



Forget-Me-Not



Volume VII, Issue III

August—November 2010

**This newsletter is sponsored by:
The WNY Perinatal Bereavement Network,
A program of Life Transitions Center, Inc.**

Member Organizations

- Brooks Memorial Hospital
- Catholic Health System
- Mercy Hospital
- Sisters of Charity Hospital
- The Center for Hospice & Palliative Care
- Kaleida Health
- Women & Children's Hospital of Buffalo
- Millard Fillmore Suburban Hospital
- Life Transitions Center, Inc.
- Medina Memorial Health Care System
- Mount St. Mary's Hospital of Lewiston
- Niagara Falls Memorial Hospital
- NYS Center for S.I.D.S.
- United Memorial Medical Center
- Wyoming County Community Health System

The editors reserve the right to grammatically edit or reject materials submitted. Views and opinions in this publication are not necessarily those of WNY Perinatal Bereavement Network or its member organizations, but those of the individual authors.

From Our Heart To Yours

The 18th Annual
Walk to Remember



will be held at
**Cheektowaga Town Park,
2600 Harlem Road**

October 10, 2010

*Registration will begin at 11:00 AM
Program will begin at Noon*

Invitations and Registration forms will be mailed at the end of this month. All participating in the Walk are encouraged to obtain donations to help support the WNYBPB. Although donations are not a requirement, they are encouraged.

We will plant a tree, release balloons, have a Kid's Zone and a picnic lunch afterwards

Please invite your family and come help make this year's Walk to Remember a celebration of Life!

This issue of the newsletter practically wrote itself! I was so pleased at how many stories and blurbs that people wanted to submit! Thank you all! And keep it coming! I'd really like to place the "Poetry" page back into the next issue—so please share your poems!

I also want to encourage you to send along drawings and such that your children have created through their journey of grief (Kid's Stuff article on page 9). It helps us to know we are not alone in

grieving... it will probably help them, as well.

I hope you will all be able to come to this year's Walk to Remember. It helps so much with our healing. It is a good day to spend with your family to remember our little ones gone too soon.

Enjoy the summer as much as you can... it'll be snowing before we know it!

Peace.

In This Issue:

Network News	2	Nicholas Bereavement Fund	8
Thoughts on Parent's Day Breakfast		Maddy's Story	8-9
	3	Gage Andrew Miller	9
WNYBPB Memorial Cookbook	4	Kids' Stuff	9
Fran's Corner	4	Fetal Death Record Info	9
CBRS Bill Info	5	Safe Arrivals	10
Thank you from Erin Neff	5	Area Support Groups	10
Journal Entry	5	Internet and Keepsake Resources	11
Forget-You-Nots	6-7	WNYBPB Wish List	11



The mission of the Western New York Perinatal Bereavement Network (WNYBPB) is to assist the community to meet the needs of people facing the pain of perinatal death. We believe all people experiencing this loss have the right to support that reflects a standard of care regardless of the facility where the birth took place. The Western New York Perinatal Bereavement Network supports an established standard of care following a perinatal death. We promote standards of bereavement intervention through educational support, community programs, and referral services to bereaved parents. The WNYBPB is a program of Life Transitions Center, Inc., an affiliate of The Center for Hospice & Palliative Care.



Network News



From the desk of Christine Scott
WNYPBN Director



Bereaved Mother of Jacob Wesley Scott—May 27, 2000

I heard a voice mail message the other day that really made me reflect. It said, "only you can be the change you want to see in the world." This statement made me think about all of the changes at the Network and all of the amazing people I have met so far on this journey that are helping us create this change for our bereaved community.

Over the last couple of months, I have met so many wonderful and caring individuals that have reached out to me and our Network because they simply just want to help – help somebody that has to face the pain and anguish of saying goodbye to their baby. I feel humbled to have crossed the paths of so many generous people that will make an impact in the life of somebody they have never met, just "because." I wish I had the space and the time to write about everyone that has reached out and touched my heart, but unfortunately, I don't. But here are a few:

I want to thank Stephen T. Watson, staff news reporter, of the Buffalo News for writing the story, "Keeping Memories Alive". The story ran in the "City and Region" section of the newspaper on May 2, 2010. The story created much-needed awareness about the WNYPBN, the Wings of Love Program and the importance of supporting bereaved families in our community. I'd like to give a heartfelt thank you to my Wings of Love families who opened their hearts and shared their painful feelings and thoughts for this story. I'd also like to thank a bereaved mom named Andrea Burtis who kept the story alive and in our minds, as she wrote a "letter to the editor." The piece ended up being entitled, "Wings of Love Helps Ease Horrible Burden" and was published on Saturday, May 8, 2010.

Last week, I took a "Buffalo Style

Lunch" (Pizza and Wings, of course!) to the owners, Meg and Tracy, and the staff at 21st Century Press in appreciation for their dedication and commitment to us. They have been printing our Newsletter gratuitously since November 2007. We couldn't be more grateful!

