

Ryan's Newsletter



The Ryan McElroy Children's Cancer Foundation
198 Route 22, The Atrium Building, Pawling, NY 12564
845-855-0211 www.ryansfoundation.org

Children's Cancer Foundation

Our Feature Story ISABELLE MALONE

Isabelle Grace Malone was born on October 3, 1998. Her birth came with such anticipation as the first child to Aaron and Kim Malone; first grandchild to maternal grandparents and first granddaughter to her paternal grandparents. She weighed 8 pounds 8 ounces and her delivery was normal; in line with a long 24 hour delivery of many first borns. She went home with her parents to begin her new life. As the months progressed there was some mounting concern that her development was delayed in some ways. She was not meeting the prescribed milestones of development for children; such as, timely holding of her head, rolling over, and sitting up and she seemed to have very poor balance. Her pediatrician felt she was still within the normal range of development; just on the slower end. Several more months went by and Isabelle was not crawling or cruising or making any progress toward standing or walking. She began seeing some developmental specialists as well as neurologists and geneticists. All the tests came back normal with no obvious trauma or injury to the brain, spine, or nervous system. The developmental specialists determined, as a diagnosis of exclusion, that Isabelle had Ataxic Cerebral Palsy. Her parents were told that this label would help Isabelle in early intervention services as well as therapy and pre-schooling. Isabelle did progress slowly and began cruising with the assistance of any furniture she could hold onto. Bouts vomiting and extreme lethargy were thought to be some type of minor stomach/bowel disfunction which seemed to clear for several weeks and even months at a time. The bouts became more severe and the periods of time between them shorter. She began to lose weight and did not have much to lose at 50 pounds. Several stays at local hospitals were able to get her re-hydrated and back home again only to have more bouts of vomiting and lethargy. She was unable to attend school and was generally unable to eat.

Her vomiting was not allowing her seizure medication to absorb properly and her seizure disorder began to worsen. On February 28, 2010, Isabelle was admitted to Maria Ferrari Children's Hospital at Westchester Medical Center. An incredible number of tests were conducted to try to determine why this condition was continuing and was unable to be controlled. Numerous medications were tried unsuccessfully to control the vomiting and lethargy. A gastric feeding tube was surgically implanted but it appeared that now her stomach was rejecting all nutrition. A battery of genetic tests were done and many doctors believed that the answer to her condition was going to be found in the results of these tests looking for mitochondrial abnormalities. During her 3 month stay Isabelle continued to lose weight and was 42 pounds at her lowest. It was decided that the best course of action was to have Isabelle transferred to the Pediatric Motility Division at Boston Children's Hospital; treatment began initially to attempt to overcome her weight loss and inability to receive nutrition other than through IV. A feeding tube was surgically implanted to completely bypass the stomach which continued to not be able to accept nutrition. Isabelle began to gain weight but her vomiting still continued on a daily basis with no known cause. After progressively gaining weight and having all the other divisions of the hospital unable to come up with a cause or cure for her vomiting, Isabelle was discharged and sent back home with her parents and sisters. It was a welcome prospect to be home, but was also filled with much anxiousness about her ongoing home care. Isabelle continues to be fed through her feeding tube and receives all her medication through the tube. She continues to vomit multiple times a day but is maintaining her weight gains. There is still no diagnosis for her condition and treatment centers on the gastroparesis of her stomach. There are numerous genetic tests still outstanding, but none seem to be the one that will open up a new set of successful treatments for

her. Isabelle's life is one that has always touched others and others have always touched hers. Throughout the difficulties that she and her family have endured it has never been done alone. There have always been those who have stood beside them during the darkest of times. Those people have helped to give hope where there appears to not be any. Hope remains through the generosity of those who know her, those who only know of her, and those who will never know her. The Ryan McElroy Foundation has generously assisted the Malone family in paying for expensive tests and medications that the family and/or insurance company could or would not pay for. These tests have not given an exact diagnosis, but have served to rule out many diseases that physicians believe Isabelle may be afflicted with. The struggle continues, but we do not do it alone. We will be forever grateful to those who gave sacrificially out of love for Isabelle.



Isabelle Grace Malone

PEOPLE WHO GIVE BACK:



2373 Route 9
Poughkeepsie, NY 12601
(845) 462-4545

The Coppola Family, who own several restaurants in the Hudson Valley, hosted a Christmas luncheon for 100 of our children and their families this past December.

It came about when a Board Member stopped in to see owner, Nick Coppola, to get a Gift Certificate for a fundraising raffle. Nick was interested in Ryan's Foundation and he was so touched how everyone involved with the Foundation worked to help sick children in the Hudson Valley. He said that cancer is an illness than has touched us all in some form; but, when it hits little children, he feels it is even more devastating.

Wanting to help in some way, he contacted the Board and said he would like to prepare a Christmas party for the children. He set aside a Saturday during the busy holiday season and prepared a bountiful brunch with an assortment of muffins, pastries, fruit, omelets, waffles, pancakes, and even Eggs Benedict! Anything you could think of was there; nothing was spared. The restaurant was beautifully decorated for Christmas and Santa even made an appearance with presents for all! It was so heartwarming to see these children smiling, not having to worry about doctors visits and chemotherapy that consumes their lives. The staff at Coppola's were all so accommodating and the children really enjoyed the pampering they got. The looks on the parents faces, seeing their very ill children enjoying themselves, is what Christmas is all about. And, Nick plans to make this an annual event!

