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# LifelineLetter

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

### Oral Rehydration Solution: A "Low Tech" Oft Neglected Therapy

By Darlene Kelly, MD and Joe Nadeau, BS, RPh

#### Introduction

Oral rehydration solution (ORS) represents the clinical application of some of the most basic concepts of cellular physiology. It offers a therapy that is inexpensive and simple with very few potential complications. ORS does not involve the genetic recombinant technology that is so much a part of advanced medicine today. This likely belies the obstacle for acceptance in the western world today! Indeed, several years ago, a patient from Bolivia who had a severe chronic diarrheal illness came to my office with a small packet of *sales de rehidratacion* saying "Doctor Kelly, you must have something better here in the US" but we did not at that time. This low-tech, inexpensive treatment had to come to us from the third world!

#### History: The Science Basis of ORS

The ORS story begins with very basic understanding of physiologic characteristics of biological membranes that evolved over the

course of three centuries, with marked advances in the mid-20th century. As early as 1938, a cell surface consisting of proteins and lipids was proposed as a barrier to diffusion into cells. Membranes consist of a bimolecular leaflet made up of a double layer of phospholipids with their hydrophilic heads oriented toward the outsides and the hydrophobic fatty acid chains oriented inwards. Embedded within these lipids are proteins that act as enzymes and antigens, as well as carriers and channels for transport of electrolytes, nutrients and water.

#### Mechanisms of Fluid and Electrolyte Absorption

Within the small intestine absorption and secretion occur as a result of specialized mechanisms located within the cells of the villus tips and the crypt cells, respectively. The basolateral membranes of the enterocytes have unique transport features that differ from

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### Specialized Nutrition: Patient's Perspective

By Elizabeth V. Tucker and Darlene G. Kelly

*Part I of this article addressed issues of transitioning from patient to consumer and adapting to using nutrition support therapy at home. Part II focused on complications, the role of the Oley Foundation and psychosocial issues. Part III will discuss travel, children on HPEN, the long-term outlook and other issues such as ostomies, depression and impact on families.*

#### Traveling

EVT: My lifestyle before I went on HPN included a great deal of travel because of my husband's job. The fact that being HPN could curtail that never even occurred to me. Several months after I started my therapy I wanted to attend a conference in Montreal, Canada. I just called up my home care company and

asked what we needed to do to make this happen. This was the first of many trips I have made out of the U.S. During the 11 years I did stress management and coping skills for companies and families dealing with chronic illness, I traveled all over the U.S. and Western Europe. For the first several years those trips were made I had to have my home care company send a pump and pole to my various destinations. It was in the days before ambulatory pumps. My first trip to Europe, with an ambulatory system, was for a National Health System Conference in Cardiff, Wales. Since that time I have been to Switzerland, Austria, the Netherlands, Italy, Germany, and the island of Grand Bahama.

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 those of the luminal surface. In all intestinal cells, there is a sodium-potassium activated ATPase pump embedded in the basolateral membrane that maintains the low intracellular sodium concentration by pumping sodium out toward the

circulation and potassium into the enterocytes. Simultaneously, the basolateral membrane allows sodium and potassium to enter the cells via a sodium-potassium-chloride co-transport mechanism, and a potassium channel allowing potassium to leave the cells into the blood. In the secretory cells there is a luminal cyclic-AMP chloride channel that is responsible for chloride secretion into the intestinal lumen. The synchronization of these transport mechanisms is critical to the maintenance of chloride secretion.

Electrolyte absorption by the enterocytes of the villus tips involves luminal permeability to sodium resulting from various mechanisms. Each segment of the intestine has somewhat different characteristics of permeability. Within the jejunum, ileum and proximal colon there is a coupling of sodium absorption with extrusion of hydrogen ions into the intestinal lumen. Because the sodium-potassium-ATPase pump in the basolateral membrane maintains the steep inwardly directed sodium gradient, net sodium absorption is favored. Additionally, within the small intestinal cells there is a co-transport system linking sodium transport to that of glucose and amino. A carrier within the luminal membrane transfers one sodium ion along with a single glucose molecule. A similar sodium-amino acid carrier has been identified in intestinal cells. Maintenance of a downhill sodium gradient by the basolateral sodium-potassium-ATPase pump is critical for the proper transport of these nutrients. Conversely, one can think of these organic compounds as driving forces for sodium absorption. Water is transported paracellularly as a result of the osmotic gradient. The osmolarity of ions and molecules in stool water is identical to that of plasma.

When glucose is present within the

intestinal lumen, sodium and water absorption is increased. This transport is stimulated up to a glucose concentration of about 50 mM, a level at which jejunal sodium absorption is increased by four fold and water absorption by six fold. Within the ileum this concentration of glucose increases sodium and water absorption by two to three times.

