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. "I saw something but doom and gloom."

"I told him about something, I can’t even remember," said Mrs. Malfara. "It’s that’s all," Ms. Malfara said. "I have learned there is nothing trivial and to really appreciate the little things."

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.

"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 community.

"I do what I can do," said Mrs. Malfara. "I have 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.

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

"We need a scientific review board to meet the requirements," Mrs. Mal- fara 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."

"We've adjusted to the fact that our normal is a little different than everybody else's, that’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) 732-700 or at www.mor- ganproject.org.