



Parents Supporting Parents of Critically Ill Newborns
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A Publication for NICU Families
www.precious-beginnings.org

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For First-Time Readers

Having a premature or seriously ill baby can be a lonely, frightening experience. What makes it worse is that few of your family and friends understand what you and your baby are experiencing.

Precious Beginnings: Parents Supporting Parents of Critically Ill Newborns is a nonprofit group of families who have parented babies in the neonatal intensive care unit (NICU). We can offer you the support that may be difficult to get elsewhere. We know what you are going through because we have been there. This newsletter is our gift to you. You are in our thoughts and prayers as you are going through this difficult time in your life.

Important Note: *The information in this newsletter is based on the experience of NICU parents. It is not intended to replace the recommendations of medical professionals. Please use this information to strengthen your partnership with your baby's medical team.*

From the Editor

Marie Gettel-Gilmartin

Four years ago, a group of parents who had babies in the Legacy Emanuel NICU formed our own nonprofit organization. We were all members of the NICU's Family Advisory Board (FAB), but we decided that forming a nonprofit support group would allow us more freedom in supporting NICU families. After filing for and receiving our nonprofit status, "Precious Beginnings: Parents Supporting Parents of Critically Ill Newborns" was born. We began hosting pizza nights, producing this newsletter, and providing support on demand to Legacy Emanuel NICU parents.

Since we began Precious Beginnings, we have dreamed about expanding to other hospitals to be able to support

more families. However, our limited numbers of volunteers have kept us from reaching this goal.

Last fall, the head of the Family-Centered Care Committee at Doernbecher Neonatal Care Center (DNCC) at Oregon Health Sciences University expressed interest in bringing Precious Beginnings to their NICU. We were excited at the prospect of being able to reach more parents in the midst of the NICU crisis.

In January, Precious Beginnings representatives met with interested parents from DNCC. We started out with introductions: each parent or family briefly summarized their own NICU story. It was a wonderful, inspiring meeting. We could feel the energy in the room. Get together a room full of NICU parents, and all boundaries just melt away.

We are in the process of figuring out what our new Precious Beginnings organization will look like and how we will support families at two hospitals. We hope that this is just the beginning, and that we can continue to reach more families and spread the concept of family-centered care in hospitals through our support network.

Our focus in the past four years has been to support families who currently have babies in the NICU. However, we would like to expand our focus to provide ongoing support to families after they leave

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the NICU. All of us who volunteer through Precious Beginnings benefit by having an informal support network through our contacts with other NICU families.

When a group of families who have left the NICU gather, it quickly becomes clear that we have much in common. Many of our children have struggles with eating, breathing, illness, and developmental delays. As parents, we continue to experience post-traumatic stress, guilt, and grief that no one else can understand. Irregardless of our baby's (or babies') outcome, we have all experienced some sort of loss—loss of the perfect pregnancy and birth experience, loss of the experience of taking a healthy baby home from the hospital, loss of innocence, loss of faith, and sometimes the tragic loss of a child. Few parents escape the NICU without being touched by death, or the awareness of the very real possibility of death, in some insightful way.

These experiences allow us to create unique bonds with each other. I encourage you to take the time to develop these friendships with other families you meet in the NICU. Call Precious Beginnings to get a parent buddy or to talk to someone about what you are experiencing. Reach out to others who understand what you are going through—it makes a tremendous difference in how you deal with the crisis of having an NICU baby.

The founding president of Precious Beginnings, Doug Fettig, has a favorite quote: "Grief reorders your address book." I think that every NICU parent understands what this means: some people in your life just don't know how to deal with you when you are fearing for your baby's life.

In the 7 years that our family has been involved with the FAB and Precious Beginnings, we have come to know the most wonderful, compassionate, loving people. They have taught us so much about life and friendship. They constantly remind us that we are not alone in our journey of dealing with the profound, life-changing experience of parenting a critically ill newborn. Our son, Christopher, not only gave us his life and courage as his precious gift; he also gave us the opportunity to grow and be enriched by the lives of others on the same journey. I look forward to working with the parents and staff at DNCC and expanding our special circle of friendship, empathy, and understanding.



