

The SPINAL COLUMN

Newsletter of Chesapeake-Potomac Spina Bifida Inc.

The CPSB Board of Directors held a retreat in January 2009 to share their vision for the future of our organization. From the session came our mission statement, “to support the needs of individuals with spina bifida and related conditions and their families”.

Programs and services that our volunteers and staff have developed to support our mission will continue. (See Page 3)

A renewed effort will be made to promote CPSB's programs and services to more individuals with spina bifida in the region and to recruit more people to be volunteers for the organization. (See Page 3)

We are pleased that a new CPSB brochure is available and that our *Directory of Services for Individuals with Spina Bifida and Related Conditions* has been updated by volunteers and the 2009 editions will be sent to our members and available in print and on our website in August.

CPSB promoted the “Cell-Based Therapies for Children with Disabilities: Future Possibilities Conference” held on June 20, 2009 at Kennedy Krieger Institute. Over 60 parents and health care professionals attended the half-day conference. An audiotape of the conference presentations and CD of resources is available.

Two new activities are planned to help teens and adults; a Mentoring Program and a survey will be conducted to assess the need for independent living options for individuals with spina bifida in the region.

A new feature page in this and future newsletters will be, *College & Career Corner* that will highlight colleges that offer specialized education and workforce development programs for students with special needs. Students will share their college experiences. (See Page 7)

We are grateful to have the continued commitment and knowledge of our CPSB founders and the energy and enthusiasm of our new Board members to help us undertake an ambitious year of programs and services to benefit our members.

Honorary Board Members Dr. Benjamin S. Carson Del. James W. Hubbard
Officers Janice Heuman, <i>President</i> Jill Hill, <i>Vice-President</i> Jeffrey S. Glaser, <i>Treasurer</i> Mickey Griffin, <i>Secretary</i>
Staff Toni Shumate <i>Executive Director</i>

In May, we welcomed Dr. Mark Wagner to the Board and elected Janice Heuman to serve as President. (See Page 2)

We invite you to attend the *CPSB Annual/General Membership Meeting* on Saturday, September 12, 2009 to learn more about our current and future programs and how you can become involved with CPSB. (See Page 2)

Have a great summer!

Letter from the President...

Dear Members,

I write this letter with a dual sense of hope and concern. Concern about how the world is changing around us and how those changes will affect our organization. The state of our economy has put stress in everyone's life but I live with the hope that we will choose to shape our future and not just sit tight and trust that others will make things all right.

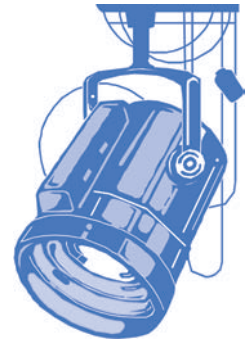
The CPSB Board of Directors has been working hard to assure that our programs and services will continue. Check out *Programs and Services* on Page 3 to catch up on our new and continuing activities and services. Our newsletter continues to improve as we have now added a feature page, *College and Career Corner* on Page 7. I hope you will take advantage of this opportunity to share your experiences with us.

Remember, we are a volunteer membership organization and one person can make a difference! Please don't just "sit tight". I encourage all of you to attend our upcoming *Annual/General Membership Meeting* on September 12th to learn how you can be a part of shaping the future of CPSB. I hope to see you there. See Page 2.

Sincerely,



Spotlight on New Board Member



We are pleased to welcome **Dr. Mark Wagner** to the CPSB Board of Directors. Mark is the parent of an adult son with spina bifida and retired health care professional. He is Professor Emeritus of the Pediatric Dentistry Department at the University of Maryland.

As former Global Director of Health and Research Initiatives, and Vice President, Health Programs of Special Olympics, Dr. Wagner will share his knowledge and experience in developing CPSB programs and services to benefit individuals with spina bifida and their families.

He will serve as Chair of our *Independent Living Options Needs Assessment Task Force* that will conduct an assessment of individuals with spina bifida in the region to determine need for independent living options, identify available resources and promising independent living models.

He will also serve on the CPSB Development, Governance, Legislative, Program Services, and Special Needs Fund Review Committees.

