



**SPINA BIFIDA
ASSOCIATION**



ANNUAL REPORT

2004 • 2005

***The mission of the Spina Bifida Association
is to promote the prevention
of Spina Bifida and to enhance the
lives of all affected.***

The Spina Bifida Association (SBA) serves the 70,000 adults and children who live with Spina Bifida.

Since 1973, SBA has served as the nation's only voluntary health agency dedicated to enhancing the lives of those with Spina Bifida and the more than 250,000 people whose lives they touch.

SBA's programs give hope and strength to those facing the challenges of Spina Bifida. Because of SBA, parents of children with Spina Bifida are empowered with information and receive much needed comfort, teens transition into newfound independence, and adults lead productive and fulfilling lives.



**SPINA BIFIDA
ASSOCIATION**

In 1973 when the Spina Bifida Association was created, the prognosis for an infant born with Spina Bifida was precarious. The future for a baby born today is much brighter.

Thanks to scientific and medical advances that were only dreamed of in 1973, there is an entire generation of adults with Spina Bifida. We're teachers and lawyers, college students and professionals, employers and employees, sons and daughters, and parents in our own right.

The leadership of the Spina Bifida Association and its partner, the Spina Bifida Foundation have been at the vanguard of this change. They have used advocacy and education with skill and vigor and they have accomplished much.

The Spina Bifida Movement is recognized by many as grassroots advocacy at its best. Dedicated volunteers have come from across the country to Washington, DC and built lasting relationships with legislators.

The Congressional Spina Bifida Caucus is a testament to their dedication. The Caucus will ensure that issues related to Spina Bifida remain in the forefront on Capitol Hill.

The National Spina Bifida Program at the Centers for Disease Control and Prevention is thriving and creating strategies that will promote health, prevent secondary conditions, and prepare people with Spina Bifida to monitor and safeguard their own health. It has also initiated an aggressive program that promotes prevention and research that brings us closer to the day we find a cure.

Those who govern this nation recognize the importance of the work being carried out at the National Spina Bifida Program and, at a time of fiscal restraint, have voted to increase funding.

Research will open new worlds for the 70,000 Americans who live with Spina Bifida. Studies are now in place that will help to unravel the mysteries that surround the myriad of conditions that affect those with Spina Bifida—hydrocephalus, paralysis, bowel and bladder conditions, learning disabilities, and sexual issues among many others.

Millions of people know about the importance of folic acid in preventing Spina Bifida because of the Spina Bifida Association's prevention programs.

There are 60 million women of childbearing age. All are at risk of having a Spina Bifida affected pregnancy. We know that half of all pregnancies are unplanned so it is imperative all of them learn the critical importance of getting enough folic acid prior to pregnancy.

There is an urgent need to reach Latina women who are at a higher risk of a Spina Bifida affected pregnancy. The Spina Bifida Association is responding with compassionate messages of prevention especially created for the Spanish-speaking population.

Those of us with Spina Bifida are living longer and more productive lives. We still face exceptional challenges.

Babies with Spina Bifida endure multiple surgeries before they reach first grade. School systems too often cannot, or will not, respond to the special needs of children with Spina Bifida as they integrate into the educational system. The transition from teenager to adult is still fraught with problems that confound both parents and children. As adults, we still encounter prejudice in the workplace, deficiencies in health insurance, and little is known about the health problems that we will encounter as we age.

There is still much to do. We will continue to turn to the leadership of the Spina Bifida Association and the Spina Bifida Foundation for inspiration and guidance. Together, we have accomplished great things and together we will continue to bring about change. We will not fail in our mission.



Douglas J. Sorocco, Esq.
Chair, Spina Bifida Association



Doug Sorocco, Chair

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“Thanks to scientific and medical advances that were only dreamed of in 1973, there is an entire generation of adults with Spina Bifida. We’re teachers and lawyers, college students and professionals, employers and employees, sons and daughters, and parents in our own right.”

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Securing the Future Through Advocacy

■ Advocacy is a Family Affair

Abigail Branson is a pretty typical seven-year-old. She has cornflower blue eyes and a tangle of golden hair. She comes from a big American family—five kids. But Abigail isn't like her brothers and sister. She has Spina Bifida.

That's why Abigail and her brightly decorated walker are a familiar sight on Capitol Hill and at the State House in Jackson, Mississippi. Abigail and her parents are actively advocating for funding for medical research to help the 70,000 Americans with Spina Bifida live a better life.

Abigail, her mom and her 14-year-old brother, Zachary, traveled from their home in Madison, Mississippi, to visit their Members of Congress and ask them to support increased funding for the National Spina Bifida Program. They spoke about the challenges that people with Spina Bifida face and explained to their representatives officials how the National Spina Bifida Program is making a difference for their family and other families across the country.

The efforts of the Bransons and families like theirs across the country will shape the future for children like Abigail.



The Bransons at the Capitol

There were 30 people on a bus headed to Capitol Hill that June morning. They came from the Spina Bifida Association's Annual Conference. Some men and some women; some with Spina Bifida and some who loved people with Spina Bifida; some first-timers and some who had made the trip many times before. They had a common goal: to improve the quality of life for people who live with Spina Bifida by asking Congress to increase funding for the National Spina Bifida Program.

