Hope for Genetic Disorders

Nevada's Leader in Children's Health

Miracle Beginnings
It was a joy to spend a beautiful afternoon with our Neonatal Intensive Care Unit (NICU) graduates and their families! These children had difficult starts in life, yet through their strength and thanks to the care they received here at Children’s Hospital of Nevada at UMC, they have blossomed into bright, energetic, and adorable youngsters. Their successes speak volumes about the care we provide at Children’s Hospital of Nevada at UMC, and the reunion was a wonderful opportunity to see just how far these early-starters have come.

In this edition of Child Life, you can read the story of one of our most memorable NICU grads, little Angel Arcos. Angel was born star of his family’s show!

You will also meet Emilee Rodriguez and learn how the pediatric specialty services here at Children’s Hospital of Nevada at UMC have helped her on her journey through treatment for a rare genetic disorder, all the while counting her blessings!

As we start off the New Year, we wish you a very healthy 2013!

Be well,
Brian Brannman
CEO

Thank You!

The physicians and staff at Children’s Hospital of Nevada at UMC would like to thank you for making our 20th annual NICU Reunion a smashing success!

We would also like to specifically thank all the sponsors. It would not be possible to impact so many lives without your help!

Additional thanks to the University of Nevada, Las Vegas; Raising Cane’s; and Project Imagine.

Lawrence Weekly
Clark County Commissioner,
Chair of Board of Trustees

9 Out Of 10 Car Seats Are Installed Wrong! Is Yours?

Kohl’s Cares 4 U at Children’s Hospital of Nevada offers Free Car Seat Checks

Call 702-383-BABY to schedule an appointment
Raising the Standard for Pediatric Care

Children’s Hospital of Nevada at UMC is recognized as one of the leading providers of pediatric care in the country.

Consumer Reports has ranked Children’s Hospital of Nevada at UMC as one of the top five pediatric intensive care units in the nation, based on the results of an annual study assessing rates of one critical statistic—bloodstream infections.

“To be one of only a handful of hospitals in the nation at the top is a tribute to the commitment we have to caring for the children of our community,” says Brian Brannman, CEO of UMC. “Parents can depend on the high quality of care we provide for their children.”

Bloodstream infections are a potentially life-threatening complication, especially among the pediatric population. Children’s immune systems are still developing, and therefore more susceptible to infections. Consumer Reports recommends that parents research the rates of bloodstream infection at hospitals before admitting their children for care.

The Foundation of Excellence

In 2010 and 2011, the Pediatric Intensive Care Unit at Children’s Hospital of Nevada at UMC had zero bloodstream infections. The key to maintaining this high quality of care lies in standardized care procedures.

Our highly professional and experienced team follows a strict set of protocols for treating each and every patient. Those standards include carefully disinfecting patient care areas, regularly changing dressings, and following standard procedure for completing common tasks with high risk of infection, such as changing catheter components.

To learn more about the high quality of care available at Children’s Hospital of Nevada at UMC, visit childrenshospitalofnevada.org.

Did You Know?

Children’s Hospital of Nevada at UMC is home to the ONLY designated Pediatric Trauma Center in Nevada!

Become a Champion for Our Children

Children’s Hospital of Nevada at UMC is a community effort, providing exceptional resources to care for every child who needs our help. With your contribution, Children’s Hospital of Nevada at UMC can continue providing extraordinary care to all children in need.

Charitable giving through the UMC Foundation is essential to advancing our healing mission. Your tax-deductible gift will help ensure lifesaving services are available for children in their greatest moments of need.

I would like to make a donation of $__________.

Please make checks payable to Children’s Hospital of Nevada at UMC, c/o the UMC Foundation.

Please contact me regarding: ☑ Volunteering my time ☑ Other ways of giving

Name: __________________________________ Address: __________________________________ Email: __________________________________

Mail this form and your donation to: Children’s Hospital of Nevada at UMC, attn: Karen Gordon, 1800 W. Charleston Blvd., Las Vegas, NV 89102

Make your donation online at: childrenshospitalofnevada.org/Give

For more information regarding Children’s Hospital of Nevada at UMC, please email CHNV@umcsn.com or call Karen Gordon at (702) 383-3995.

Thank You!
On January 16, 2007, Angel was born at 28 weeks gestation. Weighing just 2 pounds and 1 ounce, he suffered from pulmonary hypoplasia, a condition in which lung tissue is not completely developed. He was taken immediately to the Children’s Hospital of Nevada at UMC’s NICU and put on ventilator support.

“Angel was so small when he was born, I was terrified we would lose him,” recalls Bianca Romero, Angel’s mother. “We walked into the NICU, and I saw him there and felt absolutely helpless. The nurses explained he might have a long stay because of the condition affecting his lungs, and I knew then that our son would need a miracle.”

