

# 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](http://www.ryansfoundation.org)

Children's Cancer Foundation

## OUR FEATURE STORY Luciana Francesca-Marie Nicolosi

On December 28, 2007, Luciana Francesca-Marie Nicolosi, was born to parents Thomas and Lorraine Nicolosi. Like her father, Luciana was born with a mild Heart Murmur. Her doctor wasn't too concerned as many children are born with heart murmurs and eventually grow out of them. After a few days in the hospital, it was time to take Luciana home to her awaiting siblings, Brandon and Giovanna. As they had done in the past, they contacted the family's Pediatrician, Dr. Maria David, in Newburgh, NY to set up Luciana's first appointment. Immediately Dr. David noticed the heart murmur and told Lorraine and Tom, "We'll keep an eye on it but it should go away in time." The Nicolosi's took comfort in her words as these were the same words spoken by the delivery room doctor. Throughout the first year of appointments, Dr. David had paid particular attention to Luciana's murmur which had become progressively worse. It was time for Luciana to be seen by a congenital heart specialist. Dr. David recommended we take Luciana to Westchester Medical Center to consult with Dr. Levine.

After a series of in-office tests, Dr. Levine determined Luciana's murmur was not *typical*. Luciana's body was only receiving approximately 20% oxygenated blood. Dr. Levine sent her medical records to Boston Children's Hospital (BCH) to be reviewed by a panel of surgeons who would decide what course of action to take. They were told Luciana needed a Cardiac Catheterization to check blood flow and blood pressure in the chambers of the heart; also it helps find out if a congenital heart defect is present and how severe it is and sometimes it can be used to help correct the defect.

Luciana underwent three catheterizations; all were unsuccessful. Doctors said Luciana had a rare heart disease known as

*Critical Pulmonary Arterial Branch Stenoses (CPABS)*. Some children diagnosed with CPABS may have only one or two blockages, while others may have dozens, sometimes deep inside their lungs. If the obstruction isn't relieved, the blood doesn't receive enough oxygen, and high pressures are placed on the heart's right ventricle, potentially leading to heart failure and death. When the blockages occur in the major pulmonary arteries, they can be fixed surgically, but surgery cannot repair the smaller arteries that branch off inside the lungs without causing extensive lung damage. In such cases, the current standard of care is balloon angioplasty; however, the blockage persists about 40 to 60% of the time and the only option becomes a lung or a heart-lung transplant. Luciana's condition will inevitably cause her to undergo a heart-lung transplant at sometime in her life.



Weeks passed; finally, Dr. Lisa Bergerson of BCH reviewed Luciana's records and felt they could help her. Luciana underwent more testing (Blood Tests, EKG and Nuclear Tests).

In the first of six procedures performed on Luciana at BCH, there were complications, cutting the procedure short. Luciana's levels had fallen so severely an intervention was needed with

results causing future procedures every four months. Dr. Bergerson and her team decided to "aggressively attack" the ventricles to raise Luciana's oxygen levels. Her second, third, and fourth procedures yielded more negative results. In June 2010, during her fifth procedure, surgeons had more bad news...they found blood clots in Luciana's heart and were forced to induce coma. Luciana recovered and was sent home. In October 2010, Luciana underwent her sixth procedure. This time, Dr. Bergerson appeared with a look of satisfaction and the family finally received their first bit of good news! Luciana's surgery was successful on four of her ventricles. Her oxygen levels were raised to 51%. Dr. Bergerson decided to wait one year to see if these levels would hold. In October 2011, Luciana will undergo her *tenth* heart procedure. The Nicolosi family gracefully asks everyone to pray for Luciana.

The Nicolosi's medical coverage only covers 80% of the costs incurred because the family must go "out-of-network" for Luciana's care. The average out of pocket expense incurred each trip to Boston ranges from \$1800 to \$3000 depending on whether Luciana faces any complications during her procedures. The Ryan Foundation recently heard of their financial situation and paid off extensive and mounting household bills.

