

## About Spina Bifida

Spina Bifida occurs when the spine of the baby fails to close during the first month of pregnancy, leaving a permanent opening in the spinal column. Those who are born with Spina Bifida must learn to live with conditions such as hydrocephalus (fluid on the brain), full or partial paralysis, bladder and bowel complications, learning disabilities, depression, and deadly latex allergy, as well as social issues.

Affecting the lives of tens of thousands of men, women, adolescents, and children in the United States alone, Spina Bifida is the most common permanently disabling birth defect. All women of childbearing age are at risk of experiencing a Spina Bifida pregnancy. However, it is estimated that up to 70 percent of birth defects like Spina Bifida could be prevented with folic acid supplementation.

## The Spina Bifida Association

The mission of the Spina Bifida Association (SBA) is to promote the prevention of Spina Bifida and to enhance the lives of all those who are affected by it.

Since 1973, SBA has acted as the sole national voluntary health agency, working to improve the lives of those with Spina Bifida. Our programs give hope and strength to the entire Spina Bifida community – those who live each day with the effects of the birth defect and the thousands of people who love and care for them.

In addition to providing substantial support to those who are currently living with Spina Bifida, SBA is exceedingly active in advocacy, education, and research and maintains a strong focus on prevention through programs geared toward women of childbearing age.



One of the Spina Bifida Association's most vital functions is to communicate to the 65 million women of childbearing age the importance of taking 400 micrograms of folic acid every day prior to pregnancy.

## Hope for the Future

Spina Bifida is the most complex birth defect that is compatible with human life. It is especially formidable because it is not just one condition, but rather a multitude of distinct conditions that affect the mind, the body, and the spirit. Very little research has been conducted on the many components of this complex birth defect. For this reason, it is crucial that SBA maintain a strong focus on research. Over the past few years, some great strides have been made:

- In 2003, a research agenda was defined at a ground breaking conference entitled "Evidence-Based Practice in Spina Bifida." This agenda is gaining momentum and yielding first fruits.
- In partnership with the Centers for Disease Control and Prevention and the Agency for Healthcare Research and Quality, SBA is working to ensure that all people with Spina Bifida will receive uniformly excellent care.
- SBA's Professional Advisory Council and other participating organizations examined data from Spina Bifida clinics across the country at a landmark collaborative meeting.
- Together with the National Institutes of Health, SBA is exploring collaborative projects for federal funding. A meeting in November 2006 helped define opportunities and initiated a course of action that will help grow the research base.
- In 2005, SBA launched its Young Investigator Awards research program with three awards of \$25,000 each. This unique program fosters young scientists who will dedicate their skill and expertise to improving the lives of those with Spina Bifida and ultimately finding a cure. Four additional awards were given in 2006.
- SBA will sponsor an international meeting of research professionals every three years. It is the goal of the organizations involved to establish this meeting as the premiere conference on Spina Bifida Research.



4590 MacArthur Boulevard, NW Suite 250  
Washington, DC 20007  
Tel: 800-621-3141  
[www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)



## Enhancing Lives Through Advocacy, Education & Research



## Advocating Change

Aimed at increasing public funding for Spina Bifida research, education, and patient services, SBA advances public policies that help individuals with Spina Bifida and their families. SBA's broad and unyielding advocacy program achieved marked success in recent years.

In recent years, federal funding for most public health and social services organizations remained flat or was cut altogether. Despite this trend:

- SBA mobilized men, women, and children from across the nation to awaken Congress to the importance of our cause. These courageous individuals shared their personal, heartfelt stories with policy makers, giving Spina Bifida a face, a heart, and a soul.
- The National Spina Bifida Program at the Centers for Disease Control and Prevention received an unprecedented 5.1 million dollars from Congress. This was a 39 percent increase over the previous year's allocation.

Achieving critical federal funding is one of numerous advocacy goals attained over the past year. SBA also:

- Entered into a dynamic and fruitful partnership with the National Council of La Raza, Wal-Mart Stores, Inc., and GRUMA S.A. de C.V., to develop a program geared toward decreasing the occurrence of Spina Bifida in Hispanic babies by enriching corn products with folic acid.
- Partnered with the March of Dimes and the American Academy of Pediatrics, among others, to encourage the Food and Drug Administration to review its standards for folic acid enrichment.
- Worked to improve reimbursement through Medicaid and Medicare, increase educational opportunities, and secure inalienable rights for all those who live with disabilities.

## Reaching Out to Those In Need

Over the past year, more than 100 million people were touched by SBA's outreach efforts. They read articles in national and local newspapers and magazines, saw and heard public service announcements on television and radio, attended special events like the Annual Roast for Spina Bifida, and met members of the Spina Bifida Community at health fairs and other community events.

Several notable causes warranted definitive involvement from SBA:

- In the wake of Hurricane Katrina, many with Spina Bifida were left vulnerable. To achieve the most rapid and effective response, SB HELP (Hurricane Emergency Life-Support Program) quickly delivered supplies and offered comfort to the displaced. A supportive community was formed to support uplift those whose hope was waning.
- In December, 2005, the heart of our nation was touched by Baby Noor, an Iraqi infant with Spina Bifida. As is consistent with our outreach program, SBA provided media sources with spokespeople and accurate information concerning Spina Bifida and, more specifically, folic acid as a tool of prevention.
- Prevention was, and continues to be, considered urgent in the Hispanic community. Through a sophisticated outreach program, SBA worked diligently to promote prevention through folic acid supplementation and to provide additional information to ensure good health and quality of life.

## Access to Education

There is a critical need for accurate and compassionate information about Spina Bifida. Those who are affected must become experts on new medical techniques and procedures, and must have the latest information on treatment and other related issues. While the need for information can be overwhelming, the complex social implications of Spina Bifida can be isolating.