For three hours, they visited the offices of Senators and Congressional Representatives and their doors opened wide. They spoke of their hopes and dreams for the future with candor and courage and told the leaders of our nation the urgency of the needs of those who live with Spina Bifida.

This is grassroots advocacy at its finest. Our advocates are the people who are most affected by Spina Bifida. They speak from their hearts and they have made changes that were never dreamed of just three years ago.

They are driven by hope for the future and the guidance of an engaged leadership that is dedicated to change. What they have achieved is inspiring—the National Spina Bifida Program at the Centers for Disease Control and Prevention, a Congressional Spina Bifida Caucus, and a Research Agenda that will save thousands of lives and improve the quality of life for thousands more.

Empowering the Grassroots

When people who are affected by Spina Bifida take action by calling, emailing, faxing, or meeting with elected officials, Spina Bifida is elevated to the national agenda and receives the attention and funding that it deserves. The Spina Bifida Association has empowered the Spina Bifida Community to take action by providing effective and efficient tools for advocacy.

The Spina Bifida Association is there with the brave people who visit the halls of Congress and state houses, county courthouses, and the offices of local politicians to share their personal stories about how Spina Bifida has affected their lives and the necessity for legislation and funding that responds to the special needs of those in the Spina Bifida Community. Their efforts have educated the minds and affected the hearts of those in government who hold the keys to the future of all who live with Spina Bifida.

The Spina Bifida Association's advocacy efforts are not confined to personal visits. Great strides have been made because of the action taken by people who sent thousands of postcards, emails, and faxes to Capitol Hill.

A pivotal advocacy program is remarkable in its simplicity and effectiveness. Each year at the Spina Bifida Association's Annual Conference, hundreds of postcards are distributed to attendees encouraging our nation's leaders to support causes of importance to the Spina Bifida Community. When stacks of postcards are delivered by hand to representatives on Capitol Hill, the impact is undeniable.

The power of the Internet has also been harnessed to allow hundreds of individuals to participate in the Spina Bifida Association's advocacy efforts. The website has been enhanced to include Advocacy Alerts, an easy online method of sending pre-written emails to Congressional representatives. With this tool, the Spina Bifida Association is able to garner support for important issues within hours.

We are most grateful to our champions on Capitol Hill and the Congressional Spina Bifida Caucus who used their influence to circulate a “Dear Colleague” letter encouraging their colleagues to increase funding for the National Spina Bifida Program in 2005. Representatives Chris Smith (R-NJ), Bart Stupak (R-MI), Ileana Ros-Lehinen (R-FL), and Sherrod Brown (D-MI) circulated the letter to galvanize broad bipartisan support for this critical program. Their letter garnered a total of 57 signatures and helped to secure an historic funding increase for the National Spina Bifida Program in the Fiscal Year 2005 budget.

It is a testament to the effective advocacy of Spina Bifida Association volunteers, staff, and friends on Capitol Hill that, for the third year in a row, funding for the National Spina Bifida Program at the Centers for Disease Control and Prevention was increased. At a time when few domestic, discretionary programs received funding increases, a funding boost of \$657,000 brought the National Spina Bifida Program’s fiscal year 2005 budget to \$3.657 million.

A substantial part of this increase—\$200,000 has been earmarked to establish a National Spina Bifida Clearinghouse and Resource Center to be developed in collaboration with the Spina Bifida Association. More individuals and families in need will have access to reliable information than ever before as a result of this important program.

The National Spina Bifida Program has done great work to improve the quality of life for people living with Spina Bifida and to reduce and prevent the incidence and morbidity of the condition. It is our duty to continue the momentum of this invaluable program and ensure that it continues to reflect the needs of the adults, children, and families affected by Spina Bifida.

The combined efforts of the Spina Bifida Association and numerous other children’s health disability, and educational organizations were rewarded when President Bush placed his signature on the Individuals with Disabilities Education Improvement Act (IDEA). The extension of IDEA included safeguards and rights to ensure that public education for children with Spina Bifida and other disabilities is accessible, the highest quality, and the most comprehensive possible. It is lasting tangible proof of the strength of the disabilities community when it works as one entity to effect change.

Nowhere is the unity and resolve of the Spina Bifida Community more evident than in its advocacy efforts. Well-orchestrated campaigns that combine the strength of many to speak in a single voice the have brought about unprecedented success through the Spina Bifida Association’s advocacy program.

Research is Hope

Research is hope. It is the hope of a mother that her son who has Spina Bifida will grow to be an independent young man who is integrated into the fiber of life. It is the hope of a bride with Spina Bifida on the day of her wedding that one day she will bear healthy children and watch them grow to be happy adults. It is the hope of a doctor as she repairs the hole in the back of a newborn with Spina Bifida that there will be a time when this surgery is no longer needed because a cure has been found.

