



The 7th INTERNATIONAL
**GLYCOPROTEINOSSES
CONFERENCE**
TOGETHER WE ARE STRONG

AUGUST 7TH-9TH, 2025
GRADUATE
BY HILTON HOTEL



WELCOME TO MINNEAPOLIS

TOGETHER WE ARE STRONG

ISMRD is delighted to introduce you to its 7th International Glycoproteinoses Family and Scientific Conference, to be held in the lovely city of Minneapolis. We hope to see you there, making the most of three days of information-gathering, networking, making new friends and greeting old ones.

The theme of our conference is "Together We Are Strong". This is in keeping with ISMRD's Mission of seeking to detect and cure the Glycoprotein Storage Diseases, and to provide a global network of support and information, **through partnerships built with medicine, science and industry**. We have always known that working together is our greatest strength.

During these three days, families, patients, doctors, researchers and pharmaceutical companies will work together to strengthen our community and our common goals. New partnerships will be forged, the seeds of new plans and strategies will be sown, new attachments formed. Coming together during this conference will help us to become even stronger!

Our last conference was held in Atlanta, Georgia in 2019. We prefer to have conferences more frequently than that, however, COVID intervened to create chaos for the whole world, including that of non-profit organizations, doctors, researchers, and of families with a member with one of our diseases. In fact, we sadly lost several of our children to COVID or its after effects. Many of our children have fragile lungs, and COVID can be devastating for them. We also lost to COVID the much loved mother of two children with Mucopolipidosis. Our hearts go out to those families.

ISMRD was further affected in late 2020 when five board members left ISMRD to start CureML, an organisation dedicated to finding a cure for Mucopolipidosis. We welcome their initiative and their hard work to find a cure for Mucopolipidosis, and congratulate them on their progress towards a gene therapy for this terrible disease. ISMRD has found its feet, and developed a Board that is stronger, representing more continents globally and more of our nine diseases than ever before. Our founder, Paul Murphy, has once again become involved with ISMRD, praising its current progress and direction.

In Minneapolis, for the first time ever, we have speakers on all nine of the Glycoproteinoses. This is a step forward to inclusivity of all our diseases, and for awareness-raising for even the rarest of our diseases.

We will also have a session where the families and speakers related to each particular disease can get together and talk about that disease in an informal forum. We know from experience that families, doctors and researchers all enjoy such an opportunity. Being a bereaved Fucosidosis parent, I love the chance to talk with other Fucosidosis parents, and the researchers.

So, please relax, listen, learn, meet, and enjoy!

Carolyn Paisley-Dew
PRESIDENT ISMRD

CONFERENCE VISION

CONFERENCE ABSTRACT

Glycoprotein Storage Diseases are very rare, progressive, largely untreatable metabolic enzymatic defects inherited by children from both parents. The worldwide incidence for these diseases as a group has not yet been determined accurately, though they can certainly be classified as ultra-rare. The course of these disorders affects multiple systems of the body and clinical symptoms may vary patient-to-patient, and even among siblings. For most children the implications are eventual loss of mental and physical functions, and a premature death.

As the name implies, glycoproteins are complex compounds composed of a protein and a carbohydrate. There are many different types of glycoproteins and they are found in abundance in all kinds of cells, including those of the brain. Glycoproteins play many roles in cells; some of these are well known, but others have yet to be discovered. Known roles include acting as an agent for communication between cells and assisting in maintaining the cell's structure. The carbohydrate portion of glycoproteins is usually made of combinations of sugar molecules such as glucose, galactose, mannose and fucose, which are collectively known as oligosaccharides.

THE FOLLOWING DISEASES ARE SUPPORTED BY THE CONFERENCE:

Alpha-Mannosidosis
Fucosidosis
Mucopolidosis III Gamma

Aspartylglucosaminuria
Galactosialidosis
Schindler Disease

Beta-Mannosidosis
Mucopolidosis II, II/III, III alpha/beta
Sialidosis (Mucopolidosis I)

ABOUT ISMRD

ISMRD is the International Advocate for Glycoprotein Storage Diseases and is a 501(c)3 not for profit based in the United States. It has an international Board of Directors and an International Professional Advisory Board.

ISMRD is the leading advocate for families worldwide affected by a Glycoprotein Storage Disease. Through partnerships built with medicine, science and industry, we seek to detect and cure these diseases, and to provide a global network of support and information.

