

Sunlight and Shadows Newsletter-August 2010



Message from the Board President

Dear families, friends and supporters of the NW Infant Survival and SIDS Alliance,

My name is Aileen Carrell, and I am honored (and humbled) to be NISSA's Board President this year. I have volunteered for NISSA since 2004. I came to know this organization when my daughter, Lucy, died of SIDS in December of 2001. The bereavement support that my family, friends, co-workers and I received was beyond anything I could imagine. I am forever indebted.

Therefore, it is with great pleasure that I'm writing my first message to you.

Let me start by saying, "thank you" for supporting the work we do to help bereaved families suffering the horrible tragedy of the sudden death of their baby, and to provide safe sleep education and training to the people of Washington State. Without you, we could not accomplish our mission.

We are in the midst of preparing for two of our biggest fundraisers of the year. Both take place in October which is SIDS Awareness month. On October 2nd, we will host the 28th Annual Fallen Leaf 5k Run held in Spokane, WA. A couple weeks later on October 30th, we will host our 7th Annual Dinner and Benefit Auction, A Masquerade Gala, in Redmond, WA. We hope you can join us at one or both of these events. They are a tremendous amount of fun, despite the sad reason for their existence.

We are also busy giving "face lifts" to some of our community programs including updating safe sleep literature, focusing our bereavement support services, and improving the training and delivery of our Cribs-for-Kids program.

Though we have great staff that keeps our operations humming, it is volunteers from all over the state that make our fundraising and programs come to life. I am amazed at how much we get done with our modest budget and a small group of dedicated volunteers.

To that end, I am asking for your continued support. We invite you to sponsor, volunteer or join in the fun at the Fallen Leaf Run or the Masquerade Gala auction. We are also actively looking for donations for the silent and live segments of our auction. To find out more about these events, please visit our website at www.nwsids.org.

We are gearing up for a great fall and look forward to sharing our activities with you.

My best wishes to you,

Aileen

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Message from the Executive Director

Dear Families & Friends,

The NW Infant Survival & SIDS Alliance has deep roots and a rich history steeped political advocacy. Continued support needed for the United States' Stillbirth and SUID Prevention Education and Awareness Act (S1445/HR3212).

As you recall, the bill would standardize investigations of all sudden unexpected pediatric deaths up to age 4, create a national registry for these tragedies, track risk factors, fund public health messages and provide grief support services for families affected. We know all too well how each of these pieces is vital to progress.

We are focused this month on getting the support of the following Senators who all sit on the U.S. Senate Health committee. These Senators will play a key role in helping to determine if the bill moves out of committee onto the next step to becoming law. We would greatly appreciate it if you could take a few minutes to review the list below. If you live in one of their states, PLEASE fill out the quick and easy Online Advocacy Form (<http://www.cjsids.org/get-yourself-involved/advocacy/stillbirthsuid-bill.html>) now. It will generate an immediate email to them requesting they co-sponsor S1445. Emails from their constituents prior to our meeting with them would greatly help pave the way for success.

Lisa Murkowski (AK)

Pat Roberts (KS)

Tom Coburn, M.D. (OK)

Michael B Enzi (WY)

John McCain (AZ)

Richard Burr (NC)

Lamar Alexander (TN)

Patty Murray (WA)

Johnny Isakson (GA)

Judd Gregg (NH)

Orrin G Hatch (UT)

Note: If you live in one of these states and are a SIDS-SUID-SUDC parent who experienced issues with the Medical Examiner, Coroner, first responders or hospital and/or have been unable to find support services in your area please contact linda@cjsids.org with your story. We would like to provide concrete examples to these Senators.

In addition, please spread the link to the [Online Advocacy Form](#) far and wide to anyone you know in these states, as well as posting on your social networking sites. If you have any questions please feel free to email, linda@cjsids.org or Deborah at execdirector@nwsids.org.



Four Hours of Card Playing

By Wendell Tobiason

My son was born 21 years ago on Fathers' Day. How much happier could a man be ... only to have his son suddenly die three and a half months later. After all these years, the memory has not gone away. I will always have that tug on my heartstrings for my boy.