The Coppola family's overwhelming generosity is a wonderful example of what Christmas is truly about...giving hope.



Thank you to the
Coppola Family!

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IT'S SMALL ACTS OF
KINDNESS THAT MAKE A
HUGE DIFFERENCE IN THE
LIVES OF MANY!

THANK YOU TO ALL FOR
BEING SO INVOLVED IN OUR
EFFORTS TO HELP CHILDREN.

ABOUT US



Steve & Erin Reverri
Board Members

Erin was born and raised in Dutchess County, New York. Erin became involved in the Ryan McElroy Children's Cancer Foundation as a volunteer and was asked to become a Trustee due to her hard work and innovative ideas. In 2006, Erin was elected to the Board of Directors and has been responsible for such fund raisers as bracelets, Christmas cards and the Wine & Restaurant Tasting Event held at the Poughkeepsie Grandview every year. In 2009, Erin was selected for "Top 40 Under 40" by the Greater Southern Dutchess Chamber of Commerce for her dedication to children and her community. Erin is a graduate of Roy C. Ketcham High School, Dutchess Community College, Marist College, and received her Master's Degree of Education from Mercy College. Erin is currently a fourth grade teacher at Saint Columba/Saint Denis Parochial School in Hopewell Jct, NY.

Stephen became involved in the Ryan McElroy Children's Cancer Foundation after meeting Chip McElroy in 2000. Intrigued by Chip's desire to help other children and families engaged in the battle of life threatening illnesses, he simply said to Chip, "Let me know how I can help" and has been helping ever since. Steve was elected to the Board of Directors in 2006 and his first duty for Ryan's Foundation was the presentation at the 1st Annual Gala of Hope. Since then, the presentation has evolved from a slide show to a full fledged production.

Stephen is a graduate of Dutchess Community College and is working on his Bachelor's Degree in Community & Human Services at SUNY-Empire State College. He serves on the Board of Directors for New Horizon Foundation, is an auxiliary member of the Veterans of Foreign Wars #5913, a member of BPOE #275, an active member of the Poughkeepsie Yacht Club, and a member of the Fraternal Order of Police #333. For his work with Ryan's Foundation and the Dutchess County Sheriff's Office, Stephen was given the "Top 40 Under 40" award by the Greater Southern Dutchess Chamber of Commerce in 2007. Stephen was nominated for the Dutchess County Red Cross Hometown Hero's Award in 2007.

Stephen & Erin reside in Hyde Park, NY with their two dogs.



ANNUAL GALA OF HOPE

It is not too late to get your tickets to our Annual Gala of Hope at The Grandview in Poughkeepsie, NY on April 9, 2011. The Gala features a cocktail hour, formal dinner, and live and silent auctions. We rely heavily on the Gala for a significant portion of the funds we use to help families. 100% of the proceeds from the Gala goes to children and families who are faced with devastating illnesses and the hardships that these illnesses cause.

This year's honorees will be Sean and Jill Johnston of Poughquag, NY.

Tickets for the Gala are \$150 per person and \$100 of your ticket donation is tax-deductible. (Includes formal dinner and open bar.)

Call 845-855-0211 or visit www.ryansfoundation.org for more information on the Gala and other ways to help the foundation.

The Gala is the Foundation's major event of the year and it's biggest fund raiser. We hope you will be able to join us this year.

Benefiting Children with life threatening diseases

Cocktail Hour & Silent Auction	6:30 pm
Formal Dinner	7:30 pm
Live Auction	8:30 pm
Dancing	9:30 pm
Doors Close	11:30 pm

\$150 per person

**SAVE THE DATE:
APRIL 9, 2011**

"raising hope"

FUN FAMILY EVENTS - SAVE THE DATES:



MAY 7 SPIN-A-THON 1

@ World Gym Brewster, NY
7am - 12pm

May 7 is the date for the Ride to Raise Hope Spin-A-Thon at World Gym Brewster where the music is loud and the energy is high! For 5 hours individuals and team spinners will ride in support of Ryan's Foundation with five 45 minute spin sessions and a 15 minute break, 45 bikes per session. Prizes go to top team as well as top individual for raising money! Healthy snacks and drinks provided! \$25 donation per session (7:30, 8:30, 9:30, 10:30am). You will receive an email of spin time based on availability. Childcare provided. Contact for more information:

Michelle @ mibourque@ryansfoundation.org

Gina @ ginam@nycap.rr.com

Eleanor @ Enurzia@ryansfoundation.org

Sponsors needed -- please email for more info!



MAY 29 MEMORIAL DAY BBQ

@ Noah's Ark
135 Mill St. Poughkeepsie, NY
12pm - 6pm

A good old-fashioned Memorial Day BBQ is planned and a showcase of acoustic singers-songwriters.

\$35 includes food, drinks, and entertainment. Contact Jeremy Busolt at 845-702-7303 for more information.



