



“SAVING BABIES’ LIVES ONE FAMILY AT A TIME”

THE PENNSYLVANIA SHAKEN BABY SYNDROME PREVENTION PROGRAM

June 2017

Volume 13, Final Issue

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Major Program Changes Effective July 2017



Take time to enjoy the giggles this Summer!

SBS Program Management Ends After 15 Years in PA

As we at Penn State Neurosurgery end our oversight of the Pennsylvania Shaken Baby Syndrome Prevention Program, I want to take one final opportunity to thank each and every one of you for your dedication to the program and trying to eliminate this, the most serious and deadly act of child abuse. You all have an essential role in helping parents transition to their new roles as guardians for their children, and their duty to protect them from harm. **You do a fabulous job of this!** When my wife and I had a child in 1997, the nurse who cared for my wife and infant taught us so many things, including how to change his diaper, understand how to properly select and install a car seat, how to have him sleep on his back, and even how to breast feed him. At that time, in Upstate New York, there was *no such education* about the challenges of infant crying, the dangers of violent infant shaking and shaken baby syndrome, and how to wisely select other caregivers for him.

Based on my own experience dealing with my son’s crying, I determined that every parent should know about these issues - just as they were educated about sleep positioning, car seat safety, and feeding issues. Thus began the Shaken Baby Prevention Program in Upstate New York, a program that led to a nearly 50% reduction in hospitalizations for abusive head trauma/shaken baby syndrome and continues to be very effective nearly 20 years later.

Thanks to the efforts of a wonderful Pennsylvania family whose baby suffered severe injuries at the hands of a frustrated parent, and the vision and persistence of a state legislator, Shaken Baby Syndrome education became a reality throughout our state. When I moved to Hershey, I remember people asking me, “*Do you really think maternity nurses will do this education?*” to which my answer, after having talked with many of them and seeing what had transpired in Upstate New York, was “*Absolutely!*” When I (and subsequently my nurse coordinators) talked with nurses about the outcomes from Shaken Baby Syndrome, watching their eyes tear up in response, I knew in my heart they would follow through for their patients!

Unfortunately, statistics show that although the vast majority of parents fulfill their new responsibilities for a baby graciously and wisely, a select few will, because of ignorance, frustration, or anger, harm their most precious possessions through violent shaking or other types of injuries. Statistics show that about 50-75 such infants in Pennsylvania will suffer these injuries at the hands of their caregivers – the people to whom they were entrusted for their safety and care. *It can happen to anyone*, including parents of any age, marital status, ethnicity, or socioeconomic level. **To reach these select few, we have to be diligent to reach every parent, of every infant, every time!**

SBS Program Management Ends After 15 Years in PA (continued from page 1)

Sadly, one thing we learned when we analyzed our data is that program fidelity wasn't always maintained by all. Our data showed that although parents genuinely welcomed the information, only 1 in 5 had received all of the program components. Anecdotally, parents have told us that they didn't receive some or any elements of the program, some because this was a subsequent child, some because they were 'not at risk' or were 'medical professionals'. These failures may have led to our inability to demonstrate the success of the program in reducing hospitalizations in PA as we had in Upstate New York. (<http://jamanetwork.com/journals/jamapediatrics/article-abstract/2599005>)

With changes in funding priorities at both state and national levels, we will unfortunately end our involvement with this program after 15 successful years. The Pennsylvania Department of Health, which has funded our efforts, will now assume control over the program. With this transition will inevitably come change. **One thing that I fervently hope will not change is the opportunity for you to rededicate your commitment to this program.** The lives of your patients – those whom you shepherd through their transitions to parents and their newborn infants - depend on your ongoing commitment. Fully 75% of the parents we surveyed in our program remembered, *while their baby was crying*, the words of this program – *Never Shake Your Baby*.

Your ongoing commitment will change the entire world for your patients! It's been a true privilege and honor to work with all of you; I know you will keep up the tremendous work we've started, and never give up!

Mark S. Dias, MD, FAANS, FAAP

Professor of Neurosurgery and Pediatrics

Vice Chair for Neurosurgical Education/Chief of Pediatric Neurosurgery

Penn State Health Milton S. Hershey Medical Center

NY & PA Shaken Baby Syndrome Prevention Program Founder

Important Addendum to PA Department of Health Letter to Hospitals

This addendum provides clarification & website corrections to the Department of Health (DOH) recently issued mailing to PA hospitals and birthing centers regarding changes to the SBS Program.

