



Center for Infant & Child Loss

Insights

University of Maryland Baltimore Department of Pediatrics

- Maryland SIDS Information and Counseling Program
- Infant and Child Loss Program
- Education and Training Program
- Consultation Services

VOLUME 12 / NO. 1 SPRING / SUMMER 2005



Family and friends from as far away as VA and PA came to join in the fun.

7th Annual Walk/Run for Sids Raises Over \$23,000

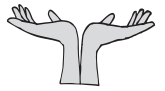
No one could have asked for a better day for the **7th Annual Walk/Run for SIDS** held on May 7, 2005. Quiet Waters Park in Annapolis offered a peaceful setting for hundreds of supporters that turned out from around the state *plus* Virginia and Pennsylvania! It was nice to see so many friends walk in support of families who have suffered the tragic loss of a child. This event is truly one of the most important to the Center as it offers a place for many

to remember their loved one and to meet others with whom they can share their feelings. Not only were there a record number of participants this year (over 325), but a remarkable amount raised: over **\$23,000**. The money raised supports the Center's many initiatives.

The day's activities included a memory table and banner for families and friends to sign, an entertaining performance from *Wayne Allen*, Corporate Illusionist and lots of great food. Special thanks to the many individuals, businesses and volunteer groups who worked tirelessly to promote and organize this event and volunteered their time. A special thanks to the teams and individuals who knocked on doors for donations and all who came to participate. It was great seeing everyone and this event just would not have happened without each one of you!

Wes Guckert of The Traffic Group, Inc., receiving the Governor's Citation award from Donna C. Becker, Center Director, for his involvement.

Volunteers Are Special People



The success of our events is within the hands of the volunteers. The number of people volunteering for the Walk was remarkable. They ensured a spectacular affair. Thanks volunteers: **Beans Family** (Adele, Robert, Mark Thoms, Joey, Erika, Tara, Jeffrey, Kevin (bugle player), Todd, Jennifer, Amanda, Nathan, and David; Mike and Sandy Campbell; Angie Crankfield; Sheree Herbert; Paula Kayton; Debbie Jones; Aalisa Lenharr; Shelby(our photographer), Kelley and John Powell; friends **Severna Park Fitness & Racquet Club**, Brian and Kirsten (personal trainers), who warmed up the crowd before they walked. Special thanks to **Mike Campbell** and **Tracy McCready**, for all hours they spent raising donations – both cash and goods. They were responsible for much of the food and drink and the beautiful flowers on the path. Also, Annapolis **Boy Scout Troop #396** joined us again this year and helped organize and set up. Thank You **Scouts** Ryan Edes, Steven Hamilton, Michael Kuhlman, Nicholas Magoon and Cooper Yelton, and **Parent Volunteers** Dave Canale, Chris Edes and Rich Kuhlman.

Continued on Page 6

Inside:

- Conference...Page 2
- Counselor's Corner...Page 3
- Reflections...Page 3
- In Memory & Honor...Page 4
- Gutberlet Scholarship...Page 4
- Support Group Info...Page 4
- Outreach & Training...Page 5
- Safe Arrivals...Page 5
- Golf Event...Page 5
- Fall Events...Page 6
- Walk Photo Gallery...Page 7



Director's Desk

It is with great pride that the Center is commemorating 30 years of providing services to families and communities. To mark this occasion the conference *When a Child Dies: Research & Support* was held (see article). The conference was provided free of charge to participants, which was made possible through the hard work and dedication of Center families and friends.

This issue always reports on the Annual Walk, spectacular success, and gives information on planned events for the remainder of the year. Please consider volunteering for one of the upcoming activities. It is a great opportunity to meet other parents and make a difference in others lives.

We have added a new project to those we already do (Empty Arms Project, Hanna's Angel Prints, Remembering Our Angels, risk reduction materials). At the suggestion of a parent and her children, the Center has obtained vinyl wristbands inscribed with *Remembering Our Angels*. They have been quite an item – even being purchased by other agencies for their activities. If you are a parent and would like a band, please call or email us and we will see that you get it.