Research projects are now in place that one day soon will help to safeguard the health and quality of life for children and adults with Spina



Research Studies Under the National Spina Bifida Program

- The University of Washington initiated two research projects: 1) to examine the use of assistive devices and the incidence of secondary conditions among adolescents and young adults, and 2) to increase understanding of issues related to health care and the most effective model of health care delivery.
- Indiana University/Purdue University-Indianapolis initiated research to examine the occurrence of secondary conditions and factors associated with the development of secondary conditions.
- The University of Arkansas initiated research to determine the prevalence of secondary conditions experienced by individuals with Spina Bifida in Arkansas.
- The Metropolitan Atlanta Congenital Defects Program is determining the prevalence of different age groups surviving with Spina Bifida in Atlanta.
- The California Birth Defects Monitoring Program is investigating the underlying mechanisms by which folic acid contributes to reduced risks for Spina Bifida.
- The National Center on Birth Defects and Developmental Disabilities is working with the Department of Veterans' Affairs to determine patterns of treatment and the accumulation of diagnoses for those individuals with Spina Bifida whose parents' exposure to Agent Orange caused their children to have Spina Bifida.

Bifida. By joining with the Centers for Disease Control and Prevention, we have funded vital research that is already yielding promising preliminary findings that will impact public health in the United States.

The National Spina Bifida Program

Because of the work that is taking place at the National Spina Bifida Program, a collaborative effort between the Centers for Disease Control and Prevention and the Spina Bifida Association, the answers to these questions and many more may be within our reach.

A Research Agenda was crafted from the results of a groundbreaking conference "Evidence-Based Practice in Spina Bifida: Developing a Research Agenda" held in Washington in 2003. The research that is taking place today as a result of this agenda will change the face of the future for those living with Spina Bifida today.

Building the Future

When the spine of the fetus fails to close during the first month of pregnancy, a complex series of reactions are set in motion that affect the formation of the brain and the central nervous system. Because of the unique challenges inherent in Spina Bifida, it is imperative that we build a foundation of individuals dedicated to unraveling the mysteries of this complex condition.

To ensure that this future generation of researchers flourishes, three \$25,000 Young Researcher Incentive Grants have been created as a result of a grant from the Centers for Disease Control and Prevention. These Incentive Grants are a vital part of the Spina Bifida Association's evolving Research Agenda and will be awarded to junior investigators to conduct research that is relevant to Spina Bifida and its secondary complications.

They will provide the building blocks of a strong and thriving research community that is committed to unraveling the mysteries of this complex birth defect.

Education Empowers All Our Communities

The cost of Spina Bifida cannot be measured only in dollars. The greater cost is the toll that it takes on families who must take on the stress of caring for a child with a serious disability, making critical medical decisions, and learning what it truly means to be a primary care provider—often 24 hours a day. As youngsters transition into adulthood, they must deal with the uncertainties of life with Spina Bifida—the constant threat of urological infections, concerns about medical coverage, and the many questions about the effects of aging that remain unanswered.

People 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 Spina Bifida. They rely on the educational programs and materials provided by the Spina Bifida Association.

Sharing Critical Information at the Annual Conference

The Annual Conference is a unique combination of cutting-edge information on the latest treatments, advances in Spina Bifida care, and sessions on the practical aspects of living with Spina Bifida. It skillfully combines the insight of leading medical authorities and seasoned clinicians with the experience of those who live with the condition.

The 31st Annual Conference was infused with a special energy as almost 1,000 adults, adolescents, children, and families affected by Spina Bifida gathered from across the country in Washington, DC on June 20-22. Education reached beyond the confines of the Conference as more than 30 attendees became part of the legislative process and visited their representatives on Capitol Hill.

Attendees were further empowered with information about the latest advances in orthopedics, urology, neurosurgery, as well as adult health, psychosocial and family issues, employment, sex, depression, latex allergy, self-determination, and learning disabilities.

During the Annual Conference, children attend Kids!Camp, the nation's only camp dedicated exclusively to children with Spina Bifida and their siblings. This remarkable camp helps build self-esteem, self-reliance, and coping skills through a carefully planned program of play and experiential learning. It is a time when children with Spina Bifida are accepted and respected for who they are. A time when dreams become reality and they experience the joy of just being a kid.

Washington, DC became a playground and a school for the children who attended Kids!Camp. Teens were challenged with seminars on the History of Civil Rights for the disabled and treated to interactive sessions presented by the National Portrait Museum and the US Postal Museum while the little ones learned skills through carefully planned play activities.

A Growing Source of Information: The National Resource Center

The Centers for Disease Control and Prevention have entrusted the Spina Bifida Association with a projected \$200,000 earmarked to create a National Spina Bifida Information and Resource Center now housed at the Spina Bifida Association. These funds will allow the Spina Bifida Association to build on the reputation of the Center as the foremost source of accurate and reliable information for those living with Spina Bifida, families, caregivers and professionals, and for the general public.

A middle-aged man who has just learned that he will need surgery to replace his shunt, a mother whose unborn child has been diagnosed with Spina Bifida, an adolescent whose high school years are marred by learning disabilities—these are just a few of the people who contact the National Resource Center. They know that they can rely on the quality and integrity of the information they will receive.

The redesigned website has expanded the outreach of the National Resource Center and empowers users with quick and accurate answers to their questions. In addition to Fact Sheets and other information, a list of Frequently Asked Questions provides brief responses to some of the most popular questions about Spina Bifida and also offers more in depth information.

