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Living with home parenteral and/or enteral nutrition (HPEN)



Special Needs Trusts *By Stephanie Pelham, RD*

A Special Needs Trust can help you meet a disabled loved one's needs and wants now and in the future. The average caregiver meets expenses and plans for a disabled loved one's continued care. The government provides several programs that offer financial assistance. Social Security, Supplemental Security Income (SSI) and Medicaid offer funds to help pay for medical care, vocational rehabilitation, group housing, job coaching, personal attendant care, transportation assistance and more.

The government however, puts a major condition on the receipt of these benefits - *none of its efforts may be duplicated*. In other words, money is provided on an as-needed basis. If an individual with a disability receives funding for any of the aforementioned purposes from an alternate source, the government cuts back support.

If you are a caregiver who needs to ensure government funding for someone, you may be limited in what you can "spend" on that person – or leave to him/her as part of your estate. Funds used to place a loved one in the residence of your choice for example, can be deemed income and jeopardize their eligibility for government benefits. More significantly, so too can gifted funds or inherited assets.

This is why many people turn to a Special Needs Trust. This estate planning tool can offer an affordable way to help meet the ongoing needs of a person with a disability or to provide him/her with a substantial gift without affecting eligibility for government funding.

Federal programs provide "health, shelter, and support". A Special Needs Trust is specifically designed not to provide funds for these purposes, but rather to supplement them. Trust funds can help pay for additional medical therapies or procedures, education, clothing, recreation, travel, guardians, transportation, vacations and other extras. Parents can also use these

Trusts, Con't. page 6

Necessity and the Art of Invention *By Dr. Robert Flute Snyder*

My story with enteral feeding started with a G-tube. The hospital dietician taught me to inject my liquid diet of formula using a two-ounce syringe.

The syringe worked fine as long as I had complete control of my mental faculties, the solution was warm, and I had three hands. My first hand held the Bard Tube™ and my other hand grasped the syringe. I don't know if my hand is too small, but I couldn't hold the syringe comfortably and reach the fully opened plunger with my thumb. The length of the syringe stroke exceeded my thumb stroke by about an ounce.

After a few months of experimentation, I learned to hold the G-tube in my left hand, hold the syringe in my right hand, and using the wall as my third hand, push the plunger mightily. Success! I could inject two ounces in just a flash, then remove the syringe from the G-tube to refill it. While holding a kink in the G-tube, I had to suck the food into the syringe and keep from slipping.

My experience as a flutist and keyboard player gave me what I considered to be superior control over my dexterity, but still problems persisted.

Sometimes I'd set up the feeding operation in the bathroom so if I dribbled, it would fall in the sink. Right? Usually. However once in awhile, the G-tube

would suffer a kink, the syringe would stop, and the food would stop flowing. So I'd push just a little harder to unplug the stoppage. What would happen then? The syringe popped out of the G-tube and formula hit the wall, flitted up to the ceiling and generally messed up the bathroom. Quickly, I'd seal off the tube, wet a washcloth, and clean the room. I got away with my accidents a couple of times and then my wife Ann caught me. She said, "If you're going to have these accidents, you're going to use the downstairs bathroom." And so down I went, never to paint the walls of the lady's room with chocolate-flavored formula again.



After six or seven months, I got the impression that my digestive system would never settle down if I continued to consume the so-called "lactose-free formula". My family's always been lactose intolerant so I read the ingredient label. Among the long list of

Invention, Con't. page 4

Managing Supplies During Stormy Weather *By June Bodden*

At the last Florida Oley meeting, June Bodden and other members were discussing that region's active hurricane season. They shared ideas and plans that were made before the storms – what food and supplies they had and what to do when the power goes off. It occurred to them that inclement weather isn't exclusive to the southeast and thought

this topic would be good to address in the *LifelineLetter*.

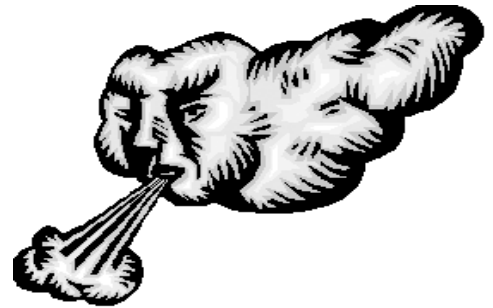
Keep a plastic/rubber chest handy with the following items enclosed: Paper goods, garbage bags, lighter/matches, batteries, Sterno, glass cookware, candles, a portable radio, extra eyeglasses, insurance information, medications, ostomy and HPEN tubing and related supplies, a first-aid kit, assorted food items such as shelf milk, juice boxes, gelatin and pudding, a manual can opener along with canned soup and spaghetti, etc. Pay attention to expiration dates and if items aren't used by the following Thanksgiving, donate them to your local food pantry.

