

Pathways

*The Newsletter for
Glycoprotein & Related
Storage Diseases*



A publication of ISMRD



Hue-Man Project Team

See Page 4
for further
details

Hue-Man Project to Begin Alpha-Mannosidosis ERT Studies!

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The International Advocates for Glycoprotein Storage Diseases

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A US 501 c3 Organization
FEIN #: 52-2164838



Our Mission:

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

From the President's Desk



By John Forman
President ISMRD



In March this year I took over the role of President from the Founder and now Past-President of ISMRD, Paul Murphy. It's about 10 years since Paul started the preliminary work that later grew into ISMRD. It has been my great honour to serve 6 of those years with him on the Board of ISMRD and work through many of the challenges and landmark achievements our tiny organization has made. Work pressure and family commitments had decided for Paul that a change in his commitments to ISMRD was necessary. He will still be with us in some key roles, but with a reduced workload that will enable him to manage the rest of his life too. Our new Executive Director, Terri Klein, has written a tribute to Paul in this issue (following page) so my commentary is a quick summary of key events for ISMRD over the past years, that have been guided and motivated by Paul.

Back then we dared to hope that real progress could be made in understanding and treating our group of diseases. Perhaps logic and realism might have suggested otherwise, but we were filled with optimism and commitment. Progress became possible when the growing support we were able to generate from many scientists and medical specialists who also had an interest, linked up with the good rare disease policy initiatives in the United States and the European Union.

Much faster than we dared hope, funds were found through the EU Rare Diseases Initiative for a major research project on Alpha-Mannosidosis. Just a few years later funds were secured for the first international scientific and family conference on our diseases, hosted by the Office of Rare Diseases and the National Institute for Neurological Disorders and Stroke. For that conference held in 2004 we took the decision, with the advice and support of our scientific and medical advisors, to broaden our constituency to include the Mucopolipidosis diseases, ML2 and ML3, a decision I'm sure all of us agree has been mutually beneficial for all of our diseases and ISMRD as a whole.

From that moment there was less emphasis on the "Mannosidosis and Related" in our formal title, and more focus on the "Glycoprotein Storage" which is the common characteristic that binds us all. We also found new energy and commitment among the ML families, delivering us some very capable parents onto the Board of ISMRD and bringing us our new Executive Director, as well as a strong cadre of families to help our organization.

Within the past few years the rate of knowledge growth on our diseases had been spectacular. Separate studies have identified novel treatments for secondary bone disease in ML and identified risk of psychosis in older children and adults with Mannosidosis. Last year at our family conference we learnt of the discovery of the molecular genetic mutations for ML2 and ML3, opening up exciting new opportunities for research and discovery. In June this year the EU gave a substantial grant to the HUE-MAN collaboration in Europe for natural history studies and enzyme production, prior to a planned clinical trial of enzyme replacement therapy for Alpha-Mannosidosis. None of these great steps forward have been achieved by individuals in isolation. At every step there has been a team effort and collaboration. But every team needs leaders. In Europe much of the leadership has come from Dag Malm, a doctor and a Mannosidosis parent, who has encouraged and cajoled his colleagues into action. In the US it has been Paul Murphy who did so much to galvanize family activity and build ISMRD into the significant international organization it is today.

Taking over the President's role from Paul gives me quite a challenge but it's one I gladly accept. I'm looking forward to more solid progress in the years to come, and to keeping Paul on a short leash so he will still be available to give us the benefit of his many skills and wide experience.

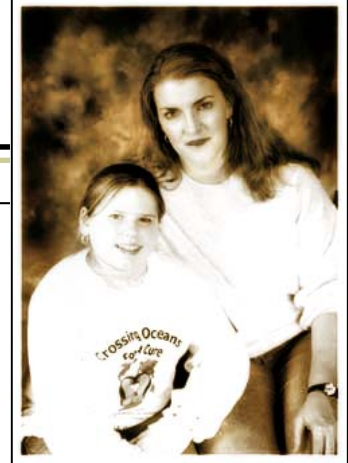
en français

ISMRD's website now has information about the Glycoprotein Storage Diseases available in French! Our undying gratitude goes out to Henry Vivet of France who volunteered to translate this important information for families!

