

# PROJECT IMPACT

Infant Mortality Policy and Communication Tools

# E-newsletter

February 2010

## Dear Colleagues:

A new year, a new decade and a new Project IMPACT endeavor: welcome to the first edition of our E-Newsletter. Over the past two years we have had the privilege of talking with MCH professionals from every state. This E-Newsletter is the result of what we learned during those conversations. We want all of you to know that there is very large national community of professionals committed to saving babies and supporting families.

Speaking of families, please take a few moments to read our featured family story. We plan to include stories in each E-Newsletter. Families are, after all, our customers. We invite you to submit stories from your state. We will try to include as many as possible.

An important focus of Project IMPACT is documenting how states sustain programs addressing risk reduction and grief support. This happens in many ways but we want to highlight two successful strategies: Regional Meetings and Promising Practices. You'll find information about both in this E-Newsletter.

A few words about the purpose of the Project IMPACT E-Newsletter... You, our listserv subscribers, have told us that staying current with research, program activities and events is a significant challenge. And, while the listserv is an important part of the solution, an E-Newsletter sent 3-4 times a year could summarize critical listserv postings, offer more detail on emerging issues and include reminders of upcoming events. So, here it is. Check it out and send us your comments.

Mary Adkins, RN, MSW  
Program Director  
Project IMPACT

## Kaelian and Me

Kaelian was born at six o'clock in the morning on January 27th, 2006, and my whole world became a 9 pound, 3.5 ounce, 21.5 inch healthy baby. She was the love of my life.

Kaelian and I enjoyed many happy months together. We sang and danced every morning, ate baby food together, read books in English and in Spanish, and both got to know her little cousin Isabella. Kaelian smiled with her eyes and lit up a room. She spent her days with her Grandma Jeanne and Cousin Bella, and could stop her Great-Grandpa Lyle in his tracks with her smile. She tested every bit of my mind, body, sanity, and patience - anyone who says that being a mother is not a learn-as-you-go process isn't humble enough.

Kaelian passed around two o'clock in the morning on August 19th of 2006. She was just over six months old. I found her a short time later, caught in some pillows in a bed she had been sleeping in for almost six months. There was nothing different about that night. Everything about the way she was laid down and the bed she slept in was the same. The only difference was that I wasn't home that night and those caring for her didn't check on her as often as I would have because they didn't want to wake her.

The day before Kaelian died I looked at her and vowed I would "never let anything happen" to her. I'm a much more humble woman now than I used to be. I truly believe Kaelian was here for her purpose. Today I spend my days trying to help people in pain, teaching people to dance and donating my time and money to those who need it more than I do. In doing so, I only hope to light up rooms the way Kaelian did.

Submitted by Kaelian's mother in loving memory of her daughter.



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### **The National SUID/Child Death and Pregnancy Loss Centers: Your resource for SUID, early child death, pregnancy loss, and stillbirth**

The federal MCHB funds four national centers to address risk reduction, prevention, Infant Safe Sleep, and bereavement support. All share the same goal of reducing sudden infant deaths and assisting bereaved families, yet each center has a unique purpose and core responsibilities. On these pages are selected updates from the four centers:

- National SUID/Child Death and Pregnancy Loss Resource Center at Georgetown University
- National SUID/Child Death and Pregnancy Loss Program Support Center at First Candle
- National SUID/Child Death and Pregnancy Loss Center Project IMPACT at ASIP
- National SUID/Child Death and Pregnancy Loss Center at the National Center for Cultural Competence at Georgetown University

### **Resource Center News:**

Easy access to up-to-the-minute resources tops our list of current and planned 2010 activities. The Resource Center's redesigned website ([www.sidscenter.org](http://www.sidscenter.org)) features updated bibliographies of journal articles on special-interest topics, including new bibliographies on SIDS in the African-American, Hispanic, and American Indian/Alaskan Native communities. We plan to update and expand our bibliographies, A to Z list, training toolkit, and multimedia focus during this year. Our multimedia page highlights safe sleep and other topics—including bereavement support—through a number of video podcasts, with more to come.

The Resource Center's 2009 publication, *Helping Baby Back to Sleep*, has been translated into Spanish and is currently being reviewed. The Spanish-language version should be available in print and pdf formats from our website's Publications page by late spring. Families and professionals can reach us through our toll-free helpline (866-866-7437) as well as our e-mailbox ([info@sidscenter.org](mailto:info@sidscenter.org)).

