

**Independence**, from pg. 6

Medicaid, it covered everything, so I didn't have to worry. I had some coverage from my parent's insurance, but when I approached their policy's maximum lifetime benefit, I knew that I had Medicaid to fall back on. And even though it was very modest, having my own income from SSI helped me gain a little independence from my parents.

The catch with Medicaid is, if you make any money, your benefits are affected immediately. As you start earning money, your monthly SSI check will likely be decreased, (even if you make as little as \$65 a month); and if you lose your SSI and earn more than another modest threshold, you may lose your insurance coverage. So if you rely on SSI, it's nearly impossible to see if you can handle full time responsibilities; you cannot make enough money at your job to become self sufficient, or put in enough hours to get insurance through your employers, before you lose your SSI benefits. It is too risky.

[Editor's Note: The Work Incentives Act tempers this a little by allowing you to retain your Medicaid coverage even after you are working, although depending upon your income, you may be required to pay a portion of your medical expenses out of pocket. The Work Incentives Act also includes provisions for an easier, more supportive reinstatement of benefits process should you become unable to work and need SSI benefits once again. For more information call Social Security, or visit their web site at <http://www.ssa.gov/work>]

Although the eligibility requirements may be difficult for young consumers to meet, you may apply for Social Security Disability (SSD). (Essentially you must have worked enough to qualify for benefits on your own; or be able to draw down on your parent's entitlements which requires that they be receiving benefits themselves.) During one of my reviews for SSI/Medicaid, my caseworker suggested I apply for SSD since I had worked enough quarters to qualify. After I got on SSD, the total amount of income I received each month from the government remained the same, but now some portions of my check came from SSD, rather than just SSI. After two years on SSD, I automatically received Medicare insurance coverage. Because I wasn't working when Medicare kicked-in, for a while Medicare was my primary insurance and Medicaid provided my secondary coverage; Medicaid actually paid all of my Medicare copays and even my Medicare premium. (Editor's note: this coverage is only available in certain states.)

When I first started looking for work I was really worried about keeping my insurance coverage. Before I even applied for jobs, I asked questions at Social Security. I spoke to several different people because sometimes you can get one story from one person and from another it could be a little different. So I spoke to as many people as I could, to make sure that when I did start working I knew what I needed to do to keep myself covered. I used this same proactive approach before I moved or got engaged, since these actions could potentially affect my benefits too.

Once I started to work for pay as an OT, I had a nine month trial period when I was able to earn money, but still receive my SSD check. (My SSI and Medicaid was discontinued with my first pay check.) I was also able to keep my SSD insurance benefits for three years from the date that I started working. Once a year, though, I have to be examined

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**Transplant**, from pg. 1

or in combination with multiple organs (multivisceral transplantation or MVT). An isolated small bowel graft is typically recommended when a patient has lost venous access. Combined small bowel/liver transplants are recommended to patients with irreversible liver failure due to HPN, or intestinal failure associated with a hypercoagulable state that can be corrected by a simultaneous liver graft. Multivisceral transplants are for patients with locally aggressive tumors that can only be removed by a massive evisceration of the abdominal organs, or patients with coexistent kidney and/or pancreatic disease.

Intestinal transplantation in humans proved clinically feasible in the late 1980's. Research shows the procedure is effective, but has considerable morbidity and mortality. Rejection episodes are relatively frequent, and patients develop lymphoproliferative disease and serious infections such as chronic cytomegalovirus or Epstein Barr virus. About half of the patients receiving intestinal transplants survive five years or more. This prognosis is somewhat better in young people ages 2 to 17.

**Analyzing the Data**

In deciding whether to cover SBT, HCFA considered several studies and two technology assessments. One of the articles, "Intestinal Transplantation: 1997 Report on the International Registry," by David Grant, et al., reported on cumulative intestinal transplantation. This article included data on 272 transplants in 269 patients from 33 intestinal transplant programs. Two-thirds of the recipients were children. Forty-one percent of the procedures were for small bowel transplants alone, 48 percent for small bowel and liver, and 11 percent for multivisceral grafts. One-year patient survival for transplants performed after February 1995 was 69 percent for small bowel alone, 66 percent for small bowel and liver transplants, and 63 percent for multivisceral.