**The Cholera Story**

Cholera is the most severe diarrheal disease known to man. The first pandemic of cholera occurred in 1817 in the Indian subcontinent. By the 1830's, another pandemic had reached western Europe, and 1866 there was an epidemic in New York (10). It is endemic in Southeast Asia, the Indian subcontinent, Africa and most recently in South America where it is found in aquatic environments. Summertime seafood-associated cholera cases occur sporadically in the United States.

Cholera occurs as a result of the bacterium *Vibrio cholerae*. The *Vibrio* releases a protein toxin that binds irreversibly to a ganglioside receptor of intestinal epithelial cells and does not enter the blood stream. The result of the toxin is stimulation of chloride and bicarbonate secretion via its effect on cyclic AMP within the enterocytes. Of clinical importance, the glucose-sodium co-transport of enterocytes is not altered by the toxin.

Cholera is characterized by vomiting and by voluminous diarrhea, often called rice-water diarrhea, as it has the appearance of water arising from soaking rice. Fluid losses in these cases can amount to 500-1000mL/hour. Severe dehydration results and about half of untreated severe cases succumb from vascular collapse, which can occur within hours of onset. Rapid, appropriate rehydration is the mainstay of therapy of cholera. In those with severe volume contraction, intravenous

**LifelineLetter**

March/April 2005 • Volume XXVI, No. 2

**Publisher:**

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**Subscriptions:**

The *LifelineLetter* is sent free of charge to those on home parenteral or enteral nutrition. For all others, the annual rate due each January is \$40.

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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.

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The secret to a successful trip for someone on HPEN is plan, plan, plan and then plan some more.

I always take a letter from my doctor in English and the language of the country I will be visiting which tells why I am on HPN and need the medical supplies I have brought with me. I always try to find the name of a medical professional or facility in the country that can give me the specialized care I might need. I work with my home care company to find out if there are any restrictions on bringing medical supplies into the country and whether I can ship anything beforehand. Check with the airlines to see whether you are going to have to pay extra for the additional baggage and weight. When they realize these are medical supplies, they may waive the fees. I also let them know that I am on a medical therapy during the flight but that I won't need any assistance.

Travel is an essential part of my life and I am always amazed when I meet people on HPEN who don't know they can go almost anywhere they want to, if they just plan, plan, plan. People I know on HPEN have taken cruises, gone to China, as well as Eastern European countries. While there may be places I wouldn't want to visit for sanitation reasons, I always feel the sky is the limit as far as travel is concerned.

DGK: The consumers in our HPN program have traveled throughout the world, even Singapore and Brazil. Those who have planned ahead and researched the rules of the destination country have had very few problems. I have encouraged them to fill out an abbreviated medical history form that can be obtained from the Oley Foundation web site. This provides information to a potential treating physician should treatment abroad be necessary. I also encourage the consumer to travel with the clinician's phone number readily available. A recent issue of the LifeLine Letter includes advice to the traveler.

I do encourage those who wish to travel, as I feel this is an important part of maintaining normal life activities.

### Choices and Attitude

EVT: You may have already gotten the impression that I believe I am the one responsible for my quality of life whether on HPEN or not. That is absolutely correct! I believe that when I wake up every morning I make a choice about whether I am going to have the best day possible or a miserable one. Then I do everything I can to make good things happen. That's not to say that I don't have bad days. I do. I may have a bowel obstruction and have to stay in bed or go into the emergency room. I may have sepsis. My Crohn's may be out of remission and I am in the bathroom 30 to 40 times during the day. I just take those days about 30 seconds at a time and still be as positive as I can be about each moment. When the problem is over I let the pain or

difficulty go, forget about it and don't carry it around with me. I enjoy the good that is in every day. It may be a beautiful flower or the warmth of the sun. It could be a call from a friend or family member. It might be the love I feel from my pets as they stay close to me. I can always find something.

I am also a great lover of clichés. They help explain my attitude in just a few words and can remind me when I am having a bad day that there is always something good in my life. Here they are:

I will bend but I won't break

A moving target is harder to hit, so I just keep moving.

I may not always have control over what happens to me, but I do have control over what I do with it.

Do unto others, as I would have them do unto me.

### Children on HPEN

EVT: As I mentioned earlier, I have met and seen grow into wonderful young adults a number of babies, toddlers, and children on HPEN. They are amazing! This is their life and you rarely see self-pity or anger. They are much better at adjusting than most adults. One of the secrets of healthy kids on HPEN, from my perspective is the parents. If the parents treat them as individuals and, as much as possible, as normal kids, they seem to blossom. If the parents are overprotective and neurotic about the child's illness or therapy, it seems to transfer to the child.

