# Ryan's Newsletter The The Ryan McElroy Children's Cancer Foundation

The Ryan McElroy Children's Cancer Foundation198 Route 22, The Atrium Building, Pawling, NY 12564845-855-0211www.ryansfoundation.org

couldn't elaborate further except to say that it was something rare.

Children's Cancer Foundation

The same night, Gaddy had an MRI which conclusively showed a tumor, 4 cm x 3 cm in size, on his brain. Surgeon Dr. Tobias was called in for emergency surgery.

The tumor was pressing on part of the brain responsible for vision. His surgery was scheduled for June 28. Surgeons saw Gaddy had a large quantity of fluid on his brain. Both the tumor and the fluid were removed over the course of the twelve hour operation, which began at 7am and finished at 7pm. (When discussing Dr. Tobias, Irene's eyes relay a gratitude that is beyond words. She states that, "Dr. Tobias is a great man. God is with him.")

It was at this point that Rogelio Cruz (better known as "Fuzzy") joined our interview. His presence brought a feeling of happiness to the household as both Gaddy and his sister happily greeted him at the door.

Despite initial claims by doctors that after the surgery Gaddy could lose the ability to control half of his body, his memory, and the ability to walk, his recovery went well with no complications. All of their fears were put to rest.

(Continued on page 2)

## OUR FEATURE STORY GADDY CRUZ

Upon entering the Cruz family home, I sat down with Gaddy's mom, Irene Reyes, to discuss the progression of her son's illness. Shortly after the interview began, Gaddy emerged from his bedroom, hand-held gaming system in hand, to sit on the couch and play Mario Kart. His sister, 4 year old Keilly, playing in her make-believe kitchen in the other room, occasionally came in to check on her brother.

Irene Reyes began by explaining what first prompted Gaddy to see the doctor. Gaddy was complaining of throat pain and was diagnosed with strep throat for which he received antibiotics. He finished the medicine and two days later he started to complain of neck pain. Irene took Gaddy back to the doctor and this time his strep test came back negative. Despite this, doctors gave him a second, stronger antibiotic. Unfortunately, this antibiotic did not make Gaddy's pain go away.

As an active karate student for four years, Irene began to think that perhaps his neck pain was due to an injury. After visiting a chiropractor, Gaddy's neck pain continued with no let up.

Gaddy began to feel tired and slept more than normal. He started to vomit and didn't want to play. Finally, Gaddy's doctor suggested going to the hospital for further testing. An X-ray was taken and blood was drawn; everything came back normal.



On June 26, 2012, Gaddy and his family went to Westchester Medical Center in Valhalla for a CT-scan which came back with some results. Unfortunately, they were not very specific.

During this time, Joyce Marino, Gaddy's first-grade teacher, provided unwavering support to the family; staying by their side in the hospital for three weeks. For this, the family is eternally grateful.

The Cruz family was told Gaddy had a mass on his brain. They Gaddy Cruz, continued from page 1

Gaddy's tumor was sent to St. Jude's Children's Hospital to perform a biopsy to determine just what type of tumor it was. After fifteen days, there was still no answer. Finally, word arrived from Dr. Oscania. Gaddy had **"Atypical teratoid rhabdoid cancer"** a rare type of cancer which affects the central nervous system and the brain.

Despite still having a small tumor in his brain and lower back, Gaddy began chemotherapy right away. The Cruz family was approached about an experimental medicine to treat Gaddy's cancer. The family discussed this option and decided to give it a try. They were going to do everything possible to save their son. Unfortunately, this medicine did nothing to help rid Gaddy of his cancer.

Gaddy began chemotherapy in August and was scheduled to have five sessions over the course of the month. During each session, an MRI was performed to determine the status of the remaining tumor. Each MRI, thus far, showed that the tumor was still there, but not growing. At his third session of chemo, the strongest dose yet, Gaddy's MRI brought devastating news. The tumor had grown. No one, especially Dr. Oscania, thought this would happen. They began to consult with St. Jude's Children's Hospital, radiation technicians, and surgeon Dr. Tobias. Doctors performed another MRI to determine if emergency surgery would be needed and to see if they could even remove the tumor due to its location in the brain. This MRI provided shocking news! Though the tumor had grown, its roots had disappeared. Nothing was feeding the tumor! Both the family and the doctors were in disbelief. When asked what they believe happened, both Mrs. Reyes and Mr. Cruz stated, "A miracle. We pray together all the time as a family. God has heard our prayers."

