



A publication of ISMRD



**Order your ISMRD  
calendar now!**

**See page 3 for details**

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### *The International Advocates for Glycoprotein Storage Diseases*

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501 (c) 3 nonprofit 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 Mark Stark*  
ISMRD



Welcome to the ISMRD fall newsletter! As you know, part of our goal at ISMRD is to help all those affected by rare diseases by providing information about treatment and care options to parents of affected children, and by providing a community of families that support each other. This newsletter is one of the ways we provide this support to those who may not be in regular contact with ISMRD, as well as provide news about activities and upcoming events that are important to everyone concerned with curing these debilitating disorders. The newsletter also helps to give some personal perspective on this disorder. This edition includes poetry, articles, and a book excerpt from families of affected children.

We are a small community of families, and we do not have a lot of resources; of course it takes a tremendous investment of money and talent to overcome these complex diseases. I am excited about the progress being made to get matching funds from other organizations to fund research, and we will be providing more details in an upcoming newsletter. In the face of government budget cuts to all programs, it is important that our elected officials hear from as many of you as possible that government funding of research is vital to continue developing treatments for extremely rare diseases. If you have any questions about how best to do this, please contact me or any board member for more information.

This newsletter also includes information on what is happening in countries around the world to support families with rare diseases, including some useful links to support organizations. Particularly in the United States, the 2014 implementation of the Affordable Care Act will make health services available to millions who do not have it today. It is important that our community of families understand what this means to rare disease patients; to that end, this newsletter includes useful links to get information; our future newsletters and web site will add personal stories of how other parents have navigated this complex environment.

It is also important that our families and our friends continue to do everything possible to keep raising funds for research. I would like to call your attention to an opportunity for a fun way to help; ISMRD has produced a 2014 calendar that includes 75 pictures of our families. This makes a great Christmas present, and is a wonderful way to remember why we are committed to curing these terrible diseases.

Thank you,

**Mark Stark**  
**President**



# ***ORDER YOUR ISMRD 2014 CALENDARS NOW***



**60 PHOTOS OF OUR CHILDREN/ADULTS**

**GREAT FOR CHRISTMAS PRESENTS**

**HELP ISMRD RAISE FUNDS FOR RESEARCH AND OUR NEXT CONFERENCE**

**ONLY USD\$12 EACH**

**(inc postage to anywhere in the world)**

If you are interested in selling calendars or would just like to order one or two for yourself, contact Susan at [kickifer1@gmail.com](mailto:kickifer1@gmail.com). Calendars can be paid for by credit card, via our Paypal account, at [http://www.ismrd.org/help\\_us/make\\_a\\_donation](http://www.ismrd.org/help_us/make_a_donation).

ISMRD Board Members Susan Kester and Tish Adkins have created the calendars. They called for photos from families, and have collaged 60 photos of children/adults who are affected by one of the nine glycoprotein storage diseases that ISMRD supports. Each photo is placed on the person's birth month in the calendar.

ISMRD's fundraising priorities for 2013-16 are:

- \$5,000 per year for scholarships to support young investigators to WORLD Symposiums, to create research interest in our disorders
- \$70,000 for the ISMRD Scientific/Family conference 2015-2016
- \$30,000 for the Natural History Study for the next four years

Please help us with this fundraising event.

Contact Susan at [kickifer1@gmail.com](mailto:kickifer1@gmail.com). Pay for calendars at [http://www.ismrd.org/help\\_us/make\\_a\\_donation](http://www.ismrd.org/help_us/make_a_donation)





## ISMARD FACEBOOK PAGE

<https://www.facebook.com/groups/82945687520/>

In the past year, we have had 49 new members sign up to our Facebook page, swelling our numbers to 316 members. A warm welcome to:

Alysha Sweitzer	Julio Santama	Nomsa Hiatschwyo
Amy Farris	Karen Bolen	Patty Wise
Angela McClure	Kari Hummer	Rachel Buckamneer
Angie McGinnis	Katie Marie	Ram Krishna
Anita Inwood	Katie Saulnier	Rebecca Smith
Anna Zukancic	Ken Medlin	Rosemary Underwood
Annelisse Rodriquez	Lauren Sims	San Jekel
Christina Fisher	Laurie Reed	Selma Bonfin
Crissy Boyles	Lonnie Tice	Sharon Meador
Eddie Sharp	Lida Yakubovskaya	Sue Curtice
Elizabeth Siebert	Liesbeth Blok-Potkamp	Sue Stanton
Felicity McManus	Lori Rudd	Tammy Van Dam
Gabriella Sesso	Margret Hancock	Tiffany Myrick
Joan Allen	Mark Moore	Tina Neuvonen
Joey Nagy	Mark Van Dam	Una Hegarty
Jon Coley	Mary Connole	
Julie Wells	Nagila Marie	

**Why don't you join them?** Our Facebook page is a great place for keeping in touch with other families with the same condition, swapping and gaining information, and getting support when times are particularly hard.

Go to <https://www.facebook.com/groups/82945687520/> and sign up. It's easy, it's free, it will put you in touch with other people in similar circumstances. Go ahead! You're worth it!

## ISMRD TWITTER PAGE FOUNDER PARKER MEADOR

Thanks to the hard work of Parker Meador in Arkansas USA, ISMRD now has a [Twitter page with over 2,000 followers. Read his story here.](#)

My name is Parker Meador. My wife's name is Sharon and we have 2 wonderful daughters. Gabrielle is 10 and Ellason is 7. My faith and belief in God is the foundation of our life and we are truly blessed. I suffer from several mental disorders that have made life difficult at times but have also strengthened me and given me a purpose in life, and that is to humble myself and to serve others whenever possible. I have been diagnosed with Social Anxiety and Obsessive Compulsive Disorder (OCD) and this often leads to depression. I have had to deal with these disorders every single day as far back as I can remember. I just turned 41 years old.



*Autumn Tobey inspired Parker's work for the ISMRD. She is 37 and has Mucopolysaccharidosis III.*

I first heard about ISMRD a few years ago but I have known Autumn Tobey's story for many years. I have become good friends with her mom, Pam Tobey, as we attend the same church. I feel that there is a special bond between us and a love that has developed and I consider them family and they have a special place in my heart.

Social media such as Facebook and Twitter have allowed me to reach out to others and share my life story and to be an open book. One day I asked if ISMRD had a Twitter page and when I found out they did not I created a page and started telling anyone who would listen about ISMRD. The fact is I knew very little about them myself, so I learned as I went. I felt like there was no time like the present to start making others aware. I put my OCD to use and spent 10 to 12 hours a day telling others about ISMRD, one person at a time.

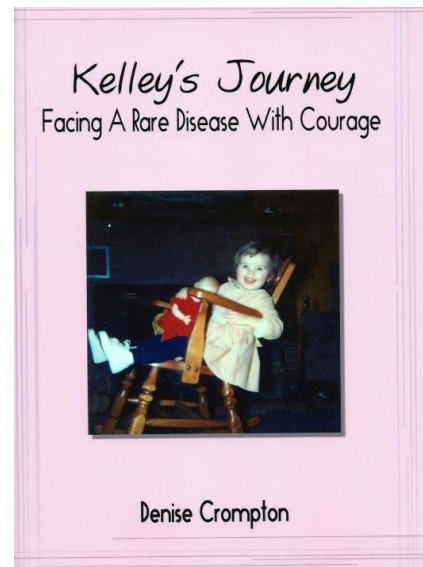
I remember typing ISMRD into the twitter search bar and not one result came up. that meant, that nowhere in the vast Twitter universe had ISMRD been mentioned or if it had it wasn't showing up in the search results.