Transplants since 1995 and programs that had performed at least 10 transplants had significantly higher patient and graft survival rates. Three quarters (77 percent) of the current survivors had stopped total parenteral nutrition and resumed oral nutrition. There was no association between type of donor, donor pretreatment or diagnosis, and graft

or patient survival. Although most intestinal transplants arise from cadaveric donors, nine patients received grafts from living donors with comparable results to cadaveric transplants. According to David Grant, because most patients function well on HPN, the risks of intestinal transplantation are only warranted when standard therapies have failed.

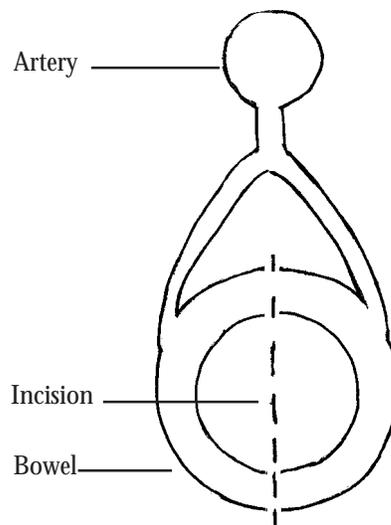
Current two-year survival rates from the University of Nebraska at Omaha are as follows: for isolated small bowel transplant, patient survival was 79 percent, graft survival 68 percent; and for liver and small bowel transplant, patient survival was 52 percent, and graft survival was 45 percent (see "Two-Year SBT Survival Rates" on page 11).

**More on Autologous GI Reconstruction**

**Kishore Iyer, FRCS & Alan Langnas, D.O.**  
**Organ Transplantation Program**  
**University of Nebraska at Omaha**

One aspect of treatment for patients with short bowel syndrome that has received limited attention is the group of non-transplant surgical options that are referred to as Autologous Gastro-Intestinal Reconstruction (AGIR). The best known of these procedures is the intestinal lengthening procedure of Bianchi. The Bianchi procedure takes advantage of the split blood supply to the small bowel and divides a 10 to 15 cm segment of dilated bowel in half; from one tube, it creates two, and then sews them end to end (see illustration). This both lengthens a short bowel and restores contractibility to a dilated or flabby segment. The Bianchi procedure, and others, such as tapering, creation of valves, reversed segments, etc. can reduce or eliminate dependency on HPN in select patients with short bowel.

Unfortunately, even surgeons interested and experienced in these procedures have only a small series of patients. This relates at least in part to the fact that these non-transplant surgical options are applicable in only a carefully selected minority of patients with intestinal failure. Bianchi (who originally developed the lengthening procedure) reported (Journal of the Royal Society of Medicine, 1997) that nine of 20 children who underwent lengthening over a 15 year period, survived long term (mean follow-up of 6.4 years). Seven of the nine were completely off parenteral nutrition and two were on partial parenteral nutrition. The experience at Omaha reported (Annals of Surgery, 1995) as part of a large series of patients with short bowel has been as encouraging: of 14 patients who underwent lengthening, 12 improved, one underwent transplantation and one died. Seven patients were able to come off HPN and in five PN was decreased. Among 160 patients with short bowel syndrome, there were 32 non-transplant surgical procedures. Overall, 84 percent of these procedures led to clinical improvement — after surgery 69 percent of patients were maintained on enteral nutrition and 25 percent required less PN.



**How a Bowel Is Lengthened**

*This cross section illustrates how a surgeon is able to use the Bianchi procedure to lengthen a piece of bowel by taking advantage of the small bowel's split blood supply. The bowel (essentially a tube) is cut in half as shown, then resewn into two tubes which are then sewn from end to end.*

Oley's North American Home Parenteral and Enteral Nutrition Patient Registry reports survival for patients on long-term HPN to be 87 to 96 percent at one year and 70 to 90 percent at three years.

After a literature review of 211 journal articles, The Center for Practice and Technology Assessment at the Agency for Healthcare Research and Quality (AHRQ) concluded that small bowel and related transplantation appear to be potentially life-saving options for patients who have failed HPN and would therefore otherwise face certain death. In addition, AHRQ found that the data are not sufficient to determine whether the risks and benefits of small bowel transplant and related procedures might yield a net benefit to patients who can continue HPN, but are considered at high risk to fail HPN sometime in the future.