General storm preparations: Have a supply of cash on hand; fill your car with gas; use up food in refrigerator and freezer (make soups, casseroles or meatloaf which is good for cold sandwiches); put water in bowls in the freezer so you can have plenty of water for drinking, remembering that you'll also need water for flushing and bathing (buying towelettes and hand-washing cleaners also helps); turn down the refrigerator and unplug appliances not in use; have bleach and an eyedropper on hand; purchase push-button lights; have two days change of clothes; put valuables, important papers and photo albums in plastic bags and store in dishwasher or car trunk; fill washing machine, bathtub and extra bottles with water; have a fire extinguisher on hand; and have tools, nails and duct tape available. When the power goes off, turn off or unplug the breaker panel and turn off the gas, fill coolers with supplies and avoid opening the refrigerator or freezer. If you must evacuate, register in advance at a special-needs shelter. Try to evacuate a few miles from home rather than a long distance to avoid heavy traffic, gas shortages, car problems or a shortage of hotel rooms.

Medical needs: Get prescriptions filled; have extra batteries for portable pumps; use separate cooler with ice packs or frozen water for three days of TPN and vitamins and limit access to the cooler to once or twice a day.

Other tips: Have an inventory of belongings for insurance purposes, have a cell phone available and keep reading materials, puzzles, cards, etc. on hand to reduce boredom. Use a generator only in well-ventilated areas. Never use one indoors or in an attached garage. If

you're in a hurricane-prone area, remember that you may need plywood for windows and to avoid the use of candles since wind can break windows and cause fires. Also, have propane on hand so you can cook on your grill and put furniture legs in plastic cups in case of mild flooding. ©



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The *LifelineLetter* is the bi-monthly newsletter of the Oley Foundation. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed with your health care provider prior to actual use. Correspondence can be sent to the Director of Publications & Information at the address above.

Medical Information Forms: Important and Available

If you are in the midst of a medical emergency, or have a problem while traveling, it's very important that you're organized and your information be readily available to healthcare personnel. Often family members are asked questions about the patient and they may not have all the answers on-hand. That's why it's important for patients with chronic illness to have readily available Patient Information Forms.

These forms can be found on the Oley Foundation's website and can be easily downloaded or printed. Go to www.oley.org, click on "Additional Oley Publications" on the right side of the page, and then click on "Packet for Travel & Hospital Admission". At the bottom of that page are links to a letter for healthcare providers, a link to an information form for all consumers and links to forms specific to parenteral consumers and enteral consumers.

To obtain these forms by mail, send a S.A.S.E. to:

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

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 PiekarC@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.

Hello,

I have posted to the United Ostomy Association's bulletin board, but I also wanted to ask here – I have a Hollister g-j vertical tube support, which is going to overlap the wafer/flange from the ileostomy pouch I'm going to start wearing when I have my ileostomy. Does anyone have any alternate suggestions for a g-j tube support that takes up less real estate? My g-j tube is just to the left of my belly button.

I also have a lot of granulation and seepage (bloody and otherwise). I put two layers of foam underneath the outer bumper, one my ostomy nurse said was made from seaweed (!) and the other is Lyfoam. Still I have to change my tube support every other day because of all the seepage (but at least I'm not bleeding through onto my clothes like I was before using the seaweed foam). Any suggestions for the seepage and blood?

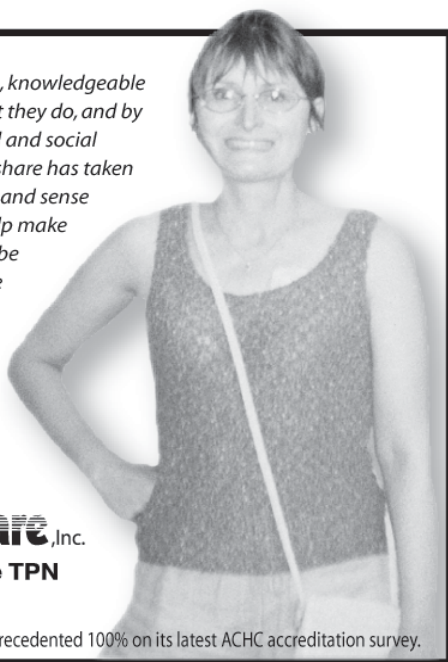
- Ellen Newman, ewn1@psulias.psu.edu

'By being thorough, knowledgeable and the best at what they do, and by offering educational and social opportunities, Nutrishare has taken away both the fears and sense of isolation. They help make it possible for me to be who I am and do the things I love.'

Mica Coffin
Nutrishare Consumer

Nutrishare, Inc.
1-800-Home TPN

Nutrishare scored an unprecedented 100% on its latest ACHC accreditation survey.



In Loving Memory of Gayle Winneberger

Thoughts by Katherine Cotter

Oley Member Gayle Winneberger was a family-oriented gardener and golfer who loved to travel and explore the world. She lived in Santa Fe, New Mexico but also had a condo on a golf course on Lake St. Marcus in California, which she visited frequently. She had a large family including her husband, two sons, two stepdaughters, two stepsons, eight grandchildren and five siblings.

Gayle loved her elderly poodle Chili and her three cats. She also enjoyed studying birds at her numerous birdfeeders and was an accomplished gardener. In fact, she owned her own greenhouse and grew beautiful orchids. She collected angels and was a huge fan of holiday celebrations. She also loved music and played the organ and sang in musicals at the Santa Fe Arts Institute. She enjoyed playing bridge with friends in her spare time as well.

