

#### ABOUT THE 4P- SUPPORT GROUP

The 4p- Support Group (4P-SG) is a non-profit association of families of children with 4p-. We offer phone support, newsletters, national biannual gathering and regional meetings to meet and exchange experiences and information. We welcome parents, foster parents, relatives, and professionals working with 4p- children and their families. The mission of the 4p- Support Group is to improve access to 4p- information to parents, family members and care providers of individuals who have 4p- (Wolf-Hirschhorn Syndrome is the main syndrome).

#### 4P-SG MERCHANDISE

This year, we are pleased to offer 4P-SG merchandise: T-shirts will have the "different by nature" SLC logo, a reusable shopping bag will have the official 4P-SG logo and a 4" white vinyl official 4P-SG logo window sticker. All T-shirts are 100% pre-shrunk white cotton. Please include your order on the conference registration form so that we will have what you want.

#### NEW!!!! MEDICAL CLINICS - JULY 29

We are pleased to offer Parent-Doctor Exchange Clinics on Thursday July 29<sup>th</sup>. For added convenience we will be holding the clinics at the Hilton Hotel. Clinics are restricted to parents and 4P- children ONLY, and selection will be filled on a "first come, first served" basis. Participation is completely voluntary. Clinics will NOT serve as a medical exam but rather an exchange of information on each child who participates. Some parents may leave a clinic gaining some insight on possible treatments to discuss with their child's physician but some parents may leave feeling they didn't gain any further information than they already knew but the doctor in that clinic may have gained more knowledge on 4P-. Please note the sign-up instructions on the Conference Registration Form. **All requests need to be made by June 1st.** Childcare will be provided at the hotel for any siblings of clinic families during their scheduled time to meet with a doctor. Parents who sign up for clinics will receive a questionnaire about their child's medical history to provide information for the clinic doctors.

#### OPTIONAL SATURDAY NIGHT OUTING - July 31

**In Planning Stage**  
**Check Back for More Info in the Next Newsletter**

#### HOTEL ACCOMODATIONS

The SLC conference will be held at the Hilton Salt Lake City Center Hotel located at 255 South West Temple, Salt Lake City, Utah, 84101. "Nestled in the heart of the downtown business and entertainment district and only eight miles from the Salt Lake International Airport, the Hilton Salt Lake City Center enjoys the most convenient location in the Salt Lake Valley. This AAA Four Diamond full service hotel is loaded with amenities and is perfectly situated within three city blocks of over 60 restaurants, two shopping malls, the EnergySolutions Arena (Home of the Utah Jazz), historic Temple Square, the Genealogy Research Center, and is across the street from the Salt Palace Convention Center." Amenities include: an indoor heated swimming pool, hot tub, fitness center, dining room and a full service spa. **Please remember to make your own reservations:** (801) 328-2000 or (800) HILTONS. Reservations must be made no later than 6/28/10 for the special 4P- Support Group rate. The 4p- Support Group rate is good for 3 days before and 3 days after conference dates. Mention the 4P- Support Group room blocks when you call to get our rate of \$99 plus tax per night, and request all special arrangements, such as a handicapped-accessible room, crib, rollaway bed, refrigerator, no smoking, and extended stay, when making the reservation.

#### ABOUT SALT LAKE CITY

Tad and Sarah Tidwell are our gracious hosts for the 2010 SLC Conference and are pleased to be able to invite you to Salt Lake City, "different by nature", as we proudly host the 18th Bi-Annual National 4P- Support Group Conference. Salt Lake City is the state capital and largest city in Utah. Founded in 1847 by religious leader Brigham Young, the city is the world headquarters of the Church of Jesus Christ of Latter-day Saints (Mormons). From its early days as a mining and railroad town, Salt Lake City has emerged as the commercial and cultural hub for a large area of the western mountain region. The city recently played host to the 2002 Winter Olympics. The nearby mountains, historical and religious landmarks, and the uniqueness of the Great Salt Lake also make the city a prominent tourist attraction. Visit [www.visittemplesquare.com](http://www.visittemplesquare.com) and [www.visitsaltlake.com](http://www.visitsaltlake.com) for great visitor's guides of area attractions, dining locations and events.

#### FOR MORE CONFERENCE INFORMATION:

Susan Bear (812) 867-6638 [lsbear@wowway.com](mailto:lsbear@wowway.com)

Amanda Lortz (614) 882-3393 [4P-SG@att.net](mailto:4P-SG@att.net)

<http://www.4p-supportgroup.org>

# SLC LOGO COMING SOON!

## 2010 4P- Support Group National Conference

### Salt Lake City, Utah July 29 to Aug. 1, 2010

For the latest information visit  
[www.4p-supportgroup.org](http://www.4p-supportgroup.org)

Visit 4P-SG's FaceBook Event Page at  
<http://www.facebook.com/?ref=home#/event.php?eid=275886563329&index=1>  
(must have a FaceBook Account)

## Conference Schedule July 29 - 31, 2010

### Thursday, July 29

11:30am – 4:30pm Childcare open (no meals)  
 12:00pm – 4:00pm Parent-Doctor Information Exchange Clinics  
 2:00pm – 5:00pm Conference Check-in  
 4:30pm – 5:00pm New families' orientation  
 5:00pm – 9:00pm Open forum - meet & greet all families  
 Hors d'oeuvres and light refreshments served

