



# NEWSLETTER

Your source of information for *Spring-for-SIDS*, the national SIDS awareness and fundraising campaign.  
Editor: Melissa Todd, *Spring-for-SIDS* Committee Member

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## A Message from Betty McEntire, PhD, Executive Director, American SIDS Institute

I would like to welcome all the new and returning *Spring-for-SIDS* teams. This last year has been an important year for the American SIDS Institute. And I want you to know how important this annual awareness and fundraising campaign is to our mission. You are an integral part of the plan to put an end to sudden infant deaths.

We decided this past year to take a more integrated approach to the problem. It involves a 3 stage process.



### I. Identify Top Research Priorities

The GAPS project is a global research collaboration led by the American SIDS Institute, the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID), The Lullaby Trust (UK) and SIDS and Kids (Australia). Its aim is to identify which gaps in research, if filled, have the most potential to reduce further the number of sudden unexpected infant deaths around the world in the next 10 years.

The process culminated with 3 international workshops. Now the international steering committee, made up of myself and 4 others, is preparing a paper which should be ready for publication this summer discussing the top 10 priorities.

### II. Layout an Effective Research Agenda and Identify Researchers

The American SIDS Institute has put together a research advisory council made up of the leading US experts in sudden infant death. With top priorities in hand from the GAPS Project, they are assembling a research agenda which they think will most likely solve the problem. Requests for grant proposals will be released soon to the scientific community. As grants come in they will be evaluated and approved based on merit and how well they fit the research agenda.

### III. Fund the Needed Research

The last stage is where we need your help. Without it the prior work is in vain. We must be able to raise the dollars needed to fund the research. Through events such as walks/runs, silent auctions, church/school events and email/Facebook campaigns thousands of dollars can be raised. We would like to thank all of you for being a part of the solution.

## FEATURED TEAM STORIES

### Shannon's Butterflies

When I met my husband Joe, he had two sons from a previous relationship. We decided to get married and then in 2012 bought a home. Not until we had bought our house did we discuss having children because we wanted to make sure we had enough room. So after buying our house in February, we started discussing when we would start trying to get pregnant and then in November of 2012 we found out that I was pregnant. I was more than ecstatic to become mom, and our beautiful Shannon was born in June of 2013. I loved being a mom. I did have to go back to work as I was still working at the time and we had to hire a babysitter. Then on the morning of September 18th, we received a call that we needed to go to the hospital both Joe and I rushed to get there. When we got there, everything was a blur...the doctors were trying to resuscitate our beautiful baby girl and we didn't know why. The doctors did everything they could but unfortunately our Shannon was gone. After finding out that there was no known cause it was ruled that it was because of SIDS.

Obviously we were both devastated, but all I could think is, "All I wanted to do was be a mommy" and I felt like I wasn't anymore because she at the time was my only, although Joe had two sons. So feeling like I had to do SOMETHING, I decided the only thing I could do was find some charity to work with in Shannon's name. So, I started doing my research.



Upon doing my research I came across the American SIDS Institute and the *Spring-for-SIDS* campaign. Our first event was very small and I did a week-long event at my work place at the time including a dress down day, and a bake sale. That first year we raised about \$600. The next year, we decided to increase the size of the event and since I had decided to become a stay at home mom after having my son I was able to put more effort in. We decided on a cocktails and color event here in Erie where you get a painting lesson and cocktails, and we also had a Chinese auction. That was last year and we raised about \$800. This year, still being a stay at home mom (now with 2 babies, our son Joseph Jr. and we just welcomed our daughter Katharine) and feeling like we got our feet wet, we decided to go bigger.

We are in the process of planning our *Spring-for-SIDS* event which is a 1920 speakeasy style party being held at the historic Warner Theatre here in Erie Pennsylvania. We're planning a costume party with a Chinese auction 50/50 s and a live band. Our goal this year is \$2,000 or more. We're looking forward to a great year, and hoping that not only can we meet our goal but exceed it as we've done in the past two years.