My next journey resulted from a bereaved mom, Emily Pratt, who recently moved to the Buffalo area from Charlotte, NC. She has an amazing talent to sew. Back in her old home town, she made bereavement gowns for tiny precious babies that were distributed at her community hospitals. She wants to extend this service into our community. She will be leading a new program under the Network called "Angel Robes." This will allow us to provide beautiful burial gowns, caps and blankets to our local hospital bereavement programs. If anyone would like to assist us with this program, please let me know.

Our community events continue to be extremely successful and impact the lives of so many. "Their Needs, Our Communication," the Professional Conference that we hosted on April 29th, educated 75 professional about supporting families experiencing perinatal loss. The program included talks on subjects ranging from Support in the Hospitals, Community Support and Burial Options. There was a parent panel of bereaved moms and dads that shared their tragic experience with the group. The attendees were able to ask questions and learned from these shared experiences. It was a very successful and educational conference.

The 1st Annual "Wings of Love" Parent's Day Breakfast was such a tribute to parents and grandparents, celebrating the children that will live on in our hearts forever. We raised almost \$1,500.00 that will assist be-

reaved parents with burial expenses (see article on page 3).

We continue to work feverishly on becoming an independent 501C3 organization. We have composed a Board of Directors that will be made up of dedicated professionals and bereaved parents. Our Network has recently become a member of NYSPA from a generous donation covering the membership dues. This membership is a wonderful state wide resource and collaboration opportunity.

As my journey continues in the fall, I have gratefully accepted and am honored to create the Reflection Room at the International Conference on Perinatal and Infant Death, cosponsored by PLIDA and the Association of SIDS and Infant Mortality Program. The international conference will be held this November in Washington DC. This conference gives me an opportunity to network with fellow professionals and meet the top researchers in the field.

The Walk to Remember is quickly approaching and the committee members have been working very hard to make this a memorable day in memory of our babies. Please save the date, October 10, 2010, and watch your mail for your invitation and registration form that will be distributed at the end of August.

As the need for support and our Network grows, our "Wish List" grows (see article on page 11). We have compiled a list of materials that we need to assist our grieving families throughout the community and in our 8 county hospitals. If you can help us out we would greatly appreciate it! And remember only you can be the change you want to see in the world.

Sincerely,

Christine

Thoughts on the Parent's Day Breakfast

By: Dawn Both-Kim

Since I joined the WNYPBN's ranks as editor of this newsletter, I've heard whispers of "wouldn't it be nice if we could do something for Mother's Day." Since taking over as Director of the WNYPBN, Christine Scott finally made those faint notions a reality.

We initially thought to have this Breakfast on Mother's Day, but that tends to be a date where extended families get together. It is difficult for extended family members to be comfortable at an event that tends to be melancholy, as most Memorial programs are. Christine felt that it was important to hold the event close to Mother's Day, so it would still be special, especially for the newly bereaved.

A lot of work went into planning a simple, yet elegant event. Chairperson Christine Scott worked to make sure the event would be all that we (the bereaved parents) needed it to be. The co-chairs, Dawn Both-Kim and Jennifer Opoka, assisted Christine with all of the details for making the event a success. The event raised \$1500 to help sponsor families through the Wings of Love Memorial Fund.

Thank you to these generous businesses and individuals for their donation of time, talent and contributions to make this breakfast a success: Charitable Foundation of Jim Ball Auto Group, Inc., Joseph Country Manor & Grove, Anderson's, DeltaSonic, Chef's Restaurant, Craig's Jewelers, Fran & Tom Kane, Lisa Jerebko, Michelle Bukowski, Fr. Richard "Duke" Zajac, Sandy Gurbacki, Lesley Jordans, Karen Cwalina, Denise Hudden, Jenine Trzewieczynski, Melissa Guido and Vickie Michalowski.

The following are some thoughts from a few moms that attended the Breakfast:

I lost my son John Paul on November 18, 1999 and I will never forget my first Mother's Day after losing him. Not one person recognized me as a mother... I wanted to gather all my friends and family together and scream at them and say, "I am a mother - why are you not recognizing that?" Of course, I knew why. Even my husband did not know what to do or say on that day: they did not want to hurt me more. But what I needed more than anything at that time was to be recognized. I needed to be acknowledged that I had a baby and I am a mother.

On Saturday, May 8, 2010, I attended the first Western New York Perinatal Bereavement Network's Parent's Day Breakfast. It was one of the most beautiful events I have ever attended in memory of our son John. Even after 10 years, it meant so very much to be recognized as a mother on Mother's Day. It was an event I wish I had been able to attend in my first years when my grief was so raw. The Parent's Day Bruch included a program where each of our children's names were read, a candle was lit in their memory, songs were sung and balloons were released.

I want to thank Christine Scott, Director of the WNYPBN, for coming up with the idea for this event and making this event a reality. I truly do hope it helped the parents that were there that day and were very fresh in their grief of losing their baby. I do hope it was a healing to them as it was to me... even after all these years.

By: Lisa Jerebko

The Parent's Day Breakfast in May was a very nice way for me and my family to honor the memory of our son, Elliot Moses. It was right before Mother's Day, which made it even more special. It is a busy time of year for us, but it was important for my family to take time out to remember our son and how much he is missed. It can be difficult around Mother's Day to explain to others how I feel because I have three other children that I am so blessed to have. But I need to be with other parents that have experienced a loss in order to express my sorrow, and to know that there are others that feel the same way.