After my son died, my wife and I had two girls. How do you answer when someone asks how many kids do you have? I have to read the person, do they really want to know and get into the discussion, or are they just making conversation? When I feel someone is open to the answer I tell them that my firstborn son died of SIDS. This often leads to a good open discussion, and warms my heart to talk about Clayton. Talking about him or doing other things to validate his life help me cope with his loss. What good can I make of his short life? I can celebrate his memory and help others.

My biggest contribution to Clayton is to help others by volunteering... even in situations where I am not very experienced, the recipients of my help are always grateful. I have volunteered at local food banks, cut firewood as part of Rotary club for seniors, participated in cleanup projects, and painting housing rooms for people inflicted with AIDS. With each venture, I learn something new, and meet nice people. But what I have really enjoyed is volunteering directly for SIDS. So many lives have been affected by SIDS before it received an official medical term. It gives me great satisfaction when I can help people in their time of need after a loss, and help raise awareness about the risk factors.

In addition to raising awareness, I have participated in the SIDS Foundation through numerous fundraisers. I normally do not like to ask people for money, but it is easy to ask someone when you can give something back to them.

This year will be my seventh SIDS Auction. Here, again, I meet new people who are willing to give their time and donate to a worthy cause. In addition to the stimulating conversation, there is good food, and lasting relationships gained after a great night with all the wonderful auction items up for sale.

Doing the auction not only gives me the opportunity to volunteer, and teach others the things I've learned over the years about this type of fundraising, but it opens up the opportunity for many other people to volunteer. No special skills are required. There are opportunities for people to be on the Procurement Committee - next time you are shopping somewhere you just need to ask the manager if they would like to donate, anything, to the auction. Just (contact the SIDS office for a procurement form); or if you own a sailboat and are willing to give a couple people a four (4) hour cruise, then you can be the donor. Everyone is welcome to attend the auction, ask the office to put you on the invitation list.

Enough advertising! Having talked about what I have done for my son has made me feel better. I try to make the effort to put energy into my son's short life as much as I can. Although I don't think it would be possible to spend as much money on him as I have on the girls!

I have learned over the years raising daughters that they don't like to play board or card games as much as boys/men do. I have been deprived by having a family that cringes when I say "let's play a game!" Maybe that should be my auction donation this year "four hours of card playing with Wendell", we'll see who bids on me!



Baby Knox symbolized by the blue elephant.

One Year

By Dawn Cort Bennett

I know that I am still in the muddy trenches of dealing with all the emotions that I've learned to cope with over the last year. I feel like I am coated, head to toe in the clay dirt that is staining my skin and clothes showing the word what I've dealt with over the last 356 days. My son was taken off of life support on August 18th 2009, after I found him unresponsive from what has been determined as SIDS during a nap. My emotions have been through a roller coaster; from surprise when I realized he wasn't responding when I picked him up to fear when I couldn't make him better instantly. Relief when the EMT's got a heartbeat, optimism when I thought he really could be okay. Sadness when I saw him helpless on life support and anger after he died. I feel a range of

these things each day, oftentimes when I am caught off guard by memories of him. Sometimes I even feel joy when my daughter does something that reminds me of him. I have more good days than bad, but this month hurts more than any other milestone yet. Each day I move closer to the official one year mark, it is another dagger into my heart that I am one day further from holding my son ever again. It doesn't always hurt and I know that eventually I will be able to think of him and not hold my breath from the pain, until then I will continue to let our friends and family know that their thoughts and kindness is welcome, and talking about my son, Knox brings me so much more joy than pain. You can survive.



Fallen Leaf Run Update

It's time to break out your running shoes! The 28th Annual Fallen Leaf Run (5K) is happening soon. The Eastern Washington staff, volunteers, and board members are hard at work to make this the best run in NISSA's history! The 3 mile run/walk is along the beautiful Spokane River on the Centennial Trail on Saturday, October 2nd at 9 am. The run begins and ends at Mirabeau Park in the Spokane Valley. We are expecting a record number of people this year due to a huge turnout of 500 runners last year. This year's run will focus more on the children who participate in the run. We have free pizza coupons from our long time sponsor Pizza Pipeline for all the kids, a

memorial "Wish Upon A Star" for our babies who have died, a balloon release with messages to heaven, children's and baby shirts, and hopefully a jumping castle and medals for all of our kids who participate in the run. If you would like to



register for the race, please log on to www.active.com or our website at www.nwsids.org. By supporting the run you're support families in our community who have lost a child. The money raised will go directly to help fund our programs and to provide bereavement service to families in the Northwest.



