



Compassionate  
Passages, Inc.

# Spring 2009 Newsletter

*Bringing awareness to and offering solutions for the challenges families face when a child is dying.*  
May 2009 🍀 Issue

Dear Family, Friends, Colleagues, and Supporters,

Wow, another year has flown by and part of the reason it has is due to Compassionate Passages being involved in many wonderful new projects. We are excited to share with you the work we have been doing improving care for ill children and their families. We are also energized by the numerous collaborations we've forged in our key areas of advocacy, education, and research. And yes, it's that time again, our annual rubber duck race fundraiser!

On behalf of the families that we represent and serve, we are grateful for your support!

*Beth Seyda and Ann Fitzsimons*

## Advocacy

**PLIDA:** Beth recently stepped down from serving a two-year term as Board President of the Pregnancy Loss and Infant Death Alliance (PLIDA [www.plida.org](http://www.plida.org)) and is now serving in a past-president role for the next two years. It was rewarding to lead this national collective community of healthcare professionals and parent advocates who are dedicated to ensuring that all families experiencing the death of a baby receive comprehensive and compassionate care. Beth is proud of helping this organization make progress in achieving its goals and hosting a successful 16<sup>th</sup> National Perinatal Bereavement Conference in October 2008 in FL. Below is a thank you note that she received from Christine Jonas-Simpson, a bereaved parent and poster presenter at the conference:

*From the bottom of my heart I want to thank you for the wonderful conference. Thank you for opening your doors to me when I was past the deadline. I had the most wonderful, inspiring experience and look so forward to the next PLIDA. It was just incredible to meet you in person and the many others I connected with over the few days we were together. Thank you for this experience and for all you do.*

Bereavement photographer Todd Hochberg moderated a parent panel that Beth was a member of. She spoke about the importance of photographs in the healing process. A person attending the session had this to say:

*Loved hearing from women who had experienced loss & willing to share personal stories & pictures, especially as each scenario was unique, compelling.*

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**Compassionate Passages**  
is the family voice for supportive  
pediatric end-of-life care via  
advocacy, education, and research.

**On the Hill:** One of most exciting projects we were involved with this past year was collaborating with First Candle, a national organization that supports families who experience the death of a baby from stillbirth or SIDS ([www.firstcandle.org](http://www.firstcandle.org)). Compassionate Passages participated in their March 2009 National Research & Advocacy Symposium held in Washington DC where more than 150 parents, health care professionals, and leading researchers gathered. We provided sponsorship funds, specifically to support families to attend. Beth attended the symposium and learned about current research efforts, preventative strategies, and educational outreach programs. She thoroughly enjoyed her first time going to Capital Hill to advocate and garner support for pending Senate and House bills that would authorize appropriations for prevention, education and awareness of stillbirth/SIDS. Beth reviewed and provided comments on the legislation drafted by US Senator Frank Lautenberg's office, a sponsor of the bill. Beth then teamed up with another NC bereaved parent, Cristi Leone, and had a full day of meetings with the

## Advocacy -- cont'd



On the Hill - cont'd: health policy staff of their Congressional Representatives David Price and Sue Myrick and US Senators Kay Hagan and Richard Burr. Beth and Cristi were thrilled to meet freshman Senator Hagan and have a quick cell phone photo op before they met with the Senator's staff (Beth, Senator Hagan and Cristi in photo to the left). All the staff thanked us for taking the time to share our personal stories and tell them about the bills, and they greatly appreciated putting names and faces of parent-constituents to the bills and not professional lobbyists. It was great experience to learn of yet another way we can make an impact and improve care -- this time through health policy at the national level! We look forward to more advocacy on the Hill. Thank you to dear friend and loyal Compassionate Passages' supporter, Diane Colasanto, for the hospitality of her perfectly located Georgetown home.

## Education

In both our writing and presentations this past year we have continued to expand our messages beyond the traditional healthcare issues and into more spiritual themes. We're trying to educate people caring for dying children and their families to not only listen with their heads, but with their hearts and souls.

Children's Hospice International 19<sup>th</sup> World Congress: Ann and Beth attended this international conference in San Francisco, CA in November 2008 and presented two sessions titled *Everlasting Bonds of Spirit: Deceased Children and their After-Death Communications with Loved Ones* and *When a Child Dies: Spiritual Struggles and Solace*. The conference was well-attended, as were our talks. It was also a great chance for us to network and catch up with friends and colleagues in the field of pediatric palliative care. We submitted presentation proposals for the 20<sup>th</sup> World Congress and are waiting to hear if we will be on our way to Cape Town, South Africa.


