



Hailey's Hope FOUNDATION

Support for NICU Families



Newsletter

December 2011

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MESSAGE FROM THE PRESIDENT

Pablo Picasso, Stevie Wonder, Albert Einstein. Geniuses? Yes, but did you also know that they were born premature? Just like one in eight babies born in America and in New York today. What else did these preemies have in common? Anguished, worried parents living through the whirlwind of uncertainties and the roller coaster of triumphs and setbacks in their newborn's first hours, days and weeks of life. If these parents were lucky, they had the resources to stay near their babies and to help nurture them through their roughest times. But, what if they didn't?

Many parents are completely unprepared for the stresses that accompany the birth of a premature or critically ill baby, who is whisked away to the Neonatal Intensive Care Unit (NICU). Their worlds are turned upside down. Every aspect of their lives is profoundly impacted and there are few avenues to turn to for the support they need. By giving NICU families greater access to local lodging, state-of-the-art medical equipment, nourishing meals, baby supplies, valuable resources and other financial assistance, our unique programs have brought them comfort and helped alleviate their burdens during this difficult time.

We truly appreciate the generosity of our donors and the dedication of our volunteers. The combination of these wonderful supporters has enabled us to pursue our mission and fill a critical void. With the new year quickly approaching, we are excited to plan our major fundraising events and look forward to expanding our programs to other local NICUs to fulfill the needs of even more NICU families.

On behalf of everyone at Hailey's Hope Foundation, we wish you and your families a joyous season and bountiful new year. ♦



(HHF Board members Ann and Marvin Siegel, HHF Vice President Donna Zion, Ronald McDonald House (GHV) Board Chairman Bryan Colley, Ronald McDonald House (GHV) Board member Mary Delaney, HHF Board member Debra Randazzo and Ronald McDonald House (GHV) Executive Director Marielena DiMatteo)

Hailey's Hope Foundation Partners with Ronald McDonald House

The new Ronald McDonald House of the Greater Hudson Valley, located on the grounds of Maria Fareri Children's Hospital in Valhalla, opened its doors in April 2011. HHF and the Ronald McDonald House joined forces to help create a financially and emotionally supportive environment for NICU families coping with their babies' serious health crisis in the hospital. In addition to sponsoring the construction of the House's two kitchens, HHF helps families pay for extended stays there while their babies are in the NICU.

"Our partnership has been a tremendous benefit to NICU families," said Board member Marvin Siegel. "We are able to keep families together, in a nurturing environment, while remaining steps away from the hospital. They are able to cook and eat meals together and find comfort in being surrounded by other families dealing with similar crises."

To date, HHF has proudly provided NICU families with over 150 overnight stays.

OUR MISSION

The mission of Hailey's Hope Foundation is to help families with premature and critically ill babies hospitalized in the Neonatal Intensive Care Unit (NICU).



(NICU Chief of the Division of Newborn Medicine Dr. Edmund F. La Gamma, Neonatologist Dr. Sergio Golombek, Senior Medical Social Worker Julie Larkin and Board member Debra Randazzo)

A New EKG Machine For The RNICU

Highly sophisticated technology is used to monitor and care for the special needs of babies in the NICU. One very important piece of equipment is called an EKG machine – an electrocardiogram that records a baby’s heart’s electric activity on a graph. Because premature babies are at great risk for heart problems, this machine provides an effective and painless way for the NICU team to get crucial information about a baby’s heart condition, including heart rate and blood pressure.

With the help of an anonymous donor, this Fall Hailey’s Hope Foundation proudly donated a new, state-of-the-art EKG machine to the RNICU at Maria Fareri Children’s Hospital.



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PROGRAMS

- Financial Support Program
- Welcome Home Discharge Bag Program
- Memories of a Lifetime Camera Program



The Lahav Lab Neonate Research Study

Anyone who has been in a Neonatal Intensive Care Unit (NICU) knows how overwhelming the noise level can be. The constant sounds of equipment alarms, crying babies and telephones ringing day and night are just a few culprits. Imagine how sensitive the auditory system of a premature baby can be and what affect these noises can have on it. Does the exposure to this level of noise adversely affect a premature baby’s growth and development? This is one of several important issues that Dr. Amir Lahav and his team at the Neonatal Research Laboratory at Boston’s Brigham and Women’s Hospital (a teaching affiliate of Harvard Medical School) are researching.

