

update



TWIN CITIES METRO SHAKEN BABY SYNDROME PREVENTION PROGRAM

Introducing the Twin Cities Metro SBS Prevention Program

by Jane Swenson, CNP, Twin Cities Metro SBS Prevention Program Coordinator

it is with great excitement that I introduce this inaugural newsletter for our Twin Cities Metro Shaken Baby Syndrome (SBS) Prevention Program! This prevention program represents a tremendous community and collaborative response for the need to educate parents and caregivers about the dangers of shaking infants and young children.

In Dec. 2001, an invitation to child abuse doctors, nurses, public health officials, and social workers was sent out by Midwest Children's Resource Center (MCRC) to bring a promising SBS prevention program model to the Twin Cities. The response was huge and the Twin Cities Metro SBS Prevention Task Force was born. (MCRC is the child abuse program at Children's Hospitals and Clinics, Minneapolis/St. Paul, Minn.)

What was so special about the new model? Mark Dias, MD, a pediatric neurosurgeon from Buffalo, New York, has said he created this model after he had his own baby and personally experienced the frustrations of caring for a crying baby.

He felt the feelings that many parents feel when they are tired, stressed, and can't calm a fussy

All parents and caregivers need to be educated about the dangers of shaking young children and ways to cope with a crying infant.

baby—feelings of anger and frustration. He put his baby down in his crib and reflected on how he felt. He figured out that “the only difference between me and someone who shakes his baby, is that I didn't.”

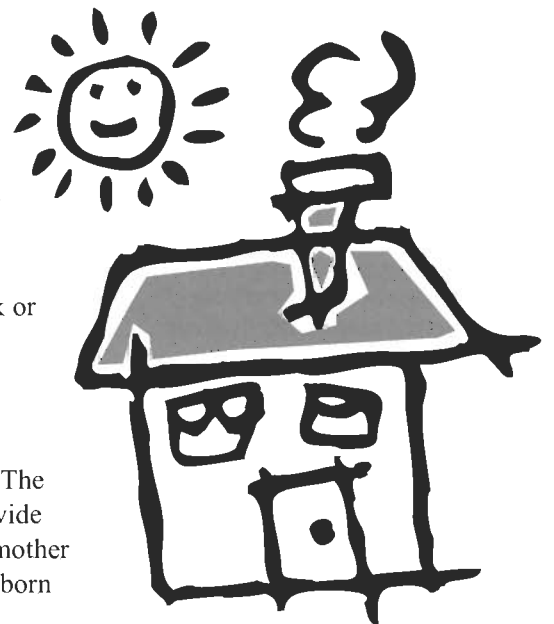
Sobering, but a comment that expresses the fact that all people are at risk for losing their composure and their ability to cope when stressors become overwhelming. No one can speak or guess what another individual is capable of doing.

The prevention program developed by Dr. Dias began in Upstate New York in Dec. 1999. The purpose of his program is to provide SBS education to both parents (mother and father figures) of all infants born

in an eight-county region of Western New York before discharge from the hospital.

The premise is that parents need to be reminded at the correct time (upon the birth of a child) about SBS, and that educated parents could be effective advocates in disseminating this information to all who care for their child. Under the program, parents receive both written and video information about SBS before leaving the hospital. Both parents are then asked to voluntarily sign a

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commitment statement affirming their receipt and understanding of this material; these commitment statements are returned and tracked by the investigator.

The initial results of this education program are noteworthy. The program tracked the incidence of SBS in the region from Dec. 1998 to Dec. 2001, comparing it with historical SBS incidence figures from the six preceding years. **The program demonstrated a sustained and consistent 63 percent reduction in incidence in these eight counties during the program.**

Subgroup analysis suggests that at least five and perhaps seven of the eight SBS cases born during this period were in families that did not receive this information. These preliminary results spread quickly and encouraged many cities and states to follow Buffalo's lead.

The TC Metro SBS Prevention Task Force recognized that bringing this model to local hospitals meant that a good deal of homework needed to be done before implementation could occur. The questions needing answers before knocking on hospital doors were:

- What is the incidence of SBS in Minnesota? By county?



Update is printed quarterly for members and friends of the Twin Cities Metro Shaken Baby Syndrome Prevention Program. Please send questions, comments, suggestions, and mailing list changes to Jane Swenson, CNP, Twin Cities Metro SBS Prevention Program Coordinator, Midwest Children's Resource Center, Children's Hospitals and Clinics, 347 North Smith Avenue, Suite 401, St. Paul, MN 55102, or e-mail jane.swenson@childrenshc.org.

