Recognizing Depression: A Step Toward Improving Health and Well-Being

Faye Clements, RNC, BS

The Oley Foundation and the University of Kansas School of Nursing research team of Carol Smith, Faye Clements, Donna Yadrich, Marilyn Werkowitch, and their many helpers (including many of you) have teamed up to carry out a study funded by the National Institutes of Health (NIH) to test a combination of home parenteral nutrition (HPN) support interventions. Dr. Smith and her team previously established, in published studies with over three hundred HPN families, that when the support methods they tested were practiced every day, fewer episodes of infection and depression occurred.

Depression is a common and recurring concern in HPN consumers (patients) and their caregivers due to the constant management HPN requires and consumer/caregiver anticipation of illness setbacks.

Depression’s Effects
Depression is a devastating illness that affects the way we think and behave. It disrupts valued relationships, social interactions, financial stability, and job productivity. Studies show depressed people are twice as likely to have poor quality of life as those free of the illness.

In addition, there is now evidence of a direct link between depression and physical health. With illness, one can become depressed; with depression, the body can suffer. Depressed people become more detached

Depression affects almost 10 percent of U.S. adults.

Camp Fills a Hole
Tim Weaver

Every year for the past six years, I have been granted the privilege of attending Double H Ranch, a Hole in the Woods camp in New York State. This is a camp for children ages six to sixteen who have chronic medical conditions. We heard about this camp from Oley. Every year, I love to head out to Lake Luzerne, in the Adirondack Mountains, for a week at camp.

Camp, cont. pg. 10

Annual Conference
June 2009

Planning is under way and excitement is building! We’re hoping you can join us at the beautiful Trade Winds Island Resort in St. Petersburg, Florida. This conference will offer you extensive opportunities to learn from the faculty at the meetings and network with other families at our social events—all in the relaxed atmosphere of a unique Gulf Coast resort. The resort offers a white sandy beach and you’ll have plenty of opportunities to curl up in a cabana to wind down, or to enjoy the many restaurants, swimming pools, walking paths, and activities that the resort offers. Enjoy a visit to the resort Web site at www.justletgo.com, and start dreaming.
Depression, from pg. 1

and less interested in day-to-day activities; they are less likely to comply with medication regimes and exercise programs, and are less likely to maintain a healthy lifestyle.

Further, with depression, health outcomes may be poorer. Depression can increase one's recovery time or lower one's chance of survival with certain illnesses. With prolonged depression there is evidence of immune suppression.

What Is Clinical Depression

Clinical depression is an actual physical illness. It is more than being “sad” and there is not always a logical reason for it. Although the exact cause of depression is unknown, there are known contributing factors.

Fatigue can bring on symptoms of depression. It can cause a downward spiral from inactivity to discouragement to disability and finally to dependency. If you are physically fatigued and sleep deprived, you may do tasks with less care and concentration, which may in turn amplify guilt.

Environmental influences, such as life situations, illness, or traumatic events (including the death of a loved one, divorce, or job loss) can contribute to depression.

Depression is more common if other family members have a history of depression.

If you have had periods of depression in the past, or are female, you may be more at risk. (Depression might be more diagnosed among women as a result of their more often seeking help with symptoms.)

Depression affects almost 10 percent of the U.S. adult population; however, it is a TREATABLE illness. Research finds early detection and intervention are successful in recognizing severe and chronic depression. Recognizing the signs and seeking professional treatment early are very important.

Reactive Depression

Reactive depression, or sadness in response to life's disappointments, mimics clinical depression with similar symptoms (loss of vigor and interest in everyday activities, disrupted sleep, and fatigue), but symptoms are usually brief. Episodes often recur around holidays or when illness causes you to miss out on daily activities. It is a natural reaction to painful circumstances and is transient; it disappears as you come to terms with your troubles. Although sad, you can cope with living.

When normal responses like anger, frustration, grief, or worry continue for two weeks or more, this may lead to clinical depression. The difference is in gloom that will not go away.

Symptoms That May Alert You to Clinical Depression

The National Center for Mental Health Screening lists several symptoms that should alert you to the possibility of clinical depression. If you experience any of these symptoms for longer than two weeks, you should contact a trusted friend, clergy member, physician, nurse, or social worker:

• loss of interest in things
• feeling sad or blue
• feeling worthless or guilty
• being anxious or worried
• having problems concentrating, thinking, remembering, or making decisions
• feeling pessimistic or hopeless
• thinking thoughts of death or suicide

Physical symptoms include:

• trouble sleeping/sleeping too much
• loss of energy/feeling tired
• headaches/other aches and pains
• digestive problems
• weight loss/gain
• sexual problems

Again, you should report symptoms of at least two weeks' duration. Remember, depression is not your fault. It is not a weakness or laziness, nor does it stem from lack of will power. It is not easy to “snap out of it” on your own.

Once you contact a health care provider, screening and other tests, including lab work and a physical exam, can be done to rule out any other causes of symptoms. Be prepared to discuss the issues with your health care provider and truthfully report how you are feeling and the difficulties you encounter.

Depression in the Caregiver

During this study, family caregivers have told us that they commonly experience fatigue and depression. One of the greatest challenges they face is to maintain their own physical and emotional health. They often find it difficult to put their own needs first and often neglect their own health and well-being.