The Oley Foundation provided Gayle with hope for the future. In fact, Regional Coordinator Katherine Cotter served as Gayle's friend for over 15 years and mentored her because Katherine had undergone major stomach surgery Gayle needed. "We served as a link for each other; we were very supportive of one another," said Katherine.

Gayle passed away on Wednesday, September 22nd at her home in Santa Fe just after her 61st birthday.

Letters to the Editor...

Hello,

My son Trever is hooked up to a feeding tube 16 hours a day. The IV pole that holds the pump is very cumbersome and limits his activity. Insurance won't pay for a portable pump unless he needs it full-time (24 hours/day). Does anyone else have this problem? Trever, who is hooked up at night and part of the day, can eat by mouth but chooses not to. The doctor told me not to worry and that Trever is getting proper nutrition. Has anyone had similar experiences? I never thought I could deal with it if my child had to be hooked up to tubes and machines; now he is. Trever has had a feeding tube for eight months now due to failure to thrive from chronic renal failure.

I still think this is temporary, but the doctor said he may need it for years, even until a kidney transplant. Proper nutrition has helped Trever grow and stay healthy and now he's a happy two year-old.

I would like to talk to other parents with children who have feeding tubes and see how they deal with it. My phone number is (616) 355-7014.

-Laura Sheppard

One question I would ask my fellow patients would be how do I go about finding a new carrying bag for my TPN? The one I have is very old, smells awful, and the clip no longer holds the TPN bag securely in place. The one that my home care company sent me (the only kind they have) is heavy and awkward! I'm sure some Oley members would be happy to share information about how they solved this dilemma. It would be great for parents helping them to not feel so alone. I think such a service would also help people new to HPEN, as they could see that hey, people are dealing with life on TPN and it's not so bad!

-Davria Cohen, cobennet@netscape.com

Equipment Exchange

The following supplies are offered free of charge to readers:

Enteral Formula

- 23 cans Subdue unflavored, exp. 6/05
- 34 Peptamen Jr. (250 cal), exp. 5/05
- 4 bottles Peptinex DT 1.5 liter, exp. 4/05
- 8 1/2 cases Nutren 1.5 vanilla flavor, exp. 3/05
- 2 liters Isocal, exp. 4/05
- 3 cases Nutren 1.0, exp. 6/05
- 12 cases Isosource, exp. 7/05
- 3 cases bottles Jevity 1 cal, exp. 3/05
- 1 case cans Jevity 1 cal, exp. 4/05
- 6 cases Jevity 1.2, exp. 6/05
- 11 cases Promote with fiber, exp. 5/05
- 4 cases Glyrol, exp. 3/05
- 4 cases Osmolite 1 cal, exp. 8/05

Tubes/Administration sets

- 5 Ross 1000 ml Companion top-fill bags
- 52 Ross 500 ml Companion Ambulatory feeding bags
- 10 Ross 1000 ml Embrace bags with pre-attached pump set
- 10 Bard button device continuous feeding tube w/ 90-degree adaptor, 18 French 24"
- 9 Mic-Key ext. sets right angle connector and 2 port Y clamp 12"
- 5 Ross 500 ml Embrace ambulatory bag w/pre-attached pump set
- 25 Ross 1000 ml Patrol bags
- 4 Mic-Key G low profile G tube kit
- 18 Ross Quantum feeding sets with attached flush bag
- 22 Ross 1000 ml Patrol bags w/attached pump set
- 26 Kangaroo 500 ml bags
- 30 Kangaroo 1000 ml pump sets (773667)
- 28 Kangaroo 1000 ml pump sets (773600)
- 100 Kangaroo 500 ml pump sets
- 8 Bard Button device bolus feeding tube w/straight adaptor, 18 French 10"

Miscellaneous

- 11 BD Saf-T PRN 0.14 ml
- 21 BD Syringe tip cap
- 24-23 G 3/4 x 12" vacutainer safety-lock blood collection set
- 1-10 ml latex-free sterile syringe w/precision glide needle
- 32 Tegaderm sterile transparent dressing 2 3/8" x 2 3/4"
- 4 Steri-Strips sterile 1/2" x 4"
- 4 Braun BC 1000 normally closed back check valve
- 34 Vista Basic pump set (15 drops/ml)
- 10 Braun rate flow regulator IV set 84", 20 drops/ml
- 37 10 ml latex-free sterile Luer-Lok syringes with blunt plastic cannula
- 22 60 cc irrigation syringes
- 52 5 ml latex-free sterile syringe w/precision glide needle
- 1 Abbott 3 liter carry case for Abbott IV pump (brand new)
- 29 10 cc slip tip syringes
- 16 1 cc slip tip syringes
- 67 Med Stream Sterile Dressing Change Tray
- 20 boxes Holister flanges
- 42 60 cc syringes
- 400 6 cc Monoject syringes
- 20 BD 2 oz. (60 ml) syringes

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.

Invention, from page 1

nutrients, I found this entry: "milk protein concentrate"? That sounded like milk to me. What to do? I had two problems now: ingestion system and diet.

