

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 RYAN BERNSTEIN

Ryan was born a normal, healthy baby boy. When he was 2 months old I noticed him flinch while he was asleep in my arms. Then another flinch..... I knew instinctively something was wrong. I called our pediatrician, Dr. Vigna, who saw us right away. Ryan was admitted to Vassar Hospital where an EEG was performed. Results came back asymmetric so an MRI was performed. Around 7pm, Dr. Vigna asked to speak with us in the parent's lounge. He told us that they found an Arachnoid Cyst on Ryan's right temporal lobe and he was being transferred to NYU that night as it was thought Ryan needed emergency brain surgery.

(Arachnoid cysts are cerebrospinal fluid-filled sacs that are located between the brain or spinal cord and the arachnoid membrane, one of the three membranes that cover the brain and spinal cord.)

Dr. Vigna consulted with a pediatric neurosurgeon and, when we got to NYU at 3 am, it was determined that emergency surgery was not needed at that point. Later that morning, Dr. LaJoie (a pediatric neurologist) came with her team and said she thought he was having seizures. Ryan was hooked up to the VEEG (Video EEG). Ryan was at NYU for 2 weeks.

From that point until Ryan was a little over a year old, he was continually admitted to NYU for about a week each time because his seizures were not under control. At one time Ryan was having about 50 seizures a day.

At six months old Ryan had his first surgery to fenestrate the cyst which took 7 hours. (Fenestration means an opening occurring naturally or created surgically.)

Just before Ryan turned one, his seizures changed. He was taken to NYU; Ryan's seizures went from "complex partials" to "infantile spasms" which can do considerable damage to the brain. Ryan was put on a medication that cost \$500 a month and we have to get it from Canada because it is not available in the US. The medication worked and stopped the spasms. Ryan was seizure-free for 6 months, but the seizures returned as complex partials.

Ryan has frequently been hospitalized for seizures and has had four brain operations. He also has had one stomach operation to tie his stomach to stop acid reflux and to place a gastric feeding tube as he was aspirating and getting pneumonia. Ryan also has bad asthma and has been hospitalized several times for that. He has been on over a dozen medications for seizures; two of which we must get from Canada.

When Ryan seizes he gets two emergency medications and his seizures last about 10 minutes. The seizures have had such an impact on Ryan. He is severely developmentally delayed and has a hard time doing anything. He is tested often and he currently sees a geneticist to see if it's something else. We have started him on a Ketogenic diet which is very high in fats and low in carbohydrates and, hopefully, may help to prevent his seizures. He has had a few while on the diet, but it has only been about 3 weeks so we are praying that it will work for him.

Ryan's illness has affected us and our two other children (Ryan has two older sisters: Kaylei and Cheyenne). He absolutely loves them and they love him and take such good care of him. Ryan is an adorable, happy little boy and we are blessed to have him.

Thank you to Ryan's Foundation for all that they do to help us through this devastating time in our lives.

Nichole & Jay Bernstein



Ryan Bernstein



Ryan and his sisters

Kaylei & Cheyenne

PEOPLE WHO GIVE BACK:



M. KATHLEEN FAGAN - ATTORNEY, DANIELS & PORCO, LLP

I have been an attorney since 1995, first practicing in New Jersey. In 1998, I moved north to the Hudson Valley, joining Daniels & Porco, LLP (which was then affiliated with another firm) and eventually settling in Rhinebeck, New York. Since that time I have focused primarily on transactional work, providing corporate legal advice to companies, particularly health care entities and not-for-profit corporations.

I first met Chip McElroy sometime in 1999. Chip had been a longtime client of the firm and had come to Dave Daniels, Managing Partner, to set up the Ryan McElroy Children's Cancer Foundation. I recall hearing about Ryan and could not imagine the pain that Chip, Judy and their family endured when Ryan's struggle with cancer ended.

Since the beginning of my legal career in 1995, I have spent many years working with not-for-profit corporations, their directors and employees, guiding them through the "back office" aspects of running nonprofit organizations. The common thread with each of these organizations is the tireless dedication of the volunteers who move the missions forward. One of my favorite aspects of my job is providing training to board members and employees of not-for-profits, and helping them gain the technical knowledge they need to do the good work that they do - successfully. When Chip formed Ryan's Foundation, I was more than happy to provide training sessions for the incredibly dedicated members of the Foundation's Board of Directors.

Chip and Judy have taken an idea born of grief and have built it into something that has touched the lives of so many people. Through their commitment and the generosity of those who recognize their vision, the Foundation has grown from an idea to a reality.

I have two healthy and happy children. Every day I wake up grateful for that one fact. It is a distinct privilege to work with people who have dedicated their lives to helping those in need and I can't imagine a need greater than families suffering through the illness of a child. I consider it a privilege to help the Foundation, in whatever way I can, in fulfilling its mission.

Kate Fagan

(Note: Kate donates her expertise to the foundation pro bono.)

BOARD OF DIRECTORS:

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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



Gary Tully
Board Member

Gary Tully is a lifelong resident of Putnam County, NY. After earning a Bachelor's Degree in Accounting from Mount St. Mary College in 2000, Gary was self-employed in the construction field. Selling his business a few years later, Gary joined the sales division of a major construction tool company where he is currently an Account Manager.

Having had the opportunity to meet Ryan during his short time with us, being involved with an organization to help children in similar situations was a no brainer for Gary. Since day one, a "never say no" attitude has prevailed.

Elected to the Board in 2007, Gary actively pursues ways to increase the Foundation's awareness and tries to exemplify what the Foundation stands for in his everyday life.