We enjoyed the music, poems and balloon release; these were all great ways for us to share our feelings and to remember our babies. There were a lot of other little things that made the breakfast special: bubbles, butterfly cookies, and a butterfly net where you could write a message to your baby.

My husband and I always try to find ways for us to remember Elliot as we go about our everyday lives, until we can all be together again. This was a nice way to be with other parents in the same situation so we can honor the memory of all our babies gone to soon, but forever in our hearts.

By Sue Mis

My husband and I enjoyed the Parent's Day Brunch. Everything was very touching since this year we looked forward to celebrating our first mother's/father's day. Our favorite parts were the songs and releasing of balloons. We definitely appreciated this event because it gave us that recognition of being parents, too... even though our angel is in heaven. Thank you for a special one.

By: Maisie Ramos

WNYPBN Memorial Cookbook



As most of you already know, the WNYPBN is creating a cookbook in memory of our angels. We need recipes in honor of your children to be a part of this publication!

If you, or someone you know, would like to submit a recipe, email the recipe to Jennifer Opoka at jnopoka@aol.com and include the type of recipe in the subject line (i.e. appetizer, salad, main dish, bread, dessert, etc). Please include your first and last name

along with a one to two line memorial (as we have in the Forget-You-Not section of the Newsletter) to your lost angel. Include your baby's name and honored date as well as parents' names to complete your Forget-You-Not. There is NO FEE to submit your recipe, and 100% of the proceeds from the sale of the cookbooks will benefit the "Wings of Love" Memorial Fund. The Fund helps parents in need to pay for the burial of their precious babies gone too soon. If you have any questions or concerns please email Jennifer Opoka or call Christine Scott at 836-6460 ext. 117.

The due date for all submissions is September 27, 2010. The cook-

books will be \$15 each. They should be available around December 10 – just in time for the 2010 Holiday Season!

If you would like to pre-order your copies, please make your check/money order payable to WNYPBN / Wings of Love. Then send your information to Christine Scott, Life Transitions Center, 150 Bennett Road, Cheektowaga, NY 14227. Pick-up dates and locations will be announced when the cookbooks become available.

By: Dawn Both-Kim

*Jennifer Opoka
Fundraiser Chairperson
& Christine Scott
Director WNYPBN*



As many of you know, my favorite book to recommend is Empty Cradle, Broken Heart: Surviving the Death of Your Baby, by Deborah Davis. The reason I like it so much is because it offers a variety of topics which help not only in the beginning but throughout your grief and healing journey. The topic which is pulling at my heart this time is responding to each others' needs during bereavement... or in other words, how are you and your partner doing?

Just as you have changed as a person through your loss, so has your relationship with your partner. Sometimes the change may feel for the better: you are communicating more, you are sharing your deepest feelings, and you are being comforted emotionally. Other times the change may not be for the better: you are arguing more, you have differing physical needs, and you are withdrawing from painful conversations. In the early stages of loss you may have felt that "closeness" that you both longed

for but as time goes on, it may feel like you both have lived through different experiences. Don't worry – this is very normal and with these few "tips" you too can survive this turbulent time.

- ◆ Share your thoughts and feelings, but be accepting of your differences. Verbalize your commitment to one another. Understand that conflict and change are inevitable.
- ◆ Try to understand each other's need for intimacy and sex. Sex may serve different purposes for each of you. Women may equate intimacy with hugging and tender stroking where as men may equate the act of sex as being intimate. In time, your feelings will change and your sexual relationship will become easier to negotiate.
- ◆ Anger and frustration are common emotions during bereavement causing outbursts and withdrawal. Reassure each other that you are not going to leave the relationship, but seek constructive ways to deal with these painful and confusing emotions.

- ◆ Constructive ways to deal with the above may include listening, acknowledging feelings, stepping back when your partner vents at times, and setting aside planned discussion times. I suggest setting a 10 minute period at the end of the day where both of you will talk about how you are "feeling".
- ◆ Stay as determined as you can that your relationship will survive. If you are having trouble seeing "eye to eye" discuss the possibility of counseling.

If you are without a partner or your partner is unwilling to enter into purposeful discussions about your/their feelings right now, seek the support you need from groups, newsletters, chat forums, or organizations such as the WNYPBN who can help you find another person in a similar circumstance.

Sincerely,

Fran

By: Fran Kane, RN
Bereavement Coordinator
*Footprints on the Heart,
Sisters of Charity Hospital*

Dear Still Parents NY,

I am so sorry to report that it did not happen for us this year.

The bill came in front of the Assembly Ways & Means committee and our bill sponsor, Assemblywoman Janele Hyer-Spencer, fought for all of us. There was a debate about the definition of stillbirth and when that was settled, our opponents then turned the tables on the title of our bill/document. At this point, even if we decided to go with some of the "suggestions" of a new title, we have run out of time to have the bill amended and presented again. It was clearly a ploy to prevent our

bill from passing this year.