Dr. Lahav and his team are exploring ways to improve the quality of life and care of premature babies in the NICU and after discharge. A significant part of this study addresses ways to reduce the overall noise level in the NICU to make it a more appropriate environment for a baby’s growth and development. In addition to monitoring NICU acoustics, Dr. Lahav has developed micro auditory technology to transmit soothing maternal sounds (i.e., recordings of the mother’s voice and heartbeat) directly into her baby’s incubator. At scheduled intervals during the day and night, the baby’s responses to these sounds are observed and recorded.

Premature babies are at a high risk for a variety of developmental issues, including learning disabilities, language disorders and communication difficulties. Dr. Lahav believes that mimicking the sounds a baby would hear while still in the womb will aid in the development of a premature baby’s brain and neurological system. His team will be following up on these babies after discharge and until they are three years old.

This year, Hailey’s Hope Foundation donated \$5,000 to the Neonatal Research Laboratory to help fund this important research. For more information on Dr. Lahav and this study, please visit our website at www.haileyshopefoundation.org or <http://lahav-lab.bwh.harvard.edu>. ♦



SPECIAL VOLUNTEERS

Hailey's Hope Foundation's volunteers are the backbone of its organization. They are compassionate and dedicated individuals who want to make a difference in the lives of NICU families and donate their time and talents to be part of something bigger than themselves. Camille Ferrara and Dawn Singer are among the many volunteers who help us run our programs and events each year. We greatly appreciate all they do for us.



Camille Ferrara

When starting a charity, Camille Ferrara is the woman you want on your team. Her business management experience, passion for helping others, and enthusiasm have helped make Hailey's Hope Foundation the success it is today. A hard-working mother of two, Camille has served as a Development Associate for the Committee for Hispanic Children and Families, Inc., a nonprofit organization in New York City, for the past eight years. Even with her busy schedule, Camille jumped at the chance to become involved with HHF. Camille joined HHF as a volunteer in early 2008 and has been a great help in many different areas, including fundraising and administrative tasks. "Whenever I am in contact with HHF, I walk away feeling that I am a better and happier person for having been with them. They have taken personal crises and tragedy and turned them into ways to help so many other people in similar situations. HHF has given me far more than I could ever have given!" says Camille. HHF is thrilled to have Camille Ferrara as part of our team. ♦



Dawn Singer

Dawn Singer was searching for a meaningful way to help other NICU families. Her twins Colin and Christopher were born prematurely at 26 weeks in 2007 weighing 1.4 lbs and 2.5 lbs. and defied the odds by surviving TTTS (Twin-to-Twin Transfusion Syndrome), a disease that affects identical twins that share the same placenta. The twins spent over 100 days in the NICU. Dawn decided to stay at home to raise her twins and son Chase and ended her ten year career as a senior scientist for Roche Molecular Systems in New Jersey. When her twins were 3, she heard about HHF and immediately came on board to volunteer in 2010. With Dawn's compassion, personal NICU experience, and attention to detail, she brings a great perspective to HHF. "I feel extremely fortunate to volunteer for HHF," says Dawn. "It gives me great satisfaction and delight knowing that I am helping others during an extremely difficult and stressful time. I lived through the trauma and anxiety and fully understand what it is like having your child cling to life by the thinnest thread. HHF provides a real comfort to families and a social network of support that is immeasurable. It helps feed my soul." ♦

NBTY Helping Hands Charity Supports Hailey's Hope Foundation



The NBTY Helping Hands Charity is a non-profit organization conceived by NBTY, Inc., a leading manufacturer and distributor of nutritional supplements worldwide. Dedicated to helping the less fortunate and financially needy, NBTY Helping Hands Charity recognized the efforts of HHF in helping NICU families. For the second year, NBTY Helping Hands donated \$10,000 to help further our mission.

In The News



Earlier this year, two special reporters gave Hailey's Hope Foundation a great boost in raising awareness of its mission and the important needs of NICU families. On June 18th, Theresa Juva of *The Journal News* (a local paper of Westchester, Rockland and Putnam counties) featured the work of HHF at Maria Fareri Children's Hospital in Westchester. In the Summer 2011 edition of *Binghamton University Magazine*, David McKay Wilson highlighted the bond among six college friends that later spawned the creation of Hailey's Hope Foundation. Please visit our website at www.haileyshopefoundation.org to read the stories in full.

