



4H Leukodystrophy Virtual Care & Disease Management Day
April 22, 2022
09:00 – 16:00 ET / 15:00 – 22:00 CET

The Yaya Foundation is proud to announce its upcoming 4H Leukodystrophy Virtual Care & Disease Management Day on Friday, April 22, 2022.

Based on input from many individuals and families affected by 4H Leukodystrophy, conference topics will focus on Supportive Care & Disease Management. The Foundation collaborated closely with leading 4H Clinician Scientist, Dr Genevieve Bernard, to identify speakers and finalize the agenda.

We look forward to bringing individuals and families affected by 4H together with leading specialty clinicians who have cared for 4H patients. Our goal is to safely include as many families as possible. To achieve that, the Virtual Care & Disease Management Day will be delivered virtually. The conference agenda will also allow opportunities for the 4H community to connect.

All sessions are free and will be available virtually. We are finalizing Spanish translation availability.

Please [register](#) today! We think this will be an amazing day together!

Topic	Speaker
Welcome	Ron Garber
POLR3-related (4H) Leukodystrophy & Disorders: An introduction to the clinical manifestations	Dr. Genevieve Bernard
What can we learn from other hypomyelinating leukodystrophies?	Dr. Nicole Wolf
Introduction to Supportive Therapies	Dr. Keith van Haren
Dysphagia & Drooling: How multidisciplinary teamwork equals better care	Dr. Sam Daniel
Spasticity: Definition, Presentation and Treatment	Dr. Marie-Emmanuelle Dilenge

Treatment of Hyperkinetic Movement Disorders	Dr. Inge Meijer
Leukodystrophy: A combination of rehabilitation and adaption. Positioning, monitoring of the hips and the spine.	Dr. Gaetan Filion
Problems with Growth & Pubertal Development	Dr. Constantin Polychronakos
B4 Fractures Occur in 4H: How to Optimize Bone Health	Dr. Annie Sbrocchi
Palliative Care	Dr. Mary Decell
4H Leukodystrophy: The Transfer to Adult Care	Dr. Roberta La Piana
Closing	All

Please reach out to Christina Butterworth, Executive Director of the Yaya Foundation, with any questions – Christina@yayafoundation4hl.org.

You are also welcome to submit anonymous questions for any of the agenda topics. The Foundation is happy to ask questions on your behalf.