"We would like to thank your organization for reaching out to help us with our household bills and other costs incurred during our time of need. We could not have given our daughter the fighting chance she needs to survive had it not been for your generosity and compassion. Your act of kindness will never be forgotten and WE WILL PAY IT FORWARD!"

If there is anyone whose child may have been diagnosed with CPABS, the Nicolosi's welcome you to contact them at [lucianascause@aol.com](mailto:lucianascause@aol.com).

# ....by Tralee McElroy

"We all die. The goal isn't to live forever, the goal is to create something that will." Through Ryan's Foundation, we have created a legacy of Ryan. My Dad's goal, through this foundation, was for people who didn't know Ryan to know him, and those that did know Ryan, to never forget him.

August 29, 1998: As the moment was happening, as I ran down the stairs, there was no farewell, no time to say goodbye. I just had to go as my parents sat there and cried. He was gone before we knew it and only God knows why. God has a plan for each of us. I have learned that because of God's plan, no one knows what will happen tomorrow, no one knows when he or she will die. Therefore, we need to live each moment as if it is our last. We need to love the people around us and never forget those that have gone before us. Ryan was always in so much pain, but he never let anyone know. He was "strong as a bull." He deserves to be with us, but he is happier in Heaven. No more medicines, no more pain, no more hospitals, and no more doctors. He is all grown up now, the big 18 is approaching. He would be playing Division One baseball wherever he dreamed. Knowing Dad, he would make it to the big leagues. Ryan's legacy created this foundation which is helping kids everyday. Ryan saves lives and helps bring smiles to others. "The goal isn't to live forever, the goal is to create something that will."

Ryan's Foundation has created hope and wishful thinking to all families and children. Ryan is finally getting his "House of Hope." A house for children to come and play, a house where miracles can come true, a house where lives can be changed. A house is built on a sturdy foundation. Without a sturdy foundation a house will not stand tall; it will fall because of lack of support. It can't be trusted to protect people. Without a foundation, the house will have no trust, no loyalty, and no structure. Ryan's Foundation is where it is today because of the people supporting Ryan and the children we have helped. Ryan's House of Hope will only stand tall and last forever if the foundation it was built upon continues to grow, continues to get support, and continues to help families in need.

"The goal isn't to live forever, the goal is to create something that will." Ryan's House of Hope is something that will last forever. For generations to come, everyone will know Ryan, the Foundation will continue to thrive, and the House of Hope will stand tall and proud, knowing it was built upon a loyal and structured foundation.

As I said, my Dad's goal was for people who didn't know Ryan to know him, and people who did know Ryan to never forget him. He's my brother.

(From the Annual Gala Address given by Tralee McElroy)

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\*\*\*\*\*

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

# Thank you!



## ABOUT US



Kirk Imperati  
Board Member

Kirk Imperati is a life long resident of Dutchess County. He and his wife, Becky, have two daughters. He is a graduate of Marist College where he received a Bachelor's Degree in Criminal Justice and his Master's degree in Public Administration.

Kirk is with the Dutchess County Sheriff's Office and, in February 2007, Kirk was promoted to Undersheriff where he oversees the day to day operations of the Sheriff's Office and oversees the budget process for the office.

Kirk has organized many of the Foundation's events, most importantly the Annual Golf Outing. This has become a huge success and attendance has grown impressively over the last few years under his leadership. He is a tremendous asset to the Foundation and, through his expertise and enthusiasm, the Foundation has experienced tremendous growth.

Kirk has dedicated a great deal of his time to the Foundation helping to promote the message of helping sick children in the Hudson Valley, a place he knows so well.



## "Ryan's House of Hope"

hope/hōp/

Noun: A feeling of expectation and desire for a certain thing to happen

Verb: Want something to happen or be the case

It has been said that the longest journey begins with the first step.

"Ryan's House of Hope" is our first step. Thanks to the generosity of Sean & Jill Johnston, Ryan's Foundation has been granted 6 acres of property in Poughquag, New York where we can put down roots. Our charitable journey will provide help to families in need of assistance in a residential setting. Ryan's House of Hope will offer a comfortable, non-institutional environment where children and their families can come free of charge. There, they can get much needed support as they travel through the labyrinth of doctors offices, hospitals, and laboratory testing they entered into when their child became sick. Our goal is to provide a place of solace and understanding while providing resources needed to get through their terrible ordeal.

