

Ryan's Newsletter



Children's Cancer Foundation

The Ryan McElroy Children's Cancer Foundation
198 Route 22, The Atrium Building, Pawling, NY 12564
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OUR FEATURED HERO – XAVIER TORRES

A Mother's Story

by Christy Torres

As a parent of a now 4 year old child with brain cancer I can say with certainty that if you can get through that first day of diagnosis, you will be able to find the strength to make it through every minute of each day that follows. ALL of which are filled with the doubt and fear of your ability to continue on the long journey that lays ahead with the strength to face every challenge that arises, each potentially life threatening or altering decision a parent must make when attempting to save the life of their precious child! The overwhelming task of trying to master all the information needed to make the "right" decision that will hopefully cure a child yet is so foreign to those of us neither familiar or employed in pediatric specialties of oncology or neurology makes choosing the "right" choice seem almost impossible. At the same time when as a parent you feel the most afraid, vulnerable & have lost all hope that you're able to shoulder it all you must find the ability to give yourself the recognition you deserve for the unthinkable strength that you have in you each time you put aside your own grief, your longing for the simpler life that once was, your overwhelming sadness

caused by the unfairness of it all, while trying to control the almost unbearable rage you often feel towards yourself and at times towards the entire world around you. Yet the endless day to day needs of your child who is so seriously ill as well as those left behind at home leaves no time for all the wondering of what life may have been or even more than a moment or two to feeling sorry for yourself or your baby as there's too much to do.



XAVIER TORRES

While a pity party of any sort is well deserved it doesn't provide any relief at a time when what your child needs is a champion fighter who's focused on doing anything and everything to save them and help them find the strength they need to do what needs to be done to keep going. Knowing that every day, even the most difficult of days is truly a blessed gift. I can't say how other parents are able to guide their family through each challenge and triumph associated with childhood cancer but I know with certainty that we were able to get through even the worst chemo or surgery after being able to survive that first day when our precious son Xavier, 3 at the time, was diagnosed. The day our world felt like it had been shattered & we thought we were going to lose him forever...the day life as we knew it would change forever in some of the worst and most amazing ways we would never have imagined could ever happen to US. That was almost a year and a half ago but that day will forever be etched in my mind. My husband Steve called from Vassar ER. He was crying as he relayed the news that they'd found "something" in Xavier's head! I was in such shock all I could say was "WHAT?!, WHAT?!"

I cried like I had never cried before in my life. I felt as though I had already lost him. He told me I needed to come to the hospital immediately before they transported him to Maria Fareri Children's Hospital at Westchester Medical Center & there wasn't much time before they would arrive to take him. I was such a mess I couldn't think straight, I didn't know what to do or what to pack.... if anything?

Somehow Steve was able to remain focused & strong enough that when I asked "Am I supposed to pack Xavier's clothes or isn't he going to need anything?" I can still hear him saying "Of course you should pack his things, he'll need them. He's going to be ok because I can't lose my boy & I know that he's coming home." With that I threw clothes for Xavier, Steve, myself & our two girls in a suitcase along with the manual breast pump the hospital gave me just a week before when I'd given birth to baby Taliana by emergency c-section. Looking back, it seems almost a blessing baby Taliana arrived a few weeks early. Ironically, her original due date turned out to be the day Xavier would have his first brain surgery. And so our journey into the unknown began. We followed the medical transport to Westchester. My brother Adam stayed with Natalia (5yrs) and Taliana (10 days old) in a hotel close by while Steve and I were at Xavier's bedside in the PICU anxiously awaiting our consult with the neurosurgery team. Just three days later a brilliant and successful total resection of the tumor was performed by the neurosurgeons at Maria Fareri with Dr. Mohan leading his team of miracle makers. There are no other words for what was performed by Dr. Mohan and his team other than a miracle! While Xavier could've lost his speech and many other cognitive functions or experienced physical deficits, paralysis in parts of his body, etc. when they wheeled him up to the PICU room where Steve and I were waiting in silent prayer, Xavier cried out "Mommy!" and tried to jump into our arms. All we could do was thank God that he was alright!

