



ANNUAL REPORT

National  
Center On  
Shaken  
Baby  
Syndrome

2005





## *M*essage from the Founder and Executive Director

In five short and remarkable years, the National Center on Shaken Baby Syndrome has become the national leader in education and prevention of shaken baby syndrome.

This growth and success in large part is dependent upon the personal donations of time, talent, generous financial gifts and grants from those of you who have remained steadfast in your commitment to keep all babies safe from harm.

We acknowledge and express our appreciation to all of you who have supported the National Center on Shaken Baby Syndrome this past year. We offer sincere appreciation to the members of our International Advisory Board and Governing Board and acknowledge the continuous and generous support of the Dr. W. C. Swanson Family Foundation.

Our future is dependent upon our ability to collaborate with other organizations in developing and implementing new education and establishing programs proven to protect infants from abuse. In order to be effective, we are committed to expanding and developing new research in effective methods to prevent shaken baby syndrome.

As the only organization in the United States with a mission dedicated to the prevention of shaken baby syndrome, we strive to prevent the devastation caused from this violent form of child abuse.

We are committed to this challenge and invite all of you to join with us so we can prevent shaken baby syndrome.



Marilyn Barr  
Founder and Executive Director

*Believe that all babies can be safe from harm ... We do.*



## Mission Statement

The National Center on Shaken Baby Syndrome has a mission to prevent shaken baby syndrome through the development and implementation of education programs, public policy and research; to establish networks, support and train families, caregivers and professionals.

## Vision Statement

To eradicate shaken baby syndrome through education and prevention programs.

## Strategic Plan Summary

In the next three to five years the National Center on Shaken Baby Syndrome is committed to strengthening its leadership role in providing awareness and education of shaken baby syndrome.

We will seek to promote shaken baby syndrome awareness in the communities we serve and among parents, families and professionals worldwide. We will strive to develop shaken baby syndrome incidence reporting and advocate research providing new empirically tested medical technology and prevention efforts.

We will continue to develop new prevention programs as their needs arise and restructure our materials to fit current research and studies. We will provide the most accurate and well-respected training and conferences on shaken baby syndrome.

We will continue collaborating with families and other organizations in a united effort to prevent shaken baby syndrome. We will focus additional means in securing appropriate funds each year to maintain and improve our efforts in preventing shaken baby syndrome.



## Governing Board Members

### **The Honorable Roger Dutton**

Chairman, Governing Board  
Second District Court Judge  
Huntsville, Utah, USA

### **Tami Swanson**

Vice Chairwoman, Governing Board  
Dr. W. C. Swanson Family Foundation  
Mother of Kelly Deaun Rust,  
victim of shaken baby syndrome  
Ogden, Utah, USA

### **Joseph Hansen**

Senior Consultant, The Greenwood Company,  
San Francisco, California  
President/CEO, (Past) McKay-Dee Hospital Foundation  
Farmington, Utah, USA

### **Alex Levin, MD, MHSc, FAAP, FAAD, FRCSC**

Chairman, International Advisory Board,  
National Center on Shaken Baby Syndrome  
Chairman, Canadian Association of Pediatric Ophthalmology  
Associate Professor in Pediatrics, Ophthalmology and  
Genetics, Hospital for Sick Children, University of Toronto  
Toronto, Ontario, Canada

### **Vickie McCall**

Associate, Jim Hansen and Associates  
Realtor, ERA Webber Real Estate  
President, (Past) Utah Defense Alliance,  
Member Utah Women's Forum  
Ogden, Utah, USA

### **Michele Poole**

Co-Founder and President, National Shaken Baby Coalition  
President, (Past) Arc of Palm Beach County, Florida  
Owner, North Ridge Electric, Inc.