SBA translates research findings into medically sound information and programs for individuals with Spina Bifida, their families, and health professionals. To respond to the need for information exchange and social interaction over the past year, SBA:

- Hosted two well-attended National Conferences, with carefully orchestrated programs that combined cutting-edge technical information with valuable insight into the practical aspects of everyday life. The 2005 Annual Conference was held in Minneapolis, Minnesota, in conjunction with the 18th Worldwide Meeting of the International Federation for Spina Bifida and Hydrocephalus. The 2006 Annual Conference was held in Atlanta, Georgia.
- Facilitated Kids!Camp, in conjunction with the Annual Conferences, to provide children with Spina Bifida a time of discovery and newfound independence at the largest camp in the nation dedicated to their special needs.
- Provided critical information to 10,000 people through the SBA National Resource Center. Information can be accessed by calling 800-621-3141.
- Delivered accurate, up-to-date information about health, advocacy, research, and other programs through the SBA website at [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org).
- Furnished a thriving online community with support and shared knowledge through eCommunities.
- Produced folic acid materials such as online tutorials for those in the healthcare field.
- Maintained a unique ListServ for members of the Nursing and Healthcare Professional Council to ask questions concerning the care of their patients and receive ideas and solutions from their peers across the country.
- Through TEAM, SBA's Mentoring Program, paired qualified mentors with teenagers to help them learn life skills and foster a spirit of self-reliance and pride.
- Awarded scholarships to young people with Spina Bifida.



Media and political luminaries speak out at the Annual Roast for Spina Bifida.



José Cordero and other representatives of the Spina Bifida Association, the Spina Bifida Foundation, and the National Council of La Raza celebrate the announcement of folic acid enrichment of corn products provided by GRUMA in conjunction with WalMart.



Following Hurricane Katrina, Julie Johnston, the outreach coordinator of the Spina Bifida Association of Greater New Orleans, became the hands and the heart of the Spina Bifida Community in that shattered city. Even as her own life was torn apart, she went from homeless shelter to homeless shelter, and hospital to hospital, searching for people with Spina Bifida.

While it was Julie who carried out this selfless and difficult task, in the end she expressed nothing but gratitude for others who responded to the overwhelming need in the Gulf Coast. "It seems so inadequate to say thank you," she said, "Thank you can't convey how much SB HELP has meant. It's been incredible how people from SBA chapters across the country have sought out our people and welcomed them as part of their families."

The noble compassion of Julie Johnston and others like her, combined with needed funding provided by caring people across the country, helped ease suffering in the wake of Katrina through SB HELP.

**FINANCIAL STATEMENTS**

**SPINA BIFIDA ASSOCIATION OF AMERICA**

**FOR THE YEAR ENDED MARCH 31, 2006  
WITH SUMMARIZED FINANCIAL  
INFORMATION FOR 2005**



# STATEMENT OF FINANCIAL POSITION

EXHIBIT A

**SPINA BIFIDA ASSOCIATION OF AMERICA  
STATEMENT OF FINANCIAL POSITION  
AS OF MARCH 31, 2006  
WITH SUMMARIZED FINANCIAL INFORMATION FOR 2005**

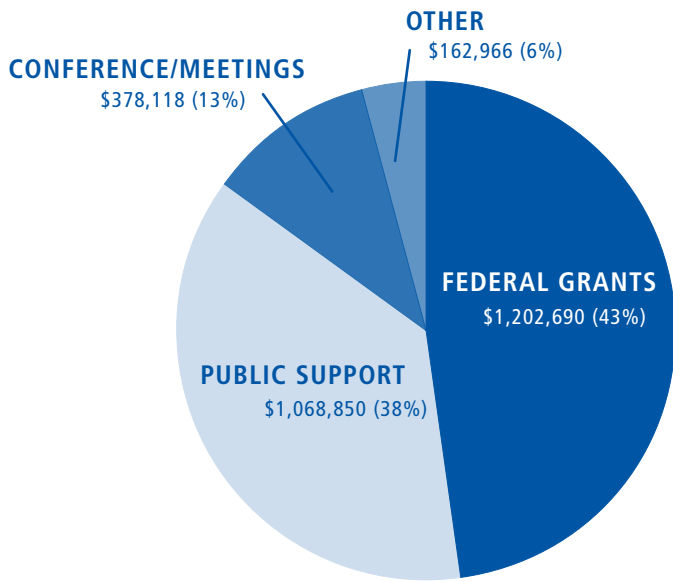
ASSETS	2006	2005
<b>CURRENT ASSETS</b>		
Cash and cash equivalents	\$ 272,067	\$ 135,487
Investments	435,239	417,003
Accounts receivable	25,030	33,476
Due from related parties	-	9,825
Grants receivable	790,000	550,000
Inventory	7,823	8,049
Prepaid expenses	39,535	59,849
<b>Total current assets</b>	<b>1,569,694</b>	<b>1,213,689</b>
<b>FURNITURE AND EQUIPMENT</b>		
Furniture	19,884	17,197
Equipment	79,509	75,094
Computer software	14,212	14,212
Less: Accumulated depreciation	113,605 (93,349)	106,503 (84,439)
<b>Net furniture and equipment</b>	<b>20,256</b>	<b>22,064</b>
<b>OTHER ASSETS - Deposits</b>	125	2,625
<b>TOTAL ASSETS</b>	<b>\$1,590,075</b>	<b>\$1,238,378</b>
<b>LIABILITIES AND NET ASSETS</b>		
<b>CURRENT LIABILITIES</b>		
Accounts payable	\$ 54,552	\$ 159,119
Accrued expenses	28,337	21,412
Deferred revenue	104,247	106,047
<b>Total current liabilities</b>	<b>187,136</b>	<b>286,578</b>
<b>NET ASSETS</b>		
Unrestricted	565,515	483,099
Temporarily restricted	827,424	458,701
Permanently restricted	10,000	10,000
<b>Total net assets</b>	<b>1,402,939</b>	<b>951,800</b>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b>\$1,590,075</b>	<b>\$1,238,378</b>

**SPINA BIFIDA ASSOCIATION OF AMERICA**  
**STATEMENT OF ACTIVITIES AND CHANGE IN NET ASSETS**  
**FOR THE YEAR ENDED MARCH 31, 2006**  
**WITH SUMMARIZED FINANCIAL INFORMATION FOR 2005**

