

United Leukodystrophy Foundation

FAMILY CONFERENCE

**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 28 - 29, 2017

The Commons Hotel, Minneapolis, MN



**United
Leukodystrophy
Foundation**

Family Conference

Tentative agenda – This schedule is subject to minor changes.

Thursday, July 27

8:00 am – 8:30 pm Registration Open
5:30 pm Cocktail Reception
6:15 pm – 8:00 pm Dinner with the Medical Professionals

Friday, July 28

7:00 am Registration Open
8:00 am Welcome and Announcements
8:15 am Neuropsychology Aspects
9:00 am Break-out Sessions
10:15 am Break
10:45 am Integrative Medicine Panel
11:30 am Biochemistry of ALD/AMN
12:15 pm Lunch and Live Auction
1:30 pm Break-out Sessions
2:15 pm Break-out Sessions
3:00 pm Break
3:30 pm Post-Treatment Perspectives on
Gene Therapy for MLD
4:00 pm Centers for Disease Control on
Newborn Screening
6:00 pm – 7:30 pm Service Award & Dinner
7:30 pm – 8:30 pm Informal Group Discussions for
Families & Doctors

Saturday, July 29

8:30 am Summary of Scientific Sessions
9:15 am Break-out Sessions
10:15 am Break
10:30 am Bone Marrow Transplants
11:15 am Gene Therapy Approaches
12:00 pm Lunch
12:45 pm Memorial Observance
1:15 pm Break-out Sessions
2:00 pm Clinical Trials
2:45 pm Break
3:00 pm (TBD)
4:00 pm – 5:00 pm Informal Group Discussions for
Families & Doctors
6:00 pm – 8:00 pm Cocktails, Silent Auction, & Dinner
with Entertainment

Sunday, July 30

8:00 am – 10:00 am Informal Breakfast & Socializing

Break-out Topics

Vanishing White Matter
ALD/AMN
Spasticity
Grief Support
Newborn Screening

Wheelchair Wellness
Integrative Medicine
Genetic Counseling
Gene Therapy
Advocacy

Clinical Trials
School Services
Seizure Management
Bone Marrow Transplant
Disability Rights & Entitlements

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Join us for great topics and speakers, roundtable discussions, memorial observance, award ceremony, and much more! We'll have some exciting live and silent auction items this year. If interested, please bring an auction item and drop it off at the registration table. All auction 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 per night, plus taxes. This rate closes on June 30th. 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.

There is no fee for children to attend, and there will be a supervised children's activity room on Friday and Saturday with games, movies, toys, and art projects.

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 the many 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 just steps from our hotel with easy access to downtown, Mall of America, and the airport.

Please Print

First & Last Name: _____

Children's First & Last Names and Ages: _____

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

- 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 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

Member registration rate	Total
\$90 x # of persons	_____
Not a member? Join ULF. Add \$35	_____
Early bird non-member rate closes June 30	
\$100 x # of persons	_____
Registrations received after June 30	
\$200 x # of persons	_____

No fee for children, and childcare will be provided at no additional cost.
All registration fees are non-refundable.

Check enclosed

Charge my MasterCard Visa AmEx Discover

Name on Card _____

Card # _____

Exp. Date _____ CVV _____

Signature _____

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



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DeKalb, IL 60115



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