THE UNITED LEUKODYSTROPHY FOUNDATION
AND
ALD CONNECT

Embassy Suites Hotel, 222 St. Paul Place, Baltimore, MD, 21202

Thursday, July 31st

4:00 pm
Registration & Hospitality

5:30 pm
Dinner

7:00 pm
Biochemistry of Leukodystrophies (Q&A)
Paul Watkins, M.D., Ph.D.

Friday, August 1st

7:00 am - 8:00 am
Registration

8:00 am - 8:15 am
Welcome and Announcements
Robert Rauner, ULF President, William Rizzo, M.D., Chairman ULF Medical & Scientific Advisory Board, and Florian Eichler, M.D., Director of ALD Connect and ULF Medical Advisory Board Member.

8:15 am - 9:15 am
Infrastructure, Governance and Funding for ALD
Alex Sherman, Clinical Database Specialist, Ben Lenail, ALD/AMN Advocate, Florian Eichler, M.D., Ali Fatemi, M.D., and Sara Hunt, ALDLife.

9:15 am - 10:15 am
Disease Mechanisms for ALD
John Fink, M.D., Robert Brown, M.D., Ph.D., Tara O’Meara, and Sanjay Magavi.

10:15 am - 10:30 am
Break

10:30 am - 11:30 am
Outcome Measures for ALD
Gerald Raymond, M.D., Kathleen Zackowski, Ph.D., O.T., Troy Lund, M.D., Ph.D., and Robert Brown, M.D., Ph.D.
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11:30am - 12:30 pm
Dissemination of ALD-related Disease Information
Amber Salzman, Ph.D., Keith van Haren, M.D., Josh Bonkowsky, M.D., Ph.D., and Leila Jamal, ScM., C.G.C.

12:30pm - 1:30 pm
Lunch

1:30 pm - 1:40 pm
Announcements
Robert Rauner, ULF President

1:40 pm - 2:20 pm
Overview of Leukodystrophies
Deborah Renaud, M.D.

2:20 pm – 2:40 pm
Adrenal Dysfunction in ALD
Aida Lteif, M.D.

2:40 pm - 3:30 pm
Discovery of New Leukodystrophies
Marjo van der Knaap, M.D., Ph.D., Sakkubai Naidu, M.D. and Genevieve Bernard, M.D., MSC, FRCPC.

3:30 pm - 3:45 pm
Break

3:45 pm - 4:20 pm
Symptom Management and Health Related Costs of Leukodystrophies
Josh Bonkowsky, M.D., Ph.D. and Keith Van Haren, M.D.

4:25 pm - 4:55 pm (Concurrent Sessions)
New Links Between Alexander Disease and other Neurological Disorders
Albee Messing, V.M.D., Ph.D.

5:00pm - 6:00 pm
Awards, CADASIL Grant Announcement and Wine Tasting
Robert Rauner, ULF President and William Rizzo, M.D., Chairman ULF Medical & Scientific Advisory Board.

6:00 pm - 7:00 pm
Dinner
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7:15 pm
Informal Group Meetings:

ALD Heterozygotes

AMN Men
Doug Bermel, David Edwin, Ph.D., Florian Eichler, M.D., Charles Peters, M.D., and Wolfgang Koehler, M.D.

Vanishing White Matter
Marjo van der Knaap, M.D., Ph.D.

Youth Group
Leila Jamal, ScM., C.G.C.

7:00 pm - 10:00 pm
Hospitality, Socializing and Silent Auction

Saturday, August 2nd

8:30 am - 9:15 am
Summary of Scientific Session (Q&A)
William Rizzo, M.D. and Ali Fatemi, M.D.

9:15 am - 10:00 am
Emerging Therapies for Leukodystrophies
Gerald Raymond, M.D., Nancy Braverman, M.D., Ph.D., Reuben Matalon, M.D., Ph.D., and Florian Eichler, M.D.

10:00 am - 10:15 pm
Break

10:15 am - 11:00 am
Dietary Treatments for Leukodystrophies
Hong Brereton, M.S., R.D., Lena Bezman, M.D., M.P.H., and Wolfgang Koehler, M.D.
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11:00 am – 11:45 am
Psychological Aspects of Leukodystrophies (Q&A)
David Edwin, Ph.D.

11:45 am - 2:15 pm
Lunch, Memorial Service and Live Auction

2:15 pm - 2:45 pm
Living with Genetic Risk of Leukodystrophy: Resources and Options for Families
Leila Jamal, ScM., C.G.C.

2:45 pm - 3:45 pm
General Fundraising
Ben Lenial, ALD/AMN Advocate, Amber Salzman, Ph.D., Steve Tuttle, KKI Development, Dara Schnee, KKI Development and Diane Kane, Esquire, Run for ALD.

3:45 pm
Concluding Remarks and Cruise Information
Robert Rauner, ULF President

4:00 pm - 5:15 pm
Exercise Therapy
Landy Askew, P.T., and Jen Keller, P.T., Kathleen Zackowski, Ph.D., O.T., and Chris Joseph, Ph.D., O.T.

6:30 pm
Boarding time at Inner Harbor, 561 Light Street - Dinner Cruise of Inner Harbor Baltimore, Spirit Cruises

7:00 pm - 10:00 pm
Dinner cruise with entertainment by Paul Watkins’ Band, The Del-Rays and a Barbershop Octet, The Heart of Maryland

Sunday, August 3rd

8:00 am - 10:00 am
Informal breakfast and socializing

10:00 am
Meeting of the Board of the Global Foundation for Peroxisomal Disorders (GFPD)