	<u>2006</u>			<u>2005</u>	
	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total</u>	<u>Total</u>
<b>REVENUE</b>					
Public support received directly:					
Contributions	\$ 458,079	\$ 34,777	\$ -	\$ 492,856	\$ 444,444
Grants	27,690	1,175,000	-	1,202,690	975,840
Special events, net of direct benefit to donors in the amount of \$120,280	258,383	-	-	258,383	149,712
Contributed services and materials	27,892	-	-	27,892	43,719
Bequests	65,665	-	-	65,665	66,148
Raffle	115,800	-	-	115,800	85,900
Public support received indirectly:					
Federated fundraising organizations	108,254	-	-	108,254	101,848
<b>Total public support</b>	<b>1,061,763</b>	<b>1,209,777</b>	<b>-</b>	<b>2,271,540</b>	<b>1,867,611</b>
Other revenue:					
Membership dues	90,914	-	-	90,914	96,547
Sales of materials and services	42,114	-	-	42,114	42,819
Investment income	20,481	-	-	20,481	7,278
Conferences and meetings	378,118	-	-	378,118	308,156
Other	9,457	-	-	9,457	21,638
<b>Total other revenue</b>	<b>541,084</b>	<b>-</b>	<b>-</b>	<b>541,084</b>	<b>476,438</b>
Net assets released from donor restrictions	841,054	(841,054)	-	-	-
<b>Total revenue</b>	<b>2,443,901</b>	<b>368,723</b>	<b>-</b>	<b>2,812,624</b>	<b>2,344,049</b>
<b>EXPENSES</b>					
Program services:					
Education	1,545,091	-	-	1,545,091	1,246,414
Information and Referral	44,095	-	-	44,095	49,977
Member Services/ Chapter Development	179,410	-	-	179,410	95,415
Government Relations	175,825	-	-	175,825	146,712
Research	43,990	-	-	43,990	53,785
<b>Total program services</b>	<b>1,988,411</b>	<b>-</b>	<b>-</b>	<b>1,988,411</b>	<b>1,592,303</b>
Supporting services:					
Management and General	188,402	-	-	188,402	233,241
Fundraising	184,672	-	-	184,672	154,224
<b>Total supporting services</b>	<b>373,074</b>	<b>-</b>	<b>-</b>	<b>373,074</b>	<b>387,465</b>
<b>Total expenses</b>	<b>2,361,485</b>	<b>-</b>	<b>-</b>	<b>2,361,485</b>	<b>1,979,768</b>
Change in net assets	82,416	368,723	-	451,139	364,281
Net assets at beginning of year	483,099	458,701	10,000	951,800	587,519
<b>NET ASSETS AT END OF YEAR</b>	<b>\$565,515</b>	<b>\$ 827,424</b>	<b>\$10,000</b>	<b>\$1,402,939</b>	<b>\$ 951,800</b>

