

Preemies Today



Families Helping Families

PREEMIE OF THE MONTH:

Our March Premie is Jack Gillespie. Despite his dramatic entrance into this world, he is now a thriving 4 year and big brother to Finn, 2. Jack's story is told by his mom, Kelley.

"You would never guess!" is what most people say when they meet Jack for the first time. That's a wonderful exclamation to hear after people learn about his very rocky beginning.

After several years of trying and many fertility procedures, John and I finally became pregnant with Jack in late 2000. It was a perfect pregnancy until we heard these terrifying words from the technician at our 21-week routine sonogram, "Uh oh". My cervix was two centimeters dilated and the baby was in grave danger of immediate miscarriage. I was rushed to triage at INOVA Fairfax Hospital and placed on inverted bed rest in the High Risk Perinatal Ward in early March, 2001.

We settled into a routine and fully expected to deliver a healthy baby, months away in July. With expert care, a Cerclage and a barrage of serious drugs, we managed to keep the constant and increasingly strong contractions under control for almost three weeks. Even though the nurses and doctors provided warnings and talked about risks and choices, around-the-clock monitoring lulled us into a rhythm. The day Jack reached 24-weeks gestation, we celebrated the milestone with a steroid shot to help his lungs develop.

But over the next two days, the contractions intensified. After 20 hours of excruciating labor, magnesium IV drips and more drugs, the doctors prepped me for surgery. The NICU was notified and a team of about 15

doctors and nurses brought Jack into the world via C-section on March 20. His Apgar score was 1, and then 3. I couldn't watch him being worked on, couldn't even bring myself to visit him the first day.

I can't say if it was shock or mourning that made it seem like an out-of-body experience, but that first trip in the wheelchair down to the NICU was the longest journey I had ever taken. The NICU can be over-



Jack on his way to being the next male supermodel!

whelming to anyone, the sounds of monitors ringing out, the shadows cast by the jaundice lights shining over the isolettes, the smells of antiseptic soap. But there's nothing like the sight of your tiny 1-pound infant hooked up to an oscillator with hair-thin wires probing every limb.

Jack spent the first week on the oscillator, and was then moved to CPAP. We allowed ourselves to celebrate a tiny bit. But, in grand premie fashion, his intestines promptly stopped processing food, his heart began to murmur and he contracted infections. He had a PDAscare that was correct-

ed with drugs. His eyes were still fused, he dropped to about one pound in weight and we realized fully what we would be facing for the next three months. His lungs collapsed and we experienced stomach-tightening panic each time his O2 sats dropped and he had to be bagged. Jack battled several more infections, had some setbacks but generally gained weight and made progress.

One day after my return to work full-time, we received a call from the doctors at 7 am asking us to rush in. Jack was very ill, and had turned ashen gray. This infection had settled into his intestines causing a distended belly and red streaks. He went back on the ventilator once again and we watched him slip each day. The worst part was the daily shift change forcing us to leave for a few hours. Jack received increasingly strong antibiotic cocktails as drugs were ruled ineffective.

After six days of constant strain, Jack's infection gradually was controlled and he began to recover. However, he was diagnosed with severe necrotizing enterocolitis (NEC) and needed surgery to remove more than half his colon. Ultimately, his eyes suffered as well, and both were operated on for retinopathy of prematurity (ROP).

We sustained ourselves throughout the ordeal by deciding that we would be Jack's strongest advocates. We believed so desperately that he would survive and we enrolled everyone around us in that possibility. Of course there were more bad days than good and we always faced that fear of losing him (we still do!), but that strength poured out every day from my hand to whatever part of his body I could reach through tape and IV lines or was allowed to touch after surgery.

Any parent who has struggled to feed their child knows what a frustrating and emotionally draining task this can be. Children who are born prematurely often have many issues that may cause difficulties with eating. Some of these include: respiratory and cardiac conditions, high or low muscle tone, uncoordinated movements, atypical reflexes and an immature or unregulated sensory system.

Many premature infants have difficulty with sucking and swallowing when they are born. They are unable to control their suck-swallow-breathe pattern, and they are at risk for aspiration. These children may not be able to swallow or control their oral motor structures. A routine that focuses on non-nutritive sucking and desensitizes oral hypersensitivities is the first step for many.

