The mission of the Spina Bifida Association® (SBA) is to promote the prevention of Spina Bifida and to enhance the lives of all affected. Since 1973, SBA has been the only national voluntary health agency dedicated to preventing Spina Bifida in future generations and improving the lives of those affected through education, advocacy, research, and service.

SBA has a presence in more than 125 communities nationwide and touches thousands of people each year. Lives are changed by the programs SBA has created, the services the organization provides, and the gains achieved through its advocacy efforts.

**SBA’S VISION STATEMENT**

We envision a world in which no babies are born with Spina Bifida. People living with Spina Bifida thrive in a barrier-free world that offers ready access to an array of effective treatment options and uniformly excellent medical care. Their individual life choices are not influenced by Spina Bifida and all experience rich and personally fulfilling lives.

**About Spina Bifida**

Spina Bifida is the most common permanently disabling birth defect in the United States affecting tens of thousands of men, women, adolescents, and children across the nation. It occurs when the spine of the baby fails to close during the first month of pregnancy creating an opening in the spinal column.

Those who are born with Spina Bifida live with the challenges of conditions like hydrocephalus (fluid on the brain), full or partial paralysis, bladder and bowel complications, learning disabilities, depression, deadly latex allergy, and social issues.

There are 65 million women of childbearing age in the United States. All are at risk of a Spina Bifida pregnancy. It is imperative that all of them know that by taking 400 micrograms of folic acid every day before they become pregnant, they can reduce the risk of having a baby with Spina Bifida by up to 70 percent.
DEAR FRIEND,

The past year set the stage for what I know will surely be one of the most remarkable periods in the history of the Spina Bifida Association (SBA). In addition to marking the 35th anniversary of our founding, in 2008 we took steps towards strengthening and formalizing partnerships that ensure our continued viability as the premier organization serving the needs of those in the Spina Bifida community.

It has been five years since the SBA took the lead in advocating to establish the National Spina Bifida Program (NSBP) at the Centers for Disease Control and Prevention (CDC). The NSBP marks the first-time ever that our federal government set aside resources specifically to address both sides of the Spina Bifida equation—prevention of the birth defect and support of quality-of-life enhancement for people living with it. I am pleased to say that this partnership has continued to flourish and has made a real and positive impact on the lives of those in our community.

In 2008, SBA, in partnership with the CDC, launched one of two groundbreaking initiatives that we believe will help to shape the standards of care for the future. The first of these, the National Spina Bifida Patient Registry, is the first formalized study of a large number of people with Spina Bifida. It is our belief that the outcomes of this study will open new doors and translate to better, brighter tomorrows for all who face the challenges of this complex birth defect.

SBA has also continued to strengthen its relationship with the leading Spina Bifida medical professionals in other ways. In addition to continuing to fund research grants to support the efforts of young investigators, SBA’s Professional Advisory Council also took the lead in initiating planning the First World Congress on Spina Bifida Research and Care – an international gathering of Spina Bifida care specialists and researchers to be held in early 2009.

Throughout the year, SBA also engaged in a process of professionalization and standardization of services at both the national and chapter level. Through an aggressive strategy developed by SBA’s Group Member Task Force, these changes ensure increased outreach to the hundreds of thousands of Americans whose lives are affected each day by Spina Bifida.

Our work is by no means finished. While we have made great strides towards accomplishing our mission, it will take the commitment and support of each and every individual dedicated to our cause to ensure that together, we will see the day when our dreams are fulfilled.

Joyce Jones
Chair, Spina Bifida Association
CONGRESS CONTINUES TO SUPPORT THE NATIONAL SPINA BIFIDA PROGRAM

There has never been a more urgent call to advocacy. The needs of all those in the disability community are great and they are especially urgent for those who live with Spina Bifida.

At a time when Federal funding for most public health and social services were cut or remained flat, Congress recognized the vital work taking place at the National Spina Bifida Program (NSBP) at the Centers for Disease Control and Prevention (CDC) and invested an unprecedented $3.54 million in the program.

