The Bumpy Road to Independence

Bette Bond, Home Infusion Consumer

Bette Bond was on HPN for several years and now infuses lipids and pain medication. Below is her story on getting through college, finding a job and gaining her independence in the process, as told during the Oley Conference in Boston this past summer. As with all articles in the Lifeline Letter, the advice given below reflects the experience of the author; before making any changes in your health care, insurance coverage, disability status, etc. the Oley Foundation recommends seeking an evaluation of your own situation by the appropriately trained professional (i.e. physician, lawyer, caseworker). A videotape of this session is available from the Oley library.

The one thing I want to stress, is that you, consumers, need to be active for yourself. There are many resources to help you, as an adult, or a child who’d like to become independent. The problem is that you are not usually told what resources are out there, what’s available to help you or for your family to help you.

Medicare to Cover Intestinal Transplantation

Early in October, the Health Care Financing Administration (HCFA) announced its intention to cover small bowel and multivisceral transplants for Medicare patients. Medicare expects to implement the policy in the spring or summer of 2001. For more information on HCFA’s policy, you may want to check HCFA’s web site at http://www.hcfa.gov/coverage/default.htm. For more information on intestinal transplants, try the Intestinal Transplant Registry web site at http://www.lhsc.on.ca/itr/ or the United Network for Organ Sharing web site at http://www.patients.unos.org/.

Most patients with short bowel syndrome and other severe gastrointestinal disorders which prevent them from maintaining a healthy nutritional status orally are maintained on home parenteral (IV) or enteral (tube-fed) nutrition (HPEN). Survival rates for HPEN patients are good, as is their prognosis for rehabilitation. With dietary counseling and adaptation of their bowel, some of these patients are able to reduce or eliminate their need for HPEN. It is estimated that 10 to 20 percent of all patients started on HPEN will remain dependent on HPEN indefinitely.

A limited number of patients may be candidates for non-transplant surgical options. These procedures that are collectively referred to as Autologous Gastro-Intestinal Reconstruction (AGIR) can be effective in allowing freedom from HPN and its complications (see “More on Autologous GI Reconstruction” on page 10).

When these options are exhausted, and a patient has ‘failed HPN,’ (usually because of liver failure or lack of IV access) then they may be a candidate for small bowel transplantation (SBT). SBT can be performed in isolation, in combination with a liver transplantation,

Save the Dates!

The 16th Annual Oley Consumer/Clinician Conference will be held June 21 to 23, 2001 in Milwaukee, Wisconsin. This strategic location offers consumers access to the expertise of nearby Chicago’s medical community, with all of the charm of a midsize midwestern city. Anyone interested in helping to plan the conference should contact Joan Bishop at (800) 776-OLEY, or BishopJ@mail.amc.edu. More information about the conference will be published in subsequent issues of the newsletter and posted on our web site at www.wizvax.net/oleyfdn/confer.
high school today according to their standards, but fortunately the public school accepted my grades, and I was able to graduate. After high school, I took a couple of years off because I was in and out of the hospital so frequently. Eventually I got to the point where I was thinking of taking just one college level class to see if I could do it.

Starting College on the Right Foot

College was amazing. Colleges have these offices which serve as a resource for 'disabled' students. Different schools have different names for them, like the "Office for Students with Disabilities," but every college has one, whether it's a community college, junior college, or a university. If you have a child, look for that office, because they can help you navigate through the system.

I started at a community college taking one class. I went into the Office for Students with Disabilities, and after speaking with one of the counselors, I got first pick on the classes offered later in the day. That was a better schedule for me, because I was usually very sick in the morning after getting off the TPN. I was also able to make arrangements for special testing situations. If my class was only offered early in the day, I was allowed to take tests for that class in the afternoon. And then, because of blood sugar problems, I was allowed to take breaks during the test to have frequent meals. They can accommodate for most special needs like this.

Just having to deal with illness and pain can make it difficult to process everything. So I requested extra test taking time. The one stipulation, is that you must have your needs documented ahead of time. This is especially important with major exams like the SAT's, college entrance exams and college boards. The best time to do that is when your kids are young. Have it documented now and it will follow them through high school and into college.

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my pump wasn't working. I needed to go to class because we were reviewing for a big test coming up. I was reluctant to go to class still attached, and even if I went, it would be difficult to accommodate. I was infusing by gravity since the pump was broken. We called the school and explained the situation. They took the class's skeleton off his rack and brought the rack to the back of the room where I infused during class. It wasn't that noticeable, and I was glad to be in class.

