

**Registration Packet**



**18th Annual Oley  
Consumer/Clinician Conference**

# **Keeping on Par**

*World Golf Village  
Renaissance Resort*

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**St. Augustine, Florida  
June 19-21, 2003**

## General Information

### Where to Call for More Information

If you need further information about the conference, please call the Oley Foundation. Information about the conference headquarters is available from the World Golf Village Renaissance Resort. For information about St. Augustine, or alternative lodging arrangements, call the visitors bureau.

**The Oley Foundation**  
214 Hun Memorial, A-28  
Albany Medical Center  
Albany, NY 12208-3478  
(518) 262-5079, (800) 776-OLEY  
FAX (518) 262-5528  
E-mail BishopJ@mail.amc.edu  
www.oley.org

### World Golf Village Renaissance Resort

500 South Legacy Trail  
St. Augustine, FL 32092  
(904) 940-8000/(888) 740-7020  
Fax: (904) 940-8008  
www.worldgolfrenaissance.com

### St. Augustine Visitors & Convention Bureau

(800) OLD-CITY  
www.visitoldcity.com

### Registration

Registration forms can be mailed or faxed to the Oley Foundation. You can also register on-line at [www.oley.org/regform.html](http://www.oley.org/regform.html). To register **after June 4, you must fax in your registration OR register on-line**. All registrants are responsible for their own hotel and transportation arrangements. Registration confirmations will not be sent. If you wish to confirm your registration, please wait at least 7 business days before calling to allow for mail delivery and processing. Refund deadline for cancellations is June 4.

### Conference Headquarters

The conference will be held at the World Golf Village Renaissance Resort in St. Augustine, Florida. (The nearest airport is in Jacksonville, approximately 40 minutes north of St. Augustine.) Attendees can reserve a single, double, triple or quad room at the Renaissance for \$99 per day. **This special room rate is in effect until May 25, 2003.** Afterwards this rate will be offered on a space available basis only. **Be sure to mention you are attending the Oley conference to receive this special rate.** The Oley Foundation encourages all conference attendees to stay at the Renaissance because it helps create a family atmosphere. Informal conversations after conference hours are an integral part of the Oley conference experience and are fostered when everyone is staying in the same place!

### Refrigeration for HomePEN Supplies

Refrigerators that can be used for HPEN supplies are available at no charge in each room at the Renaissance.

### Shipping HomePEN Supplies

When shipping your supplies, we recommend separating items that need refrigeration from those that do not — clearly indicating which supplies need to be kept cool. We suggest the package be labeled as shown below.

Your Name \_\_\_\_\_, Guest  
**World Golf Village Renaissance Resort**  
**500 South Legacy Trail**  
**St. Augustine, FL 32092**  
  
Hold for 6/\_\_\_\_\_/03 arrival  
Oley Conference Attendee

### Parking

Parking at the Renaissance is offered free of charge.

### Medical Support/Emergency Services

Emergency hospital and clinical services will be arranged for conference participants. Contact information will be published in the program, and available by calling Oley in late May.

### Child Care

Complimentary child care will be available during conference hours. Specifically it will be offered: Thursday and Friday from **8:45 a.m. to 11:45 a.m.** and **2:00 p.m. to 4:30 p.m.** Parents are responsible for their children during the lunch break. **Pre-registration and signed permission statements are required** (see Registration Form, back page).

### Why Should I Attend?

Designed to help home TPN and tube-fed patients (homePEN consumers) learn more about their therapy, the Oley Conference offers a unique opportunity to network with other homePEN consumers and families, and to learn from leading homePEN clinicians. The conference mixes learning with fun, and includes interactive morning sessions, a chance to learn about new products and services over lunch, small group discussions in the afternoon and fun social events in the evening. Come prepared to learn, and you will return to home with new ideas and friends.



# Getting Around Florida

## Travelling to the Conference

The closest airport is Jacksonville International Airport, located 45 minutes north of the hotel in Jacksonville, FL.