This victory is a testament to the passion and determination of all those who worked tirelessly to secure this critical funding. Men, women, and children—families, individuals with Spina Bifida and medical professionals representing our community from across the nation went to Capitol Hill to share their personal, heartfelt stories with policy makers with the support and guidance of SBA.

Their presence made Spina Bifida more than just one of the thousands of causes that are brought before Congress every year. These hard working individuals took time out of their busy lives to give Spina Bifida a face, a heart, and a soul. Joining them at critical times during the appropriations process, Congressional decision makers received hundreds of personalized emails, phone calls, and faxes from their constituents that were generated through SBA’s advocacy alerts.

SPINA BIFIDA AWARENESS MONTH RECOGNIZED IN CONGRESS

As part of our efforts to increase awareness and support in 2008, SBA supported a bipartisan Concurrent Resolution recognizing October as National Spina Bifida Awareness Month. Members of Congress were asked by their constituents to show their support for the Resolution by signing on to a Dear Colleague letter calling for an intensifying of the federal government’s commitment to Spina Bifida prevention, research, and quality of life improvement for those affected by this most common birth defect. The letter, authored by Senators Chris Dodd and Roger Wicker in the Senate and by Representatives Chris Smith and Bart Stupak in the House, drew added visibility to our cause during a critical time in the legislative process.

Advocating for better tomorrows
SBA CONTINUES SUPPORT OF SPINA BIFIDA RESEARCH

Spina Bifida is the most complex birth defect that is compatible with human life. It is not just one condition but rather a multitude of complications that affect the mind, the body, and the spirit. For many years SBA recognized the value and power of research in opening new doors for care and treatment of Spina Bifida. It is our belief that our hope for the future is research initiated today.

The Young Investigators Program, now in its fifth year, demonstrates the organization’s belief in the future through the support of researchers early in their careers. The program, which provides junior investigators with grants of up to $25,000 annually towards work in Spina Bifida, continues to foster young scientists who will dedicate their skill and expertise to unlocking the mysteries surrounding this complex birth defect.

The 2008 awardees, Michael Hsieh, MD, PhD and Melissa Bellin, PhD, MSW, LCSW, are both embarking upon research that factors heavily in challenges commonly facing our community. Dr. Hsieh is investigating new research into treating potentially life threatening genitourinary tract infections through the use of beneficial microorganisms known as “probiotics” rather than using antibiotics, which can have unpleasant side effects.

Dr. Bellin’s research grant will be used to further her study of transition-age individuals with Spina Bifida. In the multi-center project, Dr. Bellin and her collaborators are exploring predictors of four functional outcomes for adolescents and young adults with Spina Bifida, including self-management, continence, overall quality of life, and psychological health.

PATIENT REGISTRY LAUNCHED

In 2008, the CDC launched the National Spina Bifida Patient Registry (SBPR) under the umbrella of the National Spina Bifida Program. The goal is that this program will create a database that will allow medical professionals to: (1) identify measures that will aid in the development of national standards of care for people with Spina Bifida and assess progress towards meeting them; (2) provide a means for comparing treatment, care and outcomes among clinics, population groups, and geographic areas; and (3) identify areas for future research that will inform best practices of care and improve the lives of those with Spina Bifida.

Eight Spina Bifida clinics received grants in 2008 to pilot the SBPR:

- Children’s Hospital of Los Angeles
- Children’s Hospital of Wisconsin
- Cincinnati Children’s Hospital Medical Center
- Connecticut Children’s Medical Center
- Indiana University/Riley Hospital for Children
- Oregon Health and Science University
- University of Alabama at Birmingham
- University of Colorado, Denver

Exploring new frontiers with Spina Bifida Research
NATIONAL CONFERENCE HEATS UP IN THE DESERT

This year’s Conference, the first in Arizona in many years, took on a decidedly Western flair as all settled into the picturesque desert environment. Convening from June 22–25 in Tucson and filled with dynamic educational sessions and a bustling exhibit hall, this gathering was one for the ages.