Taking on a Bigger Load

Over time, I slowly built back up, taking two classes, then three, as I could tolerate them. A few times I had to stop for a semester and go into the hospital, but even with that, the college worked with me. I had started one semester and stopped for a semester.
Two Ideas for Ostomy Odor Control
I read the letter from Kathleen McInnes regarding odor control in the September/October Lifeline Letter. When I had an ostomy, chlorophyll tablets placed directly into the ostomy bag worked fairly well. There are also chlorophyll tablets that can be taken orally to reduce effluent odor. I purchased these at a GNC Nutrition Center. (Editor’s note: you can take some chlorophyll tablets orally, but check the directions first to make sure they are an oral preparation. Also, be forewarned, the tablets may turn your tongue green.)

— Alan Seagal
3799 S. Clayton Road
Farmersville, OH 45325
(937) 696-9305.
E-mail: asegal@hotmail.com

There is a liquid deodorant which can be added to an ostomy bag called “M 9” which is made by Hollister. Our ET nurses recommend it as an effective option for odor control.

— Laura Matarase, M.S., R.D., C.N.S.D.
Cleveland Clinic Foundation
Cleveland, OH

My First Oley Conference
Ellie Wilson, RD
Oley National Outreach Coordinator
On November 10th, I traveled to Ontario, California, to participate in my first regional conference with the Oley Foundation. I had a wonderful time, and I’d like to share some of my experiences with you.

The facility was nice, the staff was helpful, the food was good, and the bathrooms were close! Our conference and exhibits were held entirely in one room, which was a little snug, but afforded the 60 or so exhibitors and consumers more time for interaction and education.

The speakers were tremendous. Laurie Reyen, R.N., discussing how nutrition support has changed over the last 25 years, had an excellent presentation and slides illustrating the challenges that have played a role in advancing these therapies. Doug Farmer, M.D., offered thorough coverage of the issues that should be considered with intestinal transplant, including a review of the criteria used to determine suitability for transplant. Josie Stone, R.N., offered insight into the mechanics of cathers, including blood flow diagrams, terminology specific to catheter care, and advances in catheter design.

I learned a great deal from all of our speakers and round table facilitators, but I learned the most from the consumers and family members. I had some advantage as my training as a dietitian includes parenteral and enteral therapy, but meeting the participants gave me much more insight into actually living with these therapies. For example, during Laurie Reyen’s program, when a slide of the “old days” with multiple TPN formula bottles and pumps on an I.V. pole was shown, Linda Boutin leaned over and told me she had taken that contraption camping! We met several new people, who were delighted with the education and the opportunity to connect with others facing similar challenges.

The exhibitors were a gracious and informative group. Those that participated in the plenary and roundtable sessions felt they had gained valuable insight into consumer issues, and some shared ideas for using these insights to improve their company’s services. One exhibitor includes an Oley newsletter in the education materials given to their new patients. Oley now provides companies with information sheets and membership forms, so they can better meet their patients’ needs and help create a fast connection. We encourage other companies to contact us about this opportunity!

I was made to feel very welcome, and I am very grateful to the Oley Foundation for giving me the opportunity to participate in this work. What was formerly a distant and scientific part of my professional training now has a personal and human aspect.

This event would not have been possible without the tireless efforts of Patty Woods, Judy Petersen, and David and Donna Miller. We sincerely appreciate all of their assistance in helping to organize and plan this conference. Thank you also to all the regional coordinators, speakers and round table facilitators! Finally, thank you to our exhibitors and lunch sponsors: Mr. Doug Schindler, Abbott Laboratories, Inc., Alaris Medical Systems, Coram Healthcare, Curlin Medical, H ome Pharmacy of California, Intravenous Therapy Services, Kendall, Nutrishare, Inc., Pharmacy Solution Services, Vygon Corporation, and Zevex, Inc.

Oley Update

Ellie Wilson, RD
Oley National Outreach Coordinator

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Independence

about. As adults we take these skills for granted, but children growing up removed from normal social situations need to be taught how to interact with people.

Interacting with groups on campus also got me out and doing things, instead of just sitting at home. I was able to slowly build up my endurance. I actually starting going to conventions with friends. Traveling showed me that — even if it was only one night, and maybe it was only two hours away — I can deal with this stuff all on my own. I don’t have to rely on my Mom or someone else to take care of my TPN.

When you are young, you rely on someone else to take care of everything. The transition into caring for yourself can be overwhelming; so it was nice to have these little trial nights. These are something to encourage your child to do. Even if you are an adult going through a time of not working, you should volunteer and go out. It’s something you can feel good about, and again, it can help you build up your endurance.

After I graduated from the community college, I moved on to a four-year university. There again, I went to the disabilities office. I had all my classes arranged and I was accepted into occupational therapy (OT) school. I ended up going full time and trying to live on campus that year. I got a dorm room with a full kitchen so I could prepare my special meals, and have enough refrigerator space for my TPN and medication. The school was very accommodating. My supplies were delivered to the dorm office then brought up to my room so I didn’t have to carry anything. College administrators can be very helpful, but it’s up to you to find the right people and talk with them. One tip is to talk to students who are already there; they will give you cues on who is best to talk to about a specific need you may have.

