

HOLDENGRADS

a newsletter for parents by parents



SPRING 2005

Scrapbooks & Sandwiches

A New Weekly Meeting in the Holden NICU

In early January of this year, a new program in the Holden NICU began. On Thursdays from 1 to 3pm we meet in the conference room to have wrap sandwiches and work on our scrapbooks.

This program replaces the weekly Parent Meeting which has had a long and great Holden history and the Mother's Milk Gathering. Parents are no longer asked to leave the rooms during report time, which diminished our attendance at our two weekly meetings. We changed the time for this new program to earlier and made it longer, since we never want to stop the work on our scrapbooks.

At each weekly meeting families are given 7"x7" Creative Memories scrapbooks and page protectors. We have books in green, blue, plum, pink and yellow. A tray of sandwiches is delivered by Busch's Deli.

The funds for this program are provided by Max to the Millions, developed by Yvonne and Dominique Devries of Brighton, in memory of their son and brother, Max, who died last May. A scrapbook "thank you" was sent to them, with photos of happy, scrapbooking parents and their notes of gratitude. Colorbök of Dexter also generously supports our scrapbooking with beautiful papers, stickers and die-cuts which they've donated.

There is an informal atmosphere for the meetings, with parents and staff drifting in and out of the room. The lactation consultant, nurse, doctor or a social worker may stop by to see if there are questions that families might have.

Families share their photos and stories with each other as they work on their scrapbooks. The parents who have been here

longer help show those who have never worked on a scrapbook how it can be done. Several moms have taken their scrapbooks and supplies back to the bedside to work on them.



Though the meeting is scheduled to end at 3pm, we rarely leave then. At our first session, 4pm came and went; by 5:15 people were still bent over their books in relaxed concentration. One mom said that it was, "the

fastest the time has gone since we've been in Holden".

Although moms are the ones that usually attend, dads have come for sandwiches and stayed to cut out fairies and flowers for the scrapbook pages. Grandma's often come and are also given a book to work on, alongside mom. At last week's gathering, one grandma stayed to work on her book while mom was pumping and feeding her baby.

We see very creative scrapbook pages. A mom "grew" her twin's heart monitor lead wires out of paper flower pots. Then she glued paper flower petals to the adhesive leads at the top. Another mom displayed the newspaper astrology reading from the day her daughter was born.

The topics that come up are very heartfelt and deep, as in a recent discussion, between a group of premie moms. One very new mom said that she was terrified to touch her tiny baby. The veteran moms helped to reassure her, saying that as they helped to care for their babies, they became more comfortable.

The next week, the new mom talked about how involved she now is in her daughter's daily care. She looked very happy as she shared this. Her scrapbook is filling up with these memories.

Come Walk with Holden NICU Grads & Staff on May 1st

March of Dimes 'Walk America' Benefits Prematurity Research

It was a sunny spring day, in beautiful Hudson Mills MetroPark, with a three-mile walking path that wound its way through woods and by the Huron River. I was one of hundreds of people, from toddlers to grand-parents, with strollers and dogs, who completed the loop and afterwards enjoyed pizza, ice cream and other good food. A great morning, and all for a terrific cause — the annual March of Dimes 'Walk America'.



Every year, staff from the Holden NICU form a team for 'WalkAmerica'. This year we'd like to extend an invitation to all Holden NICU graduate families to join us.

The March of Dimes 'WalkAmerica' campaign has provided funding for research to help find possible causes and more importantly, to aid in the prevention of premature births.

Last year, Michigan's 35th annual WalkAmerica campaign raised nearly 3 million dollars, 96 million dollars nationally. The goal for this year is \$99 million.

In recent years the March of Dimes have initiated a number of programs nationwide to support family-centered philosophy for NICU families. The service will be offered in more than 50 NICUs by 2007.

If you'd like to team up with the Holden NICU for this year's walk, or would like to sponsor our walking team, please see the box below.

Thank you for your support and we hope to see you there!