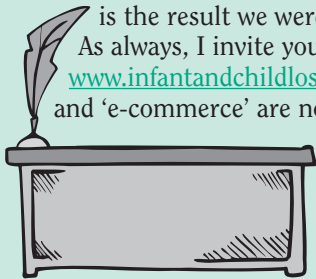
I would like to thank the staff of the OCME for their continued interest and support of the Center. In particular, I want to extend our appreciation to **Linda Thomas**. Linda not only assists us in keeping things straight, and assuring information is timely and accurate, she makes sure the Center and our projects are promoted. Thanks Linda!

We are continuing our partnership with Fox 45/WB64 – this has been a wonderful collaboration. Families are being reminded of the current best practices for safe sleep, awareness of SIDS and other child deaths, as well as Center events. We continue to receive calls for information and resources, which is the result we were seeking.

As always, I invite you to visit the website www.infantandchildloss.org. On-line registration and 'e-commerce' are now available for Center activities, memorials and donations.

I wish each of you a wonderful, safe, and healthy summer.

Donna



Special thanks to the following individuals and organizations whose financial contributions helped to offset the cost of the conference:

Abbott Laboratories, Mary Laura Beckenholdt, Jackie Best, Janice Best, Lillie Brown, Judy Churn, K.C. Councils of College Park, Thom & Lori Drescher, Karen & Fred Evanosky, Brian & Cassie Felch, Michael & Roberta Flynn, Tom Golden, Lauren Greaney, Elizabeth Helm, Lauranne E. Klyce, Rhea Lucas, Dorothy Marge, Gerardo & Deborah Orozco, Ann O'Sullivan, Sheila Palmiotto, Beverly A. Powell, Paula Ridgeway-Hall, Nancy A. Ridgway, Albert Rolle, Michelle Russell, John Rusinko, Elizabeth Sfeakas, Kristin Sorensen-Tannenbaum, Donna Stout, Mary Ann Thompson, Kathy Velte-Lee and Ling Li.

When a Child Dies: Research & Support



The Center was pleased to present the conference *When a Child Dies: Research & Support* to commemorate its 30th anniversary. The conference was attended by about 300 participants, including many parents, and was offered at no charge. The morning session concentrated on research. Henry Krous, MD, Director, San Diego SIDS/SUDC Research Project, presented current findings on Sudden Unexpected Death in Childhood (SUDC). He drew similarities between SUDC and SIDS, and also described California's system for classifying SIDS. Mary Anne Brizzi, parent and Advisory Board Chair, introduced Dr. Krous. Dr. Krous was followed by a panel of researchers: Rachel Moon, MD, Medical Director, Children's Health Center, Children's National Medical Center; Ling Li, MD, OCME and Assistant Professor, University of Maryland School of Medicine; and H. Ronald Zielke, MD, Professor and Chief, Division of Pediatrics, University of Maryland School of Medicine. Dr. Moon has done extensive research in SIDS, particularly related to daycare, and presented her research. Also, she was instrumental in the change in Maryland's daycare regulations requiring all infants be placed on their backs to sleep and all daycare providers to have "SIDS" training. Dr. Li presented findings from her study that looked at sleep position among infant deaths. This study was funded, in part, by the Center. Dr. Zielke, discussed the tissue bank and associated data. The panel was moderated by Jodi Shaefer, RN, PhD, former Director of the Center.



Jonathan Melnick presents Dr. Ronald Gutberlet a token of appreciation for his 30 years of dedication to the Center, UMSOM, Department of Pediatrics.

After a buffet lunch, Ronald Gutberlet, MD, Director, Department of Pediatrics, Mercy Medical Center, and Advisory Board Member, was recognized for his role in establishing the Center and his continued involvement during the past 30 years. Jonathan Melnick, SIDS sibling and Advisory Board Member made the presentation. The conference resumed with a focus on bereavement. Tom Golden, LCSW, author and clinician, presented findings from his book, *Swallowed by A Snake*. His presentation dealt with male grief and the roles of both sexes in the grieving process. Mr. Golden was followed by a panel discussion of services to families. Angela Burden, RN, MA, Director, CCP, Healthcare Access, moderated the panel and presented the role of the public health nurse in assisting families through the grieving process. Mary Ann Brizzi described her experience as a parent of a deceased child. Rev. David Harness, M.Div., BCC, Pastoral Care, University of Maryland Medical Center, discussed the role of pastoral care in the grief process. Mary LeSueur, BSW, Bereavement Coordinator, Center for Infant & Child Loss gave a brief overview of the Center and presented its role for families.