The need for information in the Latino Community is critical because they are at higher risk of having a child with Spina Bifida. Our library of

■ Noah's First Kids!Camp

Six-year-old Noah Leheny, has a special word for activities he loves: "Cool." For Noah, his first Kids!Camp at SBA's Annual Conference was definitely "cool."

During Noah's three days of Kids!Camp he pretended to be a water molecule, met visiting animals, raced handpowered bicycles, learned the fine art of making S'mores, and made a lifetime of memories.

Kids!Camp means as much to parents as it does kids. Noah's dad, Andy, found a sense of hope for the future as he watched 6-year-old Noah at his first Kids!Camp.

"What is important to us, Noah's parents, are the experiences that future Kids!Camps will offer him. We watched the teenagers as they wheeled down to their dance and thought about Noah's transition from boyhood to young adult.

We look forward hopefully to the day when Noah guides his wheelchair in a ballet of movement with a young lady on the dance floor."



Noah and a friend at Kids!Camp

Fact Sheets that have been translated into Spanish continues to grow and an expanding section of the website has been created in Spanish. We work closely with a translator to respond to questions in Spanish that are asked of the Resource Center.

Whether it is one of the many Fact Sheets on a breadth of topics of interest to those in the Spina Bifida Community or a referral to a local chapter that can provide strength and moral support, the National Resource Center is there for those in need of reliable information.

Enhancing Health Care Through Education

The partnership between patients and their health care providers is vital to the well being of those who live with Spina Bifida. Ongoing education for these dedicated individuals is an essential part of the Spina Bifida Association's mission.

The Nursing and Healthcare Professionals Council (NHPC) Education Day at the Spina Bifida Association's Annual Conference responds to the unique needs of this special group of professionals who dedicate their skills to working with those who live with Spina Bifida. Sessions designed to hone their skills and expand their understanding of the complexities of Spina Bifida provide the opportunity for the free exchange of experience and ideas that results in superior health care.

Innovative use of technology has offered more opportunities for professional education. The NHPC ListServ provides an instantaneous venue for members of the NHPC across the country to share their vast experience to provide the best possible care to their patients. Using this email-based network allows users to ask questions concerning treatment of their patients and receive ideas and solutions that are being used by their peers with click of their mouse.

Got a Minute? uses the Internet to provide health care professionals with a quick tutorial about folic acid and tips about how they can discuss it with their patients. This program was created through the Recurrence Prevention Campaign with the Centers for Disease Control and Prevention. It is vital and highly successful element of the Spina Bifida Association's prevention efforts because despite the proven relationship between folic acid intake and neural tube defects like Spina Bifida, many health care professionals still do not advise their female patients about the importance of taking folic acid before and during pregnancy.

Spreading Our Message of Life

We must reach out to our many communities with a sense of urgency about the need for action in treating and preventing Spina Bifida, tempered with sensitivity about its many complexities. The Spina Bifida Association has skillfully crafted an outreach program communicates our message of awareness, prevention, advocacy, and hope.

Our outreach program touches lives using an arsenal of tools—it employs technology that allows us to reach thousands with one message, a network of chapters that reaches across the nation, and the incredible power of person-to-person communication that changes one life at a time.



The Power of the Internet

The Spina Bifida Association recognized the tremendous potential of the Internet to educate, empower, and open new worlds of hope. Radical changes were made to the Spina Bifida Association's website, www.sbaa.org to make it a dynamic portal that will generate enthusiasm and action. Not only does it have a new face that is welcoming and professional, the entire site has been upgraded and reorganized to allow easy access to much-needed information.

Each month, the Spina Bifida Association's website touches an average of 26,000 people with the most current and reliable information available about all aspects of this incredibly complex condition. Young families learn about the importance of folic acid, adults learn the most recent research about aging with Spina Bifida, teachers learn how to create an effective learning experience, and parents learn how to recognize a possibly fatal hydrocephalus shunt failure.

The Internet is also revolutionizing the Spina Bifida Association's advocacy efforts with tools that can help concerned individuals ensure that their voices are heard on Capitol Hill with the click of a mouse by sending an Advocacy Alert to their Congressional representatives. Within hours, a campaign can be launched to inform legislators about the importance of their support on an issue of concern to the Spina Bifida Community.

eCommunities: the Neighborhoods of the Future

The concept of a neighborhood no longer is limited to neat frame houses, carefully trimmed lawns, and picket fences. Today's neighborhoods are bound by fiber optics and take the form of ListServes, vibrant e-mail communities that link people from across the country and allow true and lasting relationships.

The YAA (Youth and Adult Alliance) ListServ has evolved into a community of caring adults who share their joy, hopes, fears, problems, and medical concerns. It is an antidote to the isolation that many adults with Spina Bifida endure and a source of companionship for all who participate.

Parents have formed a network of support through the Parents ListServ. Information about surgeries and other treatments are shared as graduations and other milestones in their childrens' lives are celebrated.

Common sense treatment approaches work hand in glove with sophisticated medical technology as health care professionals share information about how they are helping their patients with Spina Bifida. The Health Care Professionals ListServ allows a doctor in California to exchange ideas with another doctor in Massachusetts to provide the best possible treatment for their patients.