Our 4 year old son Xavier has been fighting a pediatric brain tumor (medulloblastoma) for about a year and a half, he's had 2 brain surgeries, proton radiation and he's on his second different chemo treatment after his tumor recurred. Needless to say this battle takes its toll on a family. One thing that you don't really think about when you embark on this road is that the normal trials and tribulations of life don't go away or stop happening just because you have a child fighting cancer and at times you feel alone with nowhere to turn.

The Ryan McElroy Children's Cancer Foundation has been such a godsend for our family. Quite frankly I don't know where we'd be without them. Even with good health insurance, the cost of treatment can quickly become overwhelming. Add to that the cost of travel and lodging for treatments away from home like when my wife Christy and my son had to go to Boston for 2 months for proton radiation and you can easily find yourself in financial straits.

When we needed it most Ryan's Foundation helped us out with grants that helped us keep our power turned on at home and helped keep our car safe to drive while traveling to and from our son's treatment. Additionally, our heating unit at the house failed and thanks to the incredible people at the foundation, we're going to be able to keep our house warm this winter which, gauging from the early cold weather, promises to be especially cold.

Seeing my boy have to face this terrible disease has been far and away the most difficult and heartbreaking experience of my life, but thanks to Ryan's Foundation we've been able to focus our attention and our energy on getting our baby boy through this and that's the greatest help that any parent going through this can ask for. Along with the financial assistance we've received, Chip and his amazing team have embraced our family and truly made us feel like we're cared for, loved and most certainly not alone. The "work" that they do is so important, and I put the word work in quotations because while they are a 100% volunteer team, their time and the incredible passion that they have for helping families in need makes it clear that this is so much more than a philanthropic endeavor for them.

All families that know the devastation of having a child with cancer will inevitably need some form of help at some point. Pediatric cancer can destroy lives and not just the patient's, but also that of the families. What the Ryan McElroy Children's Cancer Foundation does is nothing short of life saving. I'll be eternally grateful for everything they've done for our family and for every family they've ever touched.



**Xavier
is a
Superman**



Torres Family
Natalia, Taliana,
and Xavier



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

sghavelka@gmail.com

ABOUT US



ARTHUR HART
Trustee

Arthur Hart is a Dutchess County native who graduated from Arlington High School. He attended Dutchess Community College as a Business Major.

Art began his career at the age of 14, working on the farm and later working in the produce department at Adams Fair Acre Farms. After High School he became a General Contractor. After several years of building houses Art was hired by Home Depot as an Assistant Department Manager where he was in charge of store inventory, ordering, and scheduling for the paint department for two years. In the fall of 1998, Art was hired by the Dutchess County Sheriff's Office where he works as a Patrol Deputy, S.W.A.T. Team, Scuba Team and a Firearms/General Instructor.

Art met Chip, Judy, and Tralee in the summer of 1999 not long after their loss. He was greeted at their home with open arms, and not allowed to leave until he had something to eat and drink for lunch. They were having a BBQ for anyone who wanted to stop over.

Art became involved with Ryan's Foundation a few years later, after attending his first Gala. He started helping with fundraising. Art and Carl Merritt (Board Member) joined forces and started the Annual Sporting Clay Shoot in 2007.

We are now hosting our 7th Annual Shoot on June 7, 2014 at TMT Preserve.

"I can only hope and pray that my small contribution to Ryan's Foundation will touch the hearts of children around the world."

It is widely believed that people who give back live longer and have more fulfilling lives. We believe this is true. Through Ryan's Foundation we have been privileged to meet many courageous children and their families as well as many generous donors who help us each and every day, month, year.