**Medicare's Decision**

Medicare takes note of the following facts: there are variations in outcomes and patients require lifelong immunosuppressive therapy; the overall 1-year survival for all intestinal transplantation is approximately 70 percent, but there is only an approximate 50 percent chance of long-term (five years) survival. Complications following surgery are common, including rejection, cytomeglovirus disease, lymphoproliferative disease and infection (see "Complications from SBT" chart). Among intestinal transplant recipients, hospital readmission occurred once every 1 to 2 years for infection, surgical procedures and/or rejection (this is similar to the HPN hospital readmission rate). Additionally, there is limited data on quality of life following intestinal transplants, and even less comparing transplantation with home parenteral nutrition.

HCFA found the evidence on which to base a determination on Medicare coverage regarding intestinal transplantation was sparse. They agreed that the various forms of intestinal transplantation (i.e., SBT, SB/LT, and MVT) may offer a life-saving therapy for patients with irreversible intestinal failure; however, because the procedure involves high risk, HCFA (and most transplant programs) believe intestinal transplantation should be reserved for patients with life-threatening complications from HPN who are expected to die without transplantation. Kishore Iyer, FRCS, from the University of Nebraska at Omaha Organ Transplantation Program explains, "while the results of intestinal transplantation are steadily improving, they are still inferior to that achieved with HPN and non-transplant surgical options for the patient with intestinal failure....[While] intuitively it would appear that if intestinal transplants were performed on patients before they were desperately ill, the results would be better, ...the overall outcome figures and risks following transplantation have to

improve considerably before transplantation can be applied as therapy of first choice for patients with intestinal failure."

Iyer believes it is vitally important for patients who may be candidates for SBT to be referred early to intestinal transplant centers. This will allow for early evaluation, with continued and coordinated care between the patient's local medical-care providers and intestinal transplant physicians who can ensure that the patient does not lose an appropriate and frequently limited window of opportunity for intestinal transplant. Early referral is especially important for children with less than 30 cm of proximal small bowel who show signs of early cirrhosis; they are at high risk for transplantation.

**Two-Year SBT Survival Rates\***

	Patient	Graft
Isolated Small Bowel	79%	68%
Liver/Small Bowel	52%	45%

\*data from University of Nebraska at Omaha

**Complications from SBT**

	SBT	SB/LT	MVT
acute graft rejection	79%	71%	56%
chronic graft rejection	13%	3%	0%
cytomegalovirus disease	24%	18%	40%
lymphoproliferative dis.	7%	11%	13%

**HCFA's Definition of 'Failed HomePN'**

The clinical indications for intestinal transplantation supported by the literature are impending liver failure due to HPN, thrombosis of major central venous channels, frequent line infection and sepsis, and severe dehydration. Thus, Medicare will cover intestinal transplantation only in the following clinical situations:

**1.) Impending or overt liver failure** due to HPN induced liver injury. The clinical manifestations include elevated serum bilirubin and/or liver enzymes, splenomegaly, thrombocytopenia, gastroesophageal varices, coagulopathy, stomal bleeding or hepatic fibrosis/cirrhosis.

**2.) Thrombosis of the major central venous channels;** jugular, subclavian, and femoral veins. Thrombosis of two or more of these vessels

is considered a life threatening complication and failure of HPN therapy. Central venous thrombosis may result in a lack of access for HPN infusion, recurrent sepsis due to infected thrombi, pulmonary embolism, superior vena cava syndrome, or chronic venous insufficiency.

**3.) Frequent line infection and sepsis.** The development of two or more episodes of systemic sepsis secondary to line infection per year that requires hospitalization indicates failure of HPN therapy. A single episode of line related fungemia, septic shock and/or Acute Respiratory Distress Syndrome are considered indicators of HPN failure. [Editor's note: The average sepsis rate for HPN adults is once every two years, and for HPN children once every year. However, many patients have periods of no infection or more frequent infection, so the decision to consider SBT should not focus too strictly on Medicare's advised guidelines.]

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### Independence, from pg. 9

by one of Social Security's approved physicians, to show that I still have my medical condition. Well for me, everything has worked out fine. I had my review earlier this year, and because of the Work Incentives Act of 1999, I can keep my insurance coverage for up to 93 months (nearly 8 years). There's even the possibility of new legislation passing that would enable me to stay on SSD forever, which would be great.