### Directions to the Renaissance from I-95:

1. Take Exit 323.
2. **From the North:** Merge right onto International Golf Pkwy.  
**From the South:** Go west on International Golf Pkwy.
3. Make a right at the first stoplight, which is World Golf Village (WGV) Boulevard. Follow 1.8 miles to the Resort.

### Transportation from the Airport

#### Shuttle:

Arrangements for shuttle transportation to the Renaissance Hotel are in the works as we go to press. Attendees are encouraged to keep checking with Oley to see what service is available by calling (800) 776-OLEY or visiting [www.oley.org](http://www.oley.org).

#### Rental Car:

The drive from Jacksonville International Airport is easy, short and may be the most affordable option. Oley staff was able to rent a car for \$140/week with insurance coverage.

**Alamo** (800) 327-9633 [www.alamo.com](http://www.alamo.com)

**AVIS** (800) 831-2847 [www.avis.com](http://www.avis.com)

**Budget** (800) 527-0700 [www.budget.com](http://www.budget.com)

**Enterprise** (800) 736-8222 [www.enterprise.com](http://www.enterprise.com)

**Hertz** (800) 654-3131 [www.hertz.com](http://www.hertz.com)

**National** (800) 227-2323 [www.national.com](http://www.national.com)

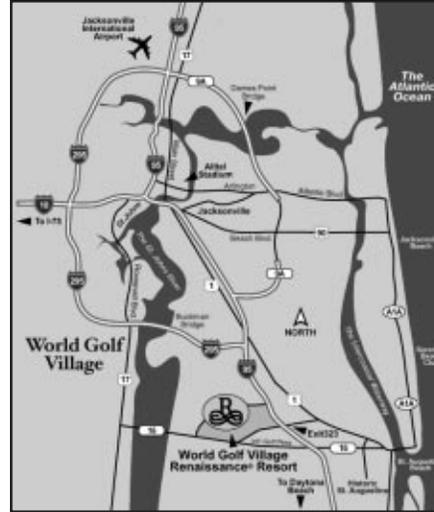
## Travel Grants: First Come, First Served!

Several companies have generously provided Oley with funding for HPEN consumers travelling to the annual conference in Florida.

A limited number of \$250 travel grants (one grant per family, please) will be distributed, on a first come-first served basis, to consumers who are not receiving any other financial assistance from home care companies, etc. for travel and/or lodging expenses related to attending the conference. If you're planning to join us in Florida— **QUICKLY CALL** us at (800) 776-OLEY to be included!

Oley will also offer a \$500 travel scholarship to a first-time conference goer, thanks to the Bruce F. Groeber Memorial Fund. Bruce was a long time lifeliner who believed his first Oley conference exposed him to how good life could be on HPEN. The same standards listed above apply, with the additional restriction that this be the first national, Oley conference the applicant has attended. Applicants for this scholarship should submit two paragraphs describing how they believe attending the conference will help them **by May 1st**.

Travel must be completed, and receipts received by Oley, before reimbursement can be made.



*St. Augustine, FL:  
The Renaissance is  
located 12 miles  
west of historic  
St. Augustine and  
45 minutes south  
of Jacksonville  
International  
Airport*

## Save on Airfare While You Help Oley!

By flying Southwest Airlines you can save on most of their already low fares and help the Oley Foundation earn free tickets. Here's how it works: Southwest Airlines offers up to 10% off most fares for air travel to and from the conference, with the convenience of Ticketless Travel. To qualify, call Southwest Airlines Group and Meetings Reservations at (800) 433-5368 and reference I.D. code # ZO178. Reservation Sales Agents are available 7:00 a.m. to 8:00 p.m. Monday to Friday, or 8:30 a.m. to 5:30 p.m. Saturday and Sunday, CST. If you have questions or problems using this service, please contact Oley immediately at (800) 776-OLEY.