Caregivers have also reported worry, guilt, and stress while providing care. Some described depression as: “I lost myself,” “I was paralyzed,” or “I didn’t have the energy to make the simplest decision.”

Caregivers have shared with us that among the difficulties of living with and caring for a chronically ill person are observing the person's pain, suffering, and changes on a day-to-day basis. Many have spoken of feeling unappreciated or ineffective, which may prompt
Tube Talk

Thank you to everyone who sent material for the “Tube Talk” column. Anyone who is interested in participating can send their tips, questions and thoughts about tube feeding to: Tube Talk, c/o The Oley Foundation, 214 Hun Memorial MC-28, Albany Medical Center, Albany, NY 12208; or E-mail Metzgel@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.

Tips for Fellow Tube Feeders

Oley member Sanford Schimel recently posted these tips on the Oley Forum. For those of you who may have missed them there, we are reprinting them here. We encourage you to join any of the ongoing dialogues, or begin a new discussion, in the Oley Forum at www.oley.org/forum.htm.

1. As I learned this year when they were the free gift [at the 2008 Oley annual conference in San Diego], rolling backpacks are FABULOUS! The bag and pump stay in the backpack with the tube snaking out the top. My shoulder doesn't get sore from carrying it over my shoulder, and I carry all sorts of stuff in the backpack, right on top of the pump.

2. Always make sure that you have an extra J-tube on hand. The company that makes the tube I use recommends that their tubes be replaced every four months, so as soon as I have the new one put in, I call my supplier and order the next one. Not every hospital has the brand I use, so I bring my own. (I've seen jaws drop when I come in for the swap and hand them my own tube.)

3. Always carry bandages, scissors, and tape with you. My stomas leak (I have separate J- and G-tubes), and the acid burns, so I always have supplies with me. (Well, not always. I have been known to make emergency stops at the local pharmacy.)

4. Keep awareness up of where excess tubing from the bag is. I have caught it on doorknobs, chair arms, chair legs (especially rolling office chairs), and other people.

5. It takes time, but after a while, you realize that anything you can do without the tube, you can do with the tube. Just more carefully.

—Sanford Schimel
sschimel@hotmail.com

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With Jevity 1.2 Cal and the Infinity Pump you can be assured you are receiving complete, balance nutrition.

Jevity has a unique fiber blend to promote normal bowel function. Concentrated calories and protein help you gain and maintain a healthy weight.

The Infinity Pump offers safe, simple operation and the flexibility of ambulatory use.

Contact your home medical equipment supplier or visit Abbott Nutrition.com for more information.
From the Desk of the Executive Director

Greetings! It’s that time of year when everyone and everything is moving at a rapid pace and we are all expected to live, laugh, and love twice as much as usual. But the true meaning of the holidays surfaces when we come to a screeching halt (some of us collapse!) and begin to give thanks. Relationships, the importance of family, and good friends top our list. Running a close second is having the good fortune of working with folks in the Oley Foundation community. Whether you are a member who has been in touch regarding an issue, a volunteer who has helped with outreach, a vendor who has provided financial support, an IT tech who’s kept our equipment running, we give thanks and feel the joy!

Annual Appeal

’Tis the season to ask for funding to support our efforts. In early December we sent you Oley’s annual appeal. Our wish is that Oley will remain on your list of organizations you consider worthy of donating to. There are other ways to support Oley as well: for example, you might consider bequeathing a gift to Oley in your will, transferring stock to Oley, arranging for an automated withdrawal from your checking or savings account, or soliciting a donation for our silent auction from your favorite store or craft venue. However you choose to give, know that every dollar raised will make a difference in how and whether our programs prevail in these economically uncertain times.

Sign Up for Camp

Early in the new year is also the time for making plans. I’d like to call attention to the articles written by Tim Weaver and his mom, Ann, regarding the summer camp opportunity at Double H Ranch. We thank Tim and Ann for sharing their stories and hope they inspire others to follow their lead. Know that Oley staff wholeheartedly endorse the Double H camp experience and will help you in any way we can to make the camp experience possible for your child. Call us with your questions or to help you implement a plan. And please take a minute to give thanks to the late Paul Newman and his family for their vision, which has brought so much joy to so many campers.

Who’s on the Bus?

We welcome a new donor, Chemique Pharmaceuticals, a home infusion provider based in Whittier, CA, at the Patron level. We look forward to accomplishing great things with Chemique, and with all of our partners, to impact the lives of our members.

We also welcome two additions to the Regional Coordinator Network, Jack Smith and Laurie McBride (profiled on pages 5 and 6). The Board of Directors recently bid a fond farewell to Trustees Alan Buchman, MD, and Sheila Messina, MA, RN, and welcomed new members Mary Patnode, Laura Matarese, PhD, RD, LDN, FADA, CNSD, and Rex Speerhas, RPh, CDE, BCNSP (profiled on page 5). Still giving thanks for these exceptional volunteers!

Finally, as we close the door on one year and glance forward to another, we send our sincerest wishes to you and your family for the happiest and healthiest holiday season.