Marie and Christopher, who was born at 24 weeks at 1 lb., 6 oz., and 11 inches long, and is now a first-grader

Legacy Emanuel NICU Reunion

To celebrate our graduates from Legacy Emanuel NICU, the staff is hosting a reunion luncheon for families and staff to reunite and share stories. The reunion will be held on the same day as the Healthy Kids Fair on Saturday, April 10, from 10 a.m. to 2 p.m., in Conference Rooms 1075 and 1077 at Emanuel Children's Hospital. The Healthy Kids Fair has many fun activities for children, including Easter egg hunts and photos with the Easter Bunny.

Precious Beginnings will be helping to create buttons with your child's picture on it so don't forget to bring a photo to the reunion. Please call 503/413-2699 to RSVP. Lunch provided by Pizza Schmizza Catering and dessert by Jana's Classics.

Want a Parent Buddy?

Marie Gettel-Gilmartin

When my son was in the NICU, the hospital did not have any kind of parent support program. Our baby was the tiniest and sickest in the whole unit, and we felt that no one there could truly understand the anguish and terror we were experiencing.

Through the wisdom and compassion of some wonderful nurses, we were given the phone number of another family who had a very small preemie. We didn't have any extra energy to call them, but fortunately they were in the hospital one day and stopped by.

I will never forget the experience of meeting with them in the atrium and observing their daughter (one year old at the time) playing and chewing on a cup. It was an indescribable feeling of relief to be able to talk to others who really understood how we were feeling.

Fortunately we now have a formal parent support program. These volunteers have parented babies in the NICU and have been through volunteer training.

Call Precious Beginnings at 503-244-3350 or e-mail p_beginnings@yahoo.com and we will attempt to match you up with a parent whose baby had a similar experience as yours. All of the Precious Beginnings volunteers have found the support of other parents invaluable in managing the roller coaster period of having a premature or sick baby.

Parent Pizza Night in the Legacy Emanuel NICU Parent Resource Room

Every second and fourth Monday from 7 to 8 p.m.
All parents welcome!



Take the opportunity to connect with other NICU families and graduate NICU parents while eating pizza. If you aren't up for socializing, but need a little energy boost, feel free to stop in and pick up a slice of pizza to take with you. **Mark your calendars!**

Upcoming pizza nights: April 12 & 26; May 10 & 24

Questions? Call us at (503) 244-3350.

*Pizza generously donated by Pizza Schmizza at 1036 NW Glisan. Their phone number is 503/546-8162, and their web site address is www.schmizza.com.

Stay tuned for more information about pizza nights starting up at DNCC in the next few months.

Preemie and Newborn Clothing Needed

Kristi Hawkins

We need your help! The Legacy Emanuel NICU is in need of donated



new or used (and in good condition) preemie and infant clothes. If you would like to donate clothes, please call the Precious Beginnings hotline at 503/244-3350 or drop them off at the NICU. Thank you!

Graduate Story

In this column, we feature stories of NICU graduates. It is important to remember that each baby's experience is unique: these babies' experiences and early childhood will probably be different from your baby's course.

Would you be willing to share your child's story? Please e-mail it to organic_mama@yahoo.com or call 503/244-3350.

Sarah Howerton's Story

By Andrea Martin

This is Sarah Brianne Howerton's miraculous story of bravery and hope.

I tried for three years to get pregnant, so when I finally did in August 1998, I was ecstatic. However, my hopes were immediately dashed when at 6 weeks I lost what we thought was the baby. My doctor performed an ultrasound and determined that I was still pregnant. The remaining baby was a surviving twin. As sad as I was, I was happy I was still pregnant and figured the loss was to make sure this baby was healthy.

I was wrong about that too. At 16 weeks I had another ultrasound and my main concern at that point was the sex of the baby; I wanted a girl. I now realize how unimportant the sex of the baby was; I found that out the hard way! We discovered my baby girl had congenital diaphragmatic hernia (CDH) and the doctors gave her about a 20% chance of survival and recommended that I terminate the pregnancy. I couldn't do that. She at least had a 20% chance of living, but if I aborted, she would have none.