Mother of Michele and Gabbi Poole,  
victims of shaken baby syndrome  
Lake Worth, Florida, USA

### **Richard Schubert**

Washington Representative of Management  
and Training Corporation  
President, (Past) American Red Cross  
President, Points of Light Foundation  
Director, National Alliance of Business  
Washington D.C., USA

### **Randy Watt**

Assistant Chief, Ogden Police Dept.  
Lieutenant-Colonel, Utah, Army National Guard's  
19th Special Forces Group  
Ogden, Utah, USA



## International Advisory Board

### **Alex Levin, MD, MHSc, FAAP, FAAD, FRCSC**

Chairman, International Advisory Board  
Staff Ophthalmologist, The Hospital for Sick Children  
Toronto, Ontario, Canada

### **David Chadwick, MD, PhD**

Vice-Chairman, International Advisory Board  
Member of the American Medical Association on  
Violence and Abuse  
Children's Hospital  
San Diego, California, USA

### **Randell Alexander, MD, PhD**

Statewide Medical Director of the Child Protection Team  
Chief, Division of Child Protection and Forensic Pediatrics,  
University of Florida  
Jacksonville, Florida, USA

### **Ronald G. Barr, MA, MDCM, FRCPC**

Canada Research Chair, Professor of Pediatrics  
University of British Columbia  
Director, Centre for Community Child Health Research  
Vancouver, British Columbia, Canada

### **Tracey Corey, MD**

Chief Medical Examiner, Commonwealth of Kentucky  
Professor of Pathology and Associate Professor  
of Pediatrics, University of Louisville  
University of Louisville School of Medicine  
Louisville, Kentucky, USA

### **Carole Jenny, MD, MBA**

Director, Child Protection Program at Hasbro  
Children's Hospital  
Past Chair of the Section of Child Abuse and Neglect  
of the American Academy of Pediatrics  
Providence, Rhode Island, USA

### **Robert Reece, MD**

Director, MSPCC Institute for Professional Education  
Executive Editor, Quarterly Child Abuse Medical Update  
Clinical Professor of Pediatrics,  
Tufts University School of Medicine  
Boston, Massachusetts, USA

### **Victor Vieth, JD**

Senior Attorney, National Center for  
Prosecution of Child Abuse  
Director, the National Child Protection Training Center  
Winona, Minnesota, USA

### **Phil Wheeler, Detective Chief Inspector**

Metropolitan Police Department  
London, England



## Year to Remember

Many children in our country are shaken each year. An estimated 1,200 -1,400 of these children receive medical treatment for shaken baby syndrome. Of these tiny victims, 25-30% die, and 80% of those who survive will have lifelong brain injuries. Beyond the deaths and injuries of these victims lies a secondary tragedy, the horror and irreparable damage to the lives of those who lost control. No family should suffer the unnecessary agony of shaken baby syndrome.

In 2005, the National Center on Shaken Baby Syndrome (NCSBS) expanded its research, education, information and referral services, continuing to broaden awareness and motivate action throughout the United States and abroad. Prevention is not simply a *desirable* goal. It is an absolute *essential* one.

### **Period of PURPLE Crying Research Program**

The *Period of PURPLE Crying*, represents a new understanding of early childhood crying. It has been developed into an educational program, based on years of research on normal infant development. Crying is the number one trigger leading a parent or caregiver to lose control and shake a baby. Ronald G. Barr, MA, MDCM, FRCPC, developed the *Period of PURPLE Crying* concept. His research, along with other scientists, has contributed to the understanding that these patterns of early crying, though frustrating, are a normal part of development.

For several years now, the NCSBS has offered brochures, bookmarks and posters that tell parents about the *Period of PURPLE Crying*. These materials provide important and helpful information, but they had not been empirically tested to determine whether they prevent shaken baby syndrome. In 2004 the NCSBS, in collaboration with the University of Washington, Harborview Injury Prevention and Research Center, and the University of British Columbia, received grants from the Doris Duke Charitable Foundation and the George S. and Delores Doré Eccles Foundation to produce new materials and an educational film and to empirically test the new program. This evaluation is in its second year of a three-year process, using the gold standard of research; randomized controlled trials. The program is being tested through four different types of delivery systems: maternity services, pediatric offices, prenatal classes and home visitor programs. We are thrilled to have this opportunity and look forward to the results.

The program will include an entirely new booklet and film and will be offered at the completion of this testing in 2007-08. The current *Period of PURPLE Crying* educational materials are still in high demand and will continue being offered to customers until the new program is published.

