

October 2018
Volume 6, Issue 2

The SB ADVisor

A newsletter of the Spina Bifida Association of the Delaware Valley



You can find us on Facebook at Spina Bifida Association of Delaware Valley

<http://www.sbadv.org>

You can find us on the web at:
www.sbadv.org



You can contact us at:
info@sbadv.org

THE SPINA BIFIDA 5K WALK, RUN, OR ROLL

CONDUCTED BY PHILADELPHIA PARKS & RECREATION

BENEFITING THE SPINA BIFIDA ASSOCIATION OF THE DELAWARE VALLEY
WWW.SBADV.ORG

SATURDAY
OCTOBER
20TH
2018

REGISTER AT:
[HTTPS://RUNSIGNUP.COM/RACE/PA/PHILADELPHIA/SPINABIFIDA5KRUNWALKORROLL](https://runsignup.com/race/pa/philadelphia/spinabifida5krunwalkorroll)

USATF Certified Course

Professionally timed by: www.runtheday.com

Location: Lloyd Hall
1 Boathouse Row
Kelly Drive
Philadelphia, PA

T-SHIRTS . RACE PRIZES . RAFFLES

Event Details:

Registration:	7:30 AM
Race Starts:	9:00 AM

Individual Fee:	\$25
Youth Fee (16 and under)	\$15

Calling All Volunteers:

SBADV is currently in **urgent** need of additional Board members to assist SBADV in meeting its mission. Board members are involved in the planning, and decision-making, and oversight of various Association responsibilities. We meet as a group 6 times per year. Meetings are held both in person and via conference call. The addition of new members to the Board is vital.

We would also welcome volunteers to assist with specific tasks for the organization, such as help before and during specific events such as the Walk 'n Roll, 5K and the Holiday Party or assistance with the Newsletter and member correspondence. Please contact us if you are interested at info@sbadv.org.

Thank You!

A BIG “Thank You” to all of the volunteers who supported our 2018 Walk ‘n’ Roll at Central Park in Doylestown. We always appreciate your support and fellowship at this important annual event. See you in 2019!



2018 Teal on the Hill

Inaugural Event to lobby for the Spina Bifida Community in the US

On May 9th, 100 people from 29 states gathered in Washington D.C. for the Spina Bifida Association's first annual Teal on the Hill event. This unique experience was an opportunity for people with Spina Bifida and their families to visit Capitol Hill and meet with their respective Senators and Members of Congress.

Participants were able to tell their life stories and discussed some specific issues that were outlined in an advocacy training that took place the previous night. Advocates encouraged legislators to sign onto the Spina Bifida Caucus, increase funding for the CDC's National Spina Bifida Program by a million dollars, and to oppose a bill that would put wheelchair parts and catheters under competitive bidding.

Participants were divided up by state and/or region. There was a total of 78 meetings throughout the day that resulted in great conversation and a few new members of the Spina Bifida Caucus. Samantha Greenberg and Frank DiEva represented SBADV and had the opportunity to meet with the office of Congressman Brendan Boyle, who represents Northeast Philadelphia.

SBA hopes to hold this event next year and make it even more successful. For information on how to get involved with advocacy efforts, visit the Spina Bifida Association's website, or feel free to contact the SBADV to get involved.

Alert about a New Financial Planning Program for persons with Disabilities

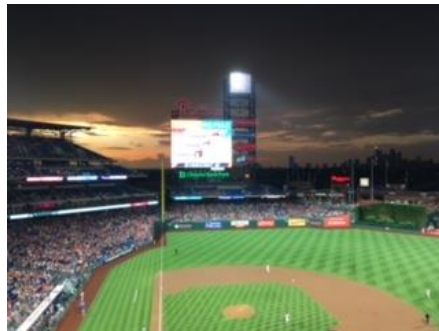
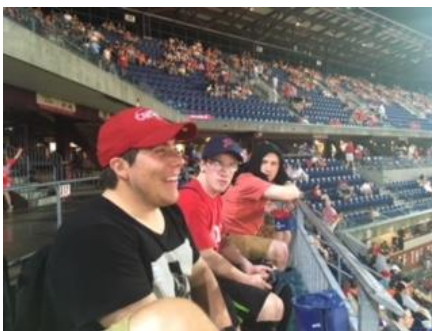
PA ABLE Savings Program for Disability-Related Expenses

A PA ABLE account gives individuals with qualified disabilities (Eligible Individuals), and their families and friends, a tax-free way to save for disability-related expenses, while maintaining government benefits. Federal and state law authorized the creation of PA ABLE accounts.