What has it accomplished so far? That's a difficult thing to answer. I know that thousands have now heard about ISMRD that hadn't before. I know that awareness is the first step and that only good things can come from that. I have no doubt that this is what I'm supposed to be doing. It feels right in every way. I feel like this form of Social Media is an awesome tool because it can accomplish in a few hours or days what it may take months or years to accomplish through other avenues. The hope I have every time I log onto the account is that this is the day that someone with a Voice will step up, take interest and fall in love with the families of ISMRD like I have. I feel its not an "if" but "when" situation

I know I have not had to fight the fight that the ISMRD families have fought and are fighting every single day but I do have a fight of my own. I have to fight every day for my own life because my mental disorders are always there battling inside my brain trying to take my life. So I will fight for ISMRD because they are a part of my heart. I will do what I can to raise awareness and funds that will some day lead to treatments and beyond until I can fight no more. The Twitter page is @ISMARD. Or the

# ISMARD MEMBER DENISE CROMPTON'S NEW BOOK

## ***Diagnosis: Rare Disease*** **IS EXPECTED IN 2014**



Many of my fellow Penguins know about my book, *Kelley's Journey: Facing A Rare Disease With Courage*, which was published in 2003. During the years that followed, I was asked many times if I was writing a sequel to the book, but until after Kelley died in 2009, I didn't have the time to work on a book. In 2010, I started to work on a revised and expanded version of *Kelley's Journey*. As I began to include the stories of many of the families we had met since the book was published, I realized that there was too much to tell without starting on a whole new project. The revised and expanded version of the original book was placed on the back burner in January 2011, while I reached out to many of the families I had met, asking them if they wanted to participate in my new book, *Diagnosis: Rare Disease*. When twelve mothers responded, I knew that this was a project worth my time. They all answered my many questions as I put together a manuscript to tell the stories about what it is like for their families to live with a rare disease. And they all earned more of my love and admiration than they will ever know.

I am happy to report that the project has been completed, thanks to the mothers of Zachie Haggett, Sergio Cardenas, Spencer Gates, Anna James, Joey Nagy, Andre Andrews, Jennifer Klein, Callie Nagle, Sammy and Huddy Anthony, Sarah and Hayden Noble, Allison Dennis and Autumn Tobey.

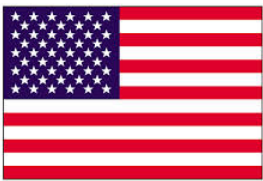
***Diagnosis: Rare Disease*** has a two-fold purpose. One is to help increase awareness by documenting the many ways in which these families have been affected by ML, and the second is to raise funds to be put toward research. Although I don't know yet who the publisher will be, I can tell you that it will be published in 2014.

Also, sometime during 2014, a *Revised and Expanded version of Kelley's Journey, including her final years* will be available on-line as an e-book for those who have e-readers.

***Kelley's Journey* is available at [Amazon.com](http://Amazon.com), and through [bookstore.authorhouse.com](http://bookstore.authorhouse.com)**

**We will let you know when *Diagnosis: Rare Disease* and the expanded *Kelley's Journey* become available**

# Developments from around the world to improve life for families battling with a rare disorder



## Affordable Care Act (USA)

The Affordable Care Act (ACA) was signed into law in March 2010. It consists of a combination of measures to control health care costs in the US, and an expansion of coverage through public insurance (broader Medicaid eligibility and Medicare coverage) and subsidized, regulated private insurance. The ACA includes numerous provisions that take effect between 2010 and 2020. Some important provisions take effect on 1 January 2014.

**The Catalyst Center** (<http://hdwg.org/catalyst/>) has created a side-by-side comparison of major provisions and the implications for children and youth with special healthcare needs (<http://hdwg.org/sites/default/files/ACAsidebyside-catalystctr.pdf>) to help describe how coverage and care will be impacted. The Center has also developed several presentations and fact sheets about the Affordable Care Act.

**The Health Care Law and You** (<http://www.hhs.gov/healthcare/rights/index.html>)

On this government site, you can find the full law, and state-specific information about the law.

[HealthCare.gov](http://www.healthcare.gov) ([www.healthcare.gov](http://www.healthcare.gov))

This is the official site of the Health Insurance Marketplace. Visit this site to answer your questions about the healthcare law and how it will affect you.