Hailey's Hope Foundation Helps 500 NICU Families

"When we set out in February 2008 with \$2,000 and a vision to help NICU families at Maria Fareri Children's Hospital in Valhalla, New York, never would we have imagined that within just three and a half years HHF would be giving financial support to 500 NICU families," said Jeffrey Randazzo, HHF President and Founder. "This Fall, we were thrilled to reach that tremendous milestone." Through our NICU experiences, we saw families struggle with basic needs because of their babies' lengthy NICU stays. The lack of support for families motivated us to create programs to help fulfill those needs and get them through this difficult time. Our Financial Support Program is our largest program that helps families overcome the financial challenges they face when their babies' are in the NICU. During this time, we help pay for local hotel lodging and Ronald McDonald House stays to keep them close to their babies' bedsides, commuting expenses, meals, hospital parking, baby supplies and more. This unique program provides families with comfort and greater opportunities to visit so they can remain actively involved in their babies' care. With long NICU hospitalizations, medical and non-medical expenses accumulate quickly. Financial assistance is a tremendous need for NICU families. HHF receives approximately 35-40 applications each month and with the help of our wonderful supporters, we have fulfilled every request for assistance. However, great demand remains.

HHF will continue to work hard to raise awareness of these needs and to support as many NICU families as possible. To make a donation, please visit www.haileyshopefoundation.org or contact us at (914) 584-8833. ♦



▲ HHF Board member Ann Siegel with Angelique Green with baby Janai, born at 36 weeks weighing 3 lbs 14 oz.



▲ The Duffy Family, baby Kevin Patrick born at 23 weeks weighing 1 lb. 10 oz.



HHF Board member Ann Siegel with Marlene Gillman and twins Helen and Elizabeth, born at 25 weeks weighing 1 lb. 11oz. and 1 lb. 14 oz. ▶



Proud father Jesse Usera with baby Angel, born at 24 weeks weighing 1 lb. 14 oz. ▶

◀ Veronica and Angelo with triplets Valentina, Victoria and Vienna who were born at 33 weeks weighing 3 – 4 lbs.



The McElroy Family... Their NICU Story

The evening of January 14th was like one typical of any pregnancy. There were “normal” feelings of pregnancy at 24 weeks, but nothing that seemed out of the ordinary, especially after reading all the pregnancy books. At about 3:45 am on January 15, our “normal” pregnancy ended and quickly turned painful. The pains that were so commonly associated with pregnancy turned out to be labor pains. That morning, my water broke and I gave birth to our beautiful baby daughter, Kenley Rian—16 weeks early! Not only was Kenley’s arrival a complete shock to us, but she made her grand entrance into this world at our home. At 4:04 a.m., my husband, Graig, now OB and first responder, delivered Kenley. Our tiny miracle weighed only 1 lb. 11 oz. He performed rescue breathing on her until the EMTs arrived. The EMTs and first responders were amazing and quickly got Kenley to Arden Hill Hospital. Due to Kenley’s extreme prematurity, she was immediately transferred to the Regional NICU at Maria Fareri Children’s Hospital at Westchester Medical Center in Valhalla, about 40 miles away. This NICU was her home for the next 122 days.

Everything seemed so normal and then changed in an instant. We were thrown into a situation that we never imagined possible. It was frightening! We had absolutely no idea what we were in for or what was going to happen. Life in the NICU took its toll on us. Kenley’s premature birth at 24 weeks and the surgeries and procedures that followed were hard to overcome. On her second day of life, she developed a significant cerebral bleed, which led to an ommaya reservoir being put in, and then a shunt. During her first 5 precious months of life, she underwent three brain surgeries (ommay, shunt and shunt revision) and one heart surgery (to close her pda). We were constantly reminded how critical and beneficial it was for us to be there for Kenley, for her survival and development. In our baby girl’s fight for her life, we knew she needed us and our love and support more than anything. It was difficult to juggle schedules and hospital visits. We made sure that we were there for her each and every day, for 122 days, snow, rain or shine. Graig would visit Kenley in the morning before work



and I would go in the evening after work. Living in Chester, New York, we traveled approximately 40 miles each way to the hospital. Some days when we got home and called the NICU for updates on Kenley’s condition, we would head right back to the hospital if we got bad news. We were back and forth a lot and easily added 20,000 miles on our brand new car, but we wouldn’t have changed a single trip.