CPSB Annual/General Membership Meeting
Saturday, September 12, 2009
9:00-11:00 a.m.
Kennedy Krieger Institute
3825 Greenspring Avenue
Bowles Bldg., 4th Floor Board Room
Baltimore, MD

Come and meet the CPSB Board of Directors and learn about current and future programs and services for individuals with spina bifida in the region. Please RSVP to CPSB at 888-733-0988 for e-mail: shumate@kennedykrieger.org by *September 7, 2009* if you plan to attend the meeting

PROGRAMS AND SERVICES

Through the programs and services developed by Chesapeake-Potomac Spina Bifida, we are serving our mission, “To support the needs of individuals with spina bifida and related conditions and their families”.

Support Network and Information Exchange- In order to increase the ability of families of individuals with spina bifida to better manage their child’s care, a support network and information exchange between parents and the association has been established. Individuals with spina bifida and their families can receive information and referral services from CPSB, Inc. by calling 888.733.0988.

www.chesapeakepinabifida.org is the official website of CPSB, Inc. The site features an on-line community where our members and visitors to the site can communicate via e-mail. There are medical and legislative updates, local chapter news and a calendar of events. E-newsletter and resource directories are available on the website.

Directory of Services for Individuals with Spina Bifida and Related Conditions, 2009 edition will be available in print and online in August 2009. The 90 page directory includes national, state and county listings of education services, individual and family support services, employment services, government agencies, recreation services, residential facilities, and transportation services for individuals with disabilities. There will be Maryland, metro Washington and Spanish versions of the directory.

The Spinal Column is our newsletter that includes information about services, resources, medical and legislative updates, and our local chapters’ activities.

Special Needs Fund- Through grants, CPSB, Inc. has established a Special Needs Fund to provide financial assistance to individuals with spina bifida. Covered services are outlined on the Special Need Fund Application which is available on our website or by calling 888.733.0988.

New Parent Visitation Program – CPSB, Inc. provides informational packets to new parents of children born with spina bifida. Parent volunteers from local chapters are available to meet with new parents.

Volunteer Program at Regional Spina Bifida Centers – Volunteers are available at the centers to connect patients to CPSB, Inc. and community resources.

Education Conference – CPSB, Inc. will plan a 2010 conference if grant funding is available.

Chesapeake-Potomac Spina Bifida, Inc. (CPSB, Inc.) is a volunteer membership organization. Through the dedication and commitment of a few parents, adults with spina bifida, and providers, CPSB, Inc. has evolved to the organization we are today. Can you help and become a CPSB, Inc. volunteer?

We need...

- . Individuals with fund raising experience to serve on our Development Committee to coordinate special events, corporate/foundation solicitations, annual giving campaigns;
- . Individuals with marketing/PR experience to serve on our Public Education Committee to promote special events, develop our publications, public education campaigns, education conferences;
- . Individuals to participate in our Parents Helping Parents Program. Volunteers for this program are available on clinic days at the regional spina bifida centers to promote our programs and services;
- . Individuals interested in forming peer and parent support groups;
- . Individuals with clerical and computer skills to help maintain databases, handle correspondence and mailings and aid with our website maintenance.

One person can make a difference! To volunteer, contact CPSB, Inc. at 888-733-0988 or shumate@kennedykrieger.org

Legislative Alert • Legislative Alert

Legislative Alert • Legislative Alert

Legislative Alert • Legislative Alert



FEDERAL

HHS Appoints New Director of Office on Disability

The Department of Health and Human Services appointed Henry Claypool as Director of the Office on Disability. Mr. Claypool has 25 years of experience developing and implementing disability policy at the federal, state, and local levels and he has personal experience with the nation's health care system from the perspective of an individual with a spinal cord injury. As Director of the Office on Disability, Mr. Claypool will serve as the primary advisor to the HHS Secretary on disability policy and will oversee the implementation of all HHS programs and initiatives pertaining to Americans with disabilities.

Source: HHS Press Office

MARYLAND

The General Assembly approved Governor O'Malley's proposed FY2010 budget for the Developmental Disabilities Administration without cuts. The budget includes funding to provide employment or other day supports to all transitioning youth with developmental disabilities in the coming year and funding to move people with developmental disabilities out of state mental health facilities into the community.

While there is additional funding for emergencies, the amount is about half of what is projected to be needed. Likewise, while the Community Services Reimbursement Rate Commission recommended a 3.58% inflationary rate increase for providers to address staff and operating costs, the FY 2010 budget includes only a .9% increase.