We are looking for others who are interested in translating parts of our website into other languages, as well. Please contact Paul Murphy at webmaster@mannosidosis.org for additional information. Merci! ¡Gracias! Thanks!

The View from Michigan

By Terri Klein
Executive Director ISMRD



Today begins a new road for ISMRD, as our founder and President, Paul Murphy, has decided to step down from his active role on ISMRD's Board of Directors. Paul has exemplified ISMRD's mission and vision everyday through his volunteer efforts and dedication, which began the day his daughter was diagnosed with Alpha-Mannosidosis in 1994. Paul truly lives the words of our organization's mission everyday (see cover page).

I am personally so very thankful for Paul's vision to form ISMRD in 1999 and gather families in uncharted territories as a nonprofit. This vision not only includes families in North America but "crosses oceans for a cure" to encompass anyone anywhere with a Glycoprotein Storage Disease. His guidance, mentoring and professionalism has enabled ISMRD and our current Board of Directors to develop the skills and strength necessary to pursue our objectives.

Many of us would not know each other today, nor have the penguin family we do, if not for Paul and his foresight in recognizing the needs of families with these ultra orphan and related diseases. It is not a miracle that he has had this organization running for this length of time. It is his unwavering commitment to combine good leadership that focused on the needs of affected families. I am certain that Paul is confident ISMRD will continue strong in the future. We are likewise confident that he will continue to provide us the strength of support that he has so humbly undeclared these many years.



Paul & Taryn Murphy

Paul's impact will continue to be felt as he takes on a more "behind the scenes" role, contributing the technical expertise that is visible on the ISMRD website, the Penguin Café, this newsletter & other projects. Much of the photos, layouts and graphic designs you access today are Paul's creations. We are very fortunate to have his commitment to quality side by side with our focus on affected children & advocacy efforts.

Please take a moment to extend your best wishes as he cares for his daughter, Taryn, and takes time to enjoy his family life. If there is one parent who understands the love and needs of their child coping with a disability, it is witnessed through the love that both Paul and Debora Murphy have for their daughter.

To our Founder & Past President, Thank You! We will catch your next act on line, on the Penguin Café or maybe you will surprise us. Thank you Paul for being a strong mentor & showing me that "family" can truly stretch around the world.

Our grateful appreciation to all our supporters who believed in ISMRD enough to contribute financially:

Gregory Arnes, Nancy Barilani, George & Joan Carter, Robert & Denise Crompton, Elizabeth Cunha, Charles & Elizabeth DeVaughn, David Dollins, N. Matthew Ellingwood DVM, Ione English, Faulner Harrisburg, Inc., Glen & Ginger Fenter, Leigh Fontenot & Thomas Groves, Aleasha Garrison, Scott & Colleen Gollinick, John & Brenda Haggett, John & Angela Hunter, Thomas & Karen Kazmir, Daryl & Dorothy Keech, Leo & Arlene Kogler, Arthur & Deborah Leondires, Martin Lutz, Merilee Magnuson, W.M. Marks, Elmer & Bonnie Marine, Mabion & Dorothy Marine, Jimmy & Renea Marine, Richard Melia, Family Fund, Sallie Motomora, Jamie & Kellie Moran, Frank & Dorothy Mueller, Mike & Miranda Nelson, Vince & Tina O'Connell, Michelle Pelna, Joseph & Lori Pietrowski, Sandra Potvin, Robert & Mary Lou Pursley, Dante & Schenita Randolph, Martin & Nancy Rehm, Ricci and Taneff, Attorneys at Law, Sue Shatas, Paul & Shirley Sheaffer, William & Tina Skojec, South Mebane Elementary School, Kevin & Barbara Stielper, Louis & Mildred Stielper, Iva Thommen, William & Nancy Tobey, F. Dave Turnage, Jr., Tyco Funds, William & Ruth Ulrich, Barbara Ward, Wilbur Smith Law Firm, Wade & Trudy Witte, Elwood & Nancy Wylie, XI Delta Epsilon Chapter of Beta Sigma Phi, Friends & Family of Zerillo Gardens



