

Sunlight and Shadows Newsletter – May 2011



Message from the Board President

Dear friends of the Northwest Infant Survival and SIDS Alliance,

Spring time is upon us – can you believe it? After months of dark clouds and lots of blustery conditions, we finally get a peek at the sunshine and the promise of warmth. This makes me think of an analogy for those enduring the loss of their babies... after the darkness and sadness, there is courage and hope. As Mother's Day and Father's Day approaches, it may not be easy to have courage and hope. The board, staff and volunteers at NISSA want parents and families to know that we are always here to help, especially during significant days of the year.

Supporting families who have suffered the loss of their babies is the heart and soul of our organization. NISSA, originally the SIDS Foundation of WA, was founded 50 years ago by a SIDS Mom. She had courage and hope that she could help families, like hers, through the grieving process. She made herself available to listen to and speak with distraught parents. She organized friends, researchers, legislators and community organizations to better support bereaved families. In her memory and footsteps, we continue.

But how can Moms and Dads continue when the loss seems unbearable? In our history we have seen many ways that SIDS parents and families have coped with their loss. To honor their babies, some parents started memorial 5K runs or annual auctions or candle-lighting events while others have volunteered to share the safe infant message at community fairs or joined the NISSA board or become grief support companions. Some families take a simpler approach...they create a scrapbook of photos and memories or bring a small cake or flowers to the cemetery on special days. Each baby and family is unique and so are the ways that Moms and Dads remember their precious infants.

When my daughter (Lucy) died, the most I could do was get through the day. Over time, I built relationships with fellow SIDS Moms. Eventually, I volunteered for the NISSA auction and attended memorial runs. 9 years later, I serve as President of the Board and am dedicated to helping families gain courage and live with hope. Like our founding SIDS Mom and many parents before me, I attest that you and your babies will not be forgotten.

As Mother's Day, Father's Day and special days are near, please stay in touch with us to share your stories or get involved. Please visit our website at www.nwsids.org or join our Facebook community - *Northwest Infant Survival SIDS Alliance (NISSA)*.

Though it may seem unusual to say or hear, I wish you a Happy Mother's Day and Father's Day... a special day you earned because of your baby's life.

May peace be with you,

Aileen Carrell

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Message from the Executive Director

People are often surprised by how powerful [the feelings of grief] are. "It just pours out," a bereaved father said. It's like a dam that breaks. It keeps coming and you wonder, is this ever going to end?" Despite what people think, those feelings may not completely disappear. But that torrential flood of grief eventually becomes a stream, and although that stream narrows, it could meander through your life forever. ~Candy Lightner and Nancy Hathaway, *Giving Sorrow Words*

Anger and guilt are the passionate emotions of grief. They are often unexpected and often dismissed by others; yet they can be almost overwhelming to a survivor. Both have positive aspects. Anger can serve as an emotionally healthy outburst of frustration and rebellion at injustice. Guilt can guide us to do right. But both also have their negative aspects. As Frederick Buechner says in the book, *Wishful Thinking: A theological ABC2*: "[Wallowing in anger is] a feast fit for a king. The chief drawback is that what you are wolfing down is yourself." Similarly, sometimes guilt goes beyond guidance, gnaws away at the survivors' conscience, and eats away at the spirit (SIDS & Infant Death Survival Guide).

We are a nation that revels in honoring motherhood and fatherhood on those yearly occurrences such as Mother's Day and Father's Day; but for a parent whose baby has died; these can often be painful reminders of loss. If your baby was your only child, the question of "Am I still considered a parent?" emerges, for others, the ever dreaded question "How many children do you have?" can often take our breath away as we contemplate just how much of our lives and pain we wish to share. The ever present, unanswered questions of "What ifs?" seems to overshadow and rob us of the joys of life. The "Could I have done anything different? Would they have survived, if only...?" Parents are often left with a lifetime of unanswered questions leaving us with feeling of guilt and anger. As we come upon special days, be kind to yourself. Set aside time of reflection while honoring the brief life of children who left us way too soon but left everlasting imprints on our hearts.

