To benefit Parent Project Muscular Dystrophy

In honor of Elliott and Henry Johnson

Date: April 22, 2017
Time: 9:00 AM race time (8:00 AM registration opens)
Place: Charles F. Patton Middle School • Kennett Square, PA
Events: 5K Run, Fun Walk, Kids Dash, Games, Gobo the Clown and more

For more information, please contact: Joanna Johnson
(484) 354-5236 unionvilleRFOS@gmail.com

Unionville - Run For Our Sons 5K

www.parentprojectmd.org/unionville

Hello, we are the Johnson family: Paul, Joanna, Elliott (13) and Henry (10). Elliott and Henry were diagnosed with Duchenne muscular dystrophy in June of 2007. Duchenne is a catastrophic muscle wasting disease that affects all the muscles of the body, including the heart and lungs. Most boys with Duchenne lose the ability to walk by their teens. This is followed by severe lung and heart complications. Survival beyond age thirty is rare. There is no cure. The day our sons were diagnosed was the darkest day of our lives. We long for the day when receiving the diagnosis of Duchenne is no longer a death sentence. We never want another parent to feel as desperate and as hopeless as we did. Parent Project Muscular Dystrophy (PPMD) shares that goal and works tirelessly for optimal care and treatments for all those with Duchenne. With the help of this amazing community and the 750 plus race participants, we are proud to say that over the last seven years of Unionville Run for our Sons, we have raised over $360,000 for PPMD to support Duchenne research. This is no small accomplishment and we are so very grateful.

We have longed to start this letter with these words and finally, the moment has come. On September 19, 2016, the Federal Drug Administration approved the first drug ever to treat Duchenne muscular dystrophy, eteplirsen, now known as Exondys51. This was a historic moment for the community and something we all worked hard for and wanted desperately. This is something we can all celebrate because it is a concrete example of how a community coming together has the power to make a change. Every dollar donated, every mile run, every person that became educated or educated someone else about this rare disease- MADE AN IMPACT AND MADE A DIFFERENCE!

Unfortunately, the drug will not be a viable option for Elliott and Henry based on their genetic mutation. But the hope is that the Exondys51approval will move approvals for other Duchenne treatments in a positive direction. In fact, a drug that will help slow the progression of Duchenne in Elliott and Henry is in review with the FDA. This represents eight years of our family participating in a drug trial and we hope these efforts will contribute to its approval.

Despite this recent win, our work is far from over. We need to continue the momentum to ensure that treatments are made available to all those that have Duchenne. Once that milestone is reached, we will continue our work until a cure is found and we can say we have ended Duchenne once and for all.

Having two children with a rare disease like Duchenne is all consuming. We worry daily about their future and how we will manage their growing needs. While we have witnessed first hand how the medicine they are taking as part of the clinical trial is slowing down disease progression, Duchenne continues to rob them of their independence. Most boys their age are doing more on their own, while our boys do less. Elliott just told us that he does not think he can do sleepovers at his best friend's house anymore. He just does not feel comfortable with the amount of help he needs. These things break our hearts but we know many other children with Duchenne who have far worse struggles. Many boys his age have lost the ability to walk. Some do not have the strength to lift their arms and cannot feed themselves. Others can no longer hug their loved ones. Heart failure plagues many families with boys as young as 10 years old. This is the reality of Duchenne. Will research succeed soon enough to help Elliott and Henry and this generation of boys?

We have to believe it will, so we continue to fight. One of our primary ways of doing this is by hosting the Unionville Run for our Sons, which is in its eighth year. We hope we can count on you to support our efforts. Elliott and Henry and boys from all over the country are counting on you. Make a difference, end Duchenne.

Our Mission

Parent Project Muscular Dystrophy's mission is to end Duchenne. We accelerate research, raise our voices in Washington, demand optimal care for all young men, and educate the global community.

About Duchenne muscular dystrophy (Duchenne)

- Duchenne is the most common fatal genetic disorder diagnosed during early childhood.
- Duchenne is a progressive muscle disorder that causes loss of muscle function and independence.
- Duchenne affects approximately one out of every 3,500 boys and 20,000 babies born each year worldwide.
- Duchenne manifests primarily in boys because the affected gene is found on the X-chromosome.
- There are approximately 15,000 young men with Duchenne alive today in the United States.
- Duchenne can occur during any pregnancy regardless of family history.
- To date, there is no cure or treatment to stop the progression of Duchenne, and young men with Duchenne typically live only into their twenties.