A very special thank you to Jimmy & Renea Marine as they gathered family and friends together for a birthday bash raising funds for research in honor of Austin's 8th Birthday!

Research News from ISMRD

By Terri Klein & Paul Murphy

European Union Provides Funding for Hue-Man Project!



The life-long dream for families of children affected by Alpha-Mannosidosis came closer to reality with the announcement recently that the European Union will grant €2.4 million for research leading to development of a pharmaceutical therapy. The research will be coordinated by Paul Saftig at Christian-Albrechts-Universität in Kiel, Germany. A team of collaborators, known as Hue-Man (*Human Enzyme Replacement Mannosidosis*), are located in Denmark, Belgium, Germany, Norway, the United Kingdom, France and the Czech Republic. Among the contributors are ISMRD's own Dag Malm, a member of our Professional Advisory Board and parent of two daughters with Mannosidosis. Dr. Malm has been on a tireless campaign to unravel the mysteries of the disease since his daughters were diagnosed in the early 1990's, and is the primary catalyst for much of the knowledge that has thus far been accumulated.

Like some other Lysosomal Diseases before it Alpha-Mannosidosis is poised to become the target of Enzyme Replacement Trials and, eventually, a safe, high quality and effective drug. However, much work remains to be done and Dr. Saftig's team, now armed with the financial resources to proceed, will work in earnest towards this eventual goal. To read more about the project and to track its progress, visit the Hue-Man website at <http://www.uni-kiel.de/Biochemie/hue-man/index.htm>. ISMRD will also keep

families informed and will revisit the subject in a more lengthy article in our year-end issue this year. To all of Hue-Man's collaborators on behalf of ISMRD and its families: thank you and best wishes!

Natural History Study Commences for Mucopolipidosis!



Summer 2006 will significantly change the future for Mucopolipidosis as approximately 20 families begin their travel to the Greenwood Genetic Center in South Carolina, following their genetic diagnostic testing results of affected family members. The Greenwood Genetic Center opened their doors to ISMRD to combine gathered data and begin the first ever Natural History Study of patients with Mucopolipidosis II and III.

Dr. Sarah Cathey of the clinic is anxiously awaiting the arrival of affected children and young adults to their facilities. For over 18 months their lab has completed extensive testing on gene mutations of ML II & III. Putting faces to names will be most rewarding from both sides. Dr. Sarah Cathey, has submitted a presentation on Clinical and Molecular Characterization of Mucopolipidosis II and III. The poster presentation is being viewed by peers and physicians in the genetics field around the world.

The evolution of the much needed Natural History Study for Mucopolipidosis will aid the GGC, families and future researchers to better understand the manifestation of ML. ISMRD is currently collaborating with Dr. Cathey and the Center to begin a Natural History Study for all 9 supported ISMRD glycoprotein storage diseases. To the left is a picture of Dr. Sarah Cathey & Jennifer Klein, (ML III) in attendance at The American College of Medical Geneticists, in San Diego, CA this past March.

Songs for Saffy

By *Sonja Woolley*

My mum Margaret, Saffy's Grandma, had been trying to think of a fundraising event for ISMRD for some time. Watching a popular Russian choral group perform at a local arts festival she'd helped to organise last year, she had an idea. If she could persuade the Russian group to return to her home town of Bewdley (a small town in the English midlands) during their 2006 UK tour she was sure she could run a profitable concert to benefit ISMRD. Never one to let the grass grow under her feet, she quickly got the Russians to agree, booked a venue (a local church – great acoustics) and then prayed she'd be able to sell the tickets!

