

Iowa SIDS Foundation

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Supporting Families Today, Educating for the Future

The Companionship of Shared Experience

Brianne Edwards



When my baby died unexpectedly, I longed for companionship and connections to other parents who shared a loss that was similar to mine. I longed to know other families who had experienced *this* kind of loss, who shared my pain and found their way to live in the world again.

I found some grief groups with others who had experienced big losses in their lives, even the losses of children. When I met these parents who had lost older children, I could see that there were many similarities in the grief we were experiencing, but I still found many areas where I was wrestling differently in my grief than they

were in theirs. With any bereaved parent, I could find the gift of companionship, but yet when the child who died was older, the loss was still different. Parents who lost older children were grieving for the things they knew about their child. They grieved with the memories of the funny things their child said and did, the quirks of their personalities, and knowing what their child loved. I grieved because I would never get to know those things about my baby.

I found the most comfort and companionship by connecting with other parents who had experienced a loss like mine. Part of me wrestled with this—the loss of a child is the loss of a child, right?! While meeting bereaved parents with a wide variety of losses was ultimately important to my grief, I had a hard time finding a wider circle of empathy until I had connected with others who experienced the unexpected death of an infant. Spending time with parents who had a similar loss gave me the opportunity to wrestle through the things that made this kind of loss unique. I thought I was being self-centered in feeling an important difference in my ability to connect with other parents who shared a loss that closely echoed mine. It turns out that this is actually a very natural part of the grieving process, and there was nothing wrong with me at all.

Dr. Joanne Cacciatore, founder of the MISS Foundation and author of *Bearing the Unbearable*, points out from her experience of leading support groups: “People often initially attend a group seeking another person whose story closely resembles their own. They want an image of self in some other. Even so, many experience a gradual softening of the heart toward those whose stories are different. And the ability to expand our sense of empathic connection grows.”

There are things that we wrestle through after the unexpected loss of a baby, that warrant the support of a community that understands the nuances of the loss. As I’ve wrestled through my grief, I’ve identified a few particular things that make grieving a SIDS death unique. There are parts of my grief that seem to be universal for all bereaved parents, but there are also distinctions in the grief that comes with a SIDS death.

First, when a loss is sudden and unexpected, that alone creates some differences in our grief. This is typically comes with very sharp edges of traumatic memories that are tied to the day our baby died. We had zero warning that we were going to have to say goodbye to this perfectly healthy baby who we love more than life itself. While there are also little blessings in not

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The Companionship of Shared Experience Continued

having to experience the anticipatory grief of knowing the death is coming, there is often an elevation in the trauma of the loss because it came without warning. Traumatic grief is its own beast.

Second, in a SIDS death, the “cause” is a non-answer. When a death is diagnosed as SIDS (or SUID), it is not an answer of understanding, but an answer that says, “We don’t know why this baby died.” We are left trying to make sense of how a perfectly happy, healthy, well-adjusted, developmentally appropriate baby can die without a cause. It leaves us wondering if something could have been missed in the evaluation, if it could happen to another child we love, and wrestling with *why* it happened in a very intense way. A SIDS death exponentially exaggerates the level of uncertainty that we have to learn to live with.

Third, the death is of an infant. In this stage of life, a child is dependent on his/her parents every minute of every day. As parents, our thoughts and actions are wrapped up with the needs of our baby day and night. Babies need our constant and nearly undivided attention, and the attachment of the child to his/her parents is as strong as it will ever be. As parents, every thought, every activity, and the way we go about every part of our day is done with the baby’s needs in mind. So when they are abruptly torn from our lives there is not a moment in the day that is untouched by the absence of that tiny person. Many mothers are even still nursing their babies when a SIDS death occurs and their very bodies are screaming for the baby who is no longer there. The level of dependence of a baby is also part of what makes an infant loss unique.

It is because of the nuance of the grief after a SIDS death that there is just something deeper and abundantly comforting when we find connections and resources that echo our own stories of loss. This comfort comes in the form of a nod from a new friend who says, “me too,” as we share the grief that comes with having to bury a lifetime of hopes and dreams for this child. It is why SIDS organizations are particularly helpful. It is the comfort of resources that speak directly to us and understand the nuance of our pain. This comfort is found in the stories of others who know this pain so intimately that when they speak of it, it seems that they have reached into our heads and hearts to find the words they are saying.