With over 700 people in attendance, including more than 130 first time attendees, the buzz from this conference was nothing but the best. Attendees were empowered with informative sessions on the latest information in orthopedics, urology, neurosurgery, employment, and learning disability challenges.

During the National Conference, SBA once again hosted Kids!Camp, the only national camp for children and teens with Spina Bifida. This remarkable camp once again worked its magic with exceptional programming designed to combine fun with education and build self-esteem, self-reliance, and coping skills.

NATIONAL RESOURCE CENTER: A VITAL SUPPORT SYSTEM

The SBA National Resource Center (NRC) provides high-quality, confidential information and referral services. During 2008, the NRC responded to over 15,000 inquiries on issues ranging from health care and education to employment and benefits.

The online portion of the NRC continues to thrive. In 2008, almost 336,000 visits to SBA’s National Web site, www.spinabifidaassociation.org. Information available through the NRC Online was bolstered by the addition of “Ask the Doctor”, a monthly question and answer format column. Responses are written by medical professionals who serve on SBA’s Professional Advisory Council (PAC).

SCHOLARSHIPS CONTINUE TO SUPPORT EDUCATION

In 2008, SBA invested over $20,000 in the leaders of tomorrow through our Annual Scholarship Program. Designed to support young people with Spina Bifida interested in continuing their education, this program has grown substantially through the years.

SBA scholarship awardees represent well-rounded students who not only value education but also demonstrate a dedicated and passionate interest in all aspects of life. Faithe Heuser, the 2008 SBA 4-year scholarship recipient, is a great example of this interest.

In addition to her academic credentials, Faithe participated in her school’s drama club, National Honor Society, Academic Decathlon, art club, and SADD (Students Against Destructive Decisions) group.

Faithe also worked diligently to raise Spina Bifida awareness among her peers starting a Facebook social networking page which attracted over 300 followers. She also reached out to those in her hometown with Spina Bifida awareness materials and pins. Through efforts like Faithe’s, SBA is well on its way to achieving its mission.

SBA LEADS THE WAY ON FOLIC ACID EDUCATION

In 2008, SBA was selected to assume the role of managing agent for the National Council on Folic Acid (NCFA). NCFA is a coalition of national organizations and associations, state folic acid councils and government agencies whose mission is to improve health by promoting the benefits and consumption of folic acid.
NATIONAL MAGAZINE GIVES NEW INSIGHTS INTO SPINA BIFIDA

There is a critical need for accurate information and a compassionate point of view about Spina Bifida. Those who are affected by Spina Bifida must become experts on new medical techniques and procedures as well as the latest information on treatment and issues associated with it. The need for information can be overwhelming and the complex social implications of Spina Bifida can be isolating.

To help address these needs, in 2008, SBA launched its new national magazine, Insights Into Spina Bifida. Created to profile inspirational personal stories from within the community and cutting edge Spina Bifida news and information, over 68,000 copies of the magazine were distributed in the first year.

With themes ranging from independence and sports and recreation to education and research, Insights offers a unique perspective on the many issues facing those affected by Spina Bifida.

SBA’S E-COMMUNITIES GO INTERNATIONAL

SBA’s eCommunities for youths, adults, parents, and health care providers continue to grow and thrive. Each day engaging and supportive conversations about Spina Bifida related issues take place with just the click of a mouse. These unique online communities provide answers, information, and most importantly support.

In 2008, with the generous support of Pfizer, SBA was able to expand these unique communities internationally. In partnership with the International Federation for Spina Bifida and Hydrocephalus (IF), SBA launched its first international ListServ which brings together members of the Spina Bifida community from every corner of the globe.