My employer reimburses me for my Medicare premium, which is very nice of them. I don't believe they are required to do that. I chose Medicare over my employer's plan because Medicare has slightly better coverage and because I was concerned about retaining good coverage for the long run. Employers can change insurance plans every year. By staying with Medicare, I know my medical needs are covered, even if my employer switches to a new insurance company or a new plan. Staying with Medicare also makes it

easier for me to switch jobs if I need to, and gives me more flexibility in my choice of a future employer; if I want to get insurance coverage through work, I would have to find a company with a large enough pool of employees to absorb my insurance coverage needs.

Everybody tells you you're not going to be able to work full time: you need your insurance coverage, and the coverage through

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**My pumps are to me, like wings are to an eagle: they allow me to fly and be free.**

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Medicare or Medicaid is much better than any private coverage you could get. This is drilled into your head when you're first diagnosed, and resurfaces with each crisis you go through. If you're not careful, the whole notion of being 'disabled' can be debilitating. In my case, I was so afraid of

and outcome measures. Specifically, HCFA will limit Medicare coverage of intestinal transplantation to centers that perform 10 or more transplants per year. At this time, the University of Pittsburgh, University of Nebraska at Omaha and University of Miami are doing the most SBTs, followed by Mount Sinai in New York City and UCLA Medical Center.

In summary, Medicare will cover intestinal transplantation for the purpose of restoring intestinal function in patients with irreversible intestinal failure only when performed on patients who have failed HPN and only when performed in centers that meet approval criteria. Survival rates for SBT are improving but the procedure is still too risky to consider if the patient is doing well on HPN or could be a candidate for non-transplant surgery. As Kishore Iyer put it, "It would be a grave error to view any aspect of treatment in isolation, but rather as different arms of a treatment plan for the challenging patient with intestinal failure. Thus, a dedicated multi-disciplinary approach to the problem of intestinal failure with careful management of diet, HPN, treatment of associated problems such as bacterial overgrowth, judicious use of AGIR and, finally intestinal transplantation will ensure the best possible results for all patients." ©

losing my insurance coverage, that for a while I was afraid to even try to get a job or to move; but you know, it's not that way. You really need to think through all of the details, and brainstorm the "what if's" of every possible scenario, when considering your insurance needs; but with hard work and persistence, you can pursue the meaningful career you want and have the insurance coverage you need.

### Questions and Answers

**Dr. Howard** (facilitator): Well, that's a very heart warming story told in very positive terms about a journey that was probably quite nerve racking at times. Are there any parents who want to ask Bette questions or make comments about their situation?

**Anna Cyr** (mother of two daughters on HPN): What you just said gives me the most hope for my older daughter's future. She's extremely bright. She wants to be a marine biologist. She's determined that's what she is going to do. You've answered a lot of questions and a lot of fears for us. Thank you.

**Bette**: That's the best thing about the Oley Foundation. When I first came to Oley, I was only taking one class. I had no hope for a future, nothing. When I came to Oley, I saw people that were working. They were making a living. They were living on their own. That gave me the best hope; and you know, once you have that hope, you can go far. Kids can make a life, and they can become independent; you just have to know the resources out there and tap into them.

**Sheila Messina, RN, MA** (HPN consumer and health care education and training specialist): I remember Bette asking a question at an Oley conference a few years back. You were in OT school at the time and you were concerned about being able to work and still keep your insurance coverage. You had felt like you were locked in. It's wonderful to see there are no barriers now. Sometimes we create our own barriers. It may appear that there are barriers out there, but you can chip, chip, chip away, and eventually you will succeed. You're a wonderful testament to that.

**Bette**: Thank you. I think with the right job you can succeed. Your outlook and persis-

### Transplant, from pg. 11

**4.) Frequent episodes of severe dehydration** despite intravenous fluid supplement in addition to HPN. Under certain medical conditions such as secretory diarrhea and non-reconstructable gastrointestinal tract, the loss of the gastrointestinal and pancreatic secretions exceeds the maximum intravenous infusion rates that can be tolerated by the cardiopulmonary system. Frequent episodes of dehydration injure all body organs particularly kidneys and the central nervous system with the development of multiple kidney stones, renal failure, and permanent brain damage. [Editor's note: This is an extremely rare circumstance]

Significant bone disease, metabolic disorders, slowed development, and significant limitations on social and personal activities are not considered indications of therapy failure.