## Recreational Activities

St. Augustine is known for its historic sites, picturesque streets and quaint shops. And at World Golf Village you can enjoy the World Golf Hall of Fame, an IMAX Theater, two 18-hole championship golf courses, a pool, a fitness center and three restaurants. More information will be published in the conference program or feel free to contact the Visitor's Bureau at (800) OLD-CITY or [www.visitoldcity.com](http://www.visitoldcity.com).

### ☆ ☆ Special Notes ☆ ☆

\*\* Jacksonville can be warm and humid in June. While most of the program will be held indoors in air conditioned rooms there are some outdoor activities. Discuss your travel plans with your physician and come prepared with extra hydration.

\*\*Be sure to request a travel sharps container from your home care company, if you use needles.

\*\*It may be possible for consumers and family members to take a tax-deduction for expenses incurred in attending the conference (travel, food, lodging, etc.) under "Medical Education Expenses." Check with a tax advisor/accountant regarding your own personal situation.

# Conference Highlights

## Oley Masters Golf Tournament **NEW!**

The conference will kick off with a Masters Golf Tournament, Wednesday, June 18, at 2:00 p.m. at the World Golf Village Slammer & Squire course. Organized in scramble format, pros and novices alike are invited to sign up as individuals or as a team. HomePEN consumers golf for FREE, \$100 for all others. Proceeds from the event will support Oley programs.

## Welcome Reception

Join us for a warm welcome and an evening of fun, Wednesday, June 18, at 7:30 p.m. As part of the event, Oley will recognize its corporate donors for their generous support, and host an award's ceremony for the Oley Masters Golf Tournament. This is a great time to see old friends and meet new ones.

## Plenary Sessions

### Oley's "The View"

*Featuring: Lyn Howard, MD; James Scolapio, MD; Tom Ziegler, MD*  
Thursday, June 19 9:30 a.m. — 11:45 a.m.

Formatted like the popular morning TV chat fest, you won't want to miss it! Oley guests will share *their VIEW* of current studies on intestinal rehabilitation, growth hormone and diet, and where they think the future will take us. We promise an enjoyable session packed with valuable information.

### Our Mixed Bag

*Featuring: Dennis Maki, MD; Moshe Shike, MD; Maurice Shils, MD*  
Friday, June 20 9:15 a.m. — 11:45 a.m.

Join us as we explore the topics of homePEN history and site and lifeline preservation. Dr. Shils, a pioneer in the field, will cover the history nutrition support and homePEN. Dr. Maki will present a wealth of information on fighting and preventing infection. And Dr. Shike will share his vast experience in the home enteral arena and unique expertise with EN access.

## Exhibits

### Grand Opening Exhibit Hall

Thursday, June 19 12:00 p.m. — 2:00 p.m.  
Come learn more about parenteral and enteral products and services from the companies that provide them. The exhibits will also be open noon to 2:00 p.m. on Friday.

### Youth Activity **PLUS** Jammin' Jammies!

The youth activity offers homePEN youth and family members a chance to meet friends and talk about life on homePEN. This activity is limited to children ages 7 to 15. Activities will be held: **Thursday & Friday from 2:15 to 4:30 p.m.**

We will also host Jammin' Jammies, a supervised evening of fun for Oley kids and siblings on Friday, 7 p.m. to 9:30 p.m. (ages 7-12), and 7 p.m. to 11 p.m. (ages 13+). Please indicate if you are interested on the back page of the registration form.

## Oley Benefit Auction

Come bid on exciting prizes at the silent auction, Thursday night at 7:30 p.m. A great time is guaranteed for the whole family! Please consider asking businesses, crafters, family and friends in your area for items. Remember, each item enhances this events and all proceeds support Oley programs!

## Access to the Experts

Back by popular demand, a panel of homePEN experts, including Drs. Jane Balint, Lyn Howard, Darlene Kelly and Ezra Steiger; Sheila Messina, RN; Reid Nishikawa, PharmD; and Melinda Parker, RD; will be available to take questions during this interactive session Friday evening, 7:00 to 8:30 p.m. Bring your concerns.