DGK: Children on HPEN present a challenge to the parents and to the siblings, as well. The process of growing up and transferring responsibility for care from the parent to the child can be a difficult time for everyone. This is one of many situations where the Oley Foundation can be particularly helpful. Many parent members of Oley have successfully accomplished this transition and can be a great resource for those about to enter this time in the child's life. Other issues that the child encounters include leaving the protective setting of "home" and entering college or the working world. Each of these steps is a new experience for the HPENER and his or her parents. Issues related to employment can be problematic, sometimes causing the interviewee who discusses his or her HPEN to be rejected for the job. Often a social worker or career counselor can be quite helpful with advice to the HPENER.

### Other Issues:

EVT: As you can probably tell, I look at life from a positive perspective. Does that mean that I have never experienced any problems? Of course not. I have actively worked to find solutions when problems occur, and I don't carry them around with me when they are over. This section is a good opportunity to discuss some of the common problems that consumers on HPEN experience.

## Equipment Exchange

The following supplies are offered free of charge to readers:

### Enteral Formula

- 2 cases Isosource - exp. 11/05
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- 3.5 cases Isosource unflavored - exp. 5/06
- 5 cases Nutren formula w/ fiber - 04/06
- 107 cases Ultracal formula - 12/05
- 4 cases Jevity 1.2 - exp.1/06
- 12 cases Osmolite - exp. 3/06
- 6 cases Fibersource HN 8 oz. Cans - exp.8/06
- 4 cases Resource Diabetic 8 oz. Cartons-12/05
- 4 cases Toxerex by Novartis - 2-1/06, 1-6/06, 1-8/06
- 2-3 cases Comply formula
- 62 cans Vivonex - exp. 10/05
- 4 cases Subdue - exp.1/06
- 20 cans Pedisure with fiber (vanilla) - exp. 1/06
- 4 boxes Neocate 1.0 - exp. 4/06
- 18 bricks Resource fruit beverage (peach) - exp. 10/05
- 17 cans Osomolite 1.0 HN - exp. 1/06
- 2 cans Optimental - exp. 3/06

### Tubes/Bags

- 50+ Kangaroo bangs 1000 ml
- 13 Kangaroo bags 1000 ml
- Kangaroo gravity bags - any size

MORE SUPPLIES are available! This is a partial listing of the products that are currently available through this program and outlines supplies that have become available in the last two months. If you have a need for any items listed above or would like to view the complete listing of the tubes, dressing kits, feeding bags, etc, etc.; visit our website at [www.oley.org](http://www.oley.org) or contact Liz Tucker at [evtucker@charter.net](mailto:evtucker@charter.net) or toll free at (866)454-7351. You should also know that items become available on a daily basis, so check periodically!

*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 such as enteral formula or infusion pumps, offer to pay the shipping.*

## HPEN Quality of Life Study

The Oley Foundation for Home Parenteral and Enteral Nutrition has, for some time, recognized the importance of assessing the quality of life (QoL) of people living on these therapies. There are QoL studies done in the first year or two of therapy but none, that we are aware of, in people who have been on 5, 10 and 15 years or longer.

Quality of Life studies play a valuable role in the management of chronic medical conditions. They are designed to reveal how therapies like homePEN impact the lives of consumers. They help identify problems and target solutions. They influence the allocation of research funds and are increasingly used to shape the reimbursement policies of insurance providers. Quality of Life studies may also impact how Medicare, which sets the direction in bowel failure management, views small bowel transplant versus homePEN.

In the months and years to come, both the clinical community and the insurance community will make important choices about how homePEN is managed and how it is reimbursed. Our goal at Oley is to ensure that consumers have a voice in this process.

If you have been on homePEN therapy for 2 years or more, we hope you will participate in this effort. The survey will be mailed to Oley consumer members and can be downloaded from the Oley website ([www.oley.org](http://www.oley.org)). Please encourage any long-term HPENer you know to get involved. For more information, contact Oley at (800) 776-6539.

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fluids are given rapidly. Even with intravenous fluid replacement, mortality may occur in up to 30% of cases. For those with less severe degrees of dehydration, oral fluid replacement can be used. The worldwide threat of cholera epidemics and of the resulting mortality led to the development of a research laboratory in Dacca, Pakistan (SEATO Pakistan Cholera Research Lab-later called the International Center for Diarrheal Disease Research, Bangladesh). This endeavor was sponsored by the National Institutes of Health, the National Naval Medical Center and the Agency for International Development, in collaboration with the World Health Organization (WHO). The center was interested in a treatment that would be available from household food staples in the third world.

### The Introduction of Oral Rehydration Solutions (ORS)

There are reports of oral replacement solutions being used in diarrheas for centuries with variable success. Some of these are described in ancient Hindu texts. The modern era of oral replacement of fluid and electrolytes in pediatric diarrheas had its beginnings in reports from Baltimore using sodium, potassium, chloride and lactate to replace losses in infantile diarrheas in the 1950's with subsequent addition of sugar to spare protein. The science of ORS was advanced

when Phillips and colleagues determined the composition of fluid lost in diarrhea. Addition of excessive amounts of carbohydrate to commercially available mixtures resulted in hypernatremia, probably as a result of their high osmolarity.