I went to the University of California-San Francisco to investigate in utero surgery. This was the hardest time of the pregnancy. I felt like I held my unborn baby's life in my hands. I didn't want to do the surgery. I felt like a guinea pig: there had not been enough of these types of surgeries yet and I didn't want them practicing on my child. But on the other hand, what if she died without it? It was painstaking to make this decision, but ultimately I decided against it.

The next 5 months were awful. I cried every day and thought my baby was going to die. I didn't have any baby showers and only barely prepared the nursery, and that

was just to give me some solace. I sat in the rocking chair and tried to imagine having my baby there with me.

The pregnancy went smoothly with no other problems. I had an amnio, which showed that the baby was otherwise normal. The bimonthly ultrasounds showed little or no changes. I had supportive doctors, friends, and family, and several churches were praying for us. I believe that these prayers, combined with Sarah's strength and will to live, saved her life.

Sarah was born on May 11, 1999. I was induced at 39 weeks and she was immediately rushed to the other room to be resuscitated and stabilized. The rest is a blur. I don't remember most of the medical and technical stuff; I think I blocked that part out.



Sarah in the NICU

She had surgery at 2 days old and then was placed on ECMO for the next 4 days. She did really well throughout all of this. She even began breastfeeding at 4 weeks old. This is also when I got to hold her for the first time... what an amazing feeling!

The rest of the hospital stay was fairly uneventful. The doctors were amazed; they had given her such bleak odds, but she was defying them all and surpassing what they thought was possible for a baby born with CDH.

Finally at 6 weeks, Sarah came home. Then a whole new roller coaster ride began. She had blood in her stool the first week she was home and her pediatrician advised me to stop breastfeeding. She cried nonstop for the next 10 months; it was awful. Sarah was diagnosed with reflux and put on medications, but that didn't help.

Finally at 10 months old, after being sick with vomiting that her pediatrician thought was the flu, we realized she had reherniated. It was decided that this had probably happened almost immediately after leaving the hospital, and that's why she never stopped crying--she was in pain.

After the repair surgery, I had a whole new baby. Sarah finally began to meet her milestones. She walked late, at 16 months, and then we realized we had a whole new issue. While she was in the NICU, she had been on ECMO and had apparently had a stroke. She couldn't walk right and held her left arm funny. She now wears an orthotic on her left foot. During the time of the second surgery, she was also diagnosed with scoliosis.

Now she has asthma and some lung issues; scoliosis that will probably require a brace; hearing loss that needs to be monitored every six months; and mild cerebral palsy that affects her left side, primarily her leg and foot. She also has some behavioral issues stemming from the fact she was catered to and spoiled for so much of her life! Now that life is easier, it's hard to treat her like a normal child. But slowly, she is becoming one. Thank God for that and for her surviving CDH. Sarah is a beautiful, outgoing, loving child who is the light of my life.



Sarah now

Precious Beginnings News

Marie Gettel-Gilmartin

Strategic Planning and Expansion: In April we are planning to conduct some strategic planning to determine the best way to expand our organization to DNCC and possibly beyond.

New Volunteer Orientation: On May 16, we will conduct a new volunteer orientation, which will include

parents from DNCC as well as Emanuel. Please contact us by e-mail or phone if you are interested in attending this orientation.

Nursing Mothers Program: Precious Beginnings is in the planning stages of developing a program to support nursing mothers. We are working with the Nursing Mothers Council and the lactation departments at both Emanuel and DNCC to develop this program. For more information, please call Precious Beginnings at the number listed above.

Emanuel NICU Reunion: We will have a table at the upcoming NICU reunion (held at the same time as the Emanuel Healthy Kids Fair, on April 10), and we will be helping parents to create buttons with their children's photos on them.

March of Dimes WalkAmerica: We will have a team walking in the March of Dimes WalkAmerica to raise money for healthy babies. See page 6 for more information. Come join us on our walk to save babies!

