Magic Moments at Disney World
Society celebrates 35th anniversary at Disney conference

Outstanding Member Awards
Society recognizes those who go above and beyond as volunteers

Fundraising in Tough Economic Times:
YES, it is possible!

MPS Society Research Program
More than $3 million awarded in research grants in last decade

Have an Extraordinary Experience
Family Support program facilitates unique opportunities
Do you have a personal story or an article idea for a future issue of Courage? Please write to us and remember to send photos!

National MPS Society
PO Box 14686
Durham, NC 27709-4686

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MISSION STATEMENT

The National MPS Society exists to find cures for MPS and related diseases. We provide hope and support for affected individuals and their families through research, advocacy and awareness of these devastating diseases.

To submit information to Courage, please send text (preferably via e-mail) to the address at right. Photos should be labeled whenever possible. Please note cutoff dates. Any information received after these dates will be included in the subsequent issue.

The articles in this newsletter are for informational purposes only, and do not necessarily reflect the opinions of the National MPS Society and its board of directors. We do not endorse any of the medications, treatments or products reported in this newsletter, and strongly advise that you check any drugs or treatments mentioned with your physician.
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Pictured on the cover:
Danny, Wyatt, Braden (all MPS I)
Blair (MPS III) and Roger Chapin
Maria, Jocelyn and Angelica (all MPS IV)
Jonathan (MPS III) with Ronald McDonald
Clarke family (Mackenzie, MPS III)

Membership & Subscription Form

Name
Affected Individual’s Name
Date of Birth
Diagnosis
Relationship
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Telephone
E-mail
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Please send your membership form and check to:
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As we move into spring I notice the days are getting longer. Deb and I are brainstorming about some different ideas for our fundraiser this year. Our MPS friends have done so many events with a wide appeal to their targeted friends and donors in their communities. Events such as run/walks, golf tournaments and dinner parties are plentiful, but I love the unique events that I had never thought of. Just imagine having a phantom run where no one runs, or a party where you make and receive donated hats that are auctioned off to the highest bidder. We also have bowl-a-thons, pool parties, race car events, game nights, etc. There are so many great ideas. The clock is ticking.

Fundraising is a great and worthwhile experience. However, just when you are finished, the real work of the Society begins. After you do a fundraiser or make a donation, you need to be sure the money is well spent for the purpose it was intended. If you are going to fund research you need to make certain the process protects your donors and the funds get to the best possible project with the greatest chance for success. Your MPS Society has worked and improved the process over several years. Our funding strategies are recognized by third parties such as Charity Navigator which ranks nonprofits on their integrity and cost-effectiveness of fundraising. Our policy dictates no more that 25 percent of a fundraiser may go toward the cost of fundraising. We also are recognized by the IRS as a 501c3 charity, so your donations may be tax deductible.

All of our funding research recommendations come from our Scientific Advisory Board, comprised of the best and brightest investigators working on MPS cures and treatments, many for most of their professional lives. This group is self-regulating, assuring those researchers who receive money do not judge or rate their own proposals. This peer review process allows the selection of the most worthy grants. Once the grant is funded the Society receives progress reports and then disseminates the information to the scientific community. The process ensures the most benefit for the dollars invested. This is the course of action also used by the Canadian and U.K. MPS Societies.

The Society has collaborated several times in past years to offer a partnership grant. Partnership grants are jointly funded by the Society and a foundation (e.g., a family research foundation), or advocacy group (e.g., International Society of Mannosidosis and Related Diseases). Our Society has received recognition and praise from the National Institutes of Health in Washington, DC, for our outreach to these other foundations. Opportunities such as this ensure that our research dollars allocated to a syndrome-specific category (e.g., MPS I), and are not dormant for a year as we await additional donations required to fund a grant. It’s also a wonderful opportunity for the MPS community to join together as we strive to meet our common goal to find the cures.

As moms and dads we are desperate for cures and will do anything to save our loved ones, however, without a process of checks and balances, including a peer review process, your Society might fund proposals that have little or no hope of yielding good science to benefit all who have MPS diseases. Looking around our MPS community we see many opportunities to contribute to research funding so we must be cautious and do so wisely. We as investors in MPS research must always be careful. If a proposal seems too good to be true and offers hopes and treatments where none of our expert scientists believe there is merit, we probably should look at other opportunities.

The MPS community worldwide is a small place. We all need to stick together as one. Although Deb and I originally funded syndrome-specific research, we now choose to have our Scientific Advisory Board be the judge of what proposals are best and should be funded. Our Society funds research that has the best chance to succeed and contribute to the MPS knowledge base. Good research that has promise for one MPS syndrome today may indeed help another syndrome tomorrow. We know now that enzyme replacement therapies developed for MPS I years ago may soon start helping MPS III patients. As your board of directors would say, “Let’s not get splintered in our thinking. Instead, let us all come together to work on our real goal—to eradicate all MPS diseases once and for all.”
As we begin the new year, we welcome two new board members, Jennifer Clarke and Gordon Wingate, and say goodbye to Sharon Cochenour and Steve Chesser. The first item the board faces in the new year is setting the budget. Although there are indicators that the economic climate is changing, the board continues with a conservative outlook. We consistently heard from the foundations to which Terri wrote grants in 2009 that their funding is down as much as 40 percent. Hopefully that will change. In the meantime, the tremendous support we received in 2009 from all our donors and families who hosted fundraisers means we can continue to offer the programs upon which families have come to rely.

We will again be offering education scholarships, family assistance grants, Extraordinary Experience grants and conference scholarships. In addition to waiving dues for families, allowing everyone the opportunity to be members of our Society, we continue to offer a complimentary one-year membership to newly diagnosed families. The largest part of our budget is allocated to research. In 2010 we will be awarding more than $400,000 in research grants, some for the second year of grants awarded in 2009 and the remaining for new grants.

We are adding new segments to the 24th National MPS Society Family Conference at Knott’s Berry Farm Resort in Los Angeles, such as sibling sessions, that many of you requested. In addition, prior to the family conference is the Celebrating Your Child’s Life Experience (CYCLE) conference, a one-day opportunity for our bereaved families to join together and then attend the family conference, if they so choose. Finally, a one-day conference for adults with MPS and related diseases will be offered for the first time, with a focus on independent living issues. Registration and scholarship materials for all three conferences will be mailed and be available on our Web site in April.

It is important that we hear from you about the work we’re doing and how we can better meet your needs. The Education/Publicity Committee is developing an online member survey addressing these issues that will soon be e-mailed to you (this will be sent by regular mail to families without e-mail). Information from the survey will help us determine the future direction of the Society.

Thank you for your support!

Barbara Anderson
Thank you to members, families and friends of the National MPS Society for making 2009 a success!

Your efforts last year raised more than $280,000 for general research in our 2009 walk/run program. Fundraising events, large and small, raised more than $183,000 for research, family assistance, scholarships and other supported Society programs.

This edition of Courage includes a summary of our annual conference presentation on fundraising. The topic presented was “Creative Fundraising in a Challenging Climate.” Our families gave 150 percent throughout the year by combining both awareness and education of MPS with their fundraising skills to reach success. Educating one person at a time about MPS and related diseases will lead us to find therapies and treatments for those suffering.

As we move forward in 2010, already new families are making contact with the Society to host a fundraising event in honor or in memory of a loved one with MPS. I look forward to each and every contact. Remember, the Society is here to support you in your fundraising efforts. We have materials available to begin the planning process. I have years of experience at hosting events myself, and I look forward to helping you.

International MPS Day is Saturday, May 15. If your family would like to take the time to increase education and awareness about MPS, please call or e-mail me directly. I can be helpful with ideas to increase your viewing platform.

Laurie F. Turner

It does not seem possible that it is already 2010. Last year was an exciting one for the Society, concluding with a magical family conference in December. It was wonderful to see so many old friends, and also to be able to meet so many of you who made Disney 2009 your first conference. We are working on making the 2010 family conference to be equally as amazing. We hope to see you and your family in Los Angeles in September. For those of you wondering about future conferences, we are excited to be heading to St. Louis in 2011. The Klenke and Merrell families will guarantee we have another exceptional conference.

As some of you are aware, the programs of the Family Support Committee are very successful, and as a result we run into the possibility of depleting budgeted funds. While we wish we had an endless supply of money, we do not, and our programs’ funds may all be awarded when you apply. If your family is interested in applying for the Family Assistance Program, I encourage you to start the process. We can not guarantee that funds will be available by year’s end. Some of our other programs are only funded once a year, such as our college scholarships and conference scholarships. Please make sure you return the completed application in advance of the deadline. This is important to ensure you are eligible for funding. Contact me directly if you have any questions or need assistance.

Please make sure you look over pages 18–19 to see the holiday photos we received. It is a wonderful time to catch up with friends whom you have not talked with in a while. We also would love to hear how things are going for your family. Send in an update and make sure you include some pictures to share with us in the next issue of Courage. We love to hear from you!
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Monroe, LA, mother of Kennedy Clinton, MPS II

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Clarke family golf tournament by Cindy Clarke in honor of MacKenzie Clarke
Cornhole toss tournament by Robb and Lisa Muller in honor of Riley Muller

Dakota’s Day golf fundraiser by Clarence Chriss
Halloween fundraiser by Mercedes Johnson in honor of Wynn and Dorian Johnson’s birthday
Klenke bowling fundraiser by Kris Klenke in honor of Kraig Klenke
Lemonade stand fundraiser by Bryn Chesser and Renee Congdon
Macy’s Shop for a Cause fundraiser by Kelly Hubert in honor of Livia Grace Hubert

Mad Hatter Tea Party fundraiser by Stephanie Bozarth in honor of Annabelle Bozarth
MPS Dance Fest fundraiser by Chelsea Montgomery in honor of Lucas Montgomery

Pumpkin Harvest fundraiser by Cynthia Anderson in memory of David Hedrick

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Making Headlines

One of the goals of the National MPS Society is to increase awareness of MPS diseases. With the assistance and persistence of our members, we are making great strides. Don’t forget to let the MPS Society know when you are featured in a media story!

Serena and Autumn Cooper (MPS I) were recently featured by KUSI News, San Diego, when the Make-A-Wish foundation gave the sisters a bedroom makeover and backyard playset. To see the video, go to www.kusi.com/features/seasonofwishes/80392407.html.
11th International Symposium on Mucopolysaccharide and Related Diseases

June 23–27, 2010
Adelaide, South Australia
“Translating Research into Clinical Reality”

Hosted by Lysosomal Diseases Australia, Mucopolysaccharide & Related Diseases Society Aust. Ltd. and Lysosomal Diseases New Zealand, this international conference will include exciting scientific and family programs that will focus on the areas of newborn screening, prognostics, understanding pathology and therapeutic options. Genuine opportunities for thorough discussion and debate, for both academics and families, will be featured. For more information, visit [www.mps2010.com.au](http://www.mps2010.com.au).

National MPS Society’s 2010 Family Conference

Plans are under way for the Society’s 2010 family conference to be held Thursday, Sept. 30, through Saturday, Oct. 2, 2010, at Knott’s Berry Farm Resort Hotel in Los Angeles, CA. In addition to presentations from leading researchers and clinicians, interactive workshops will focus on topics our members have requested. Two additional conferences will be held prior to the family conference: Celebrating Your Child’s Life Experience (CYCLE) for bereaved families, and Independent Living for Adults with MPS and Related Diseases. Information and registration materials will be sent to members soon and posted on our Web site, [www.mpssociety.org](http://www.mpssociety.org). Mark your calendars now!

MPS I, MPS II and MPS III added to Social Security’s Compassionate Allowances Program

Social Security Commissioner Michael Astrue announced on Feb. 11 the expansion of Social Security’s Compassionate Allowances program, which provides expedited review of disability applications from people with severely disabling conditions.

The National MPS Society is pleased to inform you that MPS I, MPS II and MPS III are now included in the Compassionate Allowances Program along with 37 other conditions which will become effective March 1, 2010. The program, launched under Mr. Astrue’s leadership in 2008, began with a list of 50 diseases, including 25 rare diseases and 25 cancers. This is the first expansion of the disease list.

The Social Security Administration (SSA) selected the newly added 38 conditions from those recommended during public hearings and a process of information-gathering.

In 2007 the National MPS Society was invited by Michael Astrue to participate in the public hearings. Sissi Langford, parent of two MPS children, gave public testimony expressing the need for this service for all who are affected with MPS diseases. In May of 2009, Ernie Dummann and Barbara Wedehase met with Nancy Schoenberg, acting program director of the SSA Compassionate Allowances Program, and provided input regarding MPS and related diseases. The National MPS Society’s Legislative Committee is committed to continue working with SSA administration to ensure that all MPS and related diseases are included in the Compassionate Allowances Program.

For more information go to [www.socialsecurity.gov/compassionateallowances](http://www.socialsecurity.gov/compassionateallowances).
National MPS Society Marks 35th Anniversary with Magic Moments from Disney World

Annual family conference at Disney World shares information, strengthens relationships

MPS families from around the world came together Dec. 17–20 at Walt Disney World’s Coronado Springs Resort to attend the annual family conference and to celebrate the Society’s 35th anniversary. More than 650 attendees took advantage of this wonderful opportunity to build new and strengthen existing MPS friendships, and to hear insightful information on a wide range of MPS-related topics from leading researchers.

Thanks to Roger Chapin, there were Disney characters on hand Thursday evening to kick off the event. Great photo opportunities, musical entertainment by West Steiner, balloon hats, face painting, and anniversary cake and cupcakes with the Society’s signature purple frosting rounded out the celebration. Ryan and Erica Manthy from Pure 7 Studios in Destin, FL, photographed families, giving each family a commemorative Disney photo.

During the syndrome breakout sessions families became reacquainted and met many new families attending the conference. Terri Walden and her volunteers entertained the children during these sessions in childcare with Disney movies, a visit from therapeutic dogs and a fun activity making pillows. Susan Chapin arranged for childcare volunteers and entertainment on Friday, including a visit from the Orlando Magic Basketball “Stuff” mascot; Kyle the DJ, courtesy of the Kefauver family; clowns, courtesy of the Fess family; Ronald McDonald, courtesy of Ronald McDonald House; and storyteller Tom and Mr. Richard, singing children’s songs.

The conference ended with a moving remembrance ceremony with music provided by West Steiner and a prayer by Guy Walden while everyone blew bubbles. Families had the weekend to explore the Disney parks.

The conference centered around informative presentations given by experts. Following is a recap of these presentations.

Overview and Management

Joseph Muenzer, MD, PhD, professor of Pediatrics, University of North Carolina at Chapel Hill, discussed each MPS disorder, along with the clinical features presented, diagnosis and management issues highlighted for each disorder.

Management Issues

Dr. Muenzer also conducted an interactive session that allowed patients and parents to present challenging clinical problems, such as “when to shunt for hydrocephalus” and “when should a feeding tube be placed,” followed by discussions on ways of managing these problems.

Creative Fundraising in a Challenging Climate

National MPS Society Fundraising Committee Chair Steve Holland, along with Terri Klein, development director, illustrated the support available to families interested in hosting a fundraiser. MPS parents Stephanie Bozarth, Steve and Jennifer Clarke, and Eric and Vicki Merrell discussed their events, providing inspirational ideas based on their experiences.

Policy with Partners

Austin Noll, member of the National MPS Society Legislative Committee and board of directors, focused on the Society’s political efforts, including what the Legislative Committee does to effect changes in federal policy and to increase National Institutes of Health funding for MPS and other lysosomal diseases.