Mum started by ensuring everyone she knew would be attending – she's not an easy woman to say no to (those who couldn't come bought tickets anyway!). Mum and Dad then set up a table outside all the local churches for a few Sundays, correctly guessing that the choral singers would appeal to the regular churchgoers. Finally, Mum persuaded the local newspaper to write a piece about Saffy (complete with cute picture!) and this led to Mum being interviewed by the local radio station.



Saffy & Brother Rubin

Over 200 attended the event – and although I know absolutely nothing about this type of music – even I could tell these were truly gifted singers. The first half was choral music and after the interval they sang Russian folk songs – all of the singing was completely unaccompanied and it was obvious the audience were really enjoying themselves. Saffy also enjoyed the event. I had intended to take her out once the concert got going so she couldn't disturb the singers, but from the first song she sat in delighted silence, heartedly clapping at the end of each piece. At the end she ran to the front of the church to help her Grandad thank the singers – a gesture the audience also seemed to appreciate.

Mum raised over £1500 for ISMRD, and is now considering her next venture. Martin and I, Reuben and especially Saffy want to thank her for all her efforts.

PS: Saffy is now aged 5 and 18 months post a *very* successful transplant for Alpha-Mannosidosis!!



Saffy & Her Grandma

When I put the invitation out there for a family get-together recently, in my wildest dreams I never imagined that that

anyone would want to travel to Chicago in the midst of one of our infamous winters. What I failed to realize is the great lengths our families go through in order spend some time with each other.

It wasn't long before I was taken up on my offer. I received word that the Simpsons who live in Canada wanted to come down for a visit. I was truly overjoyed at the news of seeing Bill and Jen and also my Joey (ML III) and Matthew (ML III) are of the same age and have much in common. The news spread quickly and soon, I received word that the Tices from Florida were also coming. Susan brought Lonnie (ML III), Christopher and Sarah. We were joined by Erica Thiel (MPS 1 Scheie). She took the train down all the way from Milwaukee after receiving her ERT Therapy.

When I asked the families if they wanted to sightsee or do something particular, the response was that they just wanted to sit and visit, and so that's what we did. In fact, on Saturday, we meant to take the children swimming at their hotel but we never quite made it there. The weather that weekend proved to be a little unpredictable, but the good news was we had what we would call a heat wave. While the moms and dads talked, and talked, the kids all played relentlessly outside in the afternoon sun. It was as if they had known each other their whole lives.

We were joined later that day by the Chika family, John, Diane, Emily (Mannosidosis), Katie and Heather. We all sat down for a typical Italian dinner. It was typical because it was truly chaos but it included both family and friends and that is what we had all become.

On Sunday when we had to say our goodbyes, there were many tears shed. It was really a reminder just how important and rejuvenating these get-togethers can be. For a brief time, you are with a group of people not only share you worries, but also rejoice in the special moments and this was definitely one of those times. I thank God everyday that I have met all these special people and look forward to the next time we will see each other.

Families Meet In Illinois

By *Linda Nagy, ISMRD Board Member*



Fucosidosis: Our Journey to the Unknown

By *Aycin Kulle*



Suzan Kulle

Suzan, my dearest sister, was a perfectly normal child born 1967 in London. My family decided to move to Cyprus permanently in 1972 when she was 5 years old and I was 7. Suzan had red spots on the knees and elbows and her lower back as well as on her chest. We later on discovered that they were called angiokeratomas. We could not find a cure for it and the professionals in Cyprus did not know the cause or the reason for them.

When she was 14 and studying in secondary school, she failed her exams and could not pass her class, so had to study the same class the following year. We didn't think it was abnormal, as we knew that she had other talents like embroidery. Suzan started having ear infections and her tonsils were removed at the age of around 16. She also had an operation on her adenoids.