- How would the Buffalo/Dias prevention model look in Minnesota? Use the same protocol and materials?
- How would we engage and educate hospital personnel?
- How would the multi-cultural population be addressed?
- How would we pay for this program?

These questions and charges kept the task force busy for the entire year of 2002:

- Educational materials were written and re-written.
- Minnesota Department of Health worked with physicians to develop an e-code list that could capture cases of SBS when abstracting charts.
- All materials were translated into Hmong, Spanish, Somali and soon, Russian.
- Grant requests were written.

The process and results of this work will be explained and answered in this and upcoming issues of this newsletter.

At this point in time, many of the Twin Cities metropolitan hospitals have begun implementing this educational program with their families. Some hospitals have adopted the true Dias protocol; others have decided to educate their families in a way that works best for their hospital and family education philosophy.

UPDATE will bring you quarterly progress reports about this initiative, impact on the incidence of SBS in the Twin Cities metropolitan area, medical education about SBS, comments and insight from families of SBS victims, and Web sites and conferences to further your knowledge.

Thank you to all involved in SBS prevention. Together we can make a difference!

Resources

Below is a list of resources to support staff and families in their work to prevent and understand abusive head trauma and shaken baby syndrome.



National Center on Shaken Baby Syndrome

www.dontshake.com
prevention curricula, materials, conferences

National Shaken Baby Alliance

www.shakenbaby.com
AHT/SBS family support group and resource; founded and run by victims' families

Prevent Child Abuse America

www.preventchildabuse.org
publications, materials, resources

Prevent Child Abuse Minnesota

www.pcamn.org
Minnesota-specific resources and information

Midwest Children's Resource Center at Children's Hospitals and Clinics

www.childrenshc.org or e-mail jane.swenson@childrenshc.org
"Portrait of Promise" video, brochures, hospital program materials

Inflicted traumatic brain injuries tracked statewide through medical records

by Maureen Holmes, MPH, Surveillance Coordinator, Minnesota Department of Health

The Minnesota Department of Health's Injury and Violence Prevention Unit (IVPU) has received funding from the Centers for Disease Control and Prevention since the fall of 2001 to investigate the feasibility of using hospital records for surveillance of injuries due to child maltreatment.

One area we have been able to focus on is inflicted traumatic brain injury (iTBI), which includes shaken baby syndrome. This is due in great part to the innovative work of the Midwest Children's Resource Center's staff and the direction provided by the Shaken Baby Syndrome Task Force.

At the request of MCRC and the task force, we began to try to count incidents of severe (deaths and inpatient hospitalizations) iTBI sustained by infants and young children. Potential cases are identified by diagnostic codes associated with TBI and then the medical records are abstracted to confirm iTBI cases and gather additional information.

Abstracted variables include victim demographics, victim history of abuse, hospital charges, and perpetrator and incident information. We began collecting data retrospectively from 1999 forward and are hoping to continue this effort indefinitely through the Traumatic Brain and Spinal Cord Injury Registry. The diagnostic code specific to shaken baby syndrome has been added to the list of codes mandatorily reportable to the TBI Registry by hospitals statewide.

There are a number of factors that make identifying and tracking iTBI difficult. First, our data collection efforts are dependent on physicians identifying and documenting the cause of the TBI. Medical records staff must then appropriately code the injury (and ideally the external cause of the injury) and submit the data. To ensure

complete capture of all cases of severe iTBI in Minnesota, we check with multiple other data sources (such as the Child Mortality Review, MCRC, and death certificates) to identify missed cases. The process is laborious, but rewarding.

It is only by identifying the size and scope of this problem that we can begin to understand the effectiveness of prevention efforts such as MCRC's hospital-based parent education project.

Ask Dr. Kaplan

Q Why do some shaken babies get misdiagnosed initially?

A That's a great question. Abusive head trauma (AHT) often goes unrecognized on initial presentation to a medical provider. In a large 1999 study in Denver, 30 percent of infant victims were seen at least one time by a physician after the injury without a diagnosis of abuse being made. Tragically, a number of these babies were re-injured—several fatally.

In the Denver study, the most common erroneous diagnoses included gastroenteritis, ear infection, influenza, and minor accidents. Interestingly, abuse was more frequently missed in Caucasian, intact families. Also, as one might expect, children with less severe injuries were among those most commonly missed.