Treatment and Research Updates

Mark Sands, PhD, Washington University, Division of Bone Marrow Transplantation and Stem Cell
Biology, St. Louis, MO, discussed how research into the MPS disorders has progressed rapidly over the last decade. There are now a number of protein-, small molecule-, cell- and gene-based therapies that have demonstrated efficacy in both small and large animal models of MPS. Research on protein-based therapies, more commonly referred to as enzyme replacement therapy (ERT), is progressing. Not only are additional forms of MPS being examined as targets for ERT but different routes of administration also are being tested. In addition, the enzymes themselves are being modified to target different tissues including bone and brain. Small molecule drugs are being developed that can either stabilize or simply increase expression of enzymes with specific mutations. Other small molecule drugs are being developed that can decrease production of the molecules that accumulate and thereby slow the progression of the disease. A number of cell-based therapies are being explored using different sources of stem cells such as hematopoietic, neuronal and mesenchymal. Gene therapy strategies also are being developed and modified to increase the level and distribution of the deficient enzymes. This is being accomplished by modifying the gene transfer vectors and the enzymes that are expressed from the vectors.

Recent studies also are showing that combining these novel therapies that target different aspects of disease can greatly increase the efficacy of any single therapeutic approach. Virtually all of the approaches above are being used clinically either as FDA-approved drugs (ERT) or in clinical trials in MPS or closely related disorders. ERT is already available for several of the MPS disorders and is being tested in several others. Small molecule drugs that target different aspects of disease (protein instability, premature stop signals, substrate reduction, etc.) also are in clinical trials for several disorders. Although brain-directed, neuronal stem cell-based therapies have not been performed in children with MPS, this type of clinical trial has been performed in children with a related disease (Infantile Batten disease). A brain-directed gene therapy clinical trial for MPS III B is scheduled to start in Europe in the spring of 2010. A hematopoietic-directed gene therapy clinical trial recently was performed in children with a related disease (Adrenoleukodystrophy).

**Adolescence and MPS**

Kendra J. Bjoraker, PhD, LP, Division of Pediatric Clinical Neuroscience, University of Minnesota Medical School, explained that due to medical advances, more adolescents are leading productive lives despite experiencing a rare disorder. Many face complex cognitive, physical, and psychological challenges during adolescence and during the transition into adulthood. Given the variability and broad spectrum of clinical symptoms within MPS disorders, this presentation addressed general issues that adolescents with MPS may experience during this developmental period. Issues such as developing independence, transition from adolescence to adulthood, body image issues and emotional/psychological issues. The presentation provided a better understanding of adolescents with a diagnosis of MPS, offered recommendations, and generated a discussion by parents and adolescents about which determinants of quality of life warrant further educational support and clinical research.

**Living with Loss**

Michael Campbell, PhD, LCSW, Nemours Children’s Clinic, Orlando, FL, led an interactive discussion on grief and loss and ways families can cope with loss. Dr. Campbell began the discussion by pointing out that MPS impacts the typical development for families and their children. MPS families do not follow the normal stages of development that other families follow, which often leads to uncertainty, fear and isolation. The normal stages of family development are: young adult/newly married, birth of first child, transition years, empty nest and widowhood. MPS alters these normal stages forcing families to create their own path to follow. Families dealing with MPS and other life-threatening illnesses must adapt to their situation and seek the support of family and friends who embrace their situation. Parents shared their stories with one another. There was both laughter and tears.

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**Disney Recap**

Terri Klein and Kraig Klenke (MPS II)

Dorothy Mask and Tyler Sowden (MPS III)

Karina (MPS III) and Anyssa Guajardo

continued
Connecting with other MPS families who share the same challenges provides families with a network of support they may not otherwise have available. The MPS family conferences, CYCLE conferences, regional social gatherings, fundraising events, and the MPS forum all offer opportunities for MPS families to connect and form lifelong bonds with other families facing the same daily struggles.

Palliative Care

Harriet Miller, PhD, ARNP, Advanced Practice Nursing and Research, Orlando Health, discussed why palliative is sometimes referred to as “comfort care,” designed to provide supportive and dignified care for your child and family. The focus of care has shifted away from intensive efforts to cure, to intensive efforts to provide comfort and relief from suffering. In some cases it may help you to plan for a peaceful and natural death for your child. What you can do for your child and support were discussed.

Dr. Miller began her session explaining that palliative care teams are fairly new. Hospitals may have had a palliative care nurse or hospice, but palliative care teams that are patient focused and family centered have only been developed within the last five years. A child who has been diagnosed with a serious illness or life-threatening disease can begin receiving assistance from the palliative care team as early as diagnosis, regardless of their life expectancy. The goal of this team is to assist the family in providing the best quality of life possible for your child, and to provide complete physical, emotional, social and spiritual support for the entire family to enhance their capacity to cope with the life-threatening condition.

To obtain this goal the palliative care team will:

• work closely with you and your child’s primary care team to develop a treatment/care plan that best fits your family’s desires and assist you in implementing the plan.
• assist you in obtaining services through your healthcare provider.
• assist families in locating resources in their own community.
• provide the family with counseling services.
• help families transition to hospice care.
• advise families about bereavement resources when appropriate.

Reproductive Issues

Stacie Rosenthal, MS, CGC, began her presentation by explaining that chromosomes are like chapters in a book, and genes are like sentences in a chapter. Mutations are like misspelled words or the disruption of a sentence; there are all different kinds of mutations. Genes are our body’s blueprint and instructions. They produce proteins that determine how we grow, develop and function chemically. Humans have approximately 25,000–30,000 genes, which always come in pairs—one from the mother and one from the father. These genes are made of DNA.

With the exception of MPS II which is an X-linked inherited disease, all MPS diseases are autosomal recessive. Although both parents are carriers of the defective gene, the one normal copy of the gene allows the carrier parents to be symptom free.

Any child born of carrier parents has a three in four chance of having at least one normal gene and therefore no disease. Each child also has a one in four chance of inheriting the defective gene from both parents and being affected with an MPS disease. There is a two in three chance unaffected brothers and sisters will be carriers of the gene.

Ms. Rosenthal explained that MPS II is an X-linked inheritance. That is, the mutated gene is located on the X chromosome. Males are most commonly affected; females are rarely affected but may be carriers of the gene. Females who carry the gene have a 50 percent chance of passing the gene to their sons with each pregnancy. If an affected male has children, ALL of his daughters are obligate carriers and none of his sons will be carriers or affected.

It was explained that DNA testing looks for the specific mutations that cause the gene to not function correctly, while enzyme testing measures the amount of enzyme being made. DNA analysis is the preferred method for prenatal...
testing due to its accuracy. It is important to have DNA analysis done on the affected individual as it can be very useful for other family members. Ideally DNA analysis should be done prior to pregnancy.

Initial DNA testing may take four to six weeks and can cost $900–$4,000. Insurance may or may not cover DNA analysis and in most cases Medicaid is not accepted by specialty labs doing this testing. Other reproductive options include sperm/egg donation from a non-carrier family member or from a bank, adoption and DNA banking.

There are three types of prenatal diagnosis:

- **Chorionic Villus Sampling** during the first trimester, involves inserting a small catheter to obtain placental tissue to do DNA analysis. Risks include a 1 to 1½ percent chance of pregnancy loss and infections.

- **Amniocentesis**, performed during the second trimester is done by removing a small amount of amniotic fluid. It provides diagnosis of chromosome abnormality or genetic conditions.

- **Pre-implantation genetic diagnosis (PMGD)** tests a fertilized egg for a genetic condition, and only unaffected embryos are then implanted into the uterus.

PMGD requires knowledge of the mutation causing MPS and in vitro fertilization (IVF) must be used. The cost is $7,000–$20,000 for IVF and $5,000–$10,000 for pre-implantation testing; usually not covered by insurance.

Multiple cycles may be needed to get pregnant; there is a 40–50 percent chance of getting pregnant with each cycle depending on maternal age. Prenatal diagnosis by CVS or amniocentesis is recommended.

Ms. Rosenthal also discussed ethics regarding these procedures, such as storage of “extra” unaffected blastocysts and discarding of affected embryos.
National MPS Society Recognizes Outstanding Members

Each year at the family conference awards banquet, members of the National MPS Society who go above and beyond as volunteers are recognized. This group shows visionary flair in suggesting and implementing new programs, unflagging energy providing hours of volunteer service, and enthusiasm and warmth interacting with members.

The Outstanding Members are selected by the Society’s president for “devotion of time and expertise and valuable contributions to the National MPS Society.” Recipients of the Directors’ Awards are selected by the board of directors “in recognition of time and expertise.” In addition, a Lifetime Achievement award was presented to Christine Lavery of the U.K. MPS Society for her work managing a unique U.K.-wide advocacy service, supporting the needs of more than 1,200 MPS individuals in the area of home adaptations, special education needs, access to new therapies, respite care, palliative care, and pre- and post-bereavement support.

The Friendraising Award recognizes individuals who make significant contributions raising awareness about MPS or hosting a fundraiser. Presidential Awards are given by the Society’s president because of the recipients unwavering commitment to the Society and its members.

A special thanks to everyone whose support and contributions help to strengthen our Society and meet the goals of our mission.

Outstanding Member
Steve Chesser
Tom and Anne Gniazdowski

Directors’ Awards
Debra Dummann
Montgomery family
Jennifer Restemayer
Matt and Rachel Wojnarowski

President’s Awards
Denise Dengel
Eric and Vicki Merrell

Friendraising Award
Allison Restemayer
Sharon Browne
Jonathan Formica

Lifetime Achievement Award
Christine Lavery, U.K. MPS Society

Don’t miss the next MPS Society family conference!
Knott’s Berry Farm, Los Angeles, CA
Sept. 30–Oct. 2, 2010
Teagan was chosen to represent our local hospital and the addition they are building this coming year. Teagan has been a big part of the Children’s Miracle Network, helping to raise money for this great local cause. She has participated in a local network telethon and will be featured in the upcoming radiothon. Just recently they put her picture on a billboard here in our town.

Stacey Pevler
Urbana '09 was an amazing international conference I was able to attend thanks to the MPS Extraordinary Experience Scholarship Award. More than 17,000 college students representing 79 nations attended this five-day convention, held in St. Louis, MO. It was an incredible experience. This conference is run by an organization I am involved with at my college called InterVarsity Christian Fellowship (IVCF). IVCF seeks to reach college-aged students with the story of Jesus and how he can impact your life. As I went to this conference I didn’t exactly know what to expect. When I arrived I met and shared stories with people from all over the world. I was able to share with other students the struggles I go through as a disabled person, but yet still I’m able to live life fully and happily. The main focus of the conference was reaching people in poverty and learning how to love and help people around you. They talked about how, in the college atmosphere, the community that one experiences is unlike any you will most likely experience again. It was cool to think about the opportunities I have for friendships and relationships right now, and how I can better serve and love the people I know. I learned so much while I was there and it has encouraged me to get more involved at my university. I have tried and succeeded at managing my time better which has given me more time to invest in relationships with other students. This has given me so much joy this new semester. Urbana taught me these things, and I am so grateful to the MPS Society for aiding me in this trip. I would like to encourage other students who have an MPS disorder to also apply for the Extraordinary Experience scholarship and go to a camp, conference or convention that will help them live life more fully.

I would like to share an idea I had for an MPS awareness raiser. Starbucks sells insulated coffee mugs ($10) that you can make and print your own collage at Snapfish (FREE) to fit inside. Mine says, “Ask Me About MPS” and of course I take it everywhere. Being a student nurse I have so many doctors and other healthcare professionals asking me about MPS!

Donna Kay Langan, mother of Tyler (MPS III)
Fundraising in Tough Economic Times: YES, it is possible!

Statistics abound about how difficult things are for nonprofits trying to raise funds. From large organizations to small, it has been a tough year to receive corporate donations. The good news is that individual donors are continuing to give to the groups they hold close to their hearts. Economists feel that people want to give where they know their hard-earned dollars will do the most good.

This is very good news for those of us who are family, friends and advocates for the National MPS Society. We know we have counted on our family and friends to support our very special cause. But we need to become more savvy in our fundraising efforts.

According to fundraiserhelp.com, we need to start by thanking our previous donors time and again for their support. We can’t thank them too many times. We also need to let them know our previous results. Tell them specifically the amount of money your fundraiser brought in. The amount doesn’t have to be large to show how their efforts helped. Fundraiserhelp.com says that telling your supporters how much you raised and specifically where the money went will allow them to share in your feelings of success. It shows them that you were a good steward of the much-needed dollars.

Marc A. Pitman, author of Ask Without Fear!, says fundraisers in this economy need to be positive when asking or recruiting. His theory is to not sound desperate or apologize, but to tell stories about our children and families and their strengths. As passionate advocates we can easily give many examples of how our children inspire us every day. Pitman also asks us to be honest about ways we can cut our costs in fundraising, thus sending the message that we are sensitive to families and businesses facing tough times.

Getting started

If you have held a successful fundraiser in the past, you don’t have to change what has worked for you. If you have been hesitant to have a fundraiser, start small and do something you have an interest in. Our own MPS families have had some wonderful and successful fundraisers. Those include:

Cookie fundraiser, piano recital, trivia night, Silpada jewelry sale, golf fundraiser, California Pizza Kitchen, jeans day at work, Krazy socks, bake sale, Pampered Chef, online auction, Swings and Shots for a Cure, Tupperware fundraiser, Mad Hatters Tea Party, Pumpkin Harvest, cornhole tournament, lemonade stand, bowl-a-thon, dance-a-thon, Macy’s Charity Day, wedding fundraiser, Courage Premier Gala and Dress Down Day.

In addition, 21 families held walk/runs in 2009 and raised more than $285,000.

There also are Web sites that can offer wonderful fundraising ideas. Some Internet ideas are: casino night, cow chip bingo, golf ball drop, 50/50 raffle, grocery bagger for a day, selling flowers for Valentine’s day, dog wash…the possibilities are endless!

Let your imagination run and think of creative ideas that may be unique to your area. As previously mentioned but can’t be stressed enough, every dollar raised brings us closer to a cure!

Experts advise that fundraising in 2010 can be rewarding for all involved if we acknowledge tough times but make our case for funds positive. When asking for donations from friends and stores, don’t ask for a specific amount; let them control what they feel they can contribute.

Let our families and children be our inspiration for successful fundraising in 2010!

by MaryEllen Pendleton
Annual Fund Campaign Raises $73,500 in 2009

Every year support for the Annual Fund increases. This critical component of the overall funding strategy keeps the organization strong. Through your tremendous support during difficult economic times, you have shown the Society that you understand the need of our families and those affected by MPS and related diseases. Your gift will provide support to families through our Family Assistance Program, provide funding for federal advocacy initiatives within our legislative program, and provide much-needed operating funds.

For all of you who reached into your budgets and donated to the Annual Fund in 2009, the Society gives our sincerest thanks! We can continue working strong within our mission, supporting families and funding research for a cure.