Since my ingestions go directly to my stomach, there was no reason why I shouldn't use ordinary food as long as it would flow through my syringe tip and G-tube. And so I started on a campaign to puree ordinary food and inject it. Of course, this produced more work in the form of preparing food, blending into a fine puree and finally straining it. I had a lot of fun choosing foods that would puree easily and still strain. Needless to say, I found foods that wouldn't puree: rice and peas for instance. I found other foods that wouldn't go through the strainer, like oatmeal.

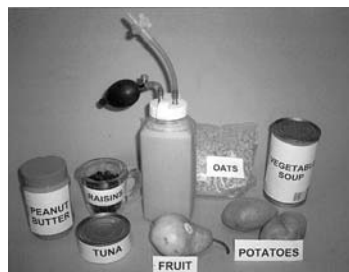
And so I cooked, prepared raw vegetables, blended, strained, syringed, blocked the tube, squirted food over the wall in the downstairs bathroom, and caused accidents in the car where the ceiling and dashboard suffered several indecencies. What do you use to wash the inside upholstery of the car when you're 50 miles from home with no towels, cloths or fresh water? Figure it out. OK. It's time to figure out a way to ingest food in a quart at a time. This two-ounce syringe business couldn't go on. That was 16 perfect injections per meal, more if some of it hit the wall! Whenever I had time to be creative, I'd design a prospective pump: a hand pump or an electrical pump, a converted oil pump, a cylindrical pump, and so on. They had one-way valves, two-way valves and other complications that I might be able to machine in my basement workshop, but didn't want to invest the time because they might not work or they'd be too cumbersome to carry in my briefcase, not to mention their need for electricity.

One night, while I waited for Ann to exit from choir practice, I designed a pump in my mind that uses a blood pressure bulb, some chainsaw fuel line, and a one-quart plastic bottle from the thrift store. Back home, I put the pump together and it has served me almost continuously ever since. I mean I've pumped six pounds of pureed food daily now for over a year. That's a little over a ton of puree!

Did I tell you that I couldn't maintain my body weight until I started using this pump? Yep, I lost weight continually. I weighed about 137 pounds at the lightest. Now I'm up to 157 pounds and still climbing. I think that works out to about 75 molecules a day, but hey, who's complaining? I've had lots of friends say I should patent my

pump, but my family's full of inventors who've never made a dime off their inventions. Why should I break an old family "habit"? ©

Dr. Snyder's home-made pump and examples of the items he blended to create a well-balanced diet.





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

Those who know me well know that I enjoy taking time to reflect! This time of year is a perfect setting for sharing some (and I apologize for not being able to cover all) of the highlights from 2004.

Oley membership now exceeds 6,500 and includes a growing number of professionals - thanks to volunteers for the time spent staffing Oley exhibit booths, passing along newsletters, etc.

The Regional Coordinator Network continues to contribute great effort and energy connecting individuals and families to peer support and the resources they need. These things are priceless. We could not do our work here at Oley without them.

Some other efforts include: Participation at Nutrition Week in Las Vegas, the DDNC Education Day on Capitol Hill, the annual conference in San Francisco (Sheila Messina and many, many others!), the regional conference in Chicago (Kathleen McInnes and Ann Weaver), the fundraising event in Columbus (the Nobles and M3 families), the Cheer Up Committee efforts (Robin Lang, Ruthann Engle and Jim Wittmann), the fundraising spark (donor envelopes in each newsletter - Liz Tucker), the Letter to the Editor of the Washington Post showcasing how full life is and how full of possibilities life can be while dependant upon TPN (in response to an article about intestinal transplant - Davria Cohen), the Oley presentation at Association for Vascular Access Mtg (Steve Swensen & Sheila Messina), and Robin Lang's "address" at the Harvard Program are all examples of volunteer efforts that benefit so many people. The folks who staff the Oley toll-free numbers (often RC's) and claim that they often walk away with more than they give are individuals that warrant recognition. Alicia Hoelle joining the Horizon Society at age nineteen comes to mind as another tremendous moment this year. Many, many thanks to everyone.

And last but not least, I struggle to find words to express gratitude for the support and acts of kindness extended to my dear friend Nader. Your thoughts and prayers provided him, his family and me with the strength we needed. It's truly overwhelming!

On behalf of Oley staff and Trustees I extend best wishes to all for a New Year that brings you the best of health. ☺

Cheer Up Committee Welcomes Two New Members

The Oley Foundation's Cheer Up Committee welcomes Jim Wittmann and Ruthann Engle. They join Robin Lang in becoming a resource for members who wish to send thoughts and greetings to people they care about - whether it be someone enduring a lengthy hospital stay or someone celebrating a birthday or anniversary. If you'd like to take advantage of the Cheer Up Committee and send a positive message to someone, contact the Oley Foundation at (800) 776-OLEY.

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Auction Items Needed

Oley needs your help to make this year's silent auction a success. Whether or not you plan to attend the event, we encourage you to think about what Oley means to you and your family, and how you can help out.