Local Ann Arbor Walksite: May 1, 2005, 9am
Hudson Mills MetroPark, 8801 N. Territorial Rd, Dexter, MI

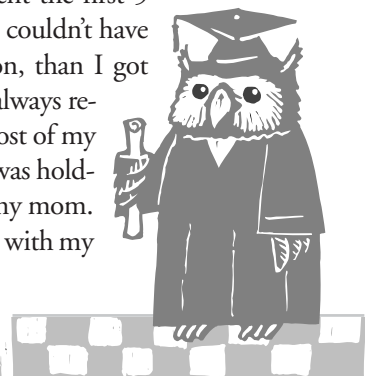
The Holden NICU team is called: University of Michigan – Holden Premie – UMS. Our team will meet at the park flagpole at 8:30am.

Register at walkamerica.org or 800-525-WALK or for more info: Molly Gates, 734-764-8113 or holdengrads.com website.

Holdenkids Sign the Holdengrads.com Guestbook

Clay: Hi everyone! It's Clay (August-December 03). I am just dropping a little note to let you know that I am doing great. I am now 16 months old and am the happiest kid around. I have now learned to army crawl and just love getting into all of my sister's toys. I am continuing with physical therapy and making huge strides. I still have my mom and dad wrapped around my finger. My mom never stops kissing me and is quick to inform me that she is the only woman ever allowed to fog up my glasses like she does. Geez mom, doesn't she know that chicks are going to just dig my ECMO scar? Thanks everyone, we hope to visit soon! Clayster

Timothy: Hi Everyone!! I miss everyone so much! Thank you for taking such good care of me and placing me into your hearts and thoughts (even to this day)! I spent the first 5 months of my life with you and I couldn't have asked for more love and attention, than I got from all of the staff in Holden. I always remember the swing that I spent most of my time in (unless one of the nurses was holding me). You were all so great to my mom. She made a very special friendship with my great primary nurse, Dana Goldsmith. I love coming and visiting everyone at Holden! I



know for a long time everyone didn't think I was going to make it, and without all of you, I wouldn't have. But look at me now, I am 10 months old. I have caught up on all of my developmental stages that I missed out on in the hospital and am perfectly healthy! I love Holden!!

Conor: Hi Everyone! I'm a healthy 3½ year old boy who loves to read, play with trucks and hang out with his friends. I scared my mommy and daddy when I was born at 27 weeks. I weighed only 2lbs. 9oz and I had to be on oxygen for awhile. I was in Holden for the entire summer of 2001. The doctors and nurses were wonderful and I'm forever thankful. I wear inserts in my shoes because my feet pronate but I'm getting stronger day by day. I also wear glasses. I used to throw my glasses off my face when I was little but now I ask my mommy to put my glasses on my face. I'm a big Michigan fan so I'll just sign off by saying, "Go Blue."

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*

U of M Is Building a New Children's Hospital

Families Are Invited Into the Design Process

Plans for the new Women and Children's Hospital to be built on the surface lot nearby the current hospital are underway, with the proposed completion in 2011. It has been nearly 40 years since the design and construction of C.S. Mott Children's Hospital, which is now too small and increasingly technologically obsolete.

Though the Holden NICU remodeled the unit last year, there are still serious space limitations. Site visits have been made recently to other hospitals in the country who have the latest in design, though design concepts are always rapidly changing. A current trend in NICU design is that of single rooms. It's not clear yet if this will be the preferred design in the new unit.

The Holden Family Advisory Council recently served as a focus group for administrators who are helping to plan the new hospital design. The seven members who were there answered questions about how they would like to be welcomed into the hospital, areas for nourishment, bedside space, family sleeping

space and parking. Coffee hours were also set up within the hospital to invite families of current patients to give feedback about design.

An interdisciplinary, Mott-wide committee began meeting to support Family Centered Care in the process of designing a new hospital and to support family centered practices until that time. A parent has been included in that committee and plans are to have families sit on design committees as the process continues.

In January, a team of five Holden NICU staff which included a parent attended a conference in Florida: The Physical and Developmental Environment of the High-Risk Infant: Neonatal Brain Research and Developmental Care, bringing back many ideas for the new hospital.

Please visit the holdengrads.com website if you have ideas for the new hospital.

Book Review: Tear Soup • A Recipe for Healing After Loss

written by Pat Schwiebert & Chuck DeKlyen illustrated by Taylor Bills

Sue Gibney, a staff nurse in Holden, is responsible for having developed our excellent bereavement program. Recently, Sue told me about a book that she thought would be great for our Holden Family Bookmobile.