Philanthropist $1,000 or more
Ron and Barbara Dengel
Ernest and Debbie Dummann
Dutch’s Daughter, Inc.
Tom and Anne Gniazdowski
Grace for a Cure, Inc. in honor of Grace Bellontine
Charles and Kendra Lesta
in memory of Christopher Lesta
Robert and Marjorie Lovell
Douglas Macleod
Joe and Jan Melnyk
Mark and MaryEllen Pendleton
Raymond and Barbara Alpert Foundation
in honor of Bryce Chesser
Tracy Szemanski
in memory of Clinton and Zachary Szemanski
Amy and Klane White
in memory of Susannah White

Leader $500–$999
Judith and Art Ackerman in honor of Jack Frye
Ann Alden in honor of Jack Mahoney
Mel and Millie Anhalt
Joel and LeeAnn Bernbaum
in memory of Mark Bernbaum
Rob and Diane Cassil
in memory of Matthew Cassil
Julie Dopheide in honor of Julia Dopheide
Rod and Kathy Finzel in honor of Mitchell Finzel
Steve and Amy Holland
in memory of Spencer Holland
Elizabeth Karas
in memory of Joseph and Jonathan Karas
Wendell and Karen Keith
in memory of Amanda Keith
Larry and Susan Kirch
Mary Jo Page in memory of Charles Page Sr.
Bernard Ray
Louise Reitan in memory of Spencer Holland
Nina Rogers in honor of the Holland family

Robert and Suzanne Washburn
in honor of Erik Fletcher
Tom and Kim Whitecotton
in honor of Scotty Whitecotton

Volunteer $250–$499
Mary Starr Adams
Laird Barber in honor of Mitchell Finzel
David Beatty in honor of Danny Miller
Cheryl Bien
John, Jenny, T.J. and Molly Birmingham
Steve and LaVonne Blechinger
in memory of McKenna Bailey
Michael and Elizabeth Burton
in honor of Bryce Chesser
Patricia Dickson
Scott and Peggy Dionne
Charles and Josephine Ellard
in honor of Karina Guajardo
Bart and Sally Finzel in memory of Harold Espinal
Donald and Romona Finzel
in honor of Mitchell Finzel
Janet Forde
Stephen and Kimberly Frye
Matthew, Roberta and Dexter Jenkins
John W. Hancock Foundation
in honor of Bryce Chesser
John and Janet Kappel in honor of Debbie Kappel
Joel and Lisa Klessens
in memory of Morgan Klessen
Fred and Joyce Koehler in memory of Ryan Mask
Lori Caldwell LeDoux in honor of Matthew Caldwell
Wayne and Paige Lewis in honor of Madison Lewis
Robert Harvey and Roxanne Maffitt
in honor of Davis Barkley
Gary and Sunni Markowitz
in honor of Connor Anhalt
Maria Meconi in honor of Denise Dengel
Austin and Dorothy Noll in honor of Austin Noll IV
Alan Pendley in honor of Bryce Chesser
Naureen Sayani

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James and Sheila Slawson
Ruben Solis
Susan Taylor in honor of Olivia Lovell
David and An Tootill
USA Couriers
Kenneth and Barbara Velten
   in honor of Bryce Chesser
Helen and Bill Vespe in honor of Caitlin Vespe
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Friend $100–$249
AG Communications, LLC
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David and Stacey Aronson
   in honor of Mitchell Finzel
Stephen Aselage
Robert and Marjorie Austin
   in honor of Matthew Caldwell
Mark and Alberta Balliet
   in memory of Richard and Jennifer Balliet
Jane Barker, MD
Dwight and Debbie Barkley
   in honor of Davis Barkley
Amy Barkley in honor of Davis Barkley
Richard Barrett
Ruth Bauerle in honor of Freeman Bauerle
Patricia Baxendale in honor of Molly Birmingham
Brad and Cherre Bickham
   in honor of Loren McClelland
Mike and Grace Bodura
   in honor of Michael Bodura
Thomas and Diana Boland and family
Katherine and Joe Bonville in honor of Allison Kirch
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Linda Burtt in honor of Sasha Segal
Mark and Stephanie Caldwell
   in honor of Matthew Caldwell
Anthony and Donna Cataldi
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Tony and Shirley Catanzarite
Michelle and Don Churchill
Michael, Margaret and Grace Ciacciarelli
   in memory of Max Ciacciarelli
Ross and Bela Coddington
   in honor of Karina Guajardo
Michael and Claire Constantine
   in memory of Chris Rosseau
Kayla Cotkin in memory of Elliott and Martin Cotkin
Bob and Laura Cowin
Kevin and Djuna Crawford
   in honor of Amanda Crawford
Bill and Jeremy Crockett
   in honor of Matthew and Camden Crockett
Linda and Dan Day in memory of Scott and Greg Day
Robert Desnick
Ray Dettmer
Jerry and Sue Deutser
John and Elissa Di Carlo
Sharon Dipkin in honor of Tyler Langan
Mr. and Mrs. Dols in honor of Nathan Roma
Bonnie and William Doster
   in honor of Mitchell Finzel
Trent and Amy Dummann
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Carla Ellard in honor of Karina Guajardo
Toni Ellard in honor of Karina Guajardo
Robert and Amy Farrell
   in memory of Joe and Maggie Langford
Gail Finney
   in memory of Clinton and Zachary Szemanski
Nancy and William Fountos
   in honor of the Cochenour family
Betsy and Steve Fowler
   in honor of Kimberly Fowler
Donald and Mary Jane Fowler
   in honor of Kimberly Fowler
Ronald and Sheila Francis
Noelle and Jonathan Frye in honor of Jack Frye
Shane and Jenifer Gibson in honor of Clara Gibson
Thomas and Jean Gniadkowski
   in memory of Danny Gniadkowski
Russell and Catherine Goodale
   in memory of Danny Gniadkowski
Blake and Ashley Graeber
   in honor of Bryant Graeber
Luis and Angela Guajardo
Charles and Shirley Hagemann
   in memory of Tom Hagemann
Johnathan and Brenda Haggett
   in honor of Zachie Haggett
Sheryl and Gerald Hall in honor of Julie Hall
Billy and Diane Hardison in memory of Brian, Christopher and Eric Hardison
Shelby and Tim Haslett
   in memory of Douglas Sampson
Mark Hopkinson in memory of Mark Bernbaum
Todd and Jennifer Howard
   in honor of Joseph Delvaux
James and Saundra Huff in honor of Sasha Segal
Mike and Joanne Huff in honor of Sasha Segal
Steve and Pat Irish in honor of Jacob Irish
Barbara M. Ives in honor of Mackenzie Clarke
W. Andrew and Lauran G. Jack
   in memory of Kyle Jack
Gary and Paula Kacer in honor of Kaylee Kacer
Jim and Mary Kalteux
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Kevin and Mary Kimmet in honor of Andrea Kimmet
Terri Klein
James Kreimers and Sally Rullman
   in honor of Ian Smith
John and Joyce Lane
Robert and Katie Lawson
   in memory of Audrey Lawson
David Lebec
Kenneth and Sandra Ledford
   in honor of Amanda Crawford
Monica Leone in memory of Kristofer Arnold
Kay and Joel Levy in honor of Connor Anhalt
Lloyd and Cheryl LoCascio
   in memory of Logan LoCascio
Gene and Cynthia Logan
   in honor of Rhianna Logan
Robert Maiden and Becky Tanamachi
Barbara and George Malina in memory of Glen Malina
Eileen Marchica in memory of Fran Greenberg
Pamela Eddy and Robert Martineau
   in memory of Danny Gniazdowski
Stephen and Marie McClurg
   in memory of Dylan McClurg
Ray McPartlin
Bernard and Evelyn Morgan
Richard and Eva Morgan
Ron and Chris Morrissey
   in memory of Cade Morrissey
Gary Mortensen
Elizabeth Neufeld
W.M. and Katherine Noble
Austin and Cheryl Noll in honor of Austin Noll IV
Anne Novak
Ann O’Malley in honor of Allison Kirch
Sharon O’Connell
Margaret Offutt in honor of Marcus Garvin
Thomas and Barbara O’Malley
Karen Patterson in honor of Spencer Gates
Kent and Nina Peter
Jeff Peters in honor of Erin Peters
Anthony and Latona Pisa
Thomas and Sharyln Pope in honor of Lauren Pope
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Michele Purves in honor of Tristan Heinz
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Sergio and Angela Stasi in honor of Erin Peters
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Merlin Tracey in honor of Marcus Garvin
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Kenneth and Victoria Warner
   in memory of Bradley Chapman
Meghan Wedehase Stark
Paul and Kristin Wehrle in memory of Peter Wehrle
Tom and Theresa Weisenbach
Claude and Roselyn Wells
   in honor of Matthew Wells
Gary and Tracy Wells
John and Ellen Williams
Lynn Ann Witt

Donor $26–$99
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Richard and Claudia Ackerman in honor of Jack Frye
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Dean and Kathy Aker in honor of Samuel Aker
Debbie Allen
   in honor of Lindsey, Hannah and Karen Efird
Ralph and Martha Anderson
   in memory of Amanda Keith
George and Gail Anderson
   in memory of Amanda Keith
Gerald and Susan Anhalt in memory of Nell Eiser
Timothy and Michelle Annis
   in honor of Stephanie Annis
Leonard and Barbara Barcousky and family
Mary Ellen Barringer
Don and Nina Bergquist
Lorraine and Frank Bien
Todd and Nicole Blancheri
David and Stephanie Bowser
   in honor of Maddy Wigglesworth
Don and Frances Bryant
   in honor of Bryant Graeber
Kevin and Kim Burke in memory of Edie Burke
Caroline Butz
Central Rockies Schipperke Club
Steven and Jennifer Clarke
Esther Conrad in memory of Joshua Williams

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in honor of Cristol Barrett O’Loughlin
Barbara and Ron Crecco  
in memory of Mark Crecco
Estelle Culpepper in memory of Geoffrey Anders
Bill and Laura Dapper
Barbara Dodane
Jeanne and Maurice Drew  
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Tara and Jack Elston in honor of Jake Elston
Darla Elswick
Brian Engel in honor of Erin Peters
Pam and Ben Feldman  
in honor of Amy and Davis Barkley
Sergio and Fernanda Felix  
in memory of Diana Rodriguez
Patrick and Amy Fitzgerald  
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Edward Flynn
Anna Funkhouser
Dennis and Chris Goggins
Lee and Tammy Gottschall  
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Greg and Toni Graham  
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Natalie Haggett in honor of Zachie Haggett
Jeffrey and Barbara Harrell  
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Lena and Rollie Harris  
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Ardis and Henry Ketterer in memory of Peg Ketterer
Gary Kirch
Andy and Meg Kramer
Scott and Gabriella Lich
Edward Ludloff
Patricia Madeux
Joseph and Jeanne Mallia in honor of Sarah Mallia
Don and Carol Manning  
in memory of Kyle Joe Manning
Michaelle and Wolfgang Mauch  
in memory of Paul Adams
Ward McKeithen  
in honor of Loy and Susan McKeithen
Judy McKinstry in memory of Adam Hale
Joe and Paige Migliozi  
in memory of Christopher Migliozi
David and Lorraine Miller  
in memory of Clinton and Zachary Szemanski
Jacqueline Miraglia in memory of Andrew Watkins
Troy and Dianne Mitchell
Scott and Patricia Morris
Nicole Morrissey  
in memory of Cade Morrissey’s 9th birthday
Michael and Anita Muonio  
in memory of Joseph and Zachariah Muonio
Emmett and Pauline Murray  
in honor of Kimberly Fowler
Carol Nareski
Beverly Nivens in memory of Edie Burke
Mary Anne Oliger in memory of James Oliger Jr.
Eileen and Larry O’Steen  
in memory of Ryan O’Steen
Anthony and Pamela Paladino  
in honor of Caden Mitchell
Jeanne and Bruce Palzer in honor of Brianna Palzer
Robert Park and Elizabeth Binkley
Ronda Paullin
Teresa Peecook
Carolyn Leer Porzel  
in memory of Robert Alvarado
Lawrence Pung in honor of Austin Noll IV
Stephanie and Edmund Rabuse  
in honor of Paul Adams
Stella Reeve in honor of Kristen Reeve
Bonnie and Ralph Rennaker
Fred and Donna Reyes  
in memory of Clinton and Zachary Szemanski
Gary and Bonita Ritondaro  
in memory of David Hedrick
Joseph and Catherine Rizzo  
in honor of Sarah Mallia
Shawna Robson
Kay Rogers
Suzanne and Ronald Ruchti
Edward and Carol Ruhnke  
in honor of Carly Ruhnke
Thomas and Carolyn Russo  
in memory of Stephanie DeAngelis
Doug and Lauren Sanford in honor of Cara Sanford
A.L. and Angela Sarantinos
Mark Schlafer
Ellen and Neal Schoeppe
Greg Sharrits in memory of Edie Burke
John and Jennifer Shepherd
Magill Shipman
David and Rebecca Silkey
Burt and Leenie Skolnik

continued
Julia Smith in memory of Greg and Scott Day
Pauline Stukus in honor of Sarah Mallia
Peter and Dagmar Suhr in memory of Paul Adams
Donald and Rachel Swicker
  in memory of Joseph and Jonathan Karas
Ellis and Jeanette Taylor in memory of Shauna and
  in honor of Jonathan Taylor
Nita Todd
Ruth and Matthew Travis
Eric and Laurie Turner
Michael and Veronica Vacca
  in honor of Richard Rotelli
Marie Wegener
  in memory of Laura and Michael Sheekey
Joan Werner in memory of Mark Bembaum
Foster and Mary Ann Wick in honor of Clay Howard
David and Diana Zimmerman
  in memory of Sara Zimmerman

Patron $5–$25
Bob Ahern
Wade V. Baise
  in memory of Erich and Garrett Baise
Charles Bell in memory of Paul Adams
Steven and Teresa Bell
Rose Ann and Dominic Bencivenga
  in memory of Stephanie DeAngelis
Walter and Olive Blough
Jimmy and Helen Carr in memory of Tyler Deskins
Steve and Karole Chesser
Kent and Karlene Classen
  in memory of Karlee Rae Classen
Dorothy and Tilford Cobb
Bob and Denise Crompton
  in memory of Kelley Crompton
Mike, Lisa, Maria, Molly, Sarah, Johnny and
  Gracie Day in memory of Greg and Scott Day
Marjorie Ditmore
Geri Lynn Edwards
Martin and Ann Elliott
  in memory of Marty Elliott Jr.
Wilbur and Irene Erhardt in honor of Matthew Wells
Olen and Donna Evans
  in honor of Blake and Paige Halk
Peter and Elena Fairchild
Geraldine Faucett in honor of Michelle Hopkins
Lois Finney
  in memory of Clinton and Zachary Szemanski
Barb Fisher in honor of Allison Kirch
David and Leesa Galloway
John and Jennie Gladysz
  in memory of Danny Gniazdowski
Jeff Granzotto
Bob Guletz in honor of Sabrina Gabriel

Cindy and Steve Hamblen
  in honor of Kimberly Fowler
Marlys Herring in honor of Bob Simmons
Robert and Marguerite Iannacone
  in memory of Kris Arnold
George and Linda Johnson
  in honor of Amanda Crawford
Russell Kacer in memory of Kaylee Kacer
Terry Kalna
Rick and Beth Kania
Brian and Kristine Klenke
Louise and Edward Kofron in honor of Erin Peters
Pam Kovach in memory of Alleis Wilson
Clint and Nikki Kremer in honor of Ava Kremer
Carol Kuhn
Paul and Alicia Leach in memory of Ryan Mask
Ralph and Lenore Liff
Barry Lyons in honor of Rachel Cumpain
James and Eleanor McCaffrey
Madeline and Merritt Moseley
  in memory of Edie Burke
Bernadine Nardin in memory of Daniel Nardin
Rena Oley in honor of Zach Haggett
Rick and Amy Owen in honor of Eric Fletcher
Mary Page in memory of Danny Gniazdowski
Patti Pair in memory of Audrey Lawson
Dave and Michelle Patterson
  in honor of Karina Guajardo
Charles and Ellyn Phillips
  in honor of Mel and Millie Anhalt
Douglas and Mary Pica
Terry and Nicole Rode in honor of Kraig Klenke
Barbara Russo in memory of Amanda Keith
Mildred Ryan
Paul and Kathy Rysz
Richard and Ellen Sidman in memory of Ryan Mask
Leonard and Linda Terrien
Anita Tomren
Carl and Mary Ann Traina
  in memory of Michelle Hopkins
Rick and Rebecca Wildman
  in honor of Matthew Wells
Bill and Fran Woody
  in memory of Danny Gniazdowski
Robyn and Paul Young
Raymond Young in honor of Kaylee Kacer
Andrew and Louise Zygmuntowicz
  in memory of Amanda Keith
Dakotah’s Day Golf Outing

We lost Dakotah Arthur Smith on April 20, 2006. He passed on the operating table as the doctors were in the process of placing a shunt in his little head.

December of that year, we, Clarence and Peggy Chriss (Dakotah’s grandparents) decided to have a fundraiser for the MPS Society to honor our beautiful little grandson. On April 20, 2007, we had the first Dakotah’s Day and MPS Society Golf Outing.