There are many reasons why medical professionals do not initially identify AHT victims. First, there is a broad range of clinical presentations ranging from vomiting and irritability to coma and death. The more mild presentations are difficult to distinguish from other common medical conditions. Second, child abuse is not an easy thing to think about and many professionals simply don't have abuse on their radar when they assess injured babies. Third, often the historian is deceptive, which makes taking a traditional medical history impossible.

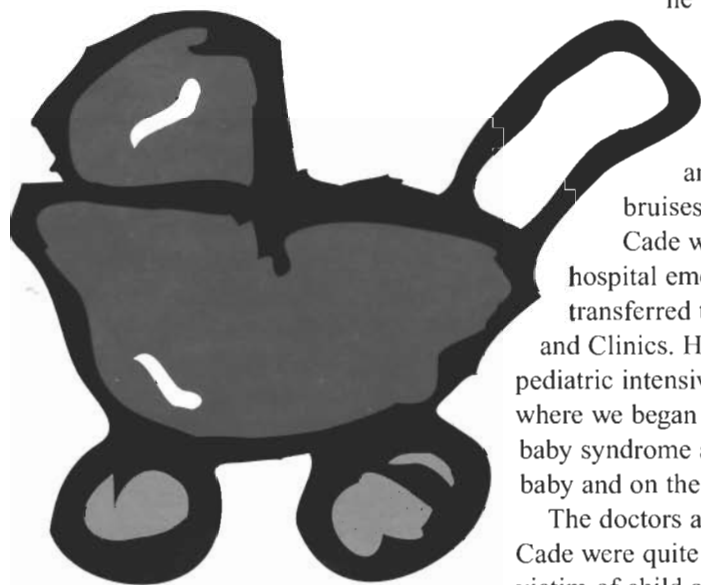
As you can see, we have our work cut out for us. We must continue to educate our present and future medical colleagues about AHT as well as other forms of child abuse. We must continue to advance our science so as to enhance our diagnostic capabilities. Finally we must continuously rededicate ourselves to the protection of the most vulnerable and most precious of people—babies.

Rich Kaplan, MD, MSW, is the associate medical director of Midwest Children's Resource Center, Children's Hospitals and Clinics, Minneapolis/St. Paul, Minn.

A parent's story

by Wendy Roepke

It seems like such an extraordinary story to tell about what seemed like an ordinary day. It seems like an extraordinary experience to happen to an ordinary family. An extraordinary change has happened in our ordinary lives.



On a December afternoon in 2001, I was called at my job by our day care provider.

There was an emergency with our 13-week-old son Cade Michael. He wasn't breathing and appeared to be having a seizure. The ambulance was called. When I arrived on the scene, it was like a bad movie. Cade was in the center of it all...he was breathing... but he was not the baby I had dropped off there.

I know that there are technical terms for all of the signs and symptoms that Cade was demonstrating, but it is easier to say that he was breathing shallow, his eyes were fixed and looking upward to the left,

he was moaning, and he did not respond to my voice or touch. He also did not have any outward signs of an injury. No scratches,

bruises, red marks, or bumps.

Cade was rushed to our local hospital emergency room and then transferred to Children's Hospitals and Clinics. He was admitted to the pediatric intensive care unit and that is where we began to learn about shaken baby syndrome and its effects on a baby and on the family.

The doctors and nurses caring for Cade were quite positive that he was a victim of child abuse. They knew this because he showed many of the classic symptoms of abusive head trauma. Many tests were performed on his tiny body and they showed that Cade had bleeding on his brain, retinal hemorrhaging, seizure activity,

difficulty eating, slow response to stimulus, and his skeletal survey showed fractured distal femurs in each leg.

Despite all of this, it turns out that we are the lucky ones. Cade has recovered from his injuries with little or no sign of permanent brain damage, seizure disorders, or paralysis. He has discontinued the occupational and physical therapy he had as a result of this abuse. His future holds the possibility of mood and behavior disorders and learning disabilities.

He is the exception to the rule. He is a miracle.

There is a lot we do not know about our experience with Cade's injury. Why did this happen? What could we have done differently to prevent this? Will Cade be okay? How did he suffer? What could he have done to deserve this? How angry must a person be to punish an innocent baby?

On the other hand, there is one thing we do know about his injury. It could have been prevented. It was the result of abuse.

Now that we have been through this experience, we have made a decision. We will tell everyone that will listen about the dangers of shaking a baby or a small child. We will ask caregivers, teachers, doctors, and nurses to be ever vigilant for infants and children that may be at risk. To reach out a helping hand for parents who may be struggling with the task of caring for a baby.

We won't forget that extraordinary experiences happen to ordinary people.

Twin Cities Metro
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