Newsletter: Ann and Beth continue to write for the Children's Project on Palliative/Hospice Services (ChiPPS) E-Newsletter, a national pediatric-focused group within the National Hospice and Palliative Care Organization. We contributed to 4 articles during the past year and these can be found at [www.nhpco.org/pediatrics](http://www.nhpco.org/pediatrics). Ann continues to serve on the Communication Committee which compiles and publishes this newsletter, and she is instrumental in securing family contributors so that a "family voice" is included in every issue.

Contributing to Book: Ann and Beth have just completed co-authoring a chapter on Infant Death for the professional textbook, *Children's Encounters with Death, Bereavement, and Coping*, edited by Charles A. Corr and David E. Balk. The book will be published by Springer Publishing Company in 2010 and is being targeted to healthcare practitioners, counselors, educators, and grief/bereavement professionals. We were honored to be invited to contribute to this prestigious publication and to work with our good friend and mentor, Chuck Corr. After seven months of hard work, the final edits were approved this week.


Healing the Grieving Heart Internet Radio Show: Gloria Horsley, president of the Open to Hope Foundation and producer/host of the internet radio show *Healing the Grieving Heart* invited Beth to be a guest on her show. Beth was on-air live in October 2008 along with a bereaved mother/author who we know, Monica Novak. The show was heard by over 40,000 people and was another way to reach and teach the general community about supporting families. Cary Sholer, from CA wrote this to Beth via email...

*I listened to your Internet radio interview this evening and heard you making yourself available to comfort others and to share through your program, movie, and speaking engagements. In your grief, you found something, something to cling to, and now you supply it to others -- hope and comfort. I listened to your message in the radio interview and noted how much emphasis you place on "being present" if you are the parent losing a child and to "find anything to lighten the work load" if you are the friend. Great advise. Great wisdom.*


**HEALING  
THE GRIEVING HEART**  
with Drs. Gloria & Heidi Horsley




THURSDAY OCTOBER 30TH 2008 AT 9AM PACIFIC (12PM EASTERN)



The Good Grief Club  
MONICA NOVAK



Compassionate Passages, Inc.



Tune in to Listen  
[www.Health.Voiceamerica.com](http://www.Health.Voiceamerica.com)  
Questions? Comments?  
Call: 1-866-472-5792


**Miscarriage and Infant Loss**

**Monica Novak** became a bereaved mother in 1995 with the stillbirth of her daughter Miranda. Monica's mission has been to bring comfort to bereaved parents and to promote awareness to the physicians, nurses, clergy, counselors, family and friends. She is the author of *The Good Grief Club*.

**Beth Seyda's** life was transformed in 1997 with the death of her newborn son, Dylan. She is Executive Director of Compassionate Passages, researcher, author, and co-producer of the award-winning educational film *When a Child Is Dying* and the accompanying *Supportive Care Handbook*.

Missed the Live Show? This episode rebroadcast at 9pm Pacific (12am Eastern)  
Past Episodes are available On Demand and Podcast Ready

For More Information on Dr. Horsley or grieving support services Visit:  
[www.TheGriefBlog.com](http://www.TheGriefBlog.com)



## Education - cont'd

Beth's show is archived and can be found at:  
[www.voiceamericapd.com/health/010157/horsley103008.mp3](http://www.voiceamericapd.com/health/010157/horsley103008.mp3)

Gloria then asked Beth to be a regular contributing author to her Open to Hope website [www.opentohope.com](http://www.opentohope.com). Beth has written a few articles, one just recently for Mother's Day. Both the radio show and articles have provided further opportunities to educate others and exposure for Compassionate Passages.

**Upcoming Conference:** Ann and Beth will be making three presentations at the 4<sup>th</sup> International Conference on Patient- and Family-Centered Care in Philadelphia later this summer. This is a new conference for us and we're excited that it offers a larger (~1,300) and broader audience to learn about pediatric palliative care issues. We'll also be spending some time at the Children's Hospital of Philadelphia (CHOP), which is one of the top (if not THE top) children's hospital in the country.

