

# HOLDENGRADS

*a newsletter for parents by parents*



WINTER 2004

## *A Great 2nd Annual Holden Graduate Family Reunion!*

*Join us for our 3rd Annual Reunion on June 25, 2005*

The second annual Holden Graduate Reunion was a very relaxed and joyous event. Unlike last year, for the first Reunion, there were no worries about storms, no worries about whether anyone would show, no worries about whether it was even a good idea! All of those (well, maybe not the weather) were a sure bet. And the weather cooperated too. It was a pleasantly cool, sunny, beautiful June afternoon as people began arriving to Kensington Park.

For many Holden staff, who had arrived early to set up, it was a moving sight to watch families pushing their strollers up the path to the reunion site. As last year, several hundred people attended, but it seemed to be a different group. The first reunion was attended by families with children of a broad age range, probably since most people heard about it from the massive mailing that we did to all graduates of the past fifteen years. This year the mailing went only to those who requested that they receive our newsletters. Also, this year a much younger group came — many, many more toddlers. That may have been because we talked about the first reunion at all our Mother's Milk Gatherings and Parent Meetings this past year. We invited everyone to come!

Once again, as at the first reunion, it was heartwarming to see groups of families who had spent time together in the unit, reunited and enjoying the development of each others' babies. For some of the most recent graduates, this was their first outing as a family, affirming how far they had come since their time in Holden.

As at the first reunion, there was face painting, swimming, baseball, T-shirt decorating and many other family activities.



*A group of graduates who had been in the unit at the same time.*

Gemini and their Good Mischief Band performed another joyful concert for the families and once again, Emily Rose, San's daughter and a 1994 Holden graduate, joined the band on violin.

Carolyn McCarthy, a professional photographer whose focus is photographing families with children who have special needs or who are critically or terminally ill, spent the day there and took many lovely

*photo by Carolyn McCarthy*

candid and group photographs. These photos can be viewed on our website: [www.holdengrads.com](http://www.holdengrads.com).

The highlights of the day centered around seeing old friends and sharing stories, expressing gratitude. Many parents shared how wonderful it was to spend time with others now that their time of stress and uncertainty was well in the past. One mother told how just two days before the reunion, her baby daughter finally was able to start breastfeeding. She was grateful for the support of the staff and other mothers who had attended the Mother's Milk Gatherings with her. Dad was also thrilled!

The reunions have been a perfect opportunity for staff and families to visit with each other. They've been a time for moms, dads, grandparents, aunts, uncles, brothers and sisters to show off their adorable, happy Holden graduates!

The intention is for the reunions to continue as an annual event, held on the last Sunday of each June. Please join us next year for the 3rd Annual Holden Graduate Family Reunion on Sunday, June 25th, 2-6pm!

# Our Family Became Strong

by Ann Shields

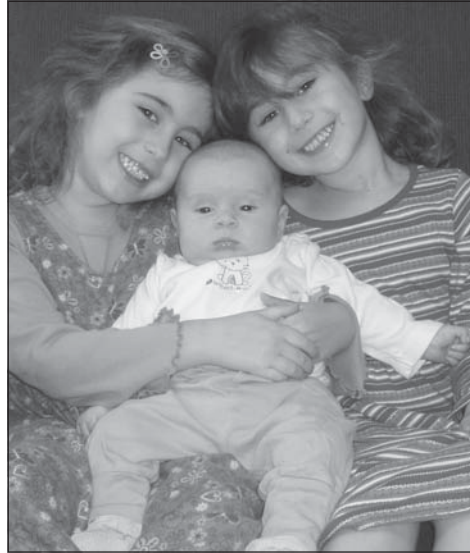
Midway through my pregnancy, we found out that one of our identical twins, Julia, wasn't growing at the same pace as her sister, Lauren. And so our journey began: a high-risk pregnancy, lots of fetal monitoring, including a 3-day hospital stay at 30 weeks, when the doctors considered delivering both babies early. While hospitalized, I was visited by a Holden NICU nurse who showed me a video of the unit, as it seemed likely that our babies would need special care after their birth. It was my first exposure to Holden. I remember thinking, "No, this can't be happening to us. I can't deal with this." I had never expected to be on this path, and it was scary because I couldn't see where this journey was taking us.

At 36 weeks, I gave birth by emergency C-section. Julia was 4lbs, 9oz and Lauren was 6lbs, 6oz. Lauren was able to room in with us but the medical team was concerned about Julia's red blood count, so she was sent to Holden for what was promised to be a pretty routine stay. We were assured that she most likely could come home with us when I was discharged for my C-section, but her discharge kept getting delayed because she wasn't eating well and didn't seem to be progressing in the way that they hoped.