### Facility Criteria

As with other organ transplants, Medicare will limit SBT coverage to centers that meet specific medical, experience and administrative criteria, such as patient selection policies, patient management protocols, and volume

tence can make a huge difference. For example, as an OT there are many different areas that I could go into. Where I am working, if I'm not feeling good one day, I don't have to jump around with the kids. I can sit down and do a tabletop activity that day. We have people that help, so even on days that I'm not feeling good, I can take it easy and do what I need to do without using a whole lot of energy. The staff members are very understanding too, and on those days, they help out a little bit more. You can adapt your work to fit your life-style, to fit your needs. You just have to be very creative about it.

**Dr. Howard:** We are going to draw this session to a close. Anything else to add Bette?

**Bette:** Oley has done so much for my life. I just want to tell others that you may not be there now, but you will get to a point in your journey where you really want to live with this therapy. There are times when you're living in bed all the time, but somebody pointed out to me once that it's just your outlook on life that needs to change. It does take time — especially for people who are newly diagnosed. First you're in denial and you just don't want to deal with it. You think, "This is not me, I'm not going to touch it." And then eventually you get to a point where you think, "Okay, maybe I can do this." As a friend told me once, "Just look at the TPN as a means that is letting you live your life." I have said this before, but my pumps are to me, like wings are to an eagle: they allow me to fly and be free. When I first got on, I kept thinking, "I'm just like a dog. I'm on a leash. I'm stuck to this thing." The pole was bigger than me: I couldn't even move it! But it's not like that anymore. I see it as a vehicle that allows me to fly and to experience my life. Yes, there are going to be ups and downs. Yes, I may not be able to eat certain things and may have surgery again; but I can still be happy and make the most of what I can do. As long as I can be the best that I can be, I'm just very happy. I'm thankful for my friends, my mom and for all of you who gave me the inspiration to do what I can. ☺

*Special thanks to Bette for sharing her experiences with us and to Carol Pelissier and Robin Lang for transcribing the video taped session this article is based on.*

## Hepatitis C: A Silent Epidemic

Our country is facing a silent epidemic in the form of Hepatitis C, a liver disease caused by the Hepatitis C Virus (HCV). An estimated 4 million Americans have been infected with HCV and a majority (70%) of them are probably not even aware that they are infected. While some people with Hepatitis C experience flu-like symptoms, many patients don't have any recognizable symptoms until they have progressed to severe liver disease.

Hepatitis C spreads by contact with an infected person's blood. The surgeon general recommends that you get tested for Hepatitis C if you:

- received a blood transfusion or solid organ transplant before July, 1992
- received a blood product for clotting problems produced before 1987
- have ever been on long-term kidney dialysis
- have been pricked with a needle that may have had infected blood on it
- have ever injected illegal drugs
- were born to a mother with hepatitis C

Your primary physician can test for the presence of HCV antibodies with a simple blood test. A positive response

would lead you to more testing by a specialist. You can also try an FDA-approved hepatitis C test kit (Hepatitis C Check<sup>sm</sup>) which is available in drugstores.

For many people hepatitis C is treatable with a drug called interferon, taken either alone or in combination with the drug ribavirin. Researchers are also conducting clinical trials of pegylated interferon, a longer lasting interferon.

It is important to seek medical attention, because HCV infection can cause liver damage, cirrhosis, liver cancer and liver failure. It is responsible for 8,000 to 10,000 deaths per year. HPN patients are especially vulnerable, since many have had blood transfusions during past surgeries, and some patients' livers may be compromised by HPN.

For more information, contact the Center for Disease Control's (CDC) Hepatitis C hotline at (888) 443-7232 or the following web sites:

- <http://www.cdc.gov/ncidod/diseases/hepatitis/c/index.htm>
- <http://www.niaid.nih.gov/information/search.htm>

You can also try the American Liver Foundation at (800) GO-LIVER or (888) 443-7222; <http://www.liverfoundation.org>.

HPN patients are especially vulnerable, since many have had blood transfusions during past surgeries, and some patients' livers may be compromised by HPN.

