

The Molly Ann Tango Memorial Foundation

Press Release

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Picture: Maria Elenni Kaloidis, Age 9

The Molly Ann Tango Foundation Helps Maria

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. She is 9 years old and in 3rd grade at Mitchell Elementary School in Woodbury CT. She loves music (especially classical, R&B and Kelly Clarkson), scary movies, Nancy Drew computer games, Sunday school, learning Greek and books on tape. She just started sharing a room with her 12 year old sister, Chryscythe and they go back and forth spilling beans about each other. Maria has dreams and they are big ones. She would like to be a songwriter, classical singer and a motivational speaker. She is already on her way to fulfilling one of those dreams as she was recently elected to the student government as a delegate. Maria is responsible for reporting the council's activities to Mrs. Campbell's second grade class once a month. She loves it and remembers everything! Her sense of humor is amazing for such a young girl. She tells me her Dad recently had open heart surgery for a valve replacement. The doctors used a pig's valve and she tells me "She hasn't heard him "oink" yet!"

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 Type I, (Werdnig-Hoffmann) is never able to lift his/her head or accomplish normal physical milestones. Swallowing and feeding may be difficult and the child may show some difficulties with their own secretions. There are respiratory problems due to a general weakness in the intercostals and accessory respiratory muscles (the muscles situated between the ribs).

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. At 8 months the diagnosis was made. 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 was involved in the Creative Arts studio where she received physical and occupational therapies as well as one on one support. Her family transformed their home into an indoor playground. Her older siblings, Vasilis and Chryscythe, created fantasy worlds with the living room couch and their imaginations. Maria thrived but longed to be involved in outside activities. She started kindergarten at Mitchell Elementary. Mitchell Elementary provided every imaginable type of support to keep Maria engaged and become an integral part of the school community. She was fully included despite the many hospitalizations and when she was out, the class was videotaped so that she could keep up with the kids she now called friends.

Now Maria is 9 and the hospitalizations have begun to slow down. Maria hopes to rejoin a Girl Scout troop next year and loves to be in the pool. She uses a motorized wheelchair at school and home that she can operate on her own most of the time. Unfortunately the motorized chair is difficult to maneuver outdoors and in many public places. It also has a problem with tipping since the wheels are small and **weighs 300lbs!** A manual wheelchair was needed to make the world more accessible for Maria. This would enable her parents to take the chair more places especially in other people's homes for play dates and holidays. When Maria is tired someone can push the chair for her and this chair can accommodate a specially made tray that Maria can do her school work on. This was not possible with the power chair.

The chair was ordered but the needed insert for support of Maria's upper body was not covered. Through a therapist working with Maria, The Molly Ann Tango Foundation was contacted and the request was made and granted. This foundation dedicated to helping families with children with special needs, made the necessary arrangements and now Maria can go places she hasn't been before. Her family describes this opportunity as another door that has been opened. Maria can go friend's homes and to her relatives for family holidays. Typical for a nine year old with a personality meant to be shared.

The Molly Ann Tango 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 Kaloidis'. Thank you Maria for the footprint!

For more information or to contact the foundation call: 203- 431-4180, PO Box 15, Ridgefield, CT 06877.