ISMRD is a community made up of clinicians, professionals and families united by a common interest in the ongoing dialogue between the scientific and clinical communities with the aims:

- to bridge the gap between the family, clinical and scientific communities
- to foster research and development in basic and clinical science and its application to healthcare
- to provide international forums for science in medicine, biology, and other industry hot topics
- to promote communication and understanding about cutting-edge developments

CONFERENCE DESCRIPTION

DATE

August 7-9, 2025

VENUE

[Graduate by Hilton Hotel](#)

615 Washington Avenue SE

Minneapolis MN 55414

PHONE: +1 (612) 379-8888

ISM RD CONFERENCE COMMITTEE

Carolyn Paisley-Dew, Australia | Danielle Forsman, USA | Sarah Forsman, USA

CONFERENCE WEBSITE

<https://www.ismrd.org>

CONFERENCE PROGRAM

The program will feature keynote presentations by International and national speakers. There will be disease related workshops where those who are presenting in the Scientific program will be encouraged to join the family workshops where the speakers have an interest. We'll kick off with a keynote presentation from Chester B Whitley, PhD, MD, Advanced Therapies Program, University of Minnesota, Minneapolis, MN, USA

CONFERENCE SCIENTIFIC ADVISORY COMMITTEE

Marc C Patterson, MD | Chester B Whitley, PhD, MD | Alessandra d'Azzo, PhD | Charles H Vite, PhD
Richard Steet, PhD | Jeanine Jarnes, PharmD | Karolina M Stepien MD, PhD

NETWORKING OPPORTUNITIES

We are committed to ensuring that every opportunity is given for networking among the sponsors, professionals, families and their children. The opportunities for networking include:

WELCOME RECEPTION:

Thursday, August 7 • 6:00pm-8:00pm

AWARDS DINNER:

Saturday, August 9 • 6:00pm-7:00pm **Reception**, 7:00pm-9:30pm **Gala Dinner**

DAILY NETWORKING OPPORTUNITIES :

- Breakfast & Lunch Buffets
- Dedicated Poster Viewing Sessions at Coffee breaks.

ATTENDANCE

It is anticipated that approximately 200 delegates will attend.

CONFERENCE MARKETING AND ENGAGEMENT

The Key Conference marketing and engagement opportunities will include the website, the mobile app, the final program, onsite signage and delegate materials. Sponsors will be profiled in selected publications depending on their level of support.

SPONSORSHIP LEVELS*

PLATINUM SPONSOR: \$35,000

6 conference registrations

6ft table display in main break area

Verbal recognition during opening and closing remarks

Premium logo placement on all pre-event advertising materials, event website, registration confirmation email, Know before you go email

Your logo on all onsite signage and the conference looping deck

Branded Conference lanyards

Welcome Reception Sponsorship- additional signage throughout and verbal recognition

Reserved premium table at awards Program on Saturday evening

Up to (4) Virtual Bag inserts in the Conference App

GOLD SPONSOR: \$25,000

4 conference registrations

6ft table display in main break area

Verbal recognition during opening and closing remarks

Your logo on all pre-event advertising materials, event website, registration confirmation email, Know before you go email

Your logo on all onsite signage and the conference looping deck

Up to (3) Virtual Bag inserts in the Conference App

SILVER SPONSOR: \$15,000

2 conference registrations

6ft table display in the main break area

Your logo on all pre-event advertising materials, event website, registration confirmation email, Know before you go email

Your logo on all onsite signage and the conference looping deck

Virtual Bag insert in the Conference App

COPPER SPONSOR: \$10,000

2 conference registrations

6ft table display in the main break area

Your logo on all pre-event advertising materials, event website, registration confirmation email, Know before you go email

Your logo on all onsite signage and the conference looping deck

BRONZE SPONSOR: \$5,000

1 conference registration

6ft table display in the main break area

Your logo on all pre-event advertising materials, event website, registration confirmation email, Know before you go email

Your logo on all onsite signage and the conference looping deck

* All Sponsorships include a 6ft table display which can feature medical research, or patient advocacy initiatives. Please contact ISMRD for details on commercial booths.

INDIVIDUAL OPPORTUNITIES

| | | |
|---|---|-----------------------------------|
| TABLE TOP | For those who want a presence to interact with the ISMRD community Includes 1 6ft table display in the main break area. | \$2,000 |
| HOTEL KEY CARDS | Given to each attendee at hotel check in | \$5,000 |
| NOTEBOOK W/PEN | Your logo printed on selected notebook, provided to all attendees | \$7,500 |
| CUSTOM TENSION STANDS | Strategically placed throughout the meeting space | \$3,500 |
| COFFEE BREAK SPONSORSHIP | Branded cups and signage at Friday & Saturday Coffee Breaks | \$10,000 |
| WI-FI | Custom password to sign into the mobile app and custom Wi-Fi related signage | \$7,500 |
| MOBILE APP: | The Conference Mobile app is the center of the attendee experience. Your logo will appear on the splash page at sign in and include one rotating banner ad. | \$7,500 |
| MOBILE APP BANNER AD: | Will rotate through the app | \$3,000 (LIMITED TO 3) |
| CONFERENCE BAG | logo on one side of conference tote bag | \$10,000 |
| CONFERENCE BAG FILLERS | Custom swag placed in the conference bag. Privilege only, all production and shipping costs are at the sponsors expense. Item approval required; suggestions include Post-it notes, pins, hand sanitizer, tissue packets etc. | \$1,500 |
| VIRTUAL BAG INSERT IN MOBILE APP | PDF flyer added to Mobile app | \$500 |

Custom sponsorships available.

Please reach out to Amanda Thomas at athomas@etherio.com to discuss additional opportunities.

