

update



TWIN CITIES METRO SHAKEN BABY SYNDROME PREVENTION PROGRAM

Learning from the Pros

Checking-in with the Upstate New York Shaken Baby Syndrome Education Program

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

Kim Smith, RN, and Kathy DeGuehery, RN, were kind enough to share some information and insights on the progress of their success with the shaken baby syndrome (SBS) education program in Upstate New York. The Twin Cities Metro Shaken Baby Syndrome Prevention Program is designed after their program model. Implemented six years ago, they have learned that this consistent, universal prevention model holds great promise for the incidence reduction of SBS.

What is your role with the Upstate New York Education Program?

We have been nurse coordinators of the Upstate NY SBS Education Program since Oct. 2000. Mark Dias, MD, hired us after the second year of his pilot study was done in the western New York region. It was then that he was awarded a four-year grant from the William B. Hoyt Children & Family Trust Fund to expand his research to the adjacent Finger Lakes Region. Our role has been to oversee hospital-based education in both the Western New York and Finger Lakes Region.

The Upstate NY SBS Education Program began in Dec. 1998 by Mark

S. Dias, MD, a neurosurgeon at Kaleida Health Women and Children's Hospital. Its' purpose is to educate both parents of all infants born in an eight-county region of Western New York, before discharge from the hospital, about the dangers of shaking infants violently. Women's and Children's Hospital of Buffalo has enlisted the participation of all 18 hospitals that delivery maternity care in the region.

What is the premise of this education program?

The premise of the program is that parents need to be reminded at the correct time (upon the birth of a child) about SBS, and that educated parents would be effective advocates by disseminating this information to all who care for their child. Under this creative community-focused program, parents receive both written and, in many cases, video materials about SBS before leaving the hospital. Both parents are then asked to voluntarily sign a commitment statement affirming their receipt and understanding of this material; these commitments statements are returned and tracked by the investigators.



Why do you feel this model is effective in reducing SBS incidence?

The program is unique in many respects:

It is universal in application, involving all hospitals providing maternity care in the entire Western New York region. This means that parents realize they are not being singled out due to socio-economic or ethnic status or suspect for some other reason, but because all parents need help in such moments.

It provides information consistently to all parents at a time when they are most receptive to information about how to best care for their child.

Although it targets both parents, it actively and specifically seeks out fathers and father figures for education. Parents and their partners

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account for 75% of shaken babies, while fathers or father figures alone account for 60% of shaken babies.

This innovative community-wide approach engages parents and requires their active participation by asking them to voluntarily sign commitment statements that reaffirm their receipt and understanding of the information.

It tracks the dissemination of the program to parents through the return of the commitment statements.

It documents success.

How are you tracking and documenting your data?

Women's and Children's Hospital of Buffalo has been tracking the incidence of SBS in the eight-county region since Dec. 1998, and comparing it with historical SBS incidence figures from the six preceding years. We have demonstrated a **sustained and consistent 50 percent reduction in incidence** in these eight counties since the inception of the program. The reach of the program has expanded into 12 hospitals in the nine counties of the Finger Lakes Region as well as seven hospitals in the three counties of the Watertown area. We now educate approximately 37,000 families per year.



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.

Has your education model changed at all?

Women's and Children's Hospital of Buffalo has introduced a new phase in the SBS Education Program in collaboration with 117 community physicians in Western New York. This involves a 'booster shot' in the form of additional educational materials provided at the doctor's office on the first visit. The goal is to reinforce the message provided at birth.

Additionally, Women's and Children's Hospital has developed an educational card to help parents cope with a crying infant, and these crying cards are shared with all parents at the baby's first visit to the pediatrician.

What do you tell potential funders about the cost effectiveness of this prevention program?

The total cost savings to society by preventing even one infant from violent shaking could well exceed several million dollars. While the societal costs of lifelong care for children with head injuries is not well established, the initial hospital costs alone (excluding physicians' fees) can average \$30,000 to \$70,000, and the medical costs for one case can exceed \$1 million. The costs of an effective primary prevention program could easily be regained from the medical savings to the community.

Most important, a prevention campaign designed to raise public awareness and educate parents and others about the dangers of violent infant shaking and abuse could potentially save the lives of many children and improve the lives of countless others. There has never been a more clarion call for public education and awareness about the dangers of violence against infants. Our program is the first to have demonstrated that a parent education program can have a documented impact in eliminating this scourge.

Upcoming conferences

North American Conference on Shaken Baby Syndrome
Montreal, Quebec, Canada
September 12-15, 2004
www.dontshake.com

2004 Midwest Regional Children's Advocacy Center Conference on Child Abuse
November 2-4, 2004
Hotel Sofitel, Bloomington, MN
www.mrcac.org



For more information on SBS

National Center on Shaken Baby Syndrome
www.dontshake.com
videos, curricula, brochures, resources

National Shaken Baby Alliance
www.shakenbaby.com
national organization of SBS victim families devoted to education and support

Prevent Child Abuse America
www.preventchildabuse.org
publications, materials, resources

Prevent Child Abuse Minnesota
www.pcamn.org
statistics, prevention materials, resources, and family support

Zach's story

hil! My name is Zach. I am 10 years old. When I was a baby, a lady didn't leave her hands to herself and hurt me. I was asked to tell you what its' like to be me.

