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2021 ULF Family Conference Session Links

FRIDAY, JUNE 25
The times indicated below are in the USA Central Time Zone.

PMD (Pelizaeus-Merzbacher Disease)
9:00 AM to 10:00 AM
Presents the basic information of the type PMD and recent developments in research and treatment.
Dr. Nicole Wolf, MD, PhD, Amsterdam UMC
Dr. Davide Tonduti, MD, PhD, Center for Diagnosis and Treatment of Leukodystrophies V. Buzzi Children's Hospital
https://zoom.us/j/94766452836?pwd=ZWZ2akEzMTJIRTQ2alB2clZMZ2l2dz09

Partner Organization: VWM (Vanishing White Matter) Consortium
9:00 AM to 1:00 PM
Please refer to the VWM specific schedule for more information.
Presents the basic information of the type VWM and recent developments in research and treatment.
Presented by the VWM Consortium in conjunction with the Amsterdam University Medical Center.
https://zoom.us/j/97302517603?pwd=dmdVeXlBQ1BtUjlxc2FwWmdoR29ndz09

Partner Organization: Cure MLD (Metachromatic Leukodystrophy) and the Calliope Joy Foundation
9:00 AM to 1:00 PM
Please refer to the MLD specific schedule for more information.
Presents topics currently relevant to the MLD community.
Presented by Cure MLD and the Calliope Joy Foundation.
https://zoom.us/j/93271221898?pwd=b3M1RzFEYnlLUFRTVVJTM2daMEdXQT09

ULF In Action – We Want You!
10:30 AM to 11:30 AM
ULF Board and Staff members present what programs are currently in progress and in the works, and how the community can become more involved in our mission.
ULF Board and Staff
https://zoom.us/j/94680414088?pwd=QXFsNUN1M1R5dmc4RDhOU2c0SFJTZz09

Global Leukodystrophy Initiative
12:00 PM to 1:00 PM
Presents information on how the Global Leukodystrophy Initiative (GLIA) Clinical Trials Network strives to provide clinical development approaches in anticipation of emerging clinical trials for the leukodystrophies. GLIA works with the leukodystrophy community to establish best practices for functional outcomes, patient reported outcomes, natural history, and biomarkers.
Dr. Adeline Vanderver, MD, Children's Hospital of Philadelphia
Dr. Florian Eichler, MD, Massachusetts General Hospital
Dr. Ali Fatemi, MD, Kennedy Krieger Institute, Johns Hopkins
https://zoom.us/j/98226545683?pwd=bjlBVE5SVU5ZeFZIbUg4emRmMUZnUT09

Meal Break: Messages from our Industry Partners
1:00 PM to 2:30 PM
Our sponsors share messages for the community, and we recognize their contribution to making this virtual meeting possible.
https://zoom.us/j/99106126459?pwd=U0p5SzcyS2tONmwzaFI3dXJlS1lOdz09

AGS (Aicardi-Goutieres Syndrome)
2:30 PM to 3:30 PM
Presents the basic information of the type AGS and recent developments in research and treatment.
Dr. Adeline Vanderver, MD, Children's Hospital of Philadelphia
https://zoom.us/j/93740721070?pwd=eUxEeHpESzlRNmVVVWlkR3dHZW02QT09

VWM: Guanabenz Trial
2:30 PM to 3:30 PM
Discussion on the Guanabenz treatment clinical trial that is currently in progress for patients with Vanishing White Matter (VWM).
Dr. Marjo van der Knaap, MD, PhD, Amsterdam UMC
https://zoom.us/j/95108196605?pwd=blBja3FLSDJmVitoc0dKdVRyQ211dz09

Leukodystrophy Newborn Screening Action Network
2:30 PM to 3:30 PM
An introduction to the efforts of the Leukodystrophy Newborn Screening Network and how families can become more involved.
Lesa Brackbill, Leukodystrophy Newborn Screening Action Network
https://zoom.us/j/95719212160?pwd=SVFZV2xldExLUnlvNGpMbGlhQjFtZz09

CTX (Cerebrotendinous Xanthomatosis)
4:00 PM to 5:00 PM
Presents the basic information of the type CTX and recent developments in research and treatment.
Dr. Andrea DeBarber, PhD, Oregon Health & Science University
Dr. Fred Vaz, MD, Amsterdam UMC
Dr. Austin Larson, MD, Children's Hospital Colorado
Dr. Florian Eichler, MD, Massachusetts General Hospital
Dr. Penelope Bonnen, PhD, Baylor College of Medicine
Dr. Michael Gelb, PhD, University of Washington
https://zoom.us/j/93464431274?pwd=dDFKaWNvRi9HcHB4am5oc1NzQ0ZiUT09

AARS/AARS2 and tRNA Synthetases
4:00 PM to 5:00 PM
Presents the basic information around these genetic mutations/types of leukodystrophy and recent developments in research and treatment.
Dr. Adeline Vanderver, MD, Children's Hospital of Philadelphia
Dr. Amena Smith Fine, MD, PhD, Kennedy Krieger Institute
Dr. Marc Engelen, MD, PhD, Amsterdam UMC, Amsterdam Leukodystrophy Center
https://zoom.us/j/99545202319?pwd=NDlZNnY1V1ZVVldvbjE5TGVSUm4vQT09

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"Harnessing Grief" Book Discussion
4:00 PM to 5:00 PM
Maria Kefalas leads a discussion about her book *Harnessing Grief*, focusing on how to navigate the emotions and struggles that families face throughout a leukodystrophy journey.
Maria Kefalas, PhD, The Calliope Joy Foundation and Cure MLD
Blyth Lord, EdM, Courageous Parents Network
https://zoom.us/j/94199988175?pwd=MUlBUElwajc1YVBJamhGZDZaSHRYQT09

Support Group: Caregivers of Adults, Moderated Discussion
5:30 PM to 6:30 PM
This session will not be recorded. An open conversation for caregivers of adult leukodystrophy patients.
https://zoom.us/j/92804933750?pwd=djJLemJ1alhXZTMzRlJvekNlQ0Qwdz09

Support Group: Newly Diagnosed Families, Moderated Discussion
5:30 PM to 6:30 PM
This session will not be recorded. An open conversation for families who recently received a leukodystrophy diagnosis.
https://zoom.us/j/91742954973?pwd=ZkdmQ05EcUdRWUdnVC9tT3pFWXBzZz09

PFDD Meetings 101
5:30 PM to 6:30 PM
Explains what Patient Focused Drug Development Meetings are, their importance in the rare disease community, and how patient participation is critical in their success in influencing the Food and Drug Administration (FDA).
https://zoom.us/j/95399164563?pwd=bEQ0U2c5VzZneTFPM2o4eVVoR0k2dz09