Publicity: Last fall Precious Beginnings received a lot of great publicity. We were profiled in the October issue of the *Portland Parent*, and a brief article about Precious Beginnings was published in the *Oregonian* op-ed pages, following the extensive story about Legacy Emanuel nursing staff.

If you have any questions about Precious Beginnings, call our phone line at 503/244-3350.

Would you like to work as a Precious Beginnings volunteer or learn more about our activities? Please call us at 503/244-3350, check out our web site at www.precious-beginnings.org, or e-mail p-beginnings@yahoo.com.

Precious Beginnings' Own Nick Hawkins Is March of Dimes 2004 Oregon Ambassador

From marchofdimes.com web site

Nick is the son of Kristi Hawkins (Precious Beginnings board member and treasurer) and her husband Doug. Now four years old, Nick is a happy, healthy and active little boy who loves to sing, color, and play in the dirt. To meet Nick today, you might never know that he was born more than 8 weeks early, weighing only 1 pound, 15 ounces, and spent his first 6 weeks struggling for life in the NICU.

Nick's miraculous survival is testament to his outstanding doctors and pioneering technology and treatments made possible by the March of Dimes.

"The mission of the March of Dimes started affecting our family long before we ever knew it," says Doug. "Who would have guessed that as kids walking in WalkAmerica in the 1970s, Kristi and I were helping to raise funds for research and development of the very programs that saved our son nearly 30 years later."

Nick, like more than 4,000 babies born in Oregon and southwest Washington each year, was born too soon. Because premature birth is a growing problem in our area and throughout the country, the March of Dimes recently launched a 5-year, \$75 million national Prematurity Campaign. March of Dimes efforts will focus on scientific research and education programs to help understand and prevent this serious problem.

Kristi began preparing for a healthy baby even before she became pregnant by taking a daily vitamin containing folic acid and leading a healthy lifestyle. Kristi also received early prenatal care and her pregnancy progressed normally until her 30th week.

In February 2000, Kristi was diagnosed with preeclampsia, a potentially dangerous disorder characterized by increased blood pressure, which can constrict the blood vessels that supply oxygen and nutrients to the baby. Kristi's doctor put her on bedrest to try to stretch the pregnancy to the 35th week. Doug and Kristi began to prepare for an early arrival.

At a checkup less than one week later, all signs were positive. Nick's fetal movement counts and vital signs were within acceptable ranges and Kristi's blood pressure was lower.

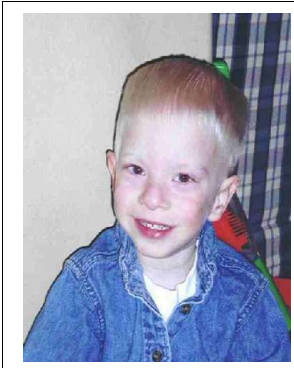
But later that night, Kristi's condition worsened. She was admitted to the hospital the next day and began having minor contractions. With every contraction, Nick's heart rate dropped. Kristi and Doug were rushed to Emanuel so Nick could be immediately sent to the NICU after birth.



Nick was delivered at 8:10 p.m. on February 18 by cesarean section. Because his tiny lungs were not fully developed, Nick struggled to breathe. He was placed on a ventilator and received surfactant to keep the tiny air sacs in his lungs from

collapsing. Nick also suffered from frightening bouts of apnea when he would forget to breathe for 20 seconds or more.

Over the next few days, Nick experienced both jaundice and anemia and received photo therapy treatments as well as vitamin supplements to help boost his red blood cell counts. Tests also revealed that he had experienced minor intraventricular hemorrhages, but they appeared to self-resolve and no treatment was necessary.



After six weeks in the NICU, Nick was allowed to come home. He weighed just 3 pounds, 7 ounces—too small for a regular infant car seat, so his parents got a car bed for Nick's first ride home. Since his discharge, Nick has gone through developmental sessions,

feeding clinics, and several operations and exams.

Thanks to the March of Dimes' advances in the areas of prenatal care, surfactant therapy and neonatal technology, Nick is alive today. At age four, he has a clean bill of health and the quality of life all parents wish for their children. Soon a baby brother will join him!

Join the March of Dimes WalkAmerica Precious Beginnings Team!



