nnpdf REGIONAL FAMILY EVENT

BERKELEY REGIONAL MEETING AGENDA

Saturday, November 7, 2026 • 10:00 AM – 3:30 PM

Sonesta Emeryville San Francisco Bay Bridge, CA

Agenda may be subject to change.

TIME	SESSION	SPEAKER(S)	DESCRIPTION
9:00 - 10:00 AM	**Registration & Breakfast**		
10:00 - 10:20 AM	**Welcome & Opening**	Heather Teal, M.Ed. Allie Stavrolakis	Welcome and opening remarks, overview of event goals and objectives, and NNPDF updates
10:20 - 10:50 AM	**Our Stories, Our Community: Family Perspectives**	Christopher Sousa Evren Ayik Justin Hopkin, MD	Hear firsthand perspectives from two family members, a sibling of someone living with Niemann-Pick disease, and person living with ASMD
10:50 - 11:20 AM	**NPC & ASMD Today: Clinical Updates and Treatment Advances**	Caroline Hastings, MD Justin Hopkin, MD	Overview of the current landscape of NPC and ASMD care, clinical developments, available treatments, and disease management
11:20 – 11:50 AM	**Genetic Testing and Counseling**	Bex Jaeger, MS-CGC Caroline Hastings, MD Justin Hopkin, MD	Explore how genetic counseling can support families after diagnosis, including family planning and testing considerations after diagnosis
11:50 - 12:10 PM	**Changing Needs Across the Lifespan**	Julie Nguyen, MSW	Learn how a social worker can support your family through life stages and care transitions
12:10 - 12:20 PM	**BREAK**		
12:20 - 12:50 PM	**Exploring New Frontiers: Early Intervention & Emerging Therapies**	Matthew Linz, MD	Explore emerging and current research in prenatal therapies, gene therapy, and gene editing
12:50 - 1:45 PM	**LUNCH**		
1:45 - 2:30 PM	**Emotional Health, Resilience & Family**	Dina Hankin, PhD	Explore the emotional impact of rare disease and strategies to support well-being and strengthen family connections
2:30 - 3:00 PM	**Community Priorities & Needs: Your Voice, Your Experience**	Heather Teal, M.Ed Allie Stavrolakis	Interactive session with live polling and discussion to share your family's priorities and help shape NNPDF's future programs
3:00 - 3:15 PM	**Why the Registry Helps to Drive Discovery**	Solomon Mbua	Overview of the International Niemann-Pick Disease Registry and its role in advancing research and improving care.
3:00 - 3:30 PM	**Community Forum: Ask the Experts**	All Panelists	Open discussion and Q&A with the day's expert speakers to dive deeper into key topics

5:00 PM Dinner on your own | **7:00 PM Optional Social Activity** *Informal networking and potential family activity*