It is in knowing the gift of companionship and comfort that comes through a shared experience of a loss, that I was inspired to write my story of loss and learning to live with the unbearable weight of grief. I hoped to provide one more resource that speaks directly to the heart of a SIDS parent. While people from many walks are finding benefits from reading *A Thousand Pounds*, the book was written first and foremost, to give companionship, comfort, and hope to the families who have experienced the unexpected death of a baby—the ones who have experienced a loss like mine.

We can be a uniquely powerful source of companionship and support for one another. By sharing our stories and creating connections, we become a lifeline of hope as we share a lifetime of grief and love.

A Thousand Pounds

A Memoir of grief after life-changing loss.

A Companion to those in the trenches of grief.

A Journey to authentic integration, peace, and hope.

Crushed by the weight of life-changing loss, how do we find the strength to carry unbearable grief with peace? This is a book that will pierce your heart and leave you changed. It is a journey from debilitating grief to a new depth of healing and hope.

With raw authenticity, Brianne Edwards shares her story of the loss of her son and gives readers a powerful encounter with the heart of a bereaved mother. Yet *A Thousand Pounds* is much more than a memoir.

Masterfully combining story and research, Brianne accompanies readers through the painful wilderness of their own grief journey. It even comes with a free companion journal download to help readers explore the depths of their own grief and wrestle, together with Brianne, through the hard parts of being bereaved.

Find today on Amazon.



**NEW
RESOURCE
FOR SIDS
GRIEF**

Bri beautifully wrestles with the hardest questions a grieving parent faces as she shares her own journey after the loss of her son, Lachlan. Combining research and story, Bri isn't afraid to go deep, and her authenticity is felt in every word. Her ability to grieve out loud holds space for the big emotions of anyone who is in the trenches of grief.

—**Jessy Paulson**
Founder of Gritty Faith Magazine

ORDER NOW! ON AMAZON
COMES WITH A FREE DOWNLOADABLE GUIDED JOURNAL

"We grieve because we love and our grief is persistent because our love is permanent."

2022 Walk for the Future

Registration for the 23rd anniversary of the Iowa SIDS Foundation's Walk for the Future has begun! The 2022 Walk is scheduled to be held on August 27th in seven cities across the state. Family, friends and community supporters will gather to raise awareness for SIDS/SUID and to honor the lives of Iowa babies. This family friendly event is our primary fundraising event for the

Foundation and funds are used to fulfill our daily mission of offering grief support to SIDS/SUID families, educating professionals and the general public regarding SIDS/SUID and safe sleep, and to fund an annual contribution to research. Get registered today!!



How to Register:

Option 1: Complete and submit a registration form to the Iowa SIDS office. These forms were mailed the week of July 4th; additional forms may be requested by calling 515-965-7655 or by email at info@iowasids.org.

Option 2: Walkers can register and make payment on line at www.iowasids.org. Payment may be made using PayPal or by using a debit or credit card.

Option 3: On or after August 6th, walkers can register on site the morning of the Walk at the location of their choice.

Note: Pre-registration is highly encouraged! Prior to 8/6, the cost is \$25 for adults and \$10 for children. On or after 8/6, each registration does increase to \$30 for adults and \$15 for children. Pre-registrations also reserves a walk shirt in your preferred size.

Weather: Rain or shine the walks will still take place. If the Walk must be delayed due to dangerous weather, announcements will be posted on our website's event page and on social media. If dangerous storms are predicted to last all morning and the Walk must be cancelled due to safety, no refunds will be provided and shirts will be given to those that pre-registered or registered the morning of the Walk.

Thank you to our 2022 Walk for the Future Sponsors!

Bronze Level: American Bank, American Family Insurance, Green State Credit Union, Grell Roofing, Iowa State Bank, L&L Distributing, Michael Wheatley, DDS, Oral Surgery Associates, Primebank, Rexwinkel Funeral Home, Wendt Repair

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Gold Level:

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Modern Woodmen

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The Birth Place at St. Anthony Regional Hospital, Carroll

William Blohm, Carroll

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2022 WALK LOCATIONS

CARROLL — NEW in 2022!

