



## ISMRD Annual Report 2025

*The International Advocate for Glycoprotein Storage Diseases*

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### Our Mission

The International Society for Mannosidosis and Related Diseases (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.

### Our Vision

We seek a future in which children with Glycoprotein Storage Diseases can be detected early, be treated effectively, and go on to live long, healthy and productive lives.

### Board of Directors (All non-salaried)

Jennifer Jackson	President	USA
Abby Lindenberg	Vice President	USA
Danielle Forsman	Treasurer	USA
Nathan Hubbard	Secretary	USA
Darko Jamnik	Board Member	Slovenia
Laurel Gregier	Board Member	USA
Lama Khalil	Board Member	Saudi Arabia
Tareq Qashou	Board Member	Saudi Arabia
Cagdas Canbolat	Board Member	United Kingdom
Erin Hubbard	Board Member	USA
Fernando Fernandez	Board Member	USA

*The ISMRD Board represents three continents and six of the nine Glycoproteinoses.*

## ISMRD Professional Advisory Board (All non-salaried)

Richard Steet	USA	Sara Cathey	USA
Steve Walkley	USA	Dag Malm	Norway
Alessandra d'Azzo	USA	Charles Vite	USA
Marc Patterson	USA	Amelia Morrone	Italy
Thomas Braulke	Germany	Vish Koppaka	USA
Enrico Moro	Italy		

Our Professional Advisory Board is an important source of scientific and medical advice and information for the Board and the President. We would like to thank each and every one of the PAB members.

## OUR ACTIVITIES FOR 2025

### Activity 1 ISMRD International Forum

ISMRD hosts The 7th International Family & Scientific Forum in Minneapolis, MN August 8-9, 2025. First time ever live webinar and in-person event with 47 in-person & 129 webinar attendees, 21 speakers with 34 presentations by scientific, medical and patient advocates on all 9 Glycoproteinoses diseases, along with first time 11 research posters presented.

Thank you to all those that sponsored, presented, and attended!

### Activity 2

ISMRD welcomes board member Abby Lindenberg to the Vice President role and welcomes new board member Fernando Fernandez.

### Activity 3

The ISMRD Board of Directors is pleased to announce that John Foreman has been voted into Board Emeritus status in recognition of his longstanding

dedication, leadership, and contributions to the organization and the rare disease community. His commitment to advancing awareness, advocacy, and support for individuals and families affected by glycoprotein disorders has had a lasting impact on ISMRD's mission and growth. We are deeply grateful for his years of service and look forward to his continued connection and guidance as a valued member of the ISMRD family.

#### Activity 4

Two separate ISMRD-Sponsored research studies on Alpha Mannosidosis, one study on "Quality of Life" research conducted by DeltaQuest Foundation Inc. Second study on "Post HSCT Patient Outcomes" research conducted by University of MN lead by Drs Julie Eisergart and Troy Lund.

#### Activity 5

ISMRD launched the 1st Patient Unmet Needs Survey for all 9 Glycoproteinoses diseases. Results shared at Forum, Zebraic Alliance documenting to publish White Paper & submission of NIH Grant application.

#### Activity 6

ISMRD teamed up with MPS UK and Rare Disease Research Partners to create 9 educational pieces for newly diagnosed patients and caregivers of Alpha Mannosidosis; this project will continue through 2026.

#### Activity 7

Carolyn Paisley-Dew Retires from ISMRD Presidency and Board of Directors after 19 years of dedicated service to our rare disease community, Thank You!

## Activity 8

ISMRD welcomed long-time patient advocate and an ISMRD Professional Advisor, Jennifer Klein Jackson, as ISMRD Board President.

## Activity 9

ISMRD gives a heartfelt thanks to Board Members that resigned in 2025. Sarah Forsman, ISMRD Communications Officer and Alpha Mannosidosis patient. Sarah graduated from Rowan University with a Bachelor's Degree in Marketing. She stepped down from her volunteer role as Communications Officer to pursue a new adventure. Board members, Patricia Gribel and Hussain Peeran, also stepped down for personal needs. ISMRD thanks you for your service!

## Fundraising and Donations

### **Giving Season Fundraiser**

ISMRD held a Giving Season fundraiser from November 3, 2025 - December 3, 2025, with a campaign of emails and social media posts on Facebook, Instagram, and LinkedIn. This campaign focused on coming together like our Forum we hosted in August. We focused on encouraging our followers and families to create fundraisers on their social platforms to not only raise awareness of our organization, but to raise awareness that we are building the future together. Throughout the campaign there were many families featured. A few personal stories were featured as well. The campaign raised over \$4,100.

### **Facebook and Instagram Fundraisers**

Facebook offers a very simple and effective way to fundraise for ISMRD. On your birthday, Facebook asks if you would like to hold a birthday fundraiser. Once you say yes, you can nominate ISMRD as your chosen charity, and the rest is easy. This seems to be a fairly new Facebook feature.

## CouponBirds

CouponBirds is a useful and regular fundraiser for ISMRD. Donations are small, but steady, and we hope that they will increase as more of our members begin to utilise CouponBirds. Join CouponBirds [here](#).