Empowering the Field

Together with our strong network of chapters, the Spina Bifida Association strives to achieve common goals for the Spina Bifida cause, including increasing awareness of Spina Bifida among the general public. It is only through partnerships with chapters across the country that we can work towards achieving this goal for the Spina Bifida Community.

A new program of Grants will enable the grassroots power of our chapters and help reach all corners of the nation. The first permitted four chapters to invest a significant sum into media outreach on Spina Bifida awareness.



The caring individuals and skilled professionals that comprise the Spina Bifida Association's chapters are our finest representatives.

Person-to-Person and Heart-to-Heart: SBA's Mentoring Program

Kids with Spina Bifida need a guiding hand. A mentor who will devote time and attention to helping them achieve all that they can and live their lives to the fullest.

TEAM (Teens and Mentors) was created to provide guidance and support to teenagers between 13 and 18 on their path to independent adulthood and help them navigate the challenges of growing up with Spina Bifida by encouraging a spirit of self-reliance and pride.

Pilot programs have been initiated at three locations: Children's Hospital Los Angeles Spina Bifida Program, the Spina Bifida Association of the Tri-State Region, and Spina Bifida Association of Wisconsin, Inc./ Children's Hospital of Wisconsin. This important program will help teens with Spina Bifida adopt and hone life-skills that will allow them to grow into successful adults.

Increasing Awareness with Laughter: Annual Roast for Spina Bifida

Leaders of Fortune 500 companies, policymakers from Capitol Hill, and media luminaries gather at the Association's Annual Roast for Spina Bifida. Since 1989, when Judy Woodruff, journalist and CNN anchor and Al Hunt, Executive Washington Editor of *The Wall Street Journal* first turned the tables on members of the 4th estate, the Roast has been a Washington tradition.

The event is not only a gala social event and fundraiser, but this high profile occasion brings critical awareness to all those who attend and draws significant media attention. This is an unequalled opportunity to educate the public about Spina Bifida and bring a message of prevention to thousands of people.

Bernard Shaw, former CNN anchor and ABC journalist was honored at the 16th Annual Roast. He was joined by a veritable who's who of journalism, politics, and sports. Broadcast legend Walter Cronkite joined Washington Redskins owner Dan Snyder, Senator Lindsey O. Graham (R-SC), and Congressman Harold E. Ford, Jr. (D-TN) on the dais as they traded good-natured political jabs and warm-hearted memories of veteran journalist Shaw. Political pundit Mark Shields once again served ably as master of ceremonies.

A highlight of the evening was the silent auction that featured some 40 impressive items ranging from dazzling jewelry and luxurious spa retreats to breathtaking travel packages and works of art, the result of donations from individuals and corporations from across the country.

The Roast is a celebration of the Spina Bifida Association's partnerships with the corporate community who each year generously support the Roast. We value our long and enduring relationships with many corporations and look forward to building strong and vital relationships with those who are joined us for the first time.



Scholarships

The students of today will be the leaders of tomorrow. Scholarships are our investment in the future. They help young people with Spina Bifida become fully participating adults with the help of a college education.

This program makes it possible for deserving students to pursue educational opportunities that are otherwise out of their financial reach.

Four-Year Scholarship

The 2004-2005 recipient is Amanda Marie Memken from Pekin, Illinois. Amanda was the top student in her class and a key member of the Science Olympiad Team. She is attending Butler University in Indianapolis where she is pursuing a six-year Doctor of Pharmacy Degree.

In her letter of application for the scholarship, she told us, "My parents did not have the opportunity to save for my college education because they were paying my medical bills. Since my parents did everything in their power to ensure that I have the best quality of life, I feel that it is my duty to do everything I can in order to ease the financial burden of college. So with your help, I believe that I can pursue my dreams and help improve the lives of many people."

Lazof Family Foundation Scholarships

Thanks to the generosity of the Lazof Family Foundation, four scholarships were offered for the first time. Each recipient of a Lazof Scholarship will receive \$2,500 each year throughout their four years in college.

One-Year Scholarships

One-year scholarships of \$1,000 each are awarded to enhance educational opportunities for deserving students. These scholarships are an important part of the Spina Bifida Association's efforts to help people born with Spina Bifida achieve their full potential through higher education.

Invest in the Lives of Those Who are the Spina Bifida Association

A donation to the Spina Bifida Association is an investment in the life of someone who is touched by Spina Bifida. It takes so little to change a life.

The support from individuals, foundations, and corporations from across the country has helped the Spina Bifida Association accomplish so much for the 70,000 Americans who live with Spina Bifida.

But there is still so much to do and we can only achieve it with your help.

A healthy start is the birthright of every child. Prevention is crucial to ensuring the health and wellbeing of future generations. There are 60 million women of childbearing age in the United States. Each one is at risk of a Spina Bifida affected pregnancy. The message of the effectiveness of a simple multivitamin with folic acid in reducing the risk of neural tube defects must reach every woman of childbearing age.

■ Letter from a Mother

Dear SBA:

I am a single mom of a boy with Spina Bifida who never walked. It was a real struggle to integrate him into public school, but one which ultimately paid off.