All the seats in the Senate and Assembly are up for election this November. There will be a lot of changes. We will lose the support of many members who will be retiring and those they may lose their election. If you are in Assemblywoman Janele Hyer-Spencer (D) 60th Assembly District, which covers the East Shore of Staten Island and Bay Ridge, Brooklyn, please consider voting for her. She has gotten our bill closer to passing than any other legislator. (Our bill has been around since 2003, she took it over in 2008). She believes in the bill and has fought harder and

louder than any other legislator we have seen.

We wish to thank everyone for sending emails, making phone calls, and getting your family and friends involved in helping. All of it has made a difference. We were lucky to get our bill heard this late in the session and now we have some new information and can pick up the fight in January 2011. It's one I plan for us to win!

I hope all of you will join in again next year. We can't do it without you.

Thank you,
Paige

www.CBRsbill.blogspot.com

Thank you, Dawn, for last issue's article about Feelings of Guilt. I could totally identify with your feelings. After just having my second subsequent child after losing Jesse, I have been asked that question a million times. At the hospital, everyone kept asking how many children I had, or what number pregnancy was this. Some I answered with, "I have

one child at home." Others I said, "I had two but only one was living." It depended on what mood I was in. If I felt like explaining it, I said two. If I felt annoyed by the question, I said just one.

The house pediatrician was checking over my daughter and he asked how many children I had. I said, "Two. My first was stillborn and my second is living." He

looked at me puzzled and said, "Okay so you have one child." I want to yell, "NO I have two and now three!" I was angry, but knew he didn't care and it was only hurting me. Thank you for writing the article and assuring the rest of us that we are not alone when answering that stupid, stupid question!

By: Erin Neff

Date of Journal Entry:

April 8th, 2010

Dear Journal,

If there was ever a doubt in my mind that my baby was now in heaven looking down on me, it is gone now. Today is my second day back at the Catholic Shop. This morning was horrible. I was so overcome with sadness, I didn't even want to get out of bed. I seriously considered calling off from both of my jobs. Somehow, I made it out of bed.

We often have customers come into the Catholic Shop looking for St. Gerard items, for expectant mothers. Today, I had my first "St. Gerard customer" after my loss. She was looking for a prayer card and a small pin or medal. We had the prayer card, but no pins and

no medals. She seemed disappointed.

Then it popped into my head that I had been carrying around a St. Gerard medal on my keys. I told her, "I think I have one, let me go check my key ring." Then I hesitated a moment, worried I was too quickly giving away a memento of my baby. Then I thought, "It didn't work for me, but maybe it will work for someone else."

I took the medal off my key ring and handed it to her. Her eyes looked so grateful, and stunned. She even teared up a bit. We shared a hug.

As she was cashing out, she told me a little bit of her story. She is an acquaintance with a man that she only sees a couple of times a year. They share their problems

with each other and encouragement to get through. Recently, he was sharing with her how his daughter is pregnant, and having a difficult time. She is due in a month, but they might have to induce her next week because the baby isn't getting nutrients.

After she left I felt so glad I could play a small part in helping. I hope the medal comforts the mother and brings safe delivery to the baby. I then realized what day it was: the one month anniversary of the death of my baby. He is in heaven. He is looking out for me, and for others. He wants me to spread love, hope, and encouragement to others. I thank God for this day. How truly blessed I am.

By: Lena Croce



“Forget-You-Not”s

In Loving Memory of:



Michael Anthony Anderson April 5, 2005



We miss you and love you.
Love, Mommy, Daddy & Mia
Parents: *Michael & Kelly Anderson*

Angelo James Guido May 30-31, 2007

Gregori James Guido May 9, 2008

Mommy and Daddy love you, oh, so much!
Until we see you again, let your wings soar!
Parents: *Greg & Melissa Guido*



Christopher Michael Browne Feb 20, 2010

Mommy & Daddy miss you so much.
Heaven has a very special angel. We
love you!



Parents: *Christopher & Melissa Browne*

John Paul Jerebko November 18, 1999

We love and miss you so much!
Parents: *Peter & Lisa Jerebko*



Gavin Joseph Buckner September 15, 2009

Mama, Daddy and Zack loved you and
miss you so much. You are our little star
in the big sky. Love you!



Parents: *Amy & Ryan Buckner*

Marrina Kim August 3-4, 2005

Ella Grace Kim June 8, 2007

We miss you so much! Lots of love and
kisses from us to you both!
Love, Mommy, Daddy & Trent
Parents: *Mark & Dawn Kim*



Angela Marie Capage August 28, 2003

Happy 7th birthday to my sweet
baby girl! I love you with all my
heart! Love, Mommy, Daddy, Julia
Matthew & Morgan
Parents: *Chuck & Lisa Capage*



Elliot Moses Mis October 23, 2008

We love you and miss you!
Parents: *Adam & Sue Mis*



Amelia Emick April 15, 2010

Mommy & Daddy love you very much.
We feel you around us all the time! And
Mommy knows what you tell me!
Parents: *Heather & Victor Emick*