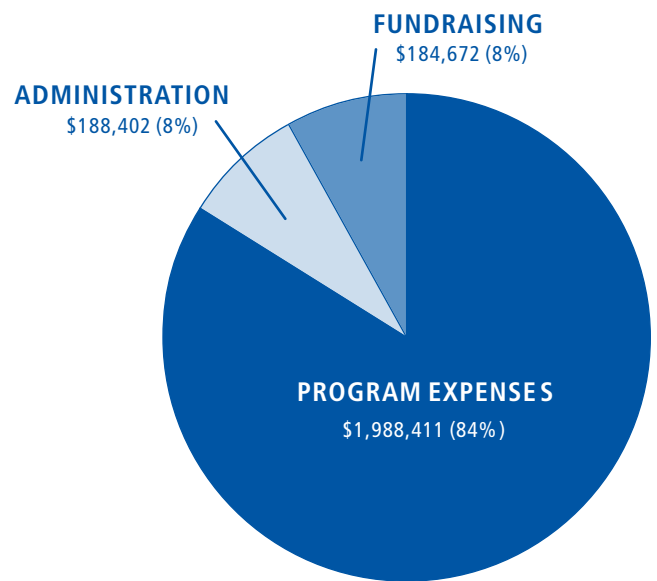
# STATEMENT OF ACTIVITIES AND CHANGE IN NET ASSETS

SPINA BIFIDA ASSOCIATION OF AMERICA  
REVENUES 2005-2006



TOTAL: \$2,812,624

SPINA BIFIDA ASSOCIATION OF AMERICA  
EXPENSES 2005-2006



TOTAL: \$2,361,485

## Spina Bifida Association

### Board of Directors

---

#### Chair

Douglas J. Sorocco, Esq.  
Oklahoma City, Oklahoma

#### Vice Chair

Joyce Jones  
Indianapolis, Indiana

#### Member at Large

Frank Pote  
Stafford, Virginia

#### Treasurer

George Sturm  
Council Bluffs, Iowa

#### Secretary

Tim Yoder  
Elkhart, Indiana

#### Immediate Past Chair

Alex Brodrick  
Southfield, Michigan

#### NHPC Liaison

Marlene Lutkenhoff, RN, MSN  
Cincinnati, Ohio

#### Professional Advisory Council Liaison

Timothy Brei, MD  
Indianapolis, Indiana

### Board Members

---

Patricia Braun, RNC, CPNP, MSN  
Maywood, Illinois

Christopher Malone  
Wilmington, Delaware

Charles Selcer  
Minneapolis, Minnesota

Julie Yindra  
Greensboro, North Carolina

## Spina Bifida Foundation

### Board of Directors

---

#### President

Harold W. Pote  
Jenkintown, Pennsylvania

#### Vice President and Treasurer

John Dewey  
Newport Beach, California

#### Secretary

Alex Brodrick  
Southfield, Michigan

### Board Members

---

Barbara J. Easterling  
Washington, DC

Albert R. Hunt  
Washington, DC

David B. Joseph, MD  
Birmingham, Alabama

Paul E. Kalb, MD, Esq.  
Washington, DC

James Oesterreicher  
Plano, Texas

Scott T. Price, Esq.  
Nashville, Tennessee

Douglas J. Sorocco, Esq.  
Oklahoma City, Oklahoma

Thomas Turnbull  
Alexandria, Virginia

## Professional Advisory Council

### Officers

#### Chair

Earl Y. Cheng, MD  
Chicago, Illinois

#### NHPC Liaison

Marlene Lutkenoff, RN, MSN  
Cincinnati, Ohio

#### Spina Bifida Foundation Liaison

David B. Joseph, MD

#### Spina Bifida Association Liaison

Timothy Brei, MD  
Indianapolis, Indiana

### Council Members

Debbie Blanchard, MSW, LCSW  
River Ridge, Louisiana

Jeffery P. Blount, MD  
Birmingham, Alabama

Robin M. Bowman, MD  
Chicago, Illinois

Mary Jo Dunleavy, RN  
Boston, Massachusetts

Jack M. Fletcher, PhD  
Houston, Texas

Amie Jackson, MD  
Birmingham, Alabama

David G. McLone, MD, PhD (Emeritus)  
Chicago, Illinois

Mark J. Merkens, MD  
Portland, Oregon

Shubhra Mukherjee, MD FRCPC  
Chicago, Illinois

Karin Muraszko, MD  
Ann Arbor, Michigan

Michael David Partington, MD, FACS  
St. Paul, Minnesota

Karl Rathjen, MD  
Dallas, Texas

Eric S. Rovner, MD  
Charleston, South Carolina

Kathleen J. Sawin, DNS, CPNP, FAAN  
Milwaukee, Wisconsin

Lee S. Segal, MD  
Hershey, Pennsylvania

Rune J. Simeonsson, PhD, MSPH  
Chapel Hill, North Carolina

Marcy Carlson Speer, PhD  
Durham, North Carolina

Jan Stilkey, RN, MSN, PNP  
Portland, Maine

Thomas S. Webb, MD, MSc  
Cincinnati, Ohio

Gordon Worley, MD  
Durham, North Carolina

**\$50,000+**

Estate of James E. Gabriel  
Mr. Harold Pote and Ms. Linda Johnson

**\$10,000 - \$49,999**

ABC News  
American Legion Child Welfare Foundation  
Astra Tech, Inc.  
Bloomberg, LP  
The Boisi Family Foundation  
Henry Brownstein, PhD and Cindy Brownstein  
Mr. and Mrs. John Dewey  
General Motors Corp.  
JPMorgan Chase  
KPMG  
Mr. and Mrs. Albert L. Lord  
Medtronic Neurosurgery  
Mentor Corporation  
Mr. and Mrs. William D. Milligan, Jr.  
Norfolk Southern Foundation  
Pfizer Inc  
The Ashley Rose Foundation  
The Scott & Ann Price Family Foundation  
Sidley, Austin, Brown & Wood, LLP  
Tischer AutoPark, Inc.  
Uromed, Inc.

**\$5,000 - \$9,999**

Albert J. & Mary R. Allegretti Foundation  
AstraZeneca LP  
Mrs. Michael Beschloss  
Blank Rome, LLP  
Canada Dry Potomac Corporation  
CCS Medical  
CharlesSchwab  
Communications Workers of America  
Mr. and Mrs. John Connarn  
Dow Jones & Company, Inc.  
Ms. Barbara J. Easterling  
Freedom Forum  
Hollister Incorporated  
Gardner Carton & Douglas, LLP  
Ms. Larlyn Jennings  
Johnson & Johnson  
Ms. Donna Marie Jones  
Paul E. Kalb, MD, Esq. and Susan M. Ascher, PhD  
NBC News, Inc.  
Ortho-McNeil Pharmaceutical  
Paralyzed Veterans of America  
Pfizer Inc

PhRMA

Mr. and Mrs. Stephen D. Ramsey  
Mr. and Mrs. Douglas J. Sorocco, Esq.  
Webster Bank  
The Weekly Standard  
Wimsatt Building Materials Corporation  
Vector Group Ltd.

**\$2,500 - \$4,999**

AAMCO Transmissions  
Mr. and Mrs. Richard M. Adams  
Mr. and Mrs. Charles R. Black  
Bristol-Myers Squibb  
Mr. Alex Brodrick  
Mr. and Mrs. Ron Clark  
CMS Foundation  
George Fish, MD and Ms. Kathleen A. Sullivan  
Ms. Alison Fitzgerald  
Ms. Debbie Goldberg and Mr. Seth Waxman  
Mr. and Mrs. Peter D. Hart  
Mr. and Mrs. Richard W. Herbst  
The Tom and Edwina Johnson Family Foundation  
Mr. and Mrs. Gary Jones  
David B. Joseph, MD  
Mr. and Mrs. Kevin W. Kennedy  
Lazof Family Foundation  
Lubert Adler Management, Inc.  
Qwest Communications  
Ross Family Fund  
Mr. and Mrs. Stephen T. Shannon  
Ms. G. Lynn Shostack Gardner  
Mr. Thomas D. Turnbull  
Mrs. Bonnie Valiant  
Mr. Joseph M. Winski

**\$1,000 - \$2,499**

Mr. and Mrs. Steven G. Barry  
Mr. and Mrs. Lee A. Beaman  
Mr. Benjamin D. Bradlee and Ms. Sally Quinn  
Timothy J. Brei, MD  
Mr. John J. Brennan  
The Chazen Foundation  
Mr. Scott Clark  
Mr. Ron Creamer and Ms. Anika Rahman  
Mr. Christopher Cross  
Mr. and Mrs. Lester Crystal  
Fairfax Adult Softball, Inc.  
Mr. David Garrison  
Mr. J. Joseph Giffels and Mr. Norman J. Lieberman  
Mr. Bradley Grantham