Tuesday, November 6, Gaddy began radiation treatments to help treat the remaining tumor. This treatment is five days a week and will last six weeks at Maria Ferrari Children's Hospital. Rogelio rises each morning at 5am with Gaddy; at 6am they take a taxi to the hospital in Westchester. As such, Mr. Cruz is unable to work during the week. When asked how long the treatments take he stated, "Sometimes we get lucky and can be home by noon. Other days, we don't get home until 9pm." Irene stays at home with Keilly who attends preschool.

The family is doing their best to cope with Gaddy's illness. In the beginning, Keilly exhibited signs of depression. She was sleeping more than normal, not eating and crying during the night for her brother while he was in the hospital. However, she is doing better now. Gaddy has regained his appetite, preferring vegetables and fruit to sugary candy and sodas.

Both Rogelio and Irene are extremely thankful to the Ryan McElroy Children's Cancer Foundation for their unwavering support during this difficult time. They stated that the foundation has been like angels for people, including them. They appreciate the help they have received to offset rent, bills, the cost of food and transportation, and a lengthy stay at the Ronald McDonald House. They are very appreciative that they were able to focus solely on the well-being of their child.

Gaddy Cruz, age 7, was born on Christmas Eve 2004.



Gaddy & Keilly Cruz (Article by Suzanne Havelka)

#### BOARD OF DIRECTORS Chip McElroy Chairman

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#### You have the power to save lives

When you help the "Be The Match Registry″your efforts can help save the life of any patient in need of a bone marrow transplant. Registry members you recruit will become part of every patient's search for matching marrow donor. You can make the difference. Visit <u>www.marrow.org</u> to find out how you can help save lives.

# THE COST OF ILLNESS

The diagnosis of cancer or other serious illness in a child can be a devastating blow to parents and other family members. Cancer creates an instant crisis in the family.

The cost of medical treatment is among the many concerns families have when a child is diagnosed with cancer. Because bills and debt can add up quickly, families seek financial help soon after being diagnosed. Although coping with daily financial responsibilities can sometimes seem overwhelming, it is important that bills don't pile up and go unpaid.

Health insurance or some kind of health coverage is a key work benefit. Having it eases some of the worry that comes with a major medical problem. Everyone knows that hospitalization, surgery, radiation therapy, chemotherapy, medicines, state-of-the-art equipment and procedures, and a medical professional's time are all costly; but no health plan has benefits that cover all the costs of treatment. Very few families know exactly what their insurance or managed care plans provide. Many are surprised to find that, even for a major illness, not everything that is ordered or prescribed will be approved or paid for by the health insurance plan. Since health insurance is becoming increasingly expensive for employers, they often limit benefits and pass along some of the extra costs to their employees. There are the expenses of deductibles and copays which are usually out-of-pocket. Families must be ready to deal with many phone calls, lots of paperwork, ongoing follow-up, and careful record keeping. This is a lot to add to their schedule, and it's even harder when you are worried about your sick child and all the other problems illness can cause. Another financial challenge may be the delay in review by the insurance company or disability provider. It is not uncommon for reviews to take several months.

There are other expenses that come with illness: transportation to and from treatment, a place to stay during treatment, food, and child care for other children in the family are not part of the health plan. Most pediatric oncology hospitals are a good distance from the Hudson Valley (Philadelphia, Cincinnati, Boston, Texas to name a few).

A parent may have to take unpaid time off work or give up a job because of treatment schedules. Missed time at work for one or both parents may cause a serious loss of income. Nursing care, a housekeeper, a counselor, treatment-related items (such as a wig) can also be part of the expenses families face.

Parents who do not have health insurance are even more concerned with how this might affect their child's treatment. Whether families have insurance or other sources of payment, most families worry about the outof-pocket costs they will face and how family income may be affected by their child's illness.