Effective July 1, 2017: the SBS Commitment Statements will be available on the DOH website: <http://www.doh.pa.gov/shakenbaby>. It is the responsibility of the individual hospitals/birthing centers to print the form via the website. Please exhaust your existing stock of Commitment Statements prior to printing the new one. The SBS brochures can still be obtained through the PA Clearinghouse website: <https://apps.ddap.pa.gov/Clearinghouse> or by contacting the DOH at 717-772-2763. As a reminder, per Act 2002-176 hospitals/birthing centers are responsible for ensuring parents are provided educational materials on SBS as well as offering them the opportunity to complete and sign the Commitment Statement at no cost to the parents. A copy of the Commitment Statement must be provided to the parent and a copy is to be maintained in the patient's medical record. Please reference the information on how to obtain the SBS video "A Life in Your Hands: Preventing Shaken Baby Syndrome©" on page 3 of this newsletter. Please direct all questions regarding the SBS program to the BFH at 717-772-2763.

Michael Yakum/Public Health Program Administrator

Bureau of Family Health/Pennsylvania Department of Health

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Highlights for Hospital Program Management Moving Forward

To assist the PA hospitals with the SBS program transition please reference the highlights below in addition to the detailed articles in this newsletter:

- As of 07/01/17, Penn State Neurosurgery will no longer coordinate the PA SBS Prevention Program.
- The PA SBS Prevention Program phone number 717-531-7498 will no longer be valid and a nurse coordinator will no longer be available for questions, staff education, or program guidance.
- **As per PA Law: 2002-176**, SBS education must be offered at the time of the infant's discharge. A duplicate commitment statement should be signed by parents verifying receipt of the education: 1 copy is to be included in the medical record and 1 copy is given to the parents as a reminder of the education.
- **As per the PA community standard of nursing practice** the education should include: (1) a discussion between the nurse & parents on infant crying, soothing measures, coping suggestions for frustrated caregivers, safe caregiver selection, & the serious consequences of shaking a baby; (2) viewing a SBS prevention video; (3) receiving written educational materials; and (4) signing a commitment statement.
- Our Nurse Coordinators have trained all PA birthing/children's hospital staff many times over the years about the standard noted above. Written nurse help cards & staff posters have been distributed to ensure education consistency. **Nurse Educators & Managers in the individual OB Units/NICUs will be responsible for the SBS/AHT staff education moving forward.**
- **Paper commitment statements will no longer be supplied to the hospitals.** The forms can be printed in 17 languages from the DOH website: <http://www.doh.pa.gov/shakenbaby> It is acceptable to replicate these forms in your hospital print shop.
- **June is the last month for commitment statement data tracking.** Please email June 2017 data to Larissa Marsini at lmarsini@pennstatehealth.psu.edu or fax to 717-531-0177. Please do NOT email Kelly Cappos your June data.
- **Commitment statements signed after July 1, 2017 no longer need to be submitted anywhere for data tracking.** It will be the responsibility of each hospital's OB/NICU Nurse Manager to do quality checks on their own staffs' documentation of the SBS education. DOH audits will be conducted to ensure compliance with PA Law: 2002-176.
- DOH SBS brochures can be ordered directly at: <https://apps.ddap.pa.gov/Clearinghouse>
- PA Chapter of the American Academy of Pediatrics help cards & crying cards can be downloaded at: <https://ww.pascan.org/prevention-materials-2>
- **The PA DOH has approved using supplemental evidence-based SBS materials to comply with the community standard of nursing practice as long as a commitment statement is still signed.** Materials such as the *Period of PURPLE Crying* program are recommended to fulfill this need. Please contact Kelly Cappos, RN at: kcappos@dontshake.org for additional information or to facilitate a connection between YOUR hospital and the NCSBS.
- To order additional copies of "A Life in Your Hands: Preventing Shaken Baby Syndrome©" contact Tiffany Harris at: 717-531-4384. There will be a charge for the LIH video moving forward.
- All questions are to be directed to Mike Yakum at the PA DOH: **Email:** myakum@pa.gov **Phone:** 717-772-2763

SBS Team Recognition as Nurse Coordinator Kelly Cappos Leaves Program



“The Three Amigos”

Marie Reed, Kelly Cappos,
& Carroll Rottmund

I want to take the opportunity in this last newsletter to acknowledge the efforts of all three of my nurse coordinators for the PA Shaken Baby Syndrome Prevention Program – Carroll Rottmund, Kelly Cappos, and Marie Reed. As our funding has dwindled over the last two years, I have had the truly sad responsibility to let go each of these truly gifted and committed individuals. Marie and Carroll were honored by Kelly Cappos, our remaining nurse coordinator, in prior newsletters. I want to now take a moment to express my sincere appreciation for Kelly’s dedication to our mission and program.



