

United Leukodystrophy Foundation

SCIENTIFIC SYMPOSIUM

**This ULF Conference
will bring together families and
medical professionals across all of
the leukodystrophies.**

**Don't miss this opportunity to
learn, share, and connect!**

July 27 - 28, 2017

The Commons Hotel, Minneapolis, MN



**United
Leukodystrophy
Foundation**

Symposium Agenda

Tentative agenda as of 4-30-17 – This schedule is subject to minor changes.

Thursday, July 27

- 8:00 am **Welcome and Introductions**
Bob Rauner, ULF Board President
William Rizzo, M.D., Chair, ULF Medical
& Scientific Advisory Board
Ann Moser, B.A., Vice Chair, ULF Medical
& Scientific Advisory Board
- 8:15 am **Marjo van der Knaap, M.D., Ph.D.**
VU University Medical Center
Natural history of Vanishing White Matter disease
- 9:00 am **Orna Elroy-Stein, Ph.D.**
Tel Aviv University
*eIF2B links translational control to mitochondrial
malfunction in Vanishing White Matter disease –
discovery, drug screening, and exciting news*
- 9:45 am **Adeline Vanderver, M.D.**
The Children's Hospital of Philadelphia
Interferon blockage in Aicardi-Goutieres syndrome
- 10:30 am **Break**
- 11:00 am **Tracy Hagemann, Ph.D.**
University of Wisconsin-Madison, Waisman Center
*Antisense oligonucleotides as a therapeutic
approach for Alexander disease*
- 11:45 am **Eva Vasiljevic, B.A.**
University of Wisconsin-Madison, McPherson
Eye Research Institute
*Carrier frequency estimation of Zellweger spectrum
disorder using ExAC database and bioinformatics tools*
- 12:15 pm **Lunch and Live Auction**
- 1:15 pm **Wolfgang Köhler, M.D.**
Hubertusburg Hospital
HSCT for adult cerebral Adrenoleukodystrophy
- 2:00 pm **Florian Eichler, M.D.**
Massachusetts General Hospital
Neuropathy treatments for Adrenomyeloneuropathy
- 2:45 pm **Paul Watkins, M.D., Ph.D.**
Kennedy Krieger Institute
*High throughput screening for drugs that lower
VLCFA in Adrenoleukodystrophy*
- 3:30 pm **Break**

- 4:00 pm **Malu-Clair van de Beek, pre-Ph.D.**
Academic Medical Center, University of Amsterdam
*Lipid-induced endoplasmic reticulum stress
in Adrenoleukodystrophy*
- 4:30 pm **Irene Huffnagel, M.D.**
Academic Medical Center, University of Amsterdam
*Prospective Dutch Adrenoleukodystrophy natural
history cohort >100 subjects*
- 5:00 pm **Wrap up**
- 5:30 - 6:15 pm **Cocktails**
- 6:15 - 8:00 pm **Dinner with the Families**

Friday, July 28

- 8:00 am **Tzipora Falik-Zaccai, M.D.**
Western Galille Hospital-Naharia
*Pilot study screening Druze newborns dried blood
spots for Cerebrotendinous xanthomatosis*
- 8:45 am **Andrea DeBarber, Ph.D.**
Oregon Health and Science University
*Update on development of newborn screening for
Cerebrotendinous xanthomatosis*
- 9:30 am **Raul Estevez, Ph.D.**
University of Barcelona
*Novel results in the molecular pathogenesis of
Megalencephalic leukoencephalopathy*
- 10:15 am **Break**
- 10:45 am **Genevieve Bernard, M.D., M.Sc., FRCPC**
McGill University, Montreal, Canada
*POLR3-related leukodystrophy: 4H leukodystrophy
research update*
- 11:15 am **Fabrice Dabertrand, Ph.D.**
University of Vermont
*Capillary control of cerebral blood flow and its
disruption in small vessel disease*
- 12:00 pm **Wrap up**
- 12:15 pm **Lunch**

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Join the Family Conference in Progress

**Details will be available on-site and on
the ULF conference web site.**

Friday, July 28

12:15 pm **Lunch**

1:00 - 5:00 pm **Sessions & Break-out Groups**

6:00 - 7:30 pm **Service Award & Dinner**

7:30 - 8:30 pm **Informal Group Discussions for Families
& Doctors**

Saturday, July 29

8:30 - 5:00 pm **Sessions, Break-out Groups, Memorial
Observance, & Lunch**

6:00 - 8:00 pm **Cocktails, Silent Auction, & Dinner
with Entertainment**

Sunday, July 30

8:00 - 10:00 am **Informal Breakfast & Socializing**

Join us for great topics and speakers, roundtable discussions, memorial observance, award ceremony, silent and live auctions, and much more! If interested, please bring an item for our auction on Friday evening and drop it off at the registration table. All proceeds benefit ULF research.

The ULF Annual Conference will be held at The Commons Hotel on the campus of the University of Minnesota in Minneapolis. The room rate is \$129, plus taxes. When making a reservation, be sure to ask for the United Leukodystrophy Foundation room block. The hotel number is 612-362-6608, or you may register on-line through the ULF Conference web site page. Accessible rooms are available. There is limited free parking at the hotel, plus a parking structure across the street with fees that max out at \$12/day. Everyone is asked to register, including invited speakers.

The University Recreation and Wellness Center is right across the street from our hotel, and free day-passes are available at the front desk. The Rec Center offers 6 floors of fitness equipment, wall climbing, swimming, and more.

You might wish to add on extra days to your trip to enjoy some of the activities and attractions in Minneapolis, such as the Mill City Museum, Sculpture Garden, U.S. Bank Stadium (home of the 2018 Super Bowl), Science Museum of MN, and Minnehaha Park with its 55-foot-high waterfall. The city is connected by the Light Rail System, an inexpensive, accessible way to travel through town. There is a rail station steps from our hotel with easy access to downtown, Mall of America, and the airport.

Please Print

First & Last Name: _____

Address: _____

City: _____ State: _____ Zip: _____

E-mail: _____ Phone: _____

Please check all appropriate boxes below for meal planning purposes.
The cost of all meals is included in your registration fee.

Lunch Information

- Thursday, July 28
- Friday, July 29
- Saturday, July 30

Dinner Information

- Thursday, July 28
- Friday, July 29
- Saturday July 30

- Vegetarian
- Gluten-free
- Kosher

Hotel Information

The Commons Hotel
615 Washington Avenue S.E.
Minneapolis, MN 55414
(612) 362-6608

This registration form can be sent to:

United Leukodystrophy Foundation
224 N. Second Street, Suite 2
DeKalb, IL 60115

or FAX registration form to 815-748-0844

or scan and email to Keely@ulf.org

Please submit this form with a credit card or check payable
to the ULF or register online at www.ulf.org/conference

Total

\$275

Not a member? Join ULF. Add \$70

Invited Speaker \$0

Registration fee is non-refundable.

Check enclosed

Charge my MasterCard Visa AmEx Discover

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All photos may be used by the ULF unless you check NO here



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