It is with this in mind that we strive to provide financial assistance to families in need. Caring for a sick child should be all parents need to concern themselves with. We have helped many families in the Hudson Valley with a myriad of expenses ranging from transportation costs, such as gas cards, hotel rooms, and food. We have also helped to keep lights on, mortgages paid, telephones working. We have supplied funds for the purchase of medical equipment, treatments, and drugs to help ease the burdens of being ill.

None of this is possible without your help. We thank all of you who come out to our fundraising events or donate to help us Raise Hope. For those of you who cannot make the events, please consider signing up for recurring payments on our website. Knowing that we have monthly income enables us to never say NO to a child or family in need. There is nothing worse than turning away someone in dire need.

### DID YOU KNOW?

★ Cancer claims the lives of more children each year than AIDS, asthma, cystic fibrosis and diabetes combined. It is the leading cause of death by disease in children and adolescents.

✤ Each year in the United States, approximately 12,400 children and adolescents younger than 20 years of age are diagnosed with cancer. Approximately 2,300 children and adolescents die of cancer each year.

✤ One out of every 300 males and one out of every 333 females in America will develop cancer before their 20th birthday.

Childhood cancer does not discriminate, sparing no ethnic group, socio-economic class or geographic region.

★ About one in 500 young adults is a childhood cancer survivor. Nearly 2/3 of the survivors later experience significant and chronic medical problems or develop secondary cancers as adults that result from the treatment of their original cancer.

✤ In the past 20 years ONLY ONE new cancer drug has been approved for pediatric cancer.

 $oldsymbol{st}$  The causes of most pediatric cancers remain a mystery and cannot be prevented.

The average childhood cancer victim loses 71 life years; a significant loss of productivity to society.

✤ Researchers estimate that 51% of moms and 40% of dads who have a child with cancer meet the criteria for "Acute Stress Disorder" within two weeks of the cancer diagnoses.



# **ABOUT US**



GEORGE BUSOLT BOARD MEMBER

George is a graduate of Pawling High School and attended Dutchess Community College. He has been in the building materials business all his life. A past Board Member of The New York State Builder's Association, George was named Associate of the Year for The New York State Builder's Association in 2001. He served as Board Member of The Builder's Association of the Hudson Valley, Officer of The Builder's Association of the Hudson Valley, and Board Member of Rebuilding Together of Dutchess County.

George was a major part of the World Trade Center Relief Committee for the NYSBA Research & Education Foundation that distributed \$6.4 million dollars to 2,300 families.

George became aware of the Foundation through his lifelong friend, Sheriff Butch Anderson. When George saw what the Foundation did for the children of the The Gala features a cocktail hour, Hudson Valley, some with no where else to turn, he immediately said, "What can I do?" and has not stopped since. George dedicates a significant portion of his day to helping families in their struggle with foundation Raise Hope. serious illness. In addition, George coordinates many of the foundation's fundraisers, including the Annual Golf Tournament and the ongoing construction of the House of Hope.



## 10<sup>th</sup> ANNIVERSARY ANNUAL GALA OF HOPE

April 27, 2013

I's hard to believe that 13 years have passed since Ryan journeyed on from this life. Yet since his passing he has touched the lives of dozens of other children affected by life threatening illnesses. While he may have only been with us for five years, his living spirit continues to shine on every time Ryan's Foundation reaches out to another family struggling with a seriously ill child.

The Annual Ryan McElroy Children's Cancer Foundation Gala of Hope will be celebrating it's 10<sup>th</sup> Anniversary! We will be holding our Gala on April 27, 2013, at the beautiful Villa Borghese in Wappingers Falls, New York where we held our very first Gala.

As you know, the Annual Gala is our biggest fundraising event of the year. We rely heavily on the Gala for a significant portion of the funds used to help families in the Hudson Valley. 100% of the proceeds raised from this event goes directly to local families.

Benefiting Children with life threatening diseases Cocktail Hour 6:00 pm Formal Dinner 7:00 pm Live Auction 8:00 pm Dancing 9:00 pm SAVE THE DATE: APRIL 27, 2013

formal dinner, with a live auction conducted by our Executive Director, Sheriff Butch Anderson, followed by dancing with DJ Johnny O.