**Health Care and You** (<http://www.whitehouse.gov/healthreform/relief-for-americans-and-businesses>)

This site reviews portions of the law currently in effect, and portions of the law that will go into effect in the future.



# Canadian Plan for Rare Diseases

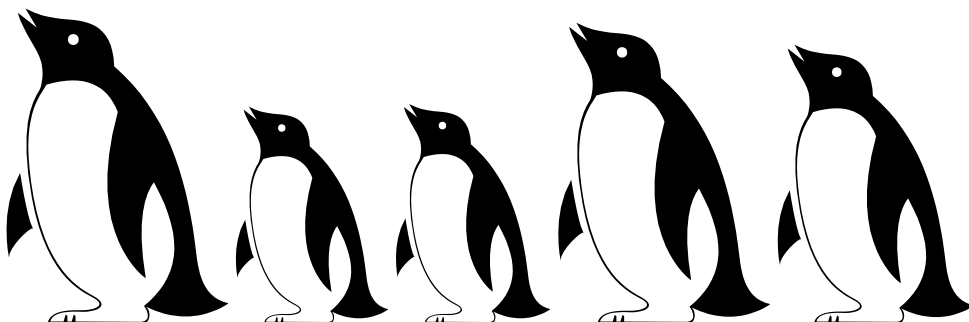
The Canadian Organization for Rare Diseases (CORD) plans to unveil a Canadian Plan for Rare Diseases on Rare Disease Day, February 28, 2014.

The Plan will include:

1. Methodology, Governance and Monitoring of the National Plan, including evaluation and sustainability
2. Definition, codification and inventorying of Rare Diseases (RD), including patient registries and databases, help lines, and training of healthcare professionals on RD
3. Research on RD, including infrastructures, funding, sustainability, priorities, patient participation, and international collaboration
4. Care for RDs - Centres of Expertise and European Reference Networks for Rare Diseases, including designation and evaluation of CEs, screening, diagnostics and testing, and good practice guidelines
5. Orphan Medicinal Products, including development support, access to treatments, compassionate use, off-label use, and pharmacovigilance
6. Social Services, including social services, specialized services, integration policies, and international support
7. Patient Engagement and Support, including support for patient organizations to provide public awareness, member support, and engagement in all other sectors

The official consultation will take place November 11-12, 2013 in Toronto, bringing together all stakeholders, including policy makers, funders, researchers, clinicians, industry, and, of course, the patients.

**Read more:** [www.raredisorders.ca](http://www.raredisorders.ca)





## Progress Toward a National Plan for Rare Diseases in Australia

The Australian Health Ministers Advisory Council will consider a scoping paper regarding a national plan for rare diseases later this month. The documentation includes extensive input from clinicians, researchers, and individuals living with rare diseases. According to Rare Voices Australia, this is the first time in Australian history that the views of individuals living with rare diseases will have been considered in a national forum.

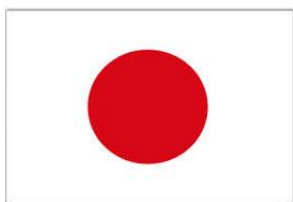
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## Germany Adopts National Plan for Rare Diseases

In keeping with the European Council recommendations, Germany has elaborated and adopted the National Plan for Rare Disease, which will guide and structure actions in rare diseases within their health and social systems. In 2010 the German Federal Ministry of Health (BMG), together with the German Federal Ministry for Education and Research (BMBF) and the Alliance of Chronic Rare Diseases (Allianz Chronisch Seltener Erkrankungen, ACHSE), founded the National Action Coalition for Persons with Rare Diseases (Nationales Aktionsbündnis für Menschen mit Seltene n Erkrankungen, NAMSE). The goal of NAMSE is to improve the quality of life of individuals with a rare disease through a concerted effort. Following a three-year process of coordinating these actions, which involved the commitment of all those involved in the healthcare sector, a total of 52 policy proposals were compiled and included in a National Plan of Action for Persons with Rare Diseases.