Then Julia's status became much more serious and our path took a big turn. I still remember that call from the hospital one morning, and the sinking feeling I had when speaking to the physician: "Come in. We need to talk to you about your baby." There was blood in her stool, and she was diagnosed with necrotizing enterocolitis (NEC). Two days later, her bowel perforated and at eight days she had her first surgery. Part of me was still screaming inside, "I can't do this. This is not the path I have chosen for my family" — so much so that I couldn't bring myself to sign the consent for her surgery and asked my husband, Mark, to do it.

Julia went for emergency surgery late that evening. Mark stayed overnight in a nesting room, but I had to leave at 1am to be with Lauren. I felt so lonely, riding home in the dead of night, leaving the hospital without my baby, and wondering whether she would be okay. It was an exhausting, frightening, and confusing time. No matter where I was (Holden or home), I had to leave one baby behind, so I was always feeling like I needed to be somewhere else. It was hard to balance the two worlds, both emotionally and physically. We would come home to a healthy baby and would do the normal family activities like giving our new baby her first bath and taking photos for the grandparents. And then we would return to Holden, where a whole different experience awaited.

At the time, we didn't know anyone who had experienced what we were going through, so we also felt very lonely and adrift. We didn't have any idea about how it would all go, of how this story would end. How would we find our way through this? Could our



Lauren, Julia and Carissa Bohm

family hold up under all this pressure? Thankfully, the Holden social worker put us in touch with parents who had been through a similar experience six months earlier. I remember how important it was to connect with others who had gone down this path, other people who had found their way through this rocky start to parenthood. The support of this family was very valuable to us, as it gave us hope and a sense of possibility. That's why I'm so committed to the mentoring program today.

Julia was in the hospital for 6½ weeks, came home for a month and then went back for her second operation, the closing of her ostomy. At that point it felt like things for our family finally began to settle down.

We continue to be grateful for the care we had received in Holden, as well as for the continued monitoring she received on outpatient follow-ups. Today, Julia is thriving. She's a feisty, funny, curious 4-year-old who is best friends with her sister, Lauren. She can tell you about the scar on her tummy and for her, it's just another chapter in the story of our family.

Two months ago, we welcomed a third daughter, Carissa Jane, to our family. During my pregnancy, I would look back to one evening during Julia's hospitalization. It was always wrenching to leave Julia at Holden, and one time we happened to get on the elevator with some parents who were taking their new baby home soon after her birth. I was still grieving the loss of my wished-for normal pregnancy and birth, and I said to Mark, "I want to do that. I want to know what that's like." I didn't know then that this experience would come to us, in time.

With Carissa, we were blessed with an uncomplicated pregnancy and birth, and it was a gift to be able to reflect back on our time in Holden from a new perspective and to recognize in an even deeper way how profoundly that experience changed our lives. After Holden, we are less likely to say, "I can't deal with this," and to say instead, "We will find our way." We cherish our time with our children, knowing that we can't take anything for granted. Most of all, we came away with renewed respect for the strength and courage of all Holden families, writing their own family stories as they face the many challenges of parenting children in the NICU.

***Many want to know how they can give back to the Holden NICU. Thanks for asking...***

Your gift can be sent to the Holden Gift Fund, Mott Children's Hospital, 1500 E. Medical Center Dr., Ann Arbor, MI 48109-0258. *The following code should be noted on your check: AGJ BNA05 ME28*

## Holden NICU Benefit Concert

### Sunday, November 28th

Gemini's family concerts at the Ark on Sunday, November 28th will mark the tenth anniversary of what has become a favorite annual tradition in Ann Arbor. Award-winning musicians, San and Laz Slomovits, have been playing Thanksgiving weekend concerts at the Ark since the early Eighties, but in 1995, they transformed this popular event into a benefit and have donated a portion of the ticket sales to the Holden NICU. San's daughter, Emily, was born and cared for in Holden in 1994.

"This is our way of giving back a little for the incredible care our child received during the three months she spent in Holden," says San. For the past three years, San and Laz have added an exciting new feature to their concerts, inviting their children, Laz's son Daniel and San's daughter Emily, to join them for part of each show.

The concerts have raised over \$7000 for Holden's Gift Fund, a fund earmarked for services to families. The Gift Fund helps provide furniture for patient rooms and nesting rooms, holiday gifts for patient families, welcome bags, the annual graduate reunions, bereavement photos and flowers, baby swings, infant massage supplies and literature, nourishment room microwave, overnight stays for some families at the Med Inn, and the new Family Book Cart.

The concert has been supported by many at Mott Children's Hospital. Sara Hickey, Program Manager has helped with publicity and promotion. Eileen Wright, Clinical Nurse Specialist, and Social Worker, Janet Allen, have organized volunteers who come on the day of the concert to serve food and drinks at the Ark and help clean up between and after the two afternoon shows. The Holden staff has been particularly supportive in this area, many of them volunteering every year. One of the nurses even brought her daughter's Girl Scout troop to volunteer several years in a row.