The walk to the NICU was a journey Angel’s parents were to make many more times during the next year.

“We went twice a day,” Bianca says. “It strengthened our marriage. Loving Angel and caring for him brought us closer.”

Angel spent 10 months in the NICU, during which he underwent four surgeries, including surgery to correct pyloric stenosis (a narrowing of the opening between the stomach and small intestine) as well as operations to place tracheotomy and feeding tubes and repair a hernia.

Throughout Angel’s treatment, Bianca got to know the nurses well. One in particular, Patricia Ingstad, RN, became attached to Angel. A NICU nurse since 1979 with 20 years of tenure at Children’s Hospital of Nevada at UMC, Ingstad has cared for many children, but none quite as remarkable as Angel.

“Angel required a lot of care,” Ingstad says. “He fought every day over the course of the 10 months he spent in the NICU, and it truly has been a miracle to see him overcome the odds and recover.”

The Journey Forward

Angel’s arrival at home was another step in his long journey. The Romero family had to learn to care for his breathing and feeding tubes.

“We had a mini-hospital in our house,” says Bianca. “Slowly, Angel’s lungs started getting stronger, and he is now breathing on his own. He has made amazing progress, and we are hopeful he may have his breathing tube removed next year.”

Bianca’s competent and loving care of Angel, in and out of the NICU, made her a natural ally for other parents with children in similar situations.

“We referred several families to Bianca, and she made herself available to parents who have premature babies with extra needs,” says Ingstad. “We asked her to give them hope that their child will grow and be healthy, just like Angel.”

For Angel Arcos, almost a year of loving care at Children’s Hospital of Nevada at UMC’s Level III Neonatal Intensive Care Unit (NICU) gave him a better start.
TLC through Teamwork

New babies need to hear the sound of their parents’ voices and feel the warm touch of their parents’ skin. In the Neonatal Intensive Care Unit (NICU), it is difficult to provide this valuable interaction, as babies may be attached to equipment that monitors vital signs and provides oxygen and nutrition.

At Children’s Hospital of Nevada at UMC, NICU staff go the extra mile to make sure parents have plenty of bonding time with babies. “We do everything we can to get babies into their parents’ arms,” says Patricia Ingstad, RN, NICU Nurse at Children’s Hospital of Nevada at UMC. “This takes teamwork; we may need a respiratory therapist and a couple of nurses to make it happen when a baby is on a ventilator, but it’s worth the extra effort to give new parents that overwhelmingly joyful feeling of holding their babies. They can feel their babies, and the babies can feel the love from their parents.”

“Today, Angel is making his own mark on the world. His younger brother and sister, Ivan, 4, and Brianna, 1, look up to him, and he helps take care of them. He plays video games and listens to his grandmother tell stories.”

At school, Angel is also making strides. Fluent in English and Spanish, he attends classes accompanied by a nurse and, according to Ingstad, is performing appropriately for his age. Angel, 6, has been on a very long journey.

“No matter how dark things seem, there is a light at the end,” says Bianca. “I tell other parents, ‘It seems hard, but there is a happy ending. Their babies can turn out to be like my Angel.”

To learn more about our NICU, please visit childrenshospitalofnevada.org and search for “NICU.”
Thank You, NICU Reunion Sponsors!
Reunited with Happy, Healthy Children

In November, we invited NICU alumni and their families to join us for a special event: Children’s Hospital of Nevada at UMC’s NICU Reunion. More than 200 people—former patients and their families along with current and retired clinical staff—attended the reunion on Saturday, November 3, at the Government Center outdoor amphitheater. NICU graduates in attendance ranged in age from 1 month to 16 years old.

This event celebrated our 20-year milestone of providing neonatal services to the community! The reunion was a tremendous success! NICU alumni enjoyed a variety of crafts, playing in a bouncy house, meeting Ronald McDonald and mascots from local sports teams, and, of course, interacting with the current and former NICU physicians and staff who helped them through some of the most difficult days of their lives.

“Several attendees of the Children’s Hospital of Nevada at UMC Neonatal Intensive Care Unit [NICU] Reunion were children I had cared for, and it was amazing to see how well they are doing—some better than we ever expected. The event was perfect validation of the work we do in the NICU.”—Antonette Bell, RN, BSN, Clinical Manager of the NICU at Children’s Hospital of Nevada at UMC

For information about the NICU and other services at Children’s Hospital of Nevada at UMC, visit childrenshospitalofnevada.org.

