

The Sudden Infant & Child Mourning Outreach Network
Of Vermont and Northern New England

The SIMON Project

(Meeting notes and up-dates for July, August and September 2006)

Happy Fall to you All.....!

I apologize if you haven't been hearing from me as regularly as usual. We (Michelle & I) have passed a milestone in our first anniversary of Simon's death on August 22nd. We are also looking forward to the arrival of our second baby, due on or near November 11th. With the imminent arrival of our second baby comes the emotional wave of fear and anxiety. We wish to thank all of you who remembered the anniversary of Simon's death – as that is now one of our most important personal dates, as well as helping us to celebrate the arrival of our new baby. Within the pain of Simon's death is the joy of our new little girls pending arrival.....such a spectrum of emotions and feelings. Many of you have already experienced just such a roller coaster. Other's, have not ever been given to opportunity to conceive and / or have a child of your own after many attempts. Please know that we are keeping you ALL in our thoughts and prayers. We are joined by the death or deaths of our beloved children – but we are also joined as human beings who experience life and death as a continuum of our personal journeys of soul and spirit. Life's energy is strong and surpasses that of our intellectual capacity. I know we all stand together regardless of our beliefs in the wonders of life and death, of pain and heartache and in joy and celebration.

1. We (as a group at the July meeting) have decided to sign and affiliate with the MISS Foundation's programs and work. We will be an independent program that will become a member chapter of the MISS Foundations Support Groups. This will afford us the training, support and experience of a wonderful organization that is already blazed a trail for this type of work for the past 10 years. Thanks to the great work of Joanne Cacciatore and her team in Arizona, nationwide, and internationally.
2. The SIMON Project web site: at the July meeting, the group agreed to use the Simon Fund monies to jump start the web site. This was originally going to cost us about \$400.00. But, as we have learned, striving to be as comprehensive as we want to be with the site, it will cost considerably more. At the September meeting, it was agreed to continue with the web site development and get it up, full of necessary content and running as soon as possible. Although the original site is still available at the address advertised, the new improved version can be viewed at (www.offthepagecreations.com/simonproject). Eventually, this will be placed at the original web address. If you take the time to really explore the site, you won't be disappointed in most cases. The link from the home page to the "what to think about just after the death of a child" content is still be developed. This is some of the most important content for the site, so we want it to be sensitive and clear. If you have ANY input on the content, organization, or have

- up dated information that needs to be placed on the site, please contact me (Jeff) either by phone or by e-mail. We are also looking for additional family stories to be added to the site – which can be done directly through the site if people want to, and photos of your children who have died to be rotated on the front / home page along with Simon and Maddie. Any and all input is welcome.....!
3. Funding / Grants.....along with my discouragement and frustration regarding this area of our project, comes the realization that we can begin small and grow. We learned that we didn't get the CJ Foundation grant back in June. We were expecting to hear from The Kinney Foundation in July, then August.....but as of today, I have not heard back from them even after leaving several messages for the grant coordinator at her office. We will continue to explore our options in this area and will begin to develop a fund raising campaign to generate the needed funding we need to buy materials to give out to parents and families for free and to training our peer to peer outreach volunteers etc. You may have noticed that people can made a donation to The SIMON Project through the web site now – via PayPal's secure system. Please encourage those interested to use the web site to become educated about our very important work and as a method of financially support our efforts reaching out to bereaved parents, families, children and communities.
 4. Additional Income: This is the area of our most unexpected but incredibly gracious sources of donations. Some very talented SIMON Project supporters and participants have set up donations to help support our work. First, is Jennifer Stocks-Dearborn – her personal story is on the web site. She is Maddie's mother. Jenn sculpts miniature clay "babies". She recently sold one on e-bay to raise money for The SIMON Project – bringing in \$80.00 in which she handed me a check for at the Sept. meeting! Thanks Jenn....! Thanks for your support of the project, your participation, the donation and your great energy! Secondly, is Heather Paine – who's business DragonFly Gifts - is producing and selling a SIMON Project Candle both on her cart at the Burlington Church Street Marketplace and in her organization fund raising projects. About \$2.00 from every SIMON Project candle sale is donated back to support our work. Check out her web page directly from The SIMON Projects "Links" button. Share this with your family and friends, especially as we approach the holidays! Heather has many other wonderful products available on her web site as well. Annually, Heather will send us a check for her sales. Thanks Heather.....! And third...is Nina Bennett. Nina and I met in Arizona at the MISS Foundation Conference. She has authored a book called "Forgotten Tears, A Grandmother's Journey Through Grief." A link to her book in on The SIMON Project web site. For every purchase from our site, Nina will donate \$2.00 back to us to support The SIMON Project. Thanks Nina.....! You will find this book to be very helpful and quite touching.
 5. The Vermont Department of Health has produced some new materials for those who have experienced a SIDS or SUDI Death. In addition, they have produced a "safe sleep" brochure and some additional materials to support parents and families. They are currently in draft form and are being edited and commented on. When they are ready for the public, they will be available on the VDH web