As the understanding of the sodium glucose co-transporter developed, the true role for carbohydrate in the early oral replacement fluids could be appreciated. The addition of glucose improved absorption of sodium (thus of water transport) to effectively treat the diarrheas encountered in children. Perfusion studies of the effect of enteral glucose and electrolyte solutions in patients with cholera demonstrated that these solutions decreased stool output. Subsequently, oral rehydration therapy was proposed as a viable alternative for cholera in areas of the world with short supplies of intravenous fluids and needles forcing clinicians to deliver oral solutions to those with cholera. This reduced mortality rates to only 3% compared to 30% of those treated in other camps with intravenous fluids. Based on this evidence, WHO and UNICEF recommended a single standard ORS formula for all ages. Critical to these fluids was not only the concentration of carbohydrate and electrolytes, but also the osmolarity (-300mosm/L). The dry ingredients were available in packets that were manufactured

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in more than 60 countries and were available to 30% of children who developed acute diarrhea, as of the early 1990's. In the US, more commonly premixed fluid forms slowly became available. It has been estimated that deaths due to diarrhea decreased by as much as 50% after introduction of ORS.

### Refinements of ORS Formulas

Adding more glucose to standard ORS was initially thought to further increase sodium and electrolyte absorption, but it was found to be counterproductive and, frankly, dangerous given the effects of the high osmotic load in the small intestine. The intestine from the pylorus to the rectum acts as a dialysis membrane when one observes fluid shifts. Consequently, the high osmotic activity of various fluids actually increases diarrhea. (Case in point, the osmolarity of prune juice is ~1265 mosm/L!)

The role of osmosis as a driving force for intestinal absorption was incorporated into ORS formulation. The substitution of polymers of glucose for simple glucose would decrease the osmolarity of the solution while providing favorable ratios of glucose to sodium. Subsequently, research focused on the use of various starches as a source of glucose. Rice powder has been shown to effectively replace the standard glucose in ORS, decreasing stool output, duration of diarrhea, and requirements for intravenous fluids compared to the WHO ORS formula. Rice syrup solids have also been shown to promote greater absorption and retention of fluids and electrolytes than the glucose-based ORS. Because the hydrolysis of starch is relatively slow in the intestinal lumen compared to that of maltose or sucrose, starch provides a continuous supply of glucose for absorption under isosmotic conditions (dubbed a "glucose battery" by Field).

In contrast to sucrose, starch provides the glucose to drive sodium and water absorption, but not at the expense of large osmotic load that would actually cause fluid shifts into the lumen. It appears that the starch or glucose polymers not only replace fluid losses, but they also lessen diarrhea. Other grains, such as lentils and wheat have been tested. In the latter study, stool output of children with acute diarrheal illnesses was decreased significantly in those using ORS based on either rice or wheat when compared to glucose-ORS, but there is concern with the wheat based solution for those with co-existing celiac disease.

The addition of other substrates for enhanced sodium co-transport has been proposed including glutamine, alanine and glycine, but none of these has a therapeutic advantage in decreasing fluid output (thus diarrheal volumes) over standard ORS. This may be in part due to the increased

osmolarity that occurred with such additions. The addition of proteins would also be expected to work similarly, but at much greater expense.

### The "New" WHO ORS

Recent developments in ORS formulas are related to concern that the sodium concentration of the standard ORS was too high at 90 mEq/L and was occasionally associated with hypernatremia. The European Society of Pediatric Gastroenterology and Nutrition recommended an ORS containing 60 mEq/L of sodium and an osmolarity between 200 and 250 for children in developed countries who are not malnourished. Subsequently WHO recommended a replacement for the standard ORS using a new formulation containing 60-75 mEq/L sodium and glucose from 75-90 mmol/L. The 1:1 molar ratio of sodium to glucose was maintained but at a lower osmotic activity. This new reduced-osmolarity ORS while as effective at reducing diarrhea in cholera had an increased risk of hyponatremia (odds ratio 2.1). This new ORS was associated with a generalized seizure in one child with hyponatremia among 341 who received the new formula. This complication has led to controversy regarding this new formula.

### ORS: Not Just a Third World Answer

Application to ORS in North America has been reported in only a few publications, mainly applying it to acute diarrhea of childhood. Clinicians have been admonished for years, because they have not applied the treatment of the third world as a simple solution for acute diarrheal diseases. Indeed, only 14 years after the introduction of ORS for cholera, Carpenter wrote "We physicians all presumably accept the 'primum no nocere' principle. On the basis of . . . studies . . . this principle would dictate that oral rehydration be accepted not only as an equal, but perhaps as the superior means of treating acute diarrheal illnesses in the sophisticated and sanitized medical centers of the Western world as well as in rural Bangladesh."

