



National Center  
on  
Shaken Baby Syndrome  
DontShake.org

## 2015-2016 ANNUAL REPORT

### Mission Statement

The National Center on Shaken Baby Syndrome is committed to prevent shaken baby syndrome and promote the well-being of infants generally through the development and implementation of programs, policy and research; and to support and educate families, caregivers and professionals.

### Vision Statement

To eradicate shaken baby syndrome and improve the overall care of infants.

### Belief Statement

Believe that all babies can be safe from harm ... we do!

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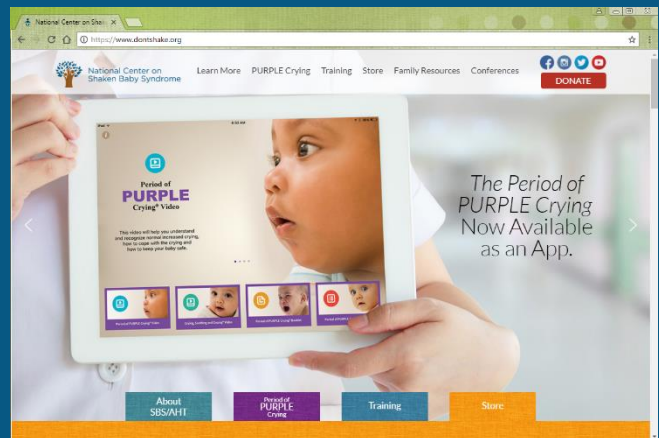
### New DontShake.org Website Released

After almost eight years, the NCSBS developed and released a new website. Best practices are ever evolving in website design and security so it was vital the NCSBS create a site that was secure, responsive and user friendly.

The new website includes a new content management system (CMS). The CMS allows the NCSBS to make a majority of updates to the formatting and content of the site. This functionality creates a big financial savings for the NCSBS and allows us to redirect more resources to supporting families and preventing abuse.

The new website also received a comprehensive security upgrade that will help prevent against future hacking attempts that had plagued the NCSBS website in the past.

Check out the new website at [www.DontShake.org](http://www.DontShake.org).



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### NCSBS and Partners Publish New Research on the Medical Costs and Quality of Life Losses Stemming from SBS/AHT

The NCSBS in partnership with colleagues from the Centers for Disease Control and Prevention (CDC) and the Pacific Institute for Research and Evaluation (PIRE) published two articles in the journal *Pediatrics* that provide estimates for the multi-year medical cost associated with abusive head trauma (AHT) and the quality of life losses stemming from these cases.

*The Medical Cost of Abusive Head Trauma in the United States* is the first study to look at the medical costs associated with abusive head trauma beyond acute care costs. Using data from a large insurance claims database known as “MarketScan” the study authors were able to identify cases of AHT and derive estimate of medical costs that extended beyond the acute care period. In the study, the authors estimated that the medical costs attributable to AHT up to four years post diagnosis average \$47,952.

In the study, *Disability-Adjusted Life-Year Burden of Abusive Head Trauma at Ages 0-4*, the study authors developed the first ever estimates of the quality of life losses stemming from cases of AHT. Using an internet based survey, the study authors developed a series of questions and an algorithm to assess injury severity of 170 abused infants. The survey was completed by victim caregivers and pediatricians who provided care to an injured infant. The internet survey also included questions to assess the functional status of the abused infants using the standardized Health Utility Index Mark 2. The study authors estimated lifetime burden averaged 4.7 disability adjusted life year's (DALY's) for mild AHT, 5.4 for moderate AHT, 24.1 for severe AHT, and 29.8 for deaths. On average, DALY loss per 30-day survivor included 7.6 years of lost life expectancy and 5.7 years lived with disability. Estimated burden of AHT incidents in 2009 was 69,925 DALYs or 0.017 DALYs per US live birth.

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### **NCSBS Welcome's New Governing Board Member**



The NCSBS is pleased to announce the appointment of Janelle Page Misbach, CEO of KickFire Marketing, to the governing board of the NCSBS. Janelle will begin her time on the board starting July, 2016.

