

Family offers hope to disabled children

Melbourne Beach child with rare genetic disease inspires parents to action

BY G.W. POMICHTER
Staff writer

It is difficult to imagine what it's like to discover one's child has a deadly and debilitating illness, but what if the only prognosis doctors can give is death?

In 1998, when the parents of then infant Morgan Malfara heard the horrific prediction that their son would not live to his fourth birthday, the situation seemed desperate. After the initial doubt and denial wore-off, they began to accept his hopeless fate as inevitable.

"It was devastating," Morgan's mother Kristen Malfara said. "I saw nothing but doom and gloom."

However, the story doesn't end there.

Fatefully, the Melbourne Beach couple stumbled onto another parent whose children suffered from the same rare disease, Leukodystrophy. The couple found this parent during an Internet search for information about the unusual condition.

"I can tell you where I found the strength to go on in two words," Kristen Malfara said. "They are 'Patty Davio.'"

Ms. Davio of Indianapolis, Md., was the mother of three sons with the rare Pelizeus-Merzbacher Leukodystrophy Disease.

"She told me about summer symposiums they attended to work with par-

ents of these children," Ms. Malfara said. "She helped us so much, and showed us we could have a different kind of normal life with Morgan."

The disease these children suffer from is an extremely rare genetic disorder that causes Morgan's body not to produce Myelin, which his brain needs to function and to develop normally. The only predictions doctors could make in Morgan's case were of his eventual death.

Inspired by their new friend, in 2001 Kristen and her husband Robert, a carpenter at Florida Tech., started the M.O.R.G.A.N. (Making Opportunity Reality Granting Assistance Nationwide) Project.

They set up a foundation, which is dedicated to helping inform parents and caregivers of children with Leukodystrophy about proper care giving, monitoring, new treatments and research in an effort to make Morgan's and many other lives as meaningful as possible.

"There was nobody there to help parents like us with their children," said Mrs. Malfara. "That's why we set up the program—to help others like Patty (Davio) helped us."

The foundation assists parents who need help navigating the federal disability process, or finding low or no-cost equipment such as wheel chairs for disabled children.

"We collect equipment and act as a go-between for families that no longer need it and those who can benefit from it," said Mrs. Malfara. "Just days ago, I donated a wheel chair that Morgan had outgrown."



Kartlin Norton/staff photographer
Melbourne Beach resident BJ Taylor, 14, sits with Robert, Kristen, and Morgan Malfara, 8, who has Pelizeus-Merzbacher Leukodystrophy, a rare genetic disorder. The Malfara family started the M.O.R.G.A.N. project, a foundation dedicated to helping families with children who have similar disabilities.

The next step for the foundation is to offer grants to families of disabled children.

The toughest part of this will be gathering a committee to review applications.

"We need a scientific review board to meet the requirements," Mrs. Malfara said. "We need doctors, nurses, parents of disabled children or anyone who has the knowledge to help decide who to give grants to."

Nearly eight years after his hopeless prognosis, Morgan is still alive, and

his parents are still fighting to make his life the best it can be.

The M.O.R.G.A.N. project is their testimony to their beloved son.

"In a way, I feel I was chosen to be this special little boy's mother, so I could help in this way," said Mrs. Malfara. "It gives meaning to his life."

The family still struggles with the constant care and monitoring of Morgan, but they have learned as much from their son as they have shared with the communi-

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ty, and they continue to be inspired by every smile or laugh their 8-year-old son shares with them.

"We've adjusted to the fact that our 'normal' is a little different than everybody else's. (hat's all," Ms. Malfara said. "I have

learned there is nothing trivial and to really appreciate the little things."

For more information about the M.O.R.G.A.N. project, contact Robert or Kristen Malfara at (.121) 72R-G700 or at www.morganproject.org.

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