



# The Fight For Jessica Takes on New Meaning

By Theresa Hoiles

Jessica Leoni turned eight last month. She had a small group of family and friends help her celebrate and blow out candles. This was a bright spot in a summer that has been difficult.

On Memorial Day weekend, Jessica experienced two grand mal seizures. These were the first of several that have continued throughout the summer. She has been to the emergency room



three times and frequents the doctor's office one to two times a week.

Seizures are often a side effect of Jessica's disease, Neimann-Pick Type C which is

a genetic disorder that causes progressive deterioration of the nervous system due to the body's inability to metabolize cholesterol. Although they may be a by-product of the disease they are not treating the seizures as a progression of the disease. Instead, Jessica, her family and doctors are working on finding a way to treat the seizures through medicine.

Jessica has spent much of her summer indoors playing games, reading books and making crafts with her family, friends and sitters. Her father, Anthony Leoni says that these seizures "can really zap her energy."

Sometimes her dance instructor, Cathy Peoples, comes by for a private ballet lesson. Although her coordination has been affected, Jessica still loves ballet and the people at Westchester Dance have been a huge part of her emotional support system.

While the medication is working to



control the grand mal seizures, Jessica can have up to 15 petit mal seizures a day. On top of that, the side-effects of the medication often cause her to be loopy, restless and generally out of sorts. Often, her mother and father must shadow her in case she has a fall during a seizure. The family admits that these seizures have completely changed their lives. Anthony said, "At this point, we are taking things day by day." Because of the seizures and the symptoms related to the medication, Jessica's dream family vacation to Hawai'i, which they had been planning for months, had to be cancelled. Jessica's spirit is also struggling to stay upbeat. As her father put it, being eight years old and spending two months sick, "is like a lifetime."

The first seizures occurred during the school year while Jessica was enrolled at Visitation School. Even though she was out the last three weeks of school, Jessica managed to finish the first grade with her class. She also celebrated her First Holy Communion last spring.

Jessica and her family felt they found a perfect fit two years ago when they enrolled Jessica in Visitation School. Anthony feels the school's principal, Dr. Carol Crede helped support Jessica's education in an inspirational way. She allowed him to speak at Back to School night giving the family a chance to explain Jessica's disease so that everyone would understand and support her throughout the year. Now, with a month before the next school year starts up again, the Leoni's are hopeful that Jessica will return but feel as if a month is too far ahead to begin planning.

Community support continues to overwhelm the Leoni family. For the past 6 years, they have hosted a casino night where the proceeds go to the Ara Pareghian Medical Research Foundation. This is a foundation that funds research to find a cure for Niemann-Pick Type C Disease. This year Casino Night will be held on October 1, at The Pointe in Long Beach. Normally, Anthony and Lisa Leoni would have been organizing the event. This year however, due to the focus on Jessica, they cannot. So, committee members from the past years as well as new committee members including, Cynthia French, Bob and Patty Fisher and Nicole Carmichael have stepped up and are making sure that this year's event is just as successful as past years. To stay updated on events related to Casino Night, go to Jessica's website, [www.fightforjessica.com](http://www.fightforjessica.com).

Visitation Church helped Jessica's cause last winter at their Celebration of Angels benefit dinner. Organizer Terry O'Connor used this event as a celebration of life event to celebrate Jessica. Jessica

played a part in the event by participating in the fashion show. The Celebration of Angels committee also decided to donate half of the proceeds to the Fight for Jessica fund.

Other community members are also helping out in their own way. Jeff and Laura Remington, founders of the Westside Children's Community theatre group, Music West, did some fundraising and awareness of their own this summer. During the production of their summer musical, "The Music Man", they sold flowers at the door to raise money for Jessica's cause. He also spoke to the audience explaining Jessica's condition and how community efforts help her, her family and the cause. Jeff had mentioned this idea to Anthony earlier this summer but due to difficulties Jessica and the family had been dealing with, Dad had forgotten about the idea. To the surprise of the Leoni's, the Remington's went ahead with the plan and helped raise money for the cause. Anthony said that it was, "heartwarming to have them take it (the idea) and run with it."

The Leoni's are also hoping to get support from families who are



also touched by this disease. The 2005 NNPDF (National Niemann-Pick Disease Foundation) Family Conference is going to be held at the Marriott Hotel in Manhattan Beach this year. It is scheduled to run August 4 through August 7. This is the 13th Annual conference and the theme is "The Magic of Our Children." This will give the Leoni family a chance to talk with other families who experience this disease, and learn more about current medical treatments and progress.

The spirit and determination of Jessica and her family to overcome this disease is starting to take a toll on them. However, they have a strong sense of faith, are surrounded by a powerful group of supporters and continue to be in the prayers of many of us in the community. We will all continue to be optimistic and pray that Jessica will blow out many more candles on her birthday cake.

**What is Neimann-Pick Type C disease?**

Niemann-Pick Type C disease is a group of rare inherited disorders of fat metabolism. Symptoms of type C occur because of impaired trafficking of large molecules within cells, which results in the accumulation of excessive amounts of cholesterol and other lipids (glycosphingolipids) tissues throughout the body. The metabolic defect in type C can lead to a secondary reduction in ASM activity in some cells.

Symptoms common to Niemann-Pick Type C disease include yellow discoloration of the skin, eyes, and/or mucous membranes (jaundice), progressive loss of motor skills, feeding difficulties, learning disabilities, and an abnormally enlarged liver and/or spleen (hepatosplenomegaly). The different types of Niemann-Pick disease are inherited as autosomal recessive traits. ([www.webmd.com](http://www.webmd.com))

**Frequency:**  
Neiman-Pick, type C affects approximately 500 children in the U.S. Children with type C usually live to their teens. They tend to have normal development for the first 2 years of life. Around school-age symptoms of the disease begin to develop.

**Symptoms include:**

- Unsteadiness of gait, clumsiness, problems in walking
- Difficulty in posturing of the limbs
- Slurred, irregular speech
- Learning difficulties and progressive intellectual decline
- Sudden loss of muscle tone, which may lead to falls
- Seizures
- Tremors accompanying movement