

# #curekrabbe Annual Family Meeting

**Saturday, June 26<sup>th</sup>, 2021**

Time	Topic	Speaker
9:00 am-9:20 am	KrabbeConnect Welcome and Organization Commitments	Stacy Pike-Langefeld, President
9:20 am-9:45 am	KrabbeCURES update and plans	Stacy Pike-Langefeld, President
9:45 am-10:15 am	Caregivers Experiences on Advocating for Krabbe disease NBS in their state	Lesa Brackbill, Kevin Cushman, and Bruce Kirbo
10:15 am-10:45 am	Navigating the Burden of This Question: How Many Children Do You Have?	Jennifer Siedman, Director of Family, Patient, and Industry Development at Courageous Parents Network
10:45 am-11:15 am	(Industry Panel) How Does Patient/Caregiver Advisory Boards Aid Drug Development	TBA
11:15 am-11:45 am	Lunch Break	
11:45 am-12:15 pm	Reserved for Industry Presentations	TBA
12:15 pm-12:30 pm	KrabbeConnect: Patient Assistance Program Role Out	Anne Rugari, Vice President
12:30 pm-1:00 pm	Brain and Tissue Banking: How Does It Work and Is It Right for Me?	Anne Rugari, Vice President
1:00 pm-1:15 pm	Community Advocate Award	Wendy Zielen, KrabbeConnect Board Secretary
1:15 pm-1:30 pm	Closing Comments	Stacy Pike-Langefeld, President