

BMF/MDS Program
Bone Marrow Failure and
Myelodysplastic Syndromes

2026 SAMD9 and SAMD9L Virtual Conference: Advancing Patient Care Through Collaboration

A global forum dedicated to the latest
clinical and research advances in SAMD9
and SAMD9L-related conditions

Friday, May 8 - Saturday, May 9, 2026

Virtual via Zoom • Hosted by St. Jude Children's Research Hospital, Memphis, TN

SCHEDULE	TIME ZONE DIFFERENCE
<p>Day 1: Basic Science Friday, May 8 • 8:00 am – 12:00 pm CT</p> <p>Day 2: Clinical Day Saturday, May 9 • 8:55 am – 3:30 pm CT</p>	<p>When Memphis, USA (CT) is 8:00 am: New York (ET) 9:00 am London (BST) 14:00 Berlin (CEST) 15:00 Tokyo (JST) 22:00 Melbourne (AEST) 23:00</p>

GENERAL INFORMATION	
Format	Virtual via Zoom
Attendance	You may join and leave any time throughout the day.
Q & A	Each talk is followed by Q&A. How? Please write your questions in the Zoom chat.
Talk Timing	Standard talks are 10 min presentation + 5 min Q&A (15 min total). Keynotes are 20 min + 10 min Q&A (30 min total).
Live Translation	Live translation is available – see separate Wordly document: Method 1: zoom pop up, beginning each conference day Method 2: scan QR code with your phone: see right → OR: open link in browser

Organized by
Marcin Wlodarski, MD, PhD • Sushree Sahoo, PhD
Support: Andrea Kennedy • Diantha Van De Vlekkert

www.stjude.org/SAMD9and9Lconference

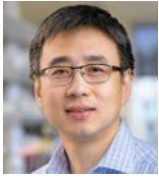




DAY 1 — BASIC SCIENCE | Friday, May 8, 2026 | 8:00 AM – 12:00 PM CT

8:00 am	Welcome - Introduction and historical overview <i>Marcin Wlodarski (St. Jude) & Sushree Sahoo (Virginia Tech)</i>
8:10 am	Housekeeping, and how to use Wordly AI live translation <i>Andrea Kennedy & Diantha Van De Vlekkert (St. Jude)</i>

Session 1: SAMD9/9L Role in Viral Defense

8:15 AM – 9:45 AM





Chairs: Diantha Van De Vlekkert, MS & Maria Carla Giarratana, MD

8:15 am	Yan Xiang, PhD <i>Professor, Department of Microbiology, Immunology, and Molecular Genetics, The University of Texas at San Antonio, San Antonio, TX, USA</i>	
	Keynote lecture: Structural mechanisms of SAMD9 autoinhibition and pathogenic dysregulation	
8:45 am	Remi Demeure <i>Doctorant, Equipe Interaction hôte-pathogène lors de l'infection lentivirale, Centre International de recherche en infectiologie (CIRI), ENS de Lyon</i>	
	Functional evolution of antiviral SAMD9/9L across kingdoms	
9:00 am	Siyuan Ding, PhD <i>Associate Professor, Department of Molecular Microbiology Washington University School of Medicine, St. Louis, MO, USA</i>	
	A novel role of SAMD9L in rotavirus host-range restriction	
9:15 am	Sébastien Nisole, PhD <i>Professor, Centre Armand-Frappier Santé Biotechnologie Institut National de la recherche Scientifique (INRS), Laval, QC, Canada</i>	
	SAMD9L as a regulator of mRNA translation: insights into antiviral defense	
9:30 am	Jia Liu, PhD <i>Associate Professor, Department of Microbiology and Immunology College of Medicine, UAMS, Little Rock, AR, USA</i>	
	Poxvirus co-opts the SAMD9 pathway for immune evasion	
9:45 am	— 15 Minute Break —	


