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LifelineLetter

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

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 **LifelineLetter**, 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.



Bettemarie (right) and HPN friends Malisa Matheny and Melinda Deater whooping it up at the Oley Conference.

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Medicare to Cover Intestinal Transplantation

Early in October, the Health Care Financing Administration (HCFA) announced it's 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 Autolo-

gous 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,

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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.

Independence, from pg. 1

My story began when I was in high school. I had been sick as a child, but my condition became much worse when I was 16 years old. High school, for me, was really messed up. I didn't get to do most of the things normal teens got to do. I had to go on home tutoring for my junior and senior year. I had been going to a Catholic high school, but ended up with tutors from the public school. When I finished my educational requirements, the Catholic school wouldn't graduate me because they didn't want to accept the public school tutor's grades and they wanted me to have a 'normal' senior year. I would still be in

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 SATs, 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.

When I was in college, everybody was so accepting. Yes, you will run into a few people who aren't, but it's rare. I remember one morning I hadn't finished my TPN because

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 classroom'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

got four weeks into it, when I wound up in the hospital and ended up staying until the summer. On her own, the anatomy instructor spoke to a student, and had her take notes for me. The instructor taped all the classes for me and dropped them off at the hospital, which was an hour away. In the end, I had to drop that semester; the hospitalization had been too long, but there is always a way to work things out. Even though I had breaks, and it took me 10 years, I was able to graduate from college with a Bachelors of Science in occupational therapy.

At the community college, I was invited into the honor society and began doing a little community service. That was helpful for me. It got me out, interacting and communicating with other people. This may sound funny, but I was worried about what I could talk about. All my experiences were around the hospital. So I made a point to read two or three articles each day in the newspaper. Then I'd go to the community center and ask people questions about the articles I'd read in the paper. That's how I started conversations and made friends — it was really helpful. Communication skills are something to think about with your kids, because when you are in the hospital a lot, it's difficult to think of other things to talk

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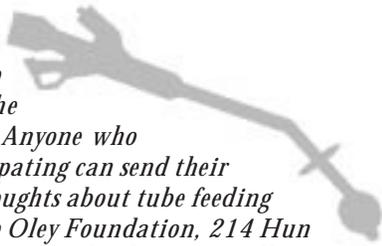
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The *LifelineLetter* is the bi-monthly newsletter of the Oley Foundation. Items published are provided as an open forum for the homePEN community and should not imply endorsement by the Oley Foundation. All items/ads/suggestions should be discussed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

Tube Talk

Thanks 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 A-28, Albany Medical Center, Albany, NY 12208; or E-mail DahlR@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.



Two Ideas for Ostomy Odor Control

I read the letter from Kathleen McInnes regarding odor control in the September/October *LifelineLetter*. 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 Segal
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 "M9" which is made by Hollister. Our ET nurses recommend it as an effective option for odor control.

— Laura Matarese, MS, RD, CNSD
Cleveland Clinic Foundation
Cleveland, OH

Equipment Exchange

The following homePEN supplies are offered free of charge:

- Pancretec Provider One portable TPN pump with rechargeable battery pack
- All-Med Tubing Reorder # 50-2232, #50-2031
- Miscellaneous TPN supplies

For more information, call Roslyn Dahl at the Oley Foundation at (800) 776-OLEY/(518) 262-5079. The Oley Foundation cannot guarantee the quality of the supplies donated through this column or be responsible for their condition.

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 catheters, 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, Home Pharmacy of California, Intravenous Therapy Services, Kendall, Nutrishare, Inc., Pharmacy Solution Services, Vygon Corporation, and Zevex, Inc. ☺

Independence, from pg. 2

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 started 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 relative. 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.

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Aaron Leppin and his mother, Tammy, registering at the Oley Conference in Boston this past summer.

Consumer Wins Award

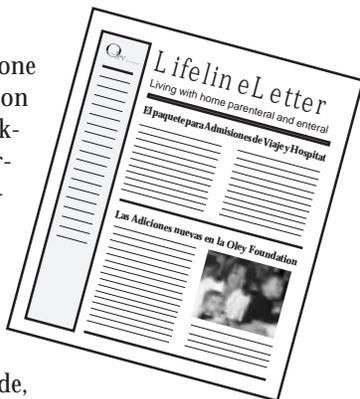
Congratulations to Aaron Leppin, a 15 year old homePN consumer who recently won two awards at the national Future Farmer of America (FFA) competition. Aaron and his five member team competed last April in the Missouri FFA competition, completing a 100 question test. Aaron's team placed first which qualified 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 has 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 water-skiing 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. ©

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Independence, from pg. 4

The ORV officer sat down with me and told me which questions employers can and cannot ask. He explained that if they ask you certain 'illegal' questions, you don't have to answer them. The OVR helped me write a resume, and gave me mock interviews. One of my OT supervisors also gave me a lot of support through the interview process. Again, there are a lot of resources you can tap into, if you make the effort to find them.

When it finally came time to interview, I ended up buying a suit; but since I am connected 24 hours a day, I wondered what I should do about the pump: "Do I take it off for the interview, or do I wear it?" I decided to wear it so they could see that this was the real me.

For the first interview, I had my pump in a nice little purse and I carried a clipboard in front to cover the tubing. The whole interview went well and they didn't notice the pump at all.

