

ATDC / Angela's Association for Technology Dependent Children HOUSE

NEWSLETTER
SPRING 2006 EDITION

Visit our website and blog
www.angelashouse.org

(631) 979—2620

Evan s Story

Born Sept 23, 1995, Evan was reported to be hypotonic upon arrival in the nursery. At 6 months old, it was noticed that he was not developing, in holding his head up or sitting unaided. He started seeing all types of doctors and had all types of tests (ex: MRI, eyes, ears, nose, throat, nerve biopsy, 2 muscle biopsies, EMG, EEG, genetic, blood, urine, metabolic, skin biopsy, etc).

He has been seen by many doctors; neurology specialists, Institute of Basic Research on Staten Island, Children's Hospital of Atlanta, Orthopedists, and Endocrinologists.

It took 4-1/2 years to get a "probable" diagnosis, since most tests came out "normal". But after a fresh muscle biopsy in Atlanta, they felt Evan had a *Mitochondrial Disease Complex I and IV Oxidative Phosphorylation* along with nocturnal seizures, global delayed development, extreme hypotonia and growth hormone deficiency.

There is no treatment or cure for Mitochondrial Disease, just to treat the patient's symptoms and keep them as healthy as possible.

Evan started with home therapies and attended a group class at LI Infant Development in Merrick, NY. At pre-school age, until 9 years of age, he attended Carman's Road School in Massapequa, NY.

Evan cannot talk or do anything for himself at all. He used to be able to roll over and pull himself up to a sitting position when laying on his back. But he no longer does either.

He is dependent on others for all daily care, in all aspects of life. He must be fed, carried, dressed, bathed, have his teeth brushed, wears diapers and be given all his medicines. Evan has always been a calm, happy, content, mellow, little boy. He just has gotten much heavier to handle.

In August 2004, we sent Evan to camp, which was the first time away from his family. Evan was hospitalized after camp due to pneumonia. He was intubated for two weeks but when he was taken off the intubation, he was never the same again!!! Evan appeared to be extremely agitated....It was awful. He looked like a crack baby or worse. He could no longer eat by mouth and a G-tube was inserted.

The doctors at the hospital had no answers!!!

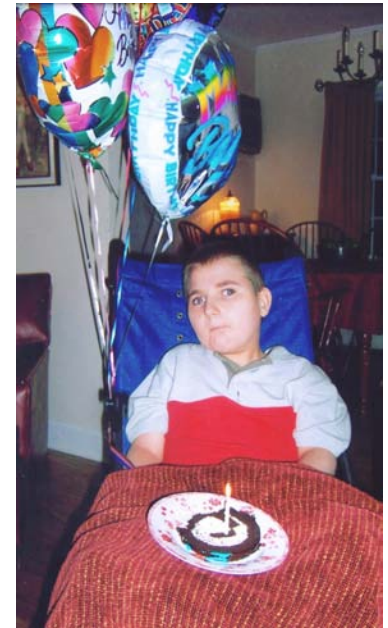
He lived at the hospital from August until late November when he was transferred to a rehab hospital. One good thing was we went to Columbia's (Parkinson) Movement Disorder doctors. They diagnosed these new symptoms as dystonia. He has been on a new drug called Kemadrin, which does help "most of the time".

He has returned to eating and drinking by mouth. We use the G-tube to give him medicines if he is asleep. We need your help now, ASAP. After 1-1/2 years Evan was discharged from the hospital at the end of February 2006. We wanted him home!! We have made our garage a bedroom for Evan on our first floor.

For this to work for Evan, we desperately need a handicapped bathroom outside his bedroom, and a wheelchair ramp. As his parents we are committed to taking care of this little boy we love, and keeping our family together and safe. We will need to depend on an LPN during the week from after school until bedtime. If we cannot provide a safe environment for Evan to be cared for, we risk an accident. Plus we risk no LPN being interested in helping us out.

We no longer can carry Evan up 14 stairs, and give him a bath in a regular tub. Our backs will give out and when he is wet and naked he is very slippery. Life could be so much better for all of us if you do realize how much we need the bathroom and ramp.

Thank you, **Evan s Mother**



During the past few months, ATDC has taken on the challenge of helping Evan with an accessible bedroom, bathroom and wheelchair ramp. We are happy to see Evan home with his family. Our goal will be to make his home environment as comfortable as possible

Message from the Executive Director

The excitement coming from our first annual Dinner Gala carries us into the spring. This was a great opportunity to reach out into our community so that they may understand the needs of our special children and their families. Our efforts continue each day to offer assistance to new families that contact us, in return, allowing us to help over 300 children this past year.

We continue to explore plans to build another Angela's House, and are also involved with hospitals and other organizations to improve the lives of children and families with medically frail children. These efforts include services for vent dependent children, step-down/transitional care and home care.

We recently received great news. In a 6 year negotiating effort, we received approval for land to build a home that can offer respite care. This home will offer temporary relief from the day-to-day care our families endure. We did see great success through the collaboration of the Coalition for Medically Fragile Children.