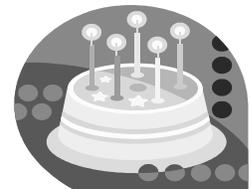
Nicholas Glomb August 19, 2009

We love you forever, we like you for
always, as long as we're living,
Our baby you'll be.
Happy 1st Birthday Nicholas!
Love, Mommy and Daddy
Parents: *Kelly & Tom Glomb Jr.*



Jesse Thomas Neff October 24, 2005

Happy 5th Birthday! We love
you and miss you so much.
Thank you for watching out
for your baby sister's safe arri-
val. Love, Daddy, Mommy,
Tyler, and Mackenzie
Parents: *Jeremy & Erin Neff*





"Forget-You-Not"s



In Loving Memory of:

Baby Opoka

November 21, 2008



Not a day goes by that we don't think of you. You will always be remembered & forever loved. All our love, Mommy & Daddy

Parents: Michael & Jennifer Opoka

Jacob Wesley Scott

May 27, 2000



We love you and think of you every day!
Love, Mommy, Daddy, Thomas & Mandy
Parents: Christine & Phillip Scott

Baby MayKayla

August 5-13, 2009

You touched our lives so completely for being with us such a short time. You are forever loved and will always be remembered!



Vivienne Pelletreau

July 31, 2009

Happy 1st birthday, beautiful baby girl! Forever our love, Mummy, Daddy & Elias

Parents: Alli & Pierre Pelletreau



Thomas Joesph Phillips

July 11, 2007



Happy 3rd birthday, Thomas! Love, Aunt Sue

Happy 3rd birthday! Daddy, Mommy and your brother Joseph miss you and love you very much. Love Mommy, Daddy and Joey

Parents: April & Terry Phillips

Kayleigh Renée Swain

January 30, 2010



Daddy and Mommy really missed you on Mother's and Father's Day. We hope you kept your Great-Grandparents super busy! We are looking forward to the Walk in October for you and all your Angel Baby friends. We miss and love you Baby Girl!

Parents: Tymon & Kate Swain

Raul Gabino Ramos III

Jan 23-26, 2010

Peanut, we miss you so much, love you and wish you can be here with us. Keep shining on us. Que Dios te Bendiga.

Parents: Maisie & Raul Ramos



Emery Nicole Tomaszewski

April 28th, 2010

Before you were conceived, we wanted you. Before you were born, we loved you. Before you were here an hour, we would die for you. We love you always and forever "Little Babygirl"/"Little E". Love, Mommy and Daddy

Parents: Mike and Nicole Tomaszewski



Dayanara Cecilia Sanchez

March 21, 2010



Not a day dawns nor a sun sets that your mommy and daddy do not think of you. We love you and miss you very much, baby girl.

Parents: Jose & Judy Sanchez

Adriana Urbino

Feb 19, 2009 – May 28, 2009



We miss you so much! Not a day goes by that we don't think about you, our little angel!

Love, Mommy, Daddy & Gabriel

Parents: Tanya Rathbun & Sam Urbino

Robert Michael Sullivan

October 20, 2004

We can't believe you would be nearly 6 years old now! We miss you more than ever! Love, Mommy, Daddy, Izik & Raymond

Parents: Tamara & Jim Sullivan



Interested in Submitting a Memorial?

Please email your baby's Forget You Not to:

forgetmenotnewsletter@hotmail.com

Submissions are due by the 15th of the month before the next issue is due out.

Family members and friends are also encouraged to submit: not just parents!

My name is Lisa Wolff, and I have been a labor and delivery nurse at Mercy Hospital since 1992. On July 23, 1989, my husband and I lost our precious son, Nicholas Anthony Wolff. He was born still.

When I was at work, I would always ask to take an assignment if there was a patient who was experiencing this same devastating loss. I could honestly relate to what they were going through, and was there to help in any way that I could. I felt I needed to do something positive for these families and give them all the memories I could. I did this out of love and remembrance of my first son. You just can't imagine all the memories

you wish you could have unless you have actually been there.

I am now the department Perinatal Bereavement Coordinator, as well as a labor and delivery nurse. I am very pleased that we have this program in place. We have chosen to call our program "Baby Steps to Healing" because that is exactly what you need to do to get through your journey of grief. They are to take baby steps.

Thanks to a very generous donation from one of our Obstetricians, Dr. Gil Farkash, I have been able to form a restricted bereavement fund through The Mercy Hospital Foundation in memory of my son

Nicholas. It is called the Nicholas Bereavement Fund and I could not be more honored. With this money, I will be able to provide our families with the much needed information, mementoes and support to all who experience the loss of their baby at our facility.

If you would like any more information about the Nicholas Bereavement Fund, please feel free to contact me at (716) 828-2618 or at Mercy Hospital, 565 Abbott Road, Buffalo 14220.

Thank you,
Lisa Wolff, RN
*Perinatal Bereavement
Coordinator, Mercy Hospital*

Maddy's Story:

My name is Tara Bukowski, and I am a wife and a mother of two. My son, Tyler, is 4 1/2 years old, and my daughter Madelynn would be 6. May 27, 2004 was the worst day of my life. I was 8 months pregnant with my daughter and already on bed rest due to pregnancy complications. I had a routine OB doctor's appointment. I'll remember that day for the rest of my life. My doctor couldn't find a heartbeat. He then did an ultrasound and it was confirmed that my little girl didn't make it. My doctor called the hospital to tell them what happened, and to expect me soon so they could induce labor. I don't really remember my drive home. I just remember calling my husband and telling him that he needed to come home immediately.