### Friday, July 30

8:00am – 8:30am Late Conference Check-in  
 8:00am – 4:00pm Childcare open (no meals)  
 8:30am – 9:00am President's Conference Welcome  
 9:00am – 10:15am Genetics, Dr. Carey  
 -New findings on WHS  
 -Announce new growth study  
 -Future of WHS studies  
 10:15am – 11:00am Nutrition/Feeding Tubes, Dr. O'Gorman  
 11:00am – 12:00pm Nutrition/Feeding Tubes  
 -Open Forum with Dysphasia Clinic Team  
 -Questions to be submitted prior to Conference  
 12:00pm – 1:00pm Boxed Lunch Donated by Gandolfo's Deli Utah  
 Childcare closes for lunch  
 1:00pm – 2:00pm Neurology, Dr. Filloux  
 2:00pm – 3:00pm Dentistry, Dr. Olson  
 3:00pm – 4:00pm Neurodevelop. Disabilities, Dr. Sarah Winter  
 4:00pm – 5:00pm Group Photos  
 5:00pm – 6:00pm Break  
 6:00pm – 10:00pm Buffet Dinner provided to Conf. Attendees  
**BACK COUNTRY BARBECUE**  
 -Salad with Red Ripe Tomatoes, Cucumbers,  
 and Croutons & Cheyenne Ranch  
 -Painted Desert Cole Slaw  
 -Roasted Red Potato Salad  
 -Pioneer Corn Bread and Biscuits  
 -Iron Skillet Pan Seared Utah Trout  
 -Grilled Breast of Chicken  
 -Sliced Barbecue Brisket  
 -IPA Barbecue Sauce  
 -Baked Beans & Grilled Squash Medley  
 -Apple Cobbler w/ Crème Anglaise  
 -Children's buffet with Mac and Cheese

## Conference Schedule July 29 - 31, 2009

### Saturday, July 31

8:00am – 5:00pm Childcare open (no meals)  
 8:00am – 9:30am Mitochondria Overview, Dr. Nicola Longo  
 9:30am – 11:00am Mitochondrial in WHS, Dr. Zollino  
 -New findings on WHS  
 11:00am – 12:00pm Break Out Sessions  
 -Cognitive and Develop. Behavior, Dr. Fisch  
 New findings on WHS  
 -Genetics, Dr. South  
 New findings on WHS  
 -Neurology, Dr. Bataglia  
 New findings on WHS (Italian Group)  
 12:00pm – 1:00pm Lunch on your own  
 Childcare closes for lunch  
 1:00pm – 2:00pm Break Out Sessions  
 -3D Imaging, Dr. Quarrell & Dr. Hammond  
 -Financial Planning (Wills/Trusts)  
 -Adaptive Equipment  
 2:00pm – 3:00pm Break Out Sessions – Family Lead  
 -Toileting (all stages)  
 -Education (Advocacy, IEPs)  
 -Family Coping Skills  
 -Grandparent Sharing Time  
 3:00pm – 4:00pm Break Out Sessions?  
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 4:00pm – 5:00pm Business Meeting  
 -Agenda TBA  
 6:00pm – ? Group Outing Planned?

### Sunday, August 1

Family Free Day  
 Church Service Mormon Tabernacle Choir (optional)  
 8:15am Doors open  
 9:15am Audience must be seated  
 9:30am Live broadcast of *Music and the Spoken Word*

### MEET THE DOCTORS

**Cognitive and Developmental Behavior**  
 Gene S. Fisch, Ph.D.  
 Research Professor, Epidemiology and Health Promotion  
 NYU Colleges of Dentistry and Nursing  
 New York

**Dentistry/Orthodontics**  
 Barney T. Olsen, DDS  
 Primary Children's Medical Center  
 Salt Lake City, Utah

### Dysphagia (feeding and swallowing)

Molly O'Gorman, MD, Medical Director  
 Joseph Andersen, RN, BSN, Clinic Coordinator  
 Primary Children's Medical Center  
 Salt Lake City, Utah

### Genetics

John C. Carey, M.D., M.P.H.  
 Professor of Pediatrics  
 University of Utah School of Medicine  
 Salt Lake City, Utah

Nicola Longo, M.D., Ph.D.  
 Chief - Division of Medical Genetics  
 University of Utah School of Medicine  
 Salt Lake City, Utah

Marcella Zollino, M.D.  
 Associate Professor of Medical Genetics  
 Università Cattolica Sacro Cuore  
 Rome, Italy

Oliver W.J. Quarrell, M.D.  
 Department of Clinical Genetics  
 Sheffield Children's Hospital  
 Sheffield, UK

Sarah T. South, Ph.D.  
 Assistant Director  
 University of Utah Division of Medical Genetics  
 Cytogenetics Laboratory  
 Salt Lake City, Utah

### Nephrology

Joseph R. Sherbotie, MD  
 Associate Professor  
 University of Utah School of Medicine  
 Salt Lake City, Utah

### Neurodevelopmental Disabilities

Sarah L. Winter, M.D.  
 Associate Professor (Clinical) General Pediatrics  
 University of Utah School of Medicine  
 Salt Lake City, Utah

### Neurology

Agatino Battaglia, M.D., DPed, DNeuro  
 Adjunct Professor of Child Neuropsychiatry  
 University of Pisa  
 Pisa, Italy

Francis M. Filloux, M.D.  
 Professor of Pediatric Neurology  
 University of Utah School of Medicine  
 Salt Lake City, Utah

### Molecular Medicine (3D Imaging)

Peter Hammond, Ph.D.  
 Professor, Molecular Medicine Unit  
 UCL Institute of Child Health  
 London, UK

### Sleep Medicine

Ameet S. Daftary, M.D.  
 Assistant Professor (Clinical) Pediatric Pulmonology  
 University of Utah School of Medicine  
 Salt Lake City, Utah