



Spring 2026

# THE RAY

The Association for Glycogen Storage Disease

## The Conference Edition

June 19 -20 , 2026

Dear AGSD Community,

It is with great enthusiasm that the AGSD Board of Directors and I invite you to join us for the 2026 AGSD Annual Family & Scientific Conference, taking place June 19–20, 2026 in Cleveland, Ohio. This year holds special meaning for me personally—Cleveland is my hometown, and it is also home to the worldrenowned Cleveland Clinic, where many individuals with GSD receive exceptional care. Hosting our conference here feels both fitting and deeply meaningful.

Each year, this gathering brings together families, adults living with GSD, clinicians, researchers, and industry partners who share a commitment to improving lives and advancing knowledge. Our time together is always a powerful reminder of the strength and resilience within our community.

For 2026, we are excited to offer a program designed to inform, empower, and connect:

**Clinical & Scientific Insights:** Presentations from leading experts on emerging research, evolving standards of care, and innovations across all types of GSD.

**Interactive Workshops & Panels:** Opportunities to learn practical strategies, ask questions, and engage directly with specialists and peers.

**Community Connection:** Dedicated spaces and social events that encourage conversation, shared experiences, and relationshipbuilding.

**Advocacy & Inspiration:** Sessions that highlight the voices, stories, and leadership of our GSD community.



We recognize that attending a national conference requires planning and resources. To support broad participation, financial assistance is available, and we encourage anyone who may benefit to apply.

Whether you are newly navigating a diagnosis, seeking updated clinical information, or returning to reconnect with familiar faces, your presence enriches our collective experience. Every attendee contributes to the knowledge, compassion, and momentum that define AGSD.

Please take a moment to review the accompanying newsletter for details on registration, agenda highlights, and accommodations. If you have questions, our team is always available at [conference@agsdus.org](mailto:conference@agsdus.org).

Thank you for your continued dedication to our mission. I look forward to welcoming you to Cleveland—my hometown—and to another year of learning, connection, and progress together.

Warm regards,

**Kim Burney**

President, Association for Glycogen Storage Disease

# Hotel

## Holiday Inn Cleveland - S Independence

6001 Rockside Rd  
Independence OH 44131  
(216) 524-8050

**Special group pricing of \$134USD for either a King or 2 Double bed room is provided for the AGSD book with link or call reservations and use code : AGSD. Deadline for group rate in May 30, 2026.**



**to BOOK NOW visit AGSDUS.org/agsd-Conference for our link, or Scan QR Code.**



Amenities include an indoor pool, fitness center, and an in hotel restaurant.

**Other near by hotels :** Candlewood Suites, SpringHill Suites, Red Roof Inn.

# Transportation

To get from Cleveland Hopkins Airport (CLE) to The Holiday Inn in Independence, Ohio, you'll likely take I-71 South, a relatively short drive (around 15-20 mins depending on traffic), using either a taxi/rideshare, rental car, or the RTA train.



# Membership & CME Updates

Membership is Included in Registration  
Once again this year.

We are proud to offer approximately **13 CMEapproved sessions for healthcare providers.** These sessions are designed to deliver highquality, evidencebased education across a range of GSDrelated topics.

A CME representative from Medical University of South Carolina, will be onsite throughout the conference to support the CME process, assist with documentation, and answer any questions from attendees.

**<https://agsdus.org/Member-benefits> to become a member today**



# 145

## People currently registered for the 2026 AGSD Conference and counting...

# Registration

**Registration is now open, visit:  
<https://agsdus.org/conference>  
to REGISTER NOW!**



Our goal is always to simplify our registration process as much as possible. When registering, please note the following:

- Each person, no matter what age, attending must be registered individually.

### Registration fees are as follows:

- Adults (ages 18 and older) \$140
  - This includes AGSD membership (July '26 - June '27)
- Junior (ages 11-17) \$90
- Child (ages 4-10) \$45
- Infant (ages 3 and under ) \$0
  - free, however please still register so we can maintain a headcount for meals and childcare

Scan the QR code to register NOW  
Questions about registration?  
Message us on Facebook - or -  
Email: [Conference@agsdus.org](mailto:Conference@agsdus.org)



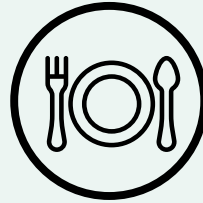
# Financial Assistance

- If you are a current AGSD member, financial assistance is available .
- Assistance is available through an application process. If approved, a hotel stay for two (2) nights will be covered for your family.

**To fill out a financial assistance application scan the QR code here, or find the link at [www.agsdus.org/agsd-conference](http://www.agsdus.org/agsd-conference)**

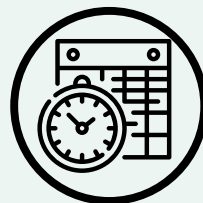


## Your Registration Includes:



***FIVE MEALS***

***Group Event & Transportation***



***A Two-Day Program***

***Childcare***



***Access to GSD physicians & professionals***

***Estimated value of over \$500 per person***

# Win a 2 night stay !

The deadline to enter the raffle for a free two-night stay during the conference has been extended!



## REGISTER FOR THE CONFERENCE BY APRIL 26,

All registered attendees will be automatically entered into a drawing where two winners will each receive a complimentary twonight stay at the conference hotel during the event.

Winners will be selected and announced on Monday, April 27.

