



Greenwich-Post

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Umbrella Club

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Section: News

As a former surgical technician, part of Jennifer Tices daily duties was to administer shots and take blood, so she is used to sticking people with needles. Still, she says, she is counting down the days to when she can throw the household sharps container away after giving her four-year-old son his last dose of steroids. A year and a half ago, Ephraim, Ms.

Tices youngest of five, was stricken with Opsodonus-Myoclonus syndrome, a rare neurological condition that causes the immune system to attack the child's brain. He had been a healthy, normal little guy enrolled at Hamilton Avenues pre-school until shortly before his third birthday when his development abruptly stopped.

"He was unable to walk, his eyes were rolling around," Ms. Tice said.

She and her husband took Ephraim to Stamford Hospital where he was diagnosed with the disorder. Ms. Tice said the diagnosis was a miracle in itself because the disease is so rare with only about 80 cases reported worldwide per year.

The syndrome is caused by one of two conditions - either it is the result of a brain tumor, or it is the body's own response to the tumor that starts attacking its own healthy cells.

Ephraim's condition was so severe, the Tices had to take him out of school and schedule him for a slew of doctors appointments, radiation treatments, bone scans and eye check-ups. On top of all this was the mountain of medication he would require not only to fight off the disease, but to combat the side effects of all the other treatments to his tiny body.

Mr. Tice had to become a stay-at-home dad to tend to Ephraim, leaving Ms. Tice to act as the sole bread-winner. Working as the office manager for a medical company, she took on extra hours as a

custodian. One night after the medical office closed, the buildings superintendent saw Ms. Tice mopping the floors.

"I told him I was trying to make some extra money. He said I'm involved with the **Umbrella Club**, and you should apply for their aid," she said.

The **Umbrella Club** is a local organization of 50 members that raises money for the families of sick and handicapped children in Fairfield County. Founded by Greenwich resident John DePoli in 1972, it started out as a few friends who got together to help a mutual friend who faced staggering medical bills. The **club** has expanded its membership and its mission since that time. Its aim is help the families who may not be at the bottom of the income scale, but who fall through the cracks for state and federal assistance for dealing with their children's health problems. Its for the people who have outrageous bills, who are out of work to tend their child, who cant face lifes surprises. The Tices were just such a case.

"You have to make a certain income to survive here," Ms. Tice said. "This **club** helps the people stuck in the middle."

The **Umbrella Club** members meet once a month in Stamford to address new cases and plan fund-raising events, which include an annual car raffle, dinner and dance and golf tournament.

Marcus Sweeney, chairman of the **clubs** membership committee, boasts that the **club** functions with nearly no overhead.

"About 98% of funds raised goes to these families," he said.

The **club** has always worked quietly and spread its assistance through word of mouth.

Someone affiliated with the **club** hears about a family in need and brings the case before the membership. Then the family applies for aid, the **club** members review the application, interview the family, meet with doctors and then present the case to the rest of the board for approval.

Most of the money donated goes to medical equipment or specific treatments. In the Tices case, the **club** cut them a check in the amount of their insurance deductible.

"We had two vials of medication that were delivered to the house one day. It said, your co-pay is \$40 after we met the deductible.

They billed the insurance company \$47,000," Ms. Tice said. "Its a juggling act. The numbers are just mind boggling and this has been the most expensive year. Ephraim is worth about half a million

dollars in his recovery."

In Ephraim's case, the Tices are hoping he'll make a full recovery. Many of the club's beneficiaries face even more tragic circumstances.

Ethan, the son of a Fairfield police detective, was diagnosed with spinal muscular atrophy.

Totally crippled, the boy is only able to move his eyes.

The Umbrella Club purchased a \$10,000 machine that keeps him breathing.

There was the family that moved from Greenwich to West Virginia. The father was a preacher who lived with his wife in a trailer. They had a child born with no division between his right or left brain, leaving him deformed and completely disabled. Then the preacher died suddenly, leaving the mother to tend for the child alone. The club donated \$35,000 worth of equipment to assist her.

There was the child who was born with no sweat glands, who couldn't step foot outside because his body couldn't regulate his temperature. The Umbrella Club paid to have his entire house air conditioned, then commissioned NASA to design a vest that controls his body heat so he can now play outside.

Peter Orrico, a Greenwich member of the club, recalled one case where a family went completely broke trying to pay for treatment for their teenage son.

"We kept their child alive for three years," Mr. Orrico said, "and then we paid for his funeral."

The members of the club work with local doctors and hospitals and have contacts in the medical supplies industries with whom they can negotiate to keep costs down. Coming from a variety of backgrounds, the club members are bonded by their mission to assist the less fortunate.

"A lot of people raising children are looking for certain milestones. The first time they smile, the first word. With these parents, they are looking at the first time a child gives any kind of response," said Mr. Sweeney.

Ms. Tice said Ephraim is heading toward recovery but there is still a ways to go.

"People who've seen him and haven't seen him in a long time are impressed with how he is doing," she said. "At one point he had been listing to one side, and drooling, nonstop drooling. We would be in

church and getting pitying looks Just now seeing him acting more like a normal child is encouraging."

The **club** members are also proud of the fact that they keep track of their beneficiaries. In Ephraim's case, the **club** was planning to donate a second \$5,000 check to meet his insurance deductible.

"We help them with a financial gift," said Mr. Orrico. "We help pay for their travel expenses to help meet their deductibles.

We don't forget them."

The **club**, which has traditionally kept a low profile, is now looking for corporate sponsors to assist in its mission.

On Nov. 20, the **club** is holding its annual dinner dance at Italian Center in Stamford. All proceeds from that event goes toward the Yale/New Haven Pediatric Eye Center, one of the **clubs** program beneficiaries.

For more information, visit umbrellaclub.org.

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