



Silver Lining Newsletter

IT'S SPRING AND THINGS ARE CHANGING!

Farewell Letter from Colin Cross

Dear Friends,

It has been my great privilege to serve as president of the SIDS Alliance of Illinois. Each year, hundreds of volunteers donate thousands of hours in support of our mission. Meeting and working with so many dedicated families was personally inspiring for me. Today, our society is so fast-paced and bottom line oriented, that our core values regarding the importance of life and family often get lost in our busy schedules. My position as an officer of this organization proved to me just how many people remain dedicated to life, health, family and well-being.

Thank you for this opportunity to serve an exceptional organization in promoting education on infant health and safety, bereavement support to families in need, and preserving what is most precious to all of us - our children.

I look forward to remaining active in the organization and passing the torch to our new president, Marie Videka, and our president-elect, Rose Havens. I know that they will provide outstanding vision, drive and dedication to the group.

Sincerely,
Colin Cross

6TH ANNUAL - JULY 12, 2003 "Day for Megan" at Geneva National Golf Club



On July 12th, the 6th Annual "Day for Megan" Golf Outing will be held at beautiful Geneva National Golf Club, located just four miles west of Lake Geneva, Wisconsin. The scenic site boasts three championship courses designed by golf legends - Arnold Palmer, Lee Trevino, and Gary Player. The \$150 registration fee per person will provide 18 holes of golf with cart and dinner. Dinner only, costs \$75.

The golf event was started in 1998 in memory of Megan Rose Klitz so that her short life would not be forgotten by anyone. Megan, daughter of Greg and Kerrie Klitz, passed away from Sudden Infant Death Syndrome at the age of three days.

If you wish to register or would like more information, call the SIDS Alliance office at 800-432-SIDS.

Welcome Letter from Marie Videka

Dear Friends,

An exciting year lies ahead where we can continue to increase SIDS awareness in our communities. Through golf outings that raise money for education and research, along with other activities, someday SIDS will be eradicated.

That is our shared dream and a goal we continually strive toward. Until that time, it is my distinct privilege to chair an organization of such dedicated families so willing to give freely of their time, energy and resources.

Through our new newsletter, *The Silver Lining*, we can more readily increase communications not only with each other,

cont'd on page 2

TABLE OF CONTENTS

- Letter from Colin Cross/"Day for Megan" Golf Outing 1
- Letter from Marie Videka 1- 2
- Collin Boyne Golf Open & Research Shows
Genetic Ties to SIDS 2
- Medical Q & A - By Dr. Jean M. Silvestri 3
- "A Day of Remembrance" Downstate Memorial 6
- Vote for a New Name for the Alliance 7
- Birthday Remembrances 8

Silver Lining Newsletter

Marie Videka's Letter cont'd

but with the community at large. SIDS continues to plague families and to devastate them. Communication, education and research are powerfully effective measures we can employ to ensure a healthier tomorrow for our families today.

I look forward to a rewarding year working with each and every one of you. Thank you for this exceptional opportunity. Together we can make this next year one of triumph.

Sincerely,
Marie Videka
President of the Board of Directors
Mother of Nicholas Videka

FUND - RAISING

SAVE THE DATE - AUGUST 2, 2003

The 4th Annual Collin Boyne Golf Open

Enjoy a day of golf on Saturday, August 2, at scenic Big Run Golf Club in Lockport, Illinois. The golf course is beautifully landscaped with towering oak trees and watered fairways. A \$150 registration fee per person provides 18 holes of golf including cart and dinner. Dinner only, costs \$50.



The event, now in its fourth year, memorializes Collin Michael, who died of SIDS September 28, 1999 at 8 months of age. Tim and Karen Boyne, Collin's parents, founded the phenomenally successful golf outing to celebrate Collin's short life and to raise funds for education and research so no other families need to experience the tragedy of SIDS.

To register for the golf outing or for more information, call Karen and Tim Boyne at 815-464-3750 or the SIDS Alliance office at 800-432-SIDS.

We look forward to seeing you there!