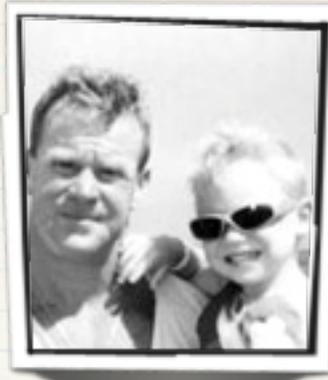
The House of Hope relies on your generosity. Over the last decade, your generous contributions have made it possible for Ryan's Foundation to improve the quality of life for many brave children in the Hudson Valley. We count on your continued generosity to move forward with Ryan's House of Hope. All donations made through the EFT feature on our webpage are dedicated to Ryan's House of Hope.

Watch for more information in upcoming issues of our Newsletter and check out our webpage.

# In Loving Memory of Ryan McElroy



Tralee & Ryan



Chip & Ryan



Judy & Ryan

**THIS ISSUE OF RYAN'S NEWSLETTER IS BEING DEDICATED TO THE MEMORY OF RYAN MCELROY WHO WOULD HAVE TURNED 18 ON SEPTEMBER 11, 2011. RYAN IS WHAT THE FOUNDATION IS ALL ABOUT**

At the age of five, surrounded by close family and friends, I reached into the big bowl of red raffle tickets. The first fundraiser for the foundation; a raffle. All proceeds went to a foundation that was founded by family and friends to help children in the Hudson Valley. Besides raising financial support for these children, my dad's goal was for people that didn't know my brother to know him, and people that did know him, to never forget him. Not understanding or realizing much at five years old, I picked out a red ticket; the winners got to go to a dinner at the Arch Restaurant in a limousine.

Little by little, we raised money in honor of my brother to go toward children fighting horrific diseases. We held softball and volleyball tournaments each spring. Each event was a family fun day, but fell short of what we needed to raise so we never had say NO to a child. Our first Gala was one of the biggest events we ever had. One hundred and fifty people in attendance and it was held at Villa Borghese.

Twelve years later, the foundation has grown to a whole other level. Working closely with Make a Wish Foundation and The Ronald McDonald House, Ryan's Foundation has been able to help more children in need than we could have ever imagined. The Foundation now holds several events throughout the year; a Golf Outing, Walk-A-Thon, Wine & Food Tasting, Clay Shoot, Spin-a-Thon, Classic Car Show & Pig Roast, and our biggest event, the Annual Gala of Hope. In comparison to our first Gala, there are now five hundred people in attendance, held at The Grand View and raising enough money to help hundreds of children with life-threatening illnesses.

The one thing that the Foundation had only dreamed about is now becoming a reality. "Ryan's House of Hope" is currently under construction. A house where children and families can go to escape the reality of their disease. Parents can get emotional and financial support and they will never be turned away. The families will never think of what they should have done or could have done because anything the family or child needs, we will do.

I have heard my father say so often that Ryan's Foundation has become more than just a foundation. It has become a community of people that care, a community filled with compassion, and a community who are committed to making a difference in the life of a child. I sit in at Board meetings and I am surrounded by a group of people who work so hard and truly care about my family, Ryan, and helping children in anyway possible. As a foundation, as a board, and as a family, we have cried, we have laughed, and we did what we had to do to help the life of a child.

I am proud to be a part of this foundation, at its inception, how it has evolved, and where it is going.

God Bless you all and thank you for your support.