Anyone who quilts, knits, makes jewelry — or any craft — is encouraged to donate items to Oley. You can also be creative in other ways: Do you shop somewhere regularly or have connections at a business that might donate a big ticket item like electronic equipment, airfare, an overnight stay at a hotel? Could you spare a few days or a week at your vacation home, time share or condo?

The more funds we can raise, the better we can support Oley's outreach and educational programs, like the *LifelineLetter*, the annual conference, and the toll-free hotlines. Every dollar helps!

Raffle and auction items can be sent along with a note detailing who to thank and approximate value, to the Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208.

Any questions? Contact Joan Bishop at bishopj@mail.amc.edu or (800) 776-OLEY / (518) 262-5079. We appreciate your support of Oley programs! ☺



The Oley Fall Gathering in Albany, NY

By Jane Freese & Robin Lang

November 5th was a chilly night, but all who gathered enjoyed the warmth of the fireplace and the warmth of being with old and new friends. Dr. Howard and Jack Alexander hosted 40+ guests for this bountiful potluck dinner.

Oley's president, Steve Swensen, and our former president, Don Young, were in attendance, as were Oley staff and board members. Consumers came from far and near.

Our gracious hosts introduced everyone. We were all surprised to learn long-term consumer Eleanor Orkis was celebrating her 80th birthday. Congratulations Eleanor!

Tabletops dripped with delicious food. Jack's mulled cider was a huge hit. The dessert table held lots of tempting treats too.

With the many children in attendance, it was only natural to show them the animals on the farm. Dr. Howard invited everyone to the barn to feed her horses. Some crawled up to the loft to drop down bales of hay; others petted the horses through their stall bars.

Later we gathered outside as Dr. Howard recited a poem explaining the British tradition of Guy Fawkes Day (Nov. 5), and then his effigy was thrown into the bonfire. Guy Fawkes was an English conspirator who plotted to blow up Parliament on Nov. 5th, 1605. The plot was foiled and to this day the English commemorate the day with fireworks and bonfires.

It was a relaxed, casual evening, and everyone enjoyed the food and unique activities. Meeting friends again was the highlight. We departed wishing each other good health and happiness. ☺

(800) 776-OLEY • LifelineLetter — 5



Meet pediatric tube-feeding needs with PediaSure® and Embrace™

Children who are tube fed need nutritional products and a delivery system that meet their special needs and the needs of their caregivers as well. PediaSure® Enteral Formulas and the Embrace™ Enteral Pump from Ross can help meet those needs. PediaSure Enteral Formulas meet the nutritional needs of children 1 to 13 years of age, and Embrace meets the needs of caregivers by offering safe, simple operation and the flexibility of ambulatory use.

Contact your home medical equipment supplier or visit Ross.com for more information.

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COLUMBUS, OHIO 43215-1724



Trusts, from page 1

savings to supplement the needs of non-disabled children who are still minors.

A Special Needs Trust is irrevocable so here are a few important issues you'll need to consider when creating a Special Needs Trust:

- Should trust funds be strictly for inclusion in your estate or also be used to help meet current expenses?
- What is the average cost of your loved ones supplemental needs (above and beyond the amount provided through government funding)?
- What level of support must you provide for other family members? You'll need to ensure you also have sufficient funds for incorporating other dependents and beneficiaries into your financial and estate plan.
- Who should your trustee(s) be? You can designate individual, joint and/or corporate trustees.
- What limits should be placed on your own or your trustees funds? Should funds be withdrawn on an "as-needed" basis or distributed on a set payment schedule?
- What funding vehicles should you use for your trust?

The funding vehicle you select for your Special Needs Trust can have a dramatic impact on the amount available for your loved one.

Investments or other financial resources can potentially multiply the value of your trust fund over the years but at the same time, today's fluctuating market and evolving tax laws can lessen the value of these savings.

Laws vary from state to state so it is important to work with lawyers and financial planners that are familiar with your state's laws, rules and regulations. Depending on the situation, Special Needs Trusts can be very simple or can be very detailed. Again, the advice of an estate attorney and financial planner familiar with your situation is your best resource. ☺

Medications Too Costly?

PhRMA, a pharmaceutical manufacturers association, has organized a **Patient Assistance Program** in an effort to help make medicines available to those who need them and are financially unable to cover the cost. Pledging that "no patient in need of their medicines will do without them", they have coordinated a wonderful web site www.HelpingPatients.org to help patients find assistance programs for which they may qualify. This site outlines member company programs, non-PhRMA company programs and federal and state-sponsored programs. The on-line program is free and completely confidential. Copies of the directory can also be obtained by calling (800) 762-4636.

On-Line Shopping?

Remember, **igive.com** will donate a portion of your spending to Oley at no charge to you, and there are hundreds of great stores to choose from! Call (800) 776-OLEY for details.

