

Agenda

Wednesday, July 14, 2004

3:00 – 10:00 pm **Registration** – Best Western
 6:00 – 10:00 pm **Hospitality Mixer**

Thursday, July 15, 2004

8:00 – 8:30 **Registration** – South Pointe Centre
 8:30 – 9:00 **Welcome to Love and Science 2004**
 Paula Brazeal, ULF President
 9:00 – 10:00 **Making Connections**
 All Participants
 10:00 – Noon **Building Blocks for Understanding
 Leukodystrophy and Genetics**
 Shari Baldinger MS
 Noon – 1:00 **Lunch**
 1:00 – 2:00 **Single Parent Issues – Coping Strategies**
 David Edwin PhD, Panel Moderator
 1:00 – 2:00 **You Are Not Alone – Where to Look for
 Help** Presentation & Open Discussion
 Polly Green RN & Kim Hollandsworth RN
 2:00 – 3:00 **Family Conflicts – Coping Strategies**
 David Edwin PhD, Panel Moderator
 2:00 – 3:00 **You Are Not Alone – Where to Look for
 Help** Presentation & Open Discussion
 Polly Green RN & Kim Hollandsworth RN
 3:30 – 5:00 **Aquatic Therapy – A Must for Most**
 John Askew PT, Jason Harnum (AMN)
 former marathon runner, Chris Kaag (AMN)
 Pizor employee. **Note** – Sign up at
 registration desk if interested in a child
 focused class
 3:30 – 5:00 **Parents Reaching Out – A Journey from
 the Heart** Annette Arvizu, ALD Parent
 3:30 – 5:00 **Nutritional Counseling**
 Sign up at registration desk for scheduled
 appointments
 6:00 **Dinner with the Docs and Ollies Dessert**
 7:30 **Second Opinion Committee**
 Pre-registered families please see list at the
 registration desk for scheduled times

Friday, July 16, 2004

8:00 – 8:30 **Registration** – South Pointe Centre
 8:30 – 10:00 **Scientific Symposium Research Summary**
 Lead by a Panel of Scientists
Opportunities for FDA Support
 Marlene Haeffner, MD
 10:00 – Noon **Auction** – Look and bid on some of the
 most eclectic items, and behaviors, ever
 gathered at one site
 Noon – 1:00 **Lunch**
 1:00 – 1:30 **“Chase, Chance, and Creativity, the
 Lucky Art of Novelty”**
 James Austin, MD
 1:30 – 5:30 **MLD Forum** - see Conference Highlights

Friday Additional Concurrent Sessions

1:30 – 2:00 **Pelizaeus Merzbacher Leukodystrophy**
 1:30 – 2:15 **Neonatal ALD / Refsums / Zellwegers**
 2:00 – 2:30 **Canavans Leukodystrophy**
 2:30 – 3:00 **Alexander Leukodystrophy**
 2:30 – 3:30 **Biochemistry for ALD**
 3:00 – 3:30 **CACH / Vanishing White Matter**
 3:30 – 4:00 **Mitochondrial Disorders**
 3:30 – 5:30 **Home Care Issues – Drop in Session**
 Questions from You, Answers from:
 Physicians, Nurses, Physical Therapists,
 Dietitians, Occupational Therapists
 4:00 – 5:00 **Undiagnosed Leukodystrophies/ White
 Matter Disorders of Unknown Origin**
 5:00 – 5:30 **Krabbes Leukodystrophy**
 6:00 **Dinner**
 7:30 **Second Opinion Committee**
 Pre-registered families please see list at the
 registration desk for scheduled times
Nutritional Counseling
 Sign up at registration desk for scheduled
 appointments

Saturday, July 17, 2004

7:00 – 8:00 **Lab Research / Blood Drawing**
 Consent forms at registration desk
 8:30 – 10:00 **Quality of Life**
 What is **your** idea of success? What are the
 statistics to date? Panel Discussion with
 Presentation and Audience Participation
 10:00 – 11:30 **Medications used for Leukodystrophies –
 Common and Disease Specific** –Please
 submit questionnaire form, available at
 registration desk, by Friday noon.
 11:30 – 12:30 **Pain Management – When is the time to
 ask (move) Criteria for specific pain**
 12:30 – 2:00 **Lunch** and Program
Remembrance
 2:00 – 5:30 **ALD Forum** – see Conference highlights
 2:00 – 2:30 **Cadasil Leukodystrophy**
 2:00 – 3:00 **Behavior Management**
 2:00 – 3:00 **Planning for an Autopsy**
 2:30 – 3:00 **Aicardi-Goutieres Syndrome**
 3:00 – 3:30 **Ovariroleukodystrophy**
 3:00 – 4:00 **Looking for Faith in a Crisis**
 6:00 **Dinner** – Midwest Cookout
 7:00 – 2:00 **Musical Entertainment with an Attitude
 Adjustment**

Sunday, July 18, 2004

9:00 – 11:00 **Breakfast Buffet** at Best Western
Your last chance to question the
 Docs.....