My son was the recipient of the 1999 SBA \$20,000 scholarship. He attended the State University of New York at New Paltz, and graduated a year ago.

Not only did he attend college in the mountains, as the only physically disabled student on campus, but he graduated in four years with a 3.3 GPA. I cannot begin to say how much the scholarship meant to him and my family.

Now, because he has graduated with little debt, he was able to apply for and has been accepted to UNC Chapel Hill for graduate work in social work and public health.

It has been a long hard road, and is still a long hard road ahead, but thanks to perseverance, and the SBA scholarship, my son is reaching his dream goals.

Thank you SBA.
Jody Jarowey



**Dennis Carmody,
the 1999 recipient of a
\$20,000 scholarship with his
sisters, Meghan and Emma**

■ The Journey of a Father & Son

"You reflect what you expect," says Scott Price, a founder and Board Member of the Spina Bifida Foundation and long-time supporter of SBA. This brand of optimism fueled Scott and his son Pat, who has Spina Bifida, on an 11 month, 57,721 mile journey to all 50 states in search of good will.

They interviewed 106 randomly selected people in restaurants, at flea markets, in stores, at car dealerships, and on the street and were never once turned down. And over and over again they heard stories that were inspiring and life and life affirming.

"In terms of looking for good will – it was so abundant. So wide and so deep across this land," says Scott. "We were overwhelmed by how easily people opened up to us. It was so refreshing to meet so many people who love where they live, love what they do, and love their spouse."

Their experiences will be published in a book entitled: *Looking for Goodwill* and the cycle of compassion will continue as the Prices donate 20 percent of the profits from the book to the Spina Bifida Foundation.

You reflect what you expect. And Scott and Pat Price reflect the very best.



Scott and Pat Price

Your donation will allow us to continue to increase public awareness about Spina Bifida and ensure the highest quality of life for all Americans affected by this serious birth defect.

Research is our hope for the future. Despite the impact of Spina Bifida on individuals, families, society, and the nation, little research has been conducted on the many components of this devastating birth defect. For some of the conditions associated with Spina Bifida, treatment options are limited. For others, they are practically nonexistent.

The vital research that is so desperately needed comes with a high price tag. We can only do it with the support of people like you—people who truly care!

Getting vital information to those in need. When a young couple learns that their long awaited baby will be born with Spina Bifida, they turn to the caring professionals at the Spina Bifida Association to receive accurate information quickly.

Reliable information must be available through every means available—the Internet, brochures, fact sheets, and our network of local chapters.

Advocating for a better tomorrow. New worlds have opened for people with Spina Bifida due to advancements in treatment and prevention. But what about tomorrow? People with Spina Bifida are still denied access to the most basic needs and treatment options for adults remain difficult if not impossible to find.

With your help, advocacy efforts will defend the quality of life for those with Spina Bifida through new legislative and funding initiatives to expand research programs, lead prevention activities, and ensure civil rights.

With your help, we will achieve all this—and more. Join with us in our mission. Join us today.

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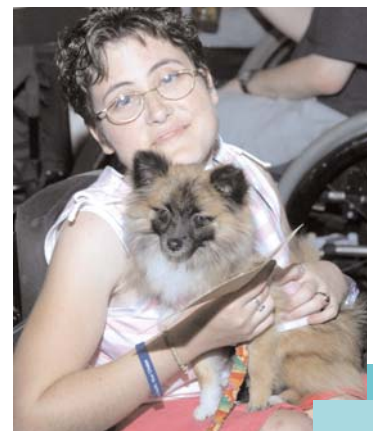
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SPINA BIFIDA ASSOCIATION OF AMERICA
STATEMENT OF FINANCIAL POSITION AS OF MARCH 31, 2005
WITH SUMMARIZED FINANCIAL INFORMATION FOR 2004