Session 2: SAMD9/9L Disease Models and Pathomechanism

10:00 am– 11:00 am


Chair: Damian Krzyzanowski, PhD & Swarna Beesetti, PhD

10:00 am	<p>Sushree Sahoo, PhD <i>Assistant Professor, Fralin Biomedical Research Institute, Virginia Tech Cancer Research Center, Washington DC, USA</i></p> <p>Understanding the impact of SAMD9L mutations on hematopoiesis</p>	
10:15 am	<p>Jason Schwartz, MD, PhD <i>Assistant Professor, Vanderbilt University Medical Center, Monroe Carell Jr. Children's Hospital at Vanderbilt, Nashville, TN, USA</i></p> <p>Understanding the lineage-specific impacts of germline SAMD9 mutations in hematopoiesis</p>	
10:30 am	<p>Melvin Thomas, PhD <i>Scientist, Department of Pathology, St. Jude Children's Research Hospital, Memphis, TN, USA</i></p> <p>Targeting inflammation in Samd9l-mutant-dependent bone marrow failure</p>	
10:45 am	<p>Toshiya Inaba, MD, PhD <i>Professor Emeritus, Research Institute for Radiation Biology and Medicine, Hiroshima University, Hiroshima, Japan</i></p> <p>Rethinking TGFβ signaling in SAMD9/9L syndromes: a role for nuclear unphosphorylated Smad2/3</p>	

Session 3: Variant Interpretation & Genetic Counseling **11:00 AM – 11:30 AM**
Chair: Kathryn Dickerson, MD

11:00 am	<p>Sara Lewis, MS, CGC <i>Mgr-Genetic Counseling, St. Jude Children's Research Hospital, USA</i></p> <p>SAMD9/9L variants: What Do They Really Mean for Patients?</p>	
11:15 am	<p>Marcin Wlodarski, MD, PhD <i>Associate Member, Director BMF/MDS Program, St. Jude Children's Research Hospital, USA</i></p> <p>How to know if a SAMD9/9L mutation is pathogenic? A step-by-step approach and the role of somatic variants</p>	

Session 4: Scientists and Patients Get Together **11:30 AM – 12:00 PM**

<p>Moderator: Amanda Pullen, MSSW, LCSW, Senior Social Worker & Marcin Wlodarski, MD, PhD, St. Jude Children's Research Hospital</p> <p><i>All scientists and patients/families are warmly invited to participate in this informal session</i></p>	
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DAY 2 — CLINICAL DAY | Saturday, May 9, 2026, | 8:55 AM – 3:30 PM CT

8:55 am **Housekeeping, and how to use Wordly AI live translation:**
Andrea Kennedy & Diantha Van De Vlekkert (St. Jude)

Session 1: Neurology **9:00 am – 10:15 am**
Chair(s): Tim Olson MD, PhD & Soniya Pinto, MBSS




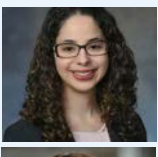

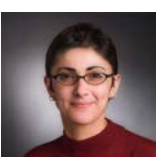
9:00 am	<p>Andrea Gropman, MD <i>Member, Department of Pediatric Medicine, St. Jude Children's Research Hospital, Memphis, TN, USA</i></p> <p>Keynote lecture: What can we learn from ataxia syndromes?</p>	
9:30 am	<p>Richard Finkel, MD <i>Member, Director, Center for Experimental Neurotherapeutics, Endowed Chair in Neurotherapeutics, St. Jude Children's Research Hospital, Memphis, TN, USA</i></p> <p>ASO therapeutics for patients with neurological diseases</p>	
9:45 am	<p>Carla Zingariello, DO <i>Assistant Professor, Saul R. Korey Department of Neurology, Children's Hospital at Montefiore, Albert Einstein College of Medicine, New York, USA</i></p> <p>Neurologic assessment of patients with SAMD9L syndrome</p>	
10:00 am	<p>Majd Khiami, MD, PMP <i>Sr. Clinical Research Associate, St. Jude Children's Research Hospital, Memphis, TN, USA</i></p> <p>Summary of neurological phenotypes in SAMD9 and SAMD9L patients</p>	

Session 2: Transplant vs. Watch and Wait **10:15 am – 11:15 am**
Chairs: Taizo Nakano, MD & Enrico Attardi, MD, PhD




10:15 am	<p>Tim Olson, MD, PhD <i>Associate Professor, Director of Research, Comprehensive Bone Marrow Failure Center, Children's Hospital of Philadelphia (CHOP), Philadelphia, PA, USA</i></p> <p>General approach to bone marrow transplantation</p>	
10:30 am	<p>Kristen Schratz, MD <i>Assistant Professor, Telomere Clinic at Johns Hopkins, Baltimore, MD, USA</i> & Hila Dias-Polak, MD <i>Attending Physician, Department of Pediatric Hematology-Oncology, Rambam Medical Center, Haifa, Israel</i></p> <p>Comprehensive molecular surveillance enables early identification of MDS driver mutations</p>	 