Swan Lake Park — East Shelter House
Registration 8:00am - Walk 9:00am

CEDAR RAPIDS

Noelridge Park — Creekside Pavilion
Registration 8:00am - Walk 9:00am

DUBUQUE

Dubuque Arboretum
Registration 8:30am - Walk 9:30am

FORT DODGE

Kennedy Memorial Park — Bob Heun Shelter
Registration 9:00am - Walk 10:00am

GRIMES

South Sports Complex — South Shelter
Registration 8:30am - Walk 9:30am

LE MARS

Willow Creek Shelter House
Registration 8:30am - Walk 9:30am

WASHINGTON

Sunset Park
Registration 8:30am - Walk 9:30am

Remembering Our Babies

Happy Birthday

July

Elizabeth Grace Atzen
Jerome Alexander Brown
Cole Edward Clark
Rylee Alizabeth Erwin
Owen Jay Fisher
Brennan Charley Godfredsen
Alana P. Gonzales
Ryder Martin Harnish
Zarena Rayne Jennings
Catherine Elizabeth Lafferty
Shelby Jo McConnell
Ethan Daniel McDermott
Darian Bea O'Connell
Jessica Lynne Otto
Carson David Phillips
Joshua Izaiah Rivera
Jaycee Marie Schilling
Jacoby James Sickels
Danielle Rae Thomas
Bryton Thompson
Jordyn N. Thompson
Easton Allin Werner

August

Braxton Timothy Charles Bell
Emmet Lee Woodyard
Zoey Kaye Bestland

Max David Bushlack
Johnathon Oscar Danner
Jennifer Lynn Dyar
Dash Riley Ellingworth
Kenna Reese Henss
Kingston Richard Hronik
Hattie Jo Jenkins
Evan Dean Klemme
Abigail Ilene Knoop
La'Tianna Jo'Nae Luten
Amara C. Magee
Carly Ann Mordock
Danielle Rose Noggle
Hope ElizaRae Ohrt
Kadyn Jo Pirie
Aaron Postel
Zachary Kyle Renaud
Aarie Jai Richardson
Analisa Ines Rodriguez
Maggie Amelia Rose Rogerson
Nolan Douglas Rubendall
Phoenix Isabelle Shank-Weaver
Jared John Smith
Hunter Dean Stevens
Cael Anthony Subject
Shane Adam Tate
Ella Elizabeth Timm
Kyle Anthony Timmons

Oakley Joe Van Patten
Shiana Lynn West
Kyler Lon Wilcox

September

Dylan Peter Christian Andersen
Maria Irene Andersen
Benjamin Blowers
Kayla Sue Brewer
Cody Michael Coleman
Kory Lynn Dunkin
Kaleb Dean Hargens
Chelsea Miranda Jones
Dominic Joseph Laurenzo
Hailey Erin Lincoln
Jacob Anthony Lipski
Ross "Rosco" Jacob McGlothlen
Brenden Meinecke
Alex Ostlund
Knox Owen Palmer
Darran Dasan Perkins
Johnathan Danial Prescott
Ariel Faith Rattler
Ashton Lavail Seaton
Gavin Lee Sievers
Beth Marie Stukerjurgan
Alec Robert Wagner
Warren Edwin White
Donna-Oyann Williamson

Noah James Zarate

October

Matthew James Avery
Cody James Beck
Robert Carl Davis III
Cara Lynn Eddie
Ryker Edward Huizenga
Alexa Jean Jonas
Peyton Jo Lehman
Dawson John Lewis
Quinten Matis
Justin Evan Miller
Robby Matthew Miller
Gunner Jacob Alex Nail
Madison "Maddy" Lynn Nesbitt
Avery Ann Palmer
Cameron Palmer
Samantha Alina Parks
Riley Jane-Marie Perkins
Isaac Thomas Pressley
Ryan Allen Robinson
DaeShawn Marquis Rodriguez
Jessica Lynn Sammons
Leavy Joel Simaj-Christianson
Kellan Rayne Christine Starrett
Erika Elizabeth Story

We talk about them, not because we're stuck or because we haven't moved on, but we talk about them because we are theirs, and they are ours, and no passage of time will ever change that. -Scribbles & Crumbs-

In Loving Memory

July

Sydney Nicole Allen
Cole Alexander Davis
Rowan James Dolezal
Owen Jay Fisher
Brooke Louise Goodyk
Marianna Sarina Guess
Logan Grant Higginbotham
Dominick Paul McFarland, Jr.
Ryan Dennis Mouglin
Matthew Timothy Otten
Mariah Pickering
Kelly Ann Pitts
Alexis Deane Rudkin
Douglas Ronald Tietge
Lauren Elizabeth Nichole Viaene
Austin Micheal Vogt