## Research

**NIH:** Last year at this time we had just learned that Beth would be a consultant on a research project funded by the National Institutes of Health (NIH). Over the past year she has worked with Danya International as an advisory panel member who reviewed research and materials developed for *Communic-Aid: Supporting Communication Needs for Families with Terminally Ill Children*. The project is developing and evaluating the Communic-Aid program -- a practical, innovative, and comprehensive resource for parents, group facilitators, and direct care providers to support family communication when a school-age child has a life-threatening illness. Beth's role on the project expanded when additional qualitative research was conducted and Compassionate Passages' network assisted with recruiting families and healthcare professionals to participate. Beth then moderated focus groups with NC families and Ann also joined the team and conducted a focus group in MI.

This project has been very rewarding in that it enables us to use our research expertise, provide a patient/family perspective, and tap into the community of families and colleagues that we have developed over many years. We are pleased that Danya Int'l recognizes the value of our contributions and has invited both of us to be part of Phase 2 of the project. The proposal for funding the next phase has been submitted and we're keeping our fingers crossed.

## Other News

**Resources Available:** We continue to donate the book *Empty Cradle, Broken Heart: Surviving the Death of Your Baby* by Deborah Davis to families. We also have the article that Beth wrote for the NJ March of Dimes on what to say/do and *not* say/do after the loss of a baby. Please do not hesitate to contact us if you or someone you know could use these resources.

Compassionate Passages has been on the receiving end as well as we had several books entitled, *Journeys of Heartache and Grace: Conversations and Life Lessons from Young People with Serious Illnesses* by Melody Chatell, gifted to us to help support families. Thank you to Melody and the family who donated these books to us.

## Other News - cont'd

International Connections: Compassionate Passages continues to make an impact around the globe and here are just a few examples.

Ann has joined the African Hospice Partnership Project being sponsored by the Foundation for Hospices in Sub-Saharan Africa (FHSSA). FHSSA's vision is for all people who are affected by HIV/AIDS to have access to and receive quality palliative and end-of-life care. Sadly, many of those who die are children. Through a connection with the Hospice of Michigan, Ann is working with a committee partnering with St. Luke's Hospice in Cape Town, South Africa to help provide the resources for the 900+ hospice patients it cares for each day.

We heard from Melanie Steilen, a nurse from NY, that she is using our award-winning educational film, *When a Child is Dying*, when she teaches pediatric palliative care to community based organizations in South America.

Just this week we received an email from Habib Alam Raza, a neonatologist (physician who takes care of newborns in the intensive care unit) in Saudi Arabia. He was working on a lecture on neonatal palliative care and came across Beth's work and "found it most inspiring." Dr. Raza asked us for recent trends and developments in this evolving field as he thinks it is still a neglected area.

Annual Rubber Duck Race Fundraiser: The river is flowing and the ducks are starting their work-outs in preparation for the 2009 race. Compassionate Passages was a top selling partner again in 2008, providing 408 ducks of the total 3,592 ducks in last year's race (see photo to right). The 2009 rubber duck race will have even more winners as there are **20** fabulous prizes this year! The race is June 6<sup>th</sup> and **your "duck adoption" paperwork and check must be received by June 3<sup>rd</sup>**. For every \$10 donated, \$5 remains with Compassionate Passages and \$5 goes to the Rotary. An order form and details are enclosed.



Charitable Donation: Please consider adopting a duck (or a ducky dozen!) or making a direct tax-deductible donation to Compassionate Passages and supporting our work improving end-of-life care for children and their families. Please make your check for a direct donation payable to Compassionate Passages, Inc. and mail it to either NC or MI address. If your employer matches your donations, please send us the matching gift form.

## In Memory

Michelle Mayer, a friend, colleague, and Compassionate Passages supporter, died in October 2008 at the age of 39 from scleroderma. Michelle and Beth first connected in 2003 when Michelle led the Elizabeth Ministry program at a local church and invited Beth to teach a session on perinatal loss/grief for their volunteer training. Michelle's illness made her a fierce advocate for herself and their common interest in patient advocacy issues was a bond. Michelle wrote about her journey at <http://diaryofadyingmom.blogspot.com>. We keep Michelle's husband and two young children in our thoughts and her spirit and passion continue to inspire us.

## Parting Thought

We are grateful to Maureen Horgan and Jane Fleming for their wonderful presentation *Hope is the Thing...The Challenges of Communicating Hope* that they presented at the international pediatric hospice conference we attended last fall. We leave you with these words about hope from Vaclav Havel...

*It is an orientation of the spirit, an orientation of the heart; it transcends the world that is immediately experienced, and is anchored somewhere beyond its horizons.*