At the Family Resource Center, There’s a Class for That

Clenched fists. Stomping feet. Exaggerated scowl. These signs tell you your toddler is about to launch into a tantrum. The best thing you can do: Keep your temper in check.

“Stay calm,” advises Antonette Bell, RN, BSN, Clinical Manager of the NICU at Children’s Hospital of Nevada at UMC. “The more you react, the more your child will do the same. Control your anger and frustration. If you tell your child he or she is going to receive time out or another appropriate punishment, be sure to follow through.”

Parents glean many of the lessons of parenthood through experience, but every bit of education—such as the best way to handle a tantrum—and preparation helps. That is why the Children’s Hospital of Nevada at UMC Family Resource Center (FRC) offers a variety of classes for moms and dads, from Baby Basics & Postpartum Care to Boot Camp for New Dads.

After all, parenthood is a journey, and every mom and dad needs a guide from time to time.

To view FRC class listings, visit childrenshospitalofnevada.org and search “Family Resource Center.”
Emilee Rodriguez is full of joy and grace. At 8 years of age, she has undergone seven surgeries and still has more to go. Born with Pfeiffer syndrome, a rare genetic disorder that primarily affects a child's facial skeleton, Emilee and her family are on the road to healing thanks to hope and help from Children's Hospital of Nevada at UMC.

Not a day goes by that Emilee’s mother, Lisa, does not count her blessings—and Emilee is at the top of her list. “We had no idea until Emilee was born there was an issue with her health,” explains Lisa. “We met with a geneticist who explained that Emilee had Pfeiffer syndrome. From that point on, we wanted to be become as educated as we could about raising a child with craniofacial differences and understand how best we could help her.”

According to the International Craniofacial Institute, Pfeiffer syndrome results when the individual bones in a baby’s skull begin to close and suture too early. Sutures allow an infant’s skull to expand as the brain grows. However, in cases of Pfeiffer syndrome, the brain continues to grow despite premature fusion of the sutures, pushing the skull into an abnormal shape. A surgical procedure known as a craniotomy can be performed to remove parts of the skull and relieve pressure on the brain. At only 5 months of age, Emilee had a craniotomy.

**A Delicate Touch**

Because children with complex craniofacial differences require the highest level of surgical expertise for aesthetic and functional correction, the Rodriguez family turned to Children’s Hospital of Nevada at UMC and John Menezes, MD, Head of the Craniofacial Surgery Division of Plastic and Reconstructive Surgery at the University of Nevada School of Medicine, for help.

In July 2012, Emilee had a craniotomy procedure at Children’s Hospital of Nevada at UMC. Following this successful procedure, she returned for mid-face advancement, during which Dr. Menezes worked to improve her facial and corporeal appearance. Despite these complicated surgeries and her lengthy recovery, Emilee is a vibrant student with limitless energy, and she continues to push through her challenges and upcoming surgeries with fierce determination.

“Children are very resilient and often make the best patients. It gives me great joy to know I can make a dramatic difference in their lives,” says Dr. Menezes. “Although Emilee came to me when she was a bit older, she responded to her procedures very well. We’ve performed two successful surgeries, and her recovery has been amazing. She keeps getting stronger by the day.”

For Emilee’s family, her experiences at Children’s Hospital of Nevada at UMC changed her life. The experiences throughout her recovery have been truly inspiring. “Emilee is such a special gift from God. I trust Dr. Menezes with her life. She has given us so much joy, and we hope others will let her share her gift with them,” says Lisa. “She has opened our eyes to the beauty that lives inside us all. Every day she teaches me the meaning of kindness and to love everyone despite our differences.”

Children’s Hospital of Nevada at UMC offers a complete range of specialized health services for children. For more information about these services, visit childrenshospitalofnevada.org/OurCare.
Boot Camp For New Dads
This is a class strictly for new or expectant dads, led by experienced dads and a male pediatrician to give expectant or new dads a chance to talk with other men about being a father. You will learn baby basics and gain confidence.
6–8:30 p.m., February 7

Baby Basics
Join us to learn the ABCs of newborns, from baby behavior, temperament and personality, crying, and calming to growth and development, in addition to tips on caring for yourself after delivery.
6–8 p.m., April 11, April 23

NEW CLASS! Baby Basics II
Would you like more information about preparation for your new baby? If so, this class is for you. This is the second part of our free Baby Basics education series for new parents or parents who need a refresher. We will continue to discuss basic baby care with a focus on sleeping and soothing techniques.
6–8 p.m., January 22

Sibling Class
Introduce brothers- and sisters-to-be to life with a new, tiny family member.
4:30–6 p.m., January 31, April 25

Infant and Child Play Groups
A great opportunity to have fun with your baby while he or she gets to play and socialize with other children. Call for dates and times.