

# Pathways

## The Newsletter for Glycoprotein Storage Diseases

ISMRD, a 501 © not-for-profit organization, FEIN 53-2164838 | website [www.ismrd.org](http://www.ismrd.org)

### Our Mission and Vision

ISMRD is the leading advocate for families world-wide affected by Glycoprotein Storage Diseases.

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.

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

### ISMRD supports the following disorders

Alpha Mannosidosis, Aspartylglucosaminuria, Beta Mannosidosis, Fucosidosis, Galactosialidosis, Mucopolipidosis II alpha/beta (I-Cell Disease), Mucopolipidosis III alpha/beta (Pseudo-Hurler Polydystrophy), Mucopolipidosis III Gamma, Schindler Disease and Sialidosis

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### Donations

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.

Donations can be made via our website using



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## From the President's Desk

*By Jackie James  
President, ISMRD*



It's hard to believe it has been a year now since many of us were together at the St Louis conference. It was at that time that the ISMRD board began talking about the Mucopolidosis Research Initiative and our goal to raise \$100,000 toward research. It seemed a very lofty target, especially when the target date for raising these funds was set for the end of June 2016!

We did it! And not only did we do it, we flew well past our goal.

We would like to extend a huge thank you to each of you that worked so hard on helping us achieve and exceed this goal. Our scientific advisory board is now in the process of finding the perfect research candidates. We are looking forward to updating each of you with the results of our search and where every dollar of the research initiative is going.

In this newsletter, we outline some very exciting research developments and opportunities that are opening up for our kids! For example, John Forman updates us on some research opportunities for Alpha-Mannosidosis and details on opportunities to sign up for clinical trials. I also talk about a week-long metabolic bone study my daughter Anna went through back in May.

John also covers the recent serious health issues that his daughter Hollie has been facing, which have culminated over the past several years. It's a good reminder to each of us that we, along with our doctors, need to bear in mind that our kids can also suffer from secondary illness, and to be alert and aware of that fact. I'm sure you will join me in wishing Hollie a very speedy recovery from her surgery last month.

We cover rare disease news from across the world, such as the first ICORD conference in the continent of Africa, the Philippines Rare Disease Act, management of patients with inherited metabolic disorders in Pakistan, and end-of-life decisions for newborns in the Netherlands.

It is with great sadness that we learn of the passing of Dr Roscoe Brady. Dr Brady was the pioneer of enzyme replacement therapy for many lysosomal storage diseases. We would like to thank him for his tireless dedication to our community.

Please take time to keep our members that have recently had surgery or an illness in your prayers. They are listed at the end of this newsletter.

I would also like to extend a warm welcome to all of our new members. Thank you for joining our community.

Last, but certainly not least, I would like to take this opportunity to introduce Rhonda Skipper to each of you. Rhonda has very kindly agreed to give her time to take care of our social media and keep you updated on all the latest ISMRD happenings. Thank you Rhonda for your generous donation of your time.

**Jackie James**  
**ISMRD Board President**  
**Mom to Anna, ML III**



## ISMRD's MucoLipidosis Research Initiative



The Wagner Foundation,  
Irish MPS Society

# WE MADE IT!

We set out to raise \$100,000 for MucoLipidosis Research, and together we raised

# \$150,000

Well done everyone!

Thank you to the following organisations who have joined in partnership with us.

*US MPS Society, Australian MPS Society, Spanish MPS Society, Irish MPS Society and the Wagner Foundation.*

Thank you for holding fundraisers, donating funds, sharing our request for donations with your friends, buying T-shirts, bracelets, tea, wine glasses, cups and drinking bottles.

This is a tremendous achievement, and now we will send out a request for researchers to submit their ideas for MucoLipidosis research, for us to review.

In the near future, we will send out a special edition of our newsletter providing more information about this initiative and highlighting a decade and a half of efforts by ISMRD to stimulate, support and fund research activities into our nine diseases.

