

Spina Bifida Association of Illinois

is a not-for-profit organization whose mission is to promote the prevention of Spina Bifida and to enhance the lives of all affected.

We accomplish our mission through public education programs, direct services, referrals to family support groups and to social service agencies and financial assistance and advocacy activities.

Helping persons with Spina Bifida develop independent living skills to the best of their abilities is an important part of our mission. As increasing numbers of persons with this birth defect reach adulthood, we are expanding our activities to serve this population.

The Spina Bifida Association of Illinois was founded in 1969 as a 501(c)3 not-for-profit organization and is a leading health and social services advocacy organization for people with Spina Bifida and their families in Illinois.

Spina Bifida (open spine) occurs when, for unknown reasons, the spinal cord of a baby does not form properly during pregnancy. The effects of this condition vary greatly, from minor back problems to paraplegia, hydrocephalus and bowel and bladder dysfunction. Spina Bifida Association of Illinois assists parents, medical professionals, teachers and other caring individuals in helping persons with Spina Bifida reach their full potential.

Public affairs programs

- Press releases, public service announcements in various media and web-site information explaining the effects of Spina Bifida and highlighting the role of folic acid in preventing Spina Bifida and other neural tube defects.
- Presentations to service groups to increase awareness of Spina Bifida and folic acid.

Direct services to persons with Spina Bifida

- Camp Ability[®], offering campers an opportunity to enjoy an exciting camp, and, at the same time, make progress toward a healthy independent lifestyle by developing skills to improve their health, mind and body. The only residential summer camp in the Midwest exclusively for children and young adults with Spina Bifida.
- Scholarships for education in colleges or vocational schools.

Assistance to families

- Referrals to other member families who offer individual advice and reassurance to new parents and guardians of babies with Spina Bifida and to relevant social service agencies.
- Social gatherings at which families share experiences and information while youngsters hone their social skills.
- Limited financial grants for uninsured medical expenses such as braces and equipment, therapy and urology supplies.

Educational opportunities

- A quarterly newsletter, *Crossroads*, mailed to all members.
- Seminars featuring nationally-known speakers.
- Monthly meetings in Central Illinois featuring speakers on pertinent topics.
- Educational packets for teachers regarding students with Spina Bifida.

Advocacy

- Cooperation with other organizations to develop programs for adults with Spina Bifida, including housing and access to appropriate medical care for adults.

To Our Members and Stakeholders

In the year 2006, we made a number of strategic moves to gain a greater visibility in the important Chicago area, to join with other Spina Bifida associations across the country in increasing public awareness of the importance of folic acid, and to respond to the changing needs of our population: individuals with Spina Bifida and their families.

In mid-year, we moved our offices from the suburban location we had occupied for more than a decade to the northwest side of the City of Chicago. We believe this new address will give us a stronger presence in the Chicago business and philanthropic community in addition to affording us greater flexibility in traveling throughout the area.

We added to our office staff a professional to handle program direction. While our association developed primarily through volunteers who planned and implemented our activities, it was becoming clear that we could no longer rely totally on volunteer efforts. While volunteers continue to play an important part in our activities, we now have greater continuity and control in our operations.

One new volunteer activity we initiated during the year is an adult advisory group. These adults are helping develop programs and suggesting advocacy arenas to meet the needs of this segment of our population, particularly in the areas of jobs and housing.

We continued our efforts to increase public awareness of the importance of folic acid in the diets of childbearing-age women to help prevent Spina Bifida and other neural tube defects. As part of the program, we increased contacts with nursing groups and school healthcare professionals. Expanding that message is a key element on this year's agenda.

We also improved some of our traditional support programs for families living with Spina Bifida by revising the informational packet sent to families and increasing our contacts with Spina Bifida clinics throughout the state.



Scott J. Munkvold
President



Adam S. Rappaport
Executive Director

In addition, we revised and strengthened the independence program for youngsters and young adults who attended Camp Ability, our unique residential summer camp.

We are now operating under the name Spina Bifida Association of Illinois. This change was made to highlight the name of the birth defect we are representing and to gain recognition with our national association and other state groups.

We anticipate that the moves we made during 2006 will carry us forward strongly in the future. As always, we extend our deep gratitude to our volunteers and our donors who continued to support us in many ways.

Spina Bifida is the nation's leading disabling birth defect. Studies indicate that if all women of childbearing age consumed 0.4 mg of folic acid daily before becoming pregnant and during the first trimester, the incidence of Spina Bifida could be reduced by 70%.