Feedback indicates the conference was well received and met many of the participants' needs for information. Thank you to those who contributed to this effort – your support always ensures success. ♡

Counselors Corner: Grief-What to Say and What NOT to Say

A few weeks ago, someone asked me to come up with a list of things to say and things to avoid saying to a newly bereaved person. Although much of it seems like common sense, it was a much more difficult task than I had originally thought. It's so difficult to know how to treat someone who has recently lost a child. It's scary and tragic. Many people avoid saying anything for fear of saying the wrong thing.

I came up with a list and welcome any additions from you. Maybe, after you read it, you can give it to someone who needs to know. Maybe it will start a dialogue in your own house. Please feel free to call me if you have suggestions.

What Helps:

- I'm sorry
- I don't know what to say
- I don't know how you feel but I want to try to help you if I can
- This must be so hard for you, I can't imagine what you are feeling
- It isn't fair
- Take all the time that you need
- I don't know why it happened
- I'm so sad for you
- I understand that you are angry
- I understand that you are hurt
- I understand that you feel guilty
- It's ok to cry
- What do you need right now?

What Doesn't Help:

- I know how you feel
- He's in a better place
- You need to move on, get on with your life
- You need closure
- She is with God now
- God needed him more than you did
- Things happen for a reason
- She will no longer be in pain
- You are so strong
- Count your blessings
- Luckily, you have other children
- Don't cry
- You shouldn't feel like that

– Mary

Reflections: SIDS

Do you really want to know what it's like to go through the experience of Sudden Infant Death Syndrome? Think of your worst dream ever coming to a reality... you wake up in a cold sweat, and in tears from the worst dream you ever had, but this time you didn't wake up, it's your reality. Your heart is pounding out of your chest, you're sweating and screaming, and yet this time you have this nightmare to face in the real world where everyone around you is in their own life and nobody stops, but for a moment to lend a hand or give a kind word. Sometimes, a not so kind word... "so, what do you do from here?"

You are now a forever, changed person. You are now parents who have lost a child. Who are you now in all of this? Where do you go from here? Every parent handles this situation different, some of the reality of what had happened to me in one full dose. Some withdraw, others keep busy so they don't have to think. I kept so busy that I don't think I sat down for the first 5 months after Ty died.

It has been a year now since that sad day, and if I allow myself to think about it deeply, I cry just as hard as the day it happened. The pain doesn't subside, you just learn to live with the reality of – you are now a parent who has lost a child. I find myself wanting to reach out to others now, where before I wanted nothing to do with helping. It was my problem and I didn't want to hear anybody else's problem, when I couldn't even handle my own.

Now I think about how I was in the beginning of all this...disbelief, fear, denial, anger...it was just too much. Now I have bouts of disbelief, but I have learned that it is in fact

my reality, so what now? I think about all those who are going through what I went through, wow, what I went through... I can handle this now, but I couldn't then. Now I must reach out to others who feel like they can't handle this and tell them that they can and that it will get easier. I want to tell them that the pain is so real and it's ok to feel it, but to know when to get up and move so that it doesn't take over them. I have this need to reach out and help.

I had a counselor named Diane. She was absolutely wonderful, God bless her soul, who was so gentle and kind. She went through the loss of her daughter years previous to now, and understood the depth of a loss like anyone who has lost a child. There are no answers to any of this, just knowing someone is there for you and truly understands, can be enough sometimes. Other times you want

answers and you have this need to know why this happened to you. What did you do so wrong to deserve this – NOTHING! You did nothing; it wasn't you or anything you had done. You have to believe this in order to go on and become focused again. Depression, without a doubt will happen, but there is a light at the end of all this. I know how hard it seems, I know that you could just lay down and never get up again. I know how much pain is in your heart and head and soul, believe me, I know...you will be ok. You will be a better person after all this is said and done, you will be able to help someone else when you start to heal. This I know, because I was where you are and I couldn't do this, but I made it here and so will you.