## Introducing Rhonda Skipper ISMARD's new Social Media Person

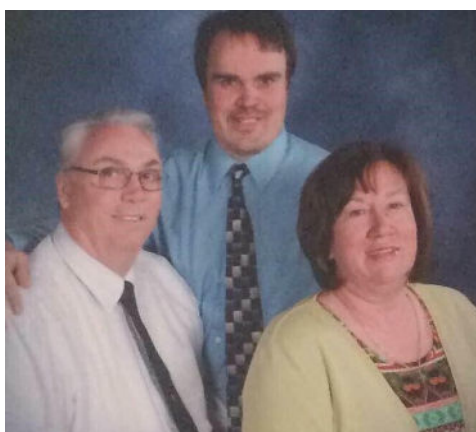
My life came to a halt on a day in 1993. My two sons Dale and Matt were diagnosed with Alpha-Mannosidosis. Then nine and 14 years of age, their lives will never be the same as their other brother Josh (who had this and a 50/50 chance of getting the disorder but did not) or their stepsister Tori who they grew up with since they were three and seven years old. They have had speech and hearing difficulties and some learning deficits but nothing like this.



David, Dale and Rhonda

The doctors told us the disease was very rare and that many affected children did not reach their 18th birthday. After considering bone marrow transplants for both boys, the doctors did not think it was feasible for them given their age. Looking back, I wish I had done more some how some way.

Now my older son Dale, who is 36, is in a facility for special needs adults who need 24/7 care. We see him weekly because the facility is 85 miles away from our home. He knows us but he has some dementia and he is having eating and drinking difficulties. It's been especially hard for me since I've taken care of him since he was born. It was only in the past several years that he started having walking and mental difficulties. It's hard to let go after all these years.



David, Matt and Rhonda

My youngest son Matt seems to have milder symptoms although now at 33 he seems to be having more walking difficulties along with the other signs he's always had: speech and hearing issues, and being mentally moderately disabled. Our middle son Josh is single and working as an engineer and our stepdaughter Toni is a teacher and has a family with two kids. They also have a candle business and her husband is a captain who does boat charters. My husband, David, is a service technician and I am a special needs

teacher with a dream of retiring in the next couple of years.

**Rhonda Skipper**





## Expert and Patient Meeting on Mucopolysaccharidosis - Northampton, UK, 9-10 April 2016

In early April of this year, I excitedly boarded a plane from St. Louis to London Heathrow to attend a two day conference hosted by the MPS society UK in Northampton. Families from across Great Britain and Ireland, as well as from countries around the world made their way to attend the "Expert Meeting on Mucopolysaccharidosis". This conference was held over two days, and I know that many families attending found much of the information shared to be an invaluable resource.

Our ISMRD Vice-President Administration, Jenny Noble, spoke at one of the sessions on Pamidronate and the positive outcome this bisphosphonate has had for our children in the relief of chronic bone pain. Many of our ML kids and adults experience debilitating bone pain and weakened bones and Jenny was able to show how bisphosphonates have been so instrumental in not just dealing with the bone pain but also strengthening weakened bone.

Several scientist and researchers attended and spoke at the conference and updated us on current research and genetic information, and provided answers to our many questions! Speakers included :

- Dr. Fiona Stewart, Consultant in Genetic Medicine, Belfast City Hospital
- Dr. Paul Orchard from the University of Minnesota
- Dr. Simon Jones from St Mary's Hospital in Manchester UK
- Kerstin Cornils with cell and gene therapy at the University Medical Center, Hamburg
- Professor Thomas Bräulke, University Medical Center, Hamburg
- Dr. Brian Bigger from the Manchester Centre for Genomic Medicine, Manchester UK.

We were also able to hear from the UK MPS Society organizers as well as other families dealing with mucopolysaccharidosis. The conference was sponsored by an organization called Blakes Genes. Paul and Louise Knaggs' son Blake was diagnosed with ML when he was 4 months old. Along with Louise's sister Joanne and friend Katie Johnson, they have worked tirelessly to raise funds for ML research. Their fundraising made it possible for the UK MPS Society to host and set up this conference. I found it very encouraging meeting families like the KnagGs and so many families that I had never had a chance to meet before. It was also very nice to catch up with families that we met last year at the ISMRD conference in Saint Louis (you know who you are!).

All in all the conference was a huge success and I believe that all the families that attending came away with more knowledge, encouragement and friendships than before they came.