"These children have made more of a difference in my life than I will ever be able to make in theirs."

Gary continues to be inspired to "Raise Hope" by seeing first hand that when ordinary people refuse to give up, extraordinary things can happen.



ANNUAL GALA OF HOPE APRIL 9, 2011

This year's Annual Gala of Hope takes place again at The Grandview in Poughkeepsie, NY on April 9, 2011 and features a cocktail hour, formal dinner, and live and silent auctions. The Foundation relies heavily on the Gala for a significant portion of its funds used to help families. 100% of the proceeds go to children and families who are faced with devastating illnesses.

This year's honoree will be Sean Johnston of Poughquag, NY.

Over the last decade your generous contributions made it possible for Ryan's Foundation to improve the quality of life for many brave children in the Hudson Valley who courageously battle life threatening illnesses.

Tickets for the Gala of Hope are \$150 per person and a portion is tax-deductible.

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 funds 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
tax deductible

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

A TIME FOR GIVING:

As the holiday season approaches many of us have made our gift list and planning who we will give gifts to this year. This year do something different as you make your gift list. Go beyond including just your family or friends and add at least one gift to your shopping list to donate to a children's charity. If you are planning to cut back on your holiday spending or can't afford another gift this season, consider spending a little less on the other fortunate people on your list to allow a donation to a sick child. Surely the others on your list would gladly give up a portion of the cost of their gift to allow a donation to be given to help a child. If you have children of your own, explain to them how donating works and ask for their ideas. You will be surprised at how interested and helpful your children will be about donating.

Many of us are struggling to make ends meet in this tough economy, but we should be grateful for what we have and consider helping other families and children that may be in a hospital during the holidays. Donate directly to a local charity; you may even know the child or family who will receive your gift.

As a parent or gift giver, you know in your heart the gratifying feeling you have knowing that your generosity will help a child in need. Even if you don't know the child, you will know in your heart that he or she has been helped by you.

Over the last 11 years, Chip McElroy and the Ryan Foundation have made Christmas in the hospital a little easier on many families. So many children don't know what it means to have hope and faith. It is up to those of us who do know to open our hearts so all children can share in the spirit that Christmas instills inside us allowing miracles to change from dreams to reality.

At the heart of everything we do is the conviction that a child should be at home, surrounded by their family, not stuck in a hospital ward. Neither Santa nor Ryan's Foundation can make such wishes come true; but, together we can deliver the HOPE that whatever dreadful disease they are battling there are people who care.... EVERYDAY.

Editorial by Susan Havelka

GOOD NEWS CORNER

We are fortunate to have so many wonderful supporters of our cause and below we show why:

Mid Hudson Medical Group held a "Blue Jeans for Health Day" and donated the proceeds received from their employees.

Topical Biomedics gave 5% of their sales from July - September 2010.

Board Member, Michelle Bourque, applied for a volunteer grant through her employer.

Slipada Jewelry Representative, Deborah LeDonne, donated a portion of her sales from the Wine Event.

Cool Candle Scents owner, Kristin Miller, donated a portion of her sales from the Wine Event.

Hudson Valley Federal Credit Union held a car wash benefit and donated their proceeds.

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.

Thank you for your contributions through Goodsearch.com and Goodshop.com.

We received a check for \$5.21! Every penny counts!

Remember to use this when doing your Christmas shopping or anytime you search online.

Thank You for your donations made through our Newsletter.

Your generosity is greatly appreciated.

Remember GOODSEARCH.COM & GOODSHOP.COM when searching or shopping online.

Sign in: RYANSFOUNDATION



2011 CALENDAR

April 9 Gala of Hope

June 4 Sporting Clay Shoot

June 12 5K Walk/Run

June 27 Golf Outing

August 20 Pig Roast
(rain date August 21st)

October - Wine Event
(Date TBD)

For more information on events planned for 2011 please see our webpage or contact a board member.

A Message from Chip

On behalf of Ryan McElroy Children's Cancer Foundation, I would like to thank you for your continued generosity. Your commitment to Ryan's Foundation is sincerely appreciated. Each year we continue to advance our mission of never having to say NO to a child battling devastating diseases. With your support of our many fund raising events throughout the year we have been able to help many families who are dealing with the worst news a parent can get and we have seen many lives changed for the better. Your support is the lifeblood of our Foundation.

Ryan's Foundation is rich in volunteerism; without that none of what we do would be possible. Our board members and volunteers come with expertise in many diverse fields and they help to further our growth. We continue to evolve by way of the many voices of our supporters, parents, and children. Our Board's focus is to maintain high ethical standards in how we raise money, manage the foundation and provide support and it reflects the respect we have for every child and adult that steps forward to volunteer and make a donation of time or money.

The Annual Gala of Hope has been very successful in the past. The goal of Ryan's Foundation is to continue to make a difference in the lives of children and families by providing support that improve their quality of life. With the help from supporters such as you, we will continue to see improvements in what we can do going forward in 2011. Thanks again for your generous support of our efforts.

Best wishes,
Chip McElroy

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



Ryan's Foundation reminds you about our EFT feature on our new 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

I want to help donation form



Enclosed is my gift of \$ _____

Name: _____

Address: _____

City/State/Zip: _____

Phone-day: _____ Phone-evening: _____

E-mail: _____

_____ My check is enclosed. (Make checks payable to: The Ryan Foundation.)

_____ Charge my donation to: _____ Master Card _____ VISA _____ Discover
Card #: _____

Expiration Date: _____

Signature _____

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.

"raising hope"