Joan Bishop
Regional Coordinators, Trustees Join Oley Team

We’d like to take this opportunity to introduce you to several new Oley Foundation board members and two new Regional Coordinator volunteers (RCs). Laura Matarese, PhD, RD, LDN, FADA, CNSD, Mary Patnode, and Rex Speerhas, RPh, CDE, BCNSP, are new to our board this year, and Laurie McBride and Jack Smith have recently volunteered to serve as Oley RCs.

We are grateful to outgoing board members Sheila Messina, MA, RN, and Alan Buchman, MD, MSPH, FACP, FACN, who each served their two, three-year terms with enthusiasm and dedication. They brought much insight to the Oley board meetings, and each contributed generously to many Oley programs, including the Lifeline Letter and Oley conferences.

Board Changes

Dr. Matarese joined the Oley board this summer. She is currently the Director of Nutrition at the Intestinal Rehabilitation and Transplant Center, Thomas E. Starzl Transplantation Institute, and an Assistant Professor of Surgery at the University of Pittsburgh School of Medicine. Before moving to Pittsburgh, Dr. Matarese was involved in the conception and development of the intestinal rehabilitation program at the Cleveland Clinic. She has more than twenty-five years experience in nutrition support, education, and program development and is a long-time supporter of the Oley Foundation.

Dr. Matarese has written over 150 books, chapters, manuscripts, abstracts, and videos (including several articles for the Lifeline Letter). She has lectured extensively, both nationally and internationally, and has spoken at several Oley conferences. Dr. Matarese has held numerous positions within the American Dietetic Association and the American Society for Parenteral and Enteral Nutrition; has received numerous awards; and is currently President-Elect of the National Board of Nutrition Support Certification. She is devoted to improving the quality of life for patients with intestinal failure as well as making enteral and parenteral nutrition safe and effective.

Mary Patnode, of Maple Grove, Minnesota, joined the Oley board this fall. She is a home parenteral nutrition (HPN) consumer, and has been on HPN since 1982. Patnode has Crohn’s disease and short bowel syndrome, and has served as an Oley RC for several years. Some of you may remember her from her presentations at some of the early Oley conferences.

Patnode recently retired from a full-time position as a psychologist in special education. “With retirement,” she says, “I have more time to give and choices to make about where to place my efforts during this next phase of my life. Serving on the Oley board will be an opportunity for me to contribute to the supportive network that is so important to HPN consumers.” With twenty-eight years of HPN experience, Patnode will contribute the much valued consumer perspective to the board.

Rex Speerhas also joined the board this fall. He is a Nutrition Support Clinical Specialist at Cleveland Clinic. Speerhas has worked at Cleveland Clinic since 1974, first as a Staff Pharmacist, then as a Staff Development Specialist, and, since 1985, as a Nutrition Support Clinical Specialist. Speerhas is also a Certified Diabetes Educator and a Board Certified Nutrition Support Pharmacist.

Speerhas has written six book chapters, fifteen papers, and has had multiple posters presented at national meetings. His areas of interest include blood glucose management and trace elements. He has been working with HPN consumers since 1991 and looks forward to bringing pharmacy insights to the Oley board.

Please join us in welcoming these dedicated individuals on the Oley Foundation Board of Trustees.

Welcome New RCs

Laurie McBride, of Victoria, British Columbia, and Jack Smith, from Southside, Alabama, have recently joined the Oley RC network. As RCs, Laurie and Jack are available to talk, network, and help spread the word about Oley to those who could benefit from Oley’s services. We encourage you to reach out to Laurie, Jack, or any of our RCs (complete list on pages 7–8, and at www.oley.org/Regional_Coordinators.html). They can answer questions, share their experiences, and just listen.

New RCs, Trustees, cont. pg. 6

InfuScience

InfuScience has become one of the fastest growing infusion providers in 2008.

Thank you for your confidence in choosing InfuScience for your care.
Laurie McBride was diagnosed with Crohn's disease in his early twenties and has a forty-year history with the disease. He has short bowel syndrome (SBS) as a result of several surgeries. Laurie was on home enteral nutrition (HEN) briefly and has been on home parenteral nutrition (HPN) for eighteen years. Laurie says he's grateful for the extended supportive network to which the Oley Foundation has introduced him. Laurie has traveled extensively, both nationally and internationally. He works in the field of real estate land development and consulting, and is a dedicated sport fisherman of both salmon and trout. As an RC, Laurie is already looking for volunteers to help coordinate an Oley Regional Conference to be held in conjunction with Clinical Nutrition Week in Vancouver in 2011. Call him if you're available!