**Jackie James, President ISMRD.**



Sarah Noble, and Lauren and Aioibhe O'Connor at the conference



ML families at the Expert and Patient Meeting on Mucopolysaccharidosis in Northampton, UK

## A call to action to all Alpha-Mannosidosis families



Two important studies are currently under way into Alpha-Mannosidosis. ISMRD is asking all Alpha-Mannosidosis families to carefully consider involvement in these studies to help gain knowledge of the natural course of this disease, and to assist the development of potential gene therapy for it.

**Study #1** - Dr Sara Cathey at Greenwood Genetic Center in South Carolina, USA, is continuing work on the Natural History Study of the Glycoproteinoses, which include Alpha-Mannosidosis. ISMRD has supported this study for over six years now. We are keen to see more families enrolled in this study to help improve knowledge of the natural progression of this disease. Importantly, we'd like to see families participating in this study **regardless of age or transplant status**. You can participate without attending the Greenwood Genetic Center. Data can be collected from your medical records, so **families from any country can consider sharing their information for this study**.

Here's the link to the study on the Clinical Trials website: <https://clinicaltrials.gov/ct2/show/NCT01891422> For more information about participating, contact Sara Cathey, MD on (843) 746-1001 or at [scathey@ggc.org](mailto:scathey@ggc.org)

**Study #2** - Dr Stephen Kaler at the National Institutes of Health in Maryland, USA, is leading a study to identify clinical biomarkers in Alpha-Mannosidosis as a step towards the development of possible gene therapy for Alpha-Mannosidosis. There are several important aspects of eligibility for this study: (1) The age range for the study has been extended to include ages 5 to 60. **Participants under 10 are particularly encouraged to join the study**, to increase the number of younger patients studied. (2) Eligibility is open **regardless of whether transplanted or not**. (3) **Travel assistance and accommodation within the US is available** to support your participation in the study. This includes travel within the US from the first port of call **for participants from other countries**.

Here's the link to the study on the Clinical Trials website: <https://clinicaltrials.gov/ct2/show/NCT02141503> For more information about participating, contact Stephen Kaler, MD on (301) 451-6034 or at [kalers@mail.nih.gov](mailto:kalers@mail.nih.gov)

Successful treatment of Alpha-Mannosidosis in the future will depend heavily on the research efforts undertaken today, and this cannot be done without the active participation of Alpha-Mannosidosis patients and their families. Please carefully consider participating in both of these studies. Would you like to discuss participation with a family which has been in both studies? If you are from outside the US and would like to be in the Clinical Biomarkers study, ISMRD may be able to assist with additional travel support for you. Please contact me at [john@johnforman.nz](mailto:john@johnforman.nz) for further information.



John Forman  
Vice-President, Research  
ISMRD [www.ismrd.org](http://www.ismrd.org)



## METABOLIC BONE STUDY FOR MUCOLIPIDOSIS

In early May of this year, my daughter Anna (ML) and I checked into Shriners Hospital Saint Louis for four nights. Anna had been accepted for a metabolic bone study with Dr Michael Whyte. We first met Dr Whyte at the ISMRD conference in St. Louis last year and he showed a fair amount of interest in the bone issues that ML kids/adults suffer with, along with the use of the Pamidronate as a treatment.

My hope of the outcome of this study was that Dr Whyte would bring more of our kids in for study, and that ultimately he would be able to find a way to not only help our kids, but understand more about why so many are affected by this secondary metabolic bone disease.



Anna spent quite a few hours being poked and prodded. We answered endless questions and met some amazing and dedicated doctors and nurses. During times where we were not needed, we spent time with the other three families that were there (different diseases), played games and did crafts with the recreational therapists in the game room or retired to our room. We had our own room, very much like a hotel room, where we could relax and watch DVDs or play x-box. The Shriners facility is amazing.

The outcome of the study led Dr Whyte to be very curious about the bone issues we deal with. He will be following up with Anna and has told me that he would like to set up further bone studies with other ML kids starting in 2017. This is very exciting news!