PG. 2

Preliminary Research Shows Genetic Ties to SIDS

A study released on January 17, 2003, found that babies who die of SIDS were more likely to have certain variants of a gene called 5-HTT. This gene regulates how the brain takes up the chemical serotonin - involved in respiration and other vital functions.

"This is the first piece (of evidence) to get people to wake up that there has to be a genetic component," said lead researcher and Medical Advisor for the SIDS Alliance of Illinois, Dr. Debra E. Weese-Mayer, Professor of Pediatrics at Rush University. Since 1992, when doctors began advising parents to put their infants on their backs to sleep, the SIDS death rate dropped by more than 40% nationally. In Illinois, the death rate due to SIDS dropped 66% since 1993. However, in Illinois, for each Caucasian baby that dies from SIDS, six African-American babies die. And, in Chicago, for each Caucasian baby that dies from SIDS, nine African-American babies succumb to SIDS.



Dr. Weese-Mayer also found differences in the 5-HTT gene between Caucasians and African-Americans. This finding indicates why genetics may explain, in part, why these babies are more likely to die from SIDS than Caucasian babies.

"SIDS still remains the leading cause of death among babies older than one month of age," said Dr. Weese-Mayer. "Babies can die of SIDS even when parents do everything right. If SIDS does have a genetic component, it may be possible to some day test babies to determine they are at higher risk." Further studies are needed to determine the full extent of genetics in SIDS. It is likely that other genes may also play a role, in addition to a complex interaction of environmental factors.

For more information, turn to "Sudden Infant Death Syndrome: Association with a Promote Polymorphism of the Serotonin Transporter Gene." Debra E. Weese-Mayer, Elizabeth M. Berry-Kravis, Brion S. Maher, Jean M. Silvestri, Mark E. Curran, and Mary L. Maransita, AMERICAN JOURNAL OF MEDICAL GENETICS, January 17, 2003.

MEDICAL Q & A

QUESTION:

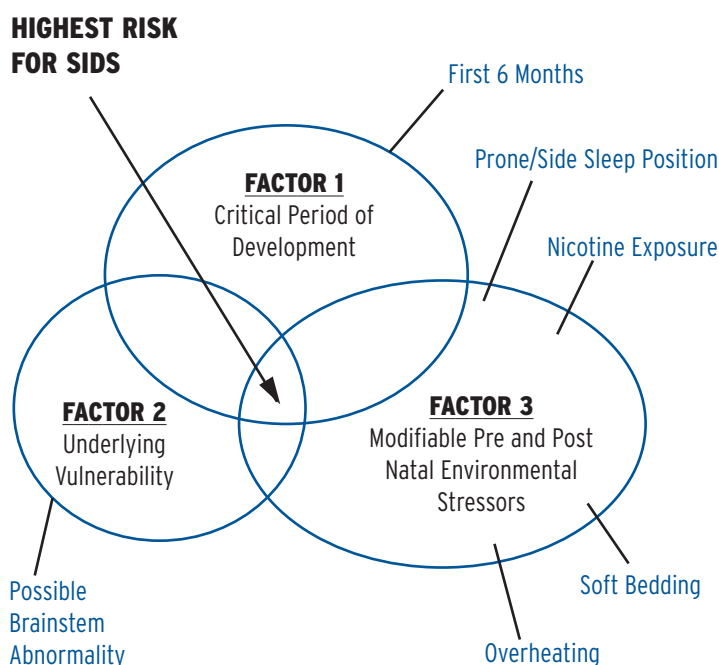
*My parents at the support group wanted to know...
What is the connection between the brainstem and SIDS?
Is the brainstem checked at autopsy? If not, why not?*

- Jennifer Dupasquier
West Chicago, IL

ANSWER:

Researchers believe there is a very important connection between SIDS and the brainstem. Knowledge acquired over the past years supports the idea that infants who die from SIDS have abnormalities at birth that make them vulnerable to potentially life-threatening challenges during infancy. The triple risk hypothesis: SIDS occurs when three things happen simultaneously in an infant: there is an underlying vulnerability in homeostatic control, there is a critical developmental period in state-related (sleep/wake) homeostatic control and an exogenous stressor (prone sleep, cigarette smoke, etc) aggravates the infant's vulnerability.

