

BABIES REMEMBERED

HONORING AND REMEMBERING LOVED BABIES WHO HAVE DIED

VOLUME: 1 ISSUE: 1 MAY/JUNE 2009

FIRST EDITION

Welcome to the FIRST EDITION of the free e-newsletter **BABIES REMEMBERED**. This first version is for both parents and professionals. As time goes on, it may be that a version for each will be sent. We welcome your thoughts on whether to offer separate ones or keep them together.

As you can see from this newsletter, I wish to share what I have learned over the years and today as I travel and visit hospitals, support groups, websites, and hear from professionals and parents. This is like a 'pass it on and inspire' project. **I hope that if we network, share with others, build on what exists, and don't reinvent wheels we can accomplish more.** It is important to share our knowledge, experience, and wisdom with others, especially our newer nurses and care providers.

I hope that you will choose to write in and share your experience, ideas, and wisdom. Each of you have something to contribute. Please send submissions to: sherokeeilse@yahoo.com.

What might you find in future newsletters?

It seems that professionals might want to know about literature, conferences and training opportunities, mementos, protocol, research, and the parent perspective.

Parents might want much of the same with some additions such as support resources and ideas to give back and make meaning of their babies lives.

It is my goal to do my best to search and share what I can from all over the world, as best as I can. And I hope that each of you will share your favorite resources and offer guidance as to what we should include.

Of course, I also hope to share some of our Wintergreen Press resources which we continually
(continued on page 2)

Review of Washington DC Symposium, March 23-25, 2009

The **Research Symposium and Lobby Congress Day** in DC was a three day event to be proud of. Thanks to **First Candle** staff for all their energy and commitment (and financial contributions) to bring so many groups and 150 parents and care providers together for the purpose of 1.) training more peer support (befriender) parents, 2.) Giving us a full day of current research and 3.) The organized opportunity to impact close to 100 Congressional offices.

Peer Support

In the peer support training that I was fortunate to facilitate, we had 13 really wonderful people!! The second half of the training took place on the phone the last week of April, and after the last one-on-one role play and screening we will have more people available to help others in their own communities and as referrals from First Candle. For more information on starting a peer training program or to inquire about being trained as a peer support, call me at 952-476-1303.

Legislation/Lobby Day

About 70 of us were split into teams thanks to FC President, Marian Sokol who worked endlessly. The reports were awesome! Legislative aides were deeply moved by the stories (like the couple who read about this on the internet and drove up from Tennessee...never, ever having done anything like this.



But they needed to tell about their son Hunter who died of SIDS while dad was in Iraq and mom was all alone far from family!). And by the beautiful Baby Album we created that shared 70 beloved babies. Thanks to the team who put that together, especially Suzanne Pullen, Heather Smith - the designer, and Heather Rotondi. I did help some, also. The feedback we received was that this book made a HUGE difference. (continued page 3)



Sherokee Ilse: The author of Empty Arms, 17 books/ pamphlets dealing with grief and loss, and the newsletter 'Babies Remembered'. I have been helping both parents and professionals in the fields of stillbirth and infant loss, as well as promoting research on probable causes for stillbirth to save babies lives, for over 27 years. I am a bereaved mother first and a professional second. Feel free to contact me re: speaking, my books, the new CEU Units I am developing or other information at www.babiesremembered.org or by phone at 952-476-1303.

Giving Care, Taking Care: Support for the Helpers

CEU Home Study Units

The goals of this 4 CEU packet are to help professionals give compassionate care and prevent caregiver burnout. It encourages care providers to put themselves at the top of their list and to know the difference between a rescuer and a helper. My book, **Giving Care, Taking Care** is the core text. It is reader friendly and practical-based. Extensive handouts and short overviews of appropriate studies are included in the program. Visit the website where it will be posted shortly. \$40 for 4 CEUs, \$20 for 2 CEUs or email me directly at sherokeeilse@yahoo.com.

Available in MN and any state that does not require accreditation organizations to sponsor CEUs. Soon it will be available for all states.

(FIRST EDITION: continued from page 1) update. When we started 27 years ago, it was my goal to have **Empty Arms** in every hospital to give to parents providing them immediate guidance at the time of their loss. This mission expanded when it became clear there was so much more that parents and their caregivers needed. More books, booklets, A-V, cards, certificates, etc. were developed or located from other publishers. Sharing these resources and offering training opportunities continue to be my primary mission, as I join the other committed parents and professionals who wish to change the world of bereavement support and help stop babies from dying. I consider it an honor to work in this field and I hold this mission sacred. Even after almost three decades, my passion and commitment remains strong.

How often will it come out?

As often as needed and as often as I can make the time to do it. Some times are very busy for me as I travel or am involved in a project. Therefore, I will

refrain from making a promise I cannot keep. At times it may be monthly, other times quarterly. Your flexibility, one of my philosophies to live by, will be my request. I am hopeful you can accept this. ♦

Mothers Remembered

As you recall
your womb cradled your baby gently,
your arms embraced your baby lovingly,
and your own mom carried you excitedly.
Remember the beauty, loves unending circle.
You are always a mom, loved by a mom.
Separation and death can't break it.
This bond and love endures,
Forever and always.
Moms remember.
Moms are to be
remembered.
It is the
only way.
The right way.
God's way.

