

The Spina Bifida
Association of
Western New York

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SBAWNY

Spring 2006

President's Message

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Message Fund Raiser

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President's Message



Greetings to all:

The year is already 1/12 gone. Hope all is going well for all of you. Our winter has been milder than expected. That's great for those of us who "tolerate" the winter snow but a disappointment for the skiers among us.

As a new year begins I want to remind all of you to get your SBAWNY membership application filled out and sent in. Our membership is drastically down from years past and your dues allow us to continue to provide you with valuable services. Some of these services include this newsletter, reimbursements from the brace and equipment fund, enrichment fund, and for educational conferences, and information through our library and web site. There is an application included in this newsletter or you can visit our web site www.sbawny.org and download the application. The cost is a deal at only \$15.00 for local and \$35.00 for national. National membership includes a subscription to the national newsletter *Insights*. This publication has articles from leading doctors and educators in the field of Spina Bifida. I hope everyone will make sending in your membership application a priority this month.

I also want to invite anyone who is interested in SBAWNY to consider serving on our board of directors. We are looking for new input and new ideas. We meet the third Monday of every month at 7:00 pm at Northwood's Medical Complex in North Tonawanda. At our next meeting we will be having a doctor from University at Buffalo who has received money from a grant and is looking for ideas to help with ambulation in children with SB. If you have any thoughts regarding this please come.

Any questions please contact me at cynthia@madbbs.com or call me at 912-6837.

Have a healthy and active new year.

Cynthia Carlson, SBAWNY President

Massage Fundraiser

The Western New York Institute of Massage will be holding a fundraiser for us on Sunday, March 12th from 11am to 6pm at the Walden Galleria Mall. They will be offering chair massages in 5 minutes intervals. Come on out and support this cause and tell your friends as well.

If you would like to volunteer for an hour or two please contact Pam Morris at 694-8567 evenings.

Address Change

Just another reminder that our address has changed. We have had several phone calls about mail sent to SBAWNY being returned. Our current mailing address is:

SBAWNY
137 Warner Avenue
North Tonawanda, NY 14120

DO NOT use the mailing address that is in the phone book. That address is attached to the location where our phone number (answering machine) is located. We **DO NOT** have anyone working there on a full time basis so if mail gets sent there it will be returned to the sender.



Andrea Sapone
President

Main: (716) 886-3077
Fax: (716) 886-3082
Cell: (716) 553-1236

15 Lafayette Avenue • Buffalo, NY 14213
asapone@bflomedical.com

Loretta Carr-Stock, RN
President



Durable Medical Equip.
Custom Wheelchairs

Dove Medical Supplies
Our Service Makes The Difference

6961 Transit Rd
East Amherst, NY 14051

Ph: (716) 688-8911
Fax: (716) 688-9193

SBA of WNY Library List of Books

The following books are available for checking out. Please contact Alyce Carpenter and she will get the book to you.

Accessible Gardening for People with Physical Disabilities—A Guide to Methods, Tools, & Plants by Janeen R. Adil

The book provides expert and practical knowledge needed for designing, planting, and maintaining a garden that fits your special needs.

Becoming More Than One (Insights to Intimacy and Beyond) by Georgia R. Delano

This book, written by a woman born with spina bifida, is about her experiencing motherhood from pregnancy through mastering early childhood management.

Brothers and Sisters—A Special Part of Exceptional Families by Thomas H. Powell & Peggy Ahrenhold Ogle

In this book the authors describe their work with brothers and sisters who have a handicapped sibling. Their work has included research, and the providing of services to siblings and their families. The book should provide insight into the experiences and needs of children and adults who have a handicapped sibling. ex-

Children with Physical Disabilities by Paula Halliday

This book provides an examination of the education and management of physically disabled young children. "Two sections discuss general and special issues of disability and placement in the school as well as effects in curriculum and extra-curricular provisions.

Children with Spina Bifida: A Parent's Guide edited by Marlene Lutkenhoff, R.N., M.S.N.

"In one comprehensive volume, Children with Spina Bifida provides parents with up-to-date information and empowering emotional support."

A Guide for Helping the Child with Spina Bifida by Gary J. Meyers, M.D., Sharon Bidwell Cerone, R.N., M.S.N., & Ardis L. Olson, M.D.