Ms. Rosemarie B. Greco and Ms. Susan Anderson  
Dr. Alan Greenspan and Ms. Andrea Mitchell  
Mr. Joseph M. Hare  
Ms. Catherine M. Helowicz  
Mr. Landon Hilliard, III  
Mr. and Mrs. Richard Jasinski  
Kline & Specter  
Mr. and Mrs. Billy Knoll  
Mr. and Mrs. James C. Lehrer  
Ms. Jane C. MacElree  
Mr. and Mrs. Timothy J. Mahoney  
Mr. Christopher Malone  
Mr. and Mrs. Bill D. McInturff  
Mr. Thomas G. Mendell  
Mr. Bruce A. Morton  
National Capital Club Managers Assoc.  
Mr. David Nieters  
Orleans Homebuilders  
Mr. and Mrs. John Paul  
Mr. Joseph Pavlock, Jr.  
Pocono Family YMCA Swim Team Parents  
Quarter Time Vending, Inc  
Honorable and Mrs. Paul G. Rogers  
Mr. Dom R. Ruscio  
Mr. and Mrs. Roger Sant  
Mr. Eugene A. Scanlan  
Mr. Keith T. Shiner  
Ms. Eunice K. Shriver  
Ms. Kathleen M. Sloane  
Ms. Lesley R. Stahl  
Mr. and Mrs. George Sturm  
Mr. and Mrs. David S. Thomas  
The Washington Post Company  
Mrs. Sharon Wester  
Mr. and Mrs. Timothy Yoder  
Mr. Ray J. Zukowski



4590 MacArthur Boulevard, NW Suite 250

Washington, DC 20007

Tel: 800-621-3141

[www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)

FINANCIAL STATEMENTS

# SPINA BIFIDA ASSOCIATION OF AMERICA

FOR THE NINE-MONTH PERIOD ENDED DECEMBER 31, 2006



# STATEMENT OF FINANCIAL POSITION

EXHIBIT A

## SPINA BIFIDA ASSOCIATION OF AMERICA STATEMENT OF FINANCIAL POSITION AS OF DECEMBER 31, 2006

### ASSETS

#### CURRENT ASSETS

Cash and cash equivalents	\$ 530,058
Investments	451,503
Accounts receivable, net of allowance for doubtful accounts of \$20,000	41,447
Grants receivable	925,000
Inventory	7,277
Prepaid expenses	25,528
<b>Total current assets</b>	<b>1,980,813</b>

#### FURNITURE AND EQUIPMENT

Furniture	19,883
Equipment	82,043
Computer software	14,212
	116,138
Less: Accumulated depreciation and amortization	(99,288)
<b>Net furniture and equipment</b>	<b>16,850</b>

<b>OTHER ASSETS - Deposits</b>	<b>125</b>
<b>TOTAL ASSETS</b>	<b>\$1,997,788</b>

### LIABILITIES AND NET ASSETS

#### CURRENT LIABILITIES

Accounts payable	\$ 35,396
Accrued expenses	27,807
Deferred revenue	47,696
<b>Total current liabilities</b>	<b>110,899</b>

#### NET ASSETS

Unrestricted	1,003,428
Temporarily restricted	873,461
Permanently restricted	10,000
<b>Total net assets</b>	<b>1,886,889</b>
<b>TOTAL LIABILITIES AND NET ASSETS</b>	<b>\$1,997,788</b>

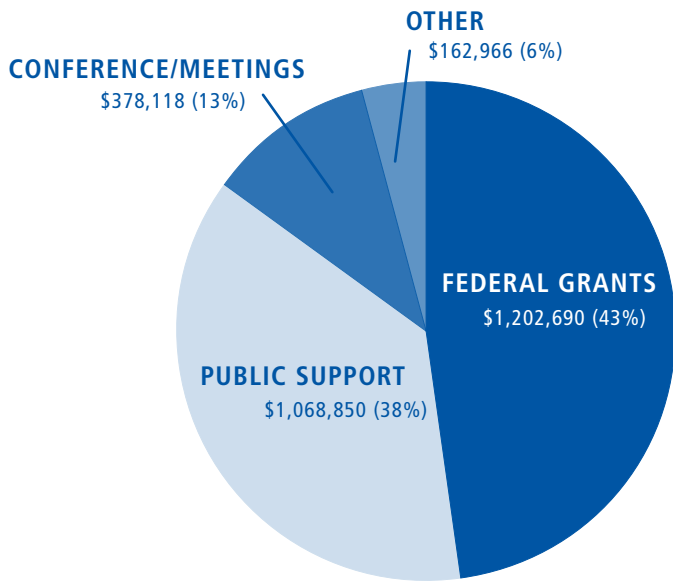
## SPINA BIFIDA ASSOCIATION OF AMERICA

STATEMENT OF ACTIVITIES AND CHANGE IN NET ASSETS  
FOR THE NINE-MONTH PERIOD ENDED DECEMBER 31, 2006

	<u>Unrestricted</u>	<u>Temporarily Restricted</u>	<u>Permanently Restricted</u>	<u>Total</u>
<b>REVENUE</b>				
Public support received directly:				
Contributions	\$ 355,314	\$ 93,283	\$ -	\$ 448,597
Grants	148,841	1,325,435	-	1,474,276
Special events, net of direct benefit to donors in the amount of \$104,083	424,935	-	-	424,935
Contributed services and materials	30,129	-	-	30,129
Bequests	28,304	-	-	28,304
Raffle	116,400	-	-	116,400
Public support received indirectly: Federated fundraising organizations	77,095	-	-	77,095
<b>Total public support</b>	<b>1,181,018</b>	<b>1,418,718</b>	<b>-</b>	<b>2,599,736</b>
Other revenue:				
Membership dues	66,424	-	-	66,424
Sales of materials and services	37,246	-	-	37,246
Investment income	12,483	-	-	12,483
Conferences and meetings	323,498	-	-	323,498
Other	8,678	-	-	8,678
<b>Total other revenue</b>	<b>448,329</b>	<b>-</b>	<b>-</b>	<b>448,329</b>
Net assets released from donor restrictions	1,372,681	(1,372,681)	-	-
<b>Total revenue</b>	<b>3,002,028</b>	<b>46,037</b>	<b>-</b>	<b>3,048,065</b>
<b>EXPENSES</b>				
Program services:				
Education	1,265,050	-	-	1,265,050
Information and Referral	141,747	-	-	141,747
Member Services / Chapter Development	453,256	-	-	453,256
Government Relations	153,873	-	-	153,873
Research	141,022	-	-	141,022
<b>Total program services</b>	<b>2,154,948</b>	<b>-</b>	<b>-</b>	<b>2,154,948</b>
Supporting services:				
Management and General	140,504	-	-	140,504
Fundraising	268,663	-	-	268,663
<b>Total supporting services</b>	<b>409,167</b>	<b>-</b>	<b>-</b>	<b>409,167</b>
<b>Total expenses</b>	<b>2,564,115</b>	<b>-</b>	<b>-</b>	<b>2,564,115</b>
Change in net assets	437,913	46,037	-	483,950
Net assets at beginning of period	565,515	827,424	10,000	1,402,939
<b>NET ASSETS AT END OF YEAR</b>	<b>\$1,003,428</b>	<b>\$ 873,461</b>	<b>\$10,000</b>	<b>\$1,886,889</b>