Auction Update

Ready to get away from it all? Then maybe you'll be the lucky winner of a 5-night stay in Mexico or Sunriver! The auction is taking shape, and we want you to join the fun! Other great items are arriving daily, including: theme park tickets, dinner gift certificates, hotel stays, museum passes, a golf outing, Harley-Davidson rentals, and more! If you would like to help by donating items for the auction, please contact Jessica (jchristensen@nwsids.org) or Laurel (auktion@nwsids.org) for procurement forms and any other help you may need.

Additionally, if you would like to make sure friends or family are added to the invitation list, please send their name and address to Laurel at auktion@nwsids.org. You can also register online on the NISSA website: <http://www.nwsids.org>. We're looking forward to a fantastic evening and hope to see you there!



Inside the Office

There have been many changes inside of the NISSA office this summer; let's take some time to get to know the new personnel.



Jessica Christensen is the new Office Manager in Seattle.

Where did you grow up: Spanish Fork, Utah

How many siblings do you have: I have 2 younger brothers, they are great! They are quite a bit younger than me (the closest one is 5 years younger), but it is a lot of fun, especially now that they are getting older.

Where did you go to school: I graduated from Spanish Fork High School and then received my BA in Political Science from Brigham Young University in Provo, Utah.

Favorite Food: Potatoes and ice cream...not together...but separately I could eat them ALL the time! I haven't found a form of potatoes yet that I don't like.

Least Favorite Food: Seafood

Favorite Movie: I am not very picky about movies, but one of my favorites is Step Up.

Favorite Book: I LOVE to read...I don't know if I can pick one book, but some of my favorites are The Outsiders, The Secret Life of Bees, Kite Runner, An Ordinary Man, Left to Tell, the list goes on and on...

What three things would you want with you on a deserted island: my husband, a good book, deck of cards

Favorite thing(s) to do in your spare time: read, watch movies, play games, spend time with my family, travel, and attend sporting events, I am a self proclaimed sports fanatic, growing up I was sometimes embarrassed by the fact that I knew more about sports than a lot of the boys.

Why are you excited to be a part of NISSA: I am excited to be able to support such a great cause and hopefully lend support to those who need it and help to educate the community about infant death. I have been involved with NISSA for just over a month, but I have already been touched and brought to tears several times by the stories and the strength of the families that I have been able to serve thus far.



Liz Montgomery is the new Eastern Washington Branch Office Coordinator.

Where did you grow up: St. Maries, Idaho...a tiny town of 2500 people.

Where did you go to school: I have a bachelor degree from University of Idaho in Education. I am a certified teacher in both Idaho and Washington. I am also certified as a Family Development Specialist.

Family: I have a very close knit family whom I love dearly! We live in Rathdrum, Idaho. I have a 15 year old daughter, Holly, a step-daughter Caiti who is also 15 and my fiancé Dave.

Favorite Food: Thai

Least Favorite Food: Raisins

Favorite Movie: Freedom Writers

Favorite Book: Secret Life of Bees by Sue Monk Kidd

Favorite thing to do in your spare time: Play at the ocean

What three things would you want with you on a deserted island: food, water, and a boat. ☺

Why are you excited to be a part of NISSA: I have been a volunteer for NISSA for the past seven years since the death of my son Mason. I am so excited to be a part of an ever growing team to put an end to SIDS.

Laurel Archey is the Auction Coordinator.

Where did you grow up: West Des Moines, Iowa

Family: My husband, Chris, and I celebrated our 18th anniversary this month, and we're having a fantastic time raising our two kids, Jacquelyn (14) and Jonathan (10). You can find me most weekends on the sidelines on a soccer or baseball field.

Favorite Food: Chocolate covered caramels

Least Favorite Food: Shellfish (I'm allergic)

Favorite Movie: Gone With the Wind

Favorite Book: Pillars of the Earth, Fox in Socks

Favorite thing(s) to do in your spare time: Play games with my family, travel.

Why are you excited to be a part of NISSA: Being able to work with and raise funds for such a worthy cause is an honor and a gift. I have loved meeting the wonderful people involved with NISSA.

Thank you to our donors!

We are so grateful for the support of all of the individuals, organizations, businesses, and grantors, who have donated directly or through special events and giving campaigns to make the work we do possible.