The FY2010 budget includes funding from a Special Fund, the Waiting List Equity Fund, to support 40 people in the community. However, this does not begin to address the DDA Waiting List because there are over 19,000 people waiting for community supports and services. Almost all (94%) of them need help now and half have been determined to be in critical need of at least one service. A multi-year funding commitment in the State budget, supplemented by a dedicated funding source for developmental disabilities services, is needed to address this critical, and growing, statewide problem. To join the End the Wait Now! Campaign, go to:

www.endthewaitnow.com

Source: Maryland Developmental Disabilities Council, 2009 Legislative Overview

Maryland Center for Developmental Disabilities Appoints New Director

Christopher L. Smith, Ph.D., has been named the new Director of the Maryland Center for Developmental Disabilities at Kennedy Krieger Institute, which is the State of Maryland's official University Center for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD). Prior to his appointment, Dr. Smith served as the Founder and Director of the Center on Quality in Human Services at the University of Kansas Center on Developmental Disabilities. He has over 25 years experience in the field of developmental disabilities working with both children and adults with various disabilities.

The mission of the Maryland Center for Developmental Disabilities at Kennedy Krieger Institute is to maximize the potential and create change to increase the capacity of the community to incorporate state-of-the-art advances so that persons of any age with, or at risk for, developmental disabilities can live independent, productive lives and be integrated and included in all facets of community life.

Source: Kennedy Krieger Institute's website

About Our Local Chapters

SBA of Maryland

2416 Lampost Lane, Baltimore, MD 21234

Contact: Sue Whelan (410) 665-1543

Website: <http://home.comcast.net/~sbamaryland/>

Officers

Sue Whelan, President (410) 665-1543

Anne Carbaugh, Vice President (410) 363-8082

Dan Palich, Treasurer (410) 833-3197

Janice Stanton, Recording Secretary (410) 484-9053

Amber Luckert, Corresponding Secretary (410) 931-2771

Committees

Brace/Camp Fund – Dan Palich (410) 833-3197

Hospitality – Ray & Phyllis Wade (410) 644-5717

Flyer/Website Committee – Michael

& Sue Whelan (410) 665-1543

Membership – Sue Whelan (410) 665-1543

Scholarship Fund – Joan Holtz Britt (410) 418-5977

History of Chapter

The chapter is a non-profit organization formed in December 1975 by a group of parents of children with spina bifida. The parents wanted to help families of children with spina bifida by providing friendship and compassion and by sharing information about spina bifida. The organization also helps by providing financial assistance, educational and group activities. The Spina Bifida Association of Maryland is run by volunteers from families affected by spina bifida. We have no paid staff.

Geographic Area Served

Baltimore City, Anne Arundel, Baltimore, Carroll, Frederick, Harford, and Howard Counties

Member Services

Financial assistance for medical expenses, specialized camps, and wheelchair sports, bi-monthly educational meetings and social activities

Membership Requirements

\$20 annual membership fee

Upcoming Activities

Annual Picnic

Saturday, August 1, 2009

Holbrook Farm

4800 Cliff Sullivan Road

Reisterstown, MD 21136

1:00-7:00 p.m.

The picnic begins at 1:00 p.m. rain or shine. Swimming is from 1:00-6:00 p.m. Just bring your appetite and swim suit! We will provide all the food. There is also a fishing pond, so if you have a life jacket and fishing pole, bring them. There must be adult supervision at the pond. Please RSVP to Sue Whelan by July 15, 2009 at 410-665-1543 or e-mail: suespalace@comcast.net

General Membership Meeting

Sunday, September 13, 2009

Trinity Assembly of God

2122 West Joppa Road

2:00-5:00 p.m.

Activities for kids

Directions: Take 695 to Falls Road (Exit 23B). At the first traffic light, make a right onto Joppa Road. Cross over the bridge and the church is located on the left. Go to the Fellowship Hall.

Happy Birthday

Ryan Free 6/20/84

Shyla Sauter 6/27/89

Giulia Motta 6/28/75

Nathanael Behles 6/30/99



SPINA BIFIDA ASSOCIATION

of the NATIONAL CAPITAL AREA

P.O. Box 523415
Springfield, VA 22152-5415
Contact: Jill Hill, President
(703) 455-4900
Web site: <http://www.sbanca.com>

Board of Directors

Jill Hill, *President*(703)455-5223
Amy Thomason, *Vice President* (703)383-0011
Cola Atkinson, *Treasurer* (703)569-7800
Georganne Friedrich, *Sec.*(301)251-5953
Daniel Pisconte, *Web Master* .(301)505-2980
Kirsten Madaus.....(202)306-4841
Lauren O'Connor(240)453-9603
Lucy Swan.....(301)260-0971

History of Chapter

The chapter formed as a non-profit organization to serve individuals with spina bifida and their families living in the District of Columbia. Over the years, the chapter has expanded their services to members in the metropolitan area including Maryland and Virginia.

