

LEADING THE WAY

By Andrea Woodhouse Staff Writer

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Manhattan Beach residents Roy and Julie Gonella hold a picture of their son Mikey, who died three years ago of Cornelia de Lange Syndrome. The couple will run the Manhattan Beach 10K in memory of their son. (Robert Casillas Staff Photographer)

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One of Julie Gonella's darkest moments in raising a child with special needs came about 20 years ago, but the Manhattan Beach resident remembers it clear as day.

As she walked along The Strand with her 2-year-old son, his face characterized by delicate, elfin features brought on by a rare genetic condition called Cornelia de Lange syndrome, a

stranger declared that little Mikey must have done something awful in a previous life to look the way he did.

"I didn't leave the house for two years after that," Gonella recalled. "It put the fear in me."

But a guiding source of light in Gonella's darkness was the Cornelia de Lange Syndrome Foundation, an advocacy and support group whose members empowered her to educate others about Mikey's condition, and provided steadfast support throughout her son's short 18-year life.

On Saturday, nearing the third anniversary of Mikey's death, Gonella and her husband, Roy, will give back to the group that helped them for so many years by running the Manhattan Beach 10K as a fundraiser for the foundation, while also raising awareness about the rare condition and honoring their son's memory.

"It's been long enough that we didn't think we'd be so teary, and we wanted to do something meaningful for him," she said. "We've had so much support from the foundation."

The race - a Manhattan Beach tradition since 1978 - begins at 7:30 a.m., looping through the town's west side and kicking off the city's Hometown Fair, which runs throughout the weekend.

Gonella has never been a runner and, in truth, the 52-year-

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old really doesn't enjoy the activity all that much - but the cause was too significant, and her personal milestone too meaningful to sit idle this year, she said.

"This is the first time I've even run in my life, and I'm probably going to walk-run it," Gonella said. "I hate it, but I feel this is so important."

Cornelia de Lange syndrome occurs in roughly one in every 10,000 births and is most often the result of a gene mutation, said Marie Malloy, the foundation's director of external affairs.

The condition ranges in severity, but can manifest physically through stomach abnormalities, missing limbs and diminutive stature, as well as distinctive facial features like upturned noses, joined eyebrows and thin, downturned lips.

Sufferers sometimes exhibit signs of autism and speech impediments, as well as slower cognitive development, Malloy said.

Nationwide, the foundation works with about 2,500 families. In California it has identified and worked with more than 200 people who have the syndrome, Malloy said.

Advocates suspect about 20,000 people in the United States live with the syndrome undiagnosed, or are unaware that a support network exists, she added.

The Avon, Conn.-based foundation was formed by parents of affected children in 1981, about

seven years before Mikey's birth in Torrance.

A doctor at Providence Little Company of Mary Medical Center connected the family with a geneticist at County Harbor-

UCLA Medical Center who diagnosed Mikey's condition, Gonella said.

Heartbroken, the family attended its first foundation conference when Mikey was still an infant, finding refuge and solace in families who were living with the disorder while seeming happy.

Through the years, as Mikey progressed through school, Gonella worked closely with the foundation, even serving on its board of directors.

But after Mikey died in 2006, Gonella was left with a unique skill-set that she wasn't sure how to utilize.

"It's been weird," she said. "I've had to get a new identity. I've always been Mikey's mom, his advocate, and I'm an expert of Cornelia de Lange syndrome, and when you don't have a kid with it anymore, that's a skill I have, but what do you do with it now?"

Since Mikey's death, the couple has stayed involved with the foundation by reaching out to other Southern California families who have children with the disorder and spreading word that a support system exists.

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Karen Miller, a Torrance resident, said connecting with the foundation and the Gonellas has been a lifesaver in raising a daughter, Nicole, who has CdLS.

Without much knowledge of the condition, doctors said Nicole would live two years at most, Miller said. She's now 16 and attends North High School in Torrance.

"Once we got in touch with the right people, they gave us more hope," Miller said. "It has just meant so much to us to have someone who knew what was happening. For me, the foundation was everything."

Miller will join the Gonellas and a team of other Manhattan Beach residents along the 10K route. She's raised about \$5,000, and the Gonellas have collected \$37,000.

Compared with many nonprofits across the country, the foundation has fared decently in the sputtering economy, but smaller donations have kept the group from expanding services and programs, Malloy said.

That makes these families' contributions so much more significant, she added.

"Some families, after a death, it's like a permanent separation from the foundation," Malloy said. "It's either too painful or they just don't think they need us anymore. But (the Gonellas) are really giving back in many ways."

How to help

Help Julie and Roy Gonella raise money for the Cornelia de Lange Syndrome Foundation by visiting www.firstgiving.com/royandjulie

gonella. Learn more about the syndrome at www.cdlsusa.org.

Want to go?

What: The Manhattan Beach 10K unofficially kicks off the city's 37th annual Hometown Fair, which includes food, crafts and games.

Where: The race starts at Third Street at Valley Drive and Ardmore Avenue and finishes at the base of the pier. The fair is at Live Oak Park, 1901 N. Valley Drive.

When: The race begins at 7:30 a.m. Saturday, leading into the fair, which runs from 10 a.m. to 5 p.m. Saturday and Sunday.

More information: Visit www.mb10k.com and www.mbfair.org

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