A Guide to Wish-Granting Foundations *Reprinted with permission from Coping® Magazine*

Sometimes a positive diversion can help improve the outlook of children with fatal or chronic diseases. The following is a partial listing of organizations that offer different ways to make this happen:

Believe in Tomorrow National Children's Foundation (800) 933-5470 http://www.believeintomorrow.org	<i>children who are hospitalized or homebound</i>	Marty Lyons Foundation Phone: (212) 977-9474 http://www.martylyonsfoundation.org <i>Limited to Northeast</i>
A Child's Wish of Greater New Orleans Phone: (504) 367-9474 http://www.achildswish.org <i>Limited to Louisiana</i>	Give Kids the World Phone: (407) 396-1114 http://www.gktw.org	New Hope for Kids Wish Program Phone: (407) 599-0909 http://www.newhopeforkids.org <i>Limited to Florida</i>
Children's Dream Fund Phone: (727) 896-6390 http://www.childrensdreamfund.org <i>Limited to Florida</i>	High Hopes Foundation of New Hampshire, Inc. Phone: (603) 429-1010 http://www.HighHopesNH.org <i>Seriously ill children living in New Hampshire</i>	A Special Wish Foundation, Inc. Phone: (614) 575-9474 http://www.spwish.org
Children's Hope and Dreams – Wish Fulfillment Foundation Phone: (973) 361-7366 http://www.childrenswishes.org	Hunt of A Lifetime Phone: (866) 345-4455 http://www.Huntofalifetime.org <i>Grants a fishing and/or hunting dream trip for youngsters with life-threatening illnesses.</i>	Sunshine Dreams for Kids Phone: (800) 461-7935 http://www.sunshine.ca
Children's Wish Foundation of Canada Phone: (905) 426-4060 http://www.childrenswish.ca/ <i>Limited to Canada</i>	Indiana Children's Wish Fund Phone: (317) 913-9474 http://www.indywish.org <i>Children who have a critical illness living in Indiana</i>	United Special Sportsmen Alliance Phone: (800) 518-8019 http://www.deerfood.com/ussa.htm
The Dream Factory, Inc. Phone: (502) 637-8700 http://www.dreamfactoryinc.com	Jason's Dreams for Kids Phone: (732) 758-0060 http://www.jasonsdreamsforkids.com	A Wish Come True, Inc. Phone: (401) 781-9199 http://www.awish.org <i>Limited to Rhode Island and Southeastern Massachusetts</i>
Dreams Do Come True Phone: (877) 347-1213 http://www.dreamsdocometrue.org	Kidd's Kids Phone: (972) 432-8595 http://www.kiddskids.com <i>Annual trips in November to Walt Disney World for children ages 5 to 12</i>	A Wish with Wings, Inc. Phone: (817) 469-9474 http://www.awishwithwings.org <i>Limited to Texas</i>
Dreams Come True Phone: (904) 296-3030 http://www.dreamscometrue.org	Kids Wish Network Phone: (813) 891-9374 http://www.kidswishnetwork.org	Wishes Can Happen, Inc. Phone: (330) 966-0043 http://www.wishescanhappen.com
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Florida in February – Nutrition Week 2005

Once again, the Oley Foundation will offer a Regional Nutrition Support Workshop in conjunction with Clinical Nutrition Week. With the generous support of the American Society for Parenteral and Enteral Nutrition, and national experts drawn from around the country, we will have an exciting and dynamic education day for consumers. This year, the program will take place at the Gaylord Palms Resort in Orlando, Florida on January 29th, 2005.

This workshop will be similar in format to regionals we offer around the country – morning speakers will cover a variety of topics pertinent to consumers using TPN or tube-feeding therapies. Afternoon roundtable sessions will focus on individual topics such as wound and skin care, preserving access, insurance issues, pediatric challenges, and enteral issues.

There are also volunteer opportunities and terrific benefits to attending this program. Those consumers who volunteer at the Oley exhibit booth gain access to the Exhibit Hall, (Sunday, January 30th) and a great opportunity to check out new technologies, products and services. Volunteers may also attend the Oley Foundation Consumer panel discussion (Tuesday, February 1st), a terrific opportunity for consumers to share insights about living on nutrition support therapies with the professionals that support them. This is always a dynamic session, and a great way to contribute to improving patient care.

Call the Oley Foundation for more information. Registration and program brochure are now available online (www.oley.org). The Seralago Inn is five minutes from the Gaylord Palms Resort and has reasonable room rates. Information on accommodations is available by calling (407) 396-4488. As all of our services are, this program is free to consumers and caregivers. Attendees are responsible for their own transportation and hotel. Plan on joining us for a great program!



Spotlight: Don Young

By Cory Piekarski

Everyone around Porter Corners, NY knows who he is. In fact, Don Young's family has lived there for eight generations. His family cemetery, located on the other side of his barn, dates back to 1800. His great, great grandfather built the statuesque brick home



across the road from Don's farm in 1864. 100 years later, Don met his wife Bonnie while at Saratoga Hospital. Later, he was rushed from Saratoga to Albany Medical Center for resection surgery.

Don's had Crohn's Disease symptoms since age 18. He was diagnosed six years later and was relieved to have a name to put to his symptoms. Because of malabsorption issues and a lot of hard work, he needed extra calories and often ate 6,000 calories a day until a blockage formed that resulted in a massive bowel resection in 1964. The surgery provided great relief but in 1975 he was placed on artificial nutrition therapy as a result of a blockage. Don has relied on it ever since and, on March 25, 2005, he'll celebrate 30 years on TPN. He is one of the longest TPN recipients in the U.S.