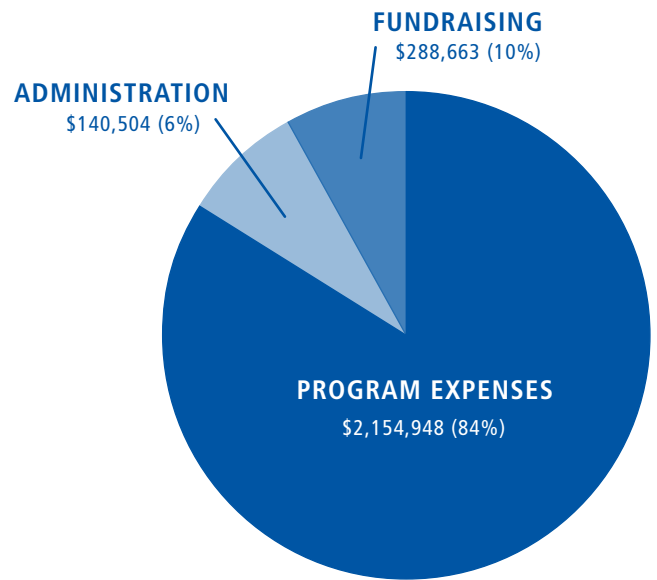
# STATEMENT OF ACTIVITIES AND CHANGE IN NET ASSETS

SPINA BIFIDA ASSOCIATION OF AMERICA  
REVENUES 2005-2006



TOTAL: \$2,812,624

SPINA BIFIDA ASSOCIATION OF AMERICA  
EXPENSES 2006



TOTAL: \$2,564,115

## Spina Bifida Association

### Board of Directors

---

#### Chair

Douglas J. Sorocco, Esq.  
Oklahoma City, Oklahoma

#### Vice Chair

Joyce Jones  
Indianapolis, Indiana

#### Member at Large

Frank Pote  
Stafford, Virginia

#### Treasurer

George Sturm  
Council Bluffs, Iowa

#### Secretary

Tim Yoder  
Elkhart, Indiana

#### Immediate Past Chair

Alex Brodrick  
Southfield, Michigan

#### Counsel

John Wester  
Washington, DC

#### NHPC Liaison

Marlene Lutkenhoff, RN, MSN  
Cincinnati, Ohio

#### Professional Advisory Council Liaison

Timothy Brei, MD  
Indianapolis, Indiana

### Board Members

---

Patricia Braun, RNC, CPNP, MSN  
Maywood, Illinois

Susan Branson  
Madison, Mississippi

Jean Brown, MS, APRN  
Greenville, South Carolina

Christopher Malone  
Wilmington, Delaware

Charles Selcer  
Minneapolis, Minnesota

Julie Yindra  
Greensboro, North Carolina

## Spina Bifida Foundation

### Board of Directors

---

#### President

Harold W. Pote  
Jenkintown, Pennsylvania

#### Vice President and Treasurer

John Dewey  
Newport Beach, California

#### Secretary

Alex Brodrick  
Southfield, Michigan

### Board Members

---

José F. Cordero, MD, MPH  
San Juan, Puerto Rico

Barbara J. Easterling  
Washington, DC

Albert R. Hunt  
Washington, DC

David B. Joseph, MD  
Birmingham, Alabama

Paul E. Kalb, MD, Esq.  
Washington, DC

James Oesterreicher  
Plano, Texas

William D. Milligan, Jr.  
New York, New York

Scott T. Price, Esq.  
Nashville, Tennessee

Douglas J. Sorocco, Esq.  
Oklahoma City, Oklahoma

Thomas D. Turnbull  
Alexandria, Virginia

## Professional Advisory Council

### Officers

#### Chair

Earl Y. Cheng, MD  
Chicago, Illinois

#### Spina Bifida Foundation Liaison

David B. Joseph, MD

#### Spina Bifida Association Liaison

Timothy Brei, MD  
Indianapolis, Indiana

### Council Members

Debbie Blanchard, MSW, LCSW  
River Ridge, Louisiana

Jeffery P. Blount, MD  
Birmingham, Alabama

Robin M. Bowman, MD  
Chicago, Illinois

Mary Jo Dunleavy, RN  
Boston, Massachusetts

Jack M. Fletcher, PhD  
Houston, Texas

Amie Jackson, MD  
Birmingham, Alabama

Lori Lowe, RN, CPNP  
Indianapolis, Indiana

David G. McLone, MD, PhD (Emeritus)  
Chicago, Illinois

Mark J. Merkens, MD  
Portland, Oregon

Shubhra Mukherjee, MD FRCPC  
Chicago, Illinois

Karin Muraszko, MD  
Ann Arbor, Michigan

Michael David Partington, MD, FACS  
St. Paul, Minnesota

Karl Rathjen, MD  
Dallas, Texas

Eric S. Rovner, MD  
Charleston, South Carolina

Kathleen J. Sawin, DNS, CPNP, FAAN  
Milwaukee, Wisconsin

Lee S. Segal, MD  
Hershey, Pennsylvania

Rune J. Simeonsson, PhD, MSPH  
Chapel Hill, North Carolina

Marcy Carlson Speer, PhD  
Durham, North Carolina

Jan Stilkey, RN, MSN, PNP  
Portland, Maine

Thomas S. Webb, MD, MSc  
Cincinnati, Ohio

Gordon Worley, MD  
Durham, North Carolina

**\$50,000+**

Lorraine B. Joseph Endowment Fund  
Mr. Harold Pote and Ms. Linda Johnson  
The John D. and Minnie R. Schneider Charitable Trust