Mother

By: Drie Chapek

The first time I heard the phrase 'your daughter' was days after she had passed. The first weeks of mothering a newborn and a two-year-old son had been so busy that I hadn't yet had time to reflect on the fact that I had a daughter. Hearing those words when I did filled me with excitement and deep painful loss.

As Mother's Day approaches for the third time since my daughter's sudden death, I still find myself confused as to what this day means to me. I'm finding I'm in a continual process of discovery, grief, joy, forgetting and acceptance. I know I am not the mom I was when I was the mother of a healthy 20-month-old boy and pregnant with my beautiful Nova lone. I know I am not the mom that I was seven months after I found my 8-week-old daughter still, blue and cold in her crib. I am now the mom of a four-year-old boy, a healthy 1-year-old girl and forever the mother of a tiny baby that will only teach me in death something I never expected.

The fact that I am able to sit here and reflect on how Nova lone's passing has affected me is in itself a milestone. I got here through living for every minute and every hour for the first year or so and after that the months seem to roll one into the other with occasional waves of grief.

I had not yet experienced death and was astounded, and still am, at how separate this aspect of life was for me. As an artist, I had already been observing the constant growth and decay of life but had not applied it to my life. I didn't even have a place to apply it. When communities are small and responsible for growing their own food and caring for all their own people, there is loss right beside their living. If the crop doesn't grow, an animal dies, or a family member dies there is loss and it is their own, in their community and visible to all of those in it. In our large city death is hidden behind closed doors, which for me is frustratingly too separate. When I am able to find an acknowledgment of death and its place in my life I find that I am made more whole by it. The loss of my aunt just four months after my daughter passed came as an odd comfort even in the midst of the sadness. Death is life's reminder that we are precious, and all that is living is precious. Because it is alive it will die and, if we can remember that, not only will we be less surprised and better prepared but we may just appreciate more of the moments we have.

Nova lone is my connection to a truth of life, which is the moment, the present, the now. It is the now that got me through the days I couldn't see past my front door, it is now that shakes me as it is so volatile and sincere. It is now that I hear my son as he speaks to his 1-year-old sister with a voice made sweeter by the loss of his first sister. Only now can I see, and with tears I write, that Nova lone's death brings gifts I never would have foreseen. It is through these gifts that I find myself a rich mother this Mother's Day.

Fathers in Grief, a Paradox for Today's Male

By: Mitch Carmody, www.heartlightstudios.net

The loss of your child can be crippling and leaves deep scars, it changes who we are and how we look at life and how we relate with the world. Five or six years out is still early in the spectrum of child loss but close to the point where positive rebuilding can begin. One thing that I have discovered that helps pull you out of the canyon of despair is compassion for others –it is in giving that we receive and in healing that we are healed.

In the first few years it is hard to even help yourself much less others and we mechanically maintain, weep a lot and lick our wounds while clinging desperately to everything of our child and in secret wish to join them. We rejoin the real world at our own time and it happens when it right for us. Everyone's journey is different, but what remains the same is the huge void that is left in our lives. How we fill it is up to us. I believe we need to fill it with something positive for others that creates a legacy of good in our child's name. We now become their legacy and we substantiate our child's life by the way we live ours.

In our "modern day" society it is especially difficult for fathers to grieve openly, caught in a Catch 22 of how to express the deep pain we are experiencing. Men don't cry, men do not emote, men do not hug (maybe at the funeral) men don't go to support groups, men don't call in sick because they are screaming inside, we are the man of the family. Fathers are the fix it guys, the protector, the strength and the rock the family needs for support. More times than not people will ask a father "how is your wife doing? This must be hard extremely for her".