### Short Bowel Syndrome

One of the earliest applications of ORS to a patient with short bowel syndrome utilized a low osmolarity solution (-210 mosm/L) consisting of ~50 mmol/L sodium and 70 mmol/L of a glucose polymer and also a commercially produced ORS containing rice starch. With the combination of these mixtures, a low disaccharide diet, and aggressive anti-diarrheals, the patient had marked reduction of stool volume and sodium output, as well as increased urine output. A second application in "un-adapted" short bowel syndrome (3 to 9 weeks post-resection) compared a glucose ORS with an iso-osmotic glucose polymer ORS enriched with glutamine, demonstrated no difference between the two formulas. No comparisons were made to fluid outputs prior

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to ORS use. We studied the effects of magnesium gluconate added to a rice-based commercial ORS and found that magnesium absorption could be enhanced with this dosing regimen compared to giving the magnesium in equivalent bolus doses.

A very recent report described discontinuation of long-term parenteral nutrition in three patients with short bowel syndrome by using nocturnal enteral infusions of ORS. Many reviews of the treatment of short bowel syndrome fail to even raise the topic of ORS.

### Practical Application of ORS

We try to tailor our selection and use of ORS based on the principles demonstrated by the literature. ORS plays an integral part in our clinical practice of gastroenterology and nutrition. We use it with particular success in treatment of high stomas output of patients who have undergone recent intestinal resections. In many of these individuals it is possible to avoid turning to parenteral solutions to maintain fluid balance. Typically, we place these individuals on a low free sugar diet (low osmolarity), optimize anti-diarrheals (both with respect to amount and timing – specifically 30 minutes before meals and at bedtime) and start an ORS, titrating volume requirements as needed to produce a urine output of at least one liter daily. One important point of the anti-diarrheals is that crushing tablets or opening capsules before dosing them is helpful in improving effectiveness. Elixirs of anti-diarrheals can also be used, but care must be taken to recognize which of the medications include sorbitol as a sweetener, thus worsening diarrhea!

Typically we discuss various options of ORS with the patient, as well as other fluids that are less desirable. Although the literature suggest that 90 mEq/L sodium is the critical concentration of ORS in short bowel syndrome, this recommendation is based on data defining the jejunal efflux in short bowel syndrome. Based on our clinical experience, these high sodium solutions are very poorly accepted by patients. Often we find that even 70 mEq/L sodium solutions must be diluted initially to allow the patient to adapt to the taste. Various flavored, artificial beverage powders are helpful in making the solutions more acceptable, however some patients find them too sweet and prefer to add sucralose or aspartame sweeteners to the unsweetened beverage packet.

We train patients in the use of ORS using a self-developed set of cartoons that explains the concept of intestinal adaptation, a re-introduction to osmolarity, a discussion of sodium absorption, and techniques to increase palatability. Most patients can follow this discussion with the use of

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## Join Us and Help!

### Association for Vascular Access Conference (AVA)

September 22-25, 2005  
New Orleans, LA

Help us distribute information at the Oley Exhibit Booth. Learn from vascular access clinicians, physicians, publishers, etc. about many different products, techniques and current research.

Questions? Contact Joan (800) 776-6539 -  
bishopj@mail.amc.edu



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THERAPEUTICS

## Nancy Groat Oley Regional Coordinator

1947-2005



We were very saddened to learn in late June of the loss of Nancy Groat. Nancy, from Grand Haven, Michigan, was an Oley RC since 2000. She struggled for many years with the challenges of intestinal lymphangectasia, a disorder that impacts absorption of protein and fat and started TPN in 1993. A Regional

Coordinator was very helpful when she started that journey and Nancy felt that becoming an RC would only complement her other support efforts, and wanted to “pass on” the help she got when she started on TPN. Oley members can read a wonderful article she wrote about this in the March/April 2002 Lifeline Letter. Nancy also coordinated a support group for those struggling with chronic illness based on the acronym ANCHOR – awareness, new insights, challenge, odyssey, and resolution.

Nancy had a great companion in her dog, Mindy. She had a terrific, supportive family. She brought her own special touches to being an RC, such as sending out Christmas cards each year to Oley members throughout her region. We have had several donations to the foundation in her memory, all noting how important her work for Oley had been to her. We are grateful for all of her efforts on behalf of Oley members everywhere, and will miss her steady presence in our ranks.