Did you know that even well-insured, middle-class families can find themselves in financial distress because of a single catastrophic illness? When insurance does run out, health care costs can be staggering for the families of children with cancer, who are already consumed with worry. Unlike adults with cancer who might be treated for a few months, young patients might undergo two to three years of treatment. The side effects of treatment (which range from heart disease to brain damage) can linger for decades and cost nearly as much as therapy for the original cancer. Some cancer treatments are especially pricey. A new leukemia medication for children, who no longer benefit from chemotherapy, costs \$45,000 for a three-week treatment cycle.

Families of children with cancer face daunting non-medical costs as well. Because pediatric cancer is relatively rare — 12,400 cases a year — children typically are treated at a small number of children's hospitals in large cities forcing many families to travel long distances. They are at greater risk of exceeding their maximum insurance benefits. Some parents quit jobs to become full-time caregivers. Others, such as single parents who fear losing their insurance, might have to continue working while their children are hospitalized far away.

Most families aren't poor enough to qualify for Medicaid (the federal health-insurance program for the indigent and disabled) or a state-run insurance program for the working poor. Most states limit benefits to families of four earning \$34,100 a year or less, according to the U.S. Department of Health and Human Services.

With the state of the economy, we understand that money is scarce and people are working longer hours to make ends meet. But together, we can *Raise Hope* by making EFT donations as little as \$10 a month. Our goal is to have 1,000 donors at \$10 a month. Won't you help us reach our goal so we never have to say NO to a child in need? Last quarter \$48,340 was dispersed to help local families.

Please consider a donation this Christmas to a non profit organization or ask your Secret Santa to make a donation in your name. You would be surprised how good it feels to know your small sacrifice means so much to someone in such a difficult situation. 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 contribution will pay for a mortgage or medicines.

As part of their "Living Faith" program, the Pre K 4 class at St. Martin de Porres School collected bottles and cans on the third Friday each month. The children sorted and counted them and two families redeemed them and sent the money to the school. This year they discussed the many organizations that benefit children and the class decided that the money should go to Ryan's Foundation! They donated \$159.45! Way to Go!!

At a recent meeting of Trustees of the James J. McCann Charitable Trust, they voted to grant Ryan's Foundation \$2,500 to aid in the support of children and families facing life threatening illnesses in our community! Thank You!

The Community Foundations of the Hudson Valley designated their 2013-2014 Grant of \$540.43 to be awarded to Ryan's Foundation for providing much needed resources in the Hudson Valley. Thank You!

Once again, the Boshart Family have shown incredible generosity in asking family and friends to donate to Ryan's Foundation in lieu of birthday gifts for their children. Thank you for your continued support!

This year we have raised over \$235,000 from January through September. We have already surpassed last year's total. The third quarter of this year was a record quarter for donations and fund raising, thanks to:

The Concert in the Park, organized by Jeremy & Gina Busolt, held at Lakeside Park in Pawling to help Caleb Gaylord and his family. People came from near and far to attend this concert. Thanks to Dan LaVoie for donating his time to this wonderful cause.

The "Angels of Gold," organized by Lori Decker, was a huge success. We raised a large sum of money to help children and their families in the Hudson Valley. A special thank you to the Thorne Family and to Elliott Gordon from the TV show "The CHEW". The event was 100% volunteer with the main entree donated by Gigi's Trattoria in Rhinebeck. Ten local restaurants along with Millbrook Winery and Coach's Foods & Spirits donated the wine. Arlington Wine & Liquor donated the champagne for our "Champagne Hayride." A special thank you to the Gentile Family from Pleasant Valley for making all of the beautiful 'angels' for the giving tree. Teddy, Joey, Derek and Johnny did a beautiful job!!

The Annual Fall Tasting Event at the Grandview, organized by Steve & Erin Reverri, was a great success. We had our best year yet! Thanks You's go out to the many vendors and volunteers (<http://www.ryansfoundation.org/about/supporters>) who year in and year out participate in this great event. And, of course, Thank You to all who came out to help us Raise Hope! (<http://www.facebook.com/ryanmcelroychildrensfoundation>).

