

Cure GM1 Foundation

2026 International GM1 Virtual Community Conference

Friday, October 2, 2026

9:00 AM – 4:55 PM Pacific Time | 100% Virtual | Zoom with Live Translation

All are welcome. Registration details and the Zoom link will be shared closer to the event.

TIME (PT)	SESSION	SPEAKER / PRESENTER
8:45 AM	Waiting Room Opens	<i>Join early if you wish</i>
9:00 AM	Children's Photo Tribute Video	
9:04 AM	State of GM1: Where We Stand Right Now	<i>Christine Waggoner, Cure GM1 Jeanine Jarnes, UMN</i>
9:11 AM	Welcome & Day Overview	<i>Moderator</i>
BLOCK 1: GM1 FAMILY STORIES AND MORE <i>Moderated by Rafael Escandon</i>		
9:14 AM	Block Introduction	<i>Rafael Escandon, Cure GM1</i>
9:17 AM	GM1 Family Speaker Series	<i>Sarah Wells, Amber Lee - GM1 Caregivers</i>
9:27 AM	KEYNOTE: It Doesn't Have to Be This Way: A Brighter Blueprint for Advocacy	<i>Lesa Brackbill, Patient Advocacy Strategies</i>
9:52 AM	Cure GM1 Initiatives and Ways to Get Involved (GM1 Matrix with Combined Brain)	<i>Christine Waggoner, Cure GM1</i>
10:07 AM	Q&A	
10:17 AM	Breakout Round 1: Introductions and Getting to Know Each Other	<i>Moderators: Varuna Gopalan, David Law</i>
10:42 AM	Return from Breakouts	
10:45 AM	Break	<i>15 minutes</i>
BLOCK 2: CLINICAL TRIALS AND PRECLINICAL RESEARCH <i>Moderated by Dawn Blessing</i>		
11:00 AM	Block Introduction	<i>Dawn Blessing, Cure GM1</i>
11:03 AM	Nizubaglustat Development in Lysosomal Diseases – An Update	<i>Christian Frietag, Azafaros</i>
11:18 AM	New Possibilities in GM1 Research: Gene Therapy Before Birth and the Center of Genome Surgery	<i>Emma Canepa, UCSF</i>
11:33 AM	Acetyllecine in the Treatment of GM1/GM2	<i>Caroline Hastings, UCSF</i>
11:48 AM	Hematopoietic Stem Cell Gene Therapy for Lysosomal Storage Disorders	<i>Maria Ester Bernardo, SR Telethon</i>
12:03 PM	Attendee Pulse	<i>Share a word describing what this research means for your family</i>
12:05 PM	Q&A	
12:15 PM	Lunch Break	<i>30 minutes — a curated resource list will be shared in the chat</i>
12:45 PM	KEYNOTE: Fighting Like a Mother	<i>Amber Freed, Founder and CEO, SLC6A1 Connect</i>
1:15 PM	Energizer Break	<i>2 minutes</i>

TIME (PT)	SESSION	SPEAKER / PRESENTER
BLOCK 3: PRECLINICAL RESEARCH AND RESEARCH LANDSCAPE <i>Moderated by Joshua Henderson</i>		
1:17 PM	Block Introduction	<i>Joshua Henderson, Cure GM1</i>
1:20 PM	Addressing the Personalized Medicine Landscape	<i>Allisandra Rha, Chapman University</i>
1:35 PM	Building a Safe AI Agent for the GM1 Community	<i>Mohsen Herjati, Basion.ai</i>
1:45 PM	Compassionate Use Venglustat	<i>Jeanine Jarnes, University of Minnesota</i>
2:00 PM	Attendee Pulse	<i>Share how you're feeling about what you've just heard</i>
2:02 PM	A Hyperactive Human β -Galactosidase for Gene Therapy of GM1 Gangliosidosis and Related Diseases	<i>Valentina Poletti, University of Padova</i>
2:12 PM	Q&A	
2:22 PM	Breakout Round 2: Caregiving & Daily Life / Advocacy & Action	<i>Moderators: Kylie Harrison, Melinda Habingreither, David Law, Rojan Vakili</i>
2:47 PM	Return from Breakouts	
2:50 PM	Break	<i>15 minutes</i>
BLOCK 4: CAREGIVER AND COMMUNITY <i>Moderated by David Law</i>		
3:05 PM	Block Introduction	<i>David Law</i>
3:08 PM	Supporting Your Partnership While Caring for a Seriously Ill Child	<i>Chrissy Salley, Courageous Parents Network</i>
3:28 PM	Disability & Special Needs Planning Made Easy	<i>Andre Sam, Disability and Special Needs Project</i>
3:58 PM	Giving Voice to Every State: AAC Strategies for Individuals with GM1	<i>Kaitlyn Ober, M.S., CCC-SLP</i>
4:18 PM	Screening for Prevention and GM1 Family Panel: IVF	<i>Vanessa Rangel Miller (Moderator), Rojan Vakili, David Law</i>
4:38 PM	Q&A	<i>David Law</i>
CLOSING: COMMUNITY COMMITMENTS		
4:48 PM	Community Commitments	<i>David Law, Cure GM1</i>
4:50 PM	Closing Remarks & Resource Drop	<i>Christine Waggoner, Cure GM1</i>
4:55 PM	Conference Closes	

Questions? Contact the Cure GM1 Foundation team. We can't wait to see you there!