

Turning Personal Tragedy into Triumph

BY LYNN ZAWACKI



DRIVE DOWN BROOKSITE DRIVE IN SMITHTOWN and you'll pass by a newly constructed, six-bedroom ranch with a "welcome" sign firmly planted in the ground by the front door. Enter and you'll find eight children inside ranging in ages from two through 13 years. Unlike Long Island's typical suburban house, however, this one has a nurses' station placed at its center. Those eight children have severe disabilities—and the house on Brooksite Drive is their "home."

The idea for establishing such a house began with Bob Policastro, whose daughter suffered brain damage when she was born in 1989. He and his wife, Angie, finding nowhere to turn for specialized care on Long Island, were

forced to seek help for their daughter in a specialty hospital in Connecticut, a two-hour drive. Their daughter Angela passed away at 14 months.

Wanting to educate the community, raise awareness and help improve the lives of other children like Angela and their families, Policastro founded the not-for-profit organization, Associations

for Technology Dependent Children (ATDC), in 1992 as a legacy to his daughter.

ATDC coordinates an array of services and programs for "technologically dependent, medically fragile, and

chronically ill children." All have complex medical conditions that require medical technology and skilled nursing care. ATDC assists families in caring for their children at home or in special homes that offer 24-hour nursing support.

"I know I can't change what happened," said Policastro, who explained that he is now "at a real good place" in dealing with his experience. "When we reach out and help a parent, it means the world to them."

ATDC, along with its affiliate Independent Group Home Living (IGHL), built its first house in 2000 in East Moriches. New York State Assemblyman Harvey Weisenberg helped secure state funding for the project. The first of its kind on Long Island, it was named Angela's House in memory of the Policastro's daughter. "IGHL was wonderful. They shaped the idea of turning a nursing home into a home model."

The second home in Smithtown,

Available Resources

There are no official statistics on how many chronically ill Long Island children are in need of specialized care. ATDC works with 200 in its programs and "guestimates" there are about 400 more. Some are on waiting lists; some have not yet been identified. "I recently identified a chronically ill child whose mother just didn't know there were resources out there to get nursing assistance in the home," said Policastro.

Getting information out to parents is crucial. In June, ATDC presented a Resource and Information Fair at SUNY Farmingdale for families of children with special health care needs and disabilities. "Each year we push to have a conference, fair or some type of workshop to help parents not yet connected to the services that can help them," said Policastro.

This year's fair, which was free to attend, featured more than 100 vendors and workshops under one roof. Said Policastro. "Without the fair, it could take families years to accomplish what they are able to do in one day."

ATDC/Angela's House
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Fund-Raiser:
Golf Outing
Oct. 3, 2005
Nissequoque Golf Club,
St. James

known as Angela's House II, opened its doors in April 2005. "The whole idea of the house is that families come throughout the day and evening to see their kids. We want them and their siblings to be comfortable." ATDC plans to create a playground in the backyard of Angela's House II. "For the kids from the house, there will be wheelchair swings and hammock swings. For their brothers and sisters who visit, there will be a set of regular swings," said Policastro.

Taking a family vacation, attending a wedding or even shopping are things most people take for granted; but not families of chronically ill children who require constant care. An even more dire situation can occur if the parent becomes ill and there is no one to care for the child. "In some cases, providing day-to-day care gets overwhelming. When they are totally engulfed with providing care, there's no room for anything else," explained Policastro.

To deal with these issues, ATDC is currently focusing on the creation of a respite home—a special house that would offer temporary care, allowing families who care for their child at home to "catch their breath." No such option currently exists for families on Long Island.

Another project on the horizon is a fourth house to care for children who require even more involved care. "Long Island currently has no beds to care for ventilator-dependent kids," said Policastro. "The only options are for the children to remain in a hospital, which can be a dangerous health environment, or to be sent to an out-of-state facility. This creates a great hardship to families and often makes a bad situation worse."

What began 15 years ago as a response to a personal tragedy has evolved into a successful campaign, improving the lives of children once hidden under the radar and lifting some of the enormous stress from their parents. Said Policastro, "Helping these children means so much to my wife and me. We will never forget how we felt. That is why we continue to push to help others." ■