When we got to the hospital, I was in complete shock. I didn't want to go to the Labor & Delivery ward because I knew that there were women up there who were going to be taking their babies home... and I wasn't. They induced labor at 3:30 PM, and at 9:56 PM my daughter was born. She was so

tiny, she only weighed 3 lbs 2 oz. She had a full head of dark wavy hair and was absolutely beautiful. I had the nurse, Erin, put her in a pink & white nightgown I had brought for her. When I first held her I noticed a few birth defects and it broke my heart all over again. Some of her fingers and toes were fused together, and she had a strange indentation across her mouth.

The nurse, Erin, was a Godsend! She was so understanding and did everything she could for us. She gave us a disposable camera so we could take the only pictures we would ever have of our daughter. She also gave us her footprints and a lock of her hair. We were able to keep our daughter with us for as long as we needed.

When I finally handed my daughter over to the nurse, I knew it was the last time I'd ever hold her... that I'd never be able to rock her to sleep or send her off to kindergarten. It's the little things that I longed to do with my daughter that most people take for granted. Two days later we had a small ceremony for her at the cemetery before she was buried next to her

great-grandfather. I didn't think I could possibly handle anymore heartache. The worst thing is to have to bury your own child who never got to experience life.

My husband and I waited agonizingly for weeks for her autopsy report so we could understand what went wrong. When the autopsy report finally came it explained nothing. We were then sent to a genetic specialist at Children's Hospital who was finally able to give us an answer. He told us that my daughter had suffered from amniotic band syndrome. It's when the bands around the amniotic sack break and causes amniotic fluid to slowly leak. The amniotic bands then wrapped around her fingers and toes causing them to fuse together during development and across her mouth cutting off the circulation to her brain when she was growing. The bigger she got, the tighter the bands got until it completely cut off all her circulation. We were told that if she would have survived she probably would have had some brain damage from the lack of

Continued on page 9 



The Newsletter Committee is looking for submissions of articles, blurbs, poems, stories, memorials, etc. Submissions may be emailed to:

forgetmenotnewsletter@hotmail.com

or addressed to: Dawn Both-Kim,
1 Montclair Ln.
Orchard Park, NY 14127

Gage Andrew Miller August 15th, 2000

To our dear, beautiful son ~
Although 10 years ago,
it seems like only yesterday we held you
and had to say good-bye.

Our hearts were broken.
But we are so lucky to have
had been blessed with you,
because your brief life has shaped us
into the parents we are today.

We are so grateful for your life!
There isn't a day we don't think of you.
There isn't a day we don't love you.
There isn't a day we don't miss you.

There isn't a day...
Celebrate with the angels...
All our love, today and always,
Mom & Dad,
Paris, Cole and Preston Miller



Kids' Stuff

We've recently added a few features to the Newsletter that we are hoping you all appreciate reading. The Network News section lets people know what the WNYPBN actually does with the monies we work hard to earn. Fran's Corner gives a little insight from our dear Bereavement Coordinator, L&D nurse, counselor and friend, Fran Kane. We were thinking about adding another feature, if we can get the support from our readers. I'd like to call this feature, "Kids' Stuff."

Children are effected by perinatal loss, whether the loss happened before or after they were born. They must work through their grief, the same as the rest of us. We'd like to publish pictures, poems, stories, etc. that were drawn/written by your bereaved children. So that the kids can know that they, too, are not alone.

If your child has drawn or written something they would like to share, please send it to the submissions address listed above. I will treat each piece carefully and will return it to you as soon as possible. If you have the means and can scan the work, please send it to: **forgetmenotnewsletter@hotmail.com**.

Thank you and let's start another new feature!

Dawn Both-Kim

Maddy's Story (Continued from page 8)

circulation, as well as other special needs. The doctor told us they don't know yet what causes amniotic band syndrome and there's no known way to prevent it. My husband and I finally had an answer, but it didn't make our pain any less.

My son was born 16 months after the loss of our daughter and it makes me realize not to take anything with him for granted. If my daughter didn't pass away, I would've never been blessed with

my son. I couldn't imagine my life without him. When my daughter passed away I was very bitter and angry. One of the only things that helped was knowing that my mother-in-law, who was never able to experience grandchildren, was up in heaven taking care of my daughter. This past October, my mother-in-law and daughter were joined in heaven by our nephew, Joseph. Thank you very much for reading my story, I hope it helps another family going through a loss.

By: Tara Bukowski

The WNYPBN has an electronic version of the Department of Health's application for a copy of Fetal Death Record. For some of us, this is our only legal proof of our baby's existence.

To obtain this form, please email **forgetmenotnewsletter@hotmail.com** or contact Christine Scott at 836-6460 ext. 117.

The form is short: one page. All that is needed for submission to the Dept of Health is a copy of the mother's driver's license or non-driver ID along with the form.