Jack Smith is familiar with HEN as a parent and foster parent. Fifteen years ago, Jack and his wife Barbara adopted an eight-month-old girl named Joy. Joy, now fifteen, has a history of bronchopulmonary dysphasia (BPD), asthma, colitis, Williams syndrome, developmental delays, and a serious feeding aversion. Joy receives her nutrition through a G-tube. If you were at the Oley conference in San Diego this summer, you might remember meeting Jack, Barbara, and Joy. Jack and Barbara also have a foster daughter, Jessica. Jessica was born with encephalo cell. Like Joy, she receives her nutrition through a G-tube. Jack and Barbara have cared for Jessica since she was six weeks old; she is now eleven. In all, Jack and Barbara have fostered eighteen medically fragile children, nine of whom have had G-tubes. Jack and Laurie look forward to talking with you. A complete listing of Regional Coordinators, which includes Jack and Laurie's contact information, can be found on pages 7 and 8. We hope you'll hold onto it for reference and will turn to these RCs frequently. Don’t forget that the Regional Coordinators regularly staff Oley’s toll-free lines, and thus are easy to contact, free of charge. See the back page of this issue for Oley’s toll-free phone schedule, or check online at http://www.oley.org/call.html.
### Regional Coordinators

Regional Coordinators are an integral part of the Oley Foundation's outreach efforts. To date, the following patients/caregivers have accepted these volunteer positions. If you need someone to speak with, or are interested in a get-together, contact the volunteer nearest you (even if he or she is not in your region). We encourage you to contact any or all of the others as they have an assortment of knowledge and experience to share. To make speaking with fellow lifeliners more affordable, Oley also circulates two toll-free numbers to experienced HPEN consumers on a monthly basis. A schedule of the toll-free numbers is printed in the *LifelineLetter*. The toll-free schedule, and updated RC list, are also posted on our webpage at www.oley.org and are available at the Oley office (800) 776-6539. Please call or email BishopJ@mail.amc.edu if you are interested in becoming a Regional Coordinator or learning more about what is involved.

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* = has info on support meetings  
HPN = parenteral (IV) nutrition  
HEN = enteral (tube-fed) nutrition  
HPEN = IV & tube-fed nutrition  
TR = small bowel transplant  
OFF = not on therapy at this time  
FC = former caregiver
**Region V (WI, MI, OH, IL, IN):**

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**Region X (WA, OR, ID, AK, HI):**

* = has info on support meetings
HPN = parenteral (IV) nutrition
HEN = enteral (tube-fed) nutrition
HPEN = IV & tube-fed nutrition
TR = small bowel transplant
OFF = not on therapy at this time
FC = former caregiver

**Please consider volunteering!**
In Memory of Sallie Waltz Simpson

Joan Bishop

Sallie Waltz Simpson of Columbia, Maryland, passed away on Wednesday, September 3, 2008. Sallie had been a longtime Oley member and served as a Regional Coordinator for more than 20 years. She is survived by her husband, Dr. Mark Simpson. Those of us who knew Sallie will remember her as someone who had a contagious zest for living. Her energy and her passion for life, in the face of a debilitating disease, inspired and touched many lives. Your day was enriched if you spent time with her. Your life was enhanced because you knew her.

Conference goers might recall that Sallie was an artist and educator; many of her fabulous stained glass pieces were featured at our silent auctions. Sallie donated these pieces to raise money for Oley programs.

But her stained glass contributions were only the tip of the iceberg. Sallie was determined to make the best of her life and to encourage others to do the same. Sallie strived to educate others, share her experiences, support her peers, and lend an ear or shoulder to those in need — all while often struggling herself.

The beauty of working with Sallie was that she expected nothing in return for her efforts. She moved forward quietly, effectively, making a significance difference in the lives of those she touched.

Please join us in remembering Sallie as she takes her place among Oley angels.

Need Formula, Tubing?

If you are having trouble paying for formula, tubing, or other supplies, try the Oley Foundation's Equipment/Supply Exchange. Loads of items are available, free of charge. For example, at press time we had more than a hundred cases of various types of formula, and dozens of different types of tubing and feeding bags available.

A description of how the program works and a complete list of available items is posted on the Oley Web site at www.oley.org/equipexchange.html. If you don’t have access to the Internet, Cathy Harrington at the Oley office can assist you. You can reach Cathy 9 a.m. to 4 p.m. EST at (800) 776-OLEY.
A Parent’s Perspective on Summer Camp

Ann Weaver

We first heard of the Double H camp more than ten years ago from an article in the Lifeline Letter. At the time, Tim was four. He was on G-tube feeds and, while recently off HPN, he still had a central line for hydration. The thought of dropping my child, with a chronic health condition, off at camp was scary, to say the least. I could not imagine relinquishing his care to a stranger, after being his primary caregiver since he was an infant. Yet less than four years later, with Tim only on tube feeds, we decided to give it a try.

Tim was filled with excitement on our first trip out east to camp. I had prepared for months for this—filled out multiple-page applications with meticulous detail, planned for about every possible eventuality—but I found myself overwhelmed with mixed emotions. I was happy for Tim while at the same time worried about how things would go. How could anyone provide the same care for my child as I had for the past eight years?

Our fifteen-hour drive east allowed for even more brewing of emotions and fears—while Tim was crawling out of his skin. Pulling into the parking lot at camp—in the beautiful pristine setting of the lower Adirondacks—we were greeted with clapping and cheering. It reminded me of being in a birthing room with the shouts of “It’s a boy!” I still get chills and am brought near tears when I think of that moment. Tim ran off with the counselors not long after we arrived without so much as a good-bye. It was very traumatic for me, but in a good way it was the beginning of letting go—for all of us.

