



AGSD

ASSOCIATION FOR GLYCOGEN
STORAGE DISEASE

Sheraton

Denver Tech Center

June

20th-21st

47th Annual AGSD Conference

2025

Childrens' Activity Room

1:30 pm – 6:30 pm on Friday, June 20, 2025

9:30 am – 4:00 pm on Saturday, June 21, 2025

Open to children 12 years old and under (at parent's discretion)

Kids' room will be **CLOSED FOR ALL MEALS**

Located in the “Evans Room”

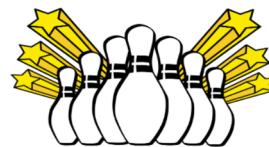


This is our very first
CME Conference!

Check the schedule as all
sessions marked with a
STAR will count as a CME
credit!



Pindustry



We are excited to share that our
Saturday evening event will be held at the
Pindustry.

Buses will be transporting all those
wanting to participate and will leave from the
hotel lobby at two times: 5:30 and 5:55 pm.

Dinner will be served at the location,
and we have an entire area reserved for
AGSD participants! This will include
bowling, darts, cornhole, billiards and much
more *for all ages!*

Program Outline, AGSD Conference 2025, Denver, CO

Ballroom	Columbia	Bierstadt	Evans	Pikes Place (9 th FL)
Friday, June 20, 2025				
9:00am	Registration (Open until 12:00 pm in hotel lobby)			
11:00 am	Poster Session			
12:00 pm	Welcome / Vendor Introductions			
12:30 pm	Lunch			
1:30 pm	GSD Reflections on returning to Denver David Weinstein, MD, MMSc			*Kids' Room is open
2:30 pm	Drug Development (pre-clinical to clinical) – Patrick Ryan, MD	Danon Disease (GSD IIb) – an emerging GSD success story – Matthew Taylor, MD, PhD	New Parent Panel – Moderated by Monica Boyer, CPN	
3:30 pm	Adult Management of GSD – Julieta Bonvin Sallago, MD, MS	Emergency Letters / Emergency care – Rebecca Riba-Wolman, MD	Quality of life Research – AGSD-UK – Flo Kinnafick, PhD	
4:30 pm	Glycogen Storage – A hepatologist perspective – Kadakkal Radhakrishnan, MD, MRCP (UK), MRCPCH, FAAP	Student Accommodations – IEP / 504 Plans – Beth Sherman, LMSW	Family planning & pregnancy with GSD Pannel – Moderated by David Weinstein, MD, MMSc	
5:30 pm	Kidney complications and surveillance in GSDI – David Rodriguez, MD	CGM usage in GSD - Monica Boyer, CPN	Teen Breakout – Nutrition (Teens only) – Heather Saavedra, MS, RD, LD and Malaya Mount, MS, RD, CDN	
6:30 pm	Dinner & Business Meeting ***Breakout by GSD Type after Dinner***			

Program Outline, AGSD Conference 2025, Denver, CO

Saturday, June 21, 2025				
8:00 am	Breakfast			
9:30 am	Gene Therapy and Type III – Giuseppe Ronzitti, PhD 	Managing GSD Across Diverse Cultural and Socioeconomic Contexts – Laura Duque-Lasio, MD, FACMG 	GSD Exercise & Health Panel – Moderated by Damian Cohen, MD	*Kids’ Room is Open
10:30 am	Ketotic Hypoglycemia in GYG1 – Related GSD Benjamin Cocanougher MD, PhD 	Dietitian Panel For types: II, III, IV, V, VI, VII, IX & rare types	Dietitian Panel for GSD Types 1A & 1B	
11:30 am	GSD Value Project – Terry Derks, MD, PhD 	GSD Type VI & IX pre-clinical and clinical updates – Rebecca Koch, PhD, RDN 	GSD Women’s Support Group (GSD women only) Monika Williams, MD Beth Sherman, LMSW	
12:30 pm	Lunch			
2:00 pm	GSD Biomarkers – Monica Boyer, CPN 	Nutrition in late onset Pompe – Rebecca Koch, PhD, RDN 	Service Dogs for Hypoglycemia – Ashley & Emilee Rivera	*Kids’ Room is Open
3:00 pm	Ultragenyx Trial Update – Rebecca Riba-Wolman, MD	Medicaid 101 – Josh Norris, JD 	Teen Breakout – Trivia & Games (Teens Only) Monika Williams, MD and Julieta Bonvin Sallago, MD, MS	
4:00 pm	Group Photo			
Leaves at 5:30 & 5:55 pm Returns at 8:45 & 9:00 pm	Leave for Community Event We will have two (2) buses making two (2) trips to the Pindustry to drop off participants and again later that evening for participant pickup. <i>Location is only 1.5 miles away</i>			

We are pleased to announce our
2026 Conference will be held in...



Please take our survey!



Your feedback really helps us!

