

August 2019  
Volume 7, 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](http://www.sbadv.org)



You can contact us at:  
[info@sbadv.org](mailto:info@sbadv.org)

## Save the Dates:

October 2019:  
**Spina Bifida Awareness Month**

10/19/2019:  
**5K Run, Walk or Roll**

12/14/2019  
**Holiday Party**

On March 23<sup>rd</sup>, the Chapter hosted a presentation by Michael Gehring, Esquire at the Carousel House on “The Nuts and Bolts of IEP’s”. The Speaker presented a basic overview of Special Education Law. What your child’s education rights are in school, including special education services and regulations that insure your child MUST receive free, appropriate programs which are proven to be effective.

He discussed FAPE (Free Appropriate Public Education), IEP (Individualized Education Program) and LRE (Least Restrictive Environment). Every child qualifies and we as parents need to do make sure no child is left behind. There are many components that have to be considered. Each child should receive a service plan per section 504 and Pennsylvania’s Chapter 15. Services should be received no matter the school (public or private). It is the job of the parent and school to find correct local education agency.

Mr. Gehring, Esquire was scheduled through McAndrews Law Offices, P.C. A large part of the practice handles special education and disability issues. Many informative articles on related topics are provided as a service on the firm’s website.

[www.McAndrewsLaw.com](http://www.McAndrewsLaw.com)

## Did You Know????

SBADV is a registered charity with **AmazonSmile**. Once you designate SBADV as your charity of choice and you shop through their website a portion of the purchase price of your product will go to SBADV. You will see many eligible products marked “Eligible for AmazonSmile donation” on their product detail pages. Thank you for your participation.

## 2019 Walk n Roll in Central Park Doylestown 05/05/2019

We'd like to express our gratitude to all who supported our Walk 'n Roll Event to benefit SBADV on May 5, 2019 in person or on-line. A special thanks goes out to those families and organizations who organized teams for the event. Thank you for bringing your spirit, enthusiasm and support to Central Park, Doylestown despite the weather! (When there was a break in the rain we did get to do our Walk.) The teams participating in the event were:

Team Tina - The Wood Family  
Dan Green – The Green Family  
Beth Cooke – The Cooke Family  
Sabrina's Super Shooting Stars – The Mercurio Family  
Sofia Sparkles – The Alphonse Family  
Amelia's Sunshine – The Thompson Family  
Team Blaine – The Traitz Family  
Team Leilani – The Rivera Family  
Ciarlo's Angels – The Liples Family

We would also like to thank Herr's Snacks and Sierra Produce for their generous donations.



# WE NEED YOUR HELP!

## Please Read!

SBADV has an **urgent** need for new Board members. We have had several Board members step off the Board due to relocation or family needs. Terms limits will soon require another long-serving member to leave at the end of the year. Our By-laws require a minimum of eight on the Board with a maximum of 13. Past-Board members can still serve on committees and in an advisory capacity. Board members are involved in the planning, and decision-making, and oversight of various Association responsibilities. Different aspects are ideally tasked to a designated member, so that responsibilities are shared. One specific need is for a Secretary, whose duties are clearly defined. The Board meets 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 for maintaining our governance responsibilities and SBADV's existence.

We are also requesting assistance with other volunteer opportunities for the Association. These include help before and during specific events such as the Walk 'n Roll, the 5K, and the Holiday Party or help with the Newsletter and member correspondence. We have recently brought on a new Executive Director, Alicia Alphonse, who will be coordinating and facilitating all Association efforts. With input and manpower, SBADV can provide the programming that will benefit children and adults with Spina Bifida in the Delaware Valley. Many hands make light work. The future of the Association is at stake. A registration form is being attached. Please complete it so we can update our records. Volunteer opportunities are indicated at the end of the form. Alicia will contact you in response.