Although the rate of premature births has been rising in the past several years (the annual rate of premature births has risen nationally by 27%), no one knows why half of these premature births occur. The March of Dimes is committed to improving treatment for premature babies in neonatal intensive care units and preventing premature births from occurring in the first place.

You have an immediate opportunity to help the March of Dimes in its campaign to help prevent prematurity and to improve the treatment provided to premies. **Join Oregon March of Dimes ambassador Nick Hawkins and his family, along with families from DNCC and Emanuel, at this year's March of Dimes**

WalkAmerica. We are assembling a Precious Beginnings team of families and children who have graduated from Emanuel's NICU and DNCC, and we would also highly welcome any staff who would like to participate. **If you are interested in walking on our team, please call the Precious Beginnings hotline at 503/244-3350 or e-mail us at p_beginnings@yahoo.com, and we'll tell you how to register.**

WalkAmerica in Portland is set for Saturday, April 24, beginning in the Rose Garden commons (that's the Rose Garden Arena, not the Washington Park Rose Gardens). Registration starts at 8:00 a.m. Parking is provided for walkers. You can choose from two routes:

3K WonderWalk: A 1-1/2-mile route for the young and young-at-heart (strollers, young families, and grandparents) starts at 9:15 a.m. At the WonderWalk check point in Holladay Park, Kindercare will have a hands-on activity booth for youngsters to enjoy throughout the morning. Look for the fire truck too!

10K Walk: The 6-mile walk starts at 9 a.m., for you hearty souls!

Here are some other details about the morning's festivities:

- **Check Point Merriment:** At six check points along the route, walkers will be given water and other goodies and cheered on their way. Walkers will be asked to vote for their favorite check point as they return to the finish line.
- **Too Pooped to Pop?** A "poop-out" van will be provided for people who feel unable to make the whole journey. They will be happy to stop and pick up passengers.
- **Lunch and Entertainment:** The "lunch stop" will be at the finish line on the Rose Quarter Commons. More than 20 vendors will be dispensing their goodies. "Five Guys Named Moe" will supply music, and there will be balloons and fun.

The March of Dimes is a national nonprofit organization whose mission is to improve the health of babies by preventing birth defects and infant mortality. For more

information, visit the March of Dimes web site at www.marchofdimes.com.

Thanks to Nancy Adams, Metro Director of the March of Dimes, for some of this information.

Music in the NICU

Karen Kurzawa, M.S., Director, Music Rx
Children's Cancer Association



Did you know that music is provided in both DNCC and Emanuel's NICU on a regular basis?

This is a FREE service provided to families by the Children's Cancer Association. A board-certified music therapist comes to DNCC every Monday and Wednesday from 4 to 5 p.m. and Emanuel NICU every Tuesday from 2 to 3 p.m.

Studies have determined the following benefits of music in the NICU:

- Provides a safe noninvasive interaction and positive sensory stimulation
- Can contribute to decreased hospital stay, decreased agitation, increased oxygen levels, increased intimacy with parents, and increased weight gain
- Can be adapted to meet individual needs
- Supports parent-infant or sibling-infant bonding

The music therapist interacts with infants via an invitation by the parent or staff only and uses simply her voice within certain parameters of pitch and volume. She is highly attuned to infant response and can offer parents, guardians, or siblings ideas and tools for bonding with their baby using voice. Customized interactions and personalized CDs are available, too.

The Music Rx Program also provides live instrumental music in the DNCC—a harpist whose music creates a peaceful environment.

The Children's Cancer Association is committed to supporting hospitalized children and families in our community, regardless of diagnosis.

For more information about the Children's Cancer Association, check out their web site at www.ChildrensCancerAssociation.org. For information about the Music Rx Program, you can call Karen Kurzawa, Director, at 503-244-3141, Ext. 118, or e-mail her at kkurzawa@cca.org.

Baby Equipment Exchange

Do you have a car seat, crib, or other baby equipment your baby has outgrown? **(Items need to be in good shape, and car seats should not have been in an accident.)** Would you be interested in donating it to another family? If so, please e-mail your item and phone number or e-mail to Precious Beginnings at p_beginnings@yahoo.com or call us at (503) 244-3350. We'll put it in the Baby Equipment Exchange corner. If another family is interested, they can contact you directly.

