needs a break.

Quality of Life
How might the pregnancy and then the baby affect your quality of life? Every parent involved with this article said that having children has enhanced their quality of life. They look forward to getting up every morning and watching their children grow.

Are they a great deal of work and consume a tremendous amount of energy? Of course. Are there future complications (fatigue, relapse of your disease, surgery, infections, obstructions, etc.) that might impact your ability to parent your child? Again, this is almost a certainty. It is apparent from all the stories gathered for this article that having a strong support team assembled is a must, but can help you realize your dream of having children. Being able to count on your husband, parents and/or siblings, in-laws or some of your friends is very important. The in-laws of one young woman have offered to add an addition to their home. It would be a place to stay when they need help with the baby. How much your support team can handle is a consideration too. The one father who helped with this article had undergone transplant surgery and was so looking forward to the time when he would be able to take some of the responsibility for their child off of his wife’s shoulders.

In summary, everyone who contributed towards this article expressed a similar sentiment though in a number of different ways. They all felt that having a child may not have cured their illness or allowed them to get off TPN, (and they still had problems occur because of those things), but participating in their children’s lives and watching them grow has only been a positive experience. As one parent said “It helps us see the world as something bigger than ourselves. We are not just our disease and not just a person on TPN. We are a parent, and being involved with our children means being involved in a larger world.”

As you can see, many of the questions and concerns are not that much different than the average person, there are just more of them for those of us on TPN. Addressing them ahead of time can keep the unpleasant surprises that come with pregnancy and parenthood to a minimum. We hope our experiences will help you if you are thinking about becoming a parent.
**Liver Disease, from pg. 2**

(ALT and/or AP), 161 (99%) had abnormal LFTs (bilirubin, albumin and/or PT) and only one patient had normal liver tests. Closer inspection on an individual basis revealed that most abnormal liver function tests were in the mild or moderate range. The high rate of LFT abnormalities reflects the fact that one of the measures used to define LFTs is albumin, which is also a marker of nutritional status. When albumin was removed from our definition of LFTs the rate of abnormality dropped to 57%.

Despite this seemingly high rate of liver test abnormality, only seven of the 162 (4.3%) patients had severe liver dysfunction. After reviewing the records of these patients we found only one instance where severe liver dysfunction could be attributed solely to the use of PN. We also found that female gender was associated with a greater likelihood of developing liver failure. Because only seven patients developed severe liver dysfunction and six happened to be women, it is possible that the association between gender and liver failure may have been by chance alone and not a true result.

**What to Look For**

The study also assessed individual patient’s PN formula. They received an average of 24.7 total calories per kilogram per day and 18.5 calories per kilogram per day of dextrose. Approximately 10% of total energy was supplied as intravenous (IV) lipid emulsion. It is our practice to provide patients with IV lipid only one or two times per week to meet their essential fatty acid requirement. Daily IV lipid emulsion is reserved for patients with diabetes or elevated blood sugar levels that are not easily controlled by adding regular insulin to the PN formula. In our study there was a trend for a higher dose of PN calories, dextrose calories and a greater duration of PN to be associated with worsening liver enzyme abnormalities. This observation was not statistically significant; however, other studies have found an association between these factors and liver failure. It is possible that these factors did not reach statistical significance because our patients were not exposed to PN for as long as patients in these other studies.

There are several theories as to why patients on PN have abnormal liver associated enzymes or liver function tests. It may be due to a nutrient deficiency or toxicity in the PN formula.

A list of nutrient deficiencies and toxicities that may lead to liver disease is shown in Table 3. Other possibilities include small bowel bacterial overgrowth that is associated with extensive bowel resection and mucosal disease; patients with short bowel syndrome; the presence of an underlying inflammatory disorder such as Crohn’s disease, cancer or pancreatitis as well as patients who are unable to take any nutrition by mouth. Another theory is that frequent sepsis from the patient’s catheter or another source may lead to abnormal liver tests.

Only 7 of the 162 patients had severe liver dysfunction...and in only one instance could severe liver dysfunction be attributed solely to the use of PN.

The conclusions reached after analyzing the data in our study are encouraging for long-term PN patients. We found that, although abnormal liver tests are quite common in these patients, severe liver dysfunction is uncommon when consumers are given moderate amounts of total calories and IV lipid emulsions that are prescribed in low amounts to meet essential fatty acid requirements.