TRIPLE RISK MODEL



© MCHC 2002

Research supports that the underlying vulnerability in the infant is located in the nervous system -- specifically the brainstem. The brainstem maintains homeostatic control (equilibrium) of many vital functions including regulation of blood pressure, heart rate, breathing, temperature, as well as sensing carbon dioxide and oxygen, maintaining an open airway, and responding to a stress and then returning back to normal after a stress has occurred.

One group of investigators over a 15-year period, has extensively studied the brainstems of 52 infants who died of SIDS and compared them to controls. From these studies, a map has emerged of the anatomy and the neurotransmitters of a part of the brain stem called the ventral medulla. Decreased binding of neurotransmitters has been found specifically muscarinic, kainite and serotonergic receptor binding, in regions of the brainstem related to homeostatic control.

It is hypothesized that SIDS or a subset of SIDS may result from these types of abnormalities. However, these findings need to be confirmed by other investigators and to further identify the underlying cellular and molecular mechanisms. The National Institute of Child Health and Human Development has identified the goal of understanding the origin and range of brain abnormalities in SIDS as one of their objectives in the 5 year Strategic Plan for Targeting Sudden Infant Death Syndrome in June 2001.

In an autopsy of a sudden and unexplained infant death, the brain is examined in terms of size and weight and anatomy using a specific protocol. However, the detailed studies described above of examining different parts of the brainstem with special studies to determine different neurotransmitters is not typically performed unless part of a research project.

- Dr. Jean M. Silvestri

Now Available from the SIDS Alliance of Illinois HALO SLEEPSACK™

SIZE CHART

SIZE	HEIGHT	WEIGHT
XSmall (Newborn)	19" to 23"	.5 to 10 lbs.
Small (0 - 6 Months)	23" to 26"	.10 to 18 lbs.
Medium (6 - 12 Months)	26" to 30"	.16 to 24 lbs.
Large (12 - 18 Months)	30" to 35"	.22 to 28 lbs.



SLEEVELESS

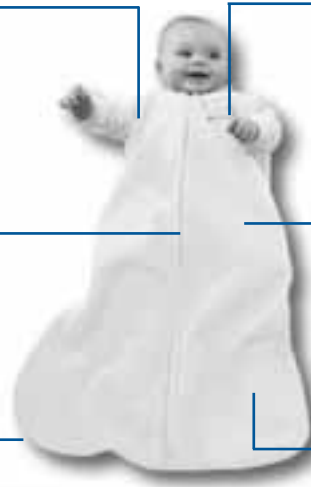
Reduces the risk of your baby rebreathing into the sleeve, reduces the risk of overheating, and is easy to slip onto your baby when he or she is sleeping.

INVERTED ZIPPER

Zips from top to bottom so it's harder for baby to unzip, and the zipper won't catch on your baby's chin. Easy to change diaper without disrobing baby.

SACK DESIGN

Babies can't kick off covers so they stay warm and comfortable all night long. Generous fit makes it easy for baby to move and kick legs.



BACK TO SLEEP LOGO

Embroidered design on front reminds caregivers (even babysitters and relatives) to put babies to sleep on their backs.

FLEECE OR COTTON

Material breathes so there is less overheating and it wicks moisture. Fabrics are durable through many washings.

FLAME-RESISTANT

Tested to meet U.S. children's sleepwear flame-resistant standards.

See form to the right to place order:

Halo SleepSack™ wearable blanket replaces loose blankets in the crib, lessening the likelihood of infants getting blankets over or around their face. The SleepSack™ is available in multiple colors and sizes to fit babies age 1 - 18 months.

MICRO-FLANNEL

Our lightweight, micro-denier, poly-flannel is a great option for areas with mild winter climates. Our supersoft, is slightly thinner, but denser than our Original Fleece, making it as warm. Meets U.S. flame-resistance standard.

www.sidsillinois.org

SAFE SLEEP FOR OUR BABIES

This is a **fund raising** event.

All monies raised through the sale of Halo SleepSack™ will be used for research so that fewer families have to suffer the tragic death of their infant.