Happy Birthday NICU Grads!

Garret Woehl turns 5 on April 7.

Madison Gray turns 4 on April 23.

Alex and Blake Gohde turn 3 on May 26.

If you would like to see your child mentioned in this column, please e-mail us at p_beginnings@yahoo.com.



In Memory of

- **Quinn Groen Mitchell**, February 2, 2001- March 7, 2001.
- **Sadie Gray**, April 7-22, 1999.



Partnering with Families in Legacy Emanuel's NICU

Marie Gettel-Gilmartin and Kristin Lutz

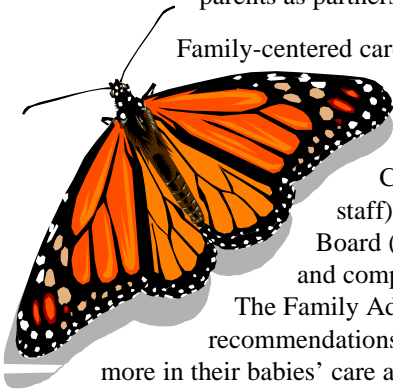
This article was solicited for and published in the 2003 Legacy Emanuel Children's Hospital newsletter, which is distributed to care providers.

During Emanuel NICU's shift change two evenings a month, "graduate" parents invite NICU families to share stories over pizza and lemonade. Having an NICU baby is terrifying, and talking to others who have survived the experience can bring indescribable relief and comfort.

"Precious Beginnings: Parents Supporting Parents of Critically Ill Newborns," a nonprofit organization founded by parents who had children in Legacy Emanuel's NICU, has been hosting pizza nights in the

NICU for four years, with pizza generously donated by Pizza Schmizza. Pizza night is one of Precious Beginnings' most successful programs, and many of the organization's volunteers choose to give back to other families because of the peer support they received at pizza nights or through some other avenue.

Precious Beginnings volunteers are welcomed in the NICU as partners with the staff. Their success in working closely with staff results from NICU management and staff's commitment to family-centered care and involving parents as partners.



Family-centered care took off in the NICU seven years ago with the formation of a Family-Centered Care Committee (made up of staff) and a Family Advisory Board (led by a nurse supervisor and composed of graduate parents).

The Family Advisory Board made recommendations toward involving parents more in their babies' care and creating a family-centered environment. Since that time, the two groups have been combined. Parents regularly share their stories at nurse orientations, skills days, and operating committee meetings.

Out of these discussions, a new idea took flight: the formation of a nonprofit family support group. In early 2000, Precious Beginnings was born. With a hotline, a web page, a newsletter, and other programs, veteran NICU parents offer support to families in crisis and are trained as hospital volunteers so that they can work in the unit. Many of our volunteers have lost children; they give back to the NICU because it was the only home their children knew.

The NICU has come a long way in its journey toward family-centered care since our tiny babies fought for their lives. Precious Beginnings is able to offer a unique form of support to parents in crisis because of our close partnership with NICU staff. This partnership would not be possible without the support and advocacy of nurse manager Jamie Rupp; medical director Pat Lewallen; former nurse manager Karen Waske; nurse supervisor Deborah Ross; and all of the awe-inspiring NICU staff who have given Precious Beginnings volunteers a warm welcome and who have encouraged parents to seek out our support.

Marie Gettel-Gilmartin (mom of 24-weeker Christopher) and Kristin Lutz (mom to 31-weeker surviving twin Aimee

and her sister Olivia) are co-presidents of Precious Beginnings.

Update: We look forward to partnering with DNCC graduate parents and staff Linda Wallen (medical director), Jan Marty (nursing director), Sandy Snider (head of the Family-Centered Care Committee), Marcia Johnson (unit social worker), and Soledad Iniquez (lactation specialist) in bringing Precious Beginnings to DNCC.

howyourbaby.com

Jamie Rupp, R.N., Legacy Emanuel NICU Nurse Manager

howyourbaby.com is a web-based, parent-reported outcome survey for parents of babies being discharged from the NICU. The NICU staff and leadership use the data to gain an understanding of how well we are meeting the needs of parents, as well as guiding us in improving our practices to support and partner with families.