As she was bored at home she started to perform work in a family friend's factory at the age of 18. Suzan soon stopped eating and drinking at home saying that she was eating at work. She lost weight and her periods stopped. She soon developed hallucinations. Cyprus is a small country and the doctors we visited did not know why she suddenly stopped eating and was acting the way she was. Suzan was terrified all the time. At one stage she also refused to go to the toilet. It became so bad that we could not cope with her anger and temper. She kept talking about killing herself, she complained that she was very ugly and thought she had hair growing on her arms; she thought that she had no teeth in her mouth. She was saying that there were soldiers following us and they were going to kill us.

On our way to the doctors, she was worried that we were going to get lost. Her temper became so bad that she through a knife at my mum at one stage. She was actually going through anorexia (no one knew). We visited every psychiatrist, psychotherapist, counsellor, general practitioner, medical consultants and hospitals in Cyprus. At this stage she was taken in as an inpatient at a mental health clinic. The antidepressants and medications were making her situation worse.

In 1986 my father decided to come back to London to seek help. They registered at a local GP (General Practitioner). The GP didn't know what her condition was, so he referred her to St Georges hospital where Suzan went through a full check up and was finally diagnosed with Fucosidosis.

We did not know anything about this disease. There was not enough information around and the only thing we knew was that this was a very rare disease and there was no cure for it. As soon as we heard the bad news my mother and I decided to move back to London to care for Suzan as her condition was deteriorating rapidly.

Over the years Suzan had lost hearing completely in one ear and had limited hearing in the other. Therefore she is now wearing a hearing aid. She also developed brittle bone condition in the spine, neck and hips, which is affecting her mobility. Suzan was on antidepressants and painkillers ever since we can remember. But she was still complaining from pain in the hips, knees and legs.

We were left in the dark for many years until 2000. This was when I learned how to use the computer and the Internet and started to use the Google search engine for information on Fucosidosis. Suzan was now 33 years old and I found out that the life expectancy for people with mild fucosidosis was 40 years. I was gutted but also determined to overcome this. The more research I did on the Internet the more questions were answered in my mind. We finally knew what to expect and that every symptom Suzan had was linked to this genetic disorder. There was still no cure for this Fucosidosis.

It wasn't until I typed Fucosidosis in the search engine again one night when I came in from work and found a website called ISMRD that our whole life was began to change. I discovered that this was an umbrella organisation for similar disorders and there were real people that really cared and really wanted to help. There was a conference about this disorder and I was determined to go. I emailed Paul Murphy and got a response immediately. Suzan and I were invited to this conference.

(Continued on page 8)

Current Events



Board Governance

Most of the Board from last year has continued on for 2006. At the April 2006 annual meeting of the board Mark Stark accepted the role of Vice-President, and continuing as Directors are Jenny Noble, Gretchen Oswald, Bill Simpson, and Harvey Triman. A new board addition is Linda Nagy, an ML parent from the USA. Terri's role has changed with her Executive Director role to become a not-voting member of the board. Harvey will soon be stepping down from the board for personal reasons and we extend to him grateful thanks for the contribution he has made to our work.



Linda & Joey Nagy

Jenny Meets NASDAQ!

On February 24th 2006, Jennifer Klein (daughter of Terri Klein, ISMRD's Executive Director) was invited by the National MPS Society to be involved in a wonderful celebration of *National MPS Awareness Day* in New York City. The festivities were capped by the "closing of the bell" ceremony at NASDAQ, the famous American stock exchange, sponsored by three pharmaceutical companies: Biomarin, Genzyme and Shire (TKT). The celebration followed a week after the U.S. Senate unanimously voted to pass the resolution designating February 25th as "National MPS Awareness Day" in an effort to raise public awareness for research aimed at early diagnosis and treatments of MPS disorders.