Kelly Cappos,
BSN, RN, CBIS

Kelly joined our program in 2004, having come to us with a background in maternity nursing, nursing management, medical documentation review, special case investigations, and medical policy development. Her presence brought a wholly new perspective to the program. Kelly immediately meshed with her colleagues, whom I began to call “the three amigos” which, of course, is Spanish for the “*three friends*”. It was as if fate had brought these three individuals together professionally in a way that fulfilled both the mission of the program and their professional and personal relationships with one other. There was never a day in the many years that we worked together that I had to worry about either the program running smoothly or, more importantly for me, interpersonal crises.

With her arrival, Kelly quickly learned the nuts and bolts of the program but more than that, she quickly became the leader of the group by dint of her personality, personal attributes, and leadership abilities. Kelly threw herself into the work with a passion that I didn’t think possible. She eagerly took on all of the jobs she was assigned including the dreaded job of maintaining the budget (something in which my wife will attest I have no interest)! She also created all of the quarterly newsletters for our program over many years, and oversaw the creation of the annual reports for the Department of Health. Additionally, Kelly took on multiple other tasks that I didn’t even assign – including, perhaps most interestingly, a discussion on infant crying and Shaken Baby Syndrome with teenage parents in the Scranton school district that she provided for over a decade. These and multiple other tasks she accomplished with cheer and aplomb. It is with great admiration and more than a touch of sadness that I honor her in this last newsletter.

Kelly has been recruited by the National Center on Shaken Baby Syndrome to be a consultant liaison for the PA hospitals and the NCSBS for the smooth transition to the *Period of PURPLE Crying* program. Additionally she hopes to secure another fulltime nurse coordinator position to remain an employee of Penn State Health Milton S. Hershey Medical Center, Penn State Children’s Hospital. **Thank you Kelly for your talents, dedication, enthusiasm, and attention to detail over the last 13 years! Although our program and my professional association with her has officially ended, our friendship will endure. Best Wishes to Kelly moving forward!-Mark S. Dias, MD**

How Do Hospitals Transition to the *Period of PURPLE Crying* Program?



Information on this evidenced-based parent education program can be found on the National Center on Shaken Baby Syndrome’s (NCSBS) website at: <https://www.dontshake.org/purple-crying> Kelly Cappos can be contacted at: kcappos@dontshake.org to facilitate a connection between YOUR hospital and the NCSBS. Or Julie Noble (pictured at left) the Director for the *Period of PURPLE Crying* program can be reached directly at jnoble@dontshake.org Julie would be happy to provide detailed information on the program & personalized training at your hospital. **Best wishes with continuing SBS/AHT education at your hospital!**

Texting Program Moves Forward at Penn State Health Milton S. Hershey Medical Center

Now that the Shaken Baby Prevention Program is transitioning to direct oversight from the Department of Health, I am being asked, “*What are you going to do now*”? Well, we haven’t been sitting idle! About 18 months ago now, we came upon the idea of repeatedly sending text messages (TM), to parents about our given topics: understanding infant crying, controlling parent frustration and anger, addressing infant crying, the dangers of violently shaking an infant, and wisely selecting caregivers for the infant. As part of a CDC funded program, we investigated having pediatric care providers’ offices offer additional educational materials (a “Crying Card”) and having parents sign a response form (similar to the Commitment Statement they signed at the time of their infants’ birth). Unfortunately, despite a tremendous effort from our three nurse coordinators, we were unable to engage these practices and get them to successfully implement this simple program, and we abandoned it. (<http://jamanetwork.com/journals/jamapeditrics/article-abstract/2599005>) We subsequently decided to ‘eliminate the middle man’ and try to engage parents directly with serial ‘positive parenting’ messages that would provide important education, support them in their parenting efforts, and reduce parental stress. We developed a simple text messaging program that addresses these three goals. With this program, which we call the Serial Text Messaging Trial (STeM), we hope to deliver to parents a total of 44 TM twice each week between the 4th and 26th week after the infant’s birth (for premature infants the text messages will be timed to the day of discharge). We will also send a true-false question-text (Q-text) every other week to which parents will be asked to respond; the number of parent Q-text answers will be used as a proxy for the degree of participation.