We will also see an increase with home care nursing rates. These rates are not scheduled to go into effect until January of 2007, and will help to bring children home that are living in the hospital, as well as, to stabilize home care. We were fortunate to have great legislative support for this bill including Senators Charles J Fuschillo, Jr., Kemp Hannon, Ceasar Trunzo, Assembly members Amy Paulin, Steve Engelbright, Robert Sweeney, Harvey Weisenberg, Carl Marcellino and Governor George Pataki.

We had a unique fundraising effort come to our aid as well. Jane Hubbard spearheaded a project to create a children's CD along with Vladimir Polezhayev. Also, not stopping there, they contacted an art class run by Mrs Joan Ann Forneiro that created a coloring book which goes along with the CD. This group came together at the Paradise Diner to celebrate the success of the project.



Bank of American Presents a Grant to ATDC / Angela's House

Robert Isaksen and Jim Maiorino from the Bank of America presented a check for \$5,000 to Bob Policastro to be used to help purchase medical supplies and equipment for the children and families we work with.



Ancient Order of Hibernians



The Ancient Order of Hibernians Division 3 recently made a generous donation to Angela's House. From the left Brian Clancy, Jack Murtagh, Bob Policastro and Tom Lambert.



Girl Scout Troop 1249 visits Angela's House

Bring the Angel of Hope Statue to Long Island



Over the years we have tragically witnessed many children that have passed away. We have spent several years looking for ideas in which to do something special for all parents that have lost a child. Our search uncovered the Angel of Hope which has been received with overwhelming support in many other places.

The Angel comes from a book called *The Christmas Box*, a best selling novel by Richard Paul Evans the main inspiration to this statue. In the story, a woman mourns the death of her little daughter by making regular trips to the child's grave, marked with an angel statue. The statue evokes a profound and miraculous connection between mother and child and helps convey valuable lessons about the true meaning of life to others. The simple story has brought hope to thousands of parents who have endured the death of a child. In 1996, in response to many spiritual reports in which grieving parents were seeking out the statue described in the book, Evans commissioned an angel statue to be erected in Salt Lake City. Since then, 60 statues have been erected in cities across the US. Now its time to bring this angel to Long Island. We will be embarking on a fundraising campaign to make this possible and hope to garner much support for it in the process.

First Annual Spring Gala

Our first annual Spring Dinner Gala was held on March 30th at the Watermill in Smithtown. The parent committee, consisting of Anne Bingham, Kelly McGrath, Adriene Mogavero, Tara Ficken, Elizabeth Yuknis and Pat Gaunay, created a unique feel for this special night. The evening was filled with a lot of excitement as people enjoyed the open bar, dancing, chinese auction, fine food and an evening of good company. Many thanks to our event sponsors, Hunter Douglas Inc, Aon Foundation, CMP Community Connection Foundation, The Whalen Agency and Allstate for their support. In thanks, we also had a beautiful board that displayed our name list sponsors.

Bob Policastro, Executive Director, addressed the room, thanking everyone for their support. He went on to explain how we helped over 300 children this past year, and showed a DVD presentation to help educate those in attendance to the lives of our children and their families.

It touched on the families lives, from the hospital to their home, as they talked about the blessing of their children and the difficulty of their day to day care.

Anne Bingham spoke about her daughter and family and how this situation has impacted them. Furthermore, she gave a prayer for the children no longer with us, which touched everyone in the room.



Your Gifts Make a Difference

The greatest gift we can give is one that can help a child in need. Your donations allow us to ease the financial burdens our families experience with the day-to-day needs of each child. We use these funds to purchase medical supplies, special food supplements, medical care, therapeutic equipment, and more. 100% of your donation goes to our children.



ATDC helps Karin with a special chair

ATDC helps Julia with a special bed



Donations Come in Many Ways:

Kids Helping Kids



Forest Brook Elementary visits Angela's House to help with yard work

Donations can be sent to:
ATDC
PO Box 5052
Hauppauge, NY 11788
 ATDC is a 501(c)(3) non-profit organization; your gift is tax deductible to the full extent of the law.



ATDC helps John with a stair glide

In Memory Of:

In a time of grieving these families have displayed great generosity by requesting donations to us in lieu of flowers. We are honored by this gesture shown by the families of the following:

- Nicholas V Morrone
- Kelly Ficken
- Cpl Robert Pope



Brownie Troop 3240 had a fun party with the children of Angela's House in East Moriches



Rocky Point Fire District Induction



Rocky Point Fire District inducted David in to the Fire Department as an Honorary Fireman.



Through donations, ATDC was able to get a specialty crib for Ariel

ATDC/Angela's House

P.O. Box 5052
Hauppauge, NY 11788

4th Annual Golf Outing

Save the Date

Tuesday, September 26th, 2006

Fox Hill Golf & Country Club

Information and sponsorships for the outing can be found at
www.angelashouse.org or by calling (631) 979—2620