Remember, mom, remember.

S. Ilse 2009

As **Mother and Father's Day** approach, I do hope you will make special plans and let people know what would help you. No matter what number Mother or Father's Day this is, you will likely experience tenderness in your hearts and a bittersweet feeling. You are the parents of EACH of your children, whether they are alive or not. Your love will always shine for them!!!

Memento Corner

Grief Watch Ceramic Hearts: www.griefwatch.com

Have you seen these beautiful ceramic hearts? Some are small hearts to hold and touch. (\$1.50/heart plus shipping. Min. order 10). Others have a small break-a-way heart (to put on baby) from the center of the Mother/Father heart (for mom or dad) (\$5.50 plus shipping). They are beautiful mementos for parents.



Baby Clothing

These are three web-based organizations who offer blankets and clothing to hospitals for miscarried, stillborn, and neonatal babies. If you wish to help sew, crochet, knit or help financially please contact them directly. Or if you need gowns/blankets they might be able to help you. Or make items and deliver them to your local hospital.

Angel Layettes: www.angellayettes.org Angel Layettes is a nonprofit corporation that provides personalized burial layettes and keepsakes. Each unique layette is made by hand and acknowledges the baby's life and provides comfort to the family while preserving their memories.



Threads of Love: www.threadsoflove.org Threads of Love, an outreach sewing ministry, through the effort and support of many participants in chapters across the country provides clothing, blankets and other handmade articles for tiny premature and sick infants.

Project Linus: www.projectlinus.org Project Linus is comprised of hundreds of local chapters and volunteers who work together to provide love, a sense of security, warmth and comfort to children who are seriously ill, traumatized, or otherwise in need through the gifts of new, handmade blankets and afghans, lovingly created by volunteer "blanketeers."

(continued from page 1)

Symposium

The 150 or so people who attended were all very impressed with the researchers, parents, health care providers, organizational leaders, and First Candle staff (I hope I did not miss anyone). We split into two different rooms - I went to hear the Stillbirth researchers. It was great.

Dr. Ruth Fretts gave us a good background on what is happening and then announced the NEW (March 09) ACOG bulletin for Stillbirth Management. It seems to be a very good start and promotes the collection of more data, standardization, promotion of autopsies, and some guidance on movement towards the end of pregnancy. She talked about risk assessment and the importance of looking at the slow down of movement at the end of pregnancy as a potential indicator of trouble. No standard protocol for gathering data and autopsies is common in the US which adds to the problem of understanding what causes stillbirth.

Dr. Jason Collins spoke about the research that supports cord issues and their influence on stillbirth. Through his extensive experience and the almost 100 patients he has followed, and the studies he presented (including a new one from Japan), he suggests that with the kind of data and the tools available, **babies should no longer die due to cord issues** - most of which can be seen on ultrasound (of course this means much teaching must go on and an openness by physicians to learn about how to see cord problems and then manage them, especially if there is nice low blood pressure). He can be reached at Jason Collins haydel1@bellsouth.net if you need to

connect with him or visit his website at www.preginst.com.

Parent advocate and Master's candidate Suzanne Pullen shared the results of her study...*Giving Birth to Death*. **It is an excellent study to give to doctors, midwives, and anyone who cares for families at the time of and after stillbirth.** I do want to say that I have been consulting with many hospitals lately and have been sharing this study with them. It has serious and important

People and Groups Who Help

A Place to Remember:

www.aplacetoremember.com

Provides the most extensive offerings for families who have troubled pregnancies or a baby die.

Announcement cards, memory boxes and clothing, memento trinkets, tons and tons of literature, ceramics, gift items and more. Chat room, resource lists and other support.

First Candle:

www.firstcandle.org

Promotes research on causes and prevention, responds to families, offers resources on Stillbirth and SIDS.

Babies Remembered:

www.babiesremembered.org

For parents and professionals - bereavement support, research, suggestions for healing, sharing corner, poetry, upcoming events, resources, links, and online store.

implications for what they tell parents early in pregnancy, how they present the diagnosis, and what support they offer at the time or shortly after diagnosis (like peer support). Everyone seems most interested in it and want to get a copy to share with their staff and especially their doctors. So far the results have not been published, but if you wish to receive a copy email me. ✦

Letters

Do you have a letter to share with our readers? Here is one we received in March. Thanks to Kristin and please keep her in your prayers. Her sadness is understandably great, and her passion to help others and make meaning of Ben's life is deep.

March 2009

Dear Sherokee,

As you know I have been meaning to gain the courage to reach out and say, "Hi" to you. Thanks to the kindness of Charmayne and her family, I have read your book, "Empty Arms" which was included in my package I received from the hospital following the loss of my son Ben. It was amazing! I heard your voice in my ear as I read it and felt you guiding my elbow in support as I made those initial phone calls/decisions.

No I'm not crazy and hearing voices! I was just alone and fortunately had the will to read (in bits) and the desire to find others on this path so I didn't continue all alone.

