

Hunter's Hope Foundation

2020 Global Virtual Leukodystrophy Symposium

Schedule Summary

Click on sessions below or scroll down to see a more detailed description.

ALL TIMES ARE IN THE EASTERN TIME ZONE

Tuesday, July 21, 2020 (10:00am – 3:00pm EDT)

Medical & Science Newborn Screening

Welcome and Overview – 10am EDT
State Labs Newborn Screening Updates – 10:10 – 11:00am EDT
Leukodystrophies NBS
Krabbe NBS Council – 11:00 – 11:30am EDT
Krabbe NBS Guidelines – 11:30am – 12:00pm EDT
LUNCH BREAK – 12:00 – 12:30pm EDT
EIKD NBS Case Study 12:30 – 1:00pm EDT
Krabbe NBS Patient Perspective Survey – 1:00 – 1:30pm EDT
ALD NBS Guidelines – 1:30 – 2:00pm EDT
ALD NBS Parent Guidelines – 2:00 – 2:30pm EDT
MLD NBS Pilot and Next Steps – 2:30 – 3:00pm EDT

Wednesday, July 22, 2020 (10:00am – 3:00pm EDT)

Leukodystrophy Care Network (LCN) and Leukodystrophy Treatments
Welcome and Overview – 10am EDT
Treatment for ALD, CTX, Krabbe, and MLD – 10:10 – 12:00pm EDT
LUNCH BREAK – 12:00 – 12:30pm EDT
LCN Certified Centers – 12:30 – 1:00pm EDT
LCN Telemedicine – 1:00 – 1:30pm EDT
LCN Center Care Coordinators – 1:30 – 1:50pm EDT
LCN Clinical Practice Guidelines (CPG) 1:50 – 2:20pm EDT
LCN Leukodystrophy Data Registry (LDR) – 2:20 – 2:50pm EDT
Family Perspective 2:50pm EDT

Wednesday Evening (7:00 pm EDT)

Welcome and Family Introductions

Thursday, July 23, 2020 (10:00am – 4:00pm EDT)

Prayer – 10:00 – 10:40am EDT
Medical and Scientific Updates for Leukodystrophy Families
Welcome – 11:00 – 11:05am EDT

LCN Certified Centers – 11:05 – 11:30am EDT
LCN Center Care Coordinators – 11:30am – 11:50am EDT
Leukodystrophy Updates 11:50am – 2pm EDT
BREAK 2:00 – 2:30pm EDT

Thursday, July 23, 2020 (2:30pm – 4:00pm EDT)

NBS Update & Hunter's Hope Family Programs
Hunter's Hope NBS Update 2:30 – 2:50pm EDT
ALD NBS Update 2:50 – 3:10pm EDT
LCN Musculoskeletal Parent Guide 3:10 – 3:30pm EDT
Hunter's Hope Family Programs 3:30 – 4:00pm EDT
Wall of Fame
Equipment and Supply Exchange
Wish Gift
Other Family Support Programs

Thursday Evening (6:00 pm EDT)

Family Symposium Virtual Walk

Family Virtual Hangout – 6:30 – 8:00pm EDT

Friday, July 24, 2020 (11:00am – 4:00pm EDT)

Family Sessions (Open to Affected Families Only)
Prayer – 11:00am EDT

Lunch (12:00pm – 1:00pm)

Friday, July 24, 2020 (1:00pm – 4:00pm EDT)

Family Perspective (1:00pm – 2:00pm EDT)
Family Breakout Sessions (2:00pm – 4:00pm EDT)
Moms – caring for a child
Moms – child in heaven
Dads – caring for a child and/or child in heaven

Friday Evening (6:00 pm EDT)

Talent Show

Family Virtual Hangout – 8:00 – 9:30pm EDT

Hunter's Hope Foundation

2020 Global Virtual Leukodystrophy Symposium

Tuesday, July 21, 2020 (10:00am – 3:00pm EDT)

Zoom Meeting link: <https://us02web.zoom.us/j/82089717954>

Meeting ID: 820 8971 7954

Medical & Science Newborn Screening

These sessions will focus on Leukodystrophy Newborn Screening updates, advancements, guidelines and best practices, as well as the most current information regarding treatments and clinical trials.