### **News from the NCCC:**

The National Sudden and Unexpected Infant/Child Death & Pregnancy Loss Project is designed to support state and local SIDS/ID programs, family support and advocacy organizations, national organizations related to SUID issues to increase the capacity of these programs and organizations to incorporate cultural and linguistic competence into their services and supports, materials and training efforts and community engagement. Individuals and programs can contact the NCCC for information and consultation at 800-788-2066 or via e-mail at [cultural@georgetown.edu](mailto:cultural@georgetown.edu).

The NCCC website provides access to a wide array of resources on cultural and linguistic competence. There are a number of products developed specifically for the SUID community. A video, *Infusing Cultural and Linguistic Competence into Health Promotion Training* is available at this link. A series of promising practices from the field exemplify how cultural and linguistic competence can be incorporated into SIDS risk reduction and bereavement support activities. The most recent product is a collaboration between the NCCC and the National Fetal Infant Mortality Review Program. The Cultural and Linguistic Competence Organizational Assessment

## Save the Date!

### **Cribs for Kids National Conference**

April 20-23, 2010

*Defining, Defending, and Disseminating  
the Infant Safe Sleep Message*

Omni William Penn Hotel  
Pittsburgh, PA

### **ISA/ISPID Conference**

October 8-10, 2010

Joint Conference International Stillbirth  
Alliance and International Society for the  
Study and Prevention of Perinatal and  
Infant Death

Sydney Masonic Center  
Sydney, Australia

### **ASIP/PLIDA International Conference**

November 4-7, 2010

International Conference on Perinatal  
and Infant Death:

Partners in Prevention, Advocacy,  
Research and Support

(Formerly ASIP National Conference and  
PLIDA National Perinatal Bereavement  
Conference)

Westin Old Town Alexandria  
Alexandria, VA.



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Instrument for Fetal and Infant Mortality Review Programs (CLCOA-FIMR) was developed with guidance from a national workgroup of state and local FIMR representatives. While there are a number of tools and instruments to assess organizational cultural and linguistic competence, this is the first specifically developed to address the unique issues of local programs such as Fetal Infant Mortality Review (FIMR) teams. Click here for the CLCOA-FIMR and the accompanying guide.

Coming soon---training toolkit and on-line learning modules to enhance the capacity of African-American Christian clergy and church leaders to support congregants who experience pregnancy loss and infant death. This project, a collaboration of the NCCC and the Program Support Center at First Candle, was developed in response to families who shared concerns about the support they received from their faith communities. Guided by an Expert Workgroup of clergy who also have expertise in bereavement support and/or counseling, the nine module training incorporates numerous audio clips of family members, clergy and national experts. It will be available later in 2010.

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### Update from the Program Support Center:

2009 has truly been a year of successful collaborative efforts for the National Sudden Unexpected Infant Child and Pregnancy Loss Program Center (PSC).

Due to the success of the SIDS continuing education program for nurses, the PSC with support from the Eunice Kennedy Shriver National Institutes of Child Health and Human Development (NICHD) expanded the program to pharmacists. Over 2,000 nurses have completed the module and more than 30,000 have been exposed to the module through national and regional conferences. Focus groups demonstrated that there was interest by pharmacists to provide SIDS risk reduction education for parents. Sessions with pharmacists have been completed in DC and Ohio and scheduled for Nevada, Arkansas as well as national meetings such as AMCHP, APHA and AMCHP. For more information contact Hanan Kallash at [HananKallash@Firstcandle.org](mailto:HananKallash@Firstcandle.org)

Every year in the United States more than 25,000 mothers experience a stillbirth and the majority of these deaths occur during the last trimester. PSC and First Candle have partnered with the Heinz Family Philanthropies, All Baby & Child, Inc. and with the support of stillbirth parents to launch an exciting and innovative new campaign, Kicks Count! The campaign is designed to educate expectant parents and their health care providers about the importance of kick counting in monitoring a baby's activity during the last trimester of pregnancy. In six months over 30,000 Kicks Count! and stillbirth bereavement brochures have been distributed nationally. To order brochures or to schedule a training for health care providers, please contact Dana Kaplin at [Danakaplin@firstcandle.org](mailto:Danakaplin@firstcandle.org) or [Kathleengraham@firstcandle.org](mailto:Kathleengraham@firstcandle.org).