The modern male is now given (by women and therapists) license to show emotions, to cry, scream, hug and express their deepest emotions and fears, to let it out. The Irony of this is if he does emote and the family has never seen this behavior, it is taken as a sign of weakness and the spouse and other family members feel they have lost their safety net, their rock of support, and feel even more helpless and rudderless on this journey of pain. If this happens he may again 'clam up' to help with his family and deal with his own pain later. He finds that 'letting it out' is an axiom of sophistry and in doing so he feels he is letting his family down. It is indeed a paradox for the wanna-be sensitive Dad.

Most men cry alone in their cars on the way to work and they explain that the red eyes are due to allergies, or a late night. When my father died when I was age 14, my Mom told me I was the man of the family now, I did not cry, I did not grieve. It was not until years later and my losses became overwhelming did I finally let it out and express my emotions for the loss of my father. It has been 16 years now since Kelly died and I still cry with my wife when we feel our loss together or even when I hear a special song like 'Wind Beneath My Wings' and I do not care who is present, you love hard, you grieve hard and it is supposed to hurt. When you recognize your own pain and express it, you automatically become more empathetic to others in similar pain and can help relieve theirs. Hell, now I cry at Hallmark Card commercials – I can't help it.

People tell us to find closure, or move on and don't dwell on it. We can, but not how they think we should. We find closure in what will never be, let go of the what ifs, the shoulda, woulda, couldas and move on with the knowledge that our children are forever by our side, only in a new relationship. We live in one sphere of existence, our loved one who has died in another, but with faith, undying love and the desire we can connect at the seam where our two worlds meet. Love never dies.

In America we are allowed a few weeks to "get over it" and get back on track. The dead are wrapped up neatly so to speak and put away and their names unspoken. I find this totally unacceptable, it has been almost 16 years and I still talk about Kelly every day and always will. We will always be bereaved parents but we will not always be experiencing

the pangs of grief. Like arthritis we learn to live with it the rest of our lives, and also realize we shall still have flare ups of pain and discomfort as we move on through the years.

A Special Birthday

Written By: Stan Debiec and Jessica Christensen

Inspired By: Max Debiec



At first glance Max Debiec is your average 8 year old boy, but if only everybody was as loving and unselfish as Max has been this year the world would be a much better place. This year Max decided to do something very special. Max lost a cousin to SIDS a few years ago and this has changed his life forever. As Max's 8th birthday was approaching and the family was deciding what to do for his birthday, Max's mother, Lisa suggested to Max that rather than receive gifts this year he ask his friends for money to be donated to NISSA in honor of his cousin, Ginger Lauren White. When his parents explained the idea to him he became excited about giving up his gifts to honor the memory of his cousin.

His parents decided to maximize the benefits of this idea by inviting all of the students in the second grade at Max's school to his party, and about 30 kids came. They played games, ate cake, and had a good time – best of all; the presents were not missed, not even by Max!

Stan, Max's dad, said "I think the real "power" of this came from the parents of Max's friends. Virtually every parent told us this was a great idea, and they may do something similar for their children's' birthdays. We also found out that another parent had lost a child to SIDS."

Following is an interview that Max's dad conducted with Max:

Reporter: What made you decide to not have friends bring any presents for your birthday?

Max: My cousin Ginger died of SIDS.

R: How much money did you raise?

M: We raised \$555 dollars.

R: How many kids do you think donated money?

M: I don't know, maybe 20 or 30.

R: Did the parents of your friends tell you this was a way better idea than buying presents?

M: Yeah, pretty much everybody.

R: Why?

M: Because it helps my cousin.

R: How will the money help people?

M: The money will help the doctors to get the medicine and then there will be no more SIDS.

R: Where did you originally get the idea to have donations instead of presents?

M: Mom

R: How did it make you feel to not have presents at your birthday?

M: I didn't really care about the presents; I already have toys and stuff.

R: Why was it a better choice for people to donate money than spend \$10 or \$20 dollars on a present for you?

M: Yes, because the doctors need the money for medicine.

R: Where do you think the money is going?

M: To the hospital to help people.

