

Zach's Run

5K RUN & FUN WALK

2011 SPONSORSHIP BROCHURE

Celebrating
Our 1st Year in WNY!
Sunday,
May 1, 2011

Clinton Avenue Little League Field • Fredonia, NY

Founders' Letter



**Making
Precious
Strides, Inc.** TM

Raising awareness. Finding a cure.™

Co-Founders
Chris Dearth
Cheryl Dearth

President
Christian Blasberg

Vice President
Alyson Koch

Secretary
Jamila Glapion

Treasurer
Kathleen Villano

Board Members
Jenna DeCicco
Megan Marczyk
Kim Monroe
Terra Roman

Dear Friends,

Dear Friends, In the summer of 2005, our son Zachary was diagnosed with a rare, life-threatening genetic disease known as Hunter Syndrome (MPS II) for which there is no cure. We are looking for your help in changing that. We founded Making Precious Strides, Inc. to create awareness and raise money to help find a cure for Hunter Syndrome. Hunter Syndrome (Mucopolysaccharidosis II or MPS II) is an inherited disorder in which an enzyme, iduronate-2-sulfatase (I2S), is deficient. I2S is involved in the breakdown of complex carbohydrates called mucopolysaccharides. Without sufficient I2S in the body, partially broken-down mucopolysaccharides accumulate in various organs and tissues of the body leading to potentially life-threatening complications. This is a permanent medical condition. Please help us find a cure for this devastating disease.

Until recently, there was relatively little research into this rare condition. Progress will continue to be slow unless we gain the support of individuals like you who recognize the precious gift of promise and hope that lives within each child with Hunter Syndrome.

We held our first Zach's Run in New Jersey during the fall of 2006 and since that time have raised over \$115,000 to help fund medical research. The success of Zach's Run depends on countless volunteers, participants and sponsors.

This spring we will be holding another 5k Race and 1 Mile Family Fun Walk in Fredonia, NY. We are calling it Zach's Run WNY and we are looking for you help in making it a success. By expanding into Western New York we hope to reach even more people and raise awareness and money to find a cure for Hunter Syndrome. Our goal is to present a check to our Making Precious Strides, Inc. board from the proceeds of Zach's Run WNY which will be added to the amount donated to fund medical research each year.

We are seeking charitable donations as well as sponsors and volunteers for Zach's Run WNY, our annual 5K race and 1-mile family fun walk, which will occur each spring. You can help by donating your time and/or money. In any amount-large or small, your contribution makes a difference. All donations and sponsor monies will be directed toward national research initiatives.

Sincerely,

Chris & Cheryl Dearth
Founders
Making Precious Strides, Inc.

Tax ID #20-4715542

3121-D Fire Road #321 • Egg Harbor Township, NJ 08234

www.MakingPreciousStrides.org

Visit www.ZachsRun.org for more information.

Executive Summary

Introduction

Making Precious Strides, Inc. (MPS, Inc.) is a 501(c)(3) nonprofit dedicated to supporting Hunter Syndrome (MPS II). The group's primary goal is to raise funds for medical research as well as generate greater awareness of the disease. Zach's Run WNY, one of the group's primary fundraisers, is a 5K run with a 1-mile walk, sidewalk run through the historic Village of Fredonia. The 5K run/walk is the group's core activity; however, other local events may be organized to raise funds and educate the community about Hunter Syndrome.

The Organization

MPS, Inc. was founded in 2006 as Making Precious Strides, Inc. by Chris and Cheryl Dearth of Fredonia, NY. The nonprofit organization was incorporated in May 2006 and obtained 501(c)(3) status in October 2006. MPS, Inc. is located in Atlantic County, New Jersey.

MPS, Inc. is governed by nine (9) board members. Organizational sub-committees are responsible for specific tasks including Governance, Marketing, Public Relations, Fundraising, and Finance.