In 2003, the members of the Holden Advisory Council, a group of parents of Holden graduates who have been meeting regularly to find ways of supporting new Holden parents, made the concert one of their top projects and did much to publicize it and sell tickets. The result was the largest crowds and most funds raised in the history of these concerts. Also, with reaching out to Holden graduates through this newsletter and last year's First Annual Holden Reunion, the Thanksgiving concerts attracted many graduate families. The occasion served as another reunion, another opportunity for graduate families to reconnect with other families they met in Holden, as well as to see staff who may have worked with them there.

This year the concerts will be on Sunday, November 28 at 1 and 3 pm. For tickets (\$8/ticket for both adults and children) please call Ticketmaster at 763-TKTS. In Ann Arbor tickets are also available at Herb David's Guitar Studio at 665-8001.

## Book Review: *Following Foo*

A TRUE STORY ABOUT INTENSIVE CARING

by B.D. Wong



I just finished reading *Following Foo* on the bus this morning, trying not to cry in front of fellow commuters. The book was inspiring, funny and it helped me remember my experience as a parent of a NICU baby just as if it had happened last month.

The author B.D. Wong, a well-known Broadway, film and TV actor, tells the story of his premature baby, Jackson Foo Wong, as well as the story of Boaz, Jackson's twin brother, who lived for just a few hours after suffering from twin-to-twin transfusion in utero. The story is also one of two dads, B.D. Wong and his partner Richie, and their relationship with the surrogate mother, Shauna, who generously pumped her breastmilk and sent it across the state for Jackson. The other main "characters", like Richie's sister, Sue, who became the egg donor, the elder Wongs who tirelessly made trips to the airport and housed the out-of-town fathers, the loving and competent NICU staff and many others receive this "love letter" of a book, with the range of feelings: terror, awe, sadness, and joy always with an underlying, heartfelt expression of gratitude.

Actor, John Lithgow writes, "*Following Foo is the story of two parents and the weeks following the difficult birth of their twin boys. But the tale and its telling are like nothing you have ever read: heartbreaking, hair-raising, hilarious, and ultimately exhilarating.*

*In his first book, B.D. Wong befriends the world.*" Jill Clayburgh, also an actor, says, "*Any parent will identify with this extraordinary, dramatic, and heart-wrenching story. Any human being will feel strengthened and inspired by the journey that was taken to bring the amazing gift of life into this fractured world.*"

As Wong learns to navigate the ups and downs of the intensive care nursery, he starts writing a series of real-time email stories to his loved ones who send them to their friends and before too long, over 1,000 well-wishers have joined his email list. Their responses, which offer so many beautiful blessings are very moving. Many of the staff, in the "Caregiver Corner", join in by emailing Wong to reassure him and his family, and to also tell Jackson's story from their perspective. Sometimes the emails are in the baby voice of Jackson, from the vantage point he has inside the incubator. The first chapter can be skipped, so don't feel bogged down there. Though funny and interesting, it's very different from the rest of the book and may put readers off.

I'm enthusiastic about recommending *Following Foo* to anyone who is a parent of a baby in the NICU, a graduate parent, a loved one who has rooted for these families, or a staff member in one of these nurseries.

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Holden NICU, Mott Children's Hospital  
University of Michigan Health Systems  
1500 Medical Center Drive  
Ann Arbor, Michigan 48109-0258



## New in the Holden NICU Family BookMobile

A long-standing dream for Holden has been to have an extensive library be available for families. This is now becoming a reality. It's now possible to browse from the Family BookMobile when it's in the rooms and hallways of Holden.

There are books like *Growing Sophia* (on prematurity), *After the Tears; Parents Talk about Raising a Child with a Disability*, *They Will Know They are Loved* (about having twins in the NICU) *You are Not Alone: The NICU Experience*, *Breastfeeding Your Premature Baby*, *Postpartum Survival Guide*, and *Kitchen Table Wisdom: Stories That Heal* (dealing with health crisis). Also, there are several children's picture books including *Rosie and Tortoise*, about a very tiny bunny and his sister who is nervous about holding him because he's so small — perfect for siblings.

The unit has always had informational textbooks available for families and we will continue to offer those books on the BookMobile. But, in addition, we'll now also have books, largely written by graduate parents, that speak to the emotional experience of being in the NICU.

The books, offered on a shiny new cart, are being paid for by the Holden Gift Fund. The gently used, like-new books were ordered online from Amazon.com for just a few dollars each. Pat Awood, one of Holden's lactation consultants, also donated some gift certificates.

If you've read some good books that you'd like to recommend, please send your suggestions to [brendamiller@comcast.net](mailto:brendamiller@comcast.net).



*A Holden mom browses through a picture book about a premature baby.*