## 20th Annual Picnic **NEWTIME!**

Bring the family and join in the fun at Oley's annual picnic, Saturday from 4:00 to 9:00 p.m. The schedule includes food, a Mini Masters Tournament, a Hole-in-One contest, and a scavenger hunt, all at World Golf Village! The event is free, but we need you to indicate your interest on the registration form.

## Farewell Brunch

Come to the hug and photo fest at the Oley farewell brunch, Sunday morning, at 10:00 a.m. This is an excellent time to wind down and say good-bye to friends. Attendance is optional, costs \$11.50 per person and must be paid for in advance (see registration form).

## Tentative Faculty Listing

**Jane Balint, MD**, Columbus Children's Hospital; **Tom Baumgartner, PharmD**, University of Florida, Gainesville; **Marcia Boatwright, RN**, Coram Healthcare; **Peggy Borum, PhD**, University of Florida, Gainesville; **Pat Brown, RN, CNSN**, Memorial Sloan Kettering Cancer Center; **Tom Diamantidis, PharmD**, Nutrishare, Inc.; **Marianne Duda, RN**, OptionCare; **Don George, MD**, Nemoors Children's Clinic; **Scott Harris, MD**, Otsuka Maryland Research Institute; **Alicia Hoelle, Consumer**; **Lyn Howard, MD**, Albany Medical Center; **Paula Johns, RN**, University of Florida, Gainesville; **Darlene Kelly, MD**, Mayo Clinic, Rochester; **Vanessa Kumpf, PharmD**, Nutrishare, Inc.; **Dennis Maki, MD**, University of Wisconsin, Madison; **Malisa Matheny, RN**, Consumer; **Sheila Messina, MS, RN**, Consumer; **Reid Nishikawa, PharmD**, Nutrishare, Inc.; **Melinda Parker, RD**, Coram Healthcare; **Betsy Bateman Rothley, RN**, Coram Healthcare; **James Scolapio, MD**, Mayo Clinic, Jacksonville; **Moshe Shike, MD**, Memorial Sloan Kettering Cancer Center; **Maurice Shils, MD**, Cornell University Medical College, Memorial Sloan Kettering Cancer Center; **Ezra Steiger, MD**, Cleveland Clinic; **Elizabeth Tucker, Consumer**; **Andrew Ukleja, MD**, Cleveland Clinic, Weston; **Marcia Wise, RN**, BD Medical; **Tom Ziegler, MD**, Emory University

# Conference Program

## Wednesday, June 18

**1:00 p.m. — 5:00 p.m. *Beat the Morning Rush!***  
**Registration/Information**

**2:00 p.m. Start Time *NEW!***  
**Oley Masters Golf Tournament**  
See "Conference Highlights" for more details.



**7:30 p.m. — 9:00 p.m.**  
**Welcome Reception**  
Join us for an evening of entertainment and lively conversation.

## Thursday, June 19

**8:30 a.m. — 4:30 p.m.**  
**Registration/Information**  
Complimentary continental breakfast available 8:30 to 10:00 a.m.

**9:00 a.m. — 9:30 a.m.**  
**Welcome/Annual Awards Ceremony**  
Join Oley in recognizing this year's award winners and nominees.

**9:30 a.m. — 11:45 p.m.**  
**Plenary Session I: Oley's "The View"**  
See "Conference Highlights" for more details.

**12:00 p.m. — 2:00 p.m.**  
**Grand Opening of the Exhibit Hall**  
Come see the new homePEN products and meet industry professionals.

**2:15 p.m. — 4:30 p.m.**  
**Youth Activity**  
Fun for homePEN consumers and family members, ages 7 to 15.

**2:15 p.m. — 3:15 p.m.**  
**Breakout Sessions I** (see descriptions next page)  
Exchange ideas and tips with fellow Oley members during these informal discussions. The sessions are arranged by topic, allowing you to join a group focused on your needs and interests.

