

NICU parents find help, hope



Donna and Isaac Zion of Rye have had four premature births since 2003, including Hailey, who died. Their family created Hailey's Hope, a charity that helps parents with babies in the Neonatal Intensive Care Unit at Maria Fareri Children's Hospital. They are photographed Tuesday with their children, Alence, 7, left, Kaden, 4 and Jake, 5, at their home in Rye. XAVIER MASCAREÑAS/THE JOURNAL NEWS

Hailey's foundation donates time, supplies to aid families of preemies

By Theresa Juva
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Donna and Isaac Zion of Rye have endured the agony of loss and the pain of seeing their tiny babies in incubators.

But they have turned that heartbreak into Hailey's Hope

Foundation, a not-for-profit they helped to create in 2007 with six relatives and friends. Since then, the volunteers have raised \$300,000 for families with babies in the Isaac & Naomi Kaplan Family Regional Neonatal Intensive Care Unit at Maria Fareri Children's Hospital in Valhalla.

"We know how wonderful even the smallest amount of help in the NICU is; we lived it," said Donna Zion, 40. "Even the smallest gestures of kindness go a long way."

The group, whose members all have NICU experiences, has assisted more than 500 families with transportation, food, lodging

and expenses for baby supplies. Parents get disposable cameras around holidays, and every family leaves the hospital with a care package. In addition, the foundation has donated \$20,000 for new kitchens at the hospital's Ronald

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NICU: Charity helps parents

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McDonald House.

Members also sometimes visit families at the NICU to offer advice and comfort.

"It's a way of making something positive out of the worst experience of our lives," said Isaac Zion, 40.

The charity is named after Hailey, a girl Isaac and Donna Zion lost in January 2003. During Donna's first pregnancy, she developed HELLP syndrome, a potentially fatal condition, and was forced to deliver at 21 weeks. A full-term pregnancy is about 40 weeks.

"I was devastated beyond devastated, thinking, 'Wake me from this nightmare. This can't be happening,'" Donna recalled.

HELLP stands for hemolysis, elevated liver enzymes and low platelet count. Zion's obstetrician, Dr. Stephen Carolan of Rye, said doctors don't know what causes the syndrome, which is uncommon and the most severe form of pregnancy-induced hypertension. The main treatment is almost always an immediate delivery to save the mother, he said.

The National Institutes of Health estimates the condition occurs in one to two pregnancies out of 1,000. Zion's case was rarer because the syndrome typically doesn't occur that early in pregnancy, Carolan said.

Zion had it during all four of her pregnancies, but it struck later with each one. All three of her children — Alence, 7, Jake, 5, and Kaden, 4 — were born premature and spent almost 12 weeks in a NICU. Her twin sister, Debra Randazzo of Goshen, N.Y., who is also a foundation member, developed the same syndrome during two of her three pregnancies and had two premature boys.

The NICU takes a huge toll on parents, she said. They have to balance jobs and other children as they struggle with unfamiliar medical language and being separated from their babies through glass.

"When you are preparing to have a baby, no one prepares you for the NICU," Randazzo said. "We have had to help families through deaths, and we've been there. We are a shoulder to lean on."

Even though no one in the foundation had babies at Maria Fareri, they chose it in part because the Level 4 unit cares for the smallest and sickest babies in the Hudson Valley. It treats about 650 to 700 babies a year, and the average length of stay is 31



Donna and Isaac Zion's children, from top, Jake, 5, Alence, 7, and Kaden, 4, were all born premature and spent almost 12 weeks in the Neonatal Intensive Care Unit. Their family created Hailey's Hope, a charity that helps parents with babies in the NICU.

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BIRTH FACTS

» There are an estimated 250,000 births every year in the state.

» About 1 in 8 babies are born premature or preterm.

» Premature babies can face mental disabilities, vision and hearing loss, and learning and respiratory problems.

Source: state Department of Health

HAILEY'S HOPE

To find out more about Hailey's Hope, call 914-584-8833 or visit www.haileyshopefoundation.org.

days, the hospital said.

Aideen and Martin Duffy of Rockland County have a son, Kevin, who spent 118 days there. He was born at 23 weeks in December 2009, weighing 1 pound, 8 ounces.

"Tough, very tough," Martin Duffy, 37, said. "We didn't

know if he would survive or not."

Worrying about their son, handling mounting bills, and finding time for their two daughters was challenging, Aideen Duffy, 39, said.

The foundation went beyond just helping with commuting and food expenses, Aideen said. She was especially moved when Randazzo and her mother visited.

"They were strangers, but they didn't feel like strangers," she said. "There is no price you could put on support during such an overwhelming experience."

The foundation has also helped Danielle O'Hare, 32, of New Rochelle. Her daughter, Faith, was born six weeks early in June 2010 and spent a month in the NICU. She weighed 4 pounds, 7 ounces.

"It can be a lonely place," she said. "People who don't know you who are reaching out, it's like a hug."

Mount Vernon's Yolanda Brown-Harris, 35, was on unpaid leave from work during the three months her

daughter, Amanda, spent in the NICU. She was born at 26 weeks in July and weighed 1 pound, 6 ounces.

"If it wasn't for the organization, I wouldn't have been able to be there as much as I was," she said.

Dr. Edmund La Gamma, chief of newborn medicine at Maria Fareri, which is part of Westchester Medical Center, said the foundation is unique because it focuses on parents' needs.

"The stress on the couple is just extraordinary," he said, but with the foundation covering expenses such as gasoline, "families are here more often and that is very important for communication (with doctors) and parental involvement."

Donna Zion said the group would like to extend its reach to more hospitals.

"We felt so many people stepped up for us, and we wanted to do that for other families because it's a very difficult journey and a journey not many people know about," she said.