

Zach's Run

5K RUN & FUN WALK

2008 SPONSORSHIP BROCHURE



Saturday, October 4, 2008
6th Street & the Boardwalk
Ocean City, NJ

Founders' Letter



Raising awareness. Finding a cure.™

Co-Founders

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Cheryl Dearth

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Tara Costantini

Secretary

Jamila Glapion

Treasurer

Kathleen Villano

Board Members

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Jenna Dearth
Alyson Koch
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Kim Monroe
Marc Nehmad
Terra Roman

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.

Now in our third year, we are proud to announce that we have moved Zach's Run from the Atlantic City Boardwalk to Ocean City this year. We are seeking charitable donations as well as sponsors and volunteers for Zach's Run, our annual 5K race and 1-mile family fun walk occurring each Fall. You can help by donating your time and/or money in any amount-large or small, your contribution matters. All donations and sponsor monies will be directed toward national research initiatives and local educational awareness programs.

Sincerely,

Chris & Cheryl Dearth
Founders
Making Precious Strides, Inc.

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

www.MakingPreciousStrides.org

Call (609) 513-4029 to Register Today

Executive Summary

Introduction

Making Precious Strides, 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, the group's primary fundraiser, is a 5K run with a 1-mile walk held along the Ocean City Boardwalk this year. 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. 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.

Making Precious Strides, Inc. is governed by eleven (11) board members and an Advisory Board. 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 South Jersey'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) in South Jersey. We will also raise funds to aid national medical research in finding a cure while supporting local families with medical needs.



Photo courtesy of Nick Valimote © 2007

Our success: Making Precious Strides, Inc. has raised over \$53,000 in net proceeds since 2006

Zach's Run is organized by Making Precious Strides, Inc.

Our tax ID number is 20-4715542.

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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, in July 2006, 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:

- At least 1 out of 162,000 children worldwide are affected by Hunter Syndrome
- 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

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Event Details



The event will be held on Saturday, October 4, rain or shine, beginning at 9:00 am at Sixth Street and the Boardwalk in Ocean City, New Jersey.

For the past two years over four hundred runners and walkers have participated in Zach's Run raising more than \$53,000 in net proceeds.

L&M Computer Sports & Event Productions, Inc. of Berlin, NJ will return as this year's race timer.

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.

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

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.



Photos courtesy of Nick Valinote © 2007

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Proceeds Benefit Medical Research

As a result of our fundraising efforts, two donations were granted for medical research initiatives at last year's Zach's Run. Making Precious Strides, Inc., the host of Zach's Run, presented checks for \$10,000 to the Children's Hospital of Philadelphia and \$15,000 to the North Carolina Children's Hospital. Both hospitals are leading programs that specialize in MPS-related research.

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



Photo courtesy of Nick Valinote © 2007

Making a Difference: Ian Williamson, Associate Director of Foundation Relations accepts a \$10,000 donation on behalf of Children's Hospital of Philadelphia.

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.

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



Photo courtesy of Nick Valinote © 2007

Zachary Dearth (age 5, on left) and friend **Mykonos Hardy**.
Zachary and Mykonos have been diagnosed with Hunter Syndrome, MPS II.

For more information visit
www.ZachsRun.org