Have faith...

Sincerely, Melonie Madzel



In Memory of...

David & Josephine Bugusko
*In loving memory of
Hannah Fine*

Suzanne Braun
*In loving memory of
Donna C. Braun*

James & Anne Marie Cutter
*In loving memory of
David Michael Cutter*

Oneita Dorhman
*In loving memory of
Zachary Lutz Dorhman*

Ryan Gielen, Project Inform
*In loving memory of
John Michael Gielen*

Evelyn Koermer
Frances Koermer
*In loving memory of
William Koermer*

Dr. & Mrs. Lee Miller
*In loving memory of
Zachary Lutz Dorhman*

Patricia E. Myers
*In loving memory of
Aaron Gray*

Jon & Stephanie Phelps
*In loving memory of
Joshua Shayne Phelps*

Florence Powell
*In loving memory of
Courtney & Lorenzo Powell*

Lucie Rosenthal
*In loving memory of
Quinlan Kolb*

Capt. Michael & Ruth Roth
*In loving memory of
Michael Waite Waller*

VFWS 7464
*In loving memory of
David Michael Cutter*

In Honor of...

Erik Rosenbaum
*In honor of
Jodi Shaefer*

Jenny Woodall
*In honor of
Linda Hurley*

Matching Donations...

Natalie Smith
Allstate Giving Campaign

Our thanks to **Verizon** for supporting their employee's volunteer efforts – they really make a difference! Rhea Lucas, Mick Smith & Katherine O'Hara.

Scholarship used for...

The Center was delighted that Mary Rose Custer, RN, Bereavement Coordinator, Peninsula Regional Medical Center, was able to make use of the Ronald L. Gutberlet Conference Scholarship Fund to attend the ASIP, (Associated SIDS and Infant Mortality Professionals) conference. Mary Rose submitted:

The seventeenth annual ASIP conference was held at the Westin Grand Hotel in Washington, DC on March 3rd, 4th and 5th. The pre-conference workshop included sessions on The National Increase in Pre-term Birth and Orientation to Child Death Review. The Virginia Institute of Forensic Science and Medicine sponsored the welcome reception on the Promenade level. The next two days of the conference were packed with information beginning with Marion Willinger's coverage on SIDS and Infant Mortality Research: Pathways to Discovery and Risk Reduction. Her review of the history of SIDS was informative, and laid good ground work for those new to the subject. Dr. Willinger shared that since 1970 the overall infant mortality rate has decreased by 65% and that the SIDS rate has decreased by 50%, proving that all the research and hard work is worth it.

Rachel Moon, MD presented the challenges the American Academy of Pediatrics (AAP) task force faces in working with SIDS risk reduction issues. Every five years the AAP will review their recommendations on everything from apnea monitors and bed sharing to pacifiers and positioning in the hospital setting and either reaffirm, revise or retire their

statements. On the closing day of the conference a panel of forensic pathologists spoke on how they approach the diagnosis of SUIDS or "Sorely Under-Investigated Deaths" The moderator, Tom Andrew, added a lot of humor to the presentation, which was welcomed after three days of reviewing such intense information. The panel, being well diversified, educated the attendees on the challenges each face as they investigate a SIDS or SUID. Space does not allow me to comment on everyone that spoke; but I will say that ASIP and all of the presenters did an outstanding job!

Ronald L. Gutberlet, M.D.

Conference Scholarship Award – Scholarships are available to parents and professionals for conferences. Please submit your inquiry via email to: caring@infantandchildloss.org for review. ✓

Support Group Information

For an up-to-date listing of support groups, please visit our website: www.infantandchildloss.org. Click on *Counseling and Support*.

If you know of any new support groups in your area, please contact us at caring@infantandchildloss.org.

To receive the newsletter online, send us your email address caring@infantandchildloss.org.

Outreach and Training Efforts

January 2005 – May 2005

TRAINING

Day Care providers	137
Professional staff	127
Parents	26
Students	18

OUTREACH

Health fairs	2
Risk reduction materials	3,220 *
Back to Sleep materials	18,100 **

* includes Spanish materials
 ** includes light switch covers provided to all birth hospitals

Partnering with . . .