We were unsure of the outcome. We were afraid. We have never done a fundraiser before. We did not know the number of golfers who would come. The weather was another big concern. There was talk of a huge nor’easter storm coming through the area. We did not know the number of sponsors we would get or what course would accommodate us. We sent out mailers, placed an ad in the local newspaper and contacted all the people we knew. We prayed and hoped for the best.

With great success, we got sponsors, volunteers, the course, caterers and door prizes. The golfers came and they kept coming. Our broker asked, “Where did all the people come from?” I smiled and said, “God and Dakotah sent them.” We had more than 130 golfers. Most importantly the weather that day was great. The sky opened up to a total “Dakotah blue sky” as we like to say. Blue was Dakotah’s favorite color. Tears of joy and success were flowing from our eyes. When it came time to send everyone out, I could hardly contain my emotions.

When it was over and everyone returned from the course for dinner, we introduced the committee and the volunteers. We gave out the skill prizes. It was stated by the head of the committee that at that moment we had raised about $11,000 for the Society. However, that was our first year and we sent all the money to the Society and we never received a donation amount. Since then, we have corrected the way we do things. The following two years we kept an account of what amount was given.

We were pleased to send to the Society a check for $8,500 from the 2008 golf outing. This year, 2009, we are sending $4,000. We had a great turnout of golfers, but the sponsors were not there.

The wonderful participants were inquiring about the following year. So we decided to do it again in 2010. We pray that our heavenly Father will shine down upon that day and the ones to follow. We also pray the outcome for future outings will net more funds for the Society. We will give our all to insure that Dakotah’s name will always be remembered and the Society will have funds to help a child and their family.

There are so many people we want to thank: Suzette Kostjal, Michele Addams, Michelle Meckley, Linda Melham, Judy Lusk, Kathy Vandenbrugh, Jeannie Jameson, James Priar, Jeffrey Smith, Spike Hensel, Shirley and John Sharpe, Lyn Robinson, Linda Judd, Allen and Vivian Muchmore, Evelyn Kalbfleisch, Linda Cullen, all the participants and sponsors, the Armitage golf course and its staff members, and The Caddy Shack.
For a decade, National MPS Society members, families and friends have committed to walk/run fundraisers throughout the country. Each of these events has brought us one step closer to finding treatments and cures for MPS and related diseases. We continue to increase awareness and funds for research by educating one person at a time.

This program continues to be a success year after year. Remarkably, these events have raised more than $2,806,000 since they began in 2000. In 2009, 21 walk/runs generated approximately $285,000. Whether large or small, each event was successful at raising awareness, reaching out among the community and involving thousands of people in cities nationwide.

The Society thanks all of the coordinators and many volunteers for their hard work in making each event successful.

5K for Katie/Do It for Danny
Oct. 11, 2009
Event Coordinators:
Linda Shine and Amy Miller

Held in Downington, PA, the 10th anniversary of the walk/run program is a tribute to Linda Shine in memory of her daughter, Katie. Linda began the walk/run program for the National MPS Society. Amy Miller is the co-coordinator of this annual event in honor of her son, Danny. They raised more than $20,000 for MPS research. This year the above logo was imprinted on T-shirts with names of all the children who have succumbed to MPS and related diseases since the first run.

10th Annual Run for Erin
Oct. 3, 2009
Event Coordinator: Stacy Peters

The Peter’s family, along with more than 50 volunteers, hosted their 10th walk/run. The event is held in honor of their daughter, Erin. Since 2000, the event has been held at Woodstock High School and has raised more than $200,000 for research. This year participants ran, walked and raised more than $17,000. Run for Erin is held annually and has a board of directors. Each year the Peter’s family finds many rewards in hosting the event as they are able to combine it with a family reunion.

Andrew’s Walk ‘n Roll for MPS
Aug. 29, 2009
Event Coordinators: Sharon Cochenour and Barbara Pryor

Held in Clarksburg, OH, this seventh annual event raised more than $3,500 in honor of Andrew Cochenour. The event includes a family picnic for attendees.

continued
BioMarin/MPS
“Run for Your Life”
Sept. 27, 2009
Event Coordinator: Kathie Ward
BioMarin hosted its seventh annual run/walk in Novato, CA. The event hosted 111 participants and 15 volunteers with tremendous support from corporate donors and families. The event raised more than $49,000.

Evan Reed Family Fun Run
Oct. 24, 2009
Event Coordinator: Laura Hiler
The 4th Annual Evan Reed Family Fun Run, held in Mountain Grove, MO, raised more than $1,000. The event hosted 73 participants and was a brisk 41 degrees.

Heartland Run for MPS
Sept. 19, 2009
Event Coordinator: Emmy Hogue
Organized by Iowa State University students in honor of MPS research completed by Dr. Matthew Ellinwood, this Ames, IA, event raised more than $1,300 for research.

Kassi’s Kause
May 30, 2009
Event Coordinators: Trisha Offenbacher and Amy Adams
Kassi’s Kause was a first-year event held at Travis Air Force Base in California. This event had children’s activities, food vendors, a silent auction and brought many MPS families together from the area. The event had more than 200 participants and 50 volunteers, and raised more than $6,000 for research.

Krusade for Khunsha
Sept. 19, 2009
Event Coordinators: Khunsha Numan and Vicky Mansfield
This first-time walk/run was held in Pittsburgh, PA, and was hosted by high school senior Khunsha Numan (MPS IV). The event had wonderful school support, 58 participants and raised $3,000.

Jack’s Run for MPS
Sept. 19, 2009
Event Coordinator: Heather Alden Pope
The 4th Annual Jack’s Run for MPS was held in Eden Prairie, MN. More than 275 participants joined 50 volunteers for race events, a silent auction and lunch. The event was covered by TV KARE 11 and raised more than $17,500.

Laps for Lucas
Aug. 30, 2009
Event Coordinators: Stacey and Lew Montgomery
Families joined the Montgomery’s for the 4th Annual Laps for Lucas in Cedar Rapids, IA. This year’s walk/run raised more than $4,500. The Montgomery family has raised more than $78,000 for MPS research in the past three years.

MacKenzie’s Run for MPS
Oct. 11, 2009
Event Coordinators: Steven and Jennifer Clarke
More than 300 participants in Poquoson, VA, and surrounding communities came out in support of the 7th Annual MacKenzie’s 5K Run/Walk for MPS. The cloudy skies and rain didn’t dampen the spirits of the crowd. Family and friends helped as well as volunteers from the Poquoson Kiwanis club. The high school was well represented by runners, walkers and volunteers. MacKenzie’s amazing team lined the streets with posters, bringing awareness to MPS. Everyone enjoyed home-baked goodies. The event raised more than $12,500.

Miles for MPS
Sept. 12, 2009
Event Coordinator: Laurel Radius
Miles for MPS celebrated its eighth annual walk/run in Grand Rapids, MI. This event is in honor of brothers Chip and David Radius with MPS II and raised more than $6,000 for research.

MPS and Mito Walk/Run 2009
Sept. 19, 2009
Event Coordinator: Kristin Myking
In Apple Valley, MN, families gathered for the fourth annual walk/run to raise approximately $1,100 for research. They have enjoyed raising awareness among the community and hope to raise funds for research in 2010 with a charity dinner.

continued
MPS Run for Their Lives
Oct. 17, 2009
Event Coordinators: Scott Hardin and Steve Holland

MPS Run for Their Lives was held in Fort Worth, TX, for the eighth consecutive year. More than 290 participants and 40 volunteers came out on a beautiful day to raise awareness and funds for MPS. A western theme was incorporated into the event. Courage medallions were provided to the many children who came to the event, which raised more than $9,500.

MPS Walk/Run LA
Oct. 17, 2009
Event Coordinator: Tami Slawson

On a hot day in October many families and friends came out in support of the 9th Annual MPS Walk/Run LA. 450 participants with many volunteers raised more than $34,000. The annual event hosts many MPS families from around California and is followed by a regional picnic and family meeting.

Nathan’s North Carolina Walk/Run
Sept. 26, 2009
Event Coordinators: Emily Trivette and Terri Klein

This event was held in Boone, NC, in honor of Nathan Bivens with MPS II. The families worked very hard throughout the community raising awareness and funds for MPS. On the day of the event 100 participants and many volunteers raised more than $12,000 for research. The event included a silent auction and luncheon for families and friends of the Bivens. The coordinators are very thankful to all media formats that contributed their time to spreading awareness throughout the community.

Post Office Café Annual 5K Run/1K Fun Run for MPS
Oct. 17, 2009
Event Coordinator: Kerri Rose

Held in Babylon, NY, this event raised more than $16,000 in honor of Mark and Casey Lessing for research.

River Run for Ryan
Sept. 5, 2009
Event Coordinators: Jonathon and Marie Hunt

This second-year event held in Guttenberg, IA, raised more than $13,000. The event is held in honor of Ryan Hunt and had more than 200 participants and 30 volunteers on a beautiful sunny day.

Ryan’s 10th Annual Run for MPS
Oct. 10, 2009
Event Coordinators: Dorothy Mask, and Fred and Joyce Koehler

This year was the 10th anniversary for Ryan’s Run for MPS. The event is held each year in Sellersville, PA. There were 85 participants and 20 volunteers who came out on a rainy day to raise awareness for MPS and $7,000 for research. Dorothy does not worry about how much money they raise or about how many people show up each year. What is important to her is having the opportunity to teach people about MPS. Dorothy continues to do fundraising for the MPS Society because it helps release the feeling of helplessness. It allows her to focus her energy on something positive and it gives her a great deal of satisfaction to know that she is doing something to find a cure for this devastating disease.

Sowden Family & Friends Walk for a Cure
Sept. 13, 2009
Event Coordinators: Josh and Sheri Sowden

On a beautiful sunny day in Auburn, MI, the Sowden family hosted their second annual Walk/Run for MPS research. The Sowden family also hosted a golf tournament to raise awareness for their Walk/Run event. They had 185 participants and 15 volunteers. The event is held in honor of their sons, Ethan and Tyler, and raised more than $24,000.

Strides for Sara
June 6, 2009
Event Coordinator: Monique Dickerson

The 2nd Annual Strides for Sara was held in Fair Haven, NY, on a beautiful summer day. There were 229 participants and 33 volunteers. The event, which raised more than $3,900, included a raffle, and hotdogs and beverages at the finish line. The Dickerson’s are thankful for the community support and look forward to next year’s event!
Ways to GIVE

• Renew your membership or sponsor another family
• Gifts in honor of a special person
• Gifts in memory of a special person
• Matching gifts through your employer (check with your human resource office)
  1. Request a matching gift form from your employer
  2. Complete the employee section of the form
  3. Mail to the Society and we’ll do the rest
• Contribute through the Combined Federal Campaign if you are employed by the federal government — CFC #0845
• Designate the Society as a member of your local United Way. You will need to supply them with the Society’s name, address and Federal ID number (FEIN #11-2734849)
• Annual Fund donation
• Major gift (usually 10 times that of your Annual Fund gift)
• Planned gift
  1. Bequest in your will
  2. Charitable remainder trust or charitable gift annuity
  3. Charitable lead trust
  4. Life insurance policy
  5. Gift of appreciated assets (stocks, mutual funds and bonds)
• Gifts may be applied to the Society’s general operating purposes or restricted to one of our designated programs.

CONTACT: terri@mpssociety.org or 877.MPS.1001

National MPS Society Receives Three-Star Charity Rating

Having received the prestigious four-star Charity Navigator rating for the last three years, the National MPS Society learned in December 2008 that we were awarded a three-star rating, indicating that we “exceed or meet industry standards and perform as well or better than most charities in its cause.” The board of directors has reviewed Charity Navigator’s detailed ratings table and scoring system in order to identify ways to earn a few more points to regain the four-star rating.

Fundraising Reminders

• Don’t forget to submit a brief article for Courage about your fundraising success stories and suggestions—they are terrific resources for other families planning events.
• Check out the fundraising section on the Web site for more information or to post your event.
• For free MPS Society brochures and donor envelopes, or to submit information for the Web site or Courage, send an e-mail to Terri Klein at terri@mpssociety.org.

Keep in mind—Casual Dress for MPS, the Annual 5K Walk/Run and the Annual Fund are great ways to raise money for the National MPS Society.
A Warm Welcome

A Warm Welcome introduces new Society members/families and also offers members yet another chance to connect with one another. If you have a moment, please contact the new family to say hello and welcome them into our MPS family. If you have been a member for a longer period of time, but would like to introduce your family to the rest of the Society, please e-mail Laurie Turner at laurie@mpssociety.org.

The National MPS Society welcomes the Hubert family.

We are the Hubert family from Roscoe, IL. My husband Jake is a high school assistant principal. I am a stay-at-home mom with two beautiful girls: Livia Grace (2½) and Finley Faith (8 months). Before I was blessed with my current situation, I was a surgical technologist.

Livia was diagnosed with MPS III A on July 8, 2009. Finley was 8 weeks old. Our lives were turned upside down and we still have our moments of “How can this be our life?” Livia hit all of her developmental milestones as a baby until it came to walking. She did not walk until she was 18 months old. Livia has “episodes” that we thought were seizures. After neurologic exams, no seizure activity was noted and the doctor said it was a habit she had formed. When her speech wasn’t developing like we thought it should, we sought out early intervention for speech therapy. Her therapist suggested that Livia had some characteristics for which we might want to see a geneticist. I shrugged it off. We had her hearing tested and it was indicated she may have a slight hearing loss, so we were referred to an ENT. This doctor thought she had fluid build-up and that tubes would help with her hearing and, in turn, speech delay. We thought this was going to solve all of our problems. After Liv’s surgery, the ENT informed us that during her surgery he came across some things that were questionable and we might want to follow up with a geneticist. This was the second time we heard geneticist, but it still didn’t register that something was wrong. During one of her routine well-baby checks, our nurse practitioner mentioned seeing a geneticist. Third time was a charm for me and I scheduled the appointment. I’m pretty sure all of you know where the story goes from here. A positive urine test and blood test confirmed the diagnosis. Finley was tested immediately and her results were that she was like her mommy and daddy, a carrier.

This diagnosis has changed our lives in so many ways. We’ve always had a strong faith, but it has been renewed 10-fold! We’ve also decided that this diagnosis does not define our family. This is in our life, but it does not rule our life so that we can’t function. We now know how important it is to have more good days than bad. We are such an active and happy family. It’s not often you find us sitting still. Livia’s diagnosis has opened our eyes in a way most people don’t get to experience. When we were first learning about Livia’s condition, I kept focusing on the future. I kept thinking about all of these horrible things that MIGHT happen to her. No one knows what their future holds. I’m able to “LIV” each and every day to its fullest. We get to experience our lives and the lives of our children in a way that was different before July 8, 2009. To me, this is a blessing. Of course I don’t want this in my life, or Livia’s life, but it is and I’m determined to give her the best life she deserves.

Livia is such a vibrant and happy child. Her speech still isn’t where it should be, but she is gaining more words each day. She also does some sign language that she enjoys helping me teach Finley.

Some of Livia’s favorite things include reading, dress-up, The Wiggles, Sesame Street, baby dolls, horses, You Tube (specifically Beyonce’s “Single Ladies” video), coloring and getting into anything she can get her hands on! Our walls and doors bear original artwork by Liv. She loves music, and Santa brought her a piano for Christmas this year. Livia loves her baby sister and Finley is such a trooper enduring all of her hugs and kisses.

Jake and I have been married for five years. We are both very into fitness and are running our first half marathon this spring. Our girls are our life. When we get free time we enjoy movies and playing games. We have a very supportive and loving family and group of friends.

From the Hubert household to yours, we are here to listen, cry and laugh with. This life is a journey and no one has to travel it alone!

Jake, Kelly, Livia and Finley Hubert

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Jennifer Wingate, MPS III
6/25/96–3/9/09

My sweet daughter Jennifer Wingate passed away peacefully in her sleep on March 9 of last year at the age of 12. Her last day was a great one. She and I went to the dog park with our dog Hailey and watched the dogs play in the cool afternoon. We went to the store, came home and watched Barney. She had a bath with lots of hugs from Daddy and went to bed. If there had to be goodbye, it was just the right one.