ACCOMMODATIONS

GRADUATE BY HILTON MINNEAPOLIS HOTEL

Discover Graduate by Hilton Minneapolis, where Gopher traditions and local legends blend with creative interiors and college nostalgia. Located in the heart of the University of Minnesota campus the hotel is perfect for exploring the Twin Cities. Enjoy Minnesota inspired guest rooms and an all-day bar and restaurant.

A block of rooms has been reserved at the Graduate by Hilton Minneapolis for August 7-10 2025 for attendees of the 7th International Glycoproteinases Conference. The Room rate is \$199 per room, per night plus taxes and fees and is available 3 nights pre or post program based on hotel availability. Please contact the conference organizers for booking information.

Conference Highlights: Together We Are Strong

- **Conference Key Note Speaker Chester B. Whitley, PhD, MD**
Advanced Therapies Program University of Minnesota,
Minneapolis, MN, USA
- **Poster Sessions**
- **Scientific Sessions**
- **Family Sessions**
- **Childcare Program**
- **Welcome Reception**
- **Memorial Service**
- **Gala Dinner**

Things to do in and Around Minneapolis :

- **Chain of Lakes Regional Park**
- **Minnehaha Falls Regional Park**
- **Minneapolis Sculpture Garden**
- **Mall of America**
- **Minnesota Zoo**



REGISTRATION RATES

REGISTRATION FOR ISMRD AUGUST 7-9 2025 CONFERENCE MINNEAPOLIS, MN

EARLY BIRD RATES CLOSE MAY 31ST 2025

| | EARLY BIRD REGISTRATION BEFORE MAY 31 ST 2025 | REGISTRATION JUNE 1 ST - JULY 31 ST |
|---|---|--|
| PARENTS OF AFFECTED CHILDREN | \$180 | \$205 |
| AFFECTED CHILD/PERSON | \$0 | \$0 |
| UNAFFECTED CHILD (0-3YRS \$0) | \$100 | \$115 |
| OTHER ADULTS (RELATIVES, CAREGIVERS, AND FRIENDS) | \$275 | \$325 |
| STUDENTS/JUNIOR DOCTORS: | \$325 | \$375 |
| NON-PROFIT ORGANIZATION REPRESENTATIVE | \$350 | \$400 |
| PROFESSIONALS (SCIENTISTS, PHYSICIANS) | \$450 | \$520 |
| BIO-TECH & PHARMA COMPANIES (INDUSTRY) | \$550 | \$600 |
| ON DEMAND ACCESS* *On Demand access will be available post conference and can be added to in-person registration or as a virtual option | \$75 | \$75 |

SPONSORSHIP SIGN UP

Use this form to officially request your sponsorship level.

Company Name: _____

(As it should appear on all conference materials)

Primary Contact Name: _____ Primary Contact Phone: _____

Primary Contact E-mail: _____

PLEASE SELECT SPONSORSHIP LEVEL

| | | |
|--------------------------|----------------|----|
| <input type="checkbox"/> | PLATINUM LEVEL | \$ |
| <input type="checkbox"/> | GOLD LEVEL | \$ |
| <input type="checkbox"/> | SILVER LEVEL | \$ |
| <input type="checkbox"/> | COPPER LEVEL | \$ |
| <input type="checkbox"/> | BRONZE LEVEL | \$ |

PLEASE SELECT INDIVIDUAL ADD ONS

| | | |
|--------------------------|----------------------------------|----|
| <input type="checkbox"/> | TABLE TOP | \$ |
| <input type="checkbox"/> | HOTEL KEY CARDS | \$ |
| <input type="checkbox"/> | NOTEBOOK W/PEN | \$ |
| <input type="checkbox"/> | CUSTOM TENSION STANDS | \$ |
| <input type="checkbox"/> | COFFEE BREAK SPONSORSHIP | \$ |
| <input type="checkbox"/> | WI-FI | \$ |
| <input type="checkbox"/> | MOBILE APP BANNER AD: | \$ |
| <input type="checkbox"/> | MOBILE APP BANNER AD: | \$ |
| <input type="checkbox"/> | CONFERENCE BAG | \$ |
| <input type="checkbox"/> | CONFERENCE BAG FILLERS | \$ |
| <input type="checkbox"/> | VIRTUAL BAG INSERT IN MOBILE APP | \$ |
| <input type="checkbox"/> | CHILDREN'S PROGRAM | \$ |

Please make checks payable to ISMRD. Company name must appear on check.

(Please type or print.) Name of Signee: _____ Title: _____

Signature: _____ Date: _____

I am an authorized representative of the Company named above with the full power and authority to sign and execute this agreement. By signing, the Company agrees to abide the Terms and Conditions contained in the agreement. The agreement becomes valid after the executed agreement is confirmed and issued by ISMRD.

Or Complete Application and send via email to: Amanda Thomas at athomas@etherio.com

PAY BY CREDIT CARD: [Click here to complete this form](#)

PAY BY CHECK: Mail application form along with payment to:

ISMRD
P.O. Box 683
Turnersville, NJ 08012