The Routine

When we bring Tim to camp, we drop off his medical supplies and meet with the nurse responsible for his care. The nurse reviews the details outlined on his application, which have been transferred to a daily medical schedule. We can update any information at this time. Tim’s first five years at camp he was on only enteral nutrition and had a central line. In 2008, I went to camp on PN. It was my first time on PN in ten years and I went out to New York from Chicago, Illinois, PN, two-week-old central line, and all. There were no problems with enteral feeds or with parenteral nutrition (PN) at camp. In 2008, I went to camp on PN. It was my first time on PN in ten years and I went out to New York from Chicago, Illinois, PN, two-week-old central line, and all. There were no issues. The dressing was changed once, I watched the nurse add all the vitamins and additives to my PN, and the line was flushed. Everything was taken care of by the incredible medical staff.

Accommodations

This summer, because of surgery, multiple hospitalizations, and a return to HPN, it looked as if camp would be out for Tim. After several calls with the admission and nursing directors, however, we were assured that they were willing and ready to take on Tim’s medical needs so long as we felt comfortable with it. In addition, they offered us the choice of any remaining camp session. They wanted Tim to make it to camp.

Our annual road trip was out of the question (a disappointment to my husband Mike and me, as we would not get our annual respite on Lake Champlain). Instead, I flew Tim out east and spent the week with Oley staff members Roz and Joan and volunteered in the Oley office after dropping Tim at camp.

While I had had my doubts and fears about the trip, I am so glad we took the chance. It was the first time all summer I really saw Tim smile. The greetings of “It’s a boy!” then “It’s Tim Weaver!” as the counselors closed in on our car, once again brought me near tears. Tim’s nurse allowed me as much time as possible to go over his care plan—and reassured me that he cared for kids on PN on a daily basis.

I took the opportunity to call regularly to check in on how Tim was doing, and was always asked how I was doing.

Lasting Rewards

Each year we see growth in Tim after the week at camp. He has matured and shows signs of accepting more responsibility for his own care. He also comes back with a renewed spirit from being uplifted by the counselors, volunteers, staff, and other campers, many of whom he stays in touch with.

While camp has been rejuvenating for Tim, it has also allowed us to step back from Tim’s care. It has helped us make the transition of letting go a little more easily.

Camp, from pg. 1

The experience is incredible. You get to meet really great people and learn about them and recognize everyone for who they are. I have made friends at camp and remain in contact with a large number of both campers and counselors.

Medical Issues

When I am at the Double H ranch, all of my medical needs are taken care of. The medical staff follows all of the medical procedures outlined by my doctor and my mom while not interfering with my camp experience. The medical care is outstanding, yet it does not curtail my independence.

Never have my health complications disrupted the camp experience. The only time I wasn’t able to swim with a central line, I enjoyed a game of kickball at Team Adventure with a slightly younger group instead. No matter what complications you have, everyone is accommodating and very accepting.

I have never had a problem with enteral feeds or with parenteral nutrition (PN) at camp. In 2008, I went to camp on PN. It was my first time on PN in ten years and I went out to New York from Chicago, Illinois, PN, two-week-old central line, and all. There were no issues. The dressing was changed once, I watched the nurse add all the vitamins and additives to my PN, and the line was flushed. Everything was taken care of by the incredible medical staff.

My Mom

People who know my mom called her insane to take these risks. She
brought me seven hundred miles with a two-week-old central line to go to this camp. That might mean something; despite all the risks, we went. Yes, she called the camp nurse every night, but she also learned to let go and not be so overprotective.

I must say that part of my mom's comfort came from me being responsible. She knew I would alert the nursing staff to how I felt, and if I felt off, tell them what I thought was best to do. Parents also get to meet with the nurse on day one of camp, and the nurse will spend as much time as the parents want going over the instructions to make sure they feel comfortable leaving their children.

Good Times

The counselors at camp are incredibly attentive to your specific desires. They are the best. They ensure that everyone is enjoying themselves and that everyone is maintaining a healthy status. (“HH” stands for Health and Happiness.)

In 2008, I had a blast playing softball, kickball, and basketball. I also could be found spinning around and around in circles at the Great Escape (a Six Flags park), and enjoying fishing and boating on Lake Vanere and horseback riding. On the last night we had a camp-wide game, a cookout, a campfire, and a talent show. Every year, I must gain several pounds from all the excellent food that I eat.

Everybody always has a great time at camp, and saying goodbye is the hardest, even though we know we will be returning the next year. Double H is truly an amazing experience. Everyone deserves at least one week in the woods. 

Paving the Way for a Double H Camp Experience

Over the years Oley Foundation staff have witnessed the excitement that fills the hearts of campers as they set off for a fun, safe experience away from home, and away from their normal caregivers. The boost in spirits and maturity we see upon their return is remarkable. The wonders the respite offers their parents is equally fulfilling to behold. We are willing to help connect families with others who have Double H experiences to share, to provide a friendly face at the Albany Airport, etc. Contact us at (800) 776-OLEY or bishopj@mail.amc.edu.

This year the folks at the Double H Ranch will offer up to 6 slots at each session for Oley members. You are invited to visit www.doublehranch.org to learn more about the camp and/or to contact the admissions office at (518) 696-5676 extension 222 or 263. The application process for 2009 begins this January and the deadline is in April.