EMPOWERMENT FOR A BETTER TOMORROW

The ability of SBA to reach the Spina Bifida community across the nation is closely tied to the relationship it shares with its chapters. In 2008, SBA took steps to formalize this relationship through an affiliation process intended to more closely tie the network of chapters and standardize programs and services.

To further this process, SBA developed a series of training Webinars entitled the Leadership Institute Educational Series or LITES. These monthly seminars tackle topics such as board development, advocacy, outreach, and development.

This strengthened relationship will result in the expansion of programs nationally and ultimately extend the reach of SBA’s chapter network. This reach is crucial to supporting families and a growing adult population facing the daily challenges of Spina Bifida.

Reaching out to those in need
Donors

GIFTS $100,000 AND ABOVE
Estate of Catherine O’Connell
Estate of Doris Morris
Estate of Jean Thompson

GIFTS $50,000 TO $99,999
Estate of James E. Gabriel
Donna Jones
Arthur Joseph
Hollister Incorporated
Schneider Charitable Trust

GIFTS $25,000 TO $49,000
Ashley Rose Foundation
The Dewey Family
Coloplast Corp.
Codman, a Johnson & Johnson Co.
Medtronic Neurologic Technologies
William and Karen Milligan
Scott T. & Ann Price
Pharmaceutical Research and Manufacturers of America (PhRMA)
Thomas Turnbull & Darrell Smith

GIFTS $10,000 TO $24,999
Astra Tech, Inc.
Cindy & Henry Brownstein
General Motors Corporation
KPMG
Marc Haas Foundation
Raymond & Linda Pitek
Patrick & Susan Sabadie
Sidley Austin, LLP
Douglas & Kristen Sorocco
Ana Ximenes & Steve Baroch

GIFTS $5,000 TO $9,999
3M Health Care
Ambassador Elizabeth Bagley & Smith Bagley
American Health Care Association
Afsaneh & Michael Beschloss
California Children’s Services
Children’s Charities Foundation, Inc.
Chevron
Katherine Cooke
Communications Workers of America
Council For Responsible Nutrition
Drinker Biddle & Reath LLP
Grand Rapids Foam Technologies
International Association of Fire Fighters
James H. Johnson
Joyce & Gary Jones
Paul E. Kalb & Susan M. Ascher
Chris & Kathleen Matthews
Jim & Pat Oesterreicher
Stephen Ramsey
RLG Defense, LLC
Mitchel Sayare
Bob & Patricia Schieffer
UroMed, Inc.
Webster Bank
William and Sylvia Silbertein Foundation, Inc.
John Grandizio
Greensboro College
Jeff Hancock
Peter and Florence Hart
Mr. & Mrs. John Hellerman
William J. Hennessy
Patrick J. Hovey
Mr. & Mrs. W. G. Hubbard
IBM Employee Giving Campaign
Illinois State University
Jim & Helen James
JPMorgan Chase
Mr. & Mrs. Harold Krauthamer
Maree B. Larson
Peter Lee
Eric & Kim McCluer
Dorothy Montgomery
Bruce A. Morton
Mr. & Mrs. Thomas Nagle
Mr. and Mrs. David M. Nieters
NutriSystem, Inc.
Oppenheimer Funds Legacy Program
Orlando Health
Maureen Orth
Brian & Cara Packard
Joseph Peyton
Polling Company/Woman Trend
Quarter Time Vending, Inc.
Carl & Karen Rauen
Bryan E. Rich
Scott Ritter
Eagle Robinson
Mike & Marie Rourke
Denis & Joanne Salamone
Shriners Hospitals for Children
Dr. & Mrs. Alexander Soutter
Samuel D. Cozen Memorial Fund
Dr. & Mrs. W. Dean Smith
Lesley R. Stahl
Ronald & Jennifer Talaga
Talent on Parade, L.L.C.
John & Cindy Tometic
Bonnie Valiant
Ms. Christine Varney
Wellpoint Foundation Employee Giving Campaign
Mr. & Mrs. James Wester
Mr. & Mrs. Maurice Whalen
Thomas & Deborah Whitesell
Wounded Warrior Brigade
Tim & Kathy Yoder
Jonathan Young
**Assets**