To purchase tickets, visit our website, <u>www.ryansfoundation.org</u>, or call 845-855-0211 for more information and other ways you can help the

RAISING HOPE .....

RYAN'S WAY

			FROM THE EDITOR
2013 CALENDAR		Ryan's Foundation reminds	Ryan's Newsletter is published by The Ryan McElroy Children's
		you about our EFT feature	non-profit 501 (c) 7
April 27	10 <sup>th</sup> Annual Gala of Hope Villa Borghese	on our webpage. Please	organization, dedicated to helping children who battle childhood illnesses and cancer by
	Wappingers Falls, NY 6:30 - 11:30 pm	consider signing up for	improve the quality of life for them and their
June	Sporting Clay Shoot TMT Hunting Preserve	recurring EFT donations so	Iamilies. If you would like to receive your news
	Staatsburg, NY	that we may continue our	letter by email & help us cut costs on printing and postage, please let us know
June 9	Ryan's Run/Kids Triathlon Lakeside Park Pawling, NY	mission of never having to	If you have a story you want us to know about
Tura	-	say NO to a child in need.	please contact our newsletter editor:
June	Annual Golf Outing Powelton Club Newburgh, NY	www.ryansfoundation.org	<u>sghavelka@gmail.com</u>
October 10	Annual Fall Tasting Event The Grandview Poughkeepsie, NY	Electronic	
*watch news	for exact dates in our upcoming eletters and on our webpage.	Funds Transfer	~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~

GOOD NEWS CORN	IER	
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$\mathbf{M}$	Bringing awareness to Childhood Cancer, the Mid-Hudson Bridge in Poughkeepsie, NY was lit up in GOLD lights
i	n honor of Ty Louis Campbell who lost his battle with cancer October 17, 2012.
V	Mid-Hudson Medical Group held another "Friday Jeans Day Fundraiser" and donated their proceeds.
$\mathbf{V}$	Topical Biomedics donated 5% of their quarterly sales.
	The Interact Club of Pawling hosted The Ryan's Foundation Dodgeball Tournament & Fundraiser on November 16.
	New Fairfield Physical Medicine donates monthly through our recurring EFT
	North East Physical Medicine donates monthly through our recurring EFT
V	Danbury Physical Medicine donates monthly through our recurring EFT
$\mathbf{V}$	Thanks to our supporters for helping us Raise Hope – in the past couple of months we've distributed over
	\$10,000 to families including mortgages, utilities, gas cards, wheelchair, Ronald McDonald House stays, and brain
Ś	surgery assistance.
	The foundation has been poured on Stage 1 of Ryan's House of Hope – the barn building is in process! Thank
>	you for your continued support and helping us Raise Hope in the Hudson Valley.
$\mathbf{V}$	Ryan's Foundation would like to thank all the many vendors, volunteers, and supporters who consistently give so
9	generously to our various events and fundraisers throughout the years. They never say NO and are always
T	ready to pitch in to do whatever it takes to Raise Hope for the children of the Hudson Valley.
	The Pawling Chamber of Commerce & Ty Louis Campbell Foundation placed a Christmas tree adorned with GOLD
l	ights in the new gazebo in Pawling in honor of Ty and Ryan.
$\mathbf{V}$	Thank you to all who search online using Goodsearch & GoodShop.com. We received a check
	For \$12.00 this month! Every donation counts.
	Tik
	Goodshop/Goodsearch: RYANSFOUNDATION or Marketamerica.com/ryanmcelroyccf
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I want	to help donation form
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	Phone-evening:
	My check is enclosed. (Make checks payable to: The Ryan Foundation.)
-	Charge my donation to:Master CardVISADiscover 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
	n will cover transportation to a hospital. A \$250 contribution will pay for food or utilities. will pay for lodging or rent. A \$1,000 contribution will pay for a mortgage or medicines.
Pleas	e help and embrace the tiny things in life. Thank you.

THANK YOU TO ALL WHO MADE A DONATION AFTER READING THIS NEWSLETTER. YOUR GENEROSITY IS WHAT MAKES ALL OF THIS POSSIBLE!