Jenny brought more joy and happiness to my world than I could ever express. As I have said before, this is not a journey that any parent would ever choose, but I am glad it was chosen for me. She also blessed the lives of her wonderful grandmother, her brothers, loving cousins, aunts and uncles, special friends and amazing caregivers, all who made sure she was loved and happy.

Jenny and I attended nearly every MPS family conference since she was diagnosed with Sanfilippo syndrome in 2000. Through the MPS Society she made a lot of friends, and she loved to visit new places. We saw the ocean in Los Angeles, the mountains in Vancouver, snow in Washington, DC, and the desert in Arizona. She saw cows and horses in Ft. Worth, the Mississippi in St. Louis, and of course everything Disney in 2004. She met senators and congressmen on Capitol Hill and in being there she told her MPS story. In between, she traveled to other places with Cheryl and me: to see buffalo in Bellville, seagulls in Galveston, and many other sights and sounds. Hers was a rich life.

Of all these things, Jenny loved watching Barney the most. Jenny loved Barney’s world, and we all loved sharing it with her. Through a strange turn of events and an e-mail friendship with one of the show’s writers, Barney got to know Jenny, too, and he said his own goodbye to Jenny. We all heard it for the first time at the end of her memorial event. It was a most special gift from her special friend.

When Jenny was first diagnosed I felt like I had been robbed of my only daughter in an unfair twist of fate. What I found was that I was given a rare opportunity to live with a different Jenny, in a different world. Every day had to be lived for itself, because I knew every day she would drift away a little more. No moment was unimportant. I loved a child that only the fortunate ones of us get the chance to know. Jenny made me who I am and touched many other people in her short time here. Her legacy will be in how we take it from here.

Bye-bye, baby. Love, Daddy.

Gordon Wingate (Jennifer’s father)

See all four Jennifer Wingate event videos by searching for gwingatetx on Youtube or Facebook.
I currently am a professor in the Departments of Internal Medicine and Genetics at Washington University School of Medicine (St. Louis, MO). My academic background is a bit unusual with degrees in medical technology, nuclear medicine technology, and doctoral training in molecular biology. I have studied lysosomal storage diseases, and MPS disorders in particular, since 1990. I first became interested in lysosomal storage diseases during my post-doctoral training at The Jackson Laboratory (Bar Harbor, ME). The MPS VII mouse had just been described by Dr. Edward Birkenmeier and this model system provided an opportunity to combine my clinical/medical interests with my molecular biology training. We cloned the GUSB gene from the mouse and determined the mutation leading to the enzyme deficiency. We then began experimenting with various therapeutic approaches including bone marrow transplantation, enzyme replacement and gene therapy. Learning the biology of these diseases and developing various therapeutic approaches was very interesting. However, I didn’t appreciate the true significance of the work until I attended my first MPS Society meeting in Philadelphia in 1994. That was the first time I had an opportunity to meet and interact with affected children and their families. This had a profound effect on me personally and put my research in perspective. From that point on I have been committed to researching these diseases in the hope of finding effective therapies.

The MPS Society played an important role at a critical juncture in my career. I was one of the first recipients of the Raymond Bryan IV Fellowship while I was a post-doctoral fellow at the University of Pennsylvania. Shortly after that I established my own research laboratory at Washington University in 1994 with the goals of better understanding the pathophysiology and developing more effective treatments for these devastating diseases. The MPS Society has continued to support me and my trainees while pursuing directions that would be considered too risky for funding by the National Institutes of Health (NIH). We have successfully converted several of these “high risk” projects into projects that have been funded by the NIH. I have been an active member of the Scientific Advisory Board for greater than 10 years, and served as its chairperson from 2006 to 2009. I have trained more than 15 graduate students and post-doctoral fellows, some of whom continue to work on these rare inherited disorders. My lab members and I have participated in numerous regional fundraisers, family gatherings and national conferences. We have learned a great deal from these experiences. Most importantly, however, these experiences are vivid reminders of why we are doing this research. My trainees and I are continually inspired by the strength and courage exhibited by the children and families. After seeing how the children struggle with these diseases and how hard the families work to better their lives we are eager to return to the laboratory and work even harder toward effective treatments. My experiences with the MPS Society and the many families I’ve come to know over the years have changed my perspective on the world and continue to drive my career.

As for my personal life, my significant other, Alice Martin, and I recently returned from a magnificent trip to the Galapagos Islands where we had the chance to experience some of what led Charles Darwin to his groundbreaking theories. I have two very high-energy Australian cattle dogs that help keep me on my toes. We also enjoy spending weekends at my family’s small “farm” in rural Missouri. It’s a wonderful place to get away and gives me a chance to recharge for the challenges of the laboratory.
2009 was an exciting year! One of the Legislative Committee’s immediate priorities for 2009 was the mentoring of new members on the committee while giving full support to our members on their questions and concerns regarding congressional delegation, communicating their family’s needs to congress, the National Institutes of Health (NIH), the U.S. Food and Drug Administration (FDA) and other governing bodies that pass legislation which affect our MPS population. The Legislative Committee was able to fund a number of trips to Washington, DC, including sending a number of Society members to advocate for our MPS needs. As a collective group, our members attended more than 100 meetings on Capitol Hill in 2009. Our advocacy efforts focused on increasing funding from the NIH, increasing funding for local respite care providers, urging the Social Security Administration to include all lysosomal diseased persons to qualify for compassionate allowances without a long and arduous process. We launched our Policy with Partners (PwP) program and have nearly 100 members and friends who will help us on a moment’s notice. As 2010 arrived, our Society joined the Rare Disease Congressional Caucus (see below). Our focus for 2010 will continue to support families through federal legislation and partnering with other organizations and nonprofits on common issues.

“I am not going to walk away just because it’s hard.”
— President Obama (on Healthcare Reform)

President Obama made it clear to an enthusiastic crowd on Jan. 28, 2010, that he is not giving up the fight for health reform that protects consumers from insurance company abuses, lowers costs, and help businesses and families around this country.

“I didn’t take up this issue to boost my poll numbers or score political points—believe me, if I were, I would have picked something a lot easier than this,” said President Obama. “No, I’m trying to solve the problems that folks here in Elyria and across this country face every day. And I am not going to walk away just because it’s hard. We’re going to keep on working to get this done with Democrats, Republicans—anyone who is willing to step up. Because I am not going to watch more people get crushed by costs, or denied the care they need by insurance company bureaucrats, or partisan politics, or special interest power in Washington.”

Caring for Caregivers

In January 2010 the Middle Class Task Force unveiled a series of initiatives in the president’s FY2011 budget that are aimed at helping families with soaring childcare costs, balancing work with caring for elderly relatives or people with disabilities, paying for college and saving for retirement. The nearly $103 million investment proposed by the Middle Class Task Force will support more respite care, counseling, training, referrals and adult day care.

President Obama has said that Vice President Biden’s Middle Class Task Force’s recommendation to increase funding for the National Family Caregiver Support Program and Lifespan Respite, along with strengthening supportive services through Title III-B of the Older Americans Act, represents a huge investment in community-based programs that support the independence of older Americans and their caregivers. These funds will enable them to access and get the critical services that they need while avoiding unnecessary and more expensive institutional care or spending down to Medicaid. The extra funding proposed by the Task Force will allow nearly 200,000 additional caregivers and three million more hours of respite care to be provided. It adds funding to programs that provide transportation help, adult day care, and in-home services including aides to help bathe and cook.

Rare Disease Congressional Caucus Announced

National Organization of Rare Diseases (NORD) Board of Directors Vice Chairman and CureTheProcess Advisory Committee Member Frank Sasinowski announced the formation of a Rare Disease Congressional Caucus to seek creative solutions to problems faced by patients and to serve as a forum for discussion of issues related to access, research and increased innovation. The caucus also will seek to increase funding for two government agencies: the NIH Office of Rare Diseases Research and the FDA Office of Orphan Products Development. In addition, it will address regulatory issues

continued
facing the pharmaceutical, biotechnology and medical device industries. One of our legislative priorities in 2009, spearheaded by Legislative Committee member Austin Noll, was to initiate or join an lysosomal disease caucus. With the help of NORD and CureTheProcess, this will become a reality. The National MPS Society was one of the first to join as partners in the formation of this caucus.

NIH Awards $18.3 Million in Recovery Act Funds to Support Science, Technology, Engineering and Mathematics Education

To remain competitive in our 21st century global economy, the nation must foster new opportunities, approaches, and technologies in math and science education. This begins with a coordinated effort to bolster science, technology, engineering and math (S.T.E.M.) education nationwide, starting at the earliest stages in education. Developing a more diverse and academically prepared workforce of individuals in S.T.E.M. disciplines will benefit all aspects of scientific and medical research and care.

As part of this national effort, the NIH announced it is awarding approximately $18.3 million to researchers over two years to strengthen and enhance efforts to attract young people to biomedical and behavioral science careers, and to improve science literacy in adults and children. The Recovery Act funds provide an opportunity to fuel the growing interest in mathematics and science, and apply rigorous scientific methods to educational research to develop practical interventions for tomorrow’s classrooms.

“Attracting the best and brightest students in science and medical careers is critical to developing a workforce capable of addressing the emerging and complex challenges in biomedical research,” said NIH Director Francis S. Collins, MD, PhD. “S.T.E.M. education has the added value of advancing scientific literacy, a high priority for our nation.”

U.S. Approves New Stem Cell Lines for Publicly Funded Research

Thirteen stem cell lines have been added to the pool that scientists can use for taxpayer-funded research, and many more such lines will soon be made available, U.S. health officials announced.

These are the first additional embryonic stem cell lines approved for research funded by the NIH since President Obama last spring lifted restrictions on stem cell research that were imposed eight years ago by then-President George W. Bush. “With these [lines] now becoming available for federally funded researchers, we believe it will speed up the process of investigating ways in which this remarkable new area of developmental biology can be explored,” said NIH Director Dr. Francis S. Collins.

Collins noted that during the past eight years, hundreds of embryonic stem cell lines have been created using private funds.

Currently, 96 more human embryonic stem cell lines are under review to see if they meet the criteria for NIH-funded research, Collins said. Only one of the Bush-approved stem cell lines is among the 96 under consideration. “There is still a ban against the creation of new stem cell lines with federal funds,” Collins stressed.

At present, 31 NIH research grants, worth $21 million, are on hold, awaiting approval of these stem cell lines. With the approval of the 13 lines, researchers can begin to look at these lines to see if they are appropriate for their projects. Those projects include efforts to grow heart muscle, neurological stem cells and neurons. Other research is focusing on ways to produce more stem cells so they can be available in greater quantities to researchers.

Embryonic stem cells are thought to be especially useful to medical science because they can be manipulated to become any type of body cell. Scientists hope to use these cells to create replacement tissues to treat a variety of diseases, such as diabetes, Parkinson’s, spinal cord injuries and Alzheimer’s disease.
Brownback/Brown Amendment to FDA Appropriations Bill (H.R. 2997 & 740) Passes!

“The beginning of treatment requires knowing that you are sick.”

Francis Collins (before becoming NIH director) talked with Sen. Brownback (R-KS) regarding rare and neglected disease regulation that led to an amendment sponsored by Sen. Brownback and Sen. Brown (D-OH) to the 2010 FDA appropriation bill.

The amendment directs the FDA to assemble a team to evaluate various aspects of the regulatory process for rare and neglected diseases and provide a report to the commissioner. This is a great gift to our efforts this year and we were happy to discover this amendment had been submitted and approved by unanimous consent. The amendment went to the Conference Committee in which the differences between the House and Senate Appropriations bills are ironed out. The House bill did not have the same amendment and the Conference Committee must decide what stays and what goes out of the bill to reach a consensus bill. The committee met last week, and the Brownback/Brown amendment was retained in the bill. The language was strengthened to say that the FDA “shall,” not just “may,” put these review groups together to evaluate their policies around rare diseases.

This amendment is a first step toward establishing what the problems are and what changes are needed at the FDA for rare and neglected diseases. This works well with our goal to create science-based changes to public policy around rare diseases.

If the group is able to better define the problems, we can set the agency and regulatory process down a path of improvement. To be able to CureTheProcess, we have to detail how the process is sick, and getting a group to clearly define that within the FDA is a step toward treatment and recovery. The amendment is saying, “Call a doctor.” We would hope to help with the diagnosis.

The passage of the Brownback/Brown amendment is an important step forward and an important first success for our CureTheProcess campaign. We look forward to working with the FDA and others on scientifically sound improvements to regulatory policy.

-- by Emil Kakkis, president, Kakkis EveryLife Foundation

FDA Launches Orphan Drug Workshops

The FDA announced the launch of an orphan drug workshop series—an opportunity for academics, biotechnology companies and larger pharmaceutical firms to spend two days creating applications for orphan status designation under the guidance of staff from the FDA’s Office of Orphan Products Development (OOPD). The first successful workshop was held in February; the second will take place this August. The intent is to simplify and demystify entry into orphan drug development. There will be an introductory lecture, but most of the time during the two-day period will be spent writing an application for orphan designation for specific products, which will be submitted at the close of the workshop. Having a product designated an “orphan” provides important incentives and can be done at any time prior to submission of a marketing application. Applying for orphan designation requires convincing the FDA OOPD that the proposed drug is for a rare disease (one with a patient population of fewer than 200,000 people) and holds promise for treating the rare disease.
NIH Appoints Director of National Human Genome Research Institute

Francis S. Collins, MD, PhD, director of the NIH, recently announced the appointment of Eric D. Green, MD, PhD, as director of the National Human Genome Research Institute (NHGRI), one of the 27 institutes and centers that comprise the NIH.

“Dr. Green is the perfect choice to be NHGRI director. He grew up professionally with the genome era and has been on the cutting edge of genomics research for more than two decades,” Dr. Collins said. “As NHGRI scientific director, Dr. Green has overseen spectacular growth and diversification of the institute’s intramural research program. Some of his notable contributions include founding and ably directing for more than a decade the NIH Intramural Sequencing Center, establishing the Social and Behavioral Research Branch, and the NIH Center for Research on Genomics and Global Health, and helping to launch innovative programs such as the Undiagnosed Diseases Program.”

NIH gets $1 bil boost in 2011 budget

A $1 billion boost for the National Institutes of Health (NIH) announced in the 2011 budget this morning (Feb. 1) has quelled fears that U.S. President Barack Obama’s proposed non-security discretionary spending freeze would decrease budgets at federal science agencies.

Numbers released from the White House’s Office of Management and Budget (OMB) tell of slight increases in the budgets of the NIH, the Department of Energy’s (DOE) Office of Science, and the National Science Foundation (NSF).

Obama requested $32.1 billion for the NIH in 2011, calling for the agency to “Initiate 30 new drug trials in 2011, and double the number of novel compounds in Phase 1–3 clinical trials by 2016,” according to information from OMB. The president requested—and got—$30.8 billion for the NIH last year. Overall, Obama requested $81.3 billion for all of the Department of Health and Human Services in 2011, an increase of almost $2 billion over the $79.6 billion HHS got in last year’s final budget.

The DOE’s Office of Science stands to get $5.1 billion in the president’s budget, $1.8 billion of which would go toward basic research into new ways to produce, store, and use energy.

The NSF would get $7.4 billion in 2011, a nearly 8 percent increase over its budget of just under $7 billion last year.

Though the president’s budget drops the budget of the U.S. Department of Agriculture by $1 billion, it requests $429 million for competitive research grants through the U.S. Department of Agriculture’s Agriculture and Food Research Initiative. If this figure survives Congress, it would be the highest funding level ever for the program.