Contribution Information:

- **Contribute up to \$15,000 each year.** This federal limit may be adjusted each year based on inflation and may be exceeded by account owners who are employed. See the [FAQs](#) for additional information on the website below.
- **Families and friends can contribute to an account.** The account limit applies to total contributions and is not per contributor.
- **Account maximum of \$511,758.** Once limit is reached, no additional contributions can be made. Interest can still be earned.
- **Deduct contributions on PA income taxes.** Contributions to a PA ABLE account may be deducted from state taxable income. **Only contributions to a PA ABLE account qualify for the PA state income tax deduction.**
- **Roll over a 529 college account.** Roll over money from a 529 college savings account to a PA ABLE account, up to the ABLE annual contribution limit (\$15,000 in 2018).
 - Information can be found at www.paable.gov

2018 SBADV at the Phillies



Financial Assistance offered by SBADV

Please submit your requests to our chapter.

SBADV provides financial assistance in the following categories. Requests for reimbursement for medical expenses must include documentation that the expense is not covered by insurance or that the request submitted is for the individual's co-pay amount. There is a yearly maximum for each fund, but the total yearly amount available to each individual with Spina Bifida is capped at \$1,500.00. The Association's fiscal year is January to December.

Requests for reimbursement must be received by March 15 of the year following the date of the incurred expense.

Direct Patient Aid provides up to \$1,500.00 for medical bills related to Spina Bifida but not covered by the Incontinence or Equipment Funds.

Equipment Fund provides up to \$1,500.00 per year for the purchase of wheelchairs, crutches, braces, and other adaptive devices.

Incontinence Fund provides up to \$1,000.00 a year for uncovered incontinence supplies.

Post-Secondary Education provides up to \$1,500.00 for expenses related to attending college, trade school or other specialized training to gain employment.

Campership Fund provides financial aid for adults and children to attend camp or other group activities during the summer for socialization. Maximums are determined yearly by the Board based on the amount budgeted for the fund and the number of individuals requesting funds.

National Event Fund provides assistance of up to \$500.00 to individuals who qualify for participation in a national-level sports, academic or talent competition.

Driver's Education Fund provides one-time funding of up to \$500.00 for behind-the-wheel driver's education training.

Conference Assistance provides funding to cover conference registration and up to \$550.00 (or an amount determined by the Board of Directors) for expenses related to attendance at SBA's Regional Conferences. Reimbursement amounts for attendance at SBA-sponsored Educations Days will vary due to location and are determined by the Board.

For all financial assistance requests, please print out the application form on www.sbadv.org and mail to: SBADV, P.O. Box 1235, Havertown, PA 19083

The SB ADVISOR

A newsletter of the Spina
Bifida Association of the
Delaware Valley

Editor:

Bill Doughty

Please send your news
items and event pictures
to: info@sbadv.org



We wish to especially thank the following families
who organized Teams to participate in the 2018 Walk-N-Roll:

The Glaser Family

Sabrina's Shooting Stars - The Cantarella/Mercurio Family

Team Anthony - The Campolei Family

Emma's Army - The Reed Family

The Green Team - Dan Green

Colton's Team - The Timko Family

Team Zoie - The Larsen Family

Team Zach - The Chamberlin Family

See you in 2019!

**SPINA BIFIDA ASSOCIATION
OF THE DELAWARE VALLEY**

P.O. Box 1235
Havertown, PA 19083