

Krabbe Family Warrior Meeting at the ULF conference

AGENDA OVERVIEW AND INFORMATION

Krabbe disease meeting: Saturday June 29th, 2024

United Leukodystrophy Family Conference: Friday, June 28th - Saturday, June 29th, 2024

Location: Eaglewood Resort and Spa | 1402 Nordic Road | Itasca, IL 60143

Hotel Number: 630-773-1400

KrabbeConnect: (800) 800-5509

DAY	DESCRIPTION	LOCATION
Thursday, June 27th	Some families plan to arrive to take advantage of the entire Leukodystrophy experience	Enjoy activities the hotel has to offer
Friday, June 28th	Krabbe disease Warrior Family Meeting from 9:00 - 12:30 pm ULF sessions in the afternoon	Conference Rm at the hotel-TBD
Saturday, June 29th	Attend sessions by ULF	See ULF agenda
Sunday, June 30th	Depart for home - thank you for attending!	Depart for home

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Agenda-Saturday, June 29th, 2024

Start time: 9:00 am **End time:** 12:30 pm

Meeting location: Hollyhock Conference Room

TIME	DESCRIPTION	PRESENTER
9:00 - 9:15 am	Welcome	Stacy Pike-Langefeld
9:15 - 9:30 am	Navigating KrabbeConnect's Financials	Carlyle Kirbo
9:30 - 9:50 am	Newborn Screening Plan for Krabbe	Lesla Brackbill, MA
9:50 - 10:15 am	Lessons Learned Using Transplant to Treat Krabbe	Dr. Deepa Rajan
10:15 - 10:45	Transplant and Dental Care: Navigating Dental Care After Transplant	Elisa Cannon, DDS
10:45 - 11:00 am	BREAK	BREAK
11:00 - 11:25 am	Industry Talk	TBD
11:25 -12:00 pm	Family Panel: How the Burroughs Family Navigated Treatment for Krabbe	Nick, Jenna, Corina, and Shaun Moderator - Dr. Deepa Rajan
12:00 - 12:20 pm	Why KrabbeConnect Can't #curekrabbe Without YOU!	Lesla Brackbill, MA