This article was reprinted from thescientist.com. Posted by Bob Grant, Feb. 1, 2010.
Let’s Give a Standing Ovation To…

The Standing Ovation Award is intended to honor amazing people in our MPS family for their resilience, courage, tenacity and passion for life while facing the many challenges of having MPS. This award was created by Denise Dengel, an adult with MPS I, who knows the daily struggles of living with MPS and envisioned an award to honor the individuals who also battle MPS each and every day.

We give a standing ovation to:

**Alicia Hemingway, MPS I, age 23, Shelburne Falls, MA**

**Tyler Trahan, MPS II, age 3, Tomball, TX**

**Max Goodell, MPS III**

Max is the happy little boy with the big smile whom everyone knows. He loves kids, dogs and horses. He loves to smile at people and loves to receive smiles in response. He loves to hold hands.

Max is 8 years old. It’s winter in Wyoming now, and we go skiing and sledding. Max is a good little skier. Mostly, though, he loves the gear. Skis, boots, poles...all that stuff. It’s so much fun. Skis can be thrown on the ground, stepped on, kicked; we don’t even have to ski on them to have fun. And now Carly, Max’s service dog, rides the ski lift with him, and loves running down the slope beside him. That makes us laugh.

At school and around town, Max and Carly are famous. For Halloween last fall they dressed up as Charlie Brown and Snoopy. Everyone says “hi” to Max, calls him by name and gets a big smile in response. He seems to spread joy. Sometimes we think this is his job. Everyone wants a smile or a high-five from Max. But our favorite things are those that make him laugh. When something is funny, Max knows how to laugh. He went to a junior high friend’s basketball game, sat in the front row, and laughed and laughed. Watching all those kids running around, chasing the ball, chasing each other...that was funny. It’s contagious. We had never really realized just how funny basketball is.

But he’s not a jester. He looks at the world very seriously, too; he tries to figure it out. And when he turns that gaze on us, he melts us. There’s not a lot of affection anymore. He’s mostly lost interest in hugs, and in kisses on the nose. But connecting with those eyes is enough.
Kaitlyn Evie, MPS IV

My name is Kaitlyn Evie, and I am 3½ years old. I will be a big sister this summer and I am so excited. I don’t know if I’m having a brother or sister yet, but I know that being a big sister is an important job so I’m practicing with my dollies. I hope I have a little sister!

I go to preschool now. My teachers say I get along with everyone in my class, even the boys! I pick my own clothes out every morning and I’m getting really good at it because I’m a big girl now. I do lots of things by myself now. Sometimes it’s hard to do something all by myself, but my mommy tells me to keep trying. When I finally do it all by myself I feel so good!

My favorite things to do are dance and sing like a princess, make artwork to show daddy, play with my friends, eat cheese-flavored Pringles, tell stories and play with my dog, Buzz.

Jeffrey Figueroa, MPS VI

Jeffrey has his infusions at the hospital and loves playing with and talking to the nurses. For the first hour of the infusion he jumps continually in his cradle and talks to everyone who comes into the infusion center, both patients and staff. He says a friendly “hola” to everyone as they enter and a “bye bye” as people leave the room. For the second hour of the infusion he usually falls asleep after so much activity. For the third hour he eats—typically macaroni and cheese (his favorite food), meat and fruit. For the last hour, he resumes socializing with everyone in the infusion center until it’s time to leave.

Jeffrey never stops moving. Friends and family say he’s had a can of Red Bull because he’s so active—opening all the drawers in the kitchen, removing all the silverware, moving furniture and running everywhere. His mother is the one who needs a nap in the afternoon.

Jeffrey loves dancing and singing to Michael Jackson. His favorite TV shows are Sponge Bob and Diego. He loves to sing along with the Sponge Bob theme song. What Jeffrey hates most is the word “no.” He’s very active and inquisitive and doesn’t like to be held back. One of the therapists he’s working with said he was VERY smart. His mom showed him a photograph of 30 people and he was able to point out his mother in the picture.
Teddy Andrews, VII

“Out beyond ideas...there is a field. I'll meet you there. When the soul lies down in that grass, the world is too full to talk about.” – Rumi

That’s when everyone will KNOW what my life is about, because it’s real hard to describe when my body and senses don’t work so well anymore. If it wasn’t for my Chief Angel, my mom, I wouldn’t be turning 30 years old this June. That is my greatest accomplishment!

When I was younger I rode horses and earned VIP and a gold metal in jumping for equestrian Special Olympics. I was honored to be poster boy with Patrick Duffy for a local charity horseshow, as well having my picture with a pony on the 4-H Hearts brochure.

I also enjoyed running in Special Olympics and eventually wheelchair races.

When I was a kid I had various rabbits and chickens. I would take the baby rabbits in my scooter basket to neighborhood stores and sell them. I loved to watch and listen to the chickens and throw food to them. I helped collect eggs and even sold some of them. But most of all I loved my poodle named Lassie.

Another accomplishment was my commencement from San Marcos High School Special Ed on June 14, 2001. I wheeled myself across the stage. My mom, aunt, cousin and even my cousin from Hawaii all cheered me on.

I have always liked to be around people. Due to my recent hydrocephalus it’s hard for me to talk, so I like to “people watch.” I love people. They give me lots of energy.

But my greatest passion, my main mission in life for which I’m known far and wide, is collecting soda cans and recycling them. They call me “the can man.” Everybody in the county helps me collect them. They toss bags of them into our yard. I cruise the ally behind our house and my mom has special baskets hung for people to put their cans in for me.

I’ve had a lot of surgeries that my mom and the medical people always told me how much courage I had. I never cried. Where the courage came from I’m not sure; I think it must be a God-given thing.

I have a painting of a wild and free Lipizzan running that faces my bed in my room, it reads:

“For God has not given us a spirit of fear; but of power, and of love and of a sound mind.”
II Timothy 1:7

Autumn Tobey, ML

My name is Autumn Tobey and I am 33 years old. I was diagnosed with ML III at age 17, after being misdiagnosed for 10 years. I am the only known case of ML in Arkansas where I was born and raised and still reside. My school years were very challenging for me because of all the surgeries I had to have. On Feb. 10 I had my 10th surgical procedure. One of my greatest accomplishments was when I graduated from college in 2004.

For the last few years I have lived with my sister and our two Shih Tzu’s, Sam and Max. My dog Sam only has one eye and my sister’s dog Max was badly burned in a fire in 2003. They are so much fun to watch and they love everybody. They are very good company for me since I am unable to work.

I like reading, watching TV and spending time with my family. Even though ML has caused me a lot of pain it also has made me a stronger person. It has helped me deal with life’s ups and downs and to have greater compassion for others who are truly suffering.
Screen Print Short-Sleeve T-Shirts “Someone I Love Needs a Cure”

Men’s Short-sleeve: white or ash gray $15; purple $18; Sizes: S, M, L, XL, XXL, XXXL

Ladies’ Short-sleeve: white or ash gray $15; purple $18; Sizes: S, M, L, XL, XXL, XXXL

Youth Short-sleeve: white or ash gray $10; purple $12; Sizes: S, M, L

Screen Print Long-Sleeve T-Shirts “Someone I Love Needs a Cure”

Men’s Long-sleeve: white or ash gray $20; purple $22; Sizes: S, M, L, XL, XXL, XXXL

Ladies’ Long-sleeve: white or ash gray $20; purple $22; Sizes: S, M, L, XL, XXL, XXXL

Youth Long-sleeve: white or ash gray $15; purple $18; Sizes: S, M, L

Polo Shirts 100% cotton pique

Men’s Polos: white, ash gray, black, purple; Sizes: S, M, L, XL = $25; XXL = $27; XXXL = $29

Ladies’ Polos: white, black, pink, purple; Sizes: XS, S, M, L, XL = $25; XXL = $27; 1X = $27; 2X = $29

T-Shirts Heavyweight 50/50 poly/cotton blend

Colors: white, black, ash gray, pink

Youth sizes: XS (2-4), S (6-8), M (10-12), L (14-16) = $14

Adult sizes: S, M, L, XL = $15; XXL = $17; XXXL = $19

Hoodies Heavyweight 50/50 poly/cotton blend

Colors: purple, black, heather gray, navy, white

Youth sizes: XS (2-4), S (6-8), M (10-12), L (14-16) = $23

Adult sizes: S, M, L, XL = $29; XXL = $31; XXXL = $33

Sweatpants Heavyweight 50/50 poly/cotton blend; elastic cuff and waistband **Youth sizes only**

Colors: black, heather gray, navy, white

Youth sizes: XS (2-4), S (6-8), M (10-12), L (14-16) = $14

Fleece Jackets

Men’s Jackets: midnight heather, black; Sizes: XS, S, M, L, XL = $35; XXL = $37; XXXL = $39

Ladies’ Jackets: light pink, black, midnight heather; Sizes: XS, S, M, L, XL = $35; XXL = $37; 1X = $39; 2X = $39

Fleece Vests

Men’s Vest: stone, midnight heather, gray heather, black; Sizes: XS, S, M, L, XL = $30; XXL = $32; XXXL = $34

Ladies’ Vest: light pink, black; midnight heather; Sizes: XS, S, M, L, XL = $30; XXL = $32; 1X = $34; 2X = $36

Youth Vest: black, grey heather, midnight heather, light pink; Sizes: XS (2-4), S (6-8), M (10-12), L (14-16) = $30

All-Season Jackets Waterproof 100% nylon shell with micro-fleece body lining

Color: black with chrome

Men’s jacket sizes: XS, S, M, L, XL = $60; XXL = $62; XXXL = $64

Ladies’ jackets sizes: XS, S, M, L, XL = $60; XXL = $62; 1X = $64; 2X = $64

Hats

Ball caps: Adjustable back, low-crown hats. Black, white, khaki = $15

Bucket hats: black, white, khaki = $20

Knit beanie caps: black, white, gray, pink = $12

Fleece Blanket with Carry Strap 50” x 60”; 100% polyester fleece

Colors: purple, pink, royal blue, black = $23

Backpack Color: black = $20

Laptop Bag OGIO Jack Pack offset ingenious features, including an airline ticket pocket, oversized and padded laptop sleeve, and lots of extra zippered pockets for superior organization. Fits most 15” laptops.

Dimensions: 14”h x 17”w x 5”d; 1,050 cubic inches.

Color: black = $60
## MPS LOGO ITEMS ORDER FORM

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Name _____________________________________________________________

Address ___________________________________________________________

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Daytime Phone _____________________________________________________

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Big Stitch Embroidery

1730 E. Elliot

Tempe, AZ 85284

Questions? Contact laurie@mpssociety.org

Thank you for your purchase!

100% of proceeds go to the National MPS Society’s Family Support Committee.

Please allow at least three weeks for delivery.

Shipping and handling charges are not included in the item total.

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**Shipping & Handling Charges**
MPS III patients needed for research study

This research project will focus on how the immune system is affected in patients with MPS III A or B. A blood test will be done to measure blood cell count. To participate, patients must:

- be less than or exactly 20 years of age with a confirmed diagnosis of MPS III A or B
- not use medications that suppress the immune system at time of enrollment
- not have respiratory, urinary or other infections at the time of enrollment

The study will take place at your local healthcare provider’s office or at The Research Institute at Nationwide Children’s Hospital, Columbus, OH. For more information and to make an appointment, contact Chelsea Rankin at 614.355.2897 or Chelsea.Rankin@nationwidechildrens.org.

University of Minnesota Children’s Hospital Offers Clinical Trial of Human Growth Hormone

A clinical trial of human growth hormone (HGH) is being conducted at the University of Minnesota Children’s Hospital. Children with MPS I, II or VI with short stature are invited to participate. HGH is a U.S. Food and Drug Administration-approved treatment for short stature, however there is no data at this time on using this treatment specifically in children with MPS. The goal of this clinical trial is to determine what, if any, effect HGH has on growth velocity, bones, and cognitive functioning of children with MPS I, II and VI.

For additional information contact Lynda Polgreen, MD, assistant professor, University of Minnesota, Pediatric Endocrinology, at 612.624.4459 or polgr001@umn.edu.

MPS II and MPS VI patients needed for research study

A research study to better understand the brain basis for learning difficulties sometimes found in MPS II and VI is being conducted at the University of Minnesota. Individuals must be over the age of 6 and under 35 and able to cooperate in an MRI imaging study without any sedation. The goal in studying the central nervous system is to better understand the brain changes in MPS disorders to find better ways of treating these problems. The MPS I portion of this study has been completed. Contact Dr. Elsa Shapiro at 612.625.1618 (shapi004@umn.edu) or Dr. Kate Delaney at 612.625.1143 (delan011@umn.edu) for more information.

Surrogate Endpoint Trial (SET) for individuals with MPS III A

Sponsored by Shire Human Genetic Therapies

SET is a one-year, multi-center study designed to study the natural progression of Sanfilippo A syndrome, or MPS III A, in approximately 20 patients. During a period of 12 months participants in the study will be evaluated to assess the severity and progression of MPS III A, as measured by developmental age and milestones, central nervous system function (including cognition, speech and motor skills) and biochemical markers of the condition (levels of heparan sulfate and its breakdown products in blood urine and cerebrospinal fluid).

Additional information can be found at www.clinicaltrials.gov (identifier NCT01047306), or contact: Shire HGT Medical Information, 484.595.8850, HGTmedcomm@shire.com or Amy K. Fisher, MS, CGC, Shire HGT Global Medical Affairs, at 857.413.9553 or afisher@shire.com.
Clinical Trials

MPS I

MPS I Intrathecal Enzyme Replacement Clinical Trial for Cognitive Decline

The Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center in Torrance, CA, and the University of Minnesota are collaborating on a study of intrathecal enzyme replacement therapy (ERT) for cognitive decline in patients with MPS I.

The purpose of this research study is to find out whether giving ERT with Aldurazyme® as an injection directly into the cerebral spinal fluid (the fluid around the spinal cord and the brain) can stabilize (keep from getting worse) or improve cognitive decline in patients who have MPS I. The term “cognitive decline” refers to a change for the worse in our ability to think and learn. Difficulty with thinking, memory, language, concentration and decision making are some signs of cognitive decline.

To be eligible for this study, you or your child must be willing and able to comply with the study procedures and meet certain criteria:

- 6 years of age or older
- diagnosed with MPS I
- show evidence of cognitive decline on a screening evaluation

Study participants will have:

- up to 10 treatments given one to three months apart over two years (treatment group) or four treatments given three months apart beginning at month 12 (control group);
- physical examinations (general and neurological);
- neuropsychological testing for cognitive decline and MRI of the brain; and
- reimbursement/payment of travel expenses.

Additional details about this clinical trial can be found at [www.clinicaltrials.gov](http://www.clinicaltrials.gov); search under “mucopolysaccharidosis.”

If you are interested in this study or would like more information, contact:

Dr. Agnes Chen or Dr. Patricia Dickson
310.222.4160 or 310.222.4145
ahchen@ucla.edu or pdickson@ucla.edu

MPS I Intrathecal Enzyme Replacement Clinical Trial for Spinal Cord Compression

The Los Angeles Biomedical Research Institute at Harbor-UCLA Medical Center in Torrance, CA, is conducting a study of intrathecal enzyme replacement therapy (ERT) for spinal cord compression in patients with MPS I.

The purpose of this research study is to find out whether giving ERT (with Aldurazyme®) as an injection directly into the spinal canal (called intrathecal injection) can help reduce spinal cord compression due to MPS I and can provide an alternative to surgery.

To be eligible for this study, you or your child must be willing and able to comply with the study procedures and meet certain criteria:

- 8 years of age or older
- diagnosed with MPS I
- diagnosed with spinal cord compression

Study participants will have:

- up to 16 intrathecal ERT treatments given one to three months apart over one and a half years; and
- physical examinations (general and neurological);
- other diagnostic tests; and
- reimbursement/payment of travel expenses.

Study centers other than at Harbor-UCLA may be available.

Additional details about this clinical trial can be found at [www.clinicaltrials.gov](http://www.clinicaltrials.gov); search under “mucopolysaccharidosis.”