The Center continues its association with **Babies R Us** and their efforts to educate parents about safe sleep environment and SIDS risk reduction by speaking in the Pasadena and Catonsville stores and attending annual Baby Safety month activities. The Center also provides BTS brochures, door hangers and light switch covers for distribution at stores.

Training Video

English/Spanish versions of "Caregivers Hurt Too" are now available in VHS and DVD formats. The Center has distributed 100 to date. This unique video depicts SIDS death in day care and its impact on providers and children. To order, call 800-808-7437.

United Way Donations

If you would like to donate to the Center via payroll deduction, please designate UMBF 9695 and 26309 for Maryland SIDS. Thank you for your consideration.



Safe Arrivals



Congratulations to . . .

Rahmi Bayrakatar, born December 31, 2004, to Florence Lecates-Bayrakatar.

Emily Grace Evanosky, born February 9, 2005, 9 lbs. 10 ozs. to Fred & Karen Evanosky.

Jillian Guckert, born April 10, 2005, to Anthony & Anna Guckert.



In search of . . .

Old golf invitational pictures from the previous 14 years to have on display the day of the event. All pictures will be returned. If you can help us by rummaging through your old photos – thanks! Call Alice Powell at 410-706-3091 with your find!

Recruiting: • Sponsors • Golfers • Volunteers

If you are interested in being part of a great golf event please visit our website at: www.infantandchildloss.org. or call the office for more details at 410-706-3091.

Golf Event



15th Annual Verizon Wireless-SIDS Verizon Wireless-SIDS Golf Invitational & Evening Reception

Friday, October 7, 2005, Indian Spring Country Club, Silver Spring, Maryland 11:00 a.m. Shotgun Start - Reception immediately follows golf.

Come and join us for the 15th Annual Annual Verizon Wireless-SIDS Golf Invitational. Thanks to you – this annual event has grown to become one of the most outstanding charity golf events in the area. This year promises to be entertaining with the addition of new golf

contests, the return of our Honorary Chairperson – **Ken Harvey**, from the Washington Redskins and our evening festivities which include great food and the easy listening sounds of **Michael Kelley & The Hot Q Blues!** Our silent and live auctions will offer some of the best items around town- get your bidding team together now! A special “welcome back” to advisory board member **Jonathan Melnick** of **Melnick Auctioneers**. Jonathan will be the live auctioneer during the evening festivities.

Golf Program Memorial Ads

Please share the memory of your child by placing a memorial in the program book for this year's golf invitational. More detailed information can be obtained by visiting our website under the Verizon Wireless-SIDS Golf logo. You can print a form to send in with a picture of your loved one. Any questions please feel free to contact the office at: 410-706-3091.

Bobby Jones We all remember you. You're in our hearts. Always.	Jenny Smith <small>Apr 2, 200 - March 4, 2001</small>
	Jenny Smith <small>Apr 2, 200 - March 4, 2001</small>

Fall Events

David Michael Cutter's MEMORIAL CRAB FEAST



David Michael Cutter's Annual Memorial Crab Feast

Saturday, September 17, 2005, Camp Wright, Stevensville, Maryland, 4:00pm - 8:00pm

Relax by the beautiful scenery of the Chesapeake Bay and enjoy all-you-can-eat Eastern Shore crabs, fried chicken, corn on the cob, and more. The committee is working hard to make this a memorable day filled with good food and entertainment for all.

Ticket Information: Tickets are \$30.00 per person, children ages 5-12 \$15.00, kids 5 years and younger are free. Space is limited reserve your tickets. To purchase tickets, get additional information or volunteer for the event please contact: Anne Marie or James Cutter at: 410-643-7081 or cutterclan@toad.net

How You Can Help

We are currently looking for people to assist in obtaining donations for the silent auction. This would include: sports memorabilia, dinner certificates, jewelry, one of a kind items and other items of interest. You can help by just asking at businesses, restaurants, and other places you frequent. For more information please contact: Anne Marie Cutter at 410-643-7081 or cutterclan@toad.net



SIDS ANNUAL BULL & OYSTER ROAST

SIDS Bull & Oyster Roast Committee members enjoying a celebratory dinner after wrapping up another successful event.