About Parent Project Muscular Dystrophy (PPMD)

- Parent Project Muscular Dystrophy (PPMD) is the largest nonprofit organization in the United States focused entirely on Duchenne muscular dystrophy.
- In part because of the efforts of PPMD, families affected by Duchenne have better access to state-of-the-art care information, research is moving forward at an accelerated pace, and legislation now exists funding Duchenne research and outreach programs.
- Parent Project Muscular Dystrophy is not only a name that reflects our grassroots origins, parent-let focus and passion, but also a name recognized around the world as the leader in the Duchenne community.
- Parent Project Muscular Dystrophy holds the highest ethical standards and consistently receives high marks from watchdog organizations.
- Parent Project Muscular Dystrophy is the only Duchenne organization that takes a comprehensive approach in the fight against Duchenne—funding research, raising awareness, promoting advocacy, connecting the community, and broadening treatment options.

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Sponsor Level Information

Event Sponsor — $1,000

- Company Logo (with link) displayed on our event website under Platinum Sponsor heading
- On site table to distribute sponsor provided marketing material
- Top billing to sponsor Logo* on event banner at finish line
- Sponsor Logo* located at the top of the back of event T-shirts
- Sponsor provided banner displayed at Start\Finish area on race day
- Sponsor name included in all promotional materials including press releases if accepted by media outlets
- Sponsor Logo* and link included in emails sent to all registered participants prior to event
- Thank You plaque to display at your place of business
- Four complimentary race day admissions

Mile Markers (2 available) — $750

- Company Logo displayed on either the 1 or 2 mile 18x24" signs
- On site table to distribute sponsor provided marketing material
- Sponsor Logo* on event banner at finish line
- Sponsor Logo* on back of event T-shirts
- Sponsor provided banner displayed at Start\Finish area on race day
- Thank You plaque to display at your place of business
- Three complimentary race day admissions

Silver — $500

- Company Logo (with link) displayed on our event website under Silver Sponsor heading
- On site table to distribute sponsor provided marketing material
- Sponsor Logo* on back of event T-shirts
- Sponsor Logo* on event banner at finish line
- Two complimentary race day admissions

Bronze — $250

- Company name (with link) displayed on our event website under Bronze Sponsor heading
- Sponsor name* on back of event T-shirts
- One complimentary race day admission

In-Kind Gift — Product or Service

- Sponsorship level determined by monetary value of the donated product or service

*** To insure inclusion on t-shirt, mile markers & banner please submit prior to April 1st.**

Parent Project Muscular Dystrophy
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Sponsorship Donation Form

Thank you very much for donating to PPMD. We sincerely appreciate all you have done.
Please fill out the information below:

Contact Information:

Company Name: _____

Contact Name: _____

Street Address: _____

City, State, Zip: _____

Phone Number: _____

Email Address: _____

Donation Level:

Bronze: $_____

Silver: $_____

Mile Marker: $_____ (2 available)

Event Sponsor: $_____

Chip Sponsor: $_____

In Kind Gift: _____ Declared Value: $_____

(Donations of goods or services, i.e.: food, location, prizes or other items donated for the event)

_____

_____

_____

Donor Signature: _____

Questions? Please contact: Joanna Johnson
PO Box 793
Downingtown, PA 19335
Phone: (484) 354-5236
Email: unionvilleRFOS@gmail.com

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Please make checks payable to Parent Project Muscular Dystrophy (www.parentprojectmd.org)
PPMD is a 501c3 charity and all donations are tax deductible - Tax ID (3)-{# 31-1405490}
PPMD is a part of the Better Business Bureau, National Health Council.
PPMD is rated as a 4 star charity on the site Charity Navigator.

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Sponsorship Registration

First Middle Last

Street Address

City State Zip

Home Phone Email Address

Birthday: / / ❍ Male ❍ Female

T-Shirt Size (Adult Sizes)*: ❍ Small ❍ Medium ❍ Large ❍ Extra Large

Event: ❍ 5K Run ❍ 1 Mile Walk

First Middle Last

Street Address

City State Zip

Home Phone Email Address

Birthday: / / ❍ Male ❍ Female

T-Shirt Size (Adult Sizes)*: ❍ Small ❍ Medium ❍ Large ❍ Extra Large

Event: ❍ 5K Run ❍ 1 Mile Walk

First Middle Last

Street Address

City State Zip

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