With seed funding from Penn State University, we developed 96 such TM and assessed their acceptability with a group of 80 parent pairs to arrive at our final 44 text messages. Our next phase, to begin shortly, will involve a randomized controlled trial recruiting parents of about 800 infants, at the time of their birth at Penn State Health Milton S. Hershey Medical Center; half of the participants will receive the TM and half of whom will not. We will test the impact of these text messages on parent knowledge, self-reported parenting practices, and parental stress using validated survey tools before and after the intervention, comparing the scores in the intervention group with those in the control group. Our hypothesis is that the intervention group will exhibit greater parent knowledge gains, positive parenting behaviors, and less parental stress compared with the control group. If we can demonstrate this, **our hope is to expand the intervention to multiple hospitals statewide and assess its impact on hospitalization rates for Abusive Head Trauma.** Larissa Marsini will continue to assist with TM program implementation. Stay tuned!!!

2016 SBS Annual Report

We wish to thank all PA birthing/children’s hospitals who faithfully sent us their commitment statements and aggregate data during 2016. The data that you submitted has been entered into the Pennsylvania SBS Database. An End of Year Report is sent annually to all hospitals. **Each Nurse Manager will receive a report specific to your hospital in this newsletter!** Individual hospital and Pennsylvania cumulative reports were sent to the PA DOH in March 2017. The data that you submitted was vitally important in assessing the effectiveness of SBS education in Pennsylvania.

EFFECTIVE JULY 1, 2017:

Commitment statement data no longer needs to be submitted to our office or the PA DOH. Each hospital will be responsible for their own data tracking and program oversight moving forward. **Thank you once again for your years of dedication to the data collection for this program!**

AHT Cases Released for 2016

The PA DHS: Child Line & Abuse Registry released the statistics of infant abusive head trauma in PA for 2016. To date there were 47 substantiated cases of infants with head injuries which were confirmed to be the result of abuse including Shaken Baby Syndrome. Of those 47 infants, 30 were male (64%) and 17 were female (36%), ranging in age from 23 days to 33 months old. Thirty-three of the perpetrators (70%) were listed as parents alone or parents with paramour. In addition, 4 identified perpetrators were paramours alone (9%), 1 babysitter (2%), 1 grandmother (2%), and 8 were unknown (17%). The abusive injuries included: skull fractures, subdural hematomas, brain edema, and retinal hemorrhages. Nine of these children died from their injuries! **To report cases of suspected child abuse call: [Child Line 1-800-932-0313](tel:1-800-932-0313)**



The Pennsylvania Shaken Baby Syndrome Prevention Program

NY & PA SBS Program Founder

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Preventing Infant Abusive Head Trauma through Parent Education

The Shaken Baby Syndrome Prevention & Awareness Program was developed in 1998 in Upstate New York by Dr. Mark Dias, Pediatric Neurosurgeon. Since the inception of the SBS program, Upstate New York has reduced the incidence of infant abusive head injuries by 50%.

In 2002, the identical program was started as a pilot study in central Pennsylvania and PA Law 2002-176: *The Shaken Baby Syndrome Education Act* was passed. The program partnered with the Pennsylvania Department of Health and by 2006 became the first state in the nation to provide consistent hospital-based education in 100% of all birthing and children's hospitals according to the Dias Model. In 2011, the Centers for Disease Control and Prevention (CDC) provided funding for the program to develop, produce, and distribute an educational abusive head trauma video entitled, "A Life in Your Hands: Preventing Shaken Baby Syndrome®" which is now being utilized in all hospitals statewide and on the Newborn Channel nationally. The Pennsylvania Shaken Baby Syndrome Prevention Program, through a grant from the Children, Youth and Families Consortium (CYFC) and the Children's Miracle Network (CMN), is currently piloting a technology initiative to provide parents with the option to receive positive parenting messages by text message until their child is 6 months old.