This book, written for parents, health care providers and educators, is an account of the problems encountered by parents and their children with Spina Bifida, and is most suitable for persons with some knowledge of Spina Bifida who may be interested in learning about Spina Bifida in general, or a specific topic in particular. in-

A House for all Children—Planning a Supportive Home Environment for Children with Disabilities by Richard V. Olsen, PhD, B. Lynn Hutchings, M.Arch., Ezra Ehrenkrantz, F.A.I.A.

"Provides guidelines for creating a safe and supportive home environment for children with disabilities".

Living with Spina Bifida: A Guide for Families and Professionals by Adrian Sandler, MD.

No description available for this book.

Meeting the ADD Challenge—A Practical Guide for Teachers by Steven B. Gordon and Michael J. Asher

A guide for teachers in dealing with Attention Deficit Disorder.

Motherhood Magnified by Jill Rose Ford

This book "offers inspiring parenting stories from a fresh affirming perspective that captures the unique challenges of raising a child with special needs".

Raising a Child Who has a Physical Disability by Donna G. Albrecht

"Parenting a child who has a physical disability can be complicated. This book will make your job easier. Compassionate, helpful and based on real-life experience, it will help you handle every facet of raising and loving your special child..."

The Source for Nonverbal Learning Disorders by Sue Thompson

This book is "an important and valuable work that demystifies the nature and needs of the child with nonverbal learning disabilities".

Increasing Fiber in Your Family's Diet

By Linda Burdett

As members and friends of SBAWNY, most of us recognize that dietary fiber is an essential part of a healthy diet for people with spina bifida. However, while fiber is probably best known for its aide in preventing or relieving constipation, fiber may also provide other important health benefits such as reducing the risk of heart disease. Therefore, dietary fiber is good for the whole family! This article provides a brief introduction to fiber, its benefits, and suggested ways to include more fiber in your diet and additional resources.

What is dietary fiber?

Dietary fiber includes parts of plant foods that your body can't digest or absorb. There are two types of fiber:

Insoluble fiber increases the movement of material through your digestive system, helping to prevent and treat constipation. Good sources of insoluble fiber are whole grain breads, cereals, and pastas, fruits with edible peel or seeds and vegetables.

Soluble fiber dissolves in water to form a gel-like material. It may help lower blood cholesterol when eaten as part of a low fat diet. Some source of oat bran, oatmeal, apples, oranges, grapefruit, cabbage, and legumes.

Tips for fitting in more fiber

- ▶ Start your day with a high fiber breakfast cereal. Or add a few tablespoons of unprocessed bran to your favorite hot cereal.
- ▶ Add crushed bran cereal or unprocessed wheat bran to baked products such as meatloaf, muffins, casseroles, cookies and cakes (apple crisp enriched with extra bran is delicious!).
- ▶ Switch to whole grain breads. Look for a brand with at least 2 grams of dietary fiber per serving.
- ▶ Eat more beans, peas and lentils. (Adding garbanzo beans or black beans to tossed salad is an excellent away to increase fiber)
- ▶ Make healthy snack choices. Fruit, raw veggies, low-fat popcorn and whole grain crackers can help to increase daily fiber.

▶ Make gradual changes in your diet

Adding too much fiber, too quickly can cause intestinal gas, abdominal bloating and cramping. Increase your intake of dietary fiber gradually over a period of a few weeks.

Remember to drink water

Be sure to drink at least six to eight glasses of water each day. Fiber works best when it absorbs water. Also, water may decrease any side effects from the increased fiber in your diet.

Here's an interesting recipe we took from www.nutrifitonline.com (Let us know how you like it, and please email us your favorite high fiber recipes and cooking tips. We'll include them in future newsletters. Thanks!)

Garbanzo Pita Pockets Yields: 4 (1 pita) servings. Working Time: 10 minutes. Total Time: 15 minutes.

- 1 (15 oz.) can reduced sodium garbanzo beans, drained and rinsed
- 1 (6 oz.) jar marinated artichoke hearts, quartered, liquid reserved
- 1 tbsp. black olives, sliced
- 1 clove garlic, minced
- 1 small green bell pepper, diced
- 1 tbsp. green olives, sliced
- 2 cups lettuce, shredded
- 1 tsp. [Nutrific Cuisine Garden Herb Salt Free Spice Blend](#)
- 1 small red bell pepper, diced
- 1 small red onion, thinly sliced
- 2 tbsp. red wine vinegar
- 4 large slices pita bread

Calories: 367, Protein: 15g, Carbohydrate: 67g, Dietary Fiber: 15g, Total Fat: 8g, Saturated Fat: 0g, Cholesterol: 0mg, Sodium: 582mg.