JUNE 4 SPORTING CLAY SHOOT

@ TMT Hunting Preserve
302 Schoolhouse Rd. Staatsburg, NY
8:30am - 5pm

If you haven't already participated, you will want to join in the fun this year. There are 15 different stations on the course and lots of shooters having a ball! The event has a live auction and plenty of raffle prizes. This is a fun day for all while helping to raise money for children. Call Carl Merritt at 845-489-8725 or Art Hart at 845-546-7928 for more information. Sponsors are needed!!!



JUNE 12 5K WALK/RUN

@ Lakeside Park
2 Lakeside Dr. Pawling, NY
8:45 1/2 mile run for Kids
9am 5K run/walk start

Help us raise money and awareness by participating in or contributing to our 5k Walk/Run at Lakeside Park. Starts at the Park and continues through the scenic village of Pawling past the special bronze memorial statue of Ryan, then back to the park. We will have food and entertainment. We encourage kids of all ages to participate for a good cause. Contact Lori Decker @ lorirun4@hotmail.com for more information.



JUNE 27 ANNUAL GOLF OUTING

@ The Powelton Club
29 Balmville Rd. Newburgh, NY
Registration 10am

The Annual Golf Outing will be held again this year at The Powelton Club in Newburgh and includes the entire family, not just golfers! The Club has opened it's doors to us which includes golf, swimming, and tennis. We hope you will join us this year for a great family day while helping us to raise money.

Please contact George Busolt at 845-797-8308 for more information.



AUGUST 20 FAMILY PIG ROAST & CLASSIC CAR SHOW

@ Freedom Park
212 Skidmore Rd. Pleasant Valley, NY
(Rain Date: August 21)
12pm - 5pm

Freedom Park will once again be our location for this year's Family Pig Roast & Classic Car Show. As in the past, we have lots of entertainment planned for the entire family; live music, clowns, petting zoo, food and drink. This is a fun day for all. We hope you can make it this year. Contact Jeremy Busolt at 845-702-7303 for more information.

Volunteers are always welcome! Contact any board member if you would like to help out!
Watch for information on more events planned for this year in upcoming Newsletters!

2011 CALENDAR

- April 9 Gala of Hope
Grandview, Poughkeepsie, NY
- May 7 Spin-A-Thon 1
World Gym Brewster, NY
- May 29 Memorial Day BBQ
Noah's, Poughkeepsie, NY
- June 4 Sporting Clay Shoot
TMT Preserve, Staatsburg, NY
- June 12 5K Walk/Run
Lakeside Park, Pawling, NY
- June 27 Golf Outing
Powelton Club, Newburgh, NY
- August 20 Family Pig Roast & Car Show
Freedom Park, LaGrangeville, NY
(Rain Date: August 21)
- September 17 Spin-A-Thon 2
World Gym Brewster, NY
- October 27 Wine & Food Event
Grandview, Poughkeepsie, NY

Ryan's Foundation reminds you about our EFT feature on our webpage. Please consider signing up for recurring EFT donations so that we may continue our mission of never having to say NO to a child in need.

www.ryansfoundation.org



FROM THE EDITOR

Ryan's Newsletter is published by The Ryan McElroy Children's Cancer Foundation, a non-profit 501 (c) 3 organization, dedicated to helping children who battle childhood illnesses and cancer by providing support that improve the quality of life for them and their families.

If you would like to receive your newsletter by email & help us cut costs on printing and postage, please let us know.

If you have a story you want us to know about, please contact our newsletter editor:

sghavelka@gmail.com



GOOD NEWS CORNER

The Foundation received it's second very generous grant from Mr. & Mrs. Reuben Mark of the Colgate-Palmolive Co.

The 14th Annual Tony Cappillino Memorial Golf Tournament, held indoor on February 20, 2011, donated their proceeds to Ryan's Foundation.

Topical Biomedics gave 5% of their sales.

New Fairfield Physical Medicine & Rehabilitation donates through EFT every month.

North East Physical Medicine & Rehabilitation donates through EFT every month.

Danbury Physical & Rehabilitation, PC donates through EFT every month.

Similar to Goodshop.com & Goodsearch.com, we are pleased to announce Marketamerica.com. These three search engines give money back to Ryan's Foundation every time you search online. All you have to do is sign in, shop at your favorite retailers and they send \$\$\$ to us. No cost to you at all!

Just sign in to Goodshop/Goodsearch: RYANSFOUNDATION

Just sign in to Marketamerica.com/ryanmcelroyccf

If you would be interested in becoming a Newsletter Sponsor, please contact our editor @ sghavelka@gmail.com Thanks!

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MAIL COMPLETED FORM WITH YOUR CHECK TO:
The Ryan McElroy Children's Cancer Foundation,
198 Route 22 Atrium Building, Pawling, NY 12564

ALL DONATIONS ARE TAX DEDUCTIBLE

A \$100 contribution will cover transportation to a hospital. A \$250 contribution will pay for food or utilities. A \$500 contribution will pay for lodging or rent. A \$1,000 will pay for a mortgage or medicines.

Please help and embrace the tiny things in life. Thank you.