Captain: Rebecca Juilfs-Mayo

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### **SIDS.Causes.Heartache.**

We have already begun our 2016 Fundraising Events! We held our first event on Friday February 12th, a Valentine's Day Bake Sale at the salon where I work. It was a HUGE SUCCESS!!!! Our next event is set for Saturday April 2nd in Heber Springs, Arkansas. It is an all-day Fundraiser that includes a car & bike show, bake sale, live entertainment, food vendors, face painting, silent auction, raffle, 50/50 raffle, t-shirt & bracelet sales, and a poker run! Our third and final event is set for Saturday April 9th in Longview, Texas. It is going to be a night time GLOW Fun Run 5K for Sky with a live DJ, face painting, a raffle where the winner will receive Chick-fil-A for a year, and lots of door prizes to the participants. 😊

Captain: Paige Hipp

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### **Avery's Quest**

Avery Matthew Bond was born healthy on October 2, 2006. He was the sweetest little guy and was loved by everyone. He was meeting his milestones and growing just perfectly. He was a true blessing!

December 28, 2006, was like any other day. Get everyone up and ready for the day. Drop Avery off at Daycare, take sissy to the Boys & Girls Club (school was still on Christmas break) and then off to work. Around 2:30 in the afternoon, I received a call from the police department. They informed me that there had been an incident with Avery at daycare and that I needed to have someone drive me to the hospital. The ride to the hospital was the longest ride ever. I was sure that Avery had rolled off the couch, one of the older kids accidentally injured him or something of that nature. When we arrived, we were immediately taken to the family room. I remember feeling like I couldn't catch my breath and there was a knot in my stomach. A doctor came in within a few minutes and began to tell me that my sweet Avery did not awake from a nap. He told me that they did all they could for him. The news was a blow to the stomach so hard, that to this day, I have yet to recover. When I finally got to see him, I laid with him, begging him to wake



up. I rubbed his head and pleaded. I pleaded for what seemed like hours. Then, they made me leave and I had to leave without my baby.

Losing your baby to SIDS is grueling. It leaves you with so many questions. Questions that you don't get answers to...SIDS – Sudden Infant Death Syndrome! Cause of Death – UNKNOWN!

In 2007, I, with the help from Rolling Meadows staff and residents, started Avery's Quest! **Avery's Quest to find answers!** The first year was small. It started with just my co-workers, some residents and ice cream. We gave out stickers and ice cream for a \$5 donation. We have not missed *Spring-for-SIDS* in 10 years. It hasn't always been big, we haven't always raised a ton of money, but we do it for Avery and in hopes to find a reason for what steals babies while they sleep.



This year will be our 4<sup>th</sup> year to do the Avery's Quest Chili Cook Off. During our event we have a basket auction, bake sale, live music, t-shirt sales, 50/50 raffle, balloon release, etc. Mostly, we make a tragedy and turn it in to a good time with family and friends. Trust me, even 10 years later, there will be tears shed. Tears will be shed by people who knew Avery and even those who didn't. My little guy is still loved by so very many. He was a blessing when he was brought in to this world, a blessing when he left and a blessing still to this day.



Captain: Erica Morrison

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### Team Patrick Jr.

I can't believe my son, Patrick would have been 5 this year. Patrick was born on February 3, 2011 and died in his sleep shortly after that on March 12, 2011. My family and I were absolutely devastated. I stumbled across *Spring-for-SIDS* when I was online looking for answers and support. Right away, I knew I had to be a part of the campaign.

We had our first benefit, a month after Patrick had passed. Our event was held at my family's local saloon. There was a suggested donation of \$20 at the door and we had raffles and sold t-shirts. Local businesses were very happy to donate items to help the cause. The power of social media is amazing. I put an invite on Facebook and over 100 people showed up and many more donated online. We raised almost \$11,000 that year. It was amazing!



I have held 3 more similar *Spring-for-SIDS* events raising approximately \$15,000.

This year in honor of Patrick's 5th birthday, I am doing an online SFS fundraiser. I posted on Facebook and emailed everyone in my contacts. We have already raised almost \$2,000. Every day, I miss and love Patrick. I will keep his memory alive forever! Thank you to The American SIDS Institute for your dedication and continued research!