The 52 policy proposals in the National plan represent a broad spectrum of tasks to be executed as it addresses the most pressing problems of the patients and their relatives. They include many concrete suggestions on implementing information management, on possible paths to diagnosis, on caretaking structures and on conducting research on rare diseases. The goal of NAMSE is to establish and provide aid to National and European networks of Reference and Expertise Centres that are adapted to the special needs of rare disease patients and make them available to patients and their doctors. This was also highlighted to be in agreement with the cross-border healthcare directive. Adequate funding and certification for these centre's will ensure timely diagnoses so patients can receive necessary care. An important goal of the National plan is to intensify the research in the area of rare disease. The National Plan provides vital contribution to the goals of the Framework Program of Healthcare Research presently being pursued by the German Federal Government. Thus funds for research in the field of rare diseases in order to improve diagnosis and treatment are provided in this plan.



## Rare Diseases and Orphan Drugs Policy in Japan

An article published in *Expert Opinion Orphan Drugs* reports on the current and future policy initiatives on rare diseases in Japan. According to the authors, these initiatives have been an element of the Japanese national health system dated as early as 1972. The authors believe that due to the extensive support from the government, rare disease policy in Japan has witnessed *“considerable progress over the past 40 years”* which encompasses the orphan drug legislation of 1993.

This legislation not only encouraged research and development of orphan drugs, but also brought changes to the pricing and reimbursement systems. The authors contend that this legislation *“facilitated access to orphan drugs, specific research programs to promote research on and development of orphan drugs, and a government-supported information center to promote the understanding of rare diseases”*.

In the article the authors contrast pricing and reimbursement strategies in EU and US, with the Japanese National Health Insurance (NHI) system. Unlike the EU and US, the NHI in Japan *“negotiates prices with pharmaceutical companies once a drug is approved for use, allowing a selling price of cost plus 10% for orphan drugs”*. Japan has designated 130 diseases as intractable or rare diseases, out of which 56 can receive reimbursement of medical expenses. The reimbursement structure allows *“30% of expenses paid by insurance companies and the rest paid by national and prefectural governments”*.

The authors describe several research programmes that are supported by the Japanese government such as the project establishing ‘Bases for Early and Exploratory Clinical Trials in Specific Research Areas’, launched in 2011 *“to promote the development of innovative orphan drugs and medical devices from Japan”*. The authors also highlight another project ‘Enhanced International Information Exchange’ launched this year which will aid in *“publicis(ing) the results of limited research on rare diseases and orphan drugs to a broader international audience”*.

Finally, the authors illustrate the example of Japan Intractable Disease Information Center – a collaborative effort of the MHLW and the Japan Intractable Diseases Research Foundation – to disseminate information about rare diseases in Japan. The authors highlight that this website gets over 15 million hits per year and is a testament to its in spreading knowledge about rare diseases in Japan .

**Read more:** <http://informahealthcare.com/doi/abs/10.1517/21678707.2013.832201>

## More efficient delivery of orphan medicinal products in less market-based countries

Orphan Drug legislations have been enacted in several countries to provide incentives for manufacturers to create new orphan drugs. These incentives have proved to be beneficial to many companies who have incurred substantial profits. However, according to the authors of an article published in *Therapeutic Innovation & Regulatory Science*, the adoption and success of orphan drugs is greatly dependent on the market forces of countries and “*these incentives directly and indirectly affect orphan drug markets and contribute to classifying a country as being more or less market based*”. Countries such as the US are considered market-based as they follow free market principles with limited governmental regulation, dictated by supply, demand, and pricing. Less market-based economies depend less on free market principles, which according to the authors are more beneficial for the adoption of orphan drugs.