I like to play football but people at school count me out. Especially the people I call my best friends. They don't really play with me. They have difficulty understanding me.

I love school, but sometimes I get irritated. I have a hard time understanding what my teacher is explaining, especially in math. Because I'm deaf, I can't always hear what is being said.

My family accepts me the way I am, especially Abby, my little sister. She is very important to me. We are very close.

I love my mom, step-mom, step-dad, and dad.

My brain is injured. We say it has a bump on it. It's easier to explain that way. I have a lot of trouble remembering things even when I write them down. I need a lot of help remembering things. It makes me feel frustrated, angry, and disappointed.

I am partially deaf because she hit me. It caused a cholesteotoma which ate up most of my bones. I have had about seven surgeries to try and fix it. I'm okay with being deaf if I don't have to have another surgery. I hope to have a hearing aid one day.



Ask Dr. Kaplan

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When an elementary school child is being evaluated for learning disabilities or behavior problems, is it possible to determine if he was shaken as a baby?

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The short answer is probably not. Suffering significant head trauma as an infant can certainly result in learning and behavioral difficulties. However, in children who only manifest problems in learning and/or behavior, the likelihood of physical or radiologic evidence of that trauma is quite remote. Additionally, the common medical findings associated with abusive head trauma such as retinal hemorrhage and fractures would have long since resolved.

We know very little about the genesis of learning and behavior problems and possible causes are many and varied. Still, a clear history of clinically significant head trauma associated with evidence of brain injury, e.g., post-traumatic coma, provides a reasonable and even probable explanation of the child's current difficulties.

All this being said, what's most important is that we make every effort to maximize the youngster's learning and provide support and therapy around the behavioral issues. Such a child may very well benefit from the involvement of a developmental pediatrician, a child neurologist or a neuropsychologist—or maybe all three. It may be frustrating not knowing for certain what led to the child's problems, but it does not preclude the possibility of effective intervention.

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

Progress on counting inflicted traumatic brain injury in Minnesota

Sara Seifert, epidemiologist, Minnesota Department of Health

as described in the last issue of this newsletter, the Minnesota Department of Health's Injury and Violence Prevention Unit has been developing a system for tracking iTBI (inflicted Traumatic Brain Injury) in Minnesota children under age four. Preliminary counts from 1999 to 2001 suggest that there were about fifty cases per year that resulted in death or an inpatient hospitalization (at this time, cases are still being abstracted).

The majority of victims (68 percent) were male and most were under age one (82 percent). Nearly half (43 percent) had previous abuse documented in their medical record. The majority of perpetrators were parents (68 percent), but a large percentage (18 percent) were day care providers. Medical records do not always differentiate between parents and parents' significant others, which possibly caused some perpetrators, who were actually a parent's partner, to appear to be a parent.

In 2001, iTBIs resulted in nearly \$1 million in hospital charges for the initial hospitalization (this includes data collected thus far and it is likely that a few more cases will be added). The average cost per inpatient hospitalization was \$34,928.

To obtain these data, information was collected from multiple sources and linked to avoid duplication. For the purposes of this project, cases of suspected iTBI were included as well as more definitive cases. Data for deaths were collected from death

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certificates, medical examiner records, the child fatality review panel coordinator, supplemental homicide reports, the femicide report, and newspaper clippings. Data for inpatient hospitalizations were collected from the Minnesota Hospital Association, medical records from hospitals statewide, the Minnesota Department of Health Traumatic Brain and Spinal Cord Injury Registry, and Midwest Children's Resource Center at Children's Hospitals and Clinics. Further efforts are planned to contact large hospitals in Minnesota and border hospitals to ensure that no cases are missed.

The data obtained for this project are only as good as the data sources, which vary widely in content and quality.

Death certificates and autopsy reports will usually include detailed information regarding the cause of death and injuries. There is usually an assignment of the intent of the injuries, but frequently no information on the perpetrator or circumstances.

The supplemental homicide reports, which are voluntarily completed by local law enforcement agencies, describe the perpetrator and circumstances if known, but will have much less information on the injuries.

The femicide Report, which is created by the Minnesota Coalition for Battered Women, relies heavily on newspaper clippings for information. Newspapers and the femicide Report may have additional information that is lacking in other sources, but do not capture all of the cases and may not have accurate demographic data.

Medical records are the main source of information for nonfatal iTBI. The Traumatic Brain and Spinal Cord Injury Registry data come from medical records. The Minnesota Hospital Association obtains their data from hospital bills whose data also originated in medical records. Documentation in medical records varies greatly by facility and provider. Often there is detailed information regarding the injury, the physician's opinion about the cause of the injury, and the child and family. There are cases though where it appears very little information was collected, or if it was collected, it was not documented.

We look forward to sharing more data as it becomes available from this investigation. If you or your facility has been collecting data on cases of iTBI or shaken baby syndrome, please contact Debra Hagel at (651) 281-9821 or debra.hagel@health.state.mn.us to help us ensure that we have identified every case in Minnesota.

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