My second interview was at a major rehab facility. An acquaintance had told me they had an entry-level position that I should apply for, so I did. I ended up getting an interview. There were six people on the interview. The first half of the interview went very well. Everybody loved me and everything went well. We talked about all kinds of things; they asked how I would handle certain situations, etc. Then most of them left. I was one on one with one of the women and I dropped my purse on the floor. She saw my tubing and I thought, "Okay, here goes." So I mentioned something about the pump. After that, the interview fell apart. She would no longer look at me. She just abruptly stopped the conversation and announced it was time for the tour. On the tour, she stopped and talked to a friend of hers for twenty minutes and did not talk to me. Once I tried to jump in on the conversation, but she gave me a curt response and turned back to her friend. At the end of the interview she said something to me about letting me know in a couple of weeks. I asked if I should call back and she said "No." A few weeks later I received a letter in the mail stating that they had no position available, no opening for an occupational therapist. That blew me out of the water!

For awhile I was devastated, but I had an interview at another company scheduled. I still didn't know what to do. Should I tell them about my pump or not? After my last experience, I was torn. Finally I decided I was just going to be me and see how it goes. I went in and talked with the people and everything went wonderfully. On the way out, I said to the woman, "Oh, by the way, I just want to let you know that I'm connected to this," and showed her the pump. She replied "That's wonderful. It will give you a better understanding of what our kids are going through." And then, right there on the spot, she said, "The position is yours," which was great.

I'm telling you this so you will know that there are jobs out there where people will accept you. Of course you are going to run into some people who won't, but there are good employers, you just have to look for them. One thing that worked out well for me is that my supervisor has had a line in for chemotherapy, so she is very understanding. In fact, everyone at work is accepting of me. At first I tried hiding my pump, but eventually I decided that these people are my friends, so I told them about it. Everybody knows and they are all accepting. Once a month we have these luncheons, and now they are making their food to accommodate my needs, which is very considerate.

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 SSI/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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Sign Up for Summer Camp

Summer camp is a wonderful growing experience that can be safely enjoyed by all children — even those on home nutrition support. Oley homePEN youth speak glowingly about their adventures at Double "H" Hole in the Woods Camp in Lake Luzerne, New York. The camp makes special arrangements so they can safely accommodate children on homePEN during their summer sessions.

The camp is free of charge, but campers are responsible for providing for their own transportation. **Oley recommends that homePEN children planning to attend camp have at least a basic understanding of their therapy and "hooking up" process.**

With help from the Oley Foundation, a limited number of camp slots have been reserved for homePEN kids at Double "H" Hole in the Woods Camp for the summer of 2001. If you're interested, call promptly and register your child to attend. Be sure to mention your child is on HPEN when you register.

Any questions or concerns? Parents can speak with camp officials, previous campers, camper's parents or Oley camp volunteers.

Where to Call for More Information

Double "H" Hole in the Woods Camp	
Camp Admissions/Wendy Clarke	(518) 696-5676
Previous Campers/Volunteers	
Camp Volunteer/Bette Bond, RN	(215) 946-0898
Camper & Volunteer/Malisa Matheny	(215) 777-7582
Camper/Mariah Abercrombie	(702) 435-6007
Parents of Previous Camper's	
Ruth Matheny	(215) 345-7783
Madaline George	(315) 492-9309
Ellen Seiz	(410) 723-0890
Felice Abercrombie	(702) 435-6007

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 business transaction always has been and always will be, let the buyer beware. This is an evenhanded policy that provides our sponsors a reasonable opportunity to market their services to discerning consumers who in turn, can make important decisions about equipment and supplies in consultation with their clinical support teams.

The precautions Oley has taken have not been entirely successful. We have heard from our members of unwanted solicitations, in some cases by individuals implying that Oley has endorsed their marketing initiatives. We have heard from providers that their customers are targeted by competitors through Oley venues. Although such incidents are rare, they are extremely threatening to the open exchange of information that is the heart of Oley. What can come of them? More restrictive marketing guidelines? Higher walls between consumers and the companies that provide them with vital medical supplies and services? Should we discourage consumers at our conferences from independently releasing personal information to industry sponsors for fear that it will later be represented as

having been obtained 'through Oley'? Should providers discourage their customers from participating in our programs for fear they will be lured away to other companies 'through Oley'? In the end, ever more restrictive policies won't protect our uniquely open community, but they could polarize it, and, in time, destroy it.

Oley's future has to be built on trust. Consumers must trust that their privacy is protected; providers must trust that Oley venues are safe for their customers; and all of us must trust that we come together out of common interests, not private ones. The challenges of homePEN are our common interests, and surely they loom sufficiently large to overshadow competing agendas and unify our community in a spirit of true collaboration and good faith. The human, clinical and financial resources we need to meet these challenges are within our reach. It is terribly disheartening to imagine that we might fail to grasp and use them for want of trust. In the circumstances, the only policy that Oley can follow is one that has always guided us: the extraordinary experience of home infusion therapy, however we may come to it, binds us all together as a family, and gives us the qualities of empathy and hope for one another. Trust and all good things will flow from that. ©

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

having been obtained 'through Oley'? Should providers discourage their customers from participating in our programs for fear they will be lured away to other companies 'through Oley'? In the end, 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 its 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.

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 *LifelineLetter* 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

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