### On-line Shopping?

Don't forget [www.igive.com](http://www.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

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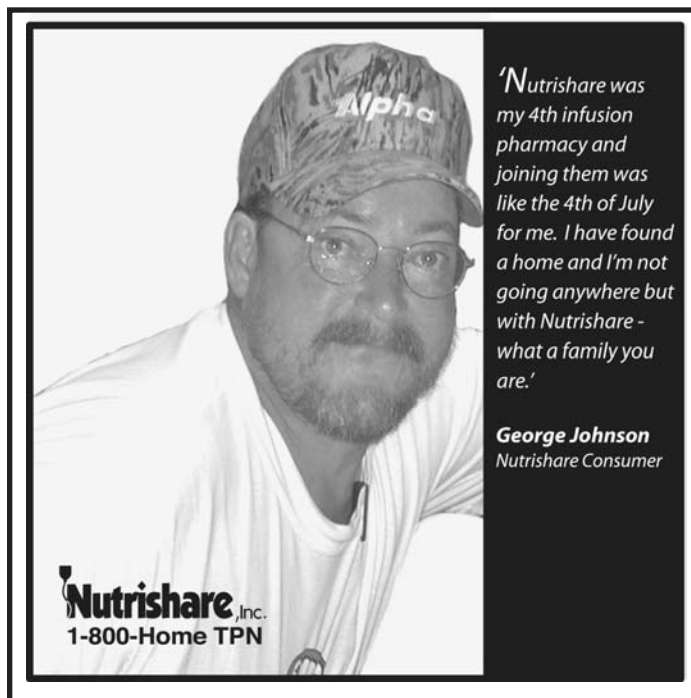
simple slides, and thus, we feel, have more likelihood of compliance. Finally, for most patients continual encouragement and recognition of adequate intakes are required for success with the ongoing use of ORS. See Table 4 for potential uses of ORS.

### ORS: The Final Word as of 2004

ORS has been called the most important advance in twentieth century (Anon, 1978). It has been credited as the major therapy responsible for decreasing deaths due to diarrhea from 5 million per year in 1980 to 2.2 million in 1999. This simple application of basic intestinal physiology has not been so readily accepted in the US. It has been estimated that the cost of NOT using ORS in acute diarrhea in the United States exceeds \$1 billion in direct medical costs annually. Added to this is its potential use in decreasing morbidity in such circumstances as chronic diarrheal diseases, as a replacement for intravenous fluids and TPN in some patients with short bowel syndrome, and to decrease dehydration and the hospital length after colectomy. Our neglect of this inexpensive therapy is a costly omission in western medicine!

*Tables and references appear online [www.oley.org](http://www.oley.org) and/or can be provided upon request*

*Reprinted with permission from Practical Gastroenterology*



*'Nutrishare was my 4th infusion pharmacy and joining them was like the 4th of July for me. I have found a home and I'm not going anywhere but with Nutrishare - what a family you are.'*

**George Johnson**  
Nutrishare Consumer

**Nutrishare**.inc.  
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### Ostomies

EVT: I, and many others on HPN, have an ostomy. The more bowel you have had surgically removed, the more the stomal output volume and liquidity seem to increase. Every time you go out of the house you have to know where the nearest bathroom will be. If you are on a road trip you have to be able to stop at a moment's notice or the bus, train, or airplane has to have a bathroom. Many of us restrict what we eat and the amount of liquid we consume in an effort to have some control over how often we need to use the restroom facility. One piece of information that has been very helpful to me, and I didn't learn it until a few years ago, is that osmolality of oral fluids can have a tremendous impact on my ostomy output. Even when my body is telling me to drink, drink, drink, putting any fluid such as soda pop and even water will just make my diarrhea worse and I will become more dehydrated and thirstier.

DGK: In the case of marked thirst the use of oral rehydration solution offers an opportunity to drink a fluid that improves absorption and minimizes the thirst. An important approach to minimizing stomal output is to limit high-osmolality fluids and to sip oral rehydration solution during waking hours.

EVT: I can't tell you how many times I have had my ostomy appliance tear or separate from my body and I had a catastrophe on my hands. It is another one of those opportunities where some aggravation and frustration are in order, but a positive attitude seems to make the cleanup go faster. Waking up at night in a large pool of feces can be particularly aggravating. As far as I know there is no perfect solution that can keep these things from happening, so you just have to adjust.

Body image is another important issue to be faced, particularly if you are single. I dated and was fortunate that the men I had a relationship with never had a problem with all my accoutrements (ostomy, central catheter, etc.) For the consumer, it may mean avoiding close relationships because of assumptions that a partner would not be able to cope. On the other hand, these issues in fact, do negatively influence some relationships.

### Impact on Families

DGK: Because relationships are very individual, the way that families cope with this therapy are very individual. On one end of the spectrum is the overprotective spouse or adult child who causes the consumer to be overly dependent. In the other extreme, the consumer may avoid integrating the other family members into the experience and makes decisions independent of everyone else, causing family

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## Who says Home TPN and tractors don't mix?

Certainly not Don Young. Whether working his land, attending a concert or visiting his loved ones, Don doesn't let being a Home TPN consumer for 30 years keep him from doing what he wants to do. Coram consumers are like that. We have a long list of consumers like Don. They know life goes on. They face challenges everyday. And Coram is there to help them. The more we get involved with consumers like Don, the more we learn from them. We got him started. And we'll be there for the long run.