The Pennsylvania Shaken Baby Syndrome Prevention Program has been honored to oversee SBS education and management in PA from 2002-2017. **Our goal has always been protecting little ones from harm by ensuring that EVERY parent of EVERY infant born in Pennsylvania receives education about shaken baby syndrome and to ultimately reduce the incidence of abusive head trauma in the youngest and most innocent victims.**

All PA SBS Newsletters can be found on our website at:

<http://www.pennstatehershey.org/web/shakenbaby/home/>

Pennsylvania Hospitals and Birth Centers Providing Abusive Head Trauma Education

Abington Memorial Hospital
ACMH Hospital
AHN Forbes Hospital
AHN Jefferson Hospital
AHN St Vincent Hospital
AHN West Penn Hospital
Birth Care & Family Health Svcs
Birth Center of Bryn Mawr
Bradford Regional Med Center
Butler Memorial Hospital
CH Moses Taylor Hospital
CH Wilkes-Barre General Hosp
Children's Hospital: Philadelphia
CKHS Crozer Chester Med Center
CKHS Del Co Mem Hospital
Clarion Hospital
Cole Memorial
Conemaugh Nason Hospital
Conemaugh Memorial Med Center
Doylestown Health
Einstein Medical Center Montgomery
Einstein Medical Center Philadelphia
Evangelical Community Hospital
Excelsa Health Westmoreland
Geisinger Bloomsburg Hospital
Geisinger Holy Spirit Hospital
Geisinger Lewistown Hospital

Geisinger Medical Center
Geisinger Wyoming Valley Med Ctr
Grand View Health
Guthrie Robert Packer Hospital
Hahnemann University Hospital
Hanover Hospital
Heritage Valley HS Beaver
Heritage Valley HS Sewickley
Holy Redeemer Hospital
Indiana Regional Medical Center
J.C. Blair Memorial Hospital
Jennersville Regional Hospital
Lebanon Valley Midwifery Birth Center
Lehigh Valley Hospital Allentown
Lehigh Valley Hospital Hazelton
Lehigh Valley Hospital Schuylkill
Lehigh Valley Muhlenberg
Lehigh Valley Pocono Medical Center
Main Line Bryn Mawr Hospital
Main Line Lankenau Medical Center
Main Line Paoli Hospital
Main Line Riddle Hospital
Meadville Medical Center
Midwife Ctr for Birth & Women's Hlth
Millcreek Community Hospital
Mt. Nittany Medical Center
Penn Highlands DuBois

Penn Highlands Elk
Penn Medicine Chester County Hosp
Penn Medicine HUP
Penn Medicine Lanc Women & Babies
Penn Medicine Pennsylvania Hospital
Penn State Hlth Milton S. Hershey Medical Ctr
Penn State Hlth St Joseph Medical Ctr
Pinnacle Hlth Carlisle Med Center
Pinnacle Hlth Harrisburg Hospital
Pinnacle Hlth Heart of Lanc Med Ctr
Pinnacle Hlth York Memorial Hospital
Punxsutawney Area Hospital Reading Hlth Birth Center
Reading Hlth Reading Medical Center
Reading Hlth Phoenixville Hospital
Reading Hlth Pottstown Medical Center
Sacred Heart Hospital
St Christopher's Hospital
St Clair Hospital
St Luke's Hospital Allentown
St Luke's Hospital Bethlehem
St Mary Medical Center
Steward Hlth Easton Hospital Steward Hlth Sharon Hospital Summit Hlth Chambersburg Hosp Summit Hlth Waynesboro Hospital Temple University Hospital

Thomas Jefferson University Hosp
Uniontown Hospital
UPMC Altoona
UPMC Bedford Memorial
UPMC Children's Hosp Pittsburgh
UPMC Horizon Shenango Valley
UPMC Magee Women's Hamot
UPMC Magee Women's Hospital
UPMC Mercy
UPMC Northwest
UPMC Soldiers/Sailors Mem Hosp
UPMC Williamsport Hospital
Valley Birth Place
Warren General Hospital
Washington Hospital
Wayne Memorial Hospital
WellSpan Ephrata Comm Hospital
WellSpan Gettysburg Hospital
WellSpan Good Samaritan Hospital
Wellspan York Hospital