### **International Advisory Board**

The nine distinguished members of the International Advisory Board (IAB) continue to play an active role in the outreach of NCSBS. They secure outstanding presenters for our national and international conferences, they offer their own keynote and general presentations for our programs, they guide the development of new initiatives, including educational materials, and they serve as valuable resources in our work with the media throughout the U.S. and abroad.

## Prevention Programs and Community Education

The NCSBS continues to provide international, national and local training and education to students, parents and professionals through its shaken baby syndrome prevention programs.

### ■ **Utah Hospital-based Shaken Baby Syndrome Prevention Program**

The Utah Hospital-based Shaken Baby Syndrome Prevention Program is conducted in all 39 birthing hospitals in the state of Utah. The program is reaching 60-70% of parents with this education. Hospitals and birthing centers present a film about shaken baby syndrome to parents of new babies, discuss infant crying, the most common trigger to shaking, and the dangers of shaking an infant. Educational materials are also provided to parents at the time of discharge.

### ■ **Dads 101 Program**

The *Dads 101* program is designed to help men learn the skills they need to become fathers and trains them how to care for their baby. This comprehensive program encourages discussion among dads about their own perceptions of fatherhood and educates them about infant crying patterns and shaken baby syndrome. Recognition and sales of the *Dads 101* program is spreading nationwide among military family advocacy centers, hospitals, schools and correctional facilities. The *Dads 101* program is being presented on a regular basis at McKay-Dee Hospital in Ogden, Utah, and at Hill Air Force Base, Utah.

### ■ **School-based Curriculum on Shaken Baby Syndrome**

The NCSBS School-based program provides educational information to junior high and high school students about the dangers of shaken baby syndrome and how to prepare and deal with the frustrations that can arise in parenting. This program was presented to Utah high schools throughout the year at the request of local teachers. Four states-Indiana, Wyoming, New Jersey and Ohio-are all working with NCSBS to implement this program into their school systems. Indiana has taken a lead and has already received support from the Indiana Department of Education to provide the program to teachers for use in family consumer science classes. Currently \$6,000 has been raised from a grant and donations to pay for the program to be instituted into approximately 400 Indiana high schools.

## Conferences, Training Sessions and Presentations

In 2005 the NCSBS began planning its eighth conference for the last 10 years. In 2006, the Sixth North American Conference on Shaken Baby Syndrome will be held on September 13-16, 2006, in Park City, Utah. The National Center has held three international conferences in Sydney, Australia (2001), Edinburgh, Scotland (2003), and Montreal, Quebec, Canada (2004). Four national conferences have been held in Salt Lake City, Utah.

In addition to national and international conferences, NCSBS conducted its first regional symposium in Canada on March 3, 2005, in Vancouver, British Columbia. A second regional symposium in Vancouver will be held on May 19, 2006. The NCSBS continues to be contacted nationwide for keynote presentations and workshops. The National Center's staff participated as keynote speakers at conferences held in Kentucky and Illinois this year. Through these conferences, the NCSBS staff educated more than 800 medical, legal and social workers about shaken baby syndrome and the National Center's prevention efforts.



### ■ **Educational Materials and Sales**

The National Center introduced a new prevention materials catalog in October to more than 35,000 professional contacts worldwide in an effort to increase awareness and education of shaken baby syndrome. The NCSBS developed 13 new educational materials and updated some of its existing materials.

### ■ **New Hospital Education Program for Maternity Services - Shaken Baby Syndrome Prevention**

The National Center's success with the Utah Hospital-based Shaken Baby Syndrome Prevention Program has provided valuable information in developing a marketable program that can be implemented specifically in hospitals and birthing centers in the United States and Canada. The National Center has taken the lead in providing this valuable shaken baby syndrome prevention program to new parents through the network of hospitals and birthing centers' nurses, midwives and physicians.