Vision

Our vision is to promote and conduct well-organized, high-quality events attracting a high percentage of returning participants and sponsors. We intend to expand through organic growth to become one of Chautauqua County's most successful nonprofit organizations, garnering widespread respect for our signature event, a premiere 5K run/walk.

Making Precious Strides will develop a strong educational program communicating news, medical updates, and relevant information to its supporters and sponsors using both mass and targeted communications. Our organization will also provide financial support for local families affected by Hunter Syndrome by establishing an annual grant.

Mission Statement

Our mission is to increase awareness for Hunter Syndrome (MPS II). We will also raise funds to aid national medical research in finding a cure while supporting families with medical needs related to the treatment of Hunter Syndrome.



Our success: Making Precious Strides, Inc. has raised over \$101,000 in net proceeds since 2006

Zach's Run is organized by Making Precious Strides, Inc.
Our tax ID number is 20-4715542.

Call (716) 269-9703 to register as a sponsor today.

What is Hunter Syndrome?

Hunter Syndrome, or mucopolysaccharidosis II (MPS II), is a serious genetic disorder that primarily affects males. Children with this disorder are deficient in the enzyme known as iduronate-2-sulfatase. As a result of the missing enzyme, the body is unable to break down specific mucopolysaccharides, which in turn build up and cause a variety of health problems.

Physical characteristics of children with Hunter Syndrome include distinct facial features, an enlarged abdomen, and a large head. These children also endure conditions such as sleep apnea, an enlarged liver or spleen, obstructive airway disease, hearing loss, joint stiffness, limited lung capacity, hernias and a thickening of the heart valves affecting cardiac functioning. Hunter Syndrome also affects the body's range of motion and mobility. Developmental delays are sometimes present due to the effects on central nervous system involvement. The rate of progression varies widely among those affected by this disease; however, Hunter Syndrome is always progressive and life-altering.

Currently, there is no cure for Hunter Syndrome. Children are treated with physical therapy and surgical procedures to lessen the impact of permanent symptoms but this does not address the underlying cause of the disease. However, recently a treatment called Elaprase was approved by the U.S. Food and Drug Administration. Elaprase, an Enzyme Replacement Therapy (ERT), is a process that replaces absent enzymes through weekly intravenous infusion. With increased support for more research and testing, this treatment method could produce the positive results we are looking for and give new hope to the families affected by Hunter Syndrome.



FAST FACTS:

- This is a rare condition affecting 1 in 100,000 to 1 in 150,000 males.
- A child affected by Hunter Syndrome may live into their 60s if their diagnosis is mild or, if they have severe Hunters, they may only reach the age of 15. However, regardless of their severity, their life will be altered dramatically.
- MPS II occurs in boys, and girls may be carriers of the gene for MPS II. Although rare, MPS II has been diagnosed in girls.
- There is an estimate in the United States that 1 in 25,000 births will result in some form of MPS.

For more information regarding Hunter Syndrome, visit www.Elaprase.com

Visit www.ZachsRun.org for more information.

Event Details

The event will be held on Sunday, May 1st, rain or shine, beginning at 9:00 am at The Clinton Avenue Little League field, Clinton Avenue in Fredonia, NY.

The event will consist of a 5K (3.1 mile) run and 1-mile fun walk open to all ages. The 5K race will feature several age group categories including men's and women's categories of 14-19, 20-24, 25-29, 30-34, 35-39, 40-44, 45-49, 50-54, 55-59, 60-64, 65-69, and 70+. Trophies and medals will be awarded for 1st, 2nd and 3rd place in each category. Awards will also be given to the overall top three runners in the men's and women's division. Lastly, the youngest finisher of the 5K race will be recognized with a special award.

Participants may register online prior to the event via the Zach's Run Web site or by filling out and returning participant forms located in local stores. Registration fees are \$20 prior to the event and \$25 the day of the event. Children under 13 are free.

Food, beverages, and entertainment will be provided to all that attend.

