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!

United Leukodystrophy Foundation

July 27 - 28, 2017
The Commons Hotel, Minneapolis, MN
## Symposium Agenda

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

### Thursday, July 27

<table>
<thead>
<tr>
<th>Time</th>
<th>Event</th>
<th>Presenter(s)</th>
<th>Institution(s)</th>
<th>Topic</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00 am</td>
<td>Welcome and Introductions</td>
<td>Bob Rauner, ULF Board President; William Rizzo, M.D., Chair, ULF Medical &amp; Scientific Advisory Board; Ann Moser, B.A., Vice Chair, ULF Medical &amp; Scientific Advisory Board</td>
<td></td>
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<tr>
<td>8:15 am</td>
<td>Natural history of Vanishing White Matter disease</td>
<td>Marjo van der Knaap, M.D., Ph.D.</td>
<td>VU University Medical Center</td>
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</tr>
<tr>
<td>9:00 am</td>
<td>eIF2B links translational control to mitochondrial malfunction in Vanishing White Matter disease – discovery, drug screening, and exciting new</td>
<td>Orna Elroy-Stein, Ph.D.</td>
<td>Tel Aviv University</td>
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<tr>
<td>9:45 am</td>
<td>Interferon blockage in Aicardi-Goutieres syndrome</td>
<td>Adeline Vanderver, M.D.</td>
<td>The Children's Hospital of Philadelphia</td>
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<tr>
<td>10:30 am</td>
<td>Break</td>
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<tr>
<td>11:00 am</td>
<td>Antisense oligonucleotides as a therapeutic approach for Alexander disease</td>
<td>Tracy Hagemann, Ph.D.</td>
<td>University of Wisconsin-Madison, Waisman Center</td>
<td></td>
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<tr>
<td>11:45 am</td>
<td>Carrier frequency estimation of Zellweger spectrum disorder using ExAC database and bioinformatics tools</td>
<td>Eva Vasiljevic, B.A.</td>
<td>University of Wisconsin-Madison, McPherson Eye Research Institute</td>
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<tr>
<td>12:15 pm</td>
<td>Lipid-induced endoplasmic reticulum stress in Adrenoleukodystrophy</td>
<td>Malu-Clair van de Beek, pre-Ph.D.</td>
<td>Academic Medical Center, University of Amsterdam</td>
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<tr>
<td>1:15 pm</td>
<td>Pilot study screening Druze newborns dried blood spots for Cerebrotendinous xanthomatosis</td>
<td>Tzipora Falik-Zaccai, M.D.</td>
<td>Western Galille Hospital-Naharia</td>
<td></td>
</tr>
<tr>
<td>2:00 pm</td>
<td>Neuropathy treatments for Adrenomyeloneuropathy</td>
<td>Florian Eichler, M.D.</td>
<td>Massachusetts General Hospital</td>
<td></td>
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<tr>
<td>2:45 pm</td>
<td>High throughput screening for drugs that lower VLCFA in Adrenoleukodystrophy</td>
<td>Paul Watkins, M.D., Ph.D.</td>
<td>Kennedy Krieger Institute</td>
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<tr>
<td>3:30 pm</td>
<td>Break</td>
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<tr>
<td>4:00 pm</td>
<td>Wrapping up</td>
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<tr>
<td>4:30 pm</td>
<td>Cocktails</td>
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<tr>
<td>5:00 pm</td>
<td>Dinner with the Families</td>
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### Friday, July 28

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<tr>
<td>8:45 am</td>
<td>Update on development of newborn screening for Cerebrotendinous xanthomatosis</td>
<td>Andrea DeBarber, Ph.D.</td>
<td>Oregon Health and Science University</td>
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</tr>
<tr>
<td>9:30 am</td>
<td>Novel results in the molecular pathogenesis of Megalencephalic leukoencephalopathy</td>
<td>Raul Estevez, Ph.D.</td>
<td>University of Barcelona</td>
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<tr>
<td>10:15 am</td>
<td>Capillary control of cerebral blood flow and its disruption in small vessel disease</td>
<td>Genevieve Bernard, M.D., M.Sc., FRCP</td>
<td>McGill University, Montreal, Canada</td>
<td></td>
</tr>
<tr>
<td>10:45 am</td>
<td>POLR3-related leukodystrophy: 4H leukodystrophy research update</td>
<td>Fabrice Dabertrand, Ph.D.</td>
<td>University of Vermont</td>
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<tr>
<td>11:15 am</td>
<td>Wrap up</td>
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<tr>
<td>12:00 pm</td>
<td>Lunch</td>
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[Retrophin](http://www.retrophin.com)
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.

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

CME credit of 10.25 hours for the Scientific Meeting will be provided through the University of Minnesota Dept. of Neurology.
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
☐ Vegetarian  ☐ Gluten-free  ☐ Kosher

Dinner Information
☐ Thursday, July 28
☐ Friday, July 29
☐ Saturday, July 30

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

Name on Card ________________________________________________________________
Card # ____________________________________________________________
Exp. Date _________________________ C V V _________________________
Signature ___________________________________________________________________

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

Register online at: www.ulf.org/conference

Have questions? Call 800-728-5483 or email Keely@ulf.org

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