Welcome and Overview – 10am EDT

State Labs Newborn Screening Updates – 10:10 – 11:00am EDT

State Leukodystrophy NBS Program updates---protocols, outcomes and upcoming plans will be presented.

Presenters

Presentations from state lab directors who are currently screening for Krabbe, ALD, and MLD and also those in the process of implementation.

NY – Dr. Joseph Orsini

MO – Tracy Klug

KY – Dr. Sainan Wei

OH – Dr. Margie Ream

TN – Dr. George Dizikes

IL – Dr. Khaja Basheeruddin

NJ – Miriam Schachter

PA – Angela Gumby

IN – Barb Lesko

SC – Kimberly Seals

Audience

These sessions will benefit NBS state lab staff, referral center providers, LCN Centers, and any provider or scientist focused on newborn screening, Leukodystrophies, and genetics, affected families, and industry partners.

Leukodystrophies NBS

These sessions are organized by Leukodystrophy (LD) disease type: ALD, Krabbe, MLD, and other LDs. Each LD disease type has unique aspects that require specific guidelines. There are similarities across some of the LDs that may be discussed within one or more of the LD presentations.

Hunter's Hope Foundation

2020 Global Virtual Leukodystrophy Symposium

Presenters

Up-to-date information will be shared by Leukodystrophy NBS Workgroup Members, who have been working diligently to address the gaps in LD NBS follow up.

Audience

Those who may want to attend these sessions include Leukodystrophy Care Network members, NBS state lab staff, referral center providers, LD medical providers and scientists focused on NBS, Leukodystrophies, and genetics, industry stakeholders, government stakeholders, medical students, affected families, and financial supporters.

Krabbe NBS Council – 11:00 – 11:30am EDT

Learn about the Council, which meets monthly to review Krabbe NBS patient cases and to continually improve standards and outcomes for Krabbe NBS.

Presented by: Dr. Joanne Kurtzberg and Dr. Joseph Orsini

Krabbe NBS Guidelines – 11:30am – 12:00pm EDT

Updated guidelines on Krabbe NBS screening protocols, patient risk classification, and short and long term follow up. Update on Psychosine as a biomarker for Krabbe Disease.

Presented by: Dr. Robert Thompson-Stone, Dr. Dieter Matern, and Dr. Joanne Kurtzberg

LUNCH BREAK – 12:00 – 12:30pm EDT

EIKD NBS Case Study 12:30 – 1:00pm EDT

A closer look into EIKD NBS patients identified and treated from Illinois, Ohio, Kentucky, and Missouri.

Presented by: Dr. Kristin Page and Dr. Margie Ream

Krabbe NBS Patient Perspective Survey – 1:00 – 1:30pm EDT

One hundred seventy (170) families affected by Krabbe NBS and Krabbe Disease were surveyed about their experience and opinions regarding Krabbe NBS. What lessons does this provide for the medical and scientific community?

Presented by: Natasha Spencer, Karlita Blackwell, Christin Webb, and Dr. Michael Gelb

ALD NBS Guidelines – 1:30 – 2:00pm EDT

An update on best practices for clinicians and state labs involved in ALD NBS.

Presented by: Dr. Ali Fatemi, Dr. Eric Mallack, and Dr. Molly Regelmann

ALD NBS Parent Guidelines – 2:00 – 2:30pm EDT

An overview of the ALD NBS Parent Guidelines, created by the Aidan Jack Seeger Foundation.

Presented by: Miranda McAuliffe

Hunter's Hope Foundation

2020 Global Virtual Leukodystrophy Symposium

MLD NBS Pilot and Next Steps – 2:30 – 3:00pm EDT

An update on the NBS screening assay for MLD and outcomes of the MLD NBS pilots.

Presented by: Dr. Michael Gelb

Wednesday, July 22, 2020 (10:00am – 3:00pm EDT)

Zoom Meeting link: <https://us02web.zoom.us/j/82089717954>

Meeting ID: 820 8971 7954

Leukodystrophy Care Network (LCN) and Leukodystrophy Treatments

For all Leukodystrophies the LCN embraces and promotes: the highest quality of life, an attitude that enhances and celebrates life, the affected individual's abilities and potential, patient care as its primary focus, long-term and comprehensive care for the prevention of potential complications, a multidisciplinary team approach, exceptional standards of care, and a commitment to increasing value and continuously improving quality.