Living in the dorm was great because it allowed me to live day to day with my peers. I ended up sharing a room with a classmate. Originally that was not my plan. I wanted my own room. Besides, I didn’t think anyone would want to share a room with me because of all of the noise my pump made at night. Somehow things got mixed up, though, and I ended up with a roommate. It worked out wonderfully. She was a great roommate; nothing bothered her at all. In fact, she joked about getting a special storage area out of the deal, since my supplies took up all of the closet space in our room.

The first year was a little hard on me. It took all of my energy going to school full time. I would wake up, go to class, do school work, get connected and go straight to bed — when all my friends were out partying. The second half of the semester, I started socializing with them more and that was wonderful. The program went very well and I was able to continue going full time. The school worked with me on test taking time, etc. Later, I ended up renting a house with my cousin off campus. It was nice trying to live on my own with a roommate. I didn’t want to go back home because I was already out of my mom’s niche. So I asked my cousin if I could move in with her. My parents were still close by if I needed them, but it gave me a chance to be on my own and do things for myself.

Getting a Job

Eventually I finished the OT program and graduated. Graduation was sort of scary because it started me thinking about what I was going to do next. I needed to start looking for a job. I had finished three internships which showed me I could actually do the work of an OT. (I was worried whether I could physically handle the job, and whether my pump would get in the way.)

Just thinking of job hunting was stressful. The idea of an interview was scary. I didn’t know what to say, and more importantly, what not to say. I ended up going to the occupational vocational rehab (ORV) office. They had given me a scholarship to help pay for my education with the hope that someday I would become self-sufficient. I had another scholarship from the honor society, which was helpful as well.

Consumer Wins Award

Congratulations to Aaron Leppin, a 15-year-old home PN consumer who recently won two awards at the national Future Farmer of America (FFA) competition. Aaron and his five member team competed last April in the Missouri FFA competition, completing a 100 question test. Aaron’s team placed first which qualified them to go to the National FFA Convention in Louisville, Kentucky this October. Aaron’s team once again placed first. Aaron scored a 98 out of 100, which awarded him the first place high individual and his team, first place team award for the National FFA Knowledge Competition.

Aaron began HPN in February of 2000. He had had digestive system problems since birth, and his condition grew progressively worse until he was no longer able to keep anything down. Diagnosed with pseudo-obstruction, Aaron has severe dysmotility and malabsorption disorders. In addition to his central line, Aaron has a G-tube which he uses for drainage. Readers may have met Aaron and his family at this summer’s Oley Conference held in Boston, Massachusetts.

Aaron is great at taking his problems in stride and getting on with his life. He is a straight “A” student and enjoys waterskiing and snow-skiing. Lifeliners can reach Aaron at aaronlep@hotmail.com or (660) 265-3867.
Oley Materials Now Available in Spanish

Is language a barrier for someone you know? The Oley Foundation is pleased to offer Spanish speaking consumers a translated version of the Oley flyer (a one-page description of Oley and its programs) and a sample newsletter. The translation is done using free software available on the internet which has its pros and cons: On the positive side, we (or anyone with internet capabilities) can translate any of our materials for people who read in Spanish, French or German. On the down side, the translation is free and you get what you pay for, a loose-translation that no one on staff can proofread for accuracy. (If any readers would volunteer to proof the materials, we’d certainly appreciate it.) All in all, we hope the materials will help Oley reach out to more consumers in need of our services. For a copy of the materials, call (800) 776-OLEY, or go to our web page at http://www.wizvax.net/oleyfdn/Spanish. (The documents available on the web page require Adobe Acrobat Reader to open them. This free software is available at www.adobe.com) You can also try the free translation site located at http://www.freetranslation.com.

ASPEN Celebrates 25 Years in Chicago

Join Oley and the greater homePEN community as we celebrate the 25th anniversary of the American Society for Parenteral and Enteral Nutrition (ASPEN) at ASPEN’s Annual Clinical Congress to be held January 21 to 23 in Chicago, Illinois.