August

Olivia Nora Aikey
Jerome Alexander Brown
Cheyanne Marie Camp
Joey Cusick

Jordan Lee Daniel
Caitlin Rose Davis
Joseph Laurence Devore
Caden DeVries
Parker G. Donaldson
Gavin Eli Gratz
Devon James Hayes-Jones
Steven Michael Jeneary
Carson David Phillips
Thomas Jay Fallon Robinson
Tara Beth Schroeder
Justin Ryker Swick
Dawson Thomas Vandello
Caleb Richard Williams

September

Mason James Bauer
Johnathon Oscar Danner
Landon Davis
Alana P. Gonzales
Mattilynn ElizabethJade Goodner
Evan Dean Klemme
Melissa Sue Lemon
Ethan Troy Livingston

Benjamin Scott Meints
Carly Ann Mordock
Hope ElizaRae Ohrt
Kaleb J. Peverill
Aarie Jai Richardson
Phoenix Isabelle Shank-Weaver
Jacoby James Sickels
Emily Rose Studer
Bryton Thompson
Andrew Jay "A.J." VanDerSchaaaf
Zachary Richard VanVleet
Easton Allin Werner
Donna-Oyann Williamson
Keaton James Wirtz
Emmet Lee Woodyard

October

Braxton Timothy Charles Bell
Zoey Kaye Bestland
Lane Kurt Carter
Thaddeus Charles Erzen
Christopher Scott Evans
Teagon Lee Fowler
Kingston Richard Hronik

Hattie Jo Jenkins
Zarena Rayne Jennings
James Allen Magruder
Jaxon Matt
Ethan Daniel McDermott
Brenden Meinecke
Danielle Rose Noggle
Darian Bea O'Connell
Bjorn Kai Packard
Aaron Postel
Joshua Izaiah Rivera
Mario Franisico Robles
Jaycee Marie Schilling
Hunter Dean Stevens
Jordyn N. Thompson
Oakley Joe Van Patten
Alec Robert Wagner
Sophia Halas Welch
Kyler Lon Wilcox



Board Member Spotlight: Meet Audrey Bush



Dr. Audrey Bush joined the Iowa SIDS Foundation Board of Directors last year in 2021. In her role as a pediatrician, she has a passion for the care of young infants and their families. In her work, she teaches families about the importance of safe sleep and supports families in their grief when SIDS occurs. Audrey shares; "As a new parent myself, this work feels even more personal and I am honored to take part in it."

When she's not at work or attending Foundation events, you can find her with her husband John and daughter Avery walking and hiking on the Des Moines area trails, traveling, cheering on the Kansas City Chiefs, and spending time with her family.

Thank you Dr. Bush for your dedication to the health and well being of babies and their families! We are thankful to have you on the Board!



Birdies for Charity: Principal Charity Classic and John Deere Classic

The Birdies for Charity is a fundraising program for local charitable organizations to generate contributions based on the number of 'birdies' made by PGA Champion Tour players during the annual event or through flat rate donations.



The 2022 Principal Charity Classic, presented by Wells Fargo, was held at the Wakonda Club in Des Moines on June 1-5, 2022. The 2022 Birdies for Charity John Deere Classic was held June 29-July 3, 2022 at the TPC Deere Run Golf Course in Silvis, Illinois.



In total in 2022, over \$7,000 was provided to the Iowa SIDS Foundation from our generous donors and the match made by the participating sponsors of the Principal Charity Classic and John Deere Classic.

Thank you to our 2022 PCC Birdies for Charity donors!

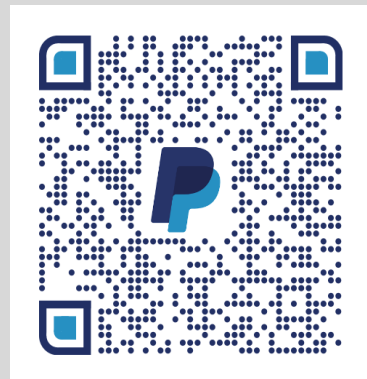
American Academy of Pediatrics Updates Safe Sleep Policy

On Tuesday June 21, the AAP released updated recommendations for safe sleep. The last update occurred in 2016. The updated guidelines expand on the 2016 recommendations providing more specific details on past recommendations and new guidelines were introduced including a statement on weighted blankets and clothing (not safe), hat usage (not to be used after leaving hospital), inclined sleep items (not safe), and tummy time. Read more on our website or by visiting the AAP website, aap.org.