The key elements of the LCN's strategy include: guided by family advocates to ensure patient centered care, learn from existing successful multidisciplinary care business models, integrated centers into established hospital systems, utilize existing resources where possible, world renowned experts in LDs and multidisciplinary care, standards of care, multidisciplinary team model, LD patient registry, ensure continuous excellence - LCN Advisory Committee, Involve government, industry, funders and other stakeholders throughout the process, promote education and growth.

Presenters

These presentations will be led by Leukodystrophy Disease Experts, LCN Coordinating Center staff, LCN Steering Committee members, LCN Certified Center Directors, Care Coordinators, Clinical Practice Guideline Authors and workgroup members, Family Advocates, and other active members of the LCN.

Audience

Those who may want to attend these sessions include Leukodystrophy Care Network members, LD medical providers, scientists, NBS staff, industry stakeholders, government stakeholders, medical students, affected families, and financial supporters.

Hunter's Hope Foundation

2020 Global Virtual Leukodystrophy Symposium

Welcome and Overview – 10am EDT

Treatment for ALD, CTX, Krabbe, and MLD – 10:10 – 12:00pm EDT

Updates from the leading clinicians and scientists on current and emerging treatment options for patients affected by these diseases.

Presented by the following

ALD and AMN – Dr. Florian Eichler and Dr. Ali Fatemi - 10:10 – 10:30am

DUOC for Leukodystrophies – Dr. Joanne Kurtzberg - 10:30 – 10:50am

Krabbe Disease – Dr. Allison Bradbury - 10:50 – 11:10am

Metachromatic Leukodystrophy (MLD) – Dr. Laura Adang - 11:10 – 11:30am

CTX (Treatment and Guidelines) Dr. Andrea DeBarber and Dr. Brian Wishart – 11:30 – 11:50am

Questions

LUNCH BREAK – 12:00 – 12:30pm EDT

LCN Certified Centers – 12:30 – 1:00pm EDT

Center presentations to share with other LCN Centers the services and operational procedures provided. These presentations are not only intended to share best practices, but also inform Centers of how to best refer patients to other Centers based on specialty and/or location if needed.

LCN Telemedicine – 1:00 – 1:30pm EDT

LCN Centers share how they have successfully implemented Telemedicine into their daily practice and how they have overcome obstacles such as third-party payer systems, technical issues, etc.

Presented by: Kim Hollandsworth

LCN Center Care Coordinators – 1:30 – 1:50pm EDT

LCN Care Coordinators are Nurse Practitioners and RNs and are at the heart of all we do through the LCN. They will share updates from their workgroup and all they've accomplished over the past year.

LCN Clinical Practice Guidelines (CPG) 1:50 – 2:20pm EDT

Workgroups of medical providers and affected families have created a variety of CPGs over the past three years. Each group will provide a detailed presentation of their Guidelines in this educational session. Family advocates will share corresponding information about their Family Companion CPGs to inform providers of how to best educate their patients on these important Guidelines.

Hunter's Hope Foundation

2020 Global Virtual Leukodystrophy Symposium

LCN Leukodystrophy Data Registry (LDR) – 2:20 – 2:50pm EDT

Updates on LDR Protocol and Collaboration in the Leukodystrophy Community.

Family Perspective 2:50pm EDT

Presented by: Amy May

<https://youtu.be/BBW5jbnH8eI>

Wednesday Evening (7:00 pm EDT)

Zoom Meeting link: <https://us02web.zoom.us/j/82089717954>

Meeting ID: 820 8971 7954

Welcome and Family Introductions

The Kelly Family will welcome families to the Symposium.

A slideshow of each family registered will be shown along with each family introducing themselves.

All are welcome to attend.