Every family is encouraged to complete the survey before discharge. Please check with your baby's nurse or any care provider. They can help you use the computer near the Level 2 entrance to log on to the survey site. The survey is easy to use and all information is confidential. After completing the survey, you will receive a summary of areas about which you would like more information. This can be used as a reference for asking questions of NICU staff or your pediatrician after discharge.

Thanks in advance for giving the NICU your confidential and anonymous feedback by completing the howyourbaby.com survey.

DNCC Parents: Stay tuned for more information coming soon about the howyourbaby.com program starting at DNCC.

The First International Conference for Family-Centered Care

Kristin Lutz, Ph.D., R.N., Precious Beginnings Copresident

In September 2003, Deborah Ross, Emanuel NICU Nursing Supervisor and staff liaison to Precious Beginnings, and I attended the 1st International Conference for Family-Centered Care, sponsored by the Institute for Family-Centered Care. More than 640 participants from all over the world came together to

share their experiences, programs, and research on family-centered care.

I gave a presentation explaining the planning, programming, and volunteer training for Precious Beginnings. Precious Beginnings grew out of the NICU Family Advisory Board at Emanuel and was established by families with the support of NICU staff, as a separate, nonprofit organization in 2000. Precious Beginnings has around 30 active volunteers, but we are always looking for new volunteers! We have a board that is made up of 7 parents and an NICU staff liaison. We offer programming in five different areas: communications, support, hospitality, fundraising, and administration. Anyone interested in volunteering with Precious Beginnings must attend and successfully complete the volunteer orientation.

We will be holding another volunteer orientation on May 16. If you are interested in joining us, please call the Precious Beginnings hotline (503/244-3350) and provide your name, address, phone number, and e-mail address (if you have one).

Some of the highlights of the conference were an informative and inspiring multimedia presentation by Bev Johnson, RN, and Bill Schwab, MD, which provided a historical review of the advances in family-centered care in legislation, innovative programs, and publications. Two other presentations were also relevant to NICU parents. In the first, Frida Ardal, MSW, spoke about the parent buddy program offered to families at the Mount Sinai Hospital NICU in Toronto, ON. They conducted research on the effects of the program on parents and found that parents with buddies experienced less parental stress in the NICU, reported less depression and anxiety at 4 months, and perceived their social support to be greater. Nearly all (96%) of the parents in the program rated the program as very helpful or helpful.

Although Precious Beginnings doesn't offer a formal "buddy" program, NICU parent volunteers offer peer support for NICU families at Emanuel. Over the next several months, we will begin offering that support at DNCC, as well. Any current NICU families are welcome to call the Precious Beginnings hotline to request contact and support from a current Precious Beginnings volunteer.

In another presentation, Bobby Phillips, MD, from the Boston Medical Center, reviewed the health benefits of breastfeeding preemies. For breastfed preemies less than 30 weeks gestation, there is a 6 to 10 times lower risk of

NEC and for preemies 30 to 37 weeks gestation, the risk of NEC is 10 to 20 times lower. In addition, breastfed preterm babies have enhanced retinal acuity and enhanced brain stem maturation. Along with the NICU and lactation staff at Emanuel and DNCC, Precious Beginnings has been invited to partner with Nursing Mothers Council to offer support for nursing moms in the NICU. We are excited about this collaborative opportunity and look forward to being able to offer nursing moms another avenue for support in the future.

Many of the presentations were collaborations between health professionals and parents, highlighting the important partnership between NICU professionals and families. The conference also offered specialty sessions on family-centered care in various health care settings and presented many networking opportunities. The next conference will be held in San Francisco on February 21 to 23, 2005. Further information regarding the next conference is available through the Institute for Family-Centered Care (www.familycenteredcare.org).

Precious Beginnings Is Online!