Tralee McElroy

## Raising Hope Ryan's Way

## Calendar of Events

### September 17 Spin-A-Thon

Spins at 8am, 9am, 10am  
45 minutes each - 15 minute turnover  
World Gym PAWLING  
\$25.00 per spin  
Sign up at: World Gym Brewster/Pawling  
or Ryans' Facebook Page or contact  
Michelle: [mibourque@ryansfoundation.org](mailto:mibourque@ryansfoundation.org)  
Gina: [ginam@nycapp.rr.com](mailto:ginam@nycapp.rr.com)  
Registration deadline September 15

### October 27 Fall Tasting Event

The Grandview, Poughkeepsie  
6:00 - 9:00 pm  
Tickets: \$50 advance purchase  
\$60 at door  
Purchase tickets online at  
[www.ryansfoundation.org](http://www.ryansfoundation.org)

RYAN'S FOUNDATION REMINDS YOU ABOUT OUR EFT FEATURE ON OUR WEBPAGE. ALL DONATIONS MADE THROUGH EFT ARE DEDICATED TO RYAN'S HOUSE OF HOPE. WE ACCEPT ALL MAJOR CREDIT CARDS AND WE ACCEPT PERSONAL CHECKS ONLINE. PLEASE CONSIDER SIGNING UP FOR RECURRING EFT DONATIONS SO THAT WE MAY CONTINUE OUR MISSION OF NEVER HAVING TO SAY NO TO A CHILD.

[www.ryansfoundation.org](http://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](mailto:sghavelka@gmail.com)



## GOOD NEWS CORNER

THE BOSHART FAMILY DID IT AGAIN! IN LIEU OF PRESENTS FOR THEIR SON CHARLIE'S FIRST BIRTHDAY, THEY RECEIVED DONATIONS TOTALING \$350 AND DONATED IT TO THE FOUNDATION. ALSO, THAT SUM WILL BE MATCHED BY THEIR EMPLOYER, MASTERCARD. THANK YOU!

DEBBIE COLE, DUTCHESS COUNTY SHERIFF'S OFFICE, OPTED FOR DONATIONS TO RYAN'S FOUNDATION IN LIEU OF GIFTS FOR HER BIRTHDAY. THANK YOU!

- TOPICAL BIOMEDICS GAVE 5% OF THEIR SALES THIS QUARTER.
- NEW FAIRFIELD PHYSICAL MEDICINE & REHABILITATION.
- NORTH EAST PHYSICAL MEDICINE & REHABILITATION
- DANBURY PHYSICAL & REHABILITATION, PC

BACK TO SCHOOL SALES START EARLY THIS YEAR AND THE COLLEGE KIDS HAVE TO HEAD BACK TO SCHOOL. DON'T FORGET CHRISTMAS SHOPPING STARTS NOW! MOST RETAILERS OFFER AWESOME COUPONS WHEN YOU SHOP ONLINE. FROM SEARCHES FOR NECESSITY ITEMS TO TRAVEL DEALS, FOLKS CAN DONATE TO US AROUND THE CLOCK AT NO ADDED EXPENSE ON THEIR PART. OFTEN YOU CAN SAVE WITH THE COUPONS AND, WITH GAS PRICES BEING RIDICULOUS, YOU DON'T HAVE TO LEAVE HOME. [GOODSHOP.COM](http://GOODSHOP.COM) & [GOODSEARCH.COM](http://GOODSEARCH.COM) & [MARKETAMERICA.COM](http://MARKETAMERICA.COM). THESE SEARCH ENGINES GIVE MONEY BACK TO RYAN'S FOUNDATION EVERY TIME YOU SEARCH OR SHOP 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](http://GOODSHOP/GOODSEARCH:RYANSFOUNDATION) OR SIGN IN TO [MARKETAMERICA.COM/RYANMCELROYCCF](http://MARKETAMERICA.COM/RYANMCELROYCCF)

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Phone (day): \_\_\_\_\_ Phone (evening): \_\_\_\_\_

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

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198 Route 22 Atrium Building, Pawling, NY 12564

ALL DONATIONS ARE TAX DEDUCTIBLE

A \$100 donation will cover transportation to a hospital. A \$250 donation will pay for food or utilities.

A \$500 donation will pay for lodging or rent. A \$1,000 donation will pay for mortgage or medicines.

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

Donate Today