Tim standing in front of the “H” trees at camp.
Depression, from pg. 2

feelings of frustration and anger. Others feel isolated from family and friends; they feel alone and that they are missing out on activities.
Caregivers can feel frustrated by not knowing how to help or how to get help when needed. Helplessness can accentuate negative emotions and fatigue. While nothing can stop the impact chronic illness has on a loved one, caregivers can, and must, learn to provide care while also maintaining their own health.

Tools to Combat Depression

For both caregivers and consumers, balancing physical and emotional needs will reduce strain. It is important to stop negative thinking and instead emphasize positive events. Resilience and connecting to inner strength can help you remember that managing an illness is not about perfection.

Experts stress the need to delay making major life decisions during “down” times, the importance of avoiding drugs and alcohol as crutches, and avoiding self-isolation. They underscore the need to preserve and boost self-esteem by taking credit where credit is due (i.e., in a job well done) and continuing to enjoy activities that in the past brought pleasure.

Specific scientific interventions tested in our study by patients and family caregivers include methods to decrease symptoms of depression and fatigue or prevent their occurrence. We teach study partners how to monitor emotions and to determine which events trigger low moods. We encourage them to write about feelings at least three times per week and especially when they are feeling discouraged. Writing about emotions has been shown to increase positive outlook, and further, it may also enhance the body’s immune system, helping to avoid infection.

Secondly, we advocate mood-elevating activities. When you are feeling “blue,” participating in enjoyable activities can help you feel better. Physical activity, like dancing, gardening, and walking, contributes to our feeling better about ourselves.

Sensory touch, which Dr. Smith defines as firm skin contact for five to ten seconds, is another method for decreasing depression. Sensory touch stimulates the nervous system and helps you relax. This simple gentle pressure helps create a sense of well-being.

Lastly, it is noted that consumers and caregivers are often awakened during sleep to attend to health concerns, pump alarms, and bathroom needs. This disrupted sleep causes stress and fatigue and the potential for error when performing medical procedures. Short naps are recommended to ease fatigue and restore alertness. Short naps have been shown to improve memory and relieve stress.

Support from Others

It has been established that partnerships with peers, support groups, friends, and neighbors are key to managing emotional and fatigue responses to care giving. Since having contact with others is important in preventing depression, two additional resources are made available in the study. One consists of contact with peers to reinforce treatment plans, receive and give support and encouragement, build confidence, and increase coping skills. Additionally, an outstanding Internet Web site has been created and is being tested. As the study continues, many more participants will be able to access this site to share HPN challenges and successes, tell personal stories, and access a wealth of information through links. [Editor’s note: Oley’s RC network (see pages 7–8) and online chat forum (www.oley.org/forum.html) are also good resources for peer support.]

Further Research

In time, we may find additional practical solutions to help improve daytime fatigue, manage brief episodes of the blues, and identify clinical depression. We hope to be able to share more insights gained from this study when the study has been completed.

In Summary

Depression is a quality of life issue, but it also has ramifications for physical health.
Depression can affect family, friends, and caregivers, as well as HPEN consumers. No one is immune from the risk of becoming depressed.
When depressed, a critical step toward feeling like your old self is seeking help.
It is imperative to be alert to symptoms of depression that persist, to report them to health care professionals, and to follow the recommended treatment.
You cannot expect clinicians to “know” how you feel. You have to make the effort to share symptoms and concerns with professional health care providers.
There are steps you can take to address some of the symptoms of depression (some suggestions are outlined in the article).
Depression is a treatable condition, and need not destroy happiness and quality of life.
Looking for Help, Information?

If so, it’s likely the Oley’s Web site (www.oley.org) can meet your needs. The site offers everything from newsletter articles to links to literally hundreds of helpful organizations. To help you become familiar with the resources available on the Web site, we’ll be highlighting some of them here in the newsletter over the coming months.

In this issue, we’d like to draw your attention to the links. Go to www.oley.org, put your cursor on “Tools for Better Living” in the purple banner, and select “Other Organizations” from the drop-down menu that appears.

The “Other Organizations” page is a tremendous resource. These links can help you quickly get to information on everything from free medical air transport, to gastroparesis support groups, to Medicare appeals, to respite care. To make your research easier, the organizations are separated into the following categories: HomePEN / GI Resources, Health Care General Resources, Insurance / Disability Benefits & Resources, Disease / Condition Specific Organizations, Resources for Parents, Caregiver Resources.

Member Support

This list of resources has grown due to member input and research into member inquiries. If you have a resource to share, or need help finding a resource, contact Roslyn Dahl at dahlr@mail.amc.edu or (800) 776-OLEY.

Help Oley Reach Out to Consumers and Clinicians

As part of Oley’s outreach efforts, we exhibit at many professional and patient-based meetings. Please consider taking a few hours to help spread the word about Oley by staffing one of our exhibit booths. If you are interested, call (800) 776-6539 or contact Kate Swensen at swensek@mail.amc.edu.

