

Sand, surf and special needs Day at the Beach program for those with developmental disabilities

BY BONNIE DELANEY • TOMS RIVER BUREAU • AUGUST 14, 2008

Chris Duffek maneuvered the chair with oversize wheels along the short path through the dunes and onto the soft, white sand. In the chair sat his 14-year-old, 125-pound son, Matthew.

Then, the older Duffek began running downhill toward the waves breaking on the beach in front of the governor's house at Island Beach State Park, with Matthew holding on and yelling "Whoo-hoo!"

The Duffek family's day at the beach would have been impossible had it not been for the beach wheelchair and special attention they received because Matthew, who has epilepsy, does not walk, said his mother, Julie.



Chris Duffek maneuvers his son, Matthew, 14, in a special chair with oversize wheels along the short path through the dunes and onto the soft, white sand. Matthew has epilepsy.

"We've been to Island Beach when Matthew was younger, but it's almost impossible now because he is too heavy to carry," she said as Matthew's siblings, twin Michael, 14, and David, 8, spread out a blanket, and unpacked towels, beach chairs and other gear necessary for a day at the beach.

The Duffek family of Hillsborough were among some 175 individuals with special needs and family members at the 18th annual Day at the Beach, sponsored by the Family Resource Network and Epilepsy Foundation of New Jersey. The event is free to families with loved ones who have developmental disabilities such as epilepsy, autism, mental retardation, spina bifida, traumatic brain injury, Down syndrome and cerebral palsy. It is held each year at the private beach in front of the governor's house at the state park.

"Because it is held at a private location, those attending don't feel overwhelmed by large crowds typically found at the Jersey Shore," said Liza Gundell, deputy director of the network and foundation.

"For many people here it is their first time in many years coming to the beach or their first time ever feeling the sand between their toes or getting their feet wet in the ocean," she said.

After families signed in, they walked past the round tables set up on the patio behind the house where they would be dining on grilled hamburgers and hot dogs, and walked on the path through the high dunes sprinkled with green spikes of dune grass before catching a glimpse of the ocean.

Once on the beach, lifeguards sitting under umbrellas kept a watchful eye on the crowd.

Dennis and Janet Costello of North Plainfield also kept a close watch on their three sons, Ethan, 13, Gavin, 7, and Mikey, 5, as they used shovels to dig holes in the sand, scooped up sand crabs in a bucket, collected shells and grabbed clear, round jellyfish out of the surf.

"They love the beach, but we haven't been able to go much this year," said Dennis Costello, explaining that the trips down to the shore were curtailed this year because Janet Costello is five months pregnant.

"But we came today because they (network and foundation) make it so easy for us to come with the whole family and socialize with other families," said Dennis Costello, whose son, Ethan, has Down syndrome.



Dennis Costello, North Plainfield, plays catch with his son Ethan, 13.

Cathy Rapsas of Lacey came to the beach with her children, Allison, 16, William, 10, and Mary, 8, and nephew Bobby Archibald, 15, of Harrison.



Cathy Rapsas, from Lacey, came to the beach with her daughter, Mary, 8. "Even though we live down the shore it's difficult to get to the beach because of Mary's epilepsy," Rapsas said, adding that her daughter was diagnosed with epilepsy at age 16 months.

"It's overcast, but it's still nice out," said Cathy Rapsas. "Plus, Mary is having a good day."

"Even though we live down the Shore, it's difficult to get to the beach because of Mary's epilepsy," Rapsas said, adding that her daughter was diagnosed with epilepsy at 16 months.

"She's had a difficult time of it and has many different kinds of seizures, but not drop seizures," said Rapsas, who noted that she and her older daughter became Hope Mentors, or advocates, to help people understand what someone diagnosed with epilepsy goes through.

"It's not always like what you see on television — someone shakes and drops to the ground. When Mary has a seizure, she sometimes looks like she is spaced

out or stoned," her mother said. "It's been a real learning process."

Rapsas said the beach day is a great way for her to talk to and network with other parents and caregivers who are caring for children with special needs.

"It's also fun for the kids to be able to relax and have fun," she said.