When a patient does have a liver function test abnormality it is important for the physician managing the PN formula to diagnose and treat any other causes of hepatobiliary disease such as gallstones, viral or autoimmune hepatitis, Wilson’s disease, and hemochromatosis. A review of a patient’s current list of medications should also be conducted to eliminate any that may be toxic to the liver. This includes H2 antagonists such as famotidine (Pepcid) or ranitidine (Zantac), which are commonly used to reduce fluid loss in high output short bowel patients, and should be discontinued if there is significant liver dysfunction. (Note: The authors have never found that withdrawal of H2 antagonists has helped and always resume the therapy because of patient need.) Another medication to consider eliminating is octreotide (Sandostatin) which is used to inhibit gastric, pancreatic or biliary secretions and intestinal motility. PN consumers should also not drink alcohol in excess.

If no reversible cause for the abnormal liver tests are found, the managing physician should follow the labs closely and consider referral to a liver specialist when they remain elevated for more than six months, or if they are elevated to a moderate or greater degree (see table 1). A rapid increase in liver tests may necessitate the withdrawal of PN and the provision of regular intravenous fluids to maintain hydration until the cause of the abnormal liver test can be determined. Patients with progressive liver dysfunction or liver failure should discuss with their physician the need for referral to a transplant center where both small bowel and liver transplantation can be performed. Hopefully future studies will help better define the cause of PN associated liver disease so that physicians can better manage and treat this condition.

**Table 3: Possible nutrient deficiencies and toxicities that may contribute to PN associated liver disease**

<table>
<thead>
<tr>
<th>Nutrient Deficiencies</th>
<th>Nutrient Toxicities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carnitine</td>
<td>Excess calories/carbohydrate</td>
</tr>
<tr>
<td>Carnitine may be supplied by lysine and methionine in PN amino acids. Serum levels can be measured; if low, may supplement in PN.</td>
<td>Total calories should be appropriate for patient’s goal weight. Excess carbohydrate may lead to fatty liver or high blood glucose levels.</td>
</tr>
<tr>
<td>Choline</td>
<td>Excess IV lipid emulsion</td>
</tr>
<tr>
<td>Not currently approved by the US FDA. Clinical trials are underway to determine if it is useful in the prevention or treatment of fatty liver.</td>
<td>Avoid lipid administration of greater than 1 g/kg/d.</td>
</tr>
<tr>
<td>Essential fatty acid deficiency</td>
<td>Manganese and copper</td>
</tr>
<tr>
<td>May occur in patients on lipid-free PN and with inadequate oral fat intake. Lipid emulsion should provide ≥ 4-8% of total calories.</td>
<td>Manganese and copper are excreted by the biliary tract. If cholestasis or restricted bile flow is present these trace elements should be temporarily removed from the PN.</td>
</tr>
</tbody>
</table>

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November/December 2006
Individual Donors Make A Difference!
The following list represents everyone who generously contributed towards Oley’s efforts between October 5 and November 15, 2006. We also want to thank all of those who are not listed below, yet have supported the Foundation by donating gifts earlier this fiscal year or have volunteered their time and talents.

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Laura has been on HPN since 1991 due to short bowel syndrome. She has experience with multiple catheters, dealing with infections and traveling. She has also returned to college at Oklahoma State and graduated in the spring 2006. She looks forward to sharing her experiences with you.

Matt has been on TPN for 20+ years due to Crohn’s disease and short bowel syndrome – so he is experienced with the up’s and down’s of TPN. He likes riding his bike and spending time with friends. He is happy to talk about anything associated with TPN or otherwise.

An Oley trustee, Sheila has been on TPN for over 20 years due to short bowel syndrome. She is an education and training specialist for case managers and has a lot of experience with managed care. She enjoys helping other lifeliners function as independently as possible and participate in their health care decisions.

Sue had a frightening, isolating and frustrating time when her daughter Emily was diagnosed with a form of pseudo-obstruction at birth and started on HPN and tube feeds. Connecting with other families in similar situations helped make life work for her whole family. Emily now has short bowel and an ostomy. Sue has lots of experience with lines, g-tubes, and ostomies as well.

Michael was diagnosed with Crohn’s Disease at the age of 9 in 1979. He was mostly HPN dependent from his teen years until late 2001 when he was fortunate enough to get off therapy thanks to good luck, diet and exercise. He has been an editor at daily newspaper for many years. He is glad to chat with anyone.

Sheila has an 8-year-old son David and 6-year-old daughter Olivia, who was diagnosed with pseudo-obstruction at the age of 2 years. Olivia is TPN dependent and has tolerated enteral feeds in the past. Olivia has a G- and a separate J-tube as well as an ileostomy. She requires catheterization overnight.

Meet Us in Cape Cod

Plan to join us June 28 to 30 at the Cape Codder Resort & Spa in Hyannis, MA, for the 2007 Oley Conference. Cape Cod offers close proximity to the nutrition support talent in Boston, as well as a chance to get away with the family for a relaxing beach vacation.