He also stated that he is in need of bone for further study. If any ML kids/adults are having surgery in the near or distant future, he has asked that the surgeon contact his office. Many times a small amount of bone or bone scrapings are discarded in surgery. If Dr Whyte is able to have that discarded bone it would very much help with his study. You can contact me at [jjames707@yahoo.com](mailto:jjames707@yahoo.com) if you would like to contribute bone and I'll put you in contact with the relevant people at Shriners. I will also keep you all updated as the study progresses.

Jackie James  
ISMRD Board President  
Mom to Anna, ML III  
[www.ismrd.org](http://www.ismrd.org)



## Hollie Forman's recent health issues – a lesson for all of us?



Hollie recuperating at home with her twin brother Timothy and mother Judith.

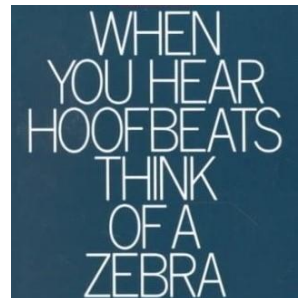
Hollie Forman has Alpha-Mannosidosis, as does her twin brother Timothy, and for both of them there have been many health complications over their 41 years. Their parents John and Judith have spent endless hours in their early years, and since they were accurately diagnosed at age 17, making sure that all the complications of Mannosidosis are carefully managed to give them the best possible health and quality of life. Some of this has meant learning the hard way, when lack of knowledge led to medical problems that would now be avoided because of the much better knowledge that has become available about symptoms, risks and best practice care.

What the Formans were not expecting was to find that Hollie's major health issues over the past 3 ½ years have finally been traced to another rare disease, quite unrelated to Mannosidosis. Fortunately it is a treatable condition and the problems of XGP (Xanthogranulomatous Pyelonephritis) which led to one of her

kidneys being destroyed in an autoimmune response, most likely from recurrent infections, should now be completely resolved as a result of having that kidney removed in late June this year.

The lesson for all of us, including treating doctors, is that patients with rare diseases also get other diseases, just like the rest of the population, and while many health problems for our kids are related to their underlying diagnosis of a glycoprotein storage disease, there is always the possibility that the problem is something else altogether.

John says they were very pleased with the thorough attention given to all of Hollie's symptoms by many thoughtful doctors, but there was a tendency to ascribe many of the presenting symptoms as typical signs of the progression of Mannosidosis. And when there was a serious and acute episode requiring hospital care, there was still a tendency to consider it as an ordinary kidney infection. The family is confident that the attention given was such that her new presenting problems would have been diagnosed earlier if they related to a common disease, but drawing the short straw of another rare disease affecting just 1 in 50,000 or so, meant the path to diagnosis and treatment was once more longer than any of us would want for our children.



The lesson? Encourage your doctors "when you hear hoof beats, consider zebras too".





## Amazon Smile

If you shop at Amazon Smile, a portion of the purchase price will be donated to the ISMRD, at no cost to you. You'll find the same low prices, vast selection and convenient shopping experience as Amazon.com.

Go to <http://smile.amazon.com> for this easy way to help raise funds for the ISMRD.

**Shop at AmazonSmile**  
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## Have you tried our delicious ISMRD specially blended tea?

Sit back and relax with this delicious fruity breakfast tea blend. A first class black Assam with mouth watering sweet all natural fruit makes this a tea you will enjoy every day!

Ingredients: Assam tea, vanilla pieces, pineapple, mango, orange slices, dried strawberries, tangerine pieces, safflower, marigold blossoms, sugar.

Doesn't that sound delicious? Only \$10 for 2 ounces (60 grams) at [www.ismrd.org/fundraisers/ismrd-shop](http://www.ismrd.org/fundraisers/ismrd-shop)





## What's happening around the world?

### Italian pharmaceutical company Chiesi completes clinical trials for enzyme replacement therapy for Alpha-Mannosidosis

It is now about 15 years since one of the first official communications made by ISMRD – a letter of support to the European Union (EU) in support of a collaborative research effort to study Alpha-Mannosidosis and work towards the development of a therapy for this disease. The EU provided two major project grants totalling more than Euro 8 million, and research laboratories across the EU were involved in this detailed work from 2003 onwards. There is a good summary of the research project work on the website of the ALPHA-MAN project at <http://www.alpha-man.eu>

Production of the therapy was undertaken by Scandinavian company Zymenex, who were bought out by Chiesi a few years ago. We have recently been advised by Chiesi that their clinical trials in A-Mann patients are complete and preparation is under way to submit a dossier in



September 2016 to the European Medicines Agency for the registration of the product. The chemical name of the ERT is Velmanase Alfa. A brand name for the treatment will be announced later.