Don has a positive relationship with his nutrition support therapy. He says that many people, including some doctors, look upon the use of artificial nutrition as a failure yet he sees it as a successful solution to a problem. Simply put, "It works."

Don has three children, Janet, Paul and Mark, and three grandchildren. He logs and loads firewood, works on his own tractor, loves bluegrass and his portly Basset Hound Dudley whom he obtained from the widow down the road. He's coached baseball, has served on his town board and is a member of his local Democratic Party. He also served as Oley's second president so he hasn't let TPN slow him down at all. In fact, for almost 30 years, he's helped others handle health issues similar to his.

Don admits he has more to contribute to people who are new to parenteral nutrition than to those who have been on it for several years and who are educated and experienced. "Many TPN patients learn what they can eat and what they can't and make their own choices," says Don. With regard to improvements in the field, he says, "Infection is a huge worry to those on TPN but risks are reduced now compared to 30 years ago." Also gone are the days of large, immobile pumps. Technology has improved because of user-friendly equipment designed for home-use. The development of home care companies has also helped improve relations between insurance company and patient by handling third-party reimbursement issues. The Oley Foundation and home-care companies have offered support to the TPN consumer who had previously received support through the hospital alone. In many cases, this ends the isolation felt by the patient and provides valuable opportunities to network with others. Don points out that more cancer patients rely on TPN than do Crohn's patients but his expertise lies with the latter. He's been issued a permanent toll-free number through Oley (1-866-454-7309) to help others with Crohn's symptoms, IVs, TPN or similar issues.

When Don was placed on TPN almost 30 years ago, he told doctors that when his youngest son Mark graduates, he will have played a nine-inning game and any time beyond that will be extra innings for Don. Well, not only did Mark graduate back in 1988, but last June, Don saw his grand daughter Britany walk across the same graduation stage. ©

C O R A M



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Twenty-one and a half years ago Megan Gravenstein went on TPN. She was a very sick little girl. Now she is twenty-two. She is in college, dating and enjoying life as a co-ed. Studying hard. Living life.

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Oley Goes to Capitol Hill

The Digestive Disease National Coalition is the leading public policy advocacy organization in our nation's capital for persons affected with digestive diseases. They will host the 15th Annual Public Policy Forum from March 6-7, 2005 in Washington, DC and invite Oley members to join them. Ann Weaver, an Oley participant writes, "This past spring my sons and I were able to participate in the DDNC Education Day on the Hill. It was a wonderful educational experience for my family.

"We initially felt very intimidated, as we had never been involved with any legislative endeavor. The first evening we were provided with background information from researchers, physicians and organizations that are developing new treatments and supporting individuals with digestive disorders. We were given a thorough picture of progress that has occurred in digestive disease research, as well as areas where more research is needed.

"While the DDNC lobbying effort emphasized the continued need for NIH funding for research and educational programs, we had the opportunity to talk to legislative staff about the cost of medical formulas and the increasing number of insurers who are eliminating coverage of these lifesaving treatments.

"Our day on the Hill started with an instructional session on the etiquette of conducting a legislative meeting. Then my sons and I, along with the Smith family from Indiana, began our visits to the offices of Dick Durbin, Peter Fitzgerald and Judy Biggert, all from Illinois. We also met with staff for Evan Bayh and Richard Lueger of Indiana.

"It was a busy day running from one side of the Hill to the other for our scheduled meetings. We walked the hallowed halls often times with our mouths wide open - looking for names of senators we

recognized, traversing underground tunnels which connected many of the buildings and going through security checkpoints.

"My son Tim and Aleah Smith, both ten years old, had the opportunity to share their stories and experiences of being enteral consumers their entire lives. Parents expressed their concerns about the medical cost, both now and as our children become adults. We asked the legislators to support a national mandate requiring insurers to cover medical formulas.

"We took a break for lunch to share our day with other volunteers and had the opportunity to meet Senator Joe Lieberman, (pictured at left with Tim Weaver, Aleah, Keely and Sky Smith) who was presented with an award for his support of legislation to benefit colon cancer awareness and research. The day ended with a debriefing to summarize our days meetings and the kids planning to do it again next year!"



We were headquartered at the Washington Court Hotel, 525 New Jersey Avenue, NW Washington, DC 20001 (hotel telephone number - (202) 628-2100). This annual event unites patients, health care providers, industry representatives, lawmakers and their legislative staff for two days of educational programs,

legislative updates and advocacy training. The goal of the forum is to brief participants from around the country on federal health care legislation and policy in order to educate members of Congress regarding issues of concern to the digestive disease community. And patient/consumer testimonials are powerful!

For additional information call Dale Dirks at the DDNC - (202) 544-7497 or visit www.DDNC.org and/or call Oley (800) 776-6539. Be sure to let the Oley staff know that you are planning to attend. We'll see you there!



Federal Internship Program Helps Disabled Students Build Careers and Community

Designed and funded by Microsoft, and administered by the American Association of People with Disabilities (AAPD), an organization with more than 90,000 members, the Microsoft-AAPD Federal IT Internship Program provides college students with disabilities summer internships at U.S. Government agencies. The internships enable the students to hone their IT skills while gaining valuable work experience.