## Back-to-Work Resource

Social Security is testing out a new position, an Employment Support Representative, whose job is to assist Social Security disability beneficiaries who want to work. Among other duties the Employment Support Reps will:

- explain how earnings affect monthly cash benefits
- explain Social Security work incentives that let beneficiaries keep cash benefits, Medicare or Medicaid coverage, and help with training and work expenses while testing their ability to work

Thirty-two pilot sites are participating in the six to eight month pilot program. Social Security will then evaluate the effectiveness of the program and make any needed changes before extending the new position to additional offices in 2001.

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Lewis & Barbara Gershman  
Philip & Roberta Haim  
Mrs. Mildred I. Hayward  
Brian & Karen Hettrick  
Frances Hovey  
Jean Jacobs  
Andrea Johnson  
Effraim Kaplan  
Bernie & Linda Karp  
William & Bernice Kasky  
Debra Kennerly  
Susan Koonin  
Kathryn Kunze

**Stronger!**

October 10, 2000 or later)

Teresa Lane  
 Paula Lerfald  
 Sheryl A. Longobardi  
 Helen & Phil Lyte  
 Phyllis Manuli  
 Pat & Joe Marcy  
 Margo Maun  
 Edward Morrisey  
 Donna J. Mummery  
 Joseph Murphy  
 Marcie & David Nagengast  
 Lewis Nahum  
 Bill & Thelma Pierce, in  
 memory of Kurt Schwartz  
 Judy & Jerry Puca  
 James Quadracci  
 Louise Quast  
 Anne Rasmussen  
 Gary Rieck  
 Elsie Roesch  
 Ursula Rychter  
 Cynthia Sabbag  
 Marie Sakowitz & Family  
 Sharon Sakowitz  
 Lawrence Schwarz &  
 Elysa Marcela  
 Donna & Jeffrey Stempin  
 Kenneth & Betsy Stinner  
 Arnold & Henrietta Swartz  
 Jennifer Thiesse  
 Mrs. Jennie Thille  
 Carolyn Thompson  
 June Trounce  
 United Way of Manatee Cty  
 Robert Wachstein  
 Weglein-Greene Families  
 Eleanor Werkheiser  
 Mary Whipple  
 Sharon Woodside  
 Lenore Heaphey Worthley  
 Charles & Betty Zollweg  
 Lisa Zovko

**IN MEMORY OF****ANTHONY DELUCA**

Mr. & Mrs. G. Cutrone  
 Mr. & Mrs. A. Deluca  
 Mr. & Mrs. J. Deluca  
 Mr. & Mrs. V. Garcia  
 Mr. & Mrs. F. Pontillo

**IN MEMORY OF JOHN****"ROOSTER" RICHARDS**

Florence & Robert Hines  
 Robin Lang  
 Joy Skiba  
 Lois & Albert Skiba  
 Peter & Lynne Skiba  
 Mary Jo & Jeff Walch

\* Oley Board Trustee

\*\* Oley Regional Coordinator

\*\*\* Oley Staff

**Thank You Kendall!**

Based in Mansfield, Massachusetts, Kendall is one of the largest manufacturers of disposable health care products in the world. The company's full line of products includes traditional and advanced wound care products, vascular therapy products, urological products, incontinent care, needles/syringes, sharps safety and a complete line of enteral nutrition therapy, which allows it to serve all patient populations. We welcome Kendall as a new corporate Friend.

**Planned Gifts for Oley**

The Oley Foundation would like to thank the following individuals and families for their planned gifts to the Oley Foundation. We invite anyone else who has made a planned gift or is considering one, to call Joan Bishop at (800) 776-OLEY.

*Katherine Cotter**Don Freeman**Groeber Family**Alfred Haas**Lyn Howard, MD**William Hoyt**Judy Petersen**Oley Staff***Oley's Corporate Donor Program**

Each year the Oley Foundation appeals to about 200 home care companies, manufacturers and suppliers to support its programs: the *LifelineLetter*, conferences, information clearinghouse, toll-free lines, etc. Those companies listed on the right have responded favorably within the past year.

This year we are hoping to expand our list of contributors; first to support our growing programs (in particular to support greater outreach to consumers through regional conferences); and second to stabilize our finances through a broader base of support.

The corporate appeal for the 2001 budget year was mailed earlier this fall. If you are serviced by any of the companies who donate to Oley, we encourage you to write them a note of thanks. If your home care company is not on the list, you might ask them to join Oley in supporting your need for accurate, up-to-date information about your therapy, and a vibrant homePEN community. Interested consumers or companies can call 800-776-OLEY for details on how they can get involved in the donor program.