By: Dawn Both-Kim



Safe Arrivals



Arianna Skye Bilz was born on June 3, 2010 at 10:05 PM to Dianah and Justin Bilz. She weighed 6 lbs and 11 oz and 19 in long. Along with their daughter Haylee, the family will teach Arianna about her big brother in heaven, Jayden Thomas (July 14, 2008). "We love you and always think of you. Thank you for blessing us with your new little sister!"

Katie and Kevin Guthrie are thrilled and blessed to announce the birth of **Miriamne Margaret Ehrin Guthrie** on November 3, 2009. She was 3 weeks and 1 day premature, but a healthy 5 lbs 10 oz. We are truly blessed with our new miracle, and will always remember with her our lost angel baby on June 18, 2006, and our beautiful baby boy Ehrin, born sleeping on April 13, 2007.

Big Brother Tyler Neff would like to introduce the world to his baby sister, **Mackenzie Anna Neff**. She

was born on April 19, 2010, and was 6 lbs 13 oz and 20 1/4 inches long. The happy parents are Jeremy and Erin Neff. The family will always remember Jesse Thomas born on October 24, 2005.

Marc and Sheila Sampson and big brother Evan are proud to announce the arrival of **Sara Maureen Sampson** on November 27, 2009. She was 6 lbs 7 oz and 21 inches long. She is being watched over by her big sister Rachel Maureen (1/17/05) and twin brothers Joshua William (12/10/05) and Nathan Joseph (12/11/05).

Gabriel Urbino was born on May 14, 2010. He was 7 lbs 4 oz and 19 inches long. Mommy & Daddy, Tanya Rathbun and Sam Urbino will teach him all about his big sister in heaven, Adriana (February 19, 2009 – May 28, 2009).



Area Support Groups



Caring Arms Support Circle

Stillbirth or Early Infant Death

When: 2nd Tuesday @ 7:00 pm

Ministry Center, Rm #4

100 St. Gregory Court, Williamsville

Next to Millard Fillmore Suburban

Contact:

Denise Hudden, RN, 568-6653

Circle of Hope

Death and/or Serious Illness-Niagara Hospice

4675 Sunset Drive, Lockport or

2186 Liberty Drive, Niagara Falls

Contact:

Outreach Department 280-0777

Footprints on the Heart

Stillbirth and early infant death.

Call for further details.

When: 4th Thursday @ 7:00 p.m.

Life Transitions Center

150 Bennett Rd.,

Cheektowaga

Contact:

Fran Kane, 862-1678



Heart to Heart

Early loss, miscarriage and ectopic pregnancy

Call for further details

When: 1st Thursday @ 5:30 p.m.

M. Steven Piver Center, Suite 100

Sisters Hospital, Seton Bldg

2157 Main St, Buffalo

Contact:

Fran Kane, 862-1678

Hopeful Hearts/Subsequent Pregnancy

Support for pregnancy after a perinatal loss

Call for further details

When: 2nd Thursday @ 5:30 p.m.

M. Steven Piver Center, Suite 100

Sisters Hospital, Seton Bldg

2157 Main St, Buffalo

Contact:

Fran Kane, 862-1678

Parent-Telephone Support Team (PTST)

Speak with another bereaved parent who has endured what you have endured.

Contact:

Lesley Jordans, 878-7773

SIDS Family Support Group

SIDS and Infant Death

Joan A. Male Family Support Center

60 Dingens St., Buffalo

Contact:

Jan Walkden, 822-0919

Sibling Grief

Young Sibling (5-16 yrs)

Adult Sibling (17 yrs-adult)

When: 2nd Wednesday of each month
6:30 pm

1st Trinity Lutheran Church

1570 Niagara Falls Blvd, Tonawanda

Contact:

Lesley Jordans, 878-7773

Storm Clouds & Rainbows

A Support group for children, teens and their caregivers after the death of a loved one.

When: Wednesdays

6:30 p.m. - 8:00 p.m.

Life Transitions Center

150 Bennett Rd., Cheektowaga

Contact: **Jim Grande, 836-6460**

"Tiniest Angels" Parent

Bereavement Support

Miscarriage, ectopic pregnancy, stillbirth, and early infant death

When: 3rd Wednesday of each month
7:00 pm

Baby's Sweet Beginnings Lactation & Wellness Center

231 Aurora Street, Lancaster

Contact:

**Polly Thomann to register or
Christine Scott, 681-8100**



Internet Support and Keepsake Resources

Ashwood Artisans

726 Main St. in East Aurora (716) 652-7333
Engrave footprints onto charms for necklaces, tie tacks, etc.

Baby Photo Retouching Service

www.babyphotoretouch.com
Transforms your precious baby photos through digital technology to correct some of the damaged image.

Born Angels Pregnancy Loss Support

www.bornangels.com
Provides links to pregnancy loss support, infertility support, neonatal loss support, and adoption resources.