Geographic Area Served

District of Columbia metropolitan area

Member Services

Monthly support groups, member directory, annual holiday party, pool party, spring and fall picnics, new parent outreach, individual support and assistance, SBA and CPSBA newsletters.

Loan Closet – contains items such as wheelchairs, standers, walkers, car seats and exercise mats. To borrow equipment or make a donation, please call (703)455-4900.

Support Groups – are open to any members who wish to attend. Occasionally have guest speakers, but generally these are informal meetings for support, discussion and socializing. Dates and locations may vary from month to month, so please call the contact person listed below for more information and to RSVP.

Support Group Meetings

Virginia – Day Group

Meets third Wednesday of the month from 9:00 – 11:30 a.m. at the Bob Evans Restaurant across from Potomac Mills Mall, Woodbridge Virginia, exit 156 from I-95.
Contact: Jill Hill (703) 455-5223.

Virginia – Evening Group

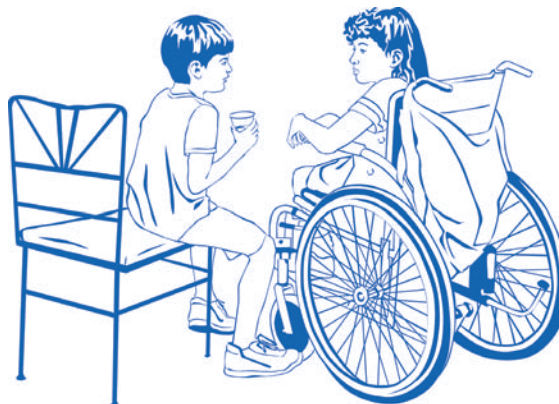
Meets third Thursday of the month from 7:00 – 9:00 p.m. at the Bob Evans Restaurant at Old Keene Mill Road and I-95, Springfield, Virginia.
Contact: Jill Hill (703) 455-5223.

Maryland/DC Group

Meets third Sunday of each month at various locations. For information, contact Georganne Friedrich at (301)251-5953.

Membership Requirements

\$45 annual membership fee includes dual membership in the Spina Bifida Association of America and the Chesapeake-Potomac Spina Bifida Inc.



COLLEGE AND CAREER CORNER

Our new feature page, *College and Career Corner*, will highlight colleges that offer specialized programs to help students with special health needs to succeed in college and enter the workforce. Our members who are college students or graduates will share their experiences.



Anne Arundel Community College

101 College Parkway Arnold, MD 21012 • 410-777-2222 • www.aacc.edu

AACC is a fully accredited, public, two-year college, where students can earn an associate degree. The college offers non-credit and continuing education courses too. Courses are offered on three campuses and through a distant learning program.

The Department of Counseling, Advising and Retention Services (CARS) houses the Career and Transfer Resource Center and the Office of Disability Support Services.

- **Career and Transfer Resource Center** – Provides individual career counseling, transfer advice, job search assistance, workshops. Students can use *DISCOVER*, a computerized career guidance system that helps them assess interests, identify strengths and weaknesses and career choices. Additionally, students can access the *AACC Job Connection*, an online job and resume database of over 2,000 employers. The college has a *Retail Skills Program* at Arundel Mills Mall and is working with Fort Meade's *Army Education Center* to prepare workers to staff new offices on the base. For more information, go to: www.aacc.edu/careers or 410-777-1239.
- **Office of Disability Support Services**- Provides equal access to educational programs for students with disabilities. A student with a disability must self-identify in order to receive the services offered by DSS, which include assistance with admissions, registration, orientation, class selection, transfer assistance, placement testing. Services include: in-class note-takers, sign-language interpreters, test modifications services. A variety of assistive technologies and software programs for students with disabilities are offered. For more information, go to: www.aacc.edu/advising/dsswelcome or 410-777-2306.