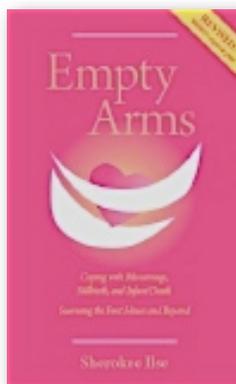
We lost Ben after 38 weeks as a result of a cord accident. He was a perfect, healthy baby without a heartbeat born Jan 20th, 2009 weighing 7 lbs 8ozs. We learned we lost him at my 38 week doctor appt when the doctor couldn't find his heartbeat. I truly wish I had your book in the hours that followed so I could have known what to expect and what to contemplate when asked to make decisions. I made some decisions which if I had contemplative guidance I would have done differently. In the end, we held Benjamin Xavier at the funeral home 2 days later and were glad to hold his little frame. We have some regrets, but not many thanks to your kind words.

I am also very interested in your efforts to assist bereaved parents and facilitate change in hospitals, governments and ultimately society. Even in the deepest portions of my grief, it has been a burning flame in my heart that I need to do something to make things better for the next mom and the next... Ben couldn't have come into my life for nothing and I can't have his time here be forgotten. It has almost been an epiphany that this is what I was meant to do – I don't know how, I don't know what...but something and somehow. I can't believe how little there is out there for moms – even in this age of internet and connectivity. I know you have done a lot – most of what I have found (from my lifetime) has your name or mark on it and for that I thank you too. You have been instrumental in ensuring up to date and applicable information is available for us. Wow.

Coming from a background in university administration, I have to admire the dedication and perseverance needed to accomplish all you have and still maintain your connectedness and compassion to each and every mom.

Kind regards, Kristin V.

BOOKS

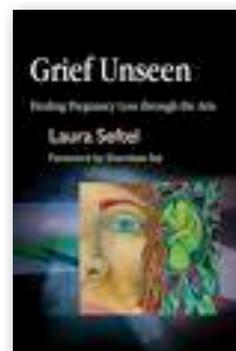


Empty Arms, Newly revised!

Sherokee Ilse

Over 300,000 copies in print. With a fresh cover, updated resources, a new order (hospital decision-making is now first), and some added insight from 27 years of living with my babies in my heart and mind and my living children in my life... **Empty Arms** is just as important as ever. This book, when given lovingly to families

(open, not closed) has been shown over and over to make a difference in bereaved parents' lives. Still loved, appreciated, and shared around the world, I am humbled every day by the letters in English and Spanish I receive that thank me for helping families feel less alone and living with fewer regrets about their 'hello and goodbye' hours with their baby... because they had read **Empty Arms** in time.



Grief Unseen: Healing Pregnancy Loss Through The Arts

Laura Seftel

"Grief Unseen" explores the experience of miscarriage and the process of healing. The second part of the book offers a wealth of practical creative exercises, using step-by-step processes to guide individuals, couples and groups through their

creative responses, offering a practical introduction to the medium of art as an aid in coming to terms with loss. An uplifting resource.

FATHER'S DAY

Dad, you support mom along the way
Waiting for the time and day
When you can hold your daughter or son
And you can finally be the one
To toss your babe above your head
And tuck him in his waiting bed
Make a toy or buy a drum
Your time was near, but did not come.
Who knew you would be standing nigh
And have to prematurely say goodbye?

This day is yours and yet it's not
Others don't see the many tears you fought
To hold within and look so strong
As you tried to do nothing wrong.

On this your special Father's Day
Remember your baby who would want to say,
"I love you Dad. You *are* the one.
I'll always be your daughter or son.
Feel my kiss upon your cheek
And know that someday I believe we'll meet.
Until then, let your tears come, (or not)
And love my mommy lots and lots."

S. Ilse 2009

Tidbits...

Social Networking-

Join our **LinkedIn** group (www.linkedin.org - set up a profile and 'friend' me). I started a networking and sharing group called, Perinatal/Infant Loss Community Leader group and I'd love it if you are a professional caregiver, a parent advocate, author or other person who is ready and working to improve the care of families and those who care for them. Together we can learn and share in unique ways any time of the day or night with people in the US, Canada, UK, Australia, Italy, Spain, New Zealand and more.

If you are on **Facebook**, check out the many groups for families and professionals. One I started was: *Babies Remembered*.

Other good ones are 1st Breath, First Candle, Stillbirth Support Group - First Candle, International Stillbirth Alliance, National Stillbirth Society, Stillbirth Babies - Forever In Our Hearts, Remembering Our Babies October 15th, Miscarriage, and Miscarriage Awareness.

Future issues:

Miscarriage care and resources
Miscarriage disposition – rights and laws
Slowing down the rush to the hospital
Taking babies home to die or after death to cuddle
Memorialization and resources
Updates on research – bereavement care, causes, etc.
And so much more...

Submit your suggestions!

Contact Information: sherokeeilse@yahoo.com

BABIES REMEMBERED

Written By: Sherokee Ilse

Edited By: Marie Hagberg

www.babiesremembered.org