R: What are they going to do with the money?

M: They're going to buy medicine and stuff to help do the things to get rid of SIDS, like research.

R: Would you recommend other kids doing something like this and if so, why?

M: Yes, because it's really nice.

R: Did you miss not getting presents from all your friends?

M: No, I got a couple from my family. And really it was fun just hanging out with my friends. I didn't even miss presents. It was a fun birthday.

R: Who do you think the money will benefit the most?

M: Ginger Lauren White

R: Well, do you think it's going to benefit her or other people later on?

M: Oh yeah... it will benefit other families later on around the country.

R: Why was this important to you?

M: For no children to get SIDS.

Eastern Washington Update

Due to financial constraints, we are not able to fund a paid Eastern Washington coordinator position. Thank you to Liz Montgomery for serving NISSA and our supporters in Eastern Washington. We appreciate the work you have done over the last nine months. Liz continues to educate the public on SIDS and safe sleep. Check out the April 20 *The Inlander* newspaper article on SIDS and Mason's story (<http://www.inlander.com/spokane/article-16436-sudden-unexplained-dead.html>).

We will, however, continue to serve the counties in Eastern Washington through our amazing network of volunteers, board members and our partner organizations that help us deliver risk reduction education and bereavement services. Now more than ever, we need volunteers to help keep the great momentum of NISSA activities going.

NISSA was a major presence at Spokane's yearly baby fair, handing out over 1,000 pieces of literature and educating many parents, grandparent's aunts and uncles in the process. This spring we have had continued talks in the community.

Thank you for your continued support of events and education in Eastern Washington. As we have done for 50 years, we will continue to provide family support and help reduce unexpected infant death.

If you would like to volunteer, make a donation or have any questions, please visit www.nwsids.org or call us at (800) 533-0376.

Sage's Run

Hello Family, Friends and Community Supporters,

For our 2011 Sage's Memorial we will still feature a dash for the kids in the park in addition a balloon release and a picnic area where families can bring and enjoy a lunch. However, there will not be a 5K run. We are regrouping and making plans for raising money next year. The good news is that this year there will be no cost to participate!



The date is set for **Saturday, July 16, 2011 at 11:00 a.m. at the Newport City Park**. Please come enjoy an afternoon in the park with family and friends in memory of a child, or as community supporters.

NISSA (Northwest Infant Survival & SIDS Alliance) will provide information packets at the memorial. A Big THANK YOU to Deborah Robinson, Executive Director of NISSA, for being there for me and for my family with all your heart.

Sherman-Knapp Funeral Home will sponsor Goody Bags for all the children that attend the Memorial.

Thank you again to everyone that had a part in last year's beautiful memorial, for all the kind volunteers, and supportive participants, we couldn't have done it without either of you. THANK YOU!

Sincerely,
Cindy Campbell and Family

You may contact me with any questions through e-mail keithandcindy5@gmail.com or by phone, 509-671-3326.

Auction Update

By: Laurel Archey

Preparations are well underway for our Dinner Auction and 50th Anniversary celebration! "An Evening of Courage and Hope" will be held at the Marriott Redmond Town Center on November 12, 2011. We are planning a wonderful event, with a little something for everyone!

Join us for coffee that morning from 10:00-11:30 a.m. during an expert panel discussion and research update with honored guest, Dr. Henry Krous. Cocktails and the Silent Auction begin at 5:00 p.m. that evening.

We've already received some wonderful items for the auction: two-night stay at Suncadia, whale watching cruise, museum tickets, dinner at the Space Needle, wine tasting, Leavenworth overnight stay, two nights at The Kalaloch Lodge, and a cooking class. We need your help in procuring more fun and interesting items!

Please visit our website's Auction page for items on our Wish List: <http://www.nwsids.org/Auction>. The Auction page is also THE place to go for procurement forms, registration information, and event updates, so check back often!

Would your company be interested in donating goods or services? Please contact Laurel Archey at auction@nwsids.org with donations, recommendations or questions.