Today, Kenley is doing amazing! She is exactly where she should be, according to her corrected age. We still have a long road ahead of us, and there are definite possibilities for obstacles, but right now, she is a very happy baby who is doing well. We truly believe that our presence during her time in the hospital, along with the great staff at the RNICU, played a significant part in where she is today.

Hailey’s Hope Foundation had an important role in helping us be there for Kenley. The support they gave us during our time in the hospital helped to ease our fears and made all of our trips easier. We are so grateful for what they did for us, and what they continue to do for families with babies in the NICU. When you find yourself in a critical situation like we did, having supporters like Hailey’s Hope there makes a tremendous difference. ♦



Ways To Help

Want to get involved with HHF and impact the life of a NICU family? Donations of money, time and talents are always welcome and are greatly appreciated. We are looking for volunteers to help in the following areas:

- Fundraising Events
- Social Media
- Donation Solicitations
- Grant Writing
- Photography
- Administrative Tasks
- Public Relations



Please contact us for more information at (914) 584-8833 or info@haileyshopefoundation.org. We are excited to hear from you!

HAILEY'S HOPE FOUNDATION FUNDRAISERS



Manursing Island Club



Sharp Business Systems' Arnold Vega, Anthony Gianino, John and Helen Castro and President Jeffrey Randazzo

Fiesta en la Playa!

Over 125 guests came out to show their support for Hailey's Hope Foundation at its "Fiesta en la Playa" benefit on April 30th at Manursing Island Club in Rye, NY. Great Mexican cuisine, cocktails, raffles, and more set the stage for a fantastic and memorable night. Dr. Edmund La Gamma, Chief of Newborn Medicine at the Regional NICU at Maria Fareri Children's Hospital, received the 2011 Hailey Zion Memorial Award for Community Spirit for his dedication to helping NICU babies and families. The event raised over \$85,000 for programs that bring hope, comfort and support to families struggling to cope with their baby's hospitalization in the NICU. The evening's sponsors included Reckson, A Division of SL Green Realty Corp., New York Capital Markets Group of Jones Lang and LaSalle, Securitas Security Services, USA, Inc., CB Richard Ellis, Saugatuck Construction Group, LLC, and Palotta Landscaping Inc.



David and Doreen Zion with Jamie Berg



Olivia Blau, Nicholas La Gamma and Kalliope La Gamma



Marianna and Ralph Berardi, Jr.



Marty, Ava and Danielle Smith

Viva Italia!

Our Viva Italia Dinner Auction Fundraiser on October 15, 2011 at Harness Racing Museum in Goshen was a great success. Sponsored by Delancey's Bar and Restaurant, guests enjoyed delicious food, drinks with great raffle and auction prizes. Orange County Executive Edward A. Diana was presented with the 2011 Hailey Zion Memorial Award for Community Spirit for his dedication to serving the needs of the community. With 100 guests in attendance, the event raised over \$20,000 to help NICU families in need at the Regional NICU at Maria Fareri Children's Hospital in Westchester, and other local NICU's, including the new Orange Regional Medical Center in Middletown.



Annie DeClerck, Heather Larsen, Susan Dwyer-Johnson, Kelly Fleming and Shelia Toohey



Kathy Miller, Patricia Hess and Jennifer McKeown



Rachel Breheny, Rondell Peters, Rebecca and Michael Bonhomme, Dawn and Roger McKelvey, John Breheny, Jon and Jennifer Van Cott and Norman Peters, Jr.



John and Melissa Clark, Jennifer and Chris Limbert and Lorene and Todd Allspach

2011 HAILEY ZION MEMORIAL AWARD FOR COMMUNITY SPIRIT RECIPIENTS

Each year, Hailey's Hope Foundation proudly recognizes extraordinary individuals for their longstanding commitment and exceptional contributions to improving their communities and furthering our mission to help NICU families in need. This award is dedicated to the memory of Hailey Zion, our beautiful baby girl who was born too soon and passed away shortly after birth.

This year's recipients of the Hailey Zion Memorial Award for Community Spirit are:

Edmund F. La Gamma, MD

Dr. La Gamma is the Chief of the Division of Newborn Medicine and the Director of the Regional Neonatal Intensive Care Unit (RNICU) at Maria Fareri Children's Hospital at Westchester Medical Center in Valhalla, New York. He also directs one of the largest Neonatal-Perinatal Medicine Fellowship Programs in the United States and is a Professor of Pediatrics, Biochemistry and Molecular Biology at New York Medical College. Dr. La Gamma has been instrumental in creating and expanding access to an extraordinary, highly specialized hub of critical care for the tiniest and acutely ill newborns at the RNICU and has been an avid supporter of Hailey's Hope Foundation.