The day included other families affected by other MPS diseases and the children stole the show! The 3 day trip was quite emotional for the Klein's as it drew awareness around the world to Jennifer's disease, Mucopolipidosis. Jennifer was asked by the National MPS Society to be a poster child for the "Join the Search" campaign and her face appears with 6 other beautiful children on the campaign's website at www.jointhesearch.org. Additionally, a photo exhibit featuring all seven children will travel across the United States to various public venues.

The Kleins would like to extend an emotional and heartfelt thank you to The National MPS Society for including Jennifer among the many children to represent our orphan Lysosomal Diseases!

Artwork Project for Christmas!

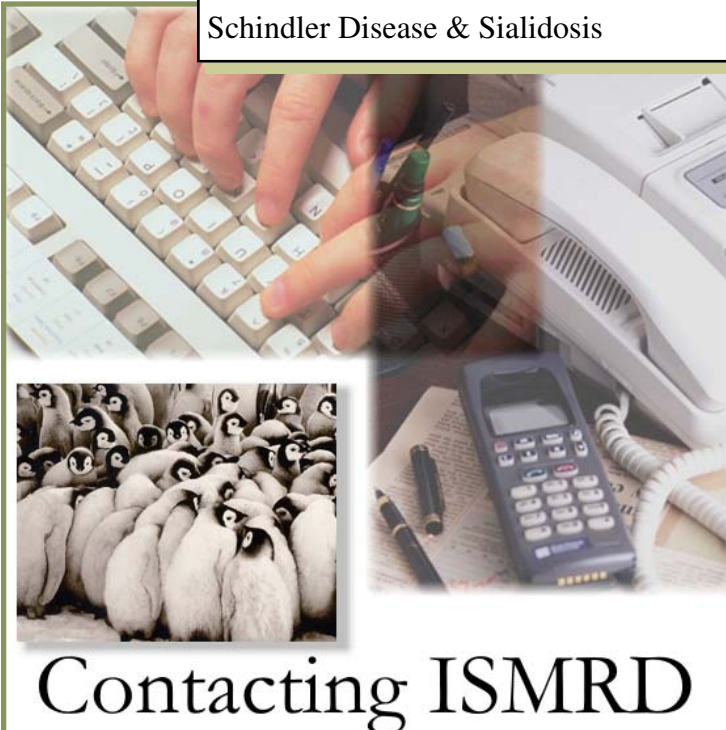
We know it's a little early to start thinking about Christmas, but before you know it, it will be here. ISMRD has a project that we need all your help with. We have an idea for our 2006 Christmas cards but we need your participation. This year for our ISMRD Christmas cards, we would like to feature the artistry of our affected children or young adults. So, we are asking everyone to put their heads together and get to work drawing. Of course your theme can encompass penguins, but be creative and colorful. Depending on participation, we are considering doing a collage, using certain parts of each submission, so that the final creation is a joint effort. In order to meet publishing deadlines, we ask that all artwork be submitted by August 31st. All submissions will be used either on the card or on a special holiday-themed area of ISMRD's website.



We will post more information online soon about the holiday artwork project. Visit the Penguin Café beginning July 1st for instructions and to exchange ideas with others. We would appreciate hearing from anyone interested in participating, so send an email to Linda Nagy at bindanagy@sbcglobal.net or send postal mail to Terri Klein at our address on the cover of this newsletter.

We can't wait to see how creative everyone can be!

The International Advocates for Alpha Mannosidosis, Aspartylglucosaminuria, Beta Mannosidosis, Fucosidosis, Galactosialidosis, I-Cell Disease, Pseudo-Hurler Polydystrophy, Schindler Disease & Sialidosis



ISMRD Board of Directors

President: John Forman | **Executive Director:** Terri Klein
Treasurer: Harvey Trimman | **VP-Secretary:** Mark Stark

Directors:

United States - Gretchen Oswald, M.S., C.G.C. | Linda Nagy

New Zealand - Jenny Noble

Canada - Bill Simpson

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(Continued from page 6)

Attending this conference also allowed us to arrange a medical assessment for Suzan while we were in America at John Hopkins hospital in Baltimore, Maryland. We packed up and travelled to America to find out every thing about this disorder and to meet other families and learn from their experiences.