If you are interested in this study or would like more information, contact:

Dr. Patricia Dickson
310.781.1399
pdickson@ucla.edu

MPS II

MPS II Intrathecal Enzyme Replacement Clinical Trial

Shire Human Genetic Therapies is sponsoring a clinical trial at the University of North Carolina at Chapel Hill to learn if direct administration
of recombinant enzyme into the fluid around the brain and spinal cord is safe and a possible treatment for children with MPS II with developmental delays. “A phase I/II safety and ascending dose ranging study of idursulfase administration via an intrathecal drug delivery device in pediatric patients with MPS II who demonstrate evidence of central nervous system involvement and who are receiving treatment with Elaprase™,” said Joseph Muenzer, MD, PhD, principal investigator for the clinical trial.

Currently there is no approved therapy for treating the brain and spinal cord in patients with the severe form of MPS II. The goal of this study is to give a new preparation of iduronate-2-sulfatase (idursulfase-IT) directly into the fluid surrounding the brain and spinal cord (intrathecal administration). The new form of iduronate-2-sulfatase has not been used before in patients with MPS II and is considered investigational. It has not been approved by the FDA or any other regulatory agency.

This phase I/II clinical trial is planning to enroll 16 patients with MPS II between the ages of 3 to 8 years with evidence of early neurocognitive decline using an open-label, three-dose trial design. This clinical trial will initially have both a treatment group (12 study patients) and a control group (four study patients) with the control group eligible to receive intrathecal enzyme after a six-month observational period. The monthly intrathecal administration of idursulfase-IT will be given using a Port-A-Cath II Low Profile™ intrathecal implantable access system manufactured by Smiths Medical MD, Inc. (St. Paul, MN) that requires surgical implantation.

To be eligible for the investigational intrathecal enzyme replacement clinical trial, study patients needs to have some developmental delay, but cannot be severely impaired, have received and tolerated a minimum of six months of weekly intravenous Elaprase and have adequate hearing (with or without hearing aids) to complete developmental assessments. Patients with MPS II are not eligible if they have a shunt for the treatment of hydrocephalus, have had a cord blood or bone marrow transplant or have other medical conditions that may place the individual at an increased risk during the investigational clinical trial.

If you are interested in obtaining more information about the clinical trial, please contact Dr. Joseph Muenzer at 919.966.1447 or the study coordinator, Heather Preiss, RN, at 919.843.5731 at the University of North Carolina at Chapel Hill, NC.

MPS III

Shire Pharmaceuticals Group, as part of its research to evaluate new approaches to the problem of treatment of the central nervous system, is hoping to move its MPS III A program forward. If the trial to directly administer the enzyme into the central nervous system of individuals with MPS II is successful, Shire hopes to expand its research initiatives to include MPS III A. The Shire Web site is www.shire.com.

MPS IV

BioMarin Pharmaceutical Inc. announced on April 21, 2009, the initiation of a phase I/II clinical trial for BMN-110 or N-acetylgalactosamine 6-sulfatase (GALNS), intended for the treatment of MPS IV A, or Morquio A syndrome. The company expects to report initial results in the first half of 2010.

The phase I/II study is designed as an open-label, within-patient dose escalation trial in approximately 20 patients followed by a treatment continuation phase. All patients to be enrolled in the study have already been identified. During the dose escalation phase of the study, subjects will receive weekly intravenous infusions of BMN-110 in three consecutive 12-week dosing intervals. The objectives of the phase I/II study will be to evaluate safety, pharmacokinetics, pharmacodynamics and to identify the optimal dose of GALNS for future studies.

BioMarin also will be conducting a Morquio Clinical Assessment Program or MorCAP that will involve about 15 centers in many countries and will evaluate the disease situation for patients globally. Finally they expect to have a phase III double-blind placebo controlled study that might include 50–100 patients from many centers. Being in the MorCAP program will improve a patient’s chances of being in the phase III. Additional information can be found at www.morquioBMRN.com.

MPS VII

A gene therapy clinical trial for MPS VII, also known as Sly syndrome, has been put on hold pending additional data.

ML II/III

There currently are no programs in place for developing treatment options for ML II/III.
Treatment Therapies

MPS I

Aldurazyme®, administered once-weekly, has been approved in the United States and in 15 countries of the European Union for long-term enzyme replacement therapy (ERT) in patients with a confirmed diagnosis of MPS I, to treat the non-neurological manifestations of the disease. Aldurazyme was developed by BioMarin and Genzyme under a joint venture agreement that assigns commercial manufacturing responsibilities to BioMarin, and worldwide sales and marketing responsibilities to Genzyme.

Additional information can be obtained at www.aldurazyme.com or by contacting Genzyme at 800.745.4447.

MPS II

Elaprase™ is a long-term ERT for patients with a confirmed diagnosis of MPS II which has been approved for use in the United States, Canada and many countries in Europe. Elaprase was developed and is produced by Shire Human Genetic Therapies (formerly TKT), and is given as weekly infusions to replace the missing enzyme that Hunter syndrome patients fail to produce in sufficient quantities.

Additional information can be obtained at www.shire.com or by contacting OnePath™ toll-free at 866.888.0660. OnePath provides assistance with insurance, product access, treatment centers and education about Elaprase and MPS II.

MPS VI

Naglazyme™ is the ERT for individuals with a confirmed diagnosis of MPS VI and has been approved for use in the United States and in many European countries. Developed and produced by BioMarin Pharmaceutical, Inc., Naglazyme has been shown to improve walking and stair-climbing capacity.

For more information, contact BioMarin Patient and Physician Support at 866.906.6100 or bpps@bmrn.com.

National MPS Society Research Program

The National MPS Society exists to find cures for MPS and related diseases. We provide hope and support for affected individuals and their families through research, advocacy and awareness of these devastating diseases.

We are committed to funding researchers who are dedicated to developing the cures. For many years the Society has awarded fellowships to aspiring young researchers. Funding is provided through research donations received from our members and supporters. In recent years the Society has significantly increased research funding.

continued
In 2000 the Society launched the annual 5k walk/runs with proceeds allocated to our research program. The first year, seven runs raised $100,000. In the last decade the walk/runs have generated more than $2.8 million in research dollars (see graph on previous page). We are very grateful to the run organizers, the supporting families and all the donors. During this same period of time, $3.17 million has been awarded in research grants, with an additional $439,000 to be awarded in 2010. Money for research is received from the walk/run program and from individual donations and family fundraisers that are allocated for research. Donations for research can be allocated for general research or for syndrome-specific research.

At the beginning of each fiscal year the board of directors sets the budget and assesses the amount of research money available in both the general research and syndrome-specific research categories. Input from our Scientific Advisory Board (SAB) helps determine the focus of the grants. Based on the recommendations of the SAB, the Society over the years has focused on central nervous system (CNS) research, bone and joint research, and general research. Offering general research grants encourages innovative treatments that can benefit all the MPS diseases. Historically, the Society’s research grants are offered for two years. Grants are only awarded when money for the life of the grant is “in the bank.”

The list of grants offered and a request for a three-page letter of intent is e-mailed to researchers around the world each February and posted on our Web site. The letters of intent are reviewed by members of our SAB, who determine which researchers will be asked to submit a complete proposal. The SAB committee reviews the proposals and recommends to the board of directors the grants to be funded. The final funding decisions are approved by the board of directors.

Funded researchers are required to submit a yearly review of their research and financial report. Grants awarded and the research reviews are included in Courage and also on our Web site.

Over the years the Society has funded Partnership Grants, where we join with a private MPS foundation or a lysosomal disease advocacy group to fund a research project. This program stretches our research dollars and provides the researcher with additional funds to advance their project. It also ensures that our research money does not languish in the bank, waiting for the funds required to offer a grant.

In 2004 we joined with other lysosomal disease (LD) support groups to form the Lysosomal Storage Disease Research Consortium (LSDRC). The LSDRC focus is on funding research to find or improve CNS treatments for LDs. The LSDRC entered an agreement with the National Institute of Neurological Disorders and Stroke for the purpose of a jointly sponsored program, CNS Therapy Development for Lysosomal Storage Disorders. Funding of $390,000 was allocated to 13 researchers, four of whom subsequently received National Institute of Health grants.

The National MPS Society is unique among rare disease support groups in that we support many diseases, each of which is defined by a specific enzyme deficiency. Our research philosophy that the treatment or cure developed for one disease can benefit the other MPS diseases also applies to the general category of LDs.

Recent advances in research have led to treatments for some of the MPS diseases and the promise of treatments for others. We remain committed in our support of this critical research to identify treatments and ultimately cures.

**NATIONAL MPS SOCIETY GRANTS AWARDED**

**2001**

**Dr. Anne Hennig**

“AAV gene therapy vector to perform in utero gene therapy in MPS VII mice”

Two-year grant, total $50,000, general research funds

Washington University School of Medicine, St. Louis, MO

**Dr. Yoshio Nishimura**

“Substrate deprivation therapy for MPS: iminosugar inhibitors of sulfotransferase”

Two-year grant, total $50,000, MPS III grant in honor of Mitchell Stump

Institute of Microbial Chemistry, Tokyo, Japan

*continued*
Mark S. Sands, PhD
“Human hematopoietic stem cell-directed gene therapy in a murine xenotransplantation model of mucopolysaccharidosis VII”
Two-year grant, total $50,000, general research funds
Washington University School of Medicine, St. Louis, MO

Mark E. Haskins, VMD, PhD
“Develop a canine model of MPS III B”
Two-year grant, total $50,000, MPS III research funds
University of Pennsylvania, Department of Pathobiology, Philadelphia, PA

2002

Dr. Doug Brooks
“GGA proteins and I-Cell disease”
Two-year grant, total $60,000; $45,000 from general research funds, $15,000 from ML research funds
Lysosomal Diseases Research Unit, North Adelaide, Australia

Ms. Briony Gliddon
“Enzyme therapy in the CNS of MPS III A mice”
Two-year grant, total $60,000; $7,400 from general research funds, $52,600 from MPS III research funds
Lysosomal Diseases Research Unit, North Adelaide, Australia

Dr. R. F. Wynn
“Autologous marrow stromal stem cells as a target of genetic manipulation in the management of MPS II”
Two-year grant, total $60,000; $35,000 from general research funds, $25,000 from MPS II research funds
Manchester Children’s Hospitals, Manchester, England

2003

Mark Haskins, VMD, PhD
“Evaluation of neonatal gene transfer in dogs and cats with MPS”
Partnership grant with the Ryan Foundation, total $40,000 for one year; $35,000 from general research funds, $5,000 from MPS II research funds
University of Pennsylvania, Philadelphia, PA

Elena Aronovich, PhD
“Sleeping Beauty transposon-mediated gene therapy for MPS I”
Two-year grant, total $60,000; $30,000 from general research funds, $30,000 from MPS I research funds
Pediatrics and Institute of Human Genetics, Minneapolis, MN

Judith Ogilvie, PhD
“Intravitreal gene therapy in MPS III B mice”
Two-year grant, total $60,000; funded by an MPS III grant from the R. A. Bryan Foundation Central Institute for the Deaf, St. Louis, MO

Philippe Moullier, MD
“Gene therapy in canine MPS III B”
Two-year grant, total $60,000, from general research funds
CHU Hotel-Dieu, Nantes, France

Dr. Sharon Byers
“Inhibition of GAG synthesis as a therapy for MPS IV A and VI”
Two-year grant, total $60,000; $30,000 from general research funds, $30,000 from MPS IV research funds
Women’s and Children’s Hospital, North Adelaide, Australia

Calogera Simonaro, PhD
“Joint and bone disease in MPS VI”
Two-year grant, total $60,000; $30,000 from general research funds, $30,000 from MPS VI research funds
Women’s and Children’s Hospital, North Adelaide, Australia

Urs Giger, DVM
“Pathological and molecular characterization of feline mucolipidosis II - first model of human I-Cell”
Two-year grant, total $60,000 from general research funds
Medical Genetics, University of Pennsylvania, Philadelphia, PA

John Hopwood, PhD
“Sleeping Beauty transgene vehicle — potential new therapy for MPS III A”
One-year partnership grant with the Sanfilippo syndrome medical research foundation, total $40,000 from general research funds
Women’s and Children’s Hospital, North Adelaide, Australia

continued
Elsa Shapiro, PhD
Neuropsychology fellowship for Dr. Kendra Bjoraker
One-year training grant, total $8,750 from general research funds
Division of Pediatric Clinical Neuroscience, University of MN, Minneapolis, MN

2004
LSDRC initiative dedicated to targeted CNS translational research, total $170,000 from general research funds

Dr. Maria Pia Cosma
“Gene therapy for MPS II”
Two-year grant, total $60,000 from MPS II research funds
Telethon Institute of Genetics & Medicine, Naples, Italy

Mark Sands, PhD
“Characterization of the systemic inflammatory response to lysosomal storage”
Two-year grant, total $60,000 from general research funds
Washington University School of Medicine, St. Louis, MO

2005

Dr. Matthew Ellinwood
“Therapy for MPS III B: Naglu targeting to the CNS”
Two-year grant, total $60,000 from MPS III research funds
Iowa State University, Department of Animal Science, Ames, IA

Dr. Donald Anson
“Lentiviral-mediated gene therapy for MPS III A”
Two-year grant, total $60,000 from MPS III research funds
Department of Genetic Medicine, North Adelaide, Australia

Dr. Calogera Simonaro
“Pathogenesis and treatment of bone and joint disease in the mucopolysaccharidoses”
Two-year grant, total $100,000 from general research funds
Mt. Sinai School of Medicine, New York, NY

Dr. Sharon Byers
“The pathogenesis of cartilage degradation in MPS VI”
Two-year grant, total $100,000 from general research funds
Department of Genetic Medicine, North Adelaide, Australia

2006
LSDRC $60,000 from general research funds

Dr. Joseph Muenzer
“AAV gene therapy for mucopolysaccharidosis II”
Two-year grant, total $120,000 from MPS II research funds
University of North Carolina, Chapel Hill, NC

Shunji Tomatsu, MD, PhD
“Development of a therapeutic bone-targeting system for MPS”
Two-year grant, total $80,000 from general research funds
Associate Professor, Department of Pediatrics, Saint Louis University, St. Louis MO

Dr. Doug Brooks
“Evaluation of enzyme enhancement therapy for mucopolysaccharidosis III A”
Two-year grant, total $90,000 from general research funds
Women’s and Children’s Hospital, North Adelaide, Australia

Dr. Maria Pia Cosma
“AAV-mediated gene therapy of the Hunter syndrome in the MPS II mouse model”
Two-year grant, total $80,000 from MPS II research funds
Telethon Institute of Genetics & Medicine, Naples, Italy

2007
ISMRD Partnership ML Grant: $19,000 from ML research funds (funded in 2008)

Dr. Katherine Ponder and Dr. Mark Haskins
“Retroviral vector-mediated gene therapy for MPS I”
Partnership one-year MPS I grant with Ryan Foundation: $19,000 from MPS I research funds
Washington University (Dr. Fonder), St. Louis, MO

continued
Dr. Alessandra Biffi  
“Novel efficacious and safe gene therapy approaches for the treatment of MPS I”  
Two-year grant, total $100,000 from general research funds  
San Raffaele Telethon Institute for Gene Therapy, Milano, Italy

Mark Haskins, VMD, PhD  
“Lentiviral vector therapy for MPS VII”  
Two-year grant, total $100,000 from general research funds  
University of Pennsylvania, Philadelphia, PA

Calogera Maria Simonaro, PhD  
“Pathogenesis and treatment of the mucopolysaccharidoses”  
Two-year grant, total $100,000 from general research funds  
Mount Sinai School of Medicine, New York, NY

Dr. Maria Fuller  
“Membrane microdomains and improved clinical management for the mucopolysaccharidoses”  
Two-year grant, total $90,000 from MPS II funds  
Lysosomal Diseases Research Unit, North Adelaide, Australia

Synthia H. Mellon, PhD  
“Neurosteroid treatment of MPS III A”  
Two-year grant, total $80,000 from MPS III research funds  
University of California, San Francisco, San Francisco, CA

2008

Expert Newborn Screening meeting: $15,000 from general research funds  

ISMRD partnership ML grant  
(carry over from 2007)

Dr. Sara Cathey  
“Natural history study for mucolipidosis”  
One-year grant, $19,000 from ML funds  
Greenwood Genetic Center, Charleston, SC

Partnership Grant with International MPS Network  

Prof. Grzegorz Wegrzy  
“Development of gene expression-targeted isoflavone therapy for MPS III”  
One-year grant, $4,000 general research funds  
University of Gdansk, Gdansk, Poland

Nicola Brunetti-Pierri, MD  
“HDAd gene therapy for lysosomal storage disorders”  
Two-year grant, total $65,000 from MPS II research funds  
Baylor College of Medicine, Houston, TX

Brett E. Crawford, PhD  
“Glycosaminoglycan inhibitors as substrate reduction therapies for MPS II”  
Two-year grant, total $65,000 from MPS II research funds  
Zacharon Pharmaceuticals Inc., La Jolla, CA

Dr. Andrea Ballabio  
“Modulation of autophagy as a potential therapeutic approach for MPS”  
Two-year partnership grant, total $60,000; $30,000 from MPS III research funds, $15,000 from Ben’s Dream Foundation and $15,000 from the Children’s Medical Research Foundation  
Telethon Institute of Genetics & Medicine, Naples, Italy

Brian Bigger, PhD  
“The effect of heparan sulphate on stem cell homing and engraftment in MPS I”  
Two-year grant, total $60,000 from general research funds  
University of Manchester, Manchester, U.K.

