



Molly Ann Tango Memorial Foundation

Enriching the lives of children with special needs and their families

Winter 2013

Nuts about the Nutcracker
production raised over \$40,000!!!
The Foundation wishes to thank...see page 6!

Helping Cubby

How the Foundation Keeps Cubby Safe

by Deb Haughney

The storms of 2011 pale in comparison to the devastation that Sandy brought to the tri-state area recently. But for one Ridgefield family, this year's hurricane did not bring the fear that last year's storms did. This year, Cubby Wax and his mom Laura, were able to ride out the storm knowing they would not lose the power that they need to keep Cubby alive.

Cubby, a bright, funny 13 year old boy, was born with SMA Type 1, a neuromuscular disease characterized by muscle weakness due to the loss of motor neurons of the spinal cord and brainstem. He has a tracheotomy for breathing that requires continuous suctioning, tube feedings for nutrition, oxygenation monitoring, a power lift and wheelchair, and full time nursing care. It's a 24 hour job which requires many hands and electricity.



Cubby

Last year when Ridgefield was hit hard by two consecutive storms, Cubby's family was without power for four days and then eight days. Not only were they without the power necessary to keep Cubby alive, but
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Calendar

February

The Foundation's Junior Board honors our local moms

March

The Foundation's Junior Board makes and delivers Easter baskets

April

Reserve a seat for our annual Mother's Day Luncheon, Salem Golf Club. Tickets go on sale soon!

May

10th Mother's Day Luncheon, Salem Golf Club, save the date

12th Run Like a Mother...for us! See story on page 2.

Cubby, continued

they were without water and septic to keep him free from infection. Nursing staff were working through the night shift with only flashlights to help them navigate all the medical equipment while trying to keep everything sterile.

Laura, a fulltime teacher in Norwalk, was running to and from Ridgefield Fire Department to charge the battery packs for the ventilator, suction machine and power chair. They blew through two generators and then finally relocated to Laura's sister's home. After the storm, Laura started researching home generators that would go on automatically once the power is lost. The cost proved way beyond her means until the Molly Ann Tango Memorial Foundation stepped in.

The generator was installed and Laura never had to worry again about losing the power necessary to keep her beautiful boy alive and well. No one could imagine the storm that would come our way in October and Laura was very thankful to the Foundation that they helped keep her family safe.

Run Like a Mother Partners with the Foundation



By Megan Searfoss
The 6th Annual Run Like a Mother 5k has partnered with the Molly Ann Tango Memorial Foundation for the

2013 5K which takes place on Mother's Day, May 12. In the past 5 years, Run Like a Mother has chosen different charities to partner with; providing funds and awareness to causes that benefit women and children while still maintaining their own mission of encouraging women to make running a part of their lives.

"We are excited to partner with the MATMF, a charity that involves so many women that are part of Run Like a Mother and the Ridgefield community," says Megan

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Meet Laney!

by Deb Haughney

Laney, 10, of Fairfield County,

like most kids her age longed to learn to ride a bike. Her sister received a bright, shiny new two-wheeler



Laney

for her 10th birthday and Laney dreamed that was what would be awaiting her as she turned 10 eleven months later.

For Laney, born with Childhood Apraxia, Developmental Coordination Disorder, and Functional Gastrointestinal Disorder, while also recovering from a skull fracture sustained because of her disability, that would not be an easy task.

"A simple thing like buying a bike, is something most parents just take for granted. They can run to Target, and zip, zip they are done!" her mother Julie explained.

Rather than devastate Laney, her parents researched alternate solutions to the bike/balance problem, and found a recumbent bike that would be a perfect solution. Unfortunately the cost was prohibitive for them but they never gave up! The Connecticut Family Support Network referred them to our Foundation.

The request was made and voted unanimously "yes" by the board. In a few short weeks, Laney was on her way!

Run Like a Mother, continued

Searfoss, Run Like a Mother's Founder.