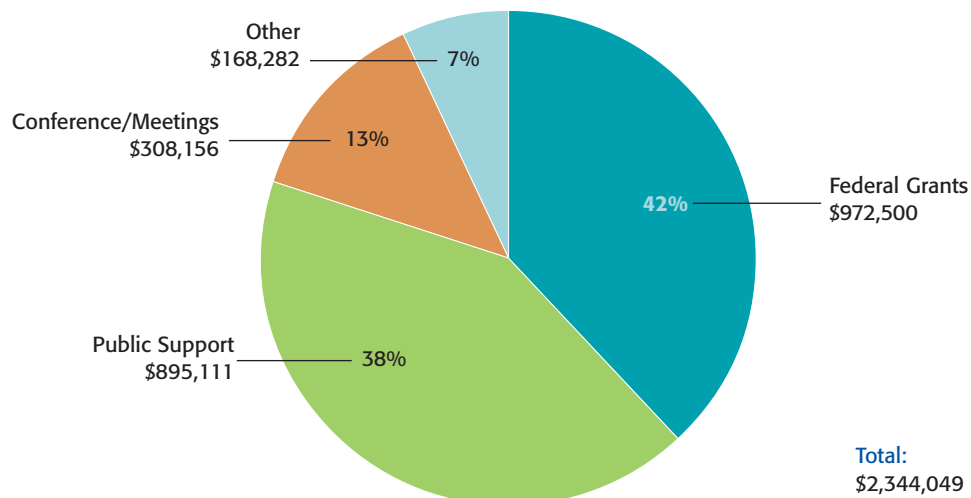
ASSETS

	2005	2004
CURRENT ASSETS		
Cash and cash equivalents	\$ 135,487	\$ 74,086
Investments	417,003	345,375
Accounts Receivable	33,476	22,068
Due from related parties	9,825	-
Grants receivable	550,000	290,000
Inventory	8,049	2,583
Prepaid expenses	59,849	45,025
Total current assets	1,213,689	779,137
FURNITURE AND EQUIPMENT		
Furniture	17,197	17,197
Equipment	75,094	64,774
Computer Software	14,212	11,843
Total Furniture and Equipment	106,503	93,814
Less: Accumulated depreciation	(84,439)	(77,202)
Net furniture and equipment	22,064	16,612
OTHER ASSETS		
Deposits	2,625	125
TOTAL ASSETS	\$ 1,238,378	\$ 795,874

LIABILITIES AND NET ASSETS

CURRENT LIABILITIES		
Accounts payable	\$ 159,119	\$ 50,039
Accrued expenses	21,412	13,599
Deferred revenue	106,047	144,717
Total current liabilities	286,578	208,355
NET ASSETS		
Unrestricted	483,099	264,664
Temporarily restricted	458,701	312,855
Permanently restricted	10,000	10,000
Total net assets	951,800	587,519
TOTAL LIABILITIES AND NET ASSETS	\$ 1,238,378	\$ 795,874

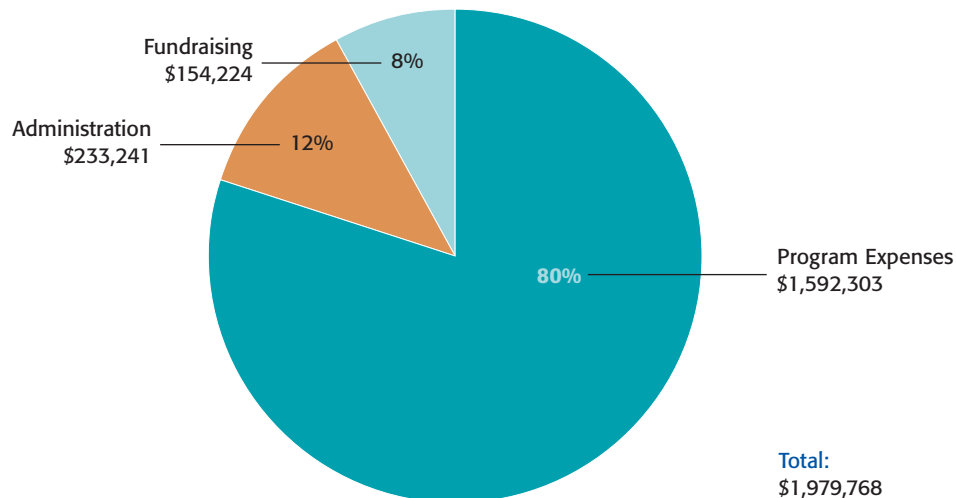
Spina Bifida Association of America
Revenues 2005



SPINA BIFIDA ASSOCIATION OF AMERICA
STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS FOR THE YEAR ENDED MARCH 31, 2005
WITH SUMMARIZED FINANCIAL INFORMATION FOR 2004

	2005			2004	
	Unrestricted	Temporarily Restricted	Permanently Restricted	Total	Total
REVENUE					
Public support received directly:					
Contributions	\$ 412,399	\$ 35,385	\$ -	\$ 447,784	\$ 315,061
Grants	5,000	967,500	-	972,500	494,300
Special events, net of direct benefit to donors in the amount of \$105,513	149,712	-	-	149,712	174,624
Contributed services and materials	43,719	-	-	43,719	24,390
Bequests	66,148	-	-	66,148	233,830
Raffle, net of direct benefit to donor in the amount \$28,000	85,900	-	-	85,900	55,405
Public support received indirectly:					
Federal fundraising organizations	101,848	-	-	101,848	95,797
Total public support	864,726	1,002,885	-	1,867,611	1,393,407
Other revenue:					
Membership dues	96,547	-	-	96,547	102,258
Sales of materials and services	42,819	-	-	42,819	45,047
Investment income	7,278	-	-	7,278	30,418
Conferences and meetings	308,156	-	-	308,156	252,458
Other	21,638	-	-	21,638	15,622
Total other revenue	476,438	-	-	476,438	445,803
Net assets released from donor restrictions	857,039	(857,039)	-	-	-
Total revenue	\$2,198,203	\$ 145,846	\$ -	\$2,344,049	\$1,839,210
EXPENSES					
Program services					
Education	\$ 1,246,414	-	-	\$ 1,246,414	\$ 969,006
Information and referral	49,977	-	-	49,977	79,343
Member Services / Chapter Development	95,415	-	-	95,415	94,940
Government Relations	146,712	-	-	146,712	170,894
Research	53,785	-	-	53,785	36,785
Total program services	1,592,303	-	-	1,592,303	1,350,968
Supporting services:					
Management and General Fundraising	233,241	-	-	233,241	146,325
Fundraising	154,224	-	-	154,224	125,969
Total supporting services	387,465	-	-	387,465	272,294
Total expenses	\$1,979,768	-	-	\$ 1,979,768	\$1,623,262
Change in net assets	218,435	145,846	-	364,281	215,948
Net assets at beginning of year	264,664	312,855	10,000	587,519	371,571
NET ASSETS AT END OF YEAR	\$ 483,099	\$ 458,701	\$ 10,000	\$ 951,800	\$ 587,519