Youth are often an underutilized resource in SIDS risk reduction and infant safe sleep efforts. A new project in Virginia that involves young women in community service promoting lifesaving safe sleep messages for babies may help change this. In 2009, PSC and Merry McKenna, the Consortium Coordinator for Perinatal Region 1 in Virginia and Virginia Perinatal Council State Chair teamed up to develop a program for the Girl Scout Skyline Regional office to for a new Lifesaver patch: Safe Sleep for Babies. Girl Scouts can be advocates and role models for safe sleep practices if they are baby sitters, care for younger siblings or become mothers in the future. For more information contact Hanan Kallash at [HananKallash@Firstcandle.org](mailto:HananKallash@Firstcandle.org).

### Did you know?

The National Fetal Infant Mortality Review (NFIMR) and Association of SIDS and Infant Mortality Programs (ASIP) have released the fourth in a series of publications entitled "When an Infant Dies: Cross Cultural Expressions of Grief and Loss IV" by Jodi Shaefer, RN, PhD. See the NFIMR website at [www.nfimr.org](http://www.nfimr.org) to order a copy



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### SUID-IM Project IMPACT Listserv Highlights

#### Who are your listserv colleagues?

We are often asked to describe the Project IMPACT listserv subscribers. In January, 2009, PI revised the listserv registration form to collect information about our constituents. You are a well-educated group! Of the new registrants since that date, 72% are Masters prepared and 17% have earned a Doctorate degree. A wide variety of degrees are listed, with 40% indicating they are nurses (RN) and 15% with an MPH. The listserv membership represents 49 states, the District of Columbia, and five U.S. territories.

#### What's everyone talking about?

The Project IMPACT listserv covered a lot of issues in 2009. Here's a summary of topics and themes: highlights of current research and journal articles, SUID/SIDS policy discussions, best practice program activities, exploring emerging issues, resources and tools for programs, infant products (pros and cons), and announcements of events and conferences on behalf of our many partners. What will you share with your listserv colleagues during 2010? View the listserv archives by clicking here.

### Project IMPACT Promising Practices

You may have noticed the recent listserv announcement of the "Promising Practices" section on the Project IMPACT website. Since that posting there have been several additions. Visit the website to review the inspiring and innovative activities from other states. Also, consider completing the Promising Practices template to add your state to the list.

### Upcoming Webinar Announcement!

The National SUID Centers will be hosting an SUID/SIDS webinar featuring renowned researchers and collaborators, Dr. Hannah Kinney and Dr. Henry Krous. Mark your calendars and plan to join us on May 20, 2010 from 3:00pm to 4:30pm EST. Join the [suid-im-projectimpact](mailto:suid-im-projectimpact@listserve.org) listserv for updates.

### Project IMPACT Regional Meetings

Staff from Project IMPACT, the Resource Center and the Center for Cultural Competence participated in three Regional Meetings to learn how states are addressing SUID and SIDS issues.

**Western Region:** California (host), Oregon, Washington, Alaska, Arizona, Colorado

**Southeastern Region:** Florida (host), Alabama, Mississippi, Louisiana, Tennessee, South Carolina, North Carolina, Georgia

**Northeastern Region:** Pennsylvania (host), New York, New Jersey, Washington DC, Maryland, Virginia, West Virginia, Massachusetts

Preliminary findings include: SUID/SIDS state program activities are stronger than ever with significant emphasis on risk reduction and training. The lack of consensus about the risk reduction message causes confusion and challenges for program staff. All participating states recommend strengthening a federal / state partnership to support SUID programs.

## Webinar News!

1,259 people registered to view the February 11, 2010 ASIP/  
AMCHP Webinar Series #1

*Sudden Unexpected Infant Death (SUID):  
Research, Success and Challenges*  
Presenters: Dr. Rachel Moon  
Dr. Marian Willinger

The webinar will be archived at [www.sidscenter.org](http://www.sidscenter.org) and [www.amchp.org](http://www.amchp.org). If you are interested in attending future webinars, please make sure you are subscribed to the [suid-im-projectimpact](mailto:suid-im-projectimpact@listserve.org) listserv to receive notification.

Project IMPACT is a partnership of the Association of SIDS and Infant Mortality Programs (ASIP) and the Maternal and Child Health Bureau (MCHB.)