If you are already registered, you're already entered. Good luck!

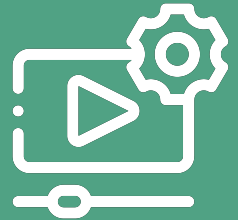
# Things to Do

Planing out your trip while in Cleveland?  
Check out our list of things to do!

- Cleveland Metroparks Zoo*
- Cleveland Museum of Natural History*
- Greater Cleveland Aquarium*
- Holden Forest & Gardens*
- Rock & Roll Hall of Fame*
- Six Flags / Cedar Point*
- Great Lakes Science Center*
- Goodtime 3, Sightseeing Cruise*

# Conference Videos

Great news! Just like last year, we'll be recording many of our conference talks and sharing them on our website and YouTube channel. In the meantime, feel free to explore our YouTube channel and catch up on any sessions from last year that you might have missed!



# Patient Advocacy Groups

We are excited to confirm that Sophie's Hope, The Children's Fund for Glycogen Storage Disease Research & the GSD III Foundation will return for this years conference. Others are still in the works and hope to have more confirmed soon!



# Program Details

	FRI 6/19	SAT 6/20
8 a.m.		Breakfast
9 a.m.	Registration	
10 a.m.		Program
11 a.m.	Program	
12 p.m.	Lunch	Lunch
1 p.m.		
2 p.m.		Program
3 p.m.	Program	
4 p.m.		
5 p.m.		Event
6 p.m.	Dinner	
7 p.m.		



**Our conference agenda is always evolving!**

**For the most up-to-date version, visit our website**

We are working diligently to provide new topics and speakers for both general GSD subject matter and research for specific Types. Here are a few of the confirmed topics we are excited to share with you so far



- The Pathology of GSD
- Emergency / Sick Day Management
- Pompe Update (GSDII)
- Bone Health for GSD
- Hearth Health for GSD
- Impact of Gene Therapies that use AAV
- GSD Type IX / VI update
- Transitional Care in Genetic Medicine
- Disordered Eating
- Mental Health for Rare
- Entering Puberty / Adulthood with GSD
- Service Dogs for Hypoglycemia
- Grocery shopping for GSD
- Ultragenyx Trial Update
- Beam Trial Update



- Womens Group
- Mens Group
- Dietitians Panel
- Teen Breakout - Fitness
- Teen Breakout - Independence
- Participating in a Clinical Trial Q&A
- Traveling with GSD
- Working with GSD



Terry Derks, MD, PhD  
 Monica Boyer, CPNP  
 Neena Champaigne, MD  
 Julieta Bonvin Sallago, MD, MS  
 Priya Kishnani, MD  
 Diva De Leon-Crutchlow, MD  
 Jeremy Do Cao, MD

Claudia Soler-Alfonso, MD  
 Lauren Ayr-Volta, PhD  
 Rebecca Riba-Wolman, MD  
 Monika Williams, MD  
 Heather Saavedra, MS, RD, LD  
 Kadakkal Radhakrishnan, MD  
 Antoine Gardin, MD



# Saturday Evening Event

We are excited to announce our group event will be held at **Top Golf - Cleveland** - Located a mile from the conference location. Transportation to event will be available for attendees without vehicles or who do not wish to walk. The AGSD has reserved a private area for our group which will include dinner on site. Our reserved area includes many golf bays, as well as a large private patio area with lawn games - perfect for the whole family, We think this will be a great event and a wonderful opportunity to spend time with those you have met during the conference!

[topgolf.com/us/cleveland](http://topgolf.com/us/cleveland)



CHECK IT OUT



## Childcare

We are happy to share that Elegant Event Sitters, Inc. will be returning to provide childcare at this year's conference! They have supported our community in both Minneapolis and Denver, and their team has shown exceptional understanding of the unique needs of our families. We are grateful for the care and professionalism they bring each year, and we hope you've enjoyed having them as part of the conference experience.

The Childcare room is available for your children to play during ALL program times , both Friday and Saturday



To ensure we reserve the right amount of staff and supplies, please remember to register your child(ren). Even though 3-year olds and under are free, please still register them separately so we have an accurate headcount and can estimate the amount of staff we will need.

# Shop the AGSD Store

AGSD 2026 Conference shirts are available for order NOW!

\*\*Conference pick up available



Order Today!



<https://agsdus.itemorder.com>



# Donations

Thank You for Fueling Our Mission  
The Association for Glycogen Storage Disease (AGSD) is a fully volunteer-run organization. Every program we offer — including our annual conference — is made possible through the generosity of donors like you. We simply couldn't do this work without your support. With heartfelt appreciation, we thank the following for their recent donations:

- R Michael Hoffmann*
- Matt Legrow*
- Knights of Columbus*
- Sacramento Regional Community Foundation (in memory of Jennifer Kuttner)*
- Diller Nursery*
- Mary Kay McNicholas*
- Barbara Heftler*  
*(in memory of her daughter Rachel Zareski Watts)*
- Kate Sullivan*
- Helen & Jon Burney*

Your contributions help us connect families, empower patients, educate clinicians, and advance research — all while keeping our events accessible and inclusive.

Thank you!

# News & Updates



Don't miss out on current GSD updates. Stay up to date on any news regarding clinical trials, articles and more in the "News" section of our website !

<https://agsdus.org/news-and-articles>