Spina Bifida Association of America
Expenses 2005



Group Members

ALABAMA

SBA of Alabama
Birmingham
Gulf Coast SBA
Mobile

ARKANSAS

SBA of Arkansas
Little Rock

ARIZONA

Arizona SBA
Phoenix

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

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Hartford

FLORIDA

SBA of Jacksonville
Jacksonville
SBA of Florida Space Coast
Merritt Island
SBA of Southeast Florida
Miami
SBA of Tampa Bay, Inc.
Tampa

GEORGIA

SBA of Georgia
Decatur

IOWA

SBA of Iowa
Des Moines

ILLINOIS

Illinois SBA
Lisle

INDIANA

SBA of Central Indiana
Indianapolis
SBA of Northern Indiana
Elkhart

KANSAS

SBA of Kansas
Wichita

KENTUCKY

SBA of Kentucky
Louisville

LOUISIANA

SBA of Greater New Orleans
Kenner

MASSACHUSETTS

Massachusetts SBA
North Andover

MARYLAND

Chesapeake-Potomac SBA
Annapolis

MICHIGAN

SBA of Upper Michigan
Ishpeming
West Michigan SBA
Grand Rapids
SW Michigan SB & Hydrocephalus
Association
Mattawan

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Brooklyn Center

MISSOURI

SBA of Greater St. Louis
St. Louis

MISSISSIPPI

SBA of Mississippi
Richland

NORTH CAROLINA

SBA of North Carolina
Indian Trail

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SBA of Nebraska
Omaha

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Flemington

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Fairport
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Scotia
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North Tonawanda

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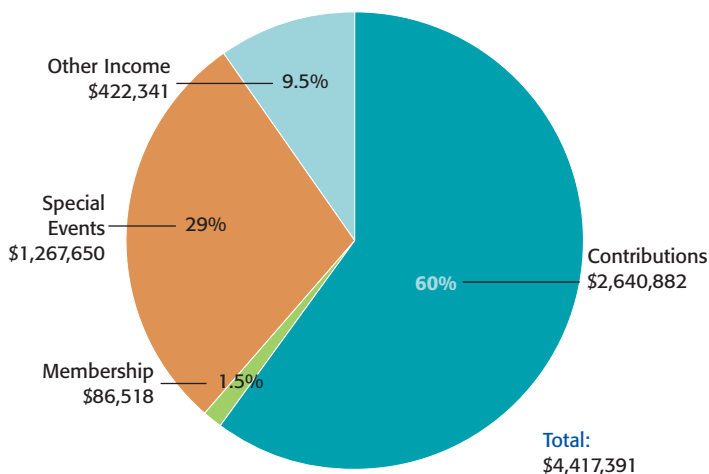
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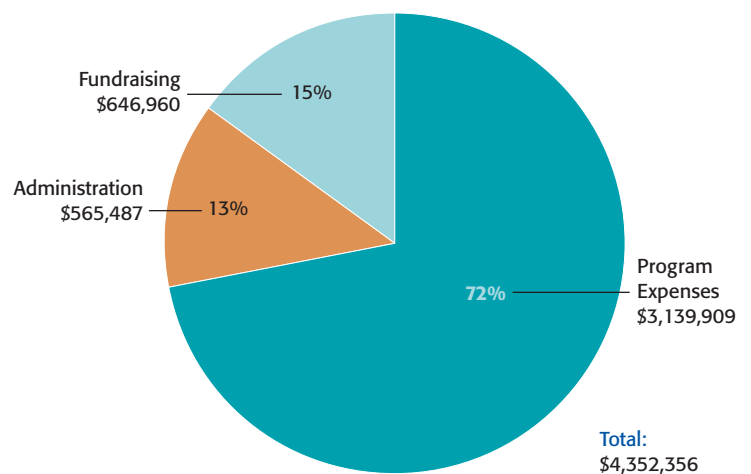
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SPINA BIFIDA ASSOCIATION NATIONAL AND GROUP MEMBERS CONSOLIDATED STATEMENT OF REVENUE AND EXPENSE FOR THE YEAR ENDED MARCH 31, 2004

Spina Bifida Association National and Group Members Revenues 2004



Spina Bifida Association National and Group Members Expenses 2004



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.

Recognition of the Many Contributions of Those Who are Dedicated to the Spina Bifida Community

The corporations, foundations, and individuals listed on the following pages have made significant contributions. The Spina Bifida Association gratefully acknowledges their extraordinary generosity, leadership, and commitment.

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**SPINA BIFIDA
ASSOCIATION**

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