<table>
<thead>
<tr>
<th>CURRENT ASSETS</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$432,842</td>
</tr>
<tr>
<td>Investments</td>
<td>945,815</td>
</tr>
<tr>
<td>Accounts receivable</td>
<td>-</td>
</tr>
<tr>
<td>Grants receivable</td>
<td>1,119,728</td>
</tr>
<tr>
<td>Inventory</td>
<td>7,277</td>
</tr>
<tr>
<td>Prepaid expenses</td>
<td>2,249</td>
</tr>
<tr>
<td>Due from related party</td>
<td>87,632</td>
</tr>
<tr>
<td><strong>TOTAL CURRENT ASSETS</strong></td>
<td><strong>$2,595,543</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FURNITURE AND EQUIPMENT</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Furniture</td>
<td>32,075</td>
</tr>
<tr>
<td>Equipment</td>
<td>101,430</td>
</tr>
<tr>
<td>Computer software</td>
<td>21,212</td>
</tr>
<tr>
<td></td>
<td>154,717</td>
</tr>
<tr>
<td>Less: Accumulated depreciation and amortization</td>
<td>(121,441)</td>
</tr>
<tr>
<td>Net furniture and equipment</td>
<td>33,276</td>
</tr>
<tr>
<td><strong>TOTAL ASSETS</strong></td>
<td><strong>$2,628,819</strong></td>
</tr>
</tbody>
</table>

**Liabilities and Net Assets**

<table>
<thead>
<tr>
<th>CURRENT LIABILITIES</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accounts payable</td>
<td>$57,562</td>
</tr>
<tr>
<td>Accrued Expenses</td>
<td>28,835</td>
</tr>
<tr>
<td>Deferred revenue</td>
<td>22,926</td>
</tr>
<tr>
<td><strong>TOTAL CURRENT LIABILITIES</strong></td>
<td><strong>$109,323</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NET ASSETS</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unrestricted</td>
<td>1,034,171</td>
</tr>
<tr>
<td>Temporarily restricted</td>
<td>1,475,325</td>
</tr>
<tr>
<td>Permanently restricted</td>
<td>10,000</td>
</tr>
<tr>
<td><strong>TOTAL NET ASSETS</strong></td>
<td><strong>2,519,496</strong></td>
</tr>
<tr>
<td><strong>TOTAL LIABILITIES AND NET ASSETS</strong></td>
<td><strong>$2,628,819</strong></td>
</tr>
</tbody>
</table>
## Statement of Activities and Change in Net Assets

**Exhibit B**

For the year ended December 31, 2008

### Revenue

<table>
<thead>
<tr>
<th>Public support received directly:</th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions</td>
<td>$1,147,579</td>
<td>$15,000</td>
<td>-</td>
<td>$1,162,579</td>
</tr>
<tr>
<td>Grants</td>
<td>30,314</td>
<td>1,593,489</td>
<td>-</td>
<td>1,623,803</td>
</tr>
<tr>
<td>Special events, net of direct benefit to donors in the amount of $98,638</td>
<td>178,432</td>
<td>-</td>
<td>-</td>
<td>178,432</td>
</tr>
<tr>
<td>Donated services</td>
<td>190,922</td>
<td>-</td>
<td>-</td>
<td>190,922</td>
</tr>
<tr>
<td>Raffle</td>
<td>51,260</td>
<td>-</td>
<td>-</td>
<td>51,260</td>
</tr>
</tbody>
</table>

| Public support received indirectly: | | |
|------------------------------------| | |
| Federated fundraising organizations | 135,414 | - | - | 135,414 |