This year we have spent over \$120,000 in family assistance, with approximately \$90,000 in direct family assistance to about 50 plus families for food, living expenses, household bills, transportation, overnight stays near out of town hospitals, hospital bills, and medical bills. Almost \$10,000 was spent in special home construction needs for various children, and almost \$10,000 for funerals for the children who lost their battles. We have also donated about \$10,000 to other local charities such as Fraxa, The Eric Trump Foundation, Make-A-Wish and The Ronald McDonald House. None of this would be possible with you. God bless and Thank You.

On Friday, November 8, **Interact Club of Pawling** hosted its third annual Ryan's Foundation Dodgeball Tournament. This year, 19 teams participated in the tournament! Teen Club of Pawling (7th & 8th Graders) was also a key component to the success of the Foundation Dodgeball Tournament organizing the bake sale and selling raffle tickets. Interact is a community service club that is made up of high school volunteers. The club helps support community organizations as well as global organizations any way they can. Since February of 2011, the Interact Club has raised and donated over \$16,000! The club is self-governing, meaning that the weekly meetings and projects are organized by the teens.

INTERACT CLUB OF PAWLING OFFICERS:

Mark DelBalzo – President
Henry O'Connor – Vice President
Rachel Sullivan – Secretary
Zack Jiskra – Treasurer

John Ammaturo – Pawling Rotary / Interact Liaison
Melissa Smith – Pawling Recreation Director
Robyn Woolley – Assistant Recreation Director / Interact Advisor
Shaun McGee – Interact Advisor
Kevin Hunter, Stephen Malone, Kristen Polgreen, Lisa Riley – Pawling Recreation
Bobby Rodriguez, Brett Schmitt – Volunteer Referees

INTERACT CLUB OF PAWLING MEMBERS:

Reece Bijou, Rose Butironi, Gianni Cedeno, Kyle Christian, Ryan Christian, Meredith Clark, Sean Dazi, Danny DelBalzo, Sophie Espinosa, Fiona Espinosa, Brennan Farrell, Jon Farrell, Joe Gentile, Avery Johnson, Luke Jorgensen, Ryan Kendra, Aiden King, Jake Koerner, Maria-Paula Lastres, Ashley Loeven, Alexa Makar, Danielle Marino, Sarah Marvin, Devin Meaney, Joseph Merendino, Katie Meyer, Melanie Mold, Anthony Morefea, Ethan Nagasing, Eric Oliva, Dylan Olvia, Michelle Piazza, Noah Pieratti, Elaine Roman, Caleb Semel-Bissette, Mikey Slattery, Brooke Smith, John Sprague, Andrew Sprague, John Sotever, Cassandra Sullivan, Andra Sullivan, Jaeson Yeung

TEEN CLUB OF PAWLING MEMBERS:

Lauren Adams, Emma Athow, Zach Castro, Dylan Christian, Kelly Cochran, Kennedy Eans, Filomena Gentile, Ryan Grossman, Kyle Grossman, Emma Herman, Luke Jiskra, Skylar Johnson, Kelly Koerner, Gabriella Kowalczyk, Matt LaBarbera, Andrew McCabe, Hannah McCoy, Lauren McGreal, Nick Rubino, Stephen Sinisi, Molly Wolff, Dylan Zamora.

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: _____ cvv _____
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

Donation made in memory of: _____
Donation made in honor of: _____
Donation made in lieu of: _____

2014 Calendar

SPRING: Looking for volunteers to help with Ryan's Run at Freedom Park in LaGrange call 845-677-4999 - Lori Decker
JUNE 7: Annual Clay Sporting Shoot, TMT Preserve.
JUNE: Annual Golf Outing - Date and Place TBD .
FALL: "Angels of Gold" Anyone interested in volunteering contact: info@pulsecyclingandfitness.com or call 845-677-4999
We are in search of a farm in the Millbrook area that has a barn that can hold up to 250-300 people.
FALL: Annual Wine Event - Date TBD

More Events are being planned - please check our webpage for dates and how to purchase tickets.