## Thank You to Our Donors!

### 2025 Marked over \$15,000 Raised through Personal Donations

Mary Alice Abbot	Linda Bell	Debbie Bruce
Amy Buchanan	Allison Colas	Mary Anne Cuiilty
David Dollins	Bryan Durnan	Leah Fisher
Forsman Family	Denise Fogel	Deborah Glass
Laurel Greiger	Nathan & Erin Hubbard	Darko Jamnik
Terri Klein	Nemanja Krstivojevic	Abby Lindenberg
David Maxwell	Maxwell Forsman Investments	Paul Murphy
Deborah Nagle	Paisley-Dew Family	Jonathan Piller
Joanne Pitt	Rosanti Flowers	Dave & Barb Shields
Alyaa Shmara	Steve & Dianne Smith	Mark Stark
Kathleen Tyree	Margaret White	John Wolfe
Woolley Family	Houtan Yaghmai-Hasti	
All the Unnamed and Anonymous Donors		

We Thank You All!

## Online Presence

### Newsletters

A quarterly newsletter was sent every three months. Other e-blasts were sent out for Rare Disease Day, the 2025 International Forum, condolences for families as loved ones passed away, leadership changes of new board members and others stepping down from their positions, ISMRD-Sponsored Alpha-Mannosidosis Research Study, and a press release for Mucopolipidosis II research projects funded by ISMRD.

## **Social Media**

We created a new YouTube account in September 2025 to host the videos from the 2025 International Forum. Utilization of the public Facebook page and disease pages were maintained.

## **Rare Disease Day Campaign**

On Rare Disease Day there was a social media post and an email that went out. We shared about the importance of this day along with a few rare disease facts and how ISMRD Board Members were celebrating Rare Disease Day.

## **Conferences and Other Development Attended**

2025 WORLDSymposium, San Diego, CA. Board Attendees:

Carolyn Paisley-Dew	Danielle Forsman	Sarah Forsman
Laurel Greiger	Erin Hubbard	

ISMRD's 7th International Family & Scientific Forum in Minneapolis, MN.

Board In-Person Attendees:

Carolyn Paisley-Dew	Abby Lindenberg	Danielle Forsman
Nathan Hubbard	Sarah Forsman	Darko Jamnik
Laurel Gregier	Cagdas Canbolat	Fernando Fernandez

## Financial Statement

Income Statement for the 2025 calendar year  
Statement of Financial Position for year end, Dec. 31, 2025

Attachment A  
Attachment B

## ISM RD CONTACT DETAILS

### Corporate Address:

3150 Almaden Expressway Ste 103  
San Jose, CA 95118  
USA

### Mailing Address:

PO Box 683  
Turnersville, NJ 08012  
USA

E-mail: [info@ismrd.org](mailto:info@ismrd.org)

Website: [www.ismrd.org](http://www.ismrd.org)

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**Income Statement (Profit and Loss)**  
**International Society for Mucopolysaccharidosis & Related Diseases**  
**For the year ended December 31, 2025**

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**Income**

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Income		
Conference Registrations		2,016.27
Conference Sponsors		53,500.00
Consulting Income		1,425.61
Interest Income		6.50
Corporate & Foundation Grants		27,500.00
Grants from other non-profits		1,000.00
Donations directed by Individuals		15,651.73
Donations - Checks	6,000.00	
Donations - PayPal, Facebook & Instagram	7,136.73	
Donations - Website Click & Pledge	3,905.00	
<b>Total Income</b>		<b>101,100.11</b>

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**Gross Profit** **101,100.11**

**Operating Expenses**

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Advertising & Marketing		1,276.21
Charity Registration		30.00
Bank & Merchant Fees		411.39
Gifts & Bereavement Flowers		715.49
Conferences & Meetings		43,211.86
Travel Reimbursement		10,393.31
Legal & Accounting		3,140.00
Liability Insurance		489.46
Office Supplies & Printing		194.46
Membership Fees		153.89
Postage & Shipping		1,292.61
Software & Database		879.20
<b>Total Operating Expenses</b>		<b>62,187.88</b>

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**Net Income** **38,912.23**

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Statement of Financial Position  
International Society for Mannosidosis and Related Diseases  
As of December 31, 2025

DISTRIBUTION ACCOUNT	TOTAL
<b>Assets</b>	
Current Assets	
Bank Accounts	
Business Advantage Sav (5661) - 2	100,006.51
Business Adv Fundamentals - 0576 - 1	14,949.31
<b>Total for Bank Accounts</b>	<b>\$114,955.82</b>
<b>Total for Current Assets</b>	<b>\$114,955.82</b>
<b>Total for Assets</b>	<b>\$114,955.82</b>
<b>Liabilities and Equity</b>	
Liabilities	
<b>Total for Liabilities</b>	
Equity	
Opening balance equity	0.00
Retained Earnings	76,043.59
Net Income	38,912.23
<b>Total for Equity</b>	<b>\$114,955.82</b>
<b>Total for Liabilities and Equity</b>	<b>\$114,955.82</b>

**ISMRD, The International Society for Mannosidosis & Related Diseases,  
a 501(c)(3) nonprofit organization. FEIN 52-2164838**