Janelle is going to a great addition to an already superb and involved board. The NCSBS is going to benefit from Janelle's experience and insight as she will be able to advise the board on successful marketing strategies that would position the NCSBS for continued success in the non-profit world.

Janelle Page Misbach is a highly sought after marketing consultant and is committed to and passionate about helping business owners grow their business. She devotes countless hours presenting and teaching at marketing boot camps and conferences across the nation. She has been profiled in *Small Business Trendsetters*, as well as featured in *Business Innovators Magazine* for her business acumen and marketing expertise.

Janelle stated "it is an honor and privilege to work alongside such distinguished and accomplished colleagues on the NCSBS board and I am enthusiastic to help educate about and prevent Shaken Baby Syndrome/Abusive Head Trauma."

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### **Online CEUs Now Provided**

The National Center on Shaken Baby Syndrome is pleased to announce that we are now offering 1.5 nursing education contact hours (ONA # 18606) upon completion of the *Period of PURPLE Crying* Online Training for Military Providers course. These credits are in addition to the available National Association of Social Workers approved CEUs.

This continuing nursing education activity was approved by the Ohio Nurses Association (OBN-001-91), an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

These education opportunities ensure the *Period of PURPLE Crying* program remains the world's leading SBS/AHT prevention but not only educating families but the health professionals working with families and caregivers.

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### **NCSBS Staff**

Ryan Steinbeigle, Executive Director

Brian Lopez, Marketing Director

Julie Noble, International Program Director, *Period of PURPLE Crying* Program

Danielle Vázquez, Development Director

Kristin Allspaugh, Marketing Specialist

Marisa McPeck-Stringham, Information & Research Specialist

Trevor Rapp, Graphic Designer  
Lisa Peirce, Financial Controller  
Paul Sargent, Assistant Controller  
Kaylea Erickson, International Program Coordinator, *Period of PURPLE Crying* Program  
Alyssa York, International Program Assistant, *Period of PURPLE Crying* Program

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### **NCSBS Governing Board**

#### **Executive Committee:**

Lori Frasier, MD, Chair  
Division Chief, Child Abuse Pediatrics  
Penn State Hershey  
Center for the Protection of Children  
(Hershey, PA, USA)

Jill Moore, Past Chair  
Former Vice President Junior League of Ogden  
(Ogden, Utah, USA)

David W. Lloyd, JD, Vice Chair  
Retired Former Director, Family Advocacy  
Program,  
Office of Secretary of Defense  
(Silver Springs, MD, USA)

Chantel Chase, Secretary/Treasurer  
Vice President & Manager  
Women's Financial Group  
Zion's First National Bank  
(Salt Lake City, UT, USA)

#### **Members:**

Nan Streeter, MS, RN  
Utah Maternal and Child Health Bureau  
Former Deputy Division Director  
(Salt Lake City, UT, USA)

Bryce Froerer, JD  
Froerer and Miles PC  
(Ogden, UT, USA)

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### **International Advisory Board Members**

#### **Chair:**

Robert Block, MD  
Past President – American Academy of Pediatrics  
Department of Pediatrics  
Oklahoma University- Tulsa Schusterman Center  
(Tulsa, OK, USA)

#### **Members:**

Alex V. Levin, MD, MHSc, FRCSC  
Chief, Pediatric Ophthalmology and Ocular  
Genetics, Wills Eye Hospital  
(Philadelphia, PA, USA)

Randell Alexander, MD  
Division of Child Protection and Forensic Pediatrics  
University of Florida- Jacksonville  
(Jacksonville, UT, USA)

Marilyn Barr, Founder of NCSBS, BIS, SSW,  
Retired Founder of National Center on Shaken Baby  
Syndrome (Vancouver, BC, Canada)

Ronald G. Barr, MDCM, FRCPC  
Developmental Neurosciences and Child Health,  
Child and Family Research Institute, BC Children's  
Hospital and University of British Columbia Faculty  
of Medicine Retired (Vancouver, BC, Canada)

Rachel Berger, MD, MPH  
Children's Hospital of Pittsburgh of UPMC  
(Pittsburgh, PA, USA)