Contact us toll-free:  
1-866-4-HomePEN (1-866-446-6373) and  
visit us on the Web at [www.coramhc.com](http://www.coramhc.com).



**Coram consumers. Going places. Doing things. Living life.**

*Be All That You Can Be*

The **Oley** Foundation

21st Annual  
Consumer/Clinician  
Conference

Sheraton City Centre  
Salt Lake City, Utah  
June 28 - July 1, 2006

➤ **Mark Your Calender!** ◀

Stay tuned to the web site [www.oley.org](http://www.oley.org) for updates!  
Call us with suggestions. Volunteer to help.

## Thank You! Thank You!!

The following list represents everyone who generously contributed towards Oley efforts between April 28 and August 9, 2005. We also want 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.

### PRESIDENTS CIRCLE (\$1,000-1,999)

Mann Wireless Ltd in the name of Donald Young  
 Rob & Laura Andolina in honor of Julie Andolina

### BENEFACTORS (\$500-\$999)

Bruce Groeber Memorial Fund  
 Lyn Howard, MD  
 Mrs. Marge Taber  
 James Cowan in honor of HPN consumers 30+ years!!

### SPONSORS (\$250-\$499)

Patricia Searle in honor of Will who died 1988  
 Patricia Brown, RN, CNSN  
 Option 1 Nutrition Solutions - Denver Branch  
 Staywell Co in honor of the efforts of Bob Hoffman

### PATRONS (\$100-\$259)

Milton Abercrombie  
 Richard Davis in memory of Dianne Nelson Binger  
 E A Swede and Aleatha Scholer  
 Ms. Kathleen Mayo via United Way of NE New York  
 Lynda Yeabower  
 James Wittmann  
 James & Suzanne Douglas in honor of grandson on TPN for 6yrs.2 months  
 Mary Friel  
 James Cowan  
 Mary Susan Curtas  
 Sheila Messina  
 Violet Schultz in memory of Willis (Dick)

Schultz  
 Davis Rick & Dianne  
 Robin Lang  
 Elias & Joan Medwar

### SUPPORTERS (\$50-\$99)

Darlene Kelly MD  
 Jim Wittmann in honor of Nader El Samaloty  
 Elizabeth Bond  
 Mary Barron  
 George & Margaret Coefer  
 Dominick Palumbo  
 Terrence Fetters in memory of Walter Yaffa  
 Donna Zimmerman in memory of Nancy Groat  
 Joseph Greaney  
 Cathy Tokarz  
 Mary Friel  
 Norberta Vosgerau  
 William Hamre  
 Paul & Margo Covell in memory of Walter Yaffa  
 Jane Lindsay  
 Angelyn Schauer in honor of Dr. Ellen Pierce  
 Nathan & Maria Schecter  
 Paul & Ann DeBarbieri  
 Rex and Karen Spearhas

### CONTRIBUTORS (\$30-\$49)

Margaret Bald in honor of receiving the LifelineLetter in Australia!  
 Carol Ryan  
 Suzy Goldman  
 Roz & Eric Dahl  
 Richard and Faith Dillon

### FRIENDS (Up to \$30)

Mrs. Betty Jane White in memory of Nancy Groat  
 Robin Lang  
 Michele Juda  
 Paul & Mary Lappin in memory of Walter Yaffa  
 Lois Cullen in memory of Walter Yaffa  
 Bob, Gail and Josh Stone in memory of Walter Yaffa  
 Gordon & Dorothy Pedersen in memory of Walter Yaffa  
 Michael Medwar in memory of Valerie Parmain  
 Donna Noble  
 Ms. Pearl Patterson in memory of Nancy Groat  
 Sheryl A Longobardi  
 Donna & Richard Noble  
 Shirley Heller in honor of her birthday and in memory of Nader El Samaloty  
 Dawn Dewar  
 Judith Martuscelli  
 Joseph Ginese  
 Kristin B Peterson in memory of Walter Yaffa  
 John Padrick  
 The Himelfarb Family in memory of Walter Yaffa  
 Mabardy & Carol Valenzano & son in honor of Joan Medwar's birthday!  
 Robin Latham  
 Roger Niosi



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members to feel very shut out of the process. Those consumers and families who are able to find the “middle of the road” and work together seem to do better in the long run.

**Depression**

EVT and DGK: Depression can also be a huge problem for those on HPEN. If the disease process is not under control, and you feel ill day after day, it is hard not to become depressed. If it only occurs for a few days or a week or so and then things get better and the consumer feels better, that is one thing. What is much more difficult is when it stays with you and every day is depressing. It is important that clinicians dealing with your care be watchful for such symptoms. Often, however, it is necessary for the consumer or a family member to speak up and discuss symptoms of depression. With the useful drugs available for depression and anxiety, there is no need for a person to suffer.