Arrangements are currently being made by ISMRD to meet with Chiesi to learn more about the results of their trials, the regulatory process, and likely dates for marketing if regulatory approval is given by the EMA. The website of Chiesi <http://www.chiesigroup.com/en> provides a small amount of information about their work on this ERT. We expect that our meetings with the company in the next few months will provide more information that we can share with our family networks about this exciting development.

**John Forman**

**ISMRD Vice-President, Research**



## The 11th International Conference on Rare Diseases and Orphan Drugs (ICORD) - 19-22 October 2016, Cape Town, South Africa



International Conference on  
Rare Diseases & Orphan Drugs

ICORD is hosted annually in different countries across the world. 2016 will be the first time that it is hosted in an African country. This is a great opportunity for Africa as a continent to be involved in Rare Disease development, while providing an ideal platform for engagement in the developing world.

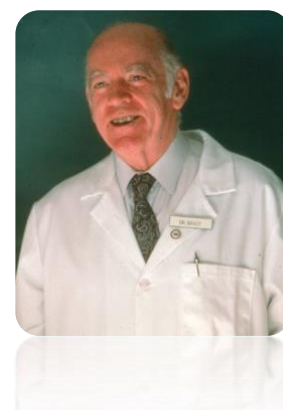
The conference program will include sessions such as global policies, diagnostics, access to treatment, rare disease research and funding, congenital malformations, improved quality of life and support for patient organisations.

ISMRD's Vice-President, Research, John Forman, is President of ICORD and will attend representing both ICORD and ISMRD. For further information, [Press Here](#)



### Thank you to Dr Roscoe Owen Brady, MD

The international rare disease community is mourning the passing of Roscoe Owen Brady, MD. Dr Brady discovered enzyme replacement therapy (ERT) for lysosomal storage disorders including Gaucher Disease and Fabry Disease. These were the first ever ERT for lysosomal diseases, and directly led to great advances in the development of ERT for some of the other lysosomal diseases, by many different researchers who were inspired by Dr Brady.



Dr Brady brought hope to the rare disease community with his work. We are very thankful for more than 25 years of service from a very distinguished scientist and pioneer in rare disease research.

## Philippines Rare Diseases Act



In the Philippines, a new law has been signed a law that will help people with a rare disease to have better access to comprehensive medical care.

Signed on March 3, the Rare Diseases Act of the Philippines defines rare diseases as “*disorders such as inherited metabolic disorders and other disease with similar rare occurrence as recognised by the Department of Health (DOH) but excluding catastrophic forms of more frequently occurring diseases.*” The DOH will lead the implementation of the Rare Diseases Act and also convene a technical working group to provide education and information on rare diseases. Rare disease patients in the Philippines will now be considered as persons with disabilities, who will be able to avail privileges like priority programmes and discounts. In coordination with the National Institute of Health (NIH), the DOH will create a rare disease registry. The DOH, NIH and the Food and Drug Administration will also work together towards providing drugs and diagnostics to rare disease patients.

In terms of social welfare, the law directs the Department of Labour and Employment to provide employment opportunities for able persons with rare diseases. The Department of the Interior and Local Government and the Department of Education are also directed by the law to ensure opportunity for public service and education for people with rare diseases, and the privileges relevant to these agencies will be given. Persons with rare diseases may avail of medical assistance and benefits provided by the Philippines Health Insurance Corporation and by the Sin Tax Reform Act.