Part of the vitamin-B complex, folic acid occurs in leafy green vegetables, beans, fresh fruits, citrus fruits and juices and peanuts. Some cereal-grain products are fortified with folic acid, such as breakfast cereals, breads, rice and pasta. Some vitamin and multivitamin pills also provide folic acid.

***Why should you take
a vitamin containing 400mcg
of folic acid everyday?***

Because it reduces your risk of having a child with Spina Bifida by 70%.

Because Spina Bifida occurs in the first 28 days of a pregnancy before most women know they are pregnant.

Because everyday, an average of 8 babies are born with serious birth defects like Spina Bifida.

*Because one little pill every day can
change your future child's life!*



**SPINA BIFIDA ASSOCIATION
OF ILLINOIS**

773-444-0305 • 800-969-ISBA

Email: sbail@sbail.org Website: www.sbail.org

This advertisement is being sponsored by SBAIL in print media.

Summary of 2006 Activities

Public Awareness

With the rise in Spina Bifida births within the Hispanic population and the knowledge that women are less aware of the importance of folic acid, SBAIL set out to make a change. We enlisted the assistance of OB-GYNs, MDs, birthing centers, fertility clinics, school nurses and more to help spread the message about folic acid. New educational materials were distributed throughout the state to these professionals. The value of folic acid is an important part of SBAIL's mission, and will remain a key aspect of our programming.

SBAIL continued its program of issuing press releases and public service announcements to newspapers and electronic media highlighting the importance of folic acid in preventing Spina Bifida and other neural tube defects, as well as releases about SBAIL activities. As part of our media relations program, SBAIL personnel and representatives appeared on several broadcast and television programs, including a Spanish radio station that airs in five states.

Camp Ability®

Camp Ability, founded by SBAIL in 1989, offers children and young adults with Spina Bifida a true camping experience while helping them develop independent living skills. In 2006, more than 90 campers gathered in three week-long sessions at the Timber Pointe Outdoor Center in Bloomington, Illinois, to participate in boating, swimming and other water sports, archery, art and horseback riding and even a high ropes course.

Over the past few years, the independence development program has been expanded and refined. Many young adults now in schools of higher education or developing their careers credit their camping experiences for giving them the self-confidence they need to succeed.

Scholarships

SBAIL grants scholarships to persons with Spina Bifida for post-secondary schooling in four-year and junior colleges, graduate schools and technical schools. During 2006, SBAIL awarded 9 scholarships for post secondary education totaling \$17,500.

Also in 2006, the first Valiant Scholarship was awarded. The recipient was a young man pursuing a doctoral degree. The Valiant Scholarship is named in honor of the late Bill Valiant, former president and long-time supporter of both SBAIL and of the national Spina Bifida organization. It is awarded to those attending post-secondary schools who demonstrate outstanding academic and leadership abilities.

Education

In addition to general public awareness efforts, calls were made on leading Spina Bifida clinics to meet with healthcare personnel and offer materials about folic acid and SBAIL for distribution to patients.

The Executive Director also appeared before numerous civic groups to explain Spina Bifida, the role of folic acid and to increase public awareness of Spina Bifida and the programs of SBAIL.

The quarterly newsletter, *Crossroads*, was expanded to include additional articles on information and sources of assistance for persons with Spina Bifida and their families. The SBAIL website was redesigned to include additional information about Spina Bifida as well as reports of the organization's activities.

Advocacy

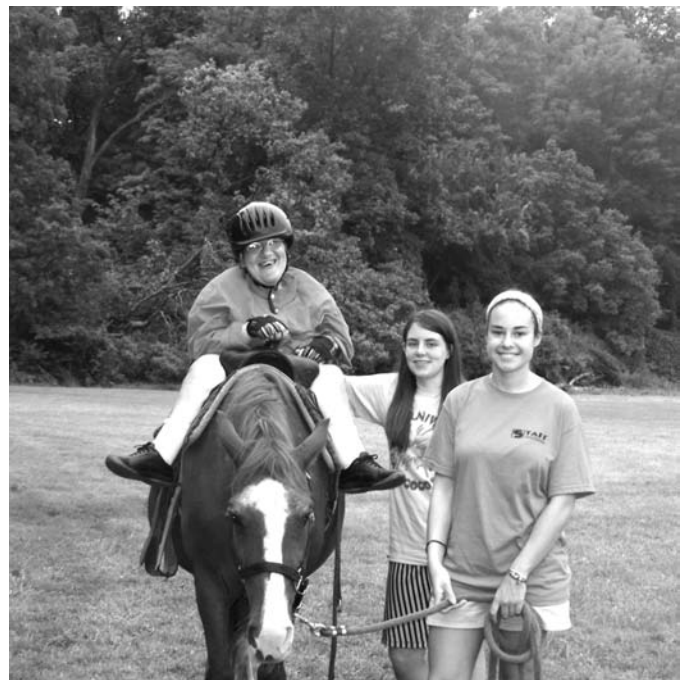
Increasing numbers of persons with Spina Bifida are reaching adulthood, and their needs for assistance mature with them. SBAIL inaugurated an Adult Advisory Committee who will help identify the most crucial areas of interest for adults and develop programs to meet those needs. SBAIL is also working with the national Spina Bifida Association to foster research and a variety of advocacy programs in the areas of education, jobs and housing.

Family Services

Our Family Outreach service provides encouragement and support for new parents. The information packet given to new parents was improved during the year, and trained volunteer parents of children with Spina Bifida offered personal support and advice through telephone calls and meetings at SBAIL social gatherings, such as the Holiday Party.

Central Illinois Support Group

A number of families living in Central Illinois held monthly meetings featuring speakers on topics related to Spina Bifida. The group also sponsors an annual holiday party for families and members living in the Central Illinois area. Candlelight bowling and Walk-and Roll-a-Thon events held during the year, combined fun with fundraising. SBAIL members in the area also responded as part of our volunteer family network to questions and concerns from families dealing with Spina Bifida for the first time.





Fundraising

Funding sources for SBAIL include grants and contributions from philanthropic and corporate sources as well as events organized by SBAIL family members, which draw support from friends and local charitable organizations.

Our most important sources of funding include:

For 17 years, The Windy City Corvettes automobile club has sponsored a raffle of a new Corvette sports car with the proceeds funding generous contributions to SBAIL. Many Windy City Corvettes members also participated in the annual Chicago Auto Show First Look for Charity benefit preview, which has been an important source of our revenue for the past fifteen years. The event is sponsored by the Chicago Automobile Trade Association, comprised of new car dealers of Chicagoland and Northwest Indiana.



In September, Walk-and-Roll-a-Thons were held in both Northern and Central Illinois on the same day. Youngsters and adults walk, roll their wheelchairs, ride bikes and are pulled in wagons to raise money from sponsors. Founded by the Marnell family, the Northern Illinois Walk has raised nearly \$125,000 over the past twelve years.



For the sixth year, SBAIL member Ron Zicha, with family and friends who are professional bowlers, has organized a Pro-Am tournament. The weekend event has grown every year, and more than 50 professional bowlers from around the country participated in the 2006 tournament. Generous contributions from both professional and amateur participants has netted over \$85,000 total since its inception.

For a number of years, the O'Malley family fundraiser has contributed more than \$13,000 annually to SBAIL. This totally volunteer run event held at the Emerald Isle in Chicago has grown every year. A night of food, friends, and fun has translated into one of the best events for SBAIL every year.



In 2006, the annual golf outing drew nearly 100 golfers and raised over \$30,000.

For the first time, SBAIL held a raffle for a Harley Davidson Road King Classic that was generously donated by John Paderta and Krahl Construction. The winners of the Harley were Chris and Areta Kohout.

We are deeply grateful to all members, and their families and friends, who have organized, attended and participated in events that support association activities.



Financial Report

A number of programs, especially Camp Ability, require substantial professional participation with related financial outlays, and plans to increase public awareness programs will require additional financial support.

INCOME SOURCES 2006

Public, corporate and foundations donations and grants	\$	46,903
Special events		312,799
Camp Ability sponsorship		70,701
Camp Ability income		12,795
Membership dues		8,205
Other income		8,461

Total \$ **459,864**

EXPENSES 2006

Outreach programs	\$	249,499
Camp Ability		92,551
Assistance programs		31,364
Fundraising		66,358
General and administrative		45,416

Total \$ **485,188**

The Association's auditor is J. P. Fox & Associates, Inc. Accounting practices are consistent with Generally Accepted Accounting Principles for not-for-profit organizations. Contributions in kind are excluded from financial reporting. Audited financial statements are available from Spina Bifida Association of Illinois.

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Windy City Corvettes

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