**3:30 p.m. — 4:30 p.m.**  
**Breakout Sessions II** (see descriptions next page)

**7:30 p.m. — 9:00 p.m.**  
**Oley Benefit Auction**  
Join us for an evening of family fun and entertainment.

## Friday, June 20

**8:30 a.m. — 4:30 p.m.**  
**Registration/Information**  
Complimentary continental breakfast available 8:30 to 10:00 a.m.

**9:00 a.m. — 9:15 a.m.**  
**In Loving Memory**  
A tribute to those in the homePEN family who have died in the past year.

**9:15 a.m. — 11:45 p.m.**  
**Plenary Session II: Our Mixed Bag**  
See "Conference Highlights" for more details.

**12:00 p.m. — 2:00 p.m.**  
**Exhibit Hall Open**  
Come and see the displays of homePEN equipment, supplies and services.

**2:15 p.m. — 4:30 p.m.**  
**Youth Activity**  
Fun for homePEN consumers and family members, ages 7 to 15.

**2:15 p.m. — 3:15 p.m.**  
**Breakout Sessions III** (see descriptions next page)  
Exchange ideas and tips with fellow Oley members during these informal discussions. The sessions are arranged by topic, allowing you to join a group focused on your needs and interests.

**3:30 p.m. — 4:30 p.m.**  
**Breakout Sessions IV** (see descriptions next page)

**7:00 p.m. — 8:30 p.m.**  
**Access to the Experts**  
See "Conference Highlights" for more details.

**7:00 p.m. — 9:30 p.m./11:00 p.m.**  
**Jammin' Jammies**  
See "Conference Highlights" for more details on this party for Oley youth, ages 7 and older.

## Saturday, June 21

**4:00 p.m. — 9:00 p.m. *NEW TIME!***  
**20th Annual Oley Picnic**  
Everyone is invited to join in the fun at Oley's annual picnic! It's a great opportunity for consumers, families, clinicians and others to get to know each other in an informal atmosphere. For details see "Conference Highlights."

## Sunday, June 22

**10:00 a.m. — 12:00 p.m.**  
**Farewell Brunch**  
See "Conference Highlights" for details.

# Breakout Sessions

*Choose 2 breakout sessions and 1 alternate for Thursday and Friday afternoon. (Indicate your choices on the registration form next page). To learn about a wider variety of topics, attend different breakout sessions from your spouse or friend. Please note the content descriptions are general and may change slightly depending on the interests of session participants.*

## Thursday, June 19 — Sessions I & II

**T-1. Concerning Access: Enteral and Parenteral**  
Learn about your options before you find yourself in need of a new catheter or tube.

**T-2. Diet, Growth Hormone... For You?**  
Discover how these two components may or may not effect your nutrient absorption capacity and/or how you might qualify to participate in future studies.

**T-3. New Approaches for Treating Crohn's Disease/IBD**  
Learn about the latest treatment for inflammatory bowel disease and what's on the horizon.

**T-4. Gutsy Issues**  
Discuss current approaches to issues of the gut i.e. diarrhea, dehydration, controlling ostomy output, etc.

**T-5. Wound Care/Site Care**  
Discuss the tender and tricky problems of skin and stoma care issues, and explore preventive measures.

**T-6. Catheter Care for Ultimate Success**  
Learn how to avoid serious catheter complications and what steps to take should problems arise.

**T-7. Pain Management**  
Explore traditional and alternative ways of dealing with pain. A wonderful peek at what is available.

**T-8. Motility Disorders**  
Explore the issues surrounding pseudo-obstruction etc. and the latest approaches to treating these complicated disorders.

**T-9. Specifically For Spouses/Significant Others**  
Share coping mechanisms and explore the concept of the "support person" with others facing similar challenges. Limited to spouses/significant others only! Always a lively session.