Marie Gettel-Gilmartin

You can have access to back issue newsletter articles, upcoming events, volunteer opportunities, and lots of resources for NICU parents. You can stay in touch with Precious Beginnings by signing up on our mailing list via the web site. Here's a glimpse of what you'll find on www.precious-beginnings.org.

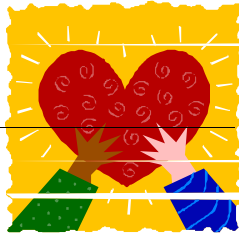
- Background of our organization
- How to contact us
- A description of some of our current programs
- Newsletter articles, including valuable info for NICU families
- Miracle stories and photos of our babies
- Resources for NICU families
- Donation opportunities

If you have any comments or suggestions for other helpful features on the website, please e-mail us at: p_beginnings@yahoo.com (the e-mail on the web site is not working).

Thanks to *Convergence Northwest, Inc.* (owned by Emanuel NICU grad parents Eric and Haika Gray), for hosting the site!

Thank you, 2004 donors and friends of Precious Beginnings!

- ◆ Ashleigh's Fund
- ◆ Convergence Northwest, Inc. (web site)
- ◆ Graphic designer Roy DeLeon (logo design)
- ◆ IKON Office Solutions (newsletter printing)
- ◆ Marni and Jim Reinmuth Oregon Photo (regular checks from store collections)
- ◆ Pizza Schmizza (pizza donations)



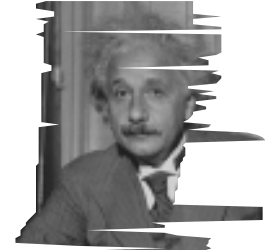
Precious Beginnings Wish List

- Color laser printer photo-quality paper
- Disposable cameras
- Travel toiletries for families: shampoo, soap, toothpaste, and toothbrushes
- Premie and infant clothes

- Your time—let us know if you'd like to volunteer!
- Of course, tax-deductible financial donations are always welcome!

Just for Fun: Famous Premies

Jean Jacques Rousseau
Sir Isaac Newton
John Keats
Charles Darwin
Charles Wesley
Victor Hugo
Napoleon Bonaparte
Daniel Webster
Voltaire
Mark Twain/Samuel Clemens
Anna Pavlova
Pierre Renoir
Winston Churchill
Albert Einstein



--From Helen Harrison's "Premature Baby Book"

Precious Beginnings Newsletter

Produced by Precious Beginnings: Parents Supporting Parents of Critically Ill Newborns
P.O. Box 19508

Portland, Oregon 97280-0508

TEL: 503/244-3350

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IKON
Office Solutions

Many thanks to IKON Office Solutions, which generously donated the printing of this newsletter!!

Parent and Family Survey

We would like to hear from you! Please take a few moments to fill out this sheet. You can mail it to us at the address listed below, or you can give it to the unit secretaries to put in our mailbox. This information will remain confidential. We will also add you to our newsletter mailing list unless you indicate otherwise. Thank you for your time and feedback!

FAMILY INFORMATION:

Baby's Name: _____ Birth Date: _____

Gestation at birth: _____ Diagnosis: _____

Parent Name(s): _____

Address: _____
Street City, State Zip Code

Phone: (____) _____ E-mail: _____

NEWSLETTER FEEDBACK: (please feel free to write more on the back of this sheet)

What did you like/dislike most?

What would you like to see in a future issue?

Would you be willing to write an article about your NICU experience? YES NO

PRECIOUS BEGINNING OPPORTUNITIES:

Precious Beginnings provides support to NICU parents and families in a variety of ways. We always welcome new volunteers and new ideas, as well as donations.

Would you like to receive more information about becoming a volunteer? YES NO

I am interested in: (please circle as many as apply)

Parent Support Pizza Night Fundraising Newsletter/Website
Hospitality (Gifts/Crafts) PR/Grant Writing Other _____

Do you have other suggestions of how we can provide support to parents/families in the NICU?

If you would like to make a donation to Precious Beginnings (either cash or items), please contact us at (503) 244-3350, E-mail organic_mama@yahoo.com or P.O. Box 19508, Portland, OR 97280-0508.