The authors analysed “*orphan drug adoption of 13 marketed orphan drugs in France, Germany, Spain, the UK, and the US*”, which revealed a “*statistically significant but negative relationship between the degree to which a country is market based and the adoption of orphan drugs*”. The study concludes that less market-based countries with regulations supporting orphan drug production lead to “*a more efficient delivery of orphan drug products to patients with rare diseases*”. The authors believe the study’s results to be “unsurprising” given that orphan drug legislations encourage research and development of orphan medicinal products to incentivize its production due to which the orphan drug markets behave differently from non-orphan drug markets.

**Read more:** <http://dij.sagepub.com/content/early/2013/01/25/2168479012471945>  
this

### Watch a naughty penguin at

<https://www.facebook.com/photo.php?fbid=121812137842746&set=a.119288041428489.14702.116952821662011&type=1&theater>



# CARERS' CORNER

## Caregivers Ad Board Brings Insight to Rare Disease Families

Where do caregivers go to reenergize? How is caregiving for people with rare diseases different from other diseases? Where do caregivers go for information and support? These are some of the questions Genzyme and the Caregiver Action Network (CAN) posed to 30 rare disease caregivers from around the world recently at Genzyme Center in Cambridge. The meeting was Genzyme's first global Rare Disease Caregiver Advisory Board gathering, and provided great insights into the needs of this inspiring community.

The goal of the meeting was to discuss the challenges of caregiving, identify possible resources for caregivers and uncover educational gaps that may exist for this important community. As CAN's Executive Director John Schall said, "For the vast majority of the population, it is not a question of whether we will one day become a caregiver, the question is when." Though that may be true, he acknowledged that the rare disease community in particular faces exceptional hurdles in terms of the lack of available support networks, broad disease awareness and resources. In addition, scarce resources often mean that patient organizations must focus their support programs on the needs of patients while the needs of the caregiver go unaddressed.

Caregivers from the Fabry, HoFH, Gaucher, MPS, Niemann-Pick B, Pompe, and Tay-Sachs patient communities participated in the two-day meeting.

***Genzyme would like to hear from you. What support does your organization give to the caregivers for the members of your organization? What would caregiver programs look like, if resources weren't limited?***

***To reply, go to***

<http://www.genzymerarecommunity.com/blog>

*Watch a penguin being tickled at*

<https://www.facebook.com/photo.php?v=658002444229376>

## Support for Caregivers

The Minnesota Leadership Education in Neurodevelopmental Disabilities program has developed a fact sheet describing the need to support family caregivers as they take care of children with special health care needs. It presents facts, needs, and solutions related to supporting family caregivers presented from the perspective of a caregiver. Go to [http://lend.umn.edu/docs/LEND-Family\\_Caregiver-FACT\\_SHEET-7-3-13.pdf](http://lend.umn.edu/docs/LEND-Family_Caregiver-FACT_SHEET-7-3-13.pdf) to see this useful resource.

You might also be interested in the caregivers virtual support group at <https://www.alpha1.org/support/caregivers-virtual-support-group>

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## Patient Network

### Bringing Your Voice to Drug and Device Approval and Safety

Have a look at the FDA's Patient Network webpage for information about drugs and their approval processes, diseases, clinical trials and treatment options:

[http://www.patientnetwork.fda.gov/?utm\\_source=Genetic+Alliance+Announcements+and+Newsletters&utm\\_campaign=a74033eecf-Weekly\\_Bulletin\\_7\\_16\\_13&utm\\_medium=email&utm\\_term=0\\_182db72825-a74033eecf-67657717](http://www.patientnetwork.fda.gov/?utm_source=Genetic+Alliance+Announcements+and+Newsletters&utm_campaign=a74033eecf-Weekly_Bulletin_7_16_13&utm_medium=email&utm_term=0_182db72825-a74033eecf-67657717)



## Rhonda Skipper dedicates the following song to her children Toni, Dale, Josh and Matt



### LOVE STORY

by Francis Lai

Where do I begin to tell the story of how great a love can be  
The sweet love story that is older than the sea  
The simple truth about the love they bring to me  
Where do I start

With their first smiles  
They gave new meaning to this empty world of mine  
There'd never be another love, another time  
They came into my life and made the living fine  
They fill my heart

They fill my heart with very special things  
With angels' songs, with wild imaginings  
They fill my soul with so much love  
That anywhere I go I'm never lonely  
With them around, who could be lonely  
I reach for their hand - it's always there

How long does it last  
Can love be measured by the hours in a day  
I have no answers now but this much I can say  
I know I'll need them till the stars all burn away  
And they'll be there.