Run Like a Mother and the MATMF together have created unique opportunities for the athlete. "Athletes can purchase a charity registration which gives them several special perks while benefitting MATMF. We created a combined registration that includes the

MATMF luncheon on Friday, May 10. Athletes that purchase this option will have a wonderful pre-race meal, additional gifts from Run Like a Mother and their Race Day Package will be delivered directly to them at the luncheon."

Race Director Deb Povinelli commented, "It is a great way to kick-off Mother's day weekend with your training partners and friends while benefitting the Molly Ann Tango Memorial Foundation.

Registration for the race has opened and the charity entries as well as regular registration can be found at www.runlikeamotherrace.com/city/ridgefield-ct/ .

A Board Member's Story

A Footprint on my Heart

by Deb Haughney

There are times in everyone's life when you meet someone who leaves a footprint on your heart. When it happens you are in state of unexpected joy. Maria Elenni left her footprint on mine.

I first met Maria and her family when she was 9. She is now 16 years old and loves music, Sunday school, learning Greek and books on tape. Maria has dreams and they are big ones. She would like to be a songwriter, classical singer and a motivational speaker.



Continued on page 4

The Molly Ann Tango Memorial Foundation Junior Board



The Molly Ann Tango Memorial Foundation Junior Board consisting of RHS students and under the direction of Board member Jean Cobelli began planning the coming year with its largest group to date.

The Junior Board's sole purpose is community awareness and recipient outreach. This year they will be doing...

- *Delivering Valentine Flowers for our Special Local Moms
- *Making Easter Baskets for our recipients
- *Assisting at our annual Mother's Day Luncheon
- *Helping at the concession booth for Run Like A Mother
- *Going on playdates with our recipients, including helping out with the Holland Division Baseball League
- *Halloween Walk in Ridgefield
- *Nuts about the Nutcracker

Footprint on my Heart, continued

Maria Elenni sounds typical but what I haven't shared is that Maria was born with Spinal Muscular Atrophy (SMA) Type 1. SMA affects the voluntary muscles for activities such as crawling, walking, head and neck control and swallowing. Usually a child with this is never able to lift his/her head or accomplish normal physical milestones. Swallowing and feeding may be difficult and there are respiratory problems as well. This form of muscular dystrophy is devastating and most infants diagnosed don't live past their second birthday.

Maria was born looking like the beautiful girl she is, but after just a few weeks her parents noticed she wasn't quite right. Maria never rolled over or achieved any milestones parents expect their infants to reach. She eventually lost her ability to move her legs and arms and couldn't hold up her head. She and her parents would begin to live in and out of the hospital for years to come.

Once Maria stabilized, her mother Ann went back to school for her doctorate in pharmacy so that she could determine what medications best worked for Maria. By keeping detailed notes she has become the best medicine Maria could ask for. Maria would for the most part be home bound until age 5. She now attends school when she is well enough.

When her family first reached out to the Foundation she needed an insert for support of Maria's upper body for her wheelchair that was not covered by their insurance. The Foundation would go on to assist Maria with a car seat for air travel, adaptive technology and a lift system.

The Foundation considers their small part in Maria's life a privilege. We hope to continue the work and mission the Foundation was founded upon for more families like the Kaloidises.

Thank you Maria, for the footprint!

Thank you!

We want to give many thanks to the **Watershed Gallery** of Ridgefield and the wonderful young artists who participated in the recent "Young at Art" event at the Gallery. Twenty-four young artists raised more than \$1,500 for our Foundation! We can't thank you enough!

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We also want to give special thanks to the **MOMs Club of South Ridgefield/Redding** and **Newcomers Club of Ridgefield**. Their Winter "Winederland" event at Woodcock Nature Center featured fine wines selected and presented by local wine merchants, canapes from some local restaurants, and a raffle, and some of the proceeds are going to the Foundation. Thanks for letting us "benefit" from your fabulous event!



facebook

For the latest news about the Foundation, please "like" us on Facebook.