*The SB ADVisor*

A newsletter of the Spina  
Bifida Association of the  
Delaware Valley

**Save the Dates:**

October 2019:  
**Spina Bifida  
Awareness Month**

October 19, 2019: **5K  
Run, Walk or Roll**

December 14, 2019:  
**Holiday Party**

Editor:

Alicia Alphonse

Please send your news  
items and event pictures  
to: [info@sbadv.org](mailto:info@sbadv.org)

**SPINA BIFIDA ASSOCIATION OF  
DELAWARE VALLEY**  
P.O. Box 1235  
Havertown, PA 19083



The SBADV Board wishes to extend our sincere  
sympathy and condolences to the families of:

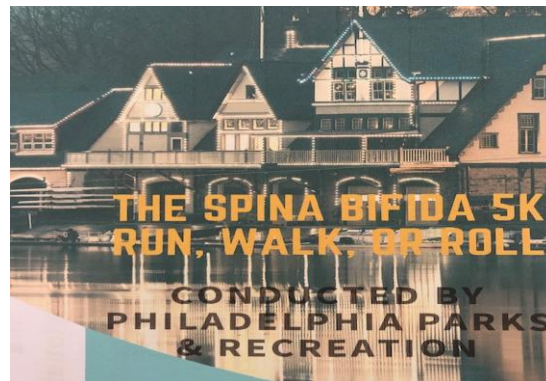
**Marie E. Kriza**

and

**Jean P. Shea, Grandmother of Dory Shea**

We are grateful to their families for designating  
SBADV for memorial donations in their names.

## It's Time For SBADV 5K!



Please join us for our Run, Walk or Roll  
sponsored by Philadelphia Parks and Recreation  
on Saturday, October 19<sup>th</sup>, 2019  
at **Boathouse Row on Kelly Drive**  
**Lloyd Hall**  
**1 Boathouse Row**  
**Kelly Drive**  
**Philadelphia, PA 19130**

# Annual Registration Form

Don't forget to send back your 2019 registration form. We have included the form *on the next page*.

Returning a completed form is the best way to update your contact information and make sure you hear about group events and news. While there is no longer a "membership" fee, please consider making a donation to help support our programs.

Mail your form back to:

SBADV

P.O. Box 1235

Havertown, PA 19083



# Spina Bifida Association of the Delaware Valley

P.O. Box 1235 Havertown, PA19083 1-800-223-0222

## 2019-20 REGISTRATION FORM

Name \_\_\_\_\_  
First Name (s) Last Name

Address \_\_\_\_\_  
Street

\_\_\_\_\_  
City State Zip Code

County: \_\_\_\_\_ Phone: \_\_\_\_\_

Email: \_\_\_\_\_ Alternate Phone: \_\_\_\_\_

### Individual and Family Registration (Individuals with Spina Bifida, their spouses, parents, and legal guardians of minors will receive the SBADV Newsletter and emails)

Please Indicate: \_\_\_\_\_ Adult with Spina Bifida \_\_\_\_\_ Parent(s) of an individual with Spina Bifida

Parents and Adults with Spina Bifida PLEASE INDICATE:

Name of individual with Spina Bifida: \_\_\_\_\_ Sex: \_\_\_ M \_\_\_ F

Date of Birth: \_\_\_\_\_ (will be kept confidential for adults)

### Associate Registration (open to anyone in the community; will receive the SBADV Newsletter)

Please indicate:

\_\_\_\_\_ Relative (s) or friend of an individual with Spina Bifida \_\_\_\_\_

(Indicate name of individual and relationship)

### Professional, Business, and Service Groups please fill in where applicable:

\_\_\_\_\_ Student in Health Field \_\_\_\_\_ Medical Professional \_\_\_\_\_ Educational Professional \_\_\_\_\_ Business

Business Name \_\_\_\_\_ Specialty \_\_\_\_\_ Title \_\_\_\_\_

**Please consider making a donation to help the Association provide assistance, newsletters, and events.**



Donation \_\_\_\_\_ (\$20.00 suggested) \_\_\_\_\_ (Other amount)

Donations can be made at [www.sbadv.org](http://www.sbadv.org) by using the “Donate Now” button.

If your company has a matching gift program, contact its human resources department to obtain information about the procedure for matching your donation.

## Would you like to volunteer?

**Consider volunteering to assist SBADV meet its mission. Help in any capacity is needed and you will be contacted. Please check the category which most interests you. Thank you.**

- \_\_\_\_\_ Board Member (participate in the governance and decision-making of SBADV)
- \_\_\_\_\_ Event Committee (suggest and shape events you would like created)
- \_\_\_\_\