We are looking forward to a fun evening, and we would love to have your friends and family to join us!

LIKE us on Facebook! Northwest Infant Survival and SIDS Alliance ~ An Evening of Courage and Hope

Auction Wishlist

Are you wondering how you can help with item procurement? Here's a great place to start! We've put together a list of items we would love to see included in our auction. Whether they are airline tickets or barbeque sauce for a silent auction basket, every single item helps! Here are some ideas:

- Airline tickets
- Hotel/condo stays
- Unique Experiences (behind the scenes tours, access to a sports team during warm-ups, skydiving, cooking lessons from a personal chef, guided fishing trip, etc...)
- Tickets to Seattle Seahawks, Sounders, Huskies, Cougars, or Mariners
- Wine to put toward an "instant wine cellar"
- Seattle restaurant gift certificates

- Friday Harbor hotel or Bed & Breakfast stay
- Department store and clothing boutique gift cards
- Handyman items; power tools, Home Depot/Lowes gift cards
- Golf outings and golf gear
- Salon and spa gift certificates
- Seattle theatre tickets
- Basket items: Barbeque/Grill Master (tools, rubs, sauces...); Italian (oils, pasta, sauces,...); Spa (bath bubbles, candles, lotions...); Husky Fan (UW gear); Cougar Fan (WSU gear); Microbrews (assortment of microbrews, snacks, mugs...)
- Amazon gift cards

Don't forget to ask your neighborhood businesses, especially those whose services you use; cleaners (\$50 worth of dry cleaning?), oil changes (one year of oil changes?), dentist (teeth whitening?), salon (haircut?), coffee shop (gift card or retail items?)...the list is endless!



SAVE the DATE: Research Update with Dr Henry Krous

Please join us **November 12 at 10:00 a.m. for coffee and a panel discussion** (visit www.nwsids.org/Auction for more details) with world renowned researcher of sudden infant-toddler deaths and featured keynote speaker, Dr Henry Krous.

Dr. Henry F. Krous is a Professor of Pathology at the University of California, San Diego School of Medicine, and Director of the San Diego SIDS/SUDC Research Project. Dr. Krous has been involved in SIDS research during the past 30 years, 20 of which have been in collaboration with Dr. Hannah Kinney. His SIDS activities also include participation in legislative development and implementation, survivor grief counseling, and public educational speaking. He has served as a consultant to the Centers for Disease Control and Prevention and the National Institute of Child and Human Development in the development of national standards for infant death scene investigation. As a SIDS advocate, he was instrumental in the design and implementation of the California Standardized Autopsy and Death Scene Investigation Protocols for sudden unexpected infant death, and the International Standardized SIDS Autopsy Protocol. Dr. Krous has represented the United States at numerous International SIDS Conferences, such as the Global Strategy Task Force Pathology Working Party for whom he was the Chair of the International Autopsy Protocol Committee. He is the author or co-author of greater than 300 research publications, abstracts, and chapters, and delivered nearly 200 invited lectures worldwide. He has co-edited with Dr. Roger Byard the book, "Sudden Infant Death Syndrome: Problems, Progress and Possibilities." Dr. Krous was the recipient of the 1999 Senator Daniel E. Boatwright Award, California's highest recognition for "extraordinary public service on behalf of Californians touched by SIDS." Dr Krous will be joined by local researchers and forensic pathology experts. The research panel is open to all families and clinicians free of charge and will be at the Marriott Hotel in Redmond, WA. This event will precede our gala dinner and auction, an evening of **Courage & Hope**. For more information or for dinner tickets, please visit our website at www.nwsids.org.

Thank You to Our Donors!

During the period November 19, 2010 – April 16, 2011, many individuals and organizations supported NISSA. We are publishing your names with a heartfelt "Thank You" for contributions that have made it possible to carry out our mission. If you do not see your name acknowledged, please contact the office to let us know so we can correct the error.

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