As an individual with spina bifida, I was fortunate to grow up with supportive parents who always encouraged me to set high goals for myself. Although I sometimes doubted whether I could handle the challenges of attending college, I decided to give it a shot. After earning my associate degree in general studies at Anne Arundel Community College, I attended Bowie State University where I studied communications with a concentration in journalism and graduated in 2004. I currently contribute to the Bowe Blade News as a sports writer. I am living proof that people with spina bifida can not only make it through college, but also can become productive members of society, and I would encourage every child with spina bifida to strongly consider taking advantage of the many benefits of having a college education. --- Tim Sparks

Montgomery College

51 Mannakee Street Rockville, MD 20850 • 240-567-5000 • www.montgomerycollege.edu

Montgomery College is a two-year college offering courses on three campuses. Through the *Developmental Education & Workforce Access Program*, two specialized programs are offered for adults with developmental disabilities: the *Graduate Transition Program (GTP)* and the *Challenge Program*.

- **Graduate Transition Program**- This is a custom-tailored learning community program for students with special needs exiting high school. GPT is a two-year, tuition-based, credit-free certificate program that is a partnership between Montgomery College, Target Community and Educational Services and Potomac Community Resources. For more information, call 240-567-1660.
- **Challenge Program** – Courses are offered during the summer for adults with developmental disabilities; art, music, drama, reading, math, computers, independent living skills. For information, call 240-567-5188.



I have participated in the Challenge Program courses during 4 summers. I have taken courses on art, chess, speech, basic keyboarding, poetry, money management. My favorite course has been drama. At the end of the course, we perform for our parents and teachers. This fall, I will be taking classes through the Graduate Transition Program at Montgomery College. --- Mark Friedrich

Resources

Spinal Network Resource Book for Wheelchair Users

Essential resource for making important life choices after spinal cord injury; topics on health, technology, attendant services, employment, travel, sports, relationships

Cost: \$41.90

To order, go to www.unitedspinal.org

Dating4Disabled

www.Dating4Disabled.com

Free disabled dating service and online community for people with disabilities. Meet new friends, date, chat, blog and more. Search thousands of personals, find support and resources.

Baltimore Singles Events – For local events, parties, cruises, go to, www.SinglesEventsBaltimore.com

Financial Assistance for Individuals with Spina Bifida in Maryland

Parents of children with spina bifida living in Maryland should explore the following sources of financial assistance.

Apply to the Developmental Disabilities Administration-

There are 20,000 individuals on waiting list for services, so apply early, regardless of how young your child is. After DDA eligibility is determined, the DDA regional office will send a letter to the individual and family/guardian stating eligibility category, services, and a priority category. Application for services can be made through a student's local school, by contacting your local regional DDA office, or by visiting the DDA website at www.ddamaryland.org For DDA regional office contact numbers, call 1-877-463-3464.

Transitioning Youth Initiative is a special category of eligibility and priority for services. Funds are earmarked for eligible students leaving school. For information go to:

www.dhnh.state.md.us/dda_md/transitioning.htm

Apply for SSI at age 18 – One month before the individual with spina bifida turns 18, they can apply for SSI by calling 1-800-772-1213, but they must be 18 on the application meeting date. For more information, go to: www.ssa.gov/ssi

Apply for Social Security Disability Benefits – When a person age 18 or older applies for SSI, the Social Security Administration also determines whether they may be eligible for Social Security Disability benefits that provide Medicare coverage after a two-year waiting period.

Apply for Rolling Access Funds – Helps individuals receive up to \$3,000 for services and supports without going through the DDA eligibility process. Funds are distributed through local agencies.

Go to, www.ddamaryland.org/rollingaccess.htm

Explore Options for Medical Assistance- Individuals determined eligible for SSI are automatically entitled to receive Medical Assistance, a comprehensive health care plan.

Other medically needy families or children who meet income eligibility requirements can apply for Medical Assistance too, call 1-800-492-5231.

Employed Individuals with Disabilities (EID) Program- provides Medical Assistance for individuals who receive too much in Social Security Disability benefits to receive SSI and some who receive no benefits from Social Security. EID is a way to get Medical Assistance by paying a monthly premium on a sliding scale that ranges from \$0-\$55.

Call 1-800-637-4113 or go to:

www.mdod.maryland.gov

Maryland Children's Health Program – can provide Medical Assistance for children who are age 18 or younger and not receiving SSI. Eligibility depends on family size and income. To apply, visit your local health department or department of social services or call, 1-800-456-8900.