6th Annual SIDS Bull & Oyster Roast

Saturday, October 8, 2005, Level Fire Hall
Havre de Grace, Maryland

As we mark the 6th anniversary of the Bull & Oyster Roast, the committee is already hard at work planning this year's event. We look forward to having yet another fun filled evening with good food, live music and dancing and of course live and silent auctions.

Bull & Oyster Roast Ticket Information:

Individual cost \$ 30.00.

Reserve a table for 10 and get a discount!
Contact for tickets or more information: Donna Hawley at 410-939-6212 or GDHMN@aol.com

The committee is currently looking for folks that can help with:

- Recruiting sponsors • Donating or soliciting auction items
- Selling tickets – individual or tables of 10 • Volunteering the night of the event

Contact: Donna Hawley at: GDHMN@aol.com or Sharon Cockerham at: 410-457-4157 for additional information.



7th Annual WALK/RUN FOR SIDS

Continued from Page 1

The Center for Infant & Child Loss gratefully acknowledges the many individuals and teams that supported this year's event.

Special Thanks

Walk/Run Committee 2005

Adele Beans, Mike Campbell, Tracy McCready, Ellen Motley, Heather Ramsey & Holly Baden-Tillson

Corporate Sponsors

BJ's of Bel Air Road Baltimore, Home Depot of Eastern Avenue and Golden Ring Baltimore, Giant of Merritt Blvd. and Bel Air Road Baltimore, Krispy Kreme of Glen Burnie, and Bel Air Road, Lowry's Forest Drive, Wal-Mart of Dundalk, and Golden Ring Mall.

Corporate Matching Donations

The Center is pleased to acknowledge the support of companies matching donations for the Walk/Run this year:

Tyco Industries - \$2,900 towards SIDS Walk/Run 2005

Freddie Mac - \$255

TEAMS
\$5,000
Campbell/McCready –
“Devin’s Crew”
\$1,000 - \$3,000
Beans
Brown –
“Kaia’s Friends”
Felch
Flynn –
“Nathan’s Ninnies”
Herbert
Ramsey
Winner –
“Brisan’s Team”
Barnes
Berger – “JEM3”
Bradbury
Forish-Pilarski
Hughes

Learning Tree of
Annapolis
Up to \$500
Adams –
“Shelby’s Shufflers”
Allen
Branton
Bushnell
Douglas/Edmonds –
“Baby Girl Storm”
Heymann
Kelley
Matthai
Parker
Redmond
Robins
Schultz
Tupper
Williams
Woodlon

Walk Gallery



CENTER FOR INFANT & CHILD LOSS

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email: caring@infantandchildloss.org

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Insights Insights Insights

THE CENTER FOR INFANT & CHILD LOSS publishes *Insights* to provide information of interest to those affected by the death of a child and to report CENTER activities. Please contact us if your address has changed or if you no longer wish to receive this newsletter.

Program Staff:

Donna C. Becker, RN, MSN
Jean Edwards, Program Coordinator
Alice Powell, Events Coordinator
Mary Le Sueur, Bereavement Counselor

Affiliation Statement: The CENTER FOR INFANT & CHILD LOSS is within the Division of Behavioral and Developmental Pediatrics, Department of Pediatrics, University of Maryland School of Medicine. The CENTER works closely with the Maryland State Office of the Chief Medical Examiner and local health departments.

Funding Statement: The Maryland State Department of Health and Mental Hygiene, Center for Maternal and Child Health provides grant funds for a portion of the Center's services. Support for this newsletter and other services provided through donations. Please contact us for further information or to ask about sponsoring specific CENTER activities.

The Center's goal is to assist families as they learn to live with the loss of their child and to have hope for the future. Our programs reach out to bereaved families and the community. Center programs foster hope by offering public education, health care provider training, and instruction for emergency responders and others who may provide support.

Each of our four programs is designed to meet individual, family, and community needs. For those families who do experience the sudden death of an infant or child, the Center makes immediate contact to give them available information about the cause of death and support in their grief.

410/706-5062 or 800/808-7437

Visit our web site:
www.infantandchildloss.org