Celebration Forest

www.celebrationforest.com
Allows you to plant a tree in honor of your deceased beloved one

Facts About Miscarriage

<http://www.pregnancyloss.info>

The Grief Recovery Institute

<http://www.grief-recovery.com>
The action program for moving beyond loss

H.A.N.D.

www.handonline.org
"Help After Neonatal Death"
Helping cope with the loss of a baby before, during, or after birth

A Heartbreaking Choice

www.aheartbreakingchoice.com
For parents who have interrupted their pregnancies after poor prenatal diagnosis.

Hygeia.org

www.hygeia.org
An online journal for pregnancy and neonatal loss.

Memory Pendants

www.memorypendants.com
Use code: **112188** to receive a discount for families affiliated with our organization
Owner Chuck Huffman- L. Huffman Studios

M.E.N.D.

www.mend.org
"Mommies Enduring Neonatal Death"
Quarterly newsletter and an internet support group site.

M.I.S.S. Foundation

www.misschildren.org
Provides immediate and ongoing support to grieving families, empowerment through community volunteerism opportunities, public policy and legislative education, and programs to reduce infant and toddler death through research and education.

National Share Office

www.nationalshare.org
To serve those whose lives are touched by the tragic death of a baby.

A Place to Remember

www.aplacetoremember.com
Uplifting support materials and resources for those who have been touched by a crisis in pregnancy or the death of a baby.

Remembering Our Babies

<http://www.october15th.com/>
The official site of pregnancy and infant loss remembrance day.

Sara's Smile

www.Sarasmile.org
Operates to fill the arms of grieving mothers with a Sare Bear© giving them something to fill that empty space as they grieve for their child.

Star Foundation

www.starfoundation.net
Gives you the opportunity to Name a Star in the sky after a friend or loved one.

Stone Art Memorial

www.stoneartmemorial.com
The Right way to commemorate your memories.

Trisomy Support

www.trisomyonline.org



WNYPBN WishList

The WNYPBN is in need of your help. As you know, we are beginning the work to become an independent, tax-exempt organization. Many of the supplies that we take for granted will need to be purchased from now on. Therefore, we are asking our Network of bereaved parents if they can help us out with our supplies.

We are in need of the following:

- Reams of paper (standard copier weight/printer paper)

- Printer ink (black: HP98, color: HP95)
- Envelops (business size and invitation size)
- Stamps (Postage!!)
- White and Off-White card stock paper (various weight)
- Thank You Cards
- Folders (file and hanging)

We also help supply volunteers who create items for memory boxes, blankets and gowns for the hospitals. Helpful items would include:

White fabric, Lace, Ribbon, Buttons, White Thread. Paints, unfinished cardboard boxes (all sizes)

If you are able to supply some or any of these items, please contact Christine Scott at 836-6460 ext. 117 or cscott@palliativecare.org to organize a time when you can drop off the donations at Life Transitions Center. Since this is a charitable donation, we would be happy to oblige you with a letter of thanks for tax purposes.



Dawn Both-Kim

Subscription Renewal

We would like to inform you of our policy regarding sending out this newsletter. We will send this newsletter, **free of charge, for 4 issues (1 year's time) after your loss.** After this time, if you would like to remain on our mailing list, we are asking for a \$5.00 contribution to help defray the publishing costs. Following this mailing, any labels not current will be removed from our mailing list. If your free subscription is no longer valid, and you wish to continue receiving our newsletter, please fill out the renewal form and forward a check for \$5.00 payable to **WNY Perinatal Bereavement Network**, c/o Christine Scott, Life Transitions Center, 150 Bennett Road, Cheektowaga, NY 14227. Please note on the check it is for the Forget-Me-Not Newsletter. This fee will cover a one year period, or 4 newsletters. Thank you very much for your cooperation as we update our mailings. If you are receiving duplicate mailings please let us know by either email or US mail. If there are any financial concerns that prohibit you from subscribing, please notify us by email or US mail, and we'll be happy to continue your subscription. If you have received this newsletter through your bereavement packet at the hospital and have not signed a release at the hospital to receive this newsletter, and you wish to assure you will receive it in the mail, please forward your name, address, baby's name, baby's date of birth/death, and hospital where loss occurred to the same address, or email to **forgetmenotnewsletter@hotmail.com**

Name: _____

Address: _____

City/State/Zip: _____

Hospital loss occurred: _____

(Please include the following if you would like your baby's name(s) listed in the memorial section of the newsletter)

Parents Names', Baby's Name(s) and Honored Dates: _____

If you would like any poems/stories/letters/etc published, please email to: forgetmenotnewsletter@hotmail.com

If you would like your name removed from the mailing list please send your request to:

Forget-Me-Not
C/O Christine Scott
Life Transitions Center
150 Bennett Road
Cheektowaga, NY 14227

Email: forgetmenotnewsletter@hotmail.com Subject: mailing list

If you would be interested in having the newsletter emailed directly to you in .pdf format as opposed to getting a paper version, please contact the email address above.

*This Newsletter has been printed courtesy of Twenty First Century Press.
Contact **Twenty First Century Press** for all your printing needs: (716) 835-5907
523 Cornwall Ave., Buffalo, NY 14215*

Forget-Me-Not
C/O Christine Scott
Life Transitions Center
150 Bennett Road
Cheektowaga, NY 14227

Forget-Me-Not
Volume VII Issue III, 2010