### ■ **New Shaken Baby Syndrome Injuries Illustrated Packet**

The NCSBS International Advisory Board assisted in helping us create a new illustration packet depicting the common injuries associated with shaken baby syndrome. The complete packet went through many revisions to correctly depict each injury. This packet was created to assist attorneys, court appointed special advocates (CASA) volunteers, investigators, medical personnel and others involved in shaken baby syndrome education instruction and training. Dr. Robert Reece and Dr. Alex Levin, IAB members, and NCSBS Art Director, Larry Stephens, were instrumental in the development of these educational tools. In addition, Reece and Levin's tireless efforts are appreciated in the development of the NCSBS's new CD-ROM-SBS: A Visual Overview, Version 3.0.

The response to these materials and others has been overwhelming. The NCSBS has established itself as the leader in shaken baby syndrome educational resources. This year proved to be our most successful year in sales revenue. We finished the year with \$237,057 in revenue, an increase of \$30,712 from 2004.

### ■ **Information and Referral Services**

The NCSBS provides free of charge, information, consultation and references on shaken baby syndrome for professionals and parents through a toll-free help line and e-mail. In 2005, the NCSBS received a total of 1,846 requests for information via phone calls, letters and emails from parents, professionals and the media. These services are used by investigators, medical providers, legal professionals, media, parents and family members of victims of shaken baby syndrome, trainers, child advocates, prevention specialists, and many others throughout the U.S. and the world. In this capacity, we offer general information, very specific resources and referrals to various local and national experts depending on the need. General information has become more accessible to the public through our expanded easy to use website launched in 2004. NCSBS staff tracks the latest information and research and monitors trends and issues to provide the most up to date, accurate information available. This knowledge is also used to ensure that our training opportunities and educational materials address current issues faced by professionals in the field.

### ■ **National Media Coverage**

The NCSBS was a helpful resource this year in providing valuable shaken baby syndrome information and statistics to NBC's *Today Show* and CBS's *Early Show*. Both networks aired stories of children who were recent victims of shaken baby syndrome. Information provided by NCSBS was used to help increase national attention to shaken baby syndrome prevention and education.



# VICTIM DATABASE RESEARCH

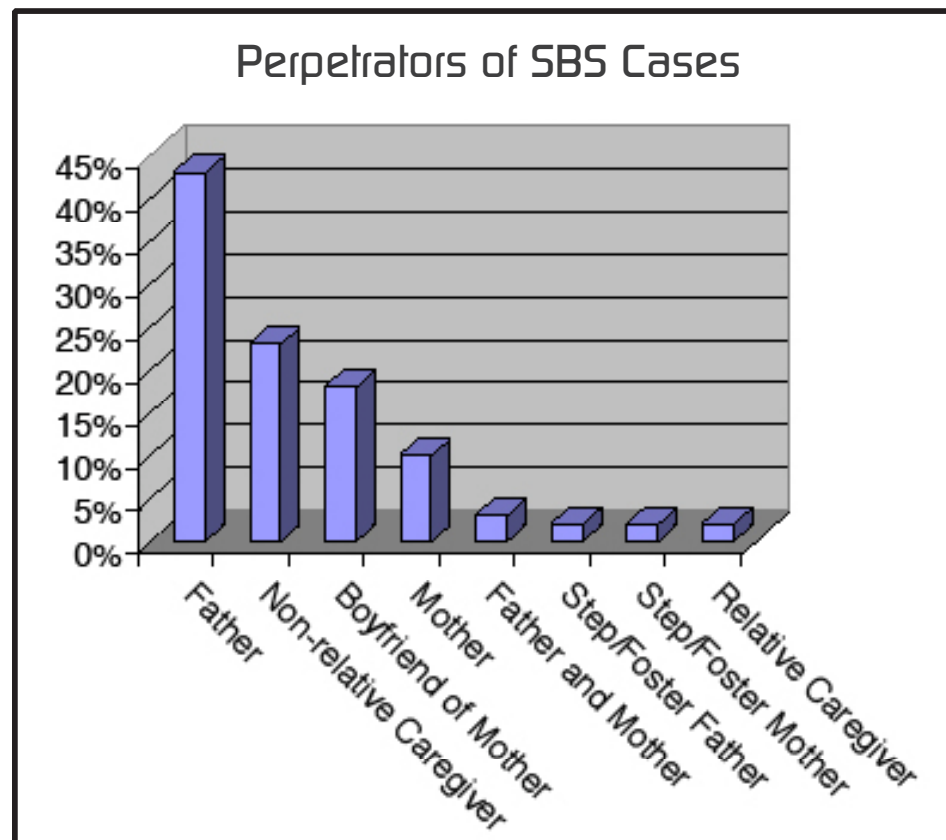
To aid in the understanding and prevention of shaken baby syndrome, the NCSBS has been tracking cases of shaken baby syndrome since 1999. Our results are as follows:

- 2,853 case files from the United States and throughout the world
- Articles from a variety of sources, including media reports and Individual case studies
- The largest database of shaken baby syndrome cases in the world

Many of the published studies on shaken baby syndrome rely on small samples from one hospital, county or state. Our database is a valuable research resource that includes information about the victim, perpetrator and legal outcomes of court cases.

The NCSBS has partnered with several organizations to analyze our data and gain a better understanding of shaken baby syndrome. Partners include: Intermountain Injury Control Research Center, University of Utah Department of Pediatrics; and Dr. Ronald G. Barr, MA, MDCM, FR-CPC with the Centre for Community Child Health Research.

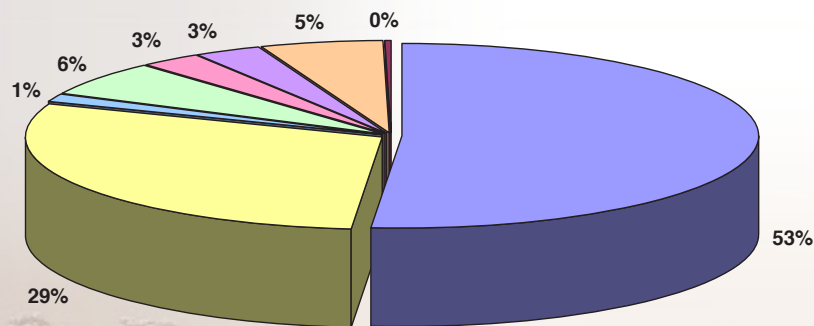
Results from their studies along with the NCSBS victim database have been submitted for publication and are currently under review.



Source: NCSBS Victim Database

# 2005 FINANCIAL REPORT

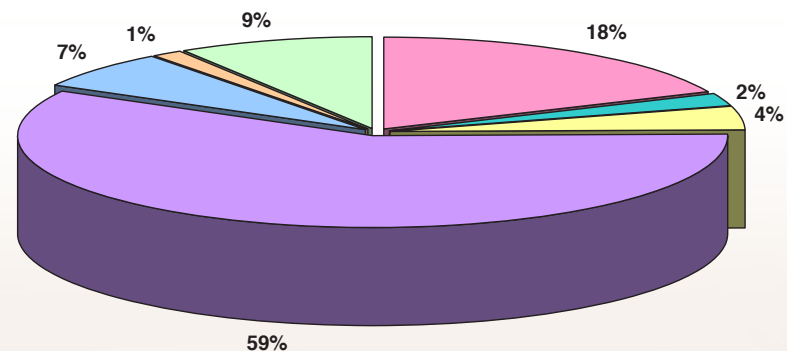
## Revenue



- FOUNDATION SUPPORT
- ANNUAL GIVING CAMPAIGN
- DONATIONS
- OTHER INCOME
- RESOURCE MATERIALS
- PURPLE RESEARCH AND OTHER GRANT INCOME
- PROGRAM INCOME
- 6TH NORTH AMERICAN CONFERENCE-PARK CITY

Total Revenue: \$811,171.75\*

## Expenses



- OPERATING EXPENSES
- COMMITTEE AND TRAINING EXPENSES
- PURPLE RESEARCH EXPENSES
- PAYROLL/BENEFITS
- MARKETING/RESOURCE DEVELOPMENT
- 6TH NORTH AMERICAN CONFERENCE-PARK CITY
- COST OF GOODS SOLD

Total Expenses: \$734,644.01

### \*Differences in Revenue and Expenses

Funds were received and set apart as restricted funds for programs including implementation of a statewide school-based program in Indiana, *Period of PURPLE Crying* research and expenses associated with the upcoming Sixth North American Conference on Shaken Baby Syndrome in Park City on September 13-16, 2006.