Some premature infants may have low muscle tone or muscle weakness, making it difficult for them to hold a nipple in their mouth and suck for an adequate amount of time without fatiguing. For these babies, changing the nipple or bottle is one approach which can be beneficial. Using a smaller nipple that requires less pressure or a specialized bottle, which can speed up or slow down the flow of liquid, can work

well. A structured oral motor routine may also be used to facilitate coordination, increase strength, and decrease oral hypersensitivities and hyposensitivities.

Premature infants who aspirate on food and liquid or who are unable to eat an adequate amount may be given a G-tube in order to meet their nutritional needs. When health professionals have determined that it is safe to take food by mouth, many families attempt to wean their child from a feeding tube. Children that have been fed by a feeding tube often have a poor hunger drive and oral motor hypersensitivities. Oral stimulation that is well tolerated during a tube feeding can assist children with the association between satiation and oral feedings.

Positioning and environment are also important factors during feeding. The child should look well supported and comfortable whether they are an infant or a toddler. If eating produces anxiety for a child, try to make meal times more fun and relaxing. Listen to their favorite music or watch a video; eat from a spoon shaped like a train or scoop from a bowl that moo's like a cow. Most importantly remain calm and set realistic goals for each meal; children are

very perceptive and easily pick up on adults frustration and anxiety.

Some infants become over stimulated during feeding. Sitting in a rocking chair, tapping their leg and listening to rhythmic music can help children to better pace their sucking or chewing. Swaddling them in a blanket may provide input to their sensory system, which can help them to regulate their nervous system and focus on eating. Warming up their mouth with exercises and rubbing their cheeks and tongue can help to stimulate the nerves and muscles around the mouth, either 'waking them up' or reducing sensitivities.

Feeding difficulties can be very frustrating for children and their families. Collaborating with professionals and development of a program with a structured and holistic approach is essential. Feeding is a complicated task with structural, neurological, sensory and social components, which must all be addressed.

This month's focus article was written by Lorna Sher, OTR/L. Ms. Sher is an occupational therapist with Therapy 4 Kids working in the early intervention program.

Continued from cover, Jack's Story

The most terrifying day was the one when he came home nearly 3 months after his birth. No more round-the-clock nursing support! No more daily x-rays and brain sonograms! Just Jack and Mom and Dad on a new journey.

That journey continues today, four years later. We have learned a whole new set of guidelines for early intervention, and focus now on his social, emotional and neurological development. He has slight problems still with gross and fine motor control, but is intelligent and thoughtful. He loves puzzles, a good joke and reading loads of books every day. Jack attends two preschools and we have regular appoints with therapists to monitor his progress and to train us to look for signs of delay. He'll always be our Miraculous Jack, and we will always choke up on his birthdays.

I volunteer now at the NICU as a Cuddler, holding babies very much like Jack. It took me almost three years to gather the strength to walk down the long hall again into the sounds and smells of the NICU, but I am trying to help the parents like us who are facing their child's illness. It's one way to thank the many nurses, doctors and healthcare professionals who believed in Jack and contributed to who he is today.

Meet your Premies Today Board

There are many people who contribute to the success of Premies Today. Every so often we will be featuring some of these hard working volunteers in the newsletter. This month we introduce a few of our dedicated board members.

Mary Beth Hazelgrove, Vice President

As a former Peace Corps volunteer, Mary Beth has vast experience in grass roots organizing. She is also an elementary school teacher and mom to Madison, born at 26 weeks, and Alexandra, born full term.

Mary Ludregan, Membership Coordinator

Mary is a busy mom with Will, a 33 weeker, and Connor a full term. Will is now four and an ambassador for the National Capitol Area March of Dimes. Mary also works for a healthcare consulting firm in Old Town Alexandria.

Deborah Discenza

Deborah's daughter, Becky, was born at 30 weeks and is now a happy and healthy one-year old. In honor of her daughter, Deborah is starting "Premie Magazine" as a resource for other parents of premature infants.

Local News:

Preemies Today's Second Annual Celebration and Silent Auction:

Preemies Today is about to celebrate our second anniversary. Kathy Paz, our founder and president, published the first edition of the Preemies Today newsletter in March of 2003. This year's celebration will take place at the Sully Governmental Center in Chantilly, Virginia on **March 20 from 4pm-7pm**. We would love to have all of our Preemies Today families come and celebrate with us. Please email us at preemiestoday@yahoo.com if you wish to attend.