Children registering for the Tot Trot will, receive a bracelet to participate in the event and other kids' activities. All receive a t-shirt, participation medal and goodie bag (while supplies last). Designed for younger children, the Tot Trot offers three age categories for children to take part.



Photos courtesy of Nick Valinote © 2010

Call (716) 269-9703 to register as a sponsor today.

Proceeds Benefit Medical Research

As a result of our fundraising efforts, a donation was granted for medical research initiatives at last year's Zach's Run. Making Precious Strides, Inc., the host of Zach's Run, presented a check for \$20,000 to the North Carolina Children's Hospital. North Carolina Children's Hospital has leading programs that specialize in MPS-related research.

Recent research and clinical trials have led to the introduction of Elaprased, an enzyme replacement therapy that has proven to reduce the effects in MPS II patients. For more information regarding Elaprased, visit www.MakingPreciousStrides.org or www.Elaprased.com.



Photo courtesy of Nick Valinote © 2010

Making a Difference: A check for \$20,000 was presented to North Carolina Children's Hospital at the 2010 event. This was the fourth donation in five years to their research program.

Sponsorships

There are many ways to support this year's event. All sponsorships provide outstanding opportunities to gain visibility and recognition for your organization. Choose one today!

Partner for a Cure

\$5,000

Sponsor will be the premier corporate partner of Making Precious Strides, Inc. for one year. Sponsor will be prominently featured on all organizational letterhead, web sites and literature. Sponsor's logo will appear on event brochures, posters/flyers, t-shirts, and Web sites for all upcoming events. Additionally, sponsor will enjoy added exposure through media partners and press releases. Sponsorship includes opportunity for company representative to speak at Zach's Run. Additionally, sponsor may elect one (1) representative to serve on the Making Precious Strides Board. Finally, Zach's Run registration fee will be waived for up to twenty (20) participants.

Platinum Plus

\$2,500

Sponsor's logo will be included in email campaign of quarterly newsletter, Strides. Sponsor's logo will be included on the event sponsor banner prominently displayed at event finish/start line. Sponsor's logo will be used on additional event materials, such as event brochures, registration forms, and posters that will be distributed in targeted marketing areas. Sponsor's name or logo will also appear on the back of the event t-shirts. Sponsor's name will be featured on the Zach's Run Web site. Sponsor's name or logo will be included on post event thank you letters. Sponsor will also enjoy the opportunity to exhibit and distribute promotional items on race day. Zach's Run registration fee waived for up to five (5) participants.

Visit www.ZachsRun.org for more information.

Platinum**\$1,000**

Sponsor's logo will be included on the event sponsor banner prominently displayed at event finish/ start line. Sponsor's logo will be used on additional event materials, such as event brochures, registration forms, and posters that will be distributed in targeted marketing areas. Sponsor's logo will also appear on the back of the event t-shirts. Sponsor's name will be featured on the Zach's Run Web site.

Gold**\$500**

Gold level sponsors will enjoy their name appearing on event materials such as the event brochure that will be distributed in targeted marketing areas. Sponsor's logo will appear on the back of the event t-shirts. Sponsor's logo will be featured on the Zach's Run Web site.

Silver**\$250**

Sponsor's name will be featured on the Zach's Run Web site and event brochures.

Friend**\$100**

Sponsor's name will be featured on the Zach's Run Web site.

	Partner	Plus	Platinum	Gold	Silver	Friend
Web site	■	■	■	■	■	■
Brochure	■	■	■	■	■	
T-Shirt	■	■	■	■		
Banner	■	■	■			
e-Newsletter	■	■				
Post Event Mailing	■	■				
Event Sponsor Table	■	■				
Free Registrations	■	■				
Press Releases	■					
Guest Speaker	■					
Board Representative	■					
Year-Long Marketing	■					

Make checks payable to "Making Precious Strides, Inc."

and mail to P.O. Box 693 Fredonia, NY 14063.

Call (716) 269-9703 to register as a sponsor today.



Photos courtesy of Nick Valinote © 2010

For more information visit
www.ZachsRun.org