**\$10,000 - \$49,999**

American Financial Realty Trust  
Anheuser-Busch Companies  
Henry Brownstein, PhD and Cindy Brownstein  
CBS, Inc.  
Determined To Win, Inc.  
Mr. and Mrs. John Dewey  
General Motors Corp.  
Hollister Incorporated  
Mr. and Mrs. Don Imus  
Ms. Donna Marie Jones  
KPMG  
Lazof Family Foundation  
Mr. and Mrs. William D. Milligan, Jr.  
Paralyzed Veterans of America  
Ms. Elissa Leonard and Mr. Jay Powell  
PhRMA  
The Scott & Ann Price Family Foundation  
Mr. Lewis S. Ranieri  
The Ashley Rose Foundation  
Mr. and Mrs. Bob Schieffer  
Sidley, Austin, Brown & Wood, LLP  
Mr. and Mrs. Jimmy F. Stokes  
Tischer AutoPark, Inc.  
Wachtell, Lipton, Rosen & Katz

**\$5,000 - \$9,999**

ABC News  
The Boisi Family Foundation  
Canada Dry Potomac Corporation  
Caterpillar, Inc.  
Chevy Chase Bank  
Mr. and Mrs. Ron Clark  
CNN  
Comcast  
Communications Workers of America  
EnTrust Capital  
GE Foundation  
Giorgio Armani Beauty  
Mr. and Mrs. Gary Jones  
Mr. and Mrs. Jim Oesterreicher  
Paul E. Kalb, MD, Esq. and Susan M. Ascher, PhD  
Mr. Bennett S. Lebow  
Mr. and Mrs. Albert L. Lord  
Medtronic Neurosurgery  
Mr. David Nieters  
Norfolk Southern Foundation

Mr. and Mrs. Stephen D. Ramsey  
Seix Advisors  
Mr. and Mrs. Douglas J. Sorocco, Esq.  
Southwestern Bell Corporation  
Stryker Orthopaedics  
Mr. Thomas D. Turnbull  
Webster Bank

**\$2,500 - \$4,999**

American Realty Capital, LLC  
CMS Foundation  
Dr. Alan Greenspan and Ms. Andrea Mitchell  
George Fish, MD and Ms. Kathleen A. Sullivan  
Ms. Debbie Goldberg and Mr. Seth Waxman  
Mr. and Mrs. Michael J. Hagan  
Mr. and Mrs. Peter D. Hart  
Mr. and Mrs. Jason Huette  
Mr. Kenneth T. Jones  
Mr. and Mrs. Kevin W. Kennedy  
Motor City Sales and Service  
National Association of Manufacturers  
NutriSystem, Inc.  
Mr. Richard J. Orlando  
Mr. and Mrs. John Paul  
Mrs. Deborah Ratner Salzberg  
Ross Family Fund  
Mr. and Mrs. David A. Sciortino  
Mr. Andy Stough and Ms. Wendy Stough  
Ms. Elisabeth H. Thompson  
ULLICO Family of Companies  
Voyageur Asset Management  
Mr. and Mrs. James Wester  
Mr. and Mrs. Timothy Yoder

**\$1,000 - \$2,499**

Mr. and Mrs. Richard M. Adams  
Naim Al-Adli  
Arch Coal, Inc.  
The Honorable and Mrs. Bruce Babbitt  
Mr. and Mrs. Michael S. Berman  
Mrs. Meredith Brake  
Mr. and Mrs. Alan Branson  
Timothy J. Brei, MD  
Mr. Michael F. Brewer and Ms. Janet Brown  
The Honorable and Mrs. Patrick J. Buchanan  
Calibre CPA Group  
Mr. Ron Creamer and Ms. Anika Rahman  
Mr. Christopher Cross  
Mr. Alessandro DeSantis  
Mr. and Mrs. Herbert Duke  
Emergent BioSolutions, Inc.  
Fairfax Adult Softball, Inc.  
Mr. Thomas FitzGerald  
From You Flowers LLC  
Mr. and Mrs. Thomas L. Friedman

Ms. Joan N. Gerson  
Ms. Jamie S. Gorelick and Mr. Richard Waldhorn  
Mr. Bradley Grantham  
Mr. Bryon Griffin  
Mr. Joseph M. Hare  
The Honorable Jane Harman and Mr. Sidney Harman  
Mr. Renee Harrington  
Mr. and Mrs. Richard W. Herbst  
Mr. Landon Hilliard  
Dr. and Mrs. Bill Kierl  
Mr. John Kocjan  
Mr. and Mrs. Peter Kovler  
Ms. Maree B. Larson  
Mr. and Mrs. James C. Lehrer  
Mr. and Mrs. Richard Lieb  
Montgomery Security Services, Ltd.  
Monitoring and Evaluation Services, Inc.  
Mr. Bruce A. Morton  
Mr. and Mrs. Brent Musburger  
Ms. Julie O'Hara  
OppenheimerFunds Legacy Program  
Mr. Alan Platt  
Mr. David E. Pitzl  
Mr. and Mrs. Abe Pollin  
Mr. Todd Pulvino  
Quarter Time Vending, Inc  
Karl Rathjen, MD  
RBS Greenwich Capital  
The Honorable and Mrs. Paul G. Rogers  
Mr. Richard P. Rome  
Mr. and Mrs. Miles Rubin  
Saks Fifth Avenue - Chevy Chase  
Mr. Charles Selcer  
Dr. and Mrs. Robert S. Siegel  
Mr. and Mrs. W. Dean Smith  
Ms. Ruth J. Smock  
Ms. Lesley R. Stahl  
The Honorable and Mrs. Pete Stark  
Mr. and Mrs. George Stevens  
Talent On Parade  
Mr. and Mrs. David S. Thomas  
Mr. and Mrs. John E. Tometich  
Mr. and Mrs. Mark Valente III  
Mr. William E. Valerius  
Mrs. Bonnie Valiant  
VP-10 Officer Spouse Club  
Mr. and Mrs. Thomas K. Warren  
The Washington Post Company  
Ms. Jean White  
Ms. Margot Wilson  
Wind Riders RC  
Ms. Linda A. Winslow  
Mr. Jonathan Young  
Mr. and Mrs. Stephen C. Youngerman