www.facebook.com/mollyanntangomemorialfoundation

NUTS ABOUT THE NUTCRACKER 2012

by Deb Haughney

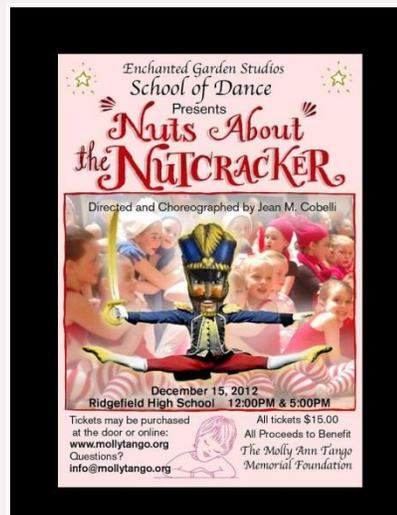
On December 15th, as the entire country tried to come to terms with the Sandy Hook tragedy, a little show with a big heart went on. *Nuts about the Nutcracker*, the annual fundraising show produced by The Enchanted Garden School of Dance took to the stage with heavy hearts and went on to raise \$40,000 for the Foundation.

It was just one day after the day never to be forgotten, but 190 cast members and volunteers knew they had to perform after rehearsing for four months to support us.

As Jean Cobelli, director and choreographer, told the audience before the first show, "We are all feeling very sad but there's a family behind this curtain that can't wait to perform and put a smile on your face." And that is just what they did. It was a magical show with traditional *Nutcracker* music as well as songs with a twist. The costumes were delightful and there was a feeling of peace.

Another cause for celebration was the debut of the book, [Nuts about the Nutcracker](#), written and illustrated by Ridgefield resident and mother of two *Nuts* dancers, Rebecca Kaufman. The book takes the reader and through the streets of Ridgefield as Clara meets all the characters of the *Nutcracker*. All proceeds go directly to the Foundation.

"This production means so much to the family of dancers. From the beginning of rehearsal they know they are dancing for a foundation that does so much for others," Ms. Cobelli states.



Fun Facts about *Nuts*

2004 - cast of 40
2012 - cast of 190

2004 show raised \$4,000
2012 show raised \$40,000

2012 *Nuts about the Nutcracker* was made into a book

2012 television debut on *Better Connecticut*

2012 the most sponsorships ever!

Every year the show has made more money and the cast has grown!

The stage crew is made up of volunteer moms and family members of the cast.

We Wish to Thank *Nuts About the Nutcracker* Business Sponsors...

The Foundation wishes to thank our business sponsors of this year's fundraising production, *Nuts about the Nutcracker*. Over \$40,000 was raised to enable the Foundation to continue to enrich the lives of children with special needs and their families.

Thank you to the following businesses:

Adam Broderick, Ancona's Market, Bissell House, Brewster Hess, Carlson Physical Therapy, Colonial Automobile, The Cutting Board, DPD Builders, Eron's Plumbing & Heating, Fairfield County Bank, Gellos Capital, Jean Cobelli Dance, LLC, KoKo Fit Club, Dr. Katherine Lambert, Kilometers, Dr. Blaine Langberg, NicDan Market Advisory LLC, Pamby Motors, Parson Law Office, Quality Labs, Ridgefield Fitness, Ridgefield Montessori School, Ridgefield Physical Therapy, Dr. Joel Segalman and SKANSKA.

Please support these local businesses that support us!

Letters of Thanks

During 2012 we spent over \$105,000 by helping more than 70 families.

Here's what some of these families had to say:

"Thanks so much for the wonderful lift. I can get from my chair to my bed and back with no pain or problems. The lift has helped me become more independent from before. I can move anytime!! I love you!" *Maria Elenni*

"You guys are awesome, really and truly awesome. We both thank you from the bottom of our hearts. You can tell by his smile that he is happy, as am I. Your help is one of the best things to happen to us in a very long time. A smile equals a thousand words." *Barbara, Richard's mom*

We're on the "A-List!"