Our 2025 Conference group photo
will be taken at
4:00 pm on Saturday evening



Location
to be announced

Don't forget to turn in your
completed Vendor passport at the
AGSD Merchandise Store for your
free conference pin!



*** While Supplies Last ***

This is our first CME Conference!

CME Lectures are marked with a 

CREDIT DESIGNATION:

The Medical University of South Carolina designates this live activity for a maximum of 9.00 AMA PRA Category 1 Credit(s)[™].

Physicians should claim only the credit commensurate with the extent of their participation in the activity.

Nurses: Most states accept CMEs that apply to a specific nursing specialty as nursing continuing education. Please check with your respective State Board of Nursing to ascertain the equivalent number of contact hours offered for 10.00 AMA PRA Category 1 Credit(s)[™].

ACCREDITATION:

The Medical University of South Carolina is accredited by the Accreditation Council for Continuing Medical Education (ACCME) to provide continuing medical education for Physicians.

DISCLOSURE STATEMENT:

In accordance with the ACCME Standards for Integrity and Independence in Accredited Continuing Education anyone involved in planning or presenting this educational activity will be required to disclose any financial relationships with any ineligible companies. An ineligible company is any entity whose primary business is producing, marketing, selling, reselling, or distributing healthcare products used by or on patients. This information is listed below. Any financial relationships with these ineligible companies have been mitigated by the MUSC Office of CME. Speakers who incorporate information about off-label or investigational use of drugs or devices will be asked to disclose that information at the beginning of their presentation. The following information has been disclosed.

Thanks to everyone who participated in making this conference a success!

AGSD Officers

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Areeg El-Gharbawy, MD, DSc

Kadakkal Radhakrishnan, MD

David Rodriguez, MD

2025 AGSD Conference Speakers

David Weinstein MD, MMSc

Patrick Ryan, MD

Market Medical Director, Hospital Medicine
Piedmont Medical Center, Rock Hill, SC

Matthew Taylor, MD, PhD

Monica Boyer, CPNP

Metabolic Nurse Practitioner
Children's Hospital of Orange County (CHOC)

Julieta Bonvin Sallago, MD, MS

Connecticut Children's
University of Connecticut

Rebecca Riba-Wolman, MD

Assistant Professor of Pediatrics
University of Connecticut School of Medicine
Division of Endocrinology Connecticut
Children's Medical center

Flo Kinnafeck, PhD

**Kadakkal Radhakrishnan, MD, MRCP (UK),
MRCPCH, FAAP**

Beth Sherman, LMSW

Clinical Associate Professor
University of Michigan School of Social Work

David Rodriguez, MD

Heather Saavedra, MS, RD, LD
Associate Professor
UTHealth- McGovern Medical School

Malaya Mount, MS, RD, CDN
Sr. Research Dietitian
Connecticut Children's & UCONN Health

Giuseppe Ronzitti, PhD
INSERM U951 and Genethon

Laura Duque-Lasio MD, FACMG

Damian Cohen, MD
Medical Director - Director of Glucolatino
LATAM GSD Community

Benjamin Cocanougher, MD, PhD

Terry Derks, MD, PhD
University Medical Center Groningen

Rebecca Koch, PhD, RDN

Monika Williams, MD

Josh Norris, JD
Attorney
Law Office of Joshua H. Norris, LLC

2025 Poster Abstracts

Qualitative Interviews to Characterize Disease and Treatment Burden at Baseline in Adult and Pediatric Patients Participating in a Pivotal Phase 3 Trial of DTX401 for the Treatment of Glycogen Storage Disease Type Ia

Richard Collis, Diane M. Turner-Bowker, Shayna Egan, Jessica Butler, John J. Mitchell

Ultragenyx Pharmaceutical Inc.

Burden of Navigating the Healthcare System on People and Families Living with Glycogen Storage Disease Type Ia (GSDIa) and Their Care Team

Malaya Mount, Adam Diamond, Tristan Di Maro, Jose Marrero, Chad Ward, Anne Blake, Elizabeth Dorn, Kristin Voorhees, Priya S. Kishnani

Connecticut Children's Medical Center

Healthcare Resource Utilization Among Pediatric and Adult Patients with Glycogen Storage Disease Type Ia (GSDIa): A Case Series from the GSDIa Odyssey Natural History Study

Kristin Voorhees, Manpreet K. Sidhu, Erru Yang, Omid Khazaie Japalaghi, Daniel Garcia

Ultragenyx Pharmaceutical Inc.

Lessons Learned from the Rare Genomes Project's Prevalence Study of GBE1-Related Disease

Rebecca L. Koch, Matthew Morgan, H. Orhan Akman, Jennifer Orthmann-Murphy, Qing Lu, Samantha Baxter, Natacha Pires

Duke University School of Medicine

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THE CHILDREN'S FUND FOR
GLYCOGEN STORAGE DISEASE RESEARCH



SOPHIE'S HOPE
FOUNDATION