4590 MacArthur Boulevard, NW Suite 250

Washington, DC 20007

Tel: 800-621-3141

[www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)

FINANCIAL STATEMENTS

**SPINA BIFIDA ASSOCIATION  
NATIONAL AND GROUP MEMBERS**

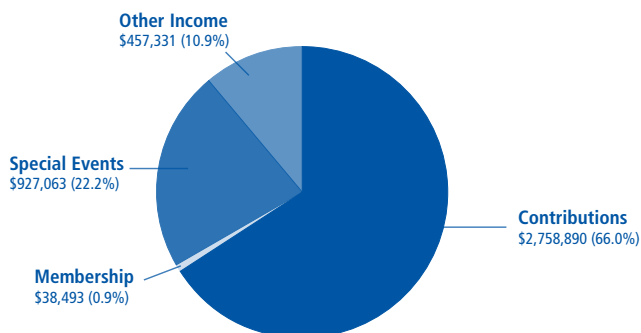
**CONSOLIDATED STATEMENT OF REVENUE AND EXPENSE  
FOR THE YEAR ENDED MARCH 31, 2006**



# GROUP MEMBERS

## SPINA BIFIDA ASSOCIATION NATIONAL AND GROUP MEMBERS

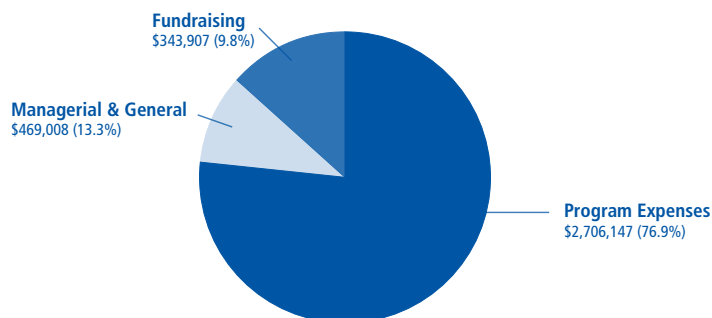
### REVENUES 2005



TOTAL \$4,181,777

## SPINA BIFIDA ASSOCIATION NATIONAL AND GROUP MEMBERS

### EXPENSES 2005



TOTAL \$3,519,061

#### UNAUDITED

Note: Each Group Member is separately incorporated, but is required to sign an affiliation agreement with National headquarters annually. The preparation of financial statements in conformity with generally accepted accounting principles requires management to make estimates and assumptions that affect the reported amounts of revenues and expenses during the reporting period. Actual results could differ from these estimates.

#### Alabama

**SBA of Alabama**  
Birmingham

#### Arizona

**Arizona Spina Bifida Association \***  
Phoenix

#### Arkansas

**SBA of Arkansas**  
Little Rock

#### California

**Greater Los Angeles SBA Group \***  
Los Angeles

**SBA of Greater San Diego**  
San Diego

**SBA of the Greater Bay Area**  
Tracy

#### Colorado

**Colorado SBA**  
Denver

#### Connecticut

**SBA of Connecticut**  
Hartford

#### Florida

**SBA of Central Florida**  
Orlando

**SBA of Jacksonville**  
Jacksonville

**SBA of Florida Space Coast**  
Melbourne

**SBA of Southeast Florida**  
Miami

**SBA of Tampa Bay**  
Tampa

#### Georgia

**SBA of Georgia**  
Decatur

#### Illinois

**SBA of Illinois**  
Chicago

#### Indiana

**SBA of Central Indiana**  
Indianapolis

**SBA of Northern Indiana**  
Elkhart

#### Iowa

**SBA of Iowa**  
Des Moines

## Kansas

**SBA of Kansas \***  
Wichita

## Kentucky

**SBA of Kentucky**  
Louisville

## Louisiana

**SBA of Greater New Orleans**  
Kenner

## Maryland

**SBA of Chesapeake-Potomac**  
Annapolis

## Massachusetts

**Massachusetts SBA**  
North Andover

## Michigan

**SBA of Upper Michigan**  
Ishpeming

**SW Michigan SB & Hydrocephalus Association\***  
Mattawan

**SBA of West Michigan**  
Ada

## Minnesota

**SBA of Minnesota**  
Brooklyn Center

## Mississippi

**SBA of Mississippi**  
Richland

## Missouri

**SBA of Greater St. Louis**  
St. Louis

## Nebraska

**SBA of Nebraska**  
Omaha

## New Jersey

**SBA of the Tri-State Region**  
Flemington

## New York

**Greater Rochester SBA**  
Fairport

**SBA of Albany/Capital District**  
Scotia

**SBA of Nassau County**  
Sound Beach

**SBA of Western New York**  
North Tonawanda

## North Carolina

**SBA of North Carolina \***  
Indian Trail

## Ohio

**SBA of Canton**  
Canton

**SBA of Central Ohio**  
Westerville

**SBA of Cincinnati**  
Cincinnati

**SBA of Greater Dayton**  
Dayton

**SBA of Northwest Ohio**  
Gibsonburg

**Tri-County SBA of Ohio**  
Warren

## Pennsylvania

**SBA of Delaware Valley**  
Worcester

**SBA of Greater Pennsylvania**  
Quarryville

**SBA of Greater Pittsburgh**  
Pittsburgh

## Tennessee

**SBA of Tennessee**  
Nashville

## Texas

**SBA of Houston Gulf Coast**  
Pasadena

**SBA of North Texas**  
Garland

**SBA of Texas**  
San Antonio

## Utah

**SBA of Utah**  
Farmington

## Virginia

**SBA of Roanoke Valley**  
Roanoke

## Washington

**SBA of Evergreen**  
Spokane

## Wisconsin

**SBA of Greater Fox Valley**  
Kimberly

**SBA of Northern Wisconsin**  
Schofield

**SBA of Wisconsin**  
Wauwatosa

\* This Group Member was not credentialed for 2006-2007.



4590 MacArthur Boulevard, NW Suite 250

Washington, DC 20007

Tel: 800-621-3141

[www.spinabifidaassociation.org](http://www.spinabifidaassociation.org)