**T-10. Maximizing Your Relationship with Your Medical Team**  
A true partnership can improve your outcomes and maximize your quality of life; learn the how-to's (like making the most of routine office visits) from veterans who have learned this delicate tango.

## Friday, June 20 — Sessions III & IV

**F-1. Will Alternative Medicine Cause Death or Injury?**  
Looking to incorporate complimentary medicine i.e. herbs, fads, etc.? Be sure to attend and learn how these alternative treatments might interact with traditional medicine.

**F-2. Small Bowel/Liver Transplantation - 2003 Update**  
Learn the latest in this evolving area of treatment -- including information about living donor transplants.

**F-3. Specifically Enteral Issues**  
Explore areas of interest i.e. tubes and tube placement (including the PEJ), formulas, medications, etc.-what works and what doesn't. Bring your questions and concerns. A do-not-miss session for the enteral consumer.

**F-4. Understanding "What's in Your Bag"**  
Learn about the different elements in your solution or formula and identify the importance of each.

**F-5. Metabolic Bone Disease**  
Discover the latest research advances in this troublesome area that affects many long term consumers.

**F-6. What's Up with Rehydration**  
Learn your options for maintaining the proper fluid and electrolyte balance enterally and orally (and thus reduce your dependence and time on IV hydration).

**F-7. Bacterial Overgrowth**  
If you're suffering from chronic bloating, gas and abdominal discomfort, learn the symptoms, risk factors and management strategies for bacterial overgrowth.

**F-8. Don't Let Them Bug You!**  
An expansion of the morning presentation, Dr. Maki, the "guru" of catheter infection, talks about the latest approach to infection prevention. Bring your questions.

**F-9. Parenting Journey: Chaos to Calm**  
Discuss the challenges of raising a technology dependant child, balancing other responsibilities, finding respite care, maintaining a healthy relationship with your child's medical team, finding time for siblings, etc.

**F-10. Conditional Essential Nutrients**  
Conditional essential nutrients are those the body can make, but may not make enough of in stressed or unusual circumstances, such a long term homePEN. Learn which signs indicate you may be deficient and how to correct the problem.



# Registration Form

## CHILDREN/YOUTH'S PROGRAM

Please indicate your child care needs.

*Activities for the children are complimentary (see "General Information" for specific times); HOWEVER, parents must sign a permission slip at the registration desk before their children can participate. Parents are responsible for their children during the lunch break.*

Please list the children you are bringing to the conference:

Name \_\_\_\_\_ Age \_\_\_\_\_

Please indicate how many children will participate in:

\_\_\_\_\_ **Child Care**

\_\_\_\_\_ **Youth Activity** (Ages 7 to 15)

\_\_\_\_\_ **Jammin' Jammies** (Ages 7 and up)

*See "Conference Highlights" for details*

### For Planning Purposes:

Would your children be allowed to swim (under lifeguard supervision) in the ocean? \_\_\_\_\_ yes \_\_\_\_\_ no

In a swimming pool? \_\_\_\_\_ yes \_\_\_\_\_ no

## REGISTRATION FEES

Please send registration fees to Oley.

- HPEN consumers, friends and family ..... FREE
- Oley professional members ..... \$50-1 day, \$80-2 days
- Company representatives ..... \$100-2 days (First two reps are free for exhibitors)

➤ *Please consider making a tax-deductible donation to help the Oley Foundation offset conference expenses.*

➤ *Checks should be made payable to "The Oley Foundation."*

Amount enclosed \$ \_\_\_\_\_

## MAILING INFORMATION

**Mail or fax to Oley by June 4.**

*To register after June 4, fax both sides of the form to Oley, OR register on-line. Be sure to make a copy for your records.*

✉ The Oley Foundation  
214 Hun Memorial, A-28  
Albany Medical Center  
Albany, NY 12208-3478

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✉ (518) 262-5528 FAX

🌐 www.oley.org

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ALBANY, N.Y.

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