## Get Well Soon



*If you know of anyone who has recently been ill or had surgery or is about to have surgery, please tell us at [cdew1@dodo.com.au](mailto:cdew1@dodo.com.au)*

*Some of our Penguin children and young adults have recently been in hospital, had surgery or are awaiting surgery*

*Your Penguin family are thinking of you and praying for a good outcome*

- Hayden Noble – Back issues
- Lonnie Tice – Laser surgery
- Grace Webb – Tracheotomy and spinal surgery
- Lucia Kesner – High fever
- Bianca Adina – Bronchitis
- Jake Wise – Ear infection
- Alli Cat Dennis – Pain pump surgery
- Allie Giunta – Tracheotomy issue



**ISMRD** are the International Advocates for the following disorders: ***Alpha Mannosidosis, Aspartylglucosaminuria, Beta Mannosidosis, Fucosidosis, Galactosialidosis, Mucopolidosis II (I-Cell Disease), Mucopolidosis III (Pseudo-Hurler Polydystrophy), Schindler Diseases and Sialidosis***



## Contacting ISMRD

### ISMRD Board of Directors

**President:** Mark Stark  
**Vice President, Administration:** Jenny Noble  
**Vice President, Fundraising:** Pam Tobey  
**Vice President, Research:** John Forman

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**United States:** Jackie James | Andrea Gates | Susan Kester |  
Melissa Rust | Tish Adkins  
**Australia:** Carolyn Paisley-Dew

### Founded in March 1999

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United States

E-mail: [info@ismrd.org](mailto:info@ismrd.org)  
Website: [www.ismrd.org](http://www.ismrd.org) | FEIN: 52-2164838

## ISMRD'S SUNSHINE CARE Committee



**ISMRD has** a group of parent volunteers called the **"Sunshine Committee"**. Our purpose is to coordinate support for families in need. The type of support varies on the circumstance -- from birthday and weddings, an illness or death in the family, or a family experiencing surgery or a medical crisis. In any case, we provide a little "sunshine" for the family by providing flowers, encouraging messages via email, cards or a phone call -- whatever we think the family would find most helpful. In order to help others, our group relies on the support of all families because, in essence, we are all part of the ISMRD "Sunshine Committee".

If you are in need of assistance or know someone in our Penguin community who is in need, **please contact Susan Kester**. She will coordinate with the appropriate parties to determine how we can best help.



## 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.

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: **3921 Country Club Drive, Lakewood, CA 90712, USA**. Documents

**Tell us how you can help!** 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 and e-mail addresses of family, friends, and professionals who would be interested in receiving our newsletter or who want to know more about our mission.
- Tell us what you can help us with
  - ☐ Fundraising
  - ☐ Publicity and communication
  - ☐ Do you have any other ideas or other ways that you can help ISMRD?

Name: \_\_\_\_\_

E-Mail: \_\_\_\_\_

### Please help our Cause

**ISMRD** is a 501(c) charitable organisation 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 requesting 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 Glycoprotein Storage Diseases.

#### Yes I would like to Contribute the following (check one)

- \_\_\_\_ \$100  
\_\_\_\_ \$75  
\_\_\_\_ \$50  
\_\_\_\_ \$25

Please Make  
Your cheque  
payable to  
**ISMRD**  
Thank you

#### Please give us your name & how to contact

Name: \_\_\_\_\_

Street: \_\_\_\_\_

Street 2: \_\_\_\_\_

City/State/ Province: \_\_\_\_\_

Country/Postal: \_\_\_\_\_

E-mail: \_\_\_\_\_