Captain: Kerry Devin

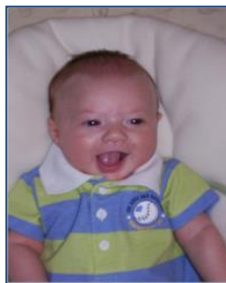
## Loving Kids, NO SIDS



In our 9th year as team "Loving Kids, NO SIDS", we continue to be humbled by the outpouring of support from family, friends, and co-workers. Our SIDS awareness team was formed in memory of our sweet baby boy, Blaise. Team events for awareness and fundraising have proven to be therapeutic for our family in the midst of devastation. This year's SFS events have already kicked off with our team tee sales! We call them our "walking billboards", and staff members at our primary school wear our tees with blue jeans every Wednesday in the month of April to support SIDS awareness. Our team will also be hosting an indoor



yard sale in the school's gym as well as a talent show for our young students! To conclude our SFS campaign, we will be selling Ozark Delight Lollipops to show that we are "suckers for SIDS awareness in Arkansas"!



Our daughter, Alissa, was 7 years old when the tragedy of SIDS struck our family. Helping her understand and learn to cope with our loss has been a heartbreaking journey. She participates in all of our events and volunteers, but as a "SIDS sister" now at 15, she wanted to do more. Alissa completed her Girl Scout Silver Award by presenting SIDS Awareness gift bags to our local hospital's women services department to be given to families with new babies.

Although our participation in SFS was sparked by an unfortunate event, we reflect and feel blessed for having the ability to make a difference in our community through one tiny life. We feel confident that the American SIDS Institute will continue to unlock the codes of the mystery of SIDS. We look forward to the education, awareness, and fundraising that this year's SFS campaign will bring.

Captain: Andrea Moore

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## Louisa's Light

On a Sunday evening in March, 2014, we were just a normal family, having a Sunday dinner at my brother and sister-in-law's house. I had put our four-month-old, Louisa, down for a nap while we ate. Then it was time to leave. My husband was out of town, and I had to get Louisa's big brothers, Will, age nine, and Elias, age six, home for school the next day. I got them out the door and into the car before returning to the house to wake Louisa from her evening nap. I walked into the bedroom to get her, turned on the light, and let out a gasp. Then a scream.

Louisa wasn't breathing. My sister-in-law started CPR, counting compressions as she tried to start Louisa's heart, while my mother-in-law attempted to breathe life back into her. My brother-in-law called 911. On some level, I think I knew that Louisa was gone. All I could say, over and over was, "This isn't happening. This isn't happening."

Our world was turned completely upside down. The loss of a child is a devastating, life-altering event. In the grief books they talk about making sense or meaning of your loss. But there is no sense to be made. Instead of feeding, bathing, soothing, and supporting Louisa as she grows up . . . we honor her. We honor her in many ways . . . by saying her name on a daily basis, by lighting a candle to remember her, by recalling her laugh and her sneeze and her smile, and through our belief that she's still out there, somewhere, touching our lives.



One way we have chosen to honor our sweet girl is to raise money for SIDS/SUID research. As soon as Louisa died, we tried to get our hands on everything we could find about SIDS. The American SIDS Institute seemed to be one of the few places that had a solid focus on research into the underlying causes of SIDS, rather than simply lists of things that parents can do to "prevent" SIDS. Once you've lost a



child to SIDS, those lists are of little comfort. You can do all the things and your baby can still die. This is a terrifying truth. If there is any possible way to stop SIDS, we want to be a part of it. To know that other parents and siblings have gone through and will go through the pain that our family has suffered breaks our hearts again and again.

Last year, and again this year, we are holding an online fundraising campaign for *Spring-for-SIDS*. We send a link to our team page to friends & family, and we post it on social media. We ask people to pass the information along to anyone and everyone. People want to help. They want to know they have done something to help our family. We ask for a minimum donation (in our case it is \$25) and in return we send people a package of note cards and envelopes. The cards have the image of a colored-pencil hummingbird, inspired by baby Louisa and designed by her mom, Beth.

Captain: Beth Olson

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## **Spring-for-SIDS Sponsors**

### **Children's Tylenol & GEICO**

American SIDS Institute

[www.sids.org](http://www.sids.org)

Spring-for-SIDS

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If you would like your team featured in the next issue of the *Spring-for-SIDS Newsletter*, please contact Melissa Todd at [melissa.todd@bxs.com](mailto:melissa.todd@bxs.com)