Hunter's Hope Foundation

2020 Global Virtual Leukodystrophy Symposium

Thursday, July 23, 2020 (10:00am – 4:00pm EDT)

Zoom Meeting link: <https://us02web.zoom.us/j/82089717954>

Meeting ID: 820 8971 7954

Prayer – 10:00 – 10:40am EDT

Praying for our Leukodystrophy Families. All are welcome to participate.

Medical and Scientific Updates for Leukodystrophy Families

The medical sessions will be a review of the prior day's sessions, but from a family advocate perspective.

Presenters

These presentations will be led by LCN Medical Providers, Family Advocates and Hunter's Hope staff. This is an opportunity for all to understand these diseases from a family perspective.

Audience

Those who may want to attend these sessions include Leukodystrophy Care Network members, LD medical providers, scientists, industry stakeholders, government stakeholders, medical students, affected families, and financial supporters.

Welcome – 11:00 – 11:05am EDT

LCN Certified Centers – 11:05 – 11:30am EDT

Center Directors' presentations to share with Leukodystrophy Families the Leukodystrophies they specialize in, a typical clinic day, telemedicine, and how they work with other LCN Centers and local care teams to provide the best possible care for their patients.

LCN Center Care Coordinators – 11:30am – 11:50am EDT

LCN Care Coordinators are Nurse Practitioners and RNs and are at the heart of all we do through the LCN. They will share updates from their workgroup and all they've accomplished over the past year.

Leukodystrophy Updates 11:50am – 2pm EDT

Krabbe Disease – Dr. Joanne Kurtzberg and Dr. Joseph Orsini – 11:50 – 12:20pm EDT

Adrenoleukodystrophy (ALD) – Dr. Ali Fatemi 12:20 – 12:40pm EDT

MLD/CTX – Dr. Michael Gelb – 12:40 – 12:55pm EDT

Hunter's Hope Foundation

2020 Global Virtual Leukodystrophy Symposium

Krabbe NBS Patient Perspective Survey – Natasha Spencer, Karlita Blackwell, Christin Webb, Dr. Michael Gelb – 12:55 – 1:15pm EDT

Family Companion Clinical Practice Guidelines and Kids' Companion – Catie Becker – 1:15 – 1:35pm EDT

Industry Partners Panel – 1:35 – 2:00pm EDT

BREAK 2:00 – 2:30pm EDT

Thursday, July 23, 2020 (2:30pm – 4:00pm EDT)

NBS Update & Hunter's Hope Family Programs

These sessions will review and solicit input on Leukodystrophy information access and Hunter's Hope Family Programs. All are encouraged to provide input with the aim of continuously improving information, access, and programs.

Presenters

These presentations will be led by Family Advocates and Hunter's Hope staff.

Audience

Those who may want to attend these sessions include affected families, LCN Care Coordinators, industry stakeholders, government stakeholders, medical students, and financial supporters.

Hunter's Hope NBS Update 2:30 – 2:50pm EDT

Federally Recommended Uniform Screening Panel, Workgroups, and Council
Hunter's Hope staff will give an overview of the progress made and our upcoming plans for NBS.

ALD NBS Update 2:50 – 3:10pm EDT

Elisa Seeger from the Aidan Jack Seeger Foundation will give an update on ALD NBS advocacy, guidelines, and parent resources.

Hunter's Hope Foundation

2020 Global Virtual Leukodystrophy Symposium

LCN Musculoskeletal Parent Guide 3:10 – 3:30pm EDT

Amy May will share the Parent Resource that has been created to correspond with the LCN Musculoskeletal Clinical Practice Guideline.

Hunter's Hope Family Programs 3:30 – 4:00pm EDT

The Hunter's Hope Family Programs are designed to meet the needs of those affected by Leukodystrophy. These sessions will inform the audience about the programs, how they are administered, how they can participate, and how we might be able to expand and enhance them.

Wall of Fame

Hundreds of Leukodystrophy families have contacted Hunter's Hope since we started the Foundation in 1997. The Wall of Fame is a tribute to all of their children and to everyone affected by Leukodystrophies. The Wall of Fame website will be shown with how a family can request to have their child included.

Equipment and Supply Exchange

The Equipment and Supply Exchange program is designed to help fulfill the equipment and/or supply needs of Leukodystrophy children as well as help families place equipment and supplies that they are no longer using. The program will be described with information on how families can participate.

