

Living and Learning Together

2004 Patient Conference

United Pompe Foundation

Friday, November 12th to Sunday, November 14th, 2004

*Shelter Pointe Hotel
San Diego, CA*





Welcome to the United Pompe Foundation Patient Conference 2004

This conference is designed to allow patients, parents and spouses to come together to talk about issues regarding Pompe disease, to learn from the experiences of others and to hear some of the latest developments as we move closer to having an available therapy. We are hopeful the conference will provide an opportunity to make new friends, renew old acquaintances and continue to organize as a patient community. The conference is open to all and we encourage physicians and other medical caregivers to attend as well.

Many thanks to our friends at Genzyme, without whose help this conference, along with hope for the future, would not be possible.

I hope the conference is successful and that you enjoy your stay in sunny San Diego. On behalf of the United Pompe Foundation and the Conference Committee, I welcome you to the UPF Patient Conference.

David Hamlin
President, United Pompe Foundation

Hotel Reservation Information

The Shelter Pointe Hotel has reserved a block of rooms from November 12 to November 14. UPF's special rates are \$125 per night. Handicapped accessible rooms are available. Please notify the hotel of the need for a handicapped room when registering.

Rooms must be reserved by no later than October 15, 2004 by calling (619-221-8000) or (800-566-2524). Please reference the "Pompe Patient Conference" in order to get the group rate.

In addition, other handicapped rooms are available at the Best Western The Palms (619-222-0561) and the Halfmoon Inn (619-224-3411).

Conference Information

Conference registration fee is \$20. Registration fee includes: Admittance to conference sessions, Friday reception and Saturday breakfast, lunch and dinner. Sea World tickets are available for \$35. Payment and registration should be sent to the United Pompe Foundation: 5100 N. Sixth St. #149, Fresno, CA 93710 ~ Fax (559-224-7510).

Financial Assistance

There is a limited amount of funding available to those who may need financial assistance to attend the conference. In order to apply please email the United Pompe Foundation at david@unitedpompe.com.

Sponsorship Opportunities

We are currently accepting assistance from parties interested in sponsoring the conference. For further information on sponsoring opportunities contact David Hamlin (559-227-1898) or at david@unitedpompe.com.





United Pompe Foundation Patient Conference 2004

Preliminary Agenda

Friday, November 12

5:00 PM Reception
Please join us for an open bar and hors d'oeuvres

Saturday, November 13

8:00 AM Continental Breakfast

8:30 AM Welcome and Introductions

8:45-9:45 AM Genzyme Update and Q&A Session
*Julie Anne Smith, Vice President, Product Strategy & Development
Dr. Pam Reeves, Director, Medical Programs*

9:45 AM Break

10:15 AM Overview of the Infusion Process
David Hamlin, UPF

11:15 AM Pulmonary Issues Related to Pompe Disease
Dr. Lawrence Kline DO, Scripps Sleep Center

12:30 PM Lunch

1:30 PM New Advances in Medical Research
Dr. Barry Byrne MD, PhD, University of Florida

2:30 PM Break

3:00 PM Nutrition and Exercise Therapy
*Dr. Alfred Slonim, MD, Schneider Children's
Hospital at North Shore*

4:00 PM Q&A/Open Dialogue

4:30 PM MDA Update
Danielle Valenciano, MDA Health Services Coordinator

6:30 PM Dinner

Sunday, November 14

Please join us for a fun-filled trip to Sea World

Many thanks to our sponsors: Genzyme and Columbia Gas Transmission.





United Pompe Foundation Patient Conference 2004

Conference Registration Form

Please complete by October 15, 2004 and mail or fax to:
United Pompe Foundation, 5100 N. Sixth Street, #149, Fresno, CA 93710 ~ Fax (559-224-7510).
For additional information please call (559-227-1898).

Name (s) _____

Address _____

City _____ State _____ Zip _____

Phone _____ Email _____

REGISTRATION: \$20 per person. A check for registration should be sent to the United Pompe Foundation at the above address. Please include an additional \$35 per person if planning to go to Sea World.

SESSION SIGN-UP: (Please indicate the number of people attending each session and/or meal).

FRIDAY # _____ Reception

SATURDAY # _____ Meeting

_____ Lunch

_____ Dinner

SUNDAY # _____ Sea World (\$35 per person)

Please list specific concerns you may have so we can better address your needs during this meeting.