Note - For each teaspoon of the Garden Herb Spice Blend, you may substitute: 1/4 tsp. basil, 1/4 tsp. marjoram, 1/4 tsp. dill weed, and 1/4 tsp. black pepper.

- ▶ In a large bowl, combine the garbanzo beans, peppers, onion, garlic, olives, artichokes, and their liquid, vinegar, and seasoning. Mix well; set aside.
- ▶ Slice off the top third of each pita bread; open the bread to form a pocket. Place an equal amount of lettuce in each pita and fill with the garbanzo filling.

For additional info, check out: <http://www.mayoclinic.com/health/fiber/NU00033> or <http://edit.ifas.ufl.edu/HE697>



THE SPINA BIFIDA PROJECT

COGNITIVE AND NEUROBIOLOGICAL VARIABILITY

The Spina Bifida Project

Now into its 7th year, the Spina Bifida Project is a collaborative effort between The Hospital for Sick Children in Toronto, The University of Texas-Houston Health Sciences Center, Baylor College of Medicine, Hermann Hospital, Texas Children's Hospital, and Shriners Children's Hospital.

The Project has two aims:

~to identify key outcomes (skills and abilities, academic and vocational achievement, behavioral and social adjustment) in children, adolescents, and young adults with spina bifida and hydrocephalus

~to relate differences in outcome to genetic patterns, medical history, brain development, and social and educational environments

To address these aims, we plan:

~to evaluate skills and abilities, academic and vocational achievement, and behavioral and social adjustment

~to conduct magnetic resonance imaging (MRI) of the brain

~to analyze genetic material

To date, more than 500 families have participated. We hope to enroll 500 families for the next 5 years of the Project.

Core Assessment

The purpose of the core assessment is to collect information about basic abilities, learning skills, social adjustment, and medical history. Some of this information is obtained from direct testing with children, adolescents, and adults with spina bifida and hydrocephalus, while other information is obtained from the parent or caregiver.

One MRI scan series of the brain will be conducted at Sick Kids. MRI scanning is a non-invasive method for obtaining clear pictures of the brain. We will not require any individual to undergo sedation in order to obtain an MRI scan.

Genetics Study

All participants will be asked to participate in the Genetics Study, which aims to discover some of the genetic factors that are involved in spina bifida. Participation typically involves the donation of a blood sample from the individual with spina bifida, as well as samples from parents and siblings, where available. Spitting into a cup to provide saliva is an alternative to donating a blood sample. Genetic material will be studied from the blood or saliva. Identifying genetic factors in spina bifida may help develop prevention and treatment strategies.

Early Learning Study

The Early Learning Study aims to understand the development of skills and abilities of children with spina bifida and hydrocephalus who were earlier studied as infants and toddlers. We now plan to study these children's skills and early learning abilities at 7, 8, and 9 years of age.

Neurocognitive Study

The Neurocognitive Study aims to understand attention, memory, visual perception, information processing, and language comprehension skills in children, adolescents, and adults with spina bifida and hydrocephalus.

Health Records

Health records and school records for children and adolescents will be reviewed to obtain information about medical history and school progress.

Compensation

Financial compensation will be offered for each visit to cover routine expenses such as transportation and parking.

Who is eligible?

- ~children and adolescents with spina bifida and hydrocephalus in the age range 7-17 years
- ~typically developing children and adolescents in the age range 7-17 years
- ~adults with spina bifida and hydrocephalus in the age range 18-50+ years
- ~typically developing adults in the age range 18-50+ years

Benefits

- ~Evaluation of neuropsychological abilities and learning skills
- ~Results will be discussed with the caregiver and made available to other professionals or school upon request
- ~Written report summarizing the results of the assessment
- ~Book on education strategies in children with spina bifida

Risks

- ~Fatigue or nervousness during testing or completion of forms. If this occurs, the child and/or caregiver will not be pressured to respond but may take a break before continuing, and may discontinue at any time.
- ~The MRI procedure is non-invasive and does not involve x-rays.
- ~Blood drawn for genetic studies may leave a small bruise or discoloration