Upcoming meetings include:

• **Clinical Nutrition Week**, Feb. 1–4, 2009, Ernest N. Morial Convention Center in New Orleans, LA
  Exhibit Setup: Saturday, Jan. 31, 8:00 am–5:00 pm
  Exhibit Open: Sunday, Feb. 1, 9:30–11:15, 12:15–1:45, and 3:00–4:15;
  Monday, Feb. 2, 9:30–11:15, 12:15–1:45, and 3:00–4:15;
  Tuesday, Feb. 3, 9:30–11:15, 12:15–1:45, and 3:00–4:15

• **Utah Dietetic Association**, April 3, 2009, Miller Conference Center in Sandy, UT

• **Infusion Nurses Society**, May 16–21, 2009, Gaylord Opryland Resort and Convention Center in Nashville, TN
  Exhibit Setup: Sunday, May 17, 8:00 am–5:00 pm
  Exhibit Open: Monday, May 18, 10:00–2:00;
  Tuesday, May 19, 10:00–2:00;
  Wednesday, May 20, 10:00–2:00

• **Association of Gastrointestinal Motility Disorders (AGMD)**, July 24–26, 2009, Doubletree Bedford Glen Hotel, Bedford, MA

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Volume XXIX, No. 6
Contributor News

Individual Donors

The following list represents everyone who contributed between September 30 and November 24, 2008. We also want to thank all of those who are not listed below, who gave earlier this year or who have supported the Foundation by volunteering their time and talents.

**Ambassadors ($2000+)***
- Laura Mulcahy, via United Way
- Meredith Nelson
- Enrica Thure, in honor of Greg Tongol’s 18+ years on HPN

**President’s Circle ($1,000–$1,999)**
- Anonymous

**Benefactors ($500–$999)**
- Laura Matarese*, PhD, RD, LDN, FADA, CNSD
- Carol Rees Parrish, RD, to help support public awareness!

**Sponsors ($250–$499)**
- Jeff Hoelle, via United Way of Southeastern Pennsylvania
- Stuart & Beth Kay
- Laura Matarese*, PhD, RD, LDN, FADA, CNSD
- Carol Rees Parrish, RD, to help support public awareness!

**Patrons ($100–$249)**
- Milton Abercrombie, via Edison International
- Mr. & Mrs. Richard Dillon
- Martha Oates, in memory of Nancy Oates
- Denise Sutton & Norman Trussell
- Don Young, in honor of Rachael Miller’s 28 years on HPN

**Supporters ($50–$99)***
- Elle Fazzaro
- Karen & Millard Mazer, in honor of Esther Adler for a speedy, safe and successful transplant

**Friends (Up to $30)**
- Davi Cohen*, in memory of her good friend Lillian Horn
- Earl & Margie Jones
- In Memory of Sallie Waltz Simpson
  - Sheila Blanton
  - James & Cooper Davidson
  - Davie County Hospital
  - Theresa Higgins, who remembers Sallie as a wonderful woman and gifted teacher who changed her life!
  - Lynn Hooker
  - Susan Horn
  - Christine Hunt
  - Rita Joseph, S.B.B.
  - Z. Shihabi
  - D. Vann Simpson
  - Wake Forrest University Baptist Medical Center Pathology & Clinical Labs

**Contributors ($30–$49)**
- S.A. Chaney, via United Way
- Elaine Fazzaro
- iGive.com online shopping
- Karen & Millard Mazer, in honor of Esther Adler for a speedy, safe and successful transplant

Conference, from pg. 1

You’ll find a sampling of the conference program and activities below. Our conference goals are to offer you ways to keep complications at bay and to help you make the best of your life dependent upon tube feedings and infused nutrition.

Personal Experience

One mom who attended the Oley Conference in San Diego in 2008 said, “It changed our life, our outlook, and our marriage. The information that we received during the seminars was amazingly helpful, the friends we made will be life long, the memories will never die. The connections we made with medical professionals and speakers there gave us confidence and hope. The research, tips and different approaches and protocols we learned about were exciting and inspiring. It was undoubtedly the best week my husband, son and I had in two years.”

How to Register

Registration packets will be available in the early spring. Watch our Web site (www.oley.org) for updates. In the meantime, you can make your hotel reservations by calling the resort at (727) 363-2215. Be sure to mention that you will be attending the Oley Annual Conference! The conference rate is $139/night (which includes the resort fee of $15/night per room).

A Preliminary Outline of Activities Planned for Conference 2009

**Note: The arrival and departure days have shifted from our typical pattern, as has the scheduling for a few of the activities.**

**Monday, June 29**
- 2:00 p.m.–5:00 p.m. Regional Coordinator Workshop: A seminar for official Regional Coordinator volunteers AND those who have an interest in learning more about serving Oley in this capacity. Join us! Contact harrinc@mail.amc.edu for additional information.
- 7:00 p.m.–9:00 p.m. Welcome Reception: A gathering of all conference attendees to kick off the activities. Learn more about Oley efforts and network with staff, trustees, speakers, consumers, and families.

**Tuesday, June 30**
- 9:00 a.m.–4:30 p.m. Main Session, to include award ceremony and formal presentations. Exhibit Hall and lunch. Informal breakout sessions in the afternoon and tube-feeding workshop in the afternoon.
- 7:30 p.m.–9:00 p.m. Silent Auction

**Wednesday, July 1**
- 9:00 a.m.–4:30 p.m. Main Session, to include memorial service and formal presentations. Exhibit Hall and lunch. Informal breakout sessions and pediatric workshop in the afternoon.
- 6:00 p.m.–10:00 p.m. Beach Party Picnic: Featuring food, fun, and fellowship!