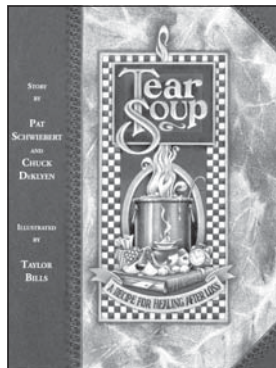
Tear Soup looks like a children's picture book and only took ten minutes to read. But its wisdom has stayed with me. This book has a unique way of communicating an important message. Whether the loss is "large" or "small", the way that grief is addressed here could be helpful to anyone.

I ordered three copies, one for the Family Bookmobile, one for a close friend who had just lost his wife, and one copy to have at home. When the books arrived, my husband, my 10 year-old daughter and I all quietly read through the story. My daughter, had been with us when we'd sat with our friend after his loss. What we read that night helped us talk to each other about how it felt to be with them. Our grieving friend also shared that the book meant a lot to him and his teenage daughter.

The picture book format and brief, straightforward writing can be read in one short sitting and can be understood even by young children.

Tear Soup begins, "There once was an old and somewhat wise woman whom everyone called Grandy. She just suffered a big loss in her life. Pops, her husband, suffered the same loss, but in his own way. This is the story of how Grandy faced her loss by setting out to make tear soup".

And in the middle of Grandy's cooking: "On some afternoons people would ask questions like, 'Is it soup yet?' or, 'How long



is it going to take? You have been at this for over a month now. It's time to get out of the kitchen'."

Making tear soup is, "hard work. Sometimes it was all she could think about. Even the things Grandy used to love to do, she didn't have the energy for, nor did she care about anymore."

The story ends with Grandy promising to leave her grandson, Chester, the recipe for her tear soup. What follows, in the back of the book was just as helpful and enlightening as the story. There are "Grandy's Cooking Tips", like, "Being at work may provide a relief from your grief, but

as soon as you get in the car and start driving home you may find your grief comes flooding back".

Then there is a section with headings like, "If you are the cook", "If you are a male chef", and "If there are two of you cooking". Under the heading, "If a child is the cook, the advice reads, "Younger children are more affected by disruptions in their environment than by the loss itself".

Finally, *Tear Soup* ends with two long pages of "Where to find help", with listings like, *Grief Watch/Perinatal Loss*.

Many feel uncertain about what to say or do for a friend or family member whose grief is considered "ambiguous". Events like a miscarriage, job loss, or as in the NICU, a less than perfect pregnancy or delivery, may not be helpfully acknowledged by others.

Tear Soup is a good resource for dealing with any type of grief or loss and is a book that could be a comfort to anyone, no matter their age or circumstance.

HOLDENGRADS

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



NEW Holdengrads.com website Grand Opening! To be unveiled on June 1st.

Two graduate dads are working hard on it. Please visit to see many exciting features and services.

Join Us at the Third Annual Holden Family Reunion! *Sunday, June 26, 2-6pm at Kensington Metropark*

We're looking forward to another great day at the third annual family reunion of Holden NICU graduate families. The setting is beautiful — a grassy hill overlooking the lake. At the first two reunions, families visited with each other, with staff and took part in fun activities like t-shirt decorating, face painting and sports. The third reunion will include all of this, plus another concert with Gemini and the Good Mischief Band. Please bring a picnic lunch and join us on the hill for a really wonderful afternoon.

You're welcome to bring your extended family and friends. Please let other graduate families know about the reunion.



Please Note: The date was incorrect on the last newsletter. Sunday, June 26th is the correct date for the reunion. Directions: Kensington Metropark is located on I-96, just east of US 23. Take Kent Lake Rd. exit #153 to the park. Follow the Holden Family Reunion signs to the North Martindale Beach area. Entrance fee is \$4 per car or \$20 for an annual Metroparks sticker.

Photographer's Note to You Post the Reunion: Thank you very much for the opportunity to share in your wonderful celebration. Throughout the day I saw so much happiness, love and dedication between families, friends and staff. I wanted to capture all the smiles and joy I saw in the faces that day. I hope you enjoy the photos on www.holdengrads.com. If you are interested in contacting me please e-mail me at carolyn@cmcpphotos.com. You may also phone me at 734.255.0440. Thank you. Carolyn D. McCarthy, Ann Arbor.