Persons to Contact for Further Information

Susan Inwood, RN, MN,

Research Nurse Coordinator (416) 813-7440

susan.inwood@sickkids.ca

Maureen Dennis, PhD,

Principal Investigator (416) 813-6988

Their website is: <http://ped1.med.uth.tmc.edu/spinabifida>

Denise Davis In Concert

Christian Recording Artist

Saturday, March 25th, 2006 at 7:30 pm

at the Historic Palace Theatre 2 East Ave. Lockport, NY

Donation \$10.00 Proceeds to benefit the Challenger Sports League

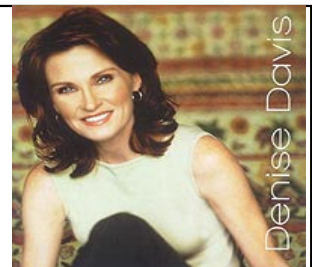
Denise Davis has led a life filled with more than enough experiences to script a movie. The singer, who has focused her musical skills on Christian music, went from singing in recording studios when she was still a teen to winning the Miss Alabama pageant and then being diagnosed with a life changing illness.

Denise says that she believes God never wastes the pain. She knows where her hope comes from and she loves to share it. "I pray that like one of my songs says, I live my faith. Most of all I pray that when I meet the Lord face to face.

Challenger Sports League is trying to purchase land in Lockport area.

If you would like to help in this fund raising event Call Mark & Brenda Zimmerman @735-9095

The Challenger Sports League is open to those with all disabilities. If you are interested or know someone who is please give Mark or Brenda a call. They are always looking for new players.



SBAWNY 2006 Membership Form

2006 Individual/Family Memberships:

First & Last Names of all Family Members (or people in household)	Ages (children)	Please note if the person(s) listed have Spina Bifida, Hydrocephalus or other Neural Tube Defect	Birth Date	Please note relationship of each person listed to the Person with Spina Bifida	Email Addresses: (This will allow us to disseminate infor- mation quicker)

Street Address: _____

City, State, Zip: _____

County: _____ **Phone Number(s):** _____

Membership dues are on a sliding scale to enable you to give as much as you can for our programs and services. We value your membership and financial support. Please circle one of the following dollar amounts and mail a check or money order for that amount to the address below.

\$15, \$20, \$25, \$30, or \$35: Local Chapter family/individual membership

\$35, \$40, \$50, \$75, or \$100: Local and National Chapter family/individual membership

2006 Professional Memberships:

Contact Name: _____ **Organization:** _____

Title of Contact: _____ **Relationship to SBAWNY:** _____

Street Address: _____

City, State, Zip: _____

County: _____ **Phone Number(s):** _____

We value your membership and your financial support. Please choose your organization's membership level .

___ **Gold (\$500)** ___ **Silver (\$250)** ___ **Bronze (\$150)** ___ **Professional (\$50)**

Please make checks payable to SBAWNY and mail with this form to:

SBAWNY, 137 Warner Ave., North Tonawanda, NY 14120

Spina Bifida Association of Western New York
137 Warner Avenue
North Tonawanda, NY 14120

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Fund Raiser at the Galleria Mall

The Western New York School of Massage will be providing Massages on Sunday, March 12th, from 11 am to 6 pm at the Walden Galleria Mall with all proceeds to benefit SBAWNY.

News from National

Our Advocacy Efforts Have Paid Off!

Congress provided the National Spina Bifida Program (NSBP) with a total allocation of \$5.049 million. That's a \$1.392 million increase over last year's allocation!

This means that that programs that we have put in place will continue to thrive and we will be able to continue with much-needed research, quality-of-life initiatives, and folic acid education and awareness efforts.

The Spina Bifida Association would like you to let your members of Congress know how thankful we are for raising the funding for the NSBP.

SEND AN E-MAIL TODAY: To your House and Senate Members thanking them for support \$5.049 million in FY 2006 funding for the CDC's National Spina Bifida Program. Visit the SBAA website at: www.sbaa.org and click on the link: send an email to your Congressional Representative.

It is important that we show our nation's leaders that those of us in the Spina Bifida Community appreciate their ongoing support and that it makes a difference for all those who live with spina bifida.