**Thursday, July 2**
- Walk-a-thon, Town Hall meeting (with late breakfast) running simultaneous with cartoon and crafts pajama party for children ages 7+.
Designate Oley as Your United Way Charity

Although the Oley Foundation is not a United Way agency, we can be supported through United Way employee giving campaigns. Workplace giving can be a convenient, painless way to give a small amount from each paycheck. You can take advantage of this by designating the Oley Foundation on your United Way campaign pledge card.

Questions? Please contact Roslyn Dahl or Joan Bishop at the Oley office by calling 800-776-OLEY, or emailing dahlr@mail.amc.edu or bishop@mail.amc.edu.

Oley Corporate Partners

The following companies provide over one-half of the funds needed to support Oley programs. Corporate relationships also strengthen our educational and outreach efforts. We are grateful for their continued interest and strong commitment.

PLATINUM LEVEL PARTNERS
($70,000+)
Apria Healthcare / Coram Inc., Specialty Infusion Services
Nutrishare, Inc.

GOLDEN MEDALLION PARTNERS ($50,000–$69,999)
NutriThrive

SILVER CIRCLE PARTNERS ($30,000–$49,999)

BRONZE STAR PARTNERS ($20,000–$29,999)
Emmaus Medical, Inc.

BENEFACTOR LEVEL PARTNERS ($10,000–$19,999)
Abbott Nutrition
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PATRON LEVEL PARTNERS ($5,000–$9,999)
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InfuScience, Inc.
Walgreens-OptionCare

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CONTRIBUTORS ($1,000–$2,499)
C.R. Bard, Inc.
Baxa Corporation
Zevex, Inc.

Oley Horizon Society

Many thanks to those who have arranged a planned gift to ensure continuing support for HPEN consumers and their families. To learn how you can make a difference contact Joan Bishop or Roslyn Dahl at 800-776-OLEY.

John Balint, MD
Joan Bishop
Ginger Bolinger
Pat Brown, RN, CNSN
Katherine Cotter
Jim Cowan
Ann & Paul DeBarbieri
Tom Diamantisidis, PharmD
Selma Ehrenpreis
Herb & Joy Emich
Don Freeman
Linda Gold
Linda Gravenstein
The Groeber Family

Valerie Gyurko, RN
Alfred Haas
Shirley Heller
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Lyn Howard, MD
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Family of Shirley Klein
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Beverly Promisel
Abraham Rich
Roslyn & Eric Scheib Dahl
Steve Swensen
Cathy Tokarz
Eleanor & Walter Wilson
James Wittmann
Patty & Darrell Woods
Roseline Ann & William Wu
Chat with Others—Free!

If you haven’t taken advantage of Oley’s Toll-Free networking, try it now! Two telephone numbers (given below) are regularly staffed by experienced home parenteral and/or enteral (homePEN) consumers or caregivers who are willing and eager to talk and listen. These volunteers are available to discuss your homePEN concerns and answer questions. Call to talk about day-to-day issues, for ideas on coping, to share suggestions, and so on. The volunteers staffing the phone lines change regularly. Check www.oley.org or call the Oley office at (800) 776-6539 for a brief biography of these volunteers. As always, advice shared by volunteers represents the experience of those individuals and should not imply endorsement by the Oley Foundation.

**January 2009**
- **Jameson Atkinson** on HPN for Short Bowel/Volvulus
  Yardley, PA – EST  (888) 610-3008
- **Mary Probus** on HPN for Short Bowel
  Louisville, KY – EST  (888) 650-3290

**February 2009**
- **Casey Kellogg** on HPN for Short Bowel/Gastroschesis
  Beavers Dam, NY – EST  (888) 610-3008
- **Davi & Steve Cohen**, Davi is on HPN for Short Bowel/Trauma
  Crofton, MD – EST  (888) 650-3290

**March 2009**
- **Kim Lorimier**, mother of Gwen on HPN for Mitochondrial Disease
  Needham, MA – EST  (888) 610-3008
- **Linda Stokes** on HPN for Short Bowel/Crohn’s Disease
  Dover, FL – EST  (888) 650-3290

Share the Wealth

When shopping for your friends and loved ones, you can allocate some of the proceeds to the Oley Foundation. It doesn’t need to cost you a cent!

**www.iGive.com/oley**
Shop your favorite online stores through iGive.com. Select Oley as your charity of choice, and a portion of your purchase will be donated to the Foundation. If you are new to iGive, when you shop within 45 days of registering they’ll donate an extra $5 to Oley!

**www.GoodSearch.com**
Use GoodSearch for all your Internet searching needs. If you select the Oley Foundation as your charity of choice, a penny is donated to Oley for every search you make—whether you are shopping or researching.

**www.GoodShop.com**
Use the GoodShop Web mall for shopping, choose Oley as your favorite charity, and up to 37 percent of your purchase will be donated to the Foundation.

**www.oley.org**
Consider giving an Oley shirt (www.oley.org/Oley_Shirts.html), or making a donation to the Oley Foundation in honor or in memory of someone special (www.chi-cash-advance.com/sforms/appeal667/contribute.asp).

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**LifelineLetter**

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