According to Mariana Nork, senior vice president for development and communications at AAPD, several interns have been hired by federal agencies or have used the experience they gained as interns to help them land jobs in the private sector. Nork adds, "The Microsoft-AAPD Federal IT Internship Program certainly opens doors of opportunity for students with disabilities, but it also opens the eyes of employers who may not realize that they are overlooking a largely untapped pool of talented workers."

In the U.S., 60 percent of working-age adults (101.4 million people between 18 and 64) have mild to severe difficulties and impairments that may impact computer use. Additionally, unemployment is exceptionally high among people with disabilities; a Harris poll released in June 2004 estimates the rate at 65 percent. One goal of the Microsoft-AAPD federal internship for students with disabilities is to address that problem.

Initially, Microsoft and AAPD developed a two-year program to provide 25 paid IT internships to college students with disabilities at more than 15 government agencies. Microsoft funded the program with a \$325,000 grant and AAPD provided administration and its experience in developing and running similar programs. The program was so successful that Microsoft extended its funding commitment for a third year.

The internship program is open to any college or university student with a disability who has demonstrated an interest in an IT career. Interns are selected through a competitive application and interview process. The benefit to participants is not only job experience but for some, it's their first taste of independence and the interns form deep bonds, support each other throughout the program and often keep in close touch after the internship has concluded.

For more information about this program, visit the AAPD website at <http://www.aapd-dc.org/> and click on the icon that says "The Washington Center Spring 2005 Internship Program For Students With Disabilities" (bottom left on homepage) or click on the link on the Oley website (www.oley.org).



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The Horizon Fund is a group of members who are securing the future of Oley programs by naming Oley as a beneficiary in their wills.

Nineteen Year-Old Inspires Parents



Inspired by their nineteen year old daughter's decision to include Oley in her will, parents and long time supporters of Oley, Rose and Jeff Hoelle (pictured above) have joined Alicia as Horizon Society members. We welcome our "old" friends in this "new" capacity and thank them for bringing their support for Oley to the next level. We look forward to continuing to reach out to the homePEN community with the quality of programs for which Oley is renowned for many, many years to come. ©

Your Support Makes Oley Stronger!

The following generous individuals have donated a gift to the Oley Foundation between September 14 and December 9, 2004. Thank you for your support! We also wish to thank all 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. A complete listing of everyone who donated in 2004 will be published in the January/February 2005 issue.

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Help provide a secure financial future for Oley by joining the Foundation's Horizon Society. It's as simple as including a gift to the Foundation — large or small — in your will, and can have tax benefits! For more information on ways you can give, contact Oley's Executive Director, Joan Bishop at (800) 776-OLEY or bishopj@mail.amc.edu.



Toll-Free Numbers Available to US and Canadian Consumers!

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

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

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

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

JAN. '05

Candace Verners
Vancouver, BC
(888) 650-3290 EST

Candace is 40 years old and has had Crohn's Disease for 20 years. She had a bowel resection when she was 23 which resulted in short bowel syndrome. She has been on TPN for the past eight years. Candace became pregnant six years ago while on TPN and now has a very healthy and happy six year-old boy. She has experience with PORT-A-CATH® catheters and REMICADE® (infliximab) therapy. The best time to call is between 9 and 5 PST.

Diane Owens
Marion, MA
(888) 610-3008 CST

Diane has been on Enteral nutrition for the past 11 years due to myotonic myopathy. She was also on TPN prior to enteral. She has experience with a variety of tube issues. She is very proactive in pushing for and receiving adequate care and looks forward to sharing her experiences with others. Please call Diane after 5 p.m. EST.

FEB. '05

Lou Pacilo
Leeds, MA
(888)650-3290 PST

Diagnosed with sarcoidosis (a swallowing disorder), Lou was on TPN briefly, then weaned to tube feeding five and a half years ago. He has a J-tube and an ostomy, and works part-time as a radiologist. He is experienced with changing feeding tubes, caring for ostomy sites and coping with not being able to swallow his own saliva in public.

Ruthann Engle
Streetsboro, OH
(888) 610-3008 EST

Ruthann has been on TPN since 1990 due to SBS. She has used a HICKMAN® catheter and PORT-A-CATH®. She enjoys being an Oley regional volunteer where she has given and received much help and support from other Oley members. She has a great love for gardening and quilting when health allows, and thankfully, a supportive husband. Please call between 9 a.m. and 7 p.m.

MARCH '05

Matthew Van Brunt
Adelanto, CA
(888) 610-3008 PST

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

Heather Abbott
Alexandria, VA
(888) 650-3290 EST

Heather is the mother of Andrew who is three and a half years old. Andrew was on TPN for the first 15 months of his life due to short bowel syndrome. He was also on continuous G-tube feeds but they have since stopped. He does have an ileostomy. Heather was a pediatric ICU nurse before having Andrew, and had attended her first Oley conference in 2003. She looks forward to connecting with others.

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LifelineLetter

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