Finally, the Department of Science and Technology in the Philippines will provide funds towards research to the study of rare diseases and their treatment. [Read the Rare Disease Act of Philippines](#)



## Management of patients with inherited metabolic disorders in Pakistan



Consanguineous unions in Pakistan have resulted in a significant burden of inherited metabolic disorders (IMDs), which is compounded by the lack of genetic and clinical services for these patients. An article published in *The Egyptian Journal of Medical Human Genetics* has presented the experience of a metabolic unit at a tertiary care hospital in Pakistan. As expected, the authors found that in this unit, 78% of the children with IMD had consanguineous parents, but only 36% of these patients underwent

metabolic biochemical testing. The authors also express the difficulty in obtaining a diagnosis for these patients, as less than 20% received a definite diagnosis. They recommend that “*preventive strategies including prenatal genetic testing and cascade screening for at risk individuals can help in reducing the financial burden on the already stretched health care system of Pakistan.*”

[Read the article](#)



## End-of-life decision for newborns in the Netherlands



In the Netherlands, there is a legal provision for euthanasia of newborns in the first year of life in extreme circumstances. Whether there was an increase in the frequency of end-of-life decisions since ultrasound examination around 20 weeks of gestation became routine in 2007 is assessed in a nationwide cross-sectional study published in the British Medical Journal. The authors report that a majority of the deaths in 2010, were preceded by an end-of-life decision, which were mainly decisions "to withdraw or withhold potentially life-sustaining treatment". Only in 1% of cases drugs were administered to hasten death, a number which was much lower than the previous years. Thus the authors believe the introduction of routine ultrasound examination as well as the legal criteria that warrants deliberately ending life within one year, have led to the considerable reduction of these deaths. [Read the abstract](#)



### Parenting with a Disability: Know Your Rights Toolkit

The Christopher and Dana Reeve Foundation and the National Council of Disability have developed a toolkit to inform US parents of disabled children about their rights.

Go to:

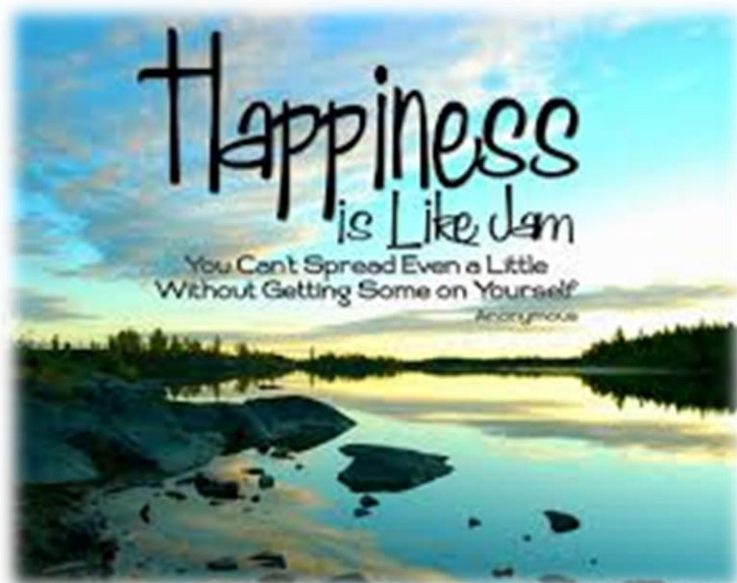
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ISMARD WARMLY WELCOMES  
YOU TO OUR FAMILY



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- 🌸 Jamie Newnam, Mucopolidosis II, Virginia USA
- 🌸 Riikka Toivanen, Finland
- 🌸 Nick Olsen, California USA
- 🌸 David Wagner, Virginia USA
- 🌸 Paul Wagner, Illinois USA









If you know of anyone who has recently been ill or had surgery or is about to have surgery, please tell us at [info@ismrd.org](mailto:info@ismrd.org)



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

-  Hollie Forman, , Alpha-Mannosidosis, New Zealand, extended and complex kidney issues resulting in removal of right kidney
-  Savahna James, Mucopolidosis, USA, kidney infection
-  Kristopher Gaffner, Alpha-Mannosidosis, Michigan, lung surgery and pneumonia
-  Mark Stark, Alpha-Mannosidosis Parent and ISMRD Treasurer, USA, knee surgery

## 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.





**ISMRD gratefully acknowledges the following people for their very generous donations**

**Without this kind of support we would not be able to carry out our mission and vision for ISMRD**

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