This was an eye opener for us. I was amazed with the whole idea. I met so many kind and helpful people. I found out so much information. I made so many friends in such a small time. Best of all, I found out about a drug called Pamidronate that might help Suzan's ongoing pain. Pamidronate was an infusion Jenny Noble was very keen and happy to use with her children. I wanted to give it a go. Jenny gave me all the information and the protocols for using this infusion.

At the medical assessment I discussed this with the consultant and he was happy for Suzan to try it. Suzan was discovered to have a murmur in her heart, which was not discovered in London.. My darling sister could have died in her sleep and we would not have known the cause to help prevent this. Our consultant in John Hopkins hospital gave us a 12-page report on Suzan's condition and he also included a future plan for her. I gave a copy to all the doctors that Suzan was seen by in London so that they would know and would follow.

I came back to London and immediately changed Suzan's Specialist Consultant, as he had no experience in this field. Again, thanks to the internet and the conference, I read and heard a few case studies by Dr Vellodi. I found his email address and emailed him regarding Suzan's condition and asked for an appointment. This was arranged and we were in the hands of an experience consultant. He agreed to treat Suzan with Pamidronate and this was arranged in January 2005. Suzan had a bone density test and this was -2.5. Suzan has been on this infusion for over a year every month and is completely free from painkillers. She is now much more active, happy and pain free. With the way Suzan's bones were deteriorating, had we had not known about this infusion at the right time, it would have been too late for the infusion to help improve Suzan's condition.

Therefore I owe a huge thank you to Paul Murphy, who supported us all the way, to Jenny Noble for her endless encouragement and support, and to Dr Goswall for arranging the appointments in John Hopkins Hospital. I also want to thank everybody I had met at the conference and wish you the best of luck with your loved ones!

Feedback Form | Donation

ISMRD would like to hear from you!

Send us your feedback, your request for further information or make a donation. Just fill out the appropriate boxes below, cut out this page and then return it to the address on the reverse side.

Donations: contributions to ISMRD are tax-deductible in many countries. Consult your nation's local or central tax-collection agency. A copy of our current financial statement is available upon request by contacting ISMRD at our address at P.O. Box 328, Dexter, MI 48130 USA. Documents and information submitted to the State of Maryland under the Maryland Charitable Solicitations Act are available from the Office of the Secretary of State for the cost of copying and postage. Please contact us for further information.

Talk to Us!

We would like to hear from you and offer you a part in our vision to link families, support research, develop therapies and find cures. Send us names of friends, family and professionals who would be interested in receiving our newsletter or know more about our mission. Join an Action Team and contribute to ISMRD's success, no matter how small that contribution may seem, Your ideas are invaluable!

Please send Pathways to:

Name: _____
 Address: _____
 City: _____ State/Province: _____
 Country: _____ Postal Code: _____

Join an Action Team:

Action team members work together to fulfill parts of ISMRD's mission. For more information, check an area that interests you and we'll contact you.

Family Support
 Fundraising
 Medical Outreach/Research
 Policy/Advocacy
 Public Awareness

My Name:

Email Address:

Phone:

Please Help Our Cause!

ISMRD is a 501 (c)(3) charitable organization based in the United States serving a global constituency. We provide our services, which include our newsletter, website, outreach activities and support of research, without requiring monthly dues or any other financial restrictions. We gratefully accept donations that will enable us to continue toward our goal of a future free of the tragic consequences of Glyco-protein Storage Diseases.

Please give us your name & how to contact you:

YES! I would like to contribute

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 ----- \$25.00
 ----- Other: \$ _____

Please make your check payable to
ISMRD
 Thank you!

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