**Total Public Support**

1,733,921 1,608,489 - 3,342,410

### Other revenue:

<table>
<thead>
<tr>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Membership dues</td>
<td>23,940</td>
<td>-</td>
<td>-</td>
<td>23,940</td>
</tr>
<tr>
<td>Sales of materials and services</td>
<td>65,293</td>
<td>-</td>
<td>-</td>
<td>65,293</td>
</tr>
<tr>
<td>Investment income</td>
<td>5,080</td>
<td>250</td>
<td>-</td>
<td>5,330</td>
</tr>
<tr>
<td>Conferences and meetings</td>
<td>307,039</td>
<td>-</td>
<td>-</td>
<td>307,039</td>
</tr>
<tr>
<td>Other</td>
<td>31,626</td>
<td>-</td>
<td>-</td>
<td>31,626</td>
</tr>
</tbody>
</table>

**Total Other Revenue**

432,978 250 - 433,228

### Other revenue:

| Net assets released from donor restrictions | 1,672,345 | (1,672,345) | - | - |

**Total Revenue**

3,839,244 (63,606) - 3,775,638

### Expenses

<table>
<thead>
<tr>
<th>Program services:</th>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>1,555,654</td>
<td>-</td>
<td>-</td>
<td>1,555,654</td>
<td></td>
</tr>
<tr>
<td>Information and Referral</td>
<td>131,943</td>
<td>-</td>
<td>-</td>
<td>131,943</td>
<td></td>
</tr>
<tr>
<td>Member Services/ Chapter Development</td>
<td>555,880</td>
<td>-</td>
<td>-</td>
<td>555,880</td>
<td></td>
</tr>
<tr>
<td>Government Relations</td>
<td>231,420</td>
<td>-</td>
<td>-</td>
<td>231,420</td>
<td></td>
</tr>
<tr>
<td>Research</td>
<td>222,550</td>
<td>-</td>
<td>-</td>
<td>222,550</td>
<td></td>
</tr>
</tbody>
</table>

**Total Program Services**

2,697,447 - - 2,697,447

<table>
<thead>
<tr>
<th>Supporting services:</th>
<th></th>
<th>Unrestricted</th>
<th>Temporarily Restricted</th>
<th>Permanently Restricted</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management and General</td>
<td>333,712</td>
<td>-</td>
<td>-</td>
<td>333,712</td>
<td></td>
</tr>
<tr>
<td>Fundraising</td>
<td>408,377</td>
<td>-</td>
<td>-</td>
<td>408,377</td>
<td></td>
</tr>
</tbody>
</table>

**Total Supporting Services**

742,089 - - 742,089

### Total Expenses

3,439,536 - - 3,439,536

### Change in net assets

399,708 (63,606) - 336,102

### Net assets at beginning of year

634,463 1,538,931 10,000 2,183,394

### Net Assets at end of year

$1,034,171 $1,475,325 $10,000 $2,519,496
Revenues and Expenses

**Revenues**
- **Public Support**: 40% ($1,488,915)
- **Federal Grants**: 43% ($1,623,803)
- **Conferences/Meetings**: 14% ($536,731)
- **Other**: 3% ($126,189)

**Expenses**
- **Program Expenses**: 78% ($2,697,447)
- **Fundraising**: 12% ($408,377)
- **Administration**: 10% ($333,712)
National and Chapters

Consolidated Financial Statement of Revenue and Expense for Year Ended December 31, 2008

Revenues

- Special Events: 17% ($547,943)
- Contributions: 74% ($2,439,131)
- Other Income: 8% ($261,943)
- Membership: 1% ($26,968)

Expenses

- Program Expenses: 76% ($3,835,932)
- Fundraising: 11% ($568,483)
- Management & General: 13% ($665,901)

Note: Each SBA Chapter is separately incorporated, but is required to sign an affiliation agreement with National Office 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. Chapters with * are included in the charts above along with National Office.