Halo SleepSack™ Order Form
 from SIDS Alliance of Illinois

ORDERED BY		DELIVER TO (if different than purchaser's)	
Name of Purchaser _____		Name of Purchaser _____	
Address _____		Address _____	
City _____	State _____ Zip _____	City _____	State _____ Zip _____
Phone Number _____			

Description/Color	Quantity/Size				Total Quantity
	X-Small	Small	Medium	Large	
Microfleece - Baby Yellow					
Fleece - Pink					
Fleece - Blue					
Fleece - Red					
Total Quantity					
Total for Merchandise					
\$20 for each					
3 or more \$15 each					

Method of Payment:

VISA/Mastercard
 Discover
 American Express
 Check/Money Order; Sorry no CODS

Shipping, Handling and Taxes included.

Charge Card Number _____

Expiration Date _____

Signature _____

How to Order

MAIL: SIDS Alliance of Illinois, Inc. 710 East Ogden Ave., Ste. 550, Naperville, IL 60563

PHONE: 1-630-305-7300

Fax: 1-630-305-4773

Thank You for your order

Silver Lining Newsletter

"A Day of Remembrance-2003" Memorial held Downstate in April

-By Wendy Harman

The Central/Southern portion of Illinois (better known as "Downstate") held its first memorial on Saturday, April 5, 2003. Despite a tornado the night before, "A Day of Remembrance-2003" took place as planned at the First United Methodist Church in Lincoln, IL. A dynamic, local team of SIDS parents planned the event- Shelley Darnell, Wendy Harman, Jody Hite, Jennifer Keller, Marc and Kathleen Miller, and Jenny Poole. Although the storm brought the expected attendance of 60 down to 30, it was a tremendous success thanks to funding by the CJ Foundation for SIDS, volunteers, and donations from various vendors.

A TIME TO REMEMBER

This event gave area parents a chance to celebrate, remember and share experiences with other local parents. Guest speakers were committee members with varying backgrounds (a married couple, single parent with a surviving twin, and a death while at daycare). These parents shared their stories in an effort to show support to other parents and their willingness to help.



Back row from L-R: Shelley Darnell, Jenny Poole, Kathleen Miller. Front row from L-R: Wendy Harman & Jody Hite. Not pictured Jennifer Keller & Marc Miller.

"DOORS TO OUR HEARTS"

The highlight of the event was the unveiling of the Central/Southern Illinois traveling memorial. Designed by committee member, Jody Hite, "Doors to Our Hearts" is constructed of three doors, attached side by side, that are each missing doorknobs and locks. It is to be decorated with pink and blue hearts that will each have a baby's name, date of birth, and date of death.

"These doors, like the doors to our hearts, can never be shut or locked," explained Jody.

In remembrance, as each baby's name was read, the families attached their heart to the doors and lit their candles. The service was concluded to the sounds of Mariah Carey's "Hero" in an effort to remind each parent that they are true heroes - heroes to their peers, family, and friends, but most of all to their babies.

Many thanks to all those who attended and to those who filled out an evaluation. The Central/Southern Illinois team hopes to have another event in October in honor of SIDS/OID Awareness Month. Anyone wishing to help may contact Wendy Harman, Central/Southern Illinois SIDS liaison at tufmommie@aol.com, (217) 412-9710 or through the SIDS Alliance.

Finally, in addition to planning this event, project "Get the Word Out" was started to inform the public about SIDS Alliance of Illinois. Committee members sent out letters to anyone who would come into contact with a family grieving the loss of an infant. While the response was tremendous, more can always be done. If you or anyone you know might benefit from these services, contact the SIDS Alliance at 1-800-432-7437 or www.sidsillinois.org.