Wish Gift

Our Wish Gift Program helps families facing extreme financial limitations attributed to the costs associated with caring for a child with Leukodystrophy. Requests are granted on a case-by-case basis and are limited to meeting needs that will enable an affected family to provide the best possible care and quality of life for their child. The program will be described with information on how families can apply.

Other Family Support Programs

There are many great resources available for families caring for a child with a Leukodystrophy. Many family advocates were involved in creating this list. The site will be reviewed with input from those attending that may be aware of additional family support programs.

Thursday Evening (6:00 pm EDT)

Zoom Meeting link: <https://us02web.zoom.us/j/82089717954>

Meeting ID: 820 8971 7954

Hunter's Hope Foundation

2020 Global Virtual Leukodystrophy Symposium

Family Symposium Virtual Walk

Remember and honor loved ones – write messages on your balloon, walk in your neighborhood, or choose a fun activity to do as a family. Share your photos on social media using #HHSymposium.

Family Virtual Hangout – 6:30 – 8:00pm EDT

Zoom Meeting link: <https://us02web.zoom.us/j/89165399896>

Meeting ID: 891 6539 9896

Hosted by: Phil and Amy May

Choose from the following “rooms” to spend time with other Leukodystrophy Families...

The Fire Pit Crew – Jenna & Mike Wallace, Sarai & Nathan Taylor

The Family Room/Symposium First-Timers – Andrea & Joel Clausen

John Harvard's Brew House – Scott & Terry Hammond

Kids' Zoom Room – Owen Hammonds, Sienna Seeger & Wyatt Abner

Hunter's Hope Foundation

2020 Global Virtual Leukodystrophy Symposium

Friday, July 24, 2020 (11:00am – 4:00pm EDT)

Family Sessions (Open to Affected Families Only)

Prayer – 11:00am EDT

Praying for our Leukodystrophy Families. All are welcome to participate.

Zoom Meeting link: <https://us02web.zoom.us/j/82089717954>

Meeting ID: 820 8971 7954

Lunch (12:00pm – 1:00pm)

Friday, July 24, 2020 (1:00pm – 4:00pm EDT)

Family Perspective (1:00pm – 2:00pm EDT)

Zoom Meeting link: <https://us02web.zoom.us/j/82089717954>

Meeting ID: 820 8971 7954

Affected families share what it's really like to be a family affected by Leukodystrophy. How life as they knew it is changed. How extended family and friends react.

Affected families from all stages of this unique journey will share and know they are not alone.

We will view a wonderful video created by Amy May – A Family Perspective. If you are not able to join us at this time for this video, you may view it at any time at this link:

<https://youtu.be/BBW5jbnH8eI>

Family Breakout Sessions (2:00pm – 4:00pm EDT)

Zoom Meeting link: <https://us02web.zoom.us/j/89165399896>

Meeting ID: 891 6539 9896

**These sessions are reserved for family members of an affected child.*

Moms – caring for a child

Moms – child in heaven

Dads – caring for a child and/or child in heaven

Hunter's Hope Foundation

2020 Global Virtual Leukodystrophy Symposium

Friday Evening (6:00 pm EDT)

Zoom Meeting link: <https://us02web.zoom.us/j/82089717954>

Meeting ID: 820 8971 7954

Talent Show

Affected children and their siblings share their MANY talents – singing, dancing, jokes, and more! The Talent Show is open to all affected families and their friends.

Join the fun!

Family Virtual Hangout – 8:00 – 9:30pm EDT

Zoom Meeting link: <https://us02web.zoom.us/j/89165399896>

Meeting ID: 891 6539 9896

Hosted by: Phil and Amy May

Choose from the following “rooms” to spend time with other Leukodystrophy Families...

The Fire Pit Crew – Jenna & Mike Wallace, Sarai & Nathan Taylor

The Family Room/Symposium First-Timers – Andrea & Joel Clausen

John Harvard's Brew House – Scott & Terry Hammond

Kids' Zoom Room – Owen Hammonds, Sienna Seeger & Wyatt Abner