Over the decades, Ancona's Market of Ridgefield and the Ancona family have contributed to hundreds of community and charitable organizations including countless sports programs, civic, service and religious groups, and a wide variety of arts and music organizations in Ridgefield, Redding, Weston, and Wilton, CT. Ancona's Market "A-List Rewards" program offers a simple and convenient way to earn cash rewards that can be used to benefit your favorite local not-for profit group. This year, we are proud that they have chosen the Foundation as one of the local charities they will support!

It's a win-win! You get to shop at a great store, and when you select the Molly Ann Tango Memorial Foundation, each time you shop at Ancona's, a percentage of your purchase will be awarded to the Foundation.

Here's what you need to do:

- 1) Pick up an A-List Rewards card at Ancona's Market. Be sure to register your card online at www.anconasmarket.com.
- 2) In order for your purchases to be credited to the non-profit of your choice, go to www.anconasmarket.com and log into your rewards account. Select the Molly Ann Tango Memorial Foundation from the drop down list.
- 3) Present your A-List Rewards card to your cashier every time you shop. *Remember you must present your card for your non-profit to receive credit!*



A look back...

Reprinted from the Ridgefield Press, 2004

Memories of Molly

Like most 10-year-old girls, Molly Tango liked to sway to the music of the boy band *NSYNC. But she also enjoyed listening to opera as much as she liked "dancing" with her older sister, Caitlin. Though unable to speak, Molly would beam happiness from "the brightest of eyes and a smile that could light up a room," said her mother, Cathy Tango.



Molly was a child with special needs who died on Dec. 23, 2003 at the age of 10. Her mother and father, Cathy and Todd Tango, have started a foundation in her name.

Designed to help families with special needs children meet the often staggering costs of providing for those children, the Molly Ann Tango Memorial Foundation is in its seminal stages. Its board of directors has just been set. But its goals are well defined.

"It's hard enough, many times, taking care of a child with special needs," Cathy Tango said from her Ridgefield home. "Then it seems that having the words 'special needs' added to the items that are needed to care for your child makes the cost go up. We want to help families facing those costs meet them."

Cathy and Todd Tango know well how expensive care of a child with special needs can be. Once homeowners, they now rent. "We had to sell our home to purchase the things that Molly needed. A car seat for her cost close to \$900. Then the time came when she needed a handicap-accessible van, when she was in a wheelchair," Todd Tango said. "We were able to find a six-year-old van that would also serve as a family car. It cost close to \$40,000."

Molly was born prematurely and her organs were not fully developed. She had brain damage and at her birth, the doctors gave little hope that she would live more than a brief time. While some items required for Molly's care were covered by insurance, often only a portion of their cost was covered. And it was always a struggle to get the insurance companies to pay up, Todd Tango said. "They'd argue that the item wasn't a medical necessity. But we believe that kids like Molly should have the ability to do what other kids do. We believe they deserve a quality of life that other children enjoy," he said.

Molly couldn't sit up or stand without support. She couldn't chew and swallow food. Her motor coordination was impaired and she couldn't manipulate utensils or toys. Special needs children like Molly require day-trainers to walk with, standers to hold them upright, booster chairs to sit up and bath chairs. Some, like Molly, are unable to eat on their own and require feeding equipment, which includes pumps and tubes and other apparatus.

"And parents need a respite. You need to get out occasionally, need a night out now and then," Todd Tango said. "You can't just get a baby-sitter. You have to have a qualified nurse come in to take care of your child. The costs mount up."

"Molly was like our little angel," Todd Tango said. "We were lucky enough to have her with us for 10 years. We don't want it to be the end. There has to be a purpose there. She forever changed us. She came up and giggled or smiled at you, and touched everyone she met."

The Foundation's Mission

The Molly Ann Tango Memorial Foundation is dedicated to enriching the lives of children with special needs and their families. The Foundation helps finance the purchase of much-needed medical equipment and services when insurance is exhausted and other social programs are not available. In addition to financial support, the Foundation helps families navigate the medical and social communities to find the products and services that will specifically meet their needs.

If you would like to apply for assistance, or know someone who does, please complete our application which can be found on our website. Thank you.

Find us online at www.mollytango.org.