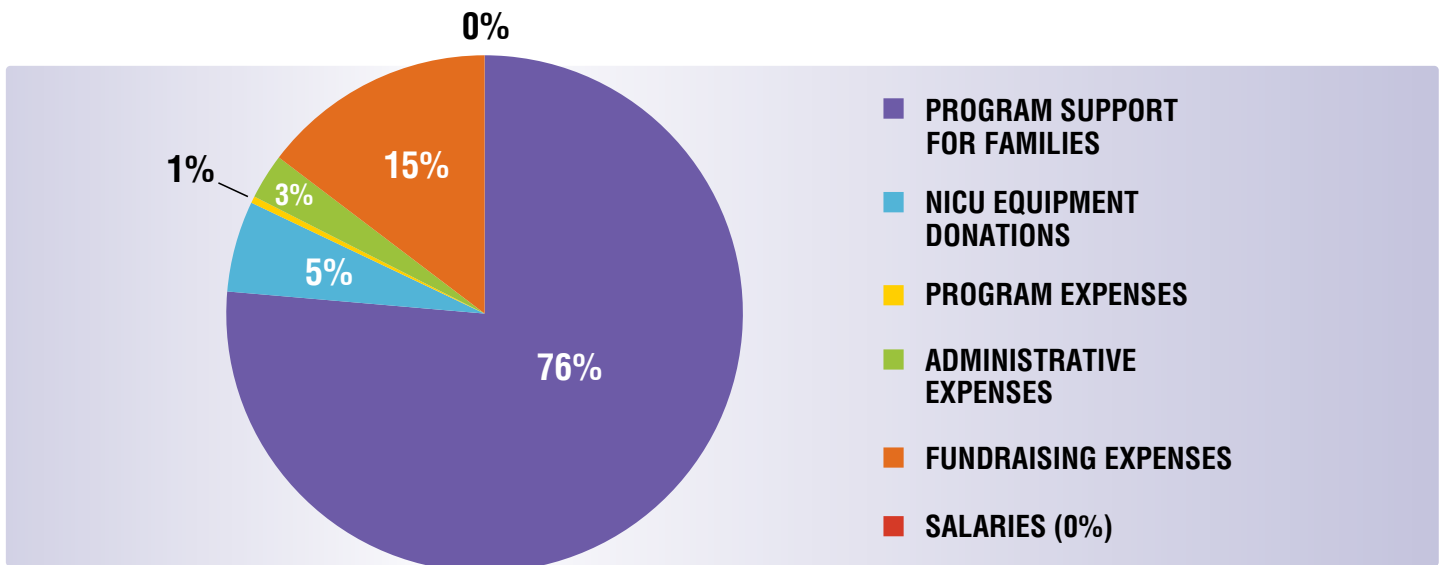


Edward A. Diana, Orange County Executive

Mr. Diana is serving his third consecutive term as Orange County Executive. He is also President of the New York State County Executives Association and a member of the Board of Directors and Second Vice-President of the New York State Association of Counties. With his lifelong roots in Orange County, passion for public service and volunteer work, Mr. Diana is not only a tremendous politician and respected community leader but also a passionate advocate for Hailey's Hope Foundation.



HOW DONATIONS WERE USED IN 2011



Period covering 1/1/11 - 12/2/11

Since its inception in December 2007, Hailey's Hope Foundation has raised over \$325,000 for NICU families. We work diligently to keep expenses low so as much money as possible can directly benefit NICU families. All of our members are volunteers; we do not have any paid positions.



Mount Saint Mary's College Red Tent Event

Students in the Psychology of Birth course at Mount Saint Mary's College donated over \$300 and wonderful baby supplies to Hailey's Hope Foundation as part of their inaugural Red Tent Event fundraiser. Over 50 friends joined the class on November 19th at Whittaker Hall to raise awareness of different birthing options available to parents and funds for a great local cause. This educational forum highlighted inspiring birth stories from several mothers and featured guest speaker, Ann Siegel of Hailey's Hope Foundation.