Some individuals who are on HPN and many on HEN are unable to eat normal foods. This can result in a major psychological problem. Not only does the HPENER have to adjust to actually doing these therapies, but he or she also suffers loss of a significant part of normal daily life. This can result in a grieving reaction because of his loss.

**The Long-Term Outlook on HPN**

EVT and DGK: While there will probably always be problems associated with being on HPEN, there seems to be more and more attention being given by medical professionals to making these therapies safer. Just since I have been on PN they have changed some of the compounds they use to lessen exposure to aluminum. We have ambulatory pump systems that allow one to go almost anywhere. More and more attention is being given to fighting PN-related bone disease and liver disease. When other options fail we now have liver and small bowel transplant.

An HPN consumer has recently published her experience as a transplant recipient.

While we wouldn't wish these therapies on anyone. We are very grateful that they exist and are improving almost every day.

## Oley Foundation Corporate Donors

**GOLDEN DONORS (\$50,000+)**  
Coram Healthcare

**SILVER CIRCLE MEMBERS (\$25,000-\$49,999)**  
Novartis Nutrition  
Nutrishare, Inc.

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**FRIENDS (4500-\$999)**  
Applied Medical Technologies  
Calea Ltd.  
First Biomedical, Inc.

## Give Oley a Sound Future

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](mailto:bishopj@mail.amc.edu). ☺

# Toll-Free Numbers Available to U.S. and Canadian Consumers!

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

*Advice given information shared by volunteer represent the experience of that individual and should not imply endorsement by the Oley Foundation. As always, any ideas or suggestions passed along to you should be discussed with your health care provider.*

<b>September '05</b>	<p><b>Eleana Shore</b> EST West Hills, CA (888)610-3008</p>	<p>Eleana's daughter Erin (age 9) is fed via G-tube due to multiple diagnoses, including Ehlers-Danlos, GERD, IBS, Arthritis and Hypomotility disorder. She has undergone three Nissen Funduplications. Eleana is constantly researching new information to help her daughter and speaks both English and Spanish fluently.</p>
	<p><b>Jim Cowan</b> EST Cleveland Hgts, OH (888)650-3290</p>	<p>A long time consumer, Jim has been on HPN since 1977 due to Crohn's disease. He supports both the Oley Foundation and the Crohn's and Colitis Foundation. Jim has experience with many of the issues surrounding home PN and can be a wonderful resource to new and long time consumers.</p>
<b>October '05</b>	<p><b>Nancy Backinger</b> EST Brooksville, FL (888)610-3008</p>	<p>Nancy has been on TPN for 17 years due to Crohn's Disease. She has short bowel syndrome and also has a jejunostomy. She has only had 1 infection in the 17 years and this was recent. She has extensive experience with traveling and looks forward to hearing from you.</p>
	<p><b>Tara &amp; Kevin Smith</b> EST Pittsboro, IN (888)650-3290</p>	<p>Tara &amp; Kevin have 3 daughters. Their oldest, Aleah (11 y.o.), was born with only 10 inches of small bowel. Aleah, went off TPN 5 years ago and went off enteral feeds just over 1 year ago. She now receives all of her nutrition by eating . Keeping her growing is now even more challenging! Tara and Kevin can share how their marriage has survived, and the difficulties of meeting healthy siblings' needs when raising a chronically-ill child.</p>
<b>November '05</b>	<p><b>Diane Cumberledge</b> EST St. Albans, WV (888)610-3008</p>	<p>Diane has vast experience as a HPN consumer. She can address the search for employment and related issues and has experience maintaining her nutritional status for a period of time without nutrition support. Diane is currently working part-time so the best time to call her is early evening.</p>
	<p><b>Rick Davis</b> MST Salt Lake City, UT (888)650-3290</p>	<p>Rick knows about HEN. He wants you to call. He is 62, cannot swallow, has been 100% dependent on HEN for 5 years and he is very active. When you call, you will probably reach him skiing where Olympic athletes skied in 2002. He and his wife travel frequently, enjoy being retired and he looks forward to hearing from you.</p>



# Consumer Alert:

## Consumer Alert:

### *Nutrition Week in New Orleans*

- In 2006, Nutrition Week will be held February 5th – 8th at the Ernest Morial Convention Center in New Orleans. Oley needs volunteers to man our exhibit booth and help distribute materials to other exhibitors. It is an opportunity to let other healthcare organizations know about Oley and what we do for consumers, clinicians, etc. This is a great opportunity to learn more about new technologies, medications, etc.

*For additional information about Nutrition Week, the website is [www.nutritionweek.org](http://www.nutritionweek.org). To volunteer for Oley, call at (800) 776-OLEY or e-mail Joan at [bishopj@mail.amc.edu](mailto:bishopj@mail.amc.edu).*

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## **LifelineLetter**

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