

2026 KLEEFSTRA SYNDROME FAMILY CONFERENCE

FRIDAY, AUGUST 7, 2026 | BOSTON, MA

Session Title	Speaker	Time	Room
BREAKFAST		8:00-9:00 AM	
CHILDCARE		8:30 AM-5:00 PM	
Welcome	Geoff Rhyne	9:00-9:15 AM	EDEN B + C
Advocacy Keynote From Patient Voice to Policy: How Families Can Shape Research, Drug Development, and Access	Ryan Fischer	9:15-10:00 AM	EDEN B + C
Meet Ari: Your Teammate in Rare Disease Care	Kelsey Frahllich	10:00-10:30 AM	EDEN B + C
Simons Searchlight Kleefstra Syndrome Registry Update	Lauren Walsh	10:30-10:50 AM	EDEN B + C
BREAK		10:50-10:55 AM	
TRACK A Understanding & Managing Gastrointestinal Concerns in Kleefstra Syndrome	Sonia Ballal	10:55-11:40 AM	EDEN B + C
TRACK B Behavioral Management, Autism & Regression	Audrey Thurm		EMERSON
BREAK		11:40-11:45AM	
TRACK A Objective Characterization of Sleep, Activity, and Heart Rate Variability in Kleefstra Syndrome	Camila Koike & Nicole Tacugue	11:45-12:30	EDEN B + C
TRACK B Seizures and Epilepsy in Kleefstra Syndrome	Kim Wilttrout		EMERSON
LUNCH		12:30-1:30 PM	
Exploration of Gene Therapy Feasibility in Kleefstra Syndrome	Steven Gray	1:30-1:45 PM	EDEN B + C
Searching for Biomarkers in Genetic Neurodevelopmental Disorders	Anna Pfalzer	1:45-2:00 PM	EDEN B + C
COMBINEDBrain: Advancing Research Across Rare Brain Conditions	Terry Jo Bichell	2:00-2:15 PM	EDEN B + C
Using DNA methylation signatures to improve diagnosis in Kleefstra syndrome and other rare diseases	Danny Miller	2:15-2:30PM	EDEN B + C
Using AI to Repurpose Existing Drugs: The Unravel and IDefine Partnership	Frederic Vigneault	2:30-2:45 PM	EDEN B + C
Can We Turn Up the Volume on EHMT1 in Kleefstra Syndrome?	Riley Sinnott	2:45-3:00 PM	EDEN B + C
BREAK		3:00-3:15 PM	
Growing "Brain Tissue" in a Dish to Understand Kleefstra Syndrome and Related Conditions	George Chen	3:15-3:30 PM	EDEN B + C
Kleefstra Brain Models Built from Patients' Own Cells — Including the Brain's Immune Cells	Angels Almenar	3:30-3:45 PM	EDEN B + C
Meet EHMT1's Partner Gene — and the Syndrome It Causes	Maria J. Barrero	3:45-4:00 PM	EDEN B + C
What We're Learning About Mental Health in Kleefstra Syndrome	Raja Pillai	4:00-4:15 PM	EDEN B + C
Session Close: Getting our Community to a Treatment	Eric Scheeff	4:15-4:45 PM	EDEN B + C
BREAK		4:45-5:00 PM	
HAPPY HOUR WITH RESEARCHERS, CLINICIANS, AND COMMUNITY		5:00-5:45 PM	
DINNER RECEPTION & FAMILY MEET AND MINGLE		6:00-7:30 PM	