**Unrestricted Corporate Donations****GOLDEN DONORS (\$50,000+)**

Coram Healthcare

**SILVER CIRCLE MEMBERS**

(\$25,000-\$49,999)

Nutrishare, Inc.

**BENEFACTORS (\$15,000-\$24,999)**

Liberty Medical Supply

**PATRONS (\$5,000-\$14,999)**

Abbott Laboratories

(the combined efforts of Abbott Alternate Site Systems and Creative Networks/Administrative Services)

**SUPPORTERS (\$2,500-\$4,999)**

Critical Care Systems

**CONTRIBUTORS (\$1,000 - \$2,499)**

B. Braun/McGaw

BD Medical Systems

Nestle Clinical Nutrition

Pharmacy Solution Services

Zevex, Inc.

**FRIENDS (\$500-\$999)**

Baxa Corporation

Cera Products, Inc.

Kendall

Pharmacy Resources

SIMS Deltac

## Reach Out and Talk to a HomePEN Consumer — Toll Free!

To make speaking with fellow lifeliners more affordable, Oley circulates two toll-free numbers to experienced homePEN consumers on a monthly basis. We strongly encourage you to take advantage of this program which enhances consumer-to-consumer networking and provides 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 15 minutes. The exception is **FRIDAYS, WHEN ALL CALLS ARE FREE** — including calls to the Oley office!

The schedule of toll-free numbers and volunteer coordinators is updated in each *LifelineLetter*, and posted on our web page @ [www.oley.org](http://www.oley.org). Comments? Call (800) 776-OLEY.

<b>JAN. '01</b>	<p><b>Diane Kane</b> Lecanto, FL (888) 610-3008 EST</p>	<p>Diane is married with two children. She has idiopathic pseudo obstruction and experience with both enteral and parenteral nutrition. She can also speak to callers about pain management issues. Diane is active in providing support to homePEN consumers living in the central Florida area.</p>
	<p><b>Alicia &amp; Rose Hoelle</b> Gibbstown, PA (888) 650-3290 EST</p>	<p>Alicia is 15 y.o. and has been on TPN (and sometimes EN) since birth due to hypoganglionis. She lives a very normal life. She goes to camp, plays sports, etc. She would love to hear from kids, teens or parents. Her mother, Rose, is an LPN and experienced caregiver. She looks forward to hearing from other parents.</p>
<b>FEB. '01</b>	<p><b>Ruth Ann Engle</b> Streetsboro, OH (888) 610-3008 EST</p>	<p>Ruth Ann is 47 years old and has been on TPN for the past ten years due to short bowel syndrome. She is an active volunteer in her community, and has recently begun a homePEN support group in northeastern Ohio with Jim Cowan. She looks forward to sharing information with fellow consumers.</p>
	<p><b>Linda Gold-Pitegoff</b> Brookline, MA (888) 650-3290 EST</p>	<p>Linda is a public health nurse with a diffused motility disorder — Hollow Visceral Myopathy. She depends on enteral feeds for her nutrition and IV for her hydration. Linda has an amazingly positive, can-do attitude. She is widowed with two adopted children. Please call her Monday to Friday, daytime only.</p>
<b>MAR. '01</b>	<p><b>Jane Golden</b> Watertown, CT (888) 610-3008 EST</p>	<p>As a result of short bowel syndrome, Jane has been on and off TPN since 1993. She believes strongly in the benefits of networking with fellow lifeliners. Jane worked hard to get back to a "normal" life and until two years ago, worked full time for IBM. She enjoys horses and has a terrific sense of humor.</p>
	<p><b>Joan Medwar</b> Sharon, MA (888) 650-3290 EST</p>	<p>Joan has had Crohn's disease for 19 years and has an ileostomy. She was on PN and EN briefly. Her son Michael (age 29) also has Crohn's and has been on TPN since age 9. Joan looks forward to sharing with callers her many years of experience in dealing with TPN related issues as a patient and a caregiver.</p>

### LifelineLetter

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

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### If You're Happy and You Know It Show Your Tubes

Six-year-old Colyn Woods considers his g-tube and central line essential parts of his positive body image as shown in his self portrait above.