Mary Case, MD  
Professor of Pathology, St. Louis University  
Health Sciences Center  
(St. Louis, MO, USA)

Thomas J. Fallon, JD  
Assistant Attorney General,  
Wisconsin Department of Justice  
(Madison, WI, USA)

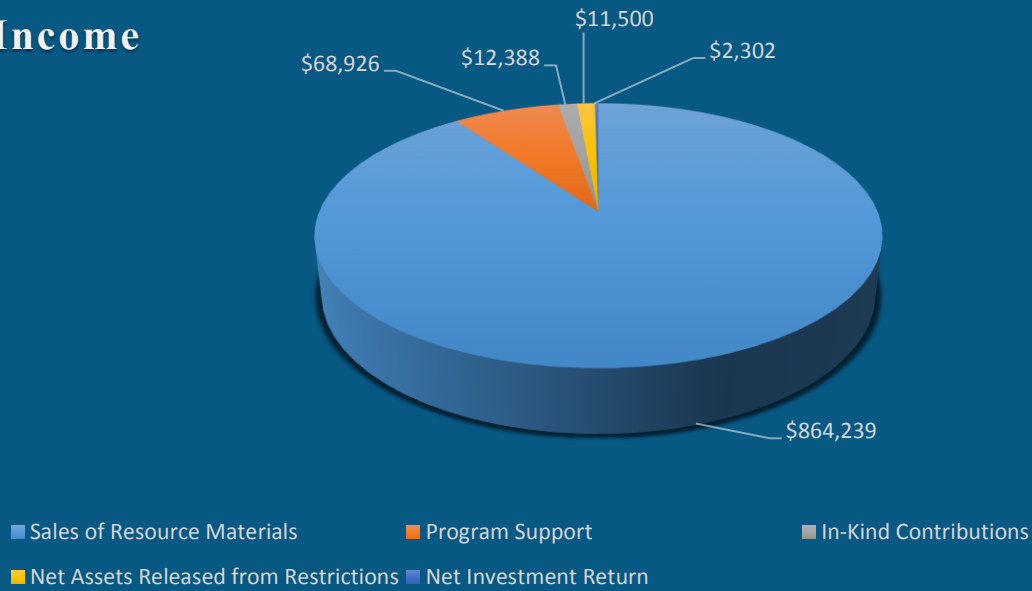
Brian Holmgren, JD  
Retired (Nashville, TN, USA)

Carole Jenny, MD, MBA, FAAP  
Professor of Pediatrics, University of Washington  
Medical School  
(Seattle, WA, USA)

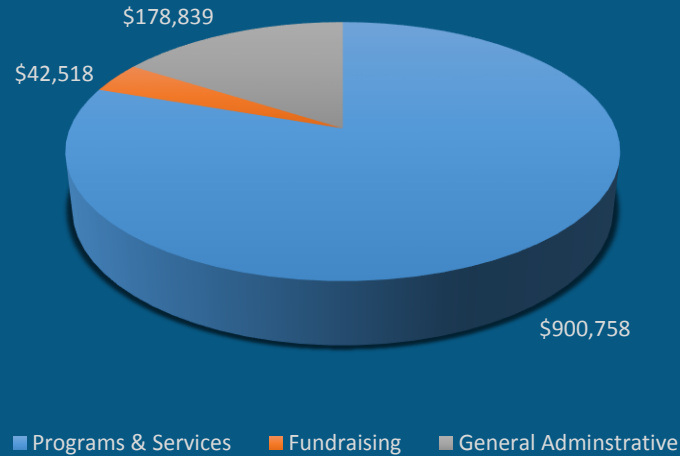
John Leventhal, MD  
Department of Pediatrics  
Yale School of Medicine  
(New Haven, CT, USA)

## Financial Overview

### Income



### Expenses



Changes in Temporarily Restricted Assets	
Grants, foundation and public support	26,567
Net assets released from restrictions	(11,500)
Change in temporarily restricted net assets	15,607
Change in Net Assets	(147,693)
Net Assets, Beginning of Year	968,880
Net Assets, End of Year	821,187