The following Oley activities held in conjunction with the ASPEN meeting offer opportunities for consumers to educate themselves and clinicians about homePEN:

Sunday, January 21
• 7:00-8:30 p.m. Oley sponsors a seminar for homePEN consumers and friends

Monday, January 22
• 9:30 a.m.-5:00 p.m. Help distribute materials at the Oley booth and learn about new technology and services from exhibitors
• 1:00-3:00 p.m. Oley coordinates a presentation, “Nutrition Support from the Consumer’s Perspective”

Tuesday, January 23
• 9:30 a.m. - 4:00 p.m. the Oley Exhibit Booth is open again

Please note that prior registration with Oley (at no charge) is required to participate in any or all of these events. For more information, contact Joan Bishop at (800) 776-6539 or BishopJ@mail.amc.edu.
Choosing Insurance Coverage

One good idea is to try to get your child qualified for disability coverage through Medicaid (Medical Assistance), or better still, through Medicare. Medicaid is the health insurance that comes with Supplemental Security Income (SSI); eligibility for Medicaid and SSI is affected by income and coverage varies by state. Medicare is the health insurance that comes with Social Security Disability (SSD). The good thing about SSD, is that it’s not based on income, it’s based on your condition. I found transitioning to financial independence easier and less stressful with SSD/Medicare (than SSD/Medicaid), but qualifying your child may be difficult. In certain circumstances, your child may be eligible for some coverage under both SSI/Medicaid and SSD/Medicare.

Medicaid/SSI really helped me to maneuver my way through the system. It was a fight. It took me three years, but once I got on

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Happy New Year!

The holiday season has wound down and we sincerely thank everyone who responded to our Annual Appeal. Your gifts, large and small, really make a difference in how we are able to move through 2001. Your support is greatly appreciated!

If you have overlooked or forgotten to include support of Oley’s precious programs in your charitable giving plan, please take a few minutes to consider sending what you can.

Your donation is tax-deductible and will help to:
- offset the cost of sending the LifelineLetter to all consumers regardless of their ability to pay
- support our new outreach efforts
- sustain consumer toll-free networking
- enhance the homePEN information clearinghouse
- encourage homePEN research

☑ YES, I believe in the work the Oley Foundation!

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We Accept Checks, VISA and Mastercard
- Make checks payable to “The Oley Foundation.”
- Credit card customers should complete the form below. Incomplete forms cannot be processed.

All gifts are tax deductible
- A copy of the Foundation’s latest New York State Report may be obtained from the New York State Department of State, Office of Charities Registration, Albany, NY 12231.

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I agree to pay for this purchase and abide by the terms of the cardholder agreement.
From the Oley Board

Oley’s Future: Built on Trust

Each year, the Oley Foundation appeals to home infusion companies to support our community of nearly four thousand homePEN families. We ask them for money. We ask them to participate in our conferences and other activities. We ask them to help us grow our community by spreading the word about Oley directly to those consumers who use their services. In return, we offer them certain limited opportunities to acquaint our membership with the products and services they provide. We extend this offer only as it is consistent with the educational objectives of the Foundation. A great many of our members explicitly desire to know more about home infusion services that are available to them. Our arrangement with our corporate sponsors accommodates that desire. It should be a win-win situation, with obvious benefits to all parties, but there are certain risks, and we have taken precautions to protect the interests of consumers and corporate sponsors alike.

Oley protects those interests in primarily two ways. First of all, our membership roster is accessible solely to Oley staff. We never share our mailing list, and we never release personal information about any of our members without their explicit permission. Any promotional mailings that Oley members receive as a part of our corporate sponsorship program are labeled and mailed directly by Oley’s mailing house, with no specific information about recipients given to sponsors. Members may at any time exempt themselves from receiving such mailings and are formally given the opportunity to do so again in this issue (see “Promotional Mailings” form on right). Our goal is to ensure that members who do not want promotional materials do not receive them, and that those who do want them, receive them with the confidence that they will not be followed by further, unwanted, contact. Secondly, Oley in no way endorses any home infusion provider, product or service. Our mission is to empower consumers to make their own informed choices, not to choose for them. We all know home infusion therapy is a business; we should not forget that the best protection any consumer has in any marketplace is his or her own ability to make their own decisions. The materials are produced by the donor for their own commercial purposes, and/or its products and services. Having the materials sent by Oley in no way implies endorsement by the Oley Foundation of the company and/or its products and services. The materials are produced by the donor for their own commercial purposes, and are for you to consider.

If you don’t want to receive these materials — please let us know, and we will remove your name from the promotional mailing list. (You will continue to receive the Lifeline Letter and other Oley materials.) Questions, and/or requests to not receive promotional materials, should be directed to Oley staff at 214 Hun Memorial, A-28, Albany Medical Center, Albany, NY 12208-3478; phone: (800) 776-OLEY/(518) 262-5079; fax (518) 262-5528; e-mail HarrinC@mail.amc.edu.

✔ Please Don’t Send Me Promotional Mail

Name: ________________________________
Address: ______________________________
City: ____________ ST _______ Zip ______

Ever more restrictive policies won’t protect our uniquely open community, but they could polarize it, and, in time, destroy it.

Promotional Mailings

The Oley Foundation has a strict policy of not sharing it’s membership list with anyone; however, companies that donate $15,000 or more in a year are allowed to send a promotional mailing to Oley members. To ensure the privacy of our members, we mail the promotional materials (videos, brochures, invitations, etc.) through our own mailing house.

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August 8, 2000