### Other In-kind Donations Not Represented in the Financial Report Include:

Office and meeting space: The Dr. W.C. Swanson Family Foundation-Ogden, Utah  
 Accounting and auditing services: James and Company CPA's-Ogden, Utah  
 Computer tech support: Crossaction Computer Specialists-Riverdale, Utah



# Financial Donors and Support

## Funds Received in 2005

### Financial Donors

Alex Levin, MD, MHSc, FAAP, FAAO, FRCSC  
 Dr. W.C. Swanson Family Foundation  
 Doris Duke Charitable Foundation  
 Jonathan D Walker, MD  
 Lawrence T. Dee and Janet T. Dee Foundation  
 Ronald Barr, MA, MDCM, FRCPC  
 Royal Canadian Mounted Police  
 State of Utah Offender Program  
 Steven G. and Susan E. Denkers Family Foundation  
 The Church of Jesus Christ of Latter-day Saints Foundation  
 The George S. and Delores Doré Eccles Foundation  
 The Helen P. VanArnam Foundation, Inc.  
 United Way Combined Federal Campaign  
 United Way of Northern Utah  
 United Way of Pennsylvania  
 United Way of Shebogyan

### Annual Giving Donors

Alex Levin, MD, MHSc, FAAP, FAAO, FRCSC  
 Allen & Laurie Harrison  
 American Housekeeping of Utah  
 American Legion Auxiliary Unit 87  
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 Cindy Purcell  
 David Ogilvie  
 Gerd & Barbara Weimer  
 Glen & Deby Burton  
 Glenda Heath  
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 Janet Bean

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 Janice Dee  
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 Paul & Allene Daines  
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 Susan Bourassa  
 Susan Glasmann  
 Varou Hairabedian  
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### In-kind Donors

Crossaction Computer Specialists  
 CyberAlert  
 Digital Bytes  
 Joan Hunt  
 National Shaken Baby Coalition  
 Neutekprint  
 Overture Photo and Video  
 Ogden City Schools, Adult Transition Program  
 Ronald Barr, MA, MDCM, FRCPC  
 Tech Soup

### Research and Education Partners

American Academy of Pediatrics  
 Children's & Women's Hospital of British Columbia  
 Foresters, Canada  
 Medicaid Program, Utah Department of Health  
 National Shaken Baby Coalition  
 Primary Children's Medical Center of Utah  
 University of British Columbia, Centre for Community & Child Health Research

University of Utah, Intermountain Injury Control & Research Center  
 University of Washington, Harborview Injury Prevention & Research Center

### In Memory Of Donors

Care Partners Foundation  
 Charles & Marian Smith  
 DonnaJean Raffeseth  
 Duane & Reatha Lyda  
 James & Mannu Thirnelliparambil  
 Kathleen Fisher  
 Marie Gulian  
 PRN Medical Resource Management  
 Spaulding Pediatric Rehabilitation  
 Stephanie Hall

### Utah Hospital Prevention Program Financial Supporters

Alta View Hospital  
 Ashley Valley Medical Center  
 Coltonwood Hospital Medical Center  
 Davis Hospital & Medical Center  
 Dee Charitable Foundation  
 Dixie Regional Medical Center  
 Kane County Hospital  
 McKay-Dee Hospital  
 San Juan Hospital  
 Uintah Basin Medical Center

### Public Support

CTAAP  
 Employees of Washington County Division of Public Health  
 Louis & Connie Loeb  
 Sabrina Filomena  
 Southeast Mechanical Contractors  
 Southwest Louisiana Area Health  
 Tami J. Hedenland  
 The Morgan Family: Ross, Hannah, Tyler and Aaron  
 Theresa Devine

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**Shaken Baby Syndrome**

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