

ATDC / Angela's Association for Technology Dependent Children HOUSE

NEWSLETTER
SPRING 2005 EDITION

Visit our website
www.angelahouse.org

(631) 979—2620

Angela's House II Opens

This beautiful home in Smithtown for medically fragile children is now open. This is the second specialty home on Long Island for children that require 24 hour nursing supervision. The first Angela's House was built in 2000 in the Policastro's 10 year effort to have a facility that could care for children on Long Island. The Policastro's daughter was in a specialty hospital in Connecticut due to the sad fact that there were no facilities locally that could care for her needs. NYS Assemblyman Harvey Weisenberg helped obtain the funding to open these special homes.

Our affiliate IGHL, Independent Group Home Living, pulled together their development and program departments to help create this state of the art home.



Ribbon Cutting

It took a great effort to make this home possible.

Assemblyman Harvey Weisenberg was excited about the home. He feels it is a great opportunity for Long Island families, especially his key point that our children should not be cared for out of state.

Walter Stockton, CEO of IGHL, thanked all the people that made this special home possible.

Bob Policastro spoke about the home being a dream come true. He explained the warm feeling, the spirit one feels as you enter into this home. He explained the never ending love families have for the children moving into Angela's House, and the tremendous courage it takes for a family to place a child.



Left to Right: Walter Stockton, CEO of IGHL, Bob Policastro, Executive Director ATDC/Angela's House, Assemblyman Harvey Weisenberg.

Message from the Executive Director

It was very exciting this spring to see Angela's House II in Smithtown open. This home offers great hope for families needing a residential alternative for their medically frail children. Since the first Angela's House opened five years ago, it has served as a model to help more families. The great thing about creating a model is the possibility that we will see more homes on Long Island created for medically frail children.

We will continue to work on important programs to offer to our community, such as a respite relief house and a home for ventilator dependent children. We have gone too long without these important services. A family should not be faced with the compounding crisis of having a chronically ill child that needs long term care, which they cannot do at home, and realize the only placement opportunities are out of state. This makes a bad situation worse and in many cases the children end up living in the hospital.

We are seeing other problems increase with families caring for their children at home. We are seeing an increase of families across Long Island go without nursing support to care for their medically fragile children. The nursing shortage is making it more difficult for families to keep things together. We have also seen a crisis with medical equipment. More children are going without necessary therapeutic equipment due to a change in NYS Medicaid policies. The nursing and equipment problems, along with other medical issues, are forcing us into a challenging time. Our effort will be to advocate harder for families and try our best to maintain a positive outlook. We cannot express enough to each family how much we care about them

A special mom writes a poem as she contemplates the courage of finding out of home placement for her child to live

WINGS

It's an end for me
A beginning for you

I know in my heart it's the right thing to do

So many emotions inside my head
How can I not be there to tuck you in bed?
Will I know if you'd rather be home instead?

And what about Syd?
This is breaking her heart
How will she handle you and her living apart?

I pray she won't hate me
I hope that she'll see
I'm doing this for you, and for her, Dad and me

No, you're not a baby anymore
I must let you experience all that's in store
And no longer hide us all behind our front door
I'm giving you wings Nicky and I know you will fly
Please don't worry no matter how much I cry
That day will be awful when I leave and say goodbye

Know I'll come see you every chance that I get
You'll probably be happy and thriving I bet
It's just the thought of you not being here that makes me upset

Your life will be rich, in time we'll all see
I can't wait for you to become all you can be
Just remember nobody loves you more than Mommy.

A Day in a Life: One Family's Story

I am writing this letter out of desperation, seeking help and hope. I have an 11 year old daughter with a neuromuscular illness who needs 24 hour nursing care. She has a trach, belly tube and is ventilator dependent at night. Unfortunately there is a severe nursing shortage on Eastern Long Island. Many times you find yourself having to stay up for 26 hours straight to provide care. You are left without help when there is bad weather, it's the holiday season, school vacations or your nurses are on vacation or sick. There are no camps or nearby places to send your child. There is no one to help you when you yourself get sick. There are no days off, no holidays, no rest from stress and sleep deprivation. No friends to help us as they have all decided this is too much of a medical problem for them to handle. We have no support system as our family lives out of the state or out of the country.

As my husband and I turn 49 & 50 this year, the stress is causing severe medical problems for each of us.

There is no long term care facility available for my child near my home where I could visit her each day. My daughter has told me in this past month, "Mommy I wish I could be velcroed to you because I miss you while I'm at school." It would break my heart and hers if I had to send her to New Jersey, a place I can't even drive to.

Due to my daughter's illness she is emotionally needy and insecure. If I were to abandon her it would have a severe impact on her health.

The time has come for these medically fragile children to be recognized and not shipped off to other states very far apart from their homes, ripping families apart.

Please open up your minds and hearts in order to create a home like facility on Long Island. My child deserves the love of her family just as any other child does, as well as recognition and protection of her rights by New York State.

Sincerely,
F. C.



St. Thomas More Walk-A-Thon



On April 23rd the rain would not stop the walk-a-thon and the spirit of the children. The children and parents filled the indoor facilities to raise money for Angela's House. The children had a great time as they walked with pride realizing their efforts were helping Medically Fragile Children.



The Torch Foundation Brings Gifts to the Children of ATDC and Angela's House

ATDC/Angela's House

P.O. Box 5052

Hauppauge, NY 11788

Save the Date

ATDC / Angela's House

Golf Outing

Monday, October 3, 2005

Nissequogue Golf Club
St. James, NY



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



Thomas Whalen from Whalen Agency presents a community grant from Allstate. This and other donations were used to have magnificent murals painted in each bedroom of Angela's House II by Splashes of Hope.