You donate, we deliver.

Help us provide support, education, and hope to Iowans. Scan our QR code and give today.



Thank You... *The Iowa SIDS Foundation wishes to thank the following donors for their generous gifts.*

In Memory Of :

Mason James Bauer

Dean and Becky Paulson

Libbi Marsha Bendickson

Alyssa Bendickson

Ryan Michael Burris

Janice Burris

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Helen Wares

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Diana VanVleet

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Rebecca Wiederholt

Ashleigh Wiederin

Donations are an important part of our support. They allow us to reach out to newly bereaved parents, provide resources to families, relatives, and professionals, print the newsletter, sponsor support group, conduct educational programs and participate in research. These donations were received as of 7/01/22.

***"Remembering Our Baby"* now on Amazon**

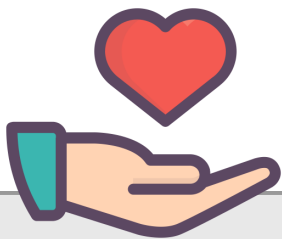
In 2021, the Iowa SIDS Foundation partnered with Words Worth Repeating, a local Des Moines business, to create a book for siblings following the loss of a baby brother or sister.

Remembering Our Baby: A book for Siblings after SIDS was created to provide a developmentally appropriate explanation of SIDS to children and to help children explore various emotions and facilitate the grieving process. Initially, the book was only available on the authors website, but as of June 2022, *Remembering Our Baby: A book for Siblings After SIDS* can now be purchased on Amazon! The book now also includes an updated section with ideas to remember baby by and a page for siblings to write and draw special memories of their baby brother or sister. The book can be purchased for \$12 with part of the proceeds coming back to the Foundation to support our mission. If you purchase the book would you consider leaving a rating and review? This helps make the book easier to find when searched. Thank you!



Facebook Campaigns Make Positive Impact on Foundation Services

A big thank you to those who choose to host an online fundraiser to benefit our Foundation. We would like to thank the following individuals who opted to celebrate their birthday by raising funds to help support newly bereaved families and to advocate safe sleep. Happy birthday to the following: Abigail Badger, Abby Delp, Connie Jo Espinoza, Jazmyne Hightower, Jordan Richardson, Emma Rodriguez, Shane Sievers, Cheyenne Speck, Roberta Studer, and Jessica Young. In addition, we appreciate your friends and family, listed below, that supported you in your campaigns. The generosity and kindness of both the event sponsors and donors assists the Foundation in supporting families and providing safe sleep education. Thank you for choosing to be a part of our Foundation and helping fulfill our mission!



We appreciate all the following individuals making a Facebook donation through 7/1/2022:

Facebook Campaign Donors:

Amanda Julson
Amy Lombardo
Amy Newkirk
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Toni Delp
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Thank you!



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23RD ANNIVERSARY IOWA SIDS FOUNDATION'S WALK FOR THE FUTURE

AUGUST 27, 2022

CARROLL-CEDAR RAPIDS-DUBUQUE
FORT DODGE-GRIMES-LE MARS-WASHINGTON



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Fall Newsletter Deadline: October 10, 2022

General Submissions

The Iowa SIDS Foundation offers all parents, grandparents, relatives, childcare providers and friends the opportunity to submit information for the newsletter. This may include letters, poems, sharing your family's story or perspective, or highlights of events held in your local community to benefit the Foundation or to bring awareness to SUID and SIDS. Please note that due to space limitations, submitted material may have to be edited or held until a later newsletter.

It is our hope to give as many parents and family members the opportunity to share. For additional information or to submit your story, please contact the Iowa SIDS Foundation by calling 515-965-7655 or by email at info@iowasids.org.

Remembering Our Babies

If you would like to honor your baby in our Remembering Our Babies section of the newsletter, we do require a written parental consent to be on file. Consents may be printed from our webpage or can be mailed or emailed to you by contacting our office by phone or email.

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