Adriana M. Montano, PhD  
“Identification of genes for keratin sulfate biosynthesis: toward development of RNAi mediated therapy”  
Two-year grant, total $60,000 from general research funds  
Saint Louis University, St. Louis, MO

Mark S. Sands, PhD  
“Metabolic adaptations and phenotypic consequences of blocking lysosomal recycling”  
Two-year grant, total $60,000 from general research funds  
Washington University School of Medicine, St. Louis, MO

Marta Serafini, PhD  
“Marrow mesenchymal stem cell therapy for MPS I”  
Two-year grant, total $60,000 from general research funds  
STEMMPS Unit, Dulbecco Telethon Institute at M. Tettamanti Research Center Clinica, Monza, Italy

continued
Richard Steet, PhD
“Investigation of the cartilage pathogenesis of ML II and MPS”
Two-year grant, total $60,000 from general research funds
University of Georgia Research Foundation, Athens, GA

2009

Dr. Sara Cathey
“Natural history study for mucolipidosis”
One-year ISMRD Partnership ML Grant, $7,000 from ML research funds
Grenwood Genetic Center, Charleston, SC

Lysosomal Disease Network grant
“Neuroimaging core activities”
One-year grant, $25,000 from general research funds
Minnesota Medical Foundation LDN Fund, Minneapolis, MN

Dr. Maria Pia Cosma
“AAV2/5CMV-IDS therapy in MPS II mice: correction of CNS defects through IDS delivery across the blood-brain barrier”
Two-year grant, total $80,000; $28,800 from general research funds, $51,200 from MPS II research funds
Telethon Institute of Genetics & Medicine, Naples, Italy

Dr. Jeffrey Esko
“Substrate reduction strategy for MPS III A”
Two-year grant, total $80,000; $26,500 from general research funds, $53,500 from MPS III research funds
University California San Diego, La Jolla, CA

Dr. Assessandro Fraldi
“Developing a systemic AAV-mediated gene therapy to cross the blood-brain barrier and treat the brain pathology in MPS III A”
Two-year grant, total $80,000; $26,500 from general research funds, $53,500 from MPS III research funds
Telethon Institute of Genetics & Medicine, Naples, Italy

Dr. Katherine Ponder
“The role of cathepsin K in cardiac valve disease in MPS”
Two-year grant, total $80,000 from general research funds
Washington University, St. Louis, MO

Dr. Calogera Simonaro
“Novel anti-inflammatory therapies for the mucopolysaccharidoses”
Two-year grant, total $80,000 from general research funds
Mount Sinai School of Medicine, New York, NY
First Hand Foundation strives to change children’s lives around the world, one child at a time

In 1995, Cerner Corporation, a leading supplier of healthcare information technology, founded the First Hand Foundation. A nonprofit organization, First Hand assists individual children with health-related needs when insurance and other financial resources have been exhausted.

The Foundation helps with clinical necessities (such as medication and surgeries), medical equipment and travel related to a child’s care. Additionally, the Foundation implores doctors, hospitals and equipment providers to discount their services below listed prices. Funding is distributed directly to the child’s immediate healthcare provider.

Since inception, the First Hand Foundation has distributed $10 million to 85,000 individuals in 66 countries.

For more information or to apply for funding, go to www.cerner.com/firsthand.

Twist ‘n Write™ Penagain Pencil makes writing easier for kids

The Twist ‘n Write pencil is a new model specifically designed to fit smaller hands and bring back the fun in writing. A thick 2 mm pencil lead never needs sharpening. The wishbone shaped design forces the school-taught “tripod” position. It is great for those with special needs (carpal tunnel, arthritis, ADHD and many more). It is being sold at Staples, Walgreens, Office Depot, CVS, Office Max and Amazon for less than $2.00. For more information, visit www.penagain.com/twistnwrite.html.

New NAGLAZYME.com Web Site Up and Running

The new NAGLAZYME.com is now live and available for you to visit. You will find expanded content about MPS VI, its diagnosis and treatment with NAGLAZYME® (galsulfase) enzyme replacement therapy. The new Web site also has expanded features and functionality.

Hunter disease e-clinic

Hunter disease e-clinic is a virtual training clinic, designed specifically for the purpose of learning to diagnose and manage patients presenting with characteristic of rare genetic metabolic diseases. For more information, visit www.sickkids.ca/lysosomalresearchgroup.

The Miracle League

The Miracle League is an organization that affords children with disabilities the opportunity to play baseball. Players are paired up with a buddy and everyone has a chance to play—batting, running the bases, etc. Even children without the use of their arms or legs can participate. The Miracle League has more than 200 leagues across the country, as well as Puerto Rico, with 100 specialized rubberized fields (for safety) and 100 fields under construction. It serves more than 80,000 children and young adults with various disabilities.

For more information, visit www.miracleleague.com, call 770.760.1933, or send an e-mail to Johnny@MiracleLeague.com.
MPS I Web site
www.MPSIdisease.com
A Web site has been developed by Genzyme to provide parents and patients with information and resources on MPS I. This site provides valuable information on the disease, diagnosis, ongoing clinical trials, and other references and services available to patients. Visit www.MPSIdisease.com.

MPS I Registry
Access to information is critical to providing the best care for patients with MPS I. However, information on the disease is limited because of its rarity. A resource developed by Genzyme is now available for your physician or health care professional that is dedicated to improving the understanding of MPS I. With the MPS I Registry, your physician can access your data and compare it to aggregate data from around the world. Ask your physician to call 1.800.745.4447 ext. 17021 for more information.

MPS II Web site
www.hunterpatients.com
Shire HGT educational Web site focuses on MPS II (Hunter syndrome). The site is a resource center for the MPS II community to access information about the genetics, diagnosis, and management of MPS II, as well as information about the drug development process. In addition, the Web site provides a comprehensive overview of MPS II, including resources for patients and healthcare professionals, information on clinical trials and a patient outcomes survey, as well as the ability to stay informed as new information about MPS II becomes available on the site. Shire HGT expects to update and expand the site on a regular basis.

MPS VI Web site
www.MPSVI.com
BioMarin’s Web site, www.MPSVI.com, is designed especially for individuals with MPS VI (Maroteaux-Lamy syndrome), their families, and for healthcare professionals who care for patients with MPS VI. This site provides education and information about MPS VI which may be helpful to share with family members, educators and healthcare providers.

Aldurazyme® Web site
www.Aldurazyme.com
A Web site has been developed by Genzyme to provide parents and patients with information on Aldurazyme. The site includes a link to ask questions regarding MPS I or anything else related to treatment. Feel free to use this mechanism to reach a healthcare professional at Genzyme who will respond to your query in a timely manner. Visit www.Aldurazyme.com.

MPS IV Registry
www.morquio.com
Information about MPS IV can be found at www.morquio.com. Also available at this Web site is the Morquio registry where adults with MPS IV can register and families can register their child with MPS IV. Once registered, it is recommended that updates be made at least yearly. This natural history information is critical for development of treatments for MPS IV, providing evidence of drug effectiveness and supporting the approval of the drug.

MPS VI Community Web site
www.MPSVI.net
Log into the first Web site devoted entirely to the MPS VI community and:
• Meet other people with MPS VI
• Tell your story
• Chat in real time
• Search postings by topic
Register for free to connect with your MPS VI community.
Drug Safety Information
www.fda.gov/cder/drugSafety.htm
The U.S. Food and Drug Administration (FDA) has added a new feature to its Web site that provides consumers with specific safety information about individual drug products. The new Drug Specific Information Web page presents information on more than 200 approved drugs. Each drug has a “core page” with links to all information about the product on the FDA’s Web site, including general risk information and any past alerts issued about the drug.

Health Care
Coverage Options
www.nahu.org/consumer/healthcare
The National Association of Health Underwriters has created a database that provides information on health insurance options for low-income U.S. residents and people who change jobs or have pre-existing health problems. The Health Care Coverage Options Database provides a state-by-state list of public health insurance programs for low-income residents, such as Medicaid and the State Children’s Health Insurance Program. It also lists 32 states that offer high-risk health insurance pools for those with pre-existing health problems.

BioMarin Offers Help with Insurance Questions for MPS VI
BioMarin has developed a free and confidential service designed to assist with healthcare insurance questions. The BioMarin Patient and Physician Support program (BPPS) can help families evaluate their current healthcare insurance coverage, provide information on potential healthcare insurance options that may be available in your state, and educate insurance companies about MPS VI. To contact a BPPS patient advocate, call their toll free number 1.866.906.6100.

Shire HGT Offers Support for MPS II
www.hunterpatients.com
Shire Human Genetic Therapies introduced OnePath support center to help understand the complex issues pertaining to ERT, coverage, coding and reimbursement. When you call OnePath, you’ll be assigned a personal case manager who will help address any questions or concerns associated with ERT. OnePath case managers have access to many important resources; they also get to know you and can anticipate your needs. OnePath case managers can also address questions about insurance and other issues related to ERT. Toll-free number: 866.888.0660

Genetics Home Reference
This Web site contains a comprehensive “Guide to Understanding Genetic Conditions,” with basic information about genetics in clear language and links to online resources.

Genzyme Treatment Support Offers MPS I Families Insurance Counseling
Genzyme Treatment Support is a free and confidential service staffed by a team of nurses, social workers, and other health care professionals act as patient advocates and provide confidential one-on-one insurance counseling to patients and their families. For more information, call 1.800.745.4447, Monday through Friday.
**Have an Extraordinary Experience**

The Family Support Committee is pleased to introduce Extraordinary Experiences, the newest Family Support program. Extraordinary Experiences was developed to help all of our unique and special children, regardless of their diagnosis or abilities, to create their own extraordinary experience.

This program was developed specifically for individuals ages 14–24 diagnosed with MPS and related diseases. Grants of up to $1,000 are available for special camps, events, class trips and other unique opportunities. The Society will partner with the individual and his or her family to help cover registration fees and travel expenses, and other fees associated with his or her extraordinary experience.

Extraordinary Experiences was initiated in response to a grant the National MPS Society received from BioMarin/Genzyme LLC to honor Spencer Holland (MPS I). Spencer was a pioneer and trailblazer for many individuals diagnosed with MPS. He and his sisters participated in clinical trials for enzyme replacement therapy. They openly shared their life experiences which inspired other children and adults affected with MPS. Spencer will always have a special place in our hearts.

The National MPS Society thanks you, Spencer, and everyone with MPS and related diseases for being an inspiration to many. Special thanks to BioMarin/Genzyme LLC for this wonderful gift which will allow special young adults to have an extraordinary experience.

More information about Extraordinary Experiences can be found at [www.mpssociety.org](http://www.mpssociety.org) or by contacting Laurie Turner at laurie@mpssociety.org or 207.843.7040.

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**Mini-Miracles**

Mini-Miracles is an adaptive clothing line designed for the special needs child. Their philosophy is to promote dignity, comfort and quality of life for every child, while giving back to the community by donating to local Canadian charities.

Mini-Miracles clothing line consists of items chosen to meet the basic needs of the special needs child. They reflect the research and experience that the owner, pediatric special needs nurse Victoria Allen, has acquired working with special needs children.

The clothing is made of the highest quality Peruvian cotton and has different options available for different needs (e.g., gastro-intestinal feeding tube access pocket, cut to fit diapers, etc.).

**Featured adaptations:**
- Flat seams to reduce friction
- Discrete adaptations so clothing looks normal
- Easy access—snaps, Velcro, stretchy fabrics
- Roomy seat to accommodate diapers (all ages)
- Longer rise in the back to accommodate sitting in a wheelchair
- Elastic waist for ease of dressing and increased comfort
- Meets Health Canada regulations for safety and flammability

**Suitable for:**
- Limited range of motion and impaired dexterity
- G-tube feeding
- Wheelchair
- Cerebral Palsy
- Muscular Dystrophy
- Developmental disabilities
- Contractures
- Toilet/changing needs
- Catheters and colostomy bags
- IV tubes
- Rigidity

Visit [www.minimiracles.ca](http://www.minimiracles.ca) for more information.
Mucopolysaccharidoses (MPS) and related diseases are genetic lysosomal storage diseases caused by the body’s inability to produce specific enzymes. Normally, the body uses enzymes to break down and recycle materials in cells. In individuals with MPS and related diseases, the missing or insufficient enzyme prevents the proper recycling process, resulting in the storage of materials in virtually every cell of the body. As a result, cells do not perform properly and may cause progressive damage throughout the body, including the heart, bones, joints, respiratory system and central nervous system. While the disease may not be apparent at birth, signs and symptoms develop with age as more cells become damaged by the accumulation of cell materials.

<table>
<thead>
<tr>
<th>Syndrome</th>
<th>Eponym</th>
<th>Enzyme Deficiency</th>
</tr>
</thead>
<tbody>
<tr>
<td>MPS I</td>
<td>Hurler, Scheie, Hurler-Scheie</td>
<td>α-L-Iduronidase</td>
</tr>
<tr>
<td>MPS II</td>
<td>Hunter</td>
<td>Iduronate sulfatase</td>
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<tr>
<td>MPS III A</td>
<td>Sanfilippo A</td>
<td>Heparan N-sulfatase</td>
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<tr>
<td>MPS III B</td>
<td>Sanfilippo B</td>
<td>α-N-Acetylglicosaminidase</td>
</tr>
<tr>
<td>MPS III C</td>
<td>Sanfilippo C</td>
<td>Acetyl CoA: α-glicosaminide acetyltransferase</td>
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<tr>
<td>MPS III D</td>
<td>Sanfilippo D</td>
<td>N-Acetylglicosamine 6-sulfatase</td>
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<tr>
<td>MPS IV A</td>
<td>Morquio A</td>
<td>Galactose 6-sulfatase</td>
</tr>
<tr>
<td>MPS IV B</td>
<td>Morquio B</td>
<td>β Galactosidase</td>
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<tr>
<td>MPS VI</td>
<td>Maroteaux-Lamy</td>
<td>N-Acetylglactosamine 4-sulfatase (arylsulfatase B)</td>
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<td>MPS VII</td>
<td>Sly</td>
<td>β-Glucuronidase</td>
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<td>MPS IX</td>
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<td>Hyaluronidase</td>
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<td>ML II/III</td>
<td>I-Cell, Pseudo-Hurler polydystrophy</td>
<td>N-acetylglicosamine-1-phosphotransferase</td>
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</table>
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