"HERO"

Words by Mariah Carey

*There's a hero if you look inside your heart
You don't have to be afraid of who you are.
There's an answer if you reach into your soul
And the sorrow that you know will melt away
And then a hero comes along with the
strength to carry on
And you cast your fears aside and you know
you can survive
So when you feel that hope is gone
Look inside you and be strong
And you'll finally see the truth –
That a hero lies in you.*

*"No act of kindness,
no matter how small,
is ever wasted."*

– Aesop 550BC

Cast Your Vote Now for SIDS' New Name

Last year we expanded our mission to include other infant deaths. Now it's time to update our new name as well. Choose from the following selections:

- 1.) Sudden Infant Death Services of Illinois (SIDS)
- 2.) Sudden Infant Death Guild of Illinois
- 3.) Sudden Infant Death Network of Illinois
- 4.) Society For Infant Health and Safety of Illinois
- 5.) _____
(Other suggestions)

E-mail your choice to pam@sidsillinois.org

MISSION STATEMENT

*The SIDS Alliance of Illinois, Inc. is a statewide,
not-for-profit organization dedicated to:*

1. Supporting family members and others who have been touched by the tragedy of a SIDS or post-neonatal infant death.
2. Educating the public and professionals about bereavement support and infant mortality reduction, and
3. Eliminating Sudden Infant Death Syndrome through the support of appropriate research.

SIDS ALLIANCE OF ILLINOIS

710 East Ogden Avenue, Suite 550 • Naperville, IL 60563

tel: (630) 305-7300 - fax: (630) 305-4773

toll free: (800) 432-SIDS

www.sidsillinois.org

BIRTHDAY REMEMBRANCES

The following babies' birthdays are remembered during the year . . .

Date of Birth	Name				
1/2/89	Daniel Alan Olvera	3/6/96	Danielle Davis	5/18/89	Michael James Kearney
1/3/94	Jordan Alexander McNulty	3/10/92	Billy Lyons	5/18/92	Terra Jean Baldwin
1/6/95	Thomas Stephen Gradle	3/11/87	David Lawton Hood	5/30/89	Scott Tyler Perna
1/12/94	Brandon Lyle Grundstrom	3/19/81	Meghan Terese Denkewalter	5/30/93	Zachary Alan Erickson
1/15/93	James Gregory Schmalz	3/22/91	Kory Lynn Cooper	6/1/85	Brendan N. Maruyama
1/16/90	Clifford (Cliffy) Charles Pazik	3/26/92	Richard Edward Pauley	6/2/00	Hayden Anthony Andrews
1/17/89	Timothy David Hulme	3/26/95	Brett Michael Grisko	6/2/00	Alexis Ann Cox
1/17/89	Michael Jason Domin	3/28/94	Lyndsay Dane Alm	6/3/95	Samantha Dawn Cutrano
1/20/99	Collin Michael Boyne	3/30/94	Kayla Anne Tiscareno	6/11/74	Julie Ann Sullivan
1/21/91	Aidan Joseph (AJ) Larsen	4/1/84	Quinn MacAndrew Failing	6/11/91	David Joseph Montgomery
1/21/93	Samuel Robert Moore	4/7/99	Alexandria Jewell Havens	6/12/93	Erica Jade Alba
1/29/91	Michael Anthony Medina	4/10/87	Jacqueline Marie Hughes	6/17/75	Craig Alan Block
2/3/93	Sarah Rose Gorell	4/10/96	Tucker Baer	6/20/67	Jeffrey Allan Boardingham
2/10/82	Mary Kelly Kohnke	4/13/90	Robert Shane Lowry	6/20/84	Lindsey Nicole Evans
2/13/94	Katelyn Marie Kajganich	5/3/91	Nicholas Thomas Fina	6/20/97	Casey Marie Haws
2/13/97	Collin Hansard	5/4/91	Matthew Henry Hunter	6/21/90	Adam Edward Veston Vaughn
2/16/81	Jennifer Lucille Yamnitz	5/4/94	Benjamin James Bullard	6/23/91	Tamara Elizabeth Huber
2/17	Lawrence Rondell William Hopkins	5/10/88	Mark Robert Kane	6/25/91	Becky Borchardt
2/19/95	Matthew Grant Meyers	5/15/84	Brian David Wesolowicz	6/25/94	Cody Nicholas Bitner
2/23/93	Karmyn Elizabeth Gaultille	5/17/92	Jeffrey Joseph Koch	6/27/97	Alondre Keys
		5/17/00	Mark Allen Lorenz		



710 East Ogden Ave.
Suite 550
Naperville, IL 60563