We would like to thank the Cooley Godward LLP for helping sponsor the event. We would also like to thank Whole Foods, Einstein bagels, Outback Steakhouse, The Kennedy Center, Trader Joes, My Gym, Signing Time, DC United, Buy Buy Baby, The Great American Restaurants, Elite Pressure Washing, Toys R Us, Table to Table, Simply Create, South Moon Under, Zaidee Coco, Silverbrook Nursery, Caribou Coffee and Costco for donating silent auction and/or food items.

Walk America 2005:

Walk America is the March of Dimes annual fund-raiser. Please join us in helping the March of Dimes to continue its mission to save the lives of babies through research, education, community service, and advocacy.

Locations and Dates:

Fredericksburg	4/23/05	Old Mill Park
Manassas	4/17/05	Loy Harris Pavilion
Reston	5/1/05	Lake Fairfax Park
Springfield	4/17/05	Lake Accotink Park
Washington DC	5/1/05	Constitution Gardens

Join the Preemies Today team by contacting us at preemiestoday@yahoo.com. Last year, Preemies Today raised over \$7000 for the 2004 Walk America Campaign.

Support Resources:

"A Friend to Talk to"

Our "Friend to Talk to" support line is up and running. Please feel free to give us a call and one of our preemie parent volunteers can offer you some much needed support. The support line telephone number is 703-994-6624.

NICU Support Group

INOVAHealthsource is continuing to offer a NICU Support group for current INOVA Fairfax NICU families. The meetings are held on the unit and vary month to month. The group is led by Lynn Kuba, RN and is a great opportunity to talk about your experience in the NICU. For more information contact INOVAHealthsource at 703-204-3366.

Maryland Families Unite!

Maryland families, your Preemies Today coordinator is looking for you. We are beginning to organize events and meetings in Maryland. Please contact Susan for more details at 301-977-3230 or email her at zambusch@hotmail.com.

Preemies Today Online Chat

Join us every 1st and 3rd Thursday of every month at 8:30 pm for an online chat. For more information contact Julie at jkipers@lmi.org.

Local Support Groups

Local support groups are going strong! On the 2nd and 4th Wednesdays at 7:30 pm we hold our local support group meetings. For more information contact us at preemiestoday@yahoo.com

Preemies Today Playgroups

Preemies Today continues to offer monthly playgroups. Monthly playgroups offer our children a stress-free environment to play. Playgroups typically meet in a member's home or in a location of the group's choice. For more information contact Deborah at Deborah_Leaf@yahoo.com

Helpful Resources:

The following are some helpful resources available by phone and online:

Prince William County Social Services:

www.co.prince-william.va.us/csb/program-sandservices/

Fairfax County Department of Family Services:

(703) 324-7500

www.co.fairfax.va.us/services/dfs/

Social Security Administration:

1-800-772-1213

www.ssa.org

SIDS Mid-Atlantic

(703) 933-9100

www.sidsma.org

March of Dimes

1-800-326-BABY

(703) 425-BABY (Metro DC)

www.marchofdimes.com

Sidelines National Support

1-888-447-4754

www.sidelines.org

Early Intervention/ Infant Toddler Connection

Fairfax County- (703) 246-7121

Alexandria- (703) 838-5060

Prince William- (703) 792-7879

Calvert County- (410) 535-1955

WIC

Manassas- (703) 792-4703

Woodbridge- (703) 792-7319

Springfield (703) 569-1031

Mount Vernon (703) 660-7100

Fairfax- (703) 246-7100

For a list of online resources please go to:

www.PreemiesToday.com

Misson of Preemies Today:

The birth of a premature infant is an extremely frightening and life altering time. Preemies Today strives to form a network of families to offer help, comfort, and understanding to one another through their knowl - edge and personal experience.

Membership/Subscription

Information:

We offer the Premies Today newsletter, family outings, parent support groups, preemie play-groups, and “A Friend to Talk To”, our call-in line for parents and families of preemies.

To subscribe to the newsletter please contact us at (703) 944-6624. If you would like to become a member of Premies Today please contact Mary at mlundregan@strategicm.com or call (703) 535-1421. Our website is **www.PremiesToday.com**

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