- site. We will have a direct link from The SIMON Project web site to this information as well. An offer went to VDH's Central Office SIDS / SUDI Program and the Office of the Chief Medical Examiner in Burlington to develop a page on The SIMON Project's web site with their information and educational material – but to date, they have not responded. We reviewed the new VDH materials at the September meeting. Language seems to be the most pressing concern. We would like to see the phrase “reducing the risk” instead of “ways to prevent” in the case of SIDS / SUDI.
6. Congratulations....! To the SHARE HOPE group in Burlington. This is the newest of groups started to support parents who have experienced some type of infant death in the Champlain Valley. A group of professionals and parents have started this group up as a project of Fletcher Allen Health Care and the Maternal Child Health Coalition of Chittenden Cty. They will be using a facilitated group process with leaders trained in the Share (a national bereavement support training program). You can see their brochure and group information on The SIMON Project web site under Vermont Resources / groups / SHARE HOPE. They have also recently conducted a media campaign and (were / will be) featured on a news spot with channel 5. Thanks to you all in this large and caring group of people who saw the need and developed the necessary programming in the Champlain Valley to support bereaved parents. Because Burlington (FAHC) is the only community in Vermont to have a Neo-Natal Unit (NICU) and Pediatric Intensive Care Unit (PICU), many more families end up there initially if they experience complications with their pregnancy, births or pre-maturity etc. Great work to the entire group, Thanks for your efforts.....!
 7. Amanda Shiverick, LICSW of Lamoille Home Health and Hospice donated a book to The SIMON Project that outlines all the legal information about funerals and caring for the dead – it is a comprehensive state by state listing. We will use this to develop our section on the web about parent's rights and planning for memorial / funeral services at home and caring for and transporting the deceased. Thanks Mandy for your support and participation of The SIMON Project.
 8. Up-Coming public relations events: I (Jeff) am meeting with the Barre Clergy Council in early October to present The SIMON Project information as well as the Waterbury Rotary Club and the Central Vermont Early Childhood Council in November. If you know of a group that would be interested in hearing more about our work or who would be interested in helping to support our work, please let me know and I'll follow-up with a call to set up a meeting with their membership. We would like to begin using these methods as a way to raise local monies to support various programming, education, support, resources etc. for groups like SHARE HOPE, our own MISS Chapter Groups, Peer to Peer support and other bereavement supports across the state.

If you have any additions, corrections or comments, please feel free to call or e-mail me at 802-635-7696 (jahmdl@sover.net)

If you would please share this information with any other parent who might be interested in joining The SIMON Project, or who would like to contribute to our work in any way, please refer them to me or to Kathy Roosa via the web site or by phone.

In Love, Peace, and in celebration of the fall solstice and the circle of life...

My Best & remember to Smile and be Kind in our children's honor.....Jeff

www.offthepagecreations.com/simonproject