10:45 am	<p>Miriam Erlacher, MD, PhD <i>Professor, Medical Director, Pediatric Hematology/Oncology, Ulm, Germany, EWOG-MDS national coordinator for Germany</i></p> <p>Is it safe to stop hematologic surveillance?</p>	
11:00 am	<p>Maria Carla Giarratana, MD <i>Pediatric Hematology/Oncology Physician, Gaslini Hospital, Genoa, Italy</i></p> <p>Regression vs. persistence patterns in patients with monosomy 7</p>	
11:15 am	— 15-Minute Break —	

Session 3: Multisystem Manifestations 11:30 am – 12:45 pm
 Chairs: Nathan Gray, PA & Majd Khiami, MD

11:30 am	<p>Emma Wakeling, MBBS, PhD <i>Northeast Thames Regional Genetic Service, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK</i></p> <p>Lessons from UK SAMD9 patients: multisystem evolution including dysautonomia</p>	
11:45 am	<p>Federica Buonocore, PhD <i>Senior Research Fellow, Genetics and Genomic Medicine UCL Great Ormond Street Institute of Child Health, London, UK</i></p> <p>Endocrine Manifestations in SAMD9</p>	
12:00 pm	<p>Yuki Yamada, MD <i>Division of Pediatric Endocrinology, Metabolism and Nephrology, Children's Medical Center, Osaka City General Hospital, Osaka, Japan</i></p> <p>Renal manifestations of SAMD9 abnormalities: a case of living-donor kidney transplantation</p>	
12:15 pm	<p>Aline Andrucioni, MD <i>Pediatric Critical Care Fellow</i> & Nathan Serazin, MD <i>Medical Director, TICU Assistant Professor of Pediatrics and Critical Care Medicine, Baylor College of Medicine, Houston, TX, USA</i></p> <p>What can we learn from our patients: SAMD9 case presentation</p>	 
12:30 pm	<p>Serine Avagyan, MD, PhD <i>Assistant Professor, Department of Pediatrics University of California, San Francisco, CA, USA</i></p> <p>Hiding in plain sight: a diagnostic journey for SAMD9L</p>	

Session 4: Immunology / Inflammation **12:45 pm – 1:30 pm**
 Chair: Serine Avagyan, MD, PhD

12:45 pm	<p>Enrico Attardi, MD, PhD <i>Department of Biomedicine and Prevention, University of Rome Tor Vergata, Rome, Italy</i></p> <p>Immunological phenotypes: what can we learn from a prospective cohort</p>	
1:00 pm	<p>Maaïke Kusters, MD, PhD <i>Honorary Associate Professor at UCL Institute of Child Health, Innovation Officer DRIVE GOSH, ESID treasurer, Immunology Department, Great Ormond Street Hospital, London, UK</i></p> <p>Perspectives from an immunologist: Interplay of SAMD9 and infections</p>	
1:15 pm	<p>Filippo Consonni, MD <i>Assistant Professor of Pediatrics at University of Brescia, Italy. MD/PhD candidate at University of Florence, Italy</i></p> <p>Deep immunophenotypic analysis in SAMD9</p>	
1:30 pm	— 30-Minute Break —	

"You Are Not Alone" — Patient Journeys **2:00 pm – 2:20 pm**
 Chair: Michelle Boals, NP

2:00 pm	Michelle, UK: SAMD9 Patient Journey
2:10 pm	Brittany, USA: SAMD9L Patient Journey
2:20 pm	— Thank you and farewell —

Closed Sessions (Parallel) **2:25 pm – 3:30 pm**

<p>Patients Meet Patients <i>Who? For patients and families only - please stay at the same Zoom meeting.</i></p> <p>Facilitators: Nancy Ballinger, BS, Sr. Clinical Program Manager, St. Jude Children’s Research Hospital Patient representatives Nathan & Nancy</p>	<p>Clinical Consensus Guidelines — Kick-off <i>Who? Invited clinical providers only - a separate Zoom link will be sent.</i></p> <p>Facilitators: Taizo Nakano, MD (Denver) and Marcin Wlodarski, MD, PhD (Memphis)</p>
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Support: Andrea Kennedy • Diantha Van De Vlekkert
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