Announcements

High School Inclusion & Post-School Transition Planning

BWTech Center, University of Maryland Baltimore Co.
1450 S. Rolling Road, Baltimore, MD 21228

August 4-5, 2009

Two-day Summer Institute presented by the Maryland Coalition for Inclusive Education for transition coordinators, high school special educators, high school students with disabilities and family members. Cost: \$200

To register, go to: www.mcie.org or call: 410-859-5400

2009 Kids Sports Spectacular

Wachovia Center, Philadelphia, PA

Saturday, August 22, 2009

Kids age 3-21 who are wheelchair users and their family members can join in and take part in events such as wheelchair tennis, basketball, power soccer, hand-cycling, hockey and bowling; speakers and lunch. The event is *free!*

To register, go to www.unitedspinal.org

*** FOR SALE***

Wheelchair Accessible Van

2006 Dodge Grand Caravan SE Butane Blue with Braun Enterna II lowered floor. Van has automatic side ramp, hand controls, and easy lock compatible with select brands of power wheelchairs. Cost: \$30,000.

For more information, contact Kris Boyles at krboyles@hughes.net or 301-751-3682.



SKIN CARE

Skin health is critical to living well. Prevention is the key. Check your skin every day.

People with spina bifida usually have a loss of sensation of the skin below the level of their lesion. This condition, called *insensate skin*, means that you may not feel pain, touch, or respond to heat or cold on the area of skin below the level of your lesion. If you take medications for the kidneys and to help keep you dry, you need to be aware that these drugs can cause decreased sweating. As a result, you may become overheated quickly which makes your skin dry.

Signs of *insensate skin* are:

- Lack of feeling
- Poor circulation
- Inability to sweat
- Bruising and slowness in healing

It takes extra time and thought to care for skin you cannot feel. It is very important to make sure taking care of your skin is part of your daily routine.

Overall Skin Care

- Check skin for cuts, bruises, scratches, swelling, and red marks—especially inspect the buttocks and all sides of the feet and between toes.
- Use a large handheld mirror to look at any place on your body that you cannot see.
- Shower or bathe daily.
- Dry skin well
- Check temperature of water before getting into your shower or bath.
- Use only soap and water. Don't use body creams or gels because they may irritate your skin.
- Be careful with any item that has been heated.
- Apply sunscreen lotion with SPF 15 or higher to all exposed skin before spending time in the sun. Wear a hat or avoid being out in the sun for a long time.
- Don't smoke.
- Eat healthy foods.
- Drink 6-8 glasses of water a day.
- Wear cotton socks and shoes at all times.
- Care for nails and toes; cut toenails carefully or see a podiatrist.

Pressure Sores/Skin Breakdown

It is very important to check your skin everyday to look for: red marks, cuts or scratches, blisters, burns, bruises. All of these can become open sores within as little as 3 hours unless pressure is removed. If your braces, shoes, or wheelchair does not fit well or if you don't transfer the right way, you can cause skin marks.

If your skin becomes reddened:

- Take off braces or tight clothes.
- Stay off affected area until skin color returns to normal.

If the skin does not return to normal within 20-30 minutes, this is a sign of damage and you need to seek care from a health care professional.

If you find an area of skin breakdown, be sure that you:

- Take complete weight or pressure off of affected area.
- Do not wear braces if sore is on legs and feet.
- Elevate legs if that is the area affected.
- Seek care from a health care professional. Special dressings or treatments will be necessary to help heal sores.

Source: *Health Guide for Adults Living with Spina Bifida*

**CHESAPEAKE-POTOMAC
SPINA BIFIDA, INC.**

P.O. BOX 1750
ANNAPOLIS, MD 21404



Return Service Requested

An Invitation to Join Chesapeake-Potomac Spina Bifida, Inc.

CPSB represents individuals with spina bifida and related conditions living in Maryland, Virginia, and the District of Columbia. Through educational programs and materials, information/referral services and direct services, the Association seeks to promote the prevention of spina bifida and related conditions and support the needs of individuals with spina bifida and their families.

As a member of CPSB, your financial contribution will enable us to continue our efforts. Members receive quarterly newsletters, legislative alerts, information and referral services, notice of public education programs, publications, reduced registration fees for CPSB sponsored conferences, assistance with medical expenses and support services.

Yes, I would like to join CPSB. Enclosed is my \$25 annual membership fee. Please make check payable to:
CPSB, P.O. Box 1750, Annapolis, MD 21404.

I would like to join, but am unable to make a donation due to financial hardship.

I am a _____ parent of a child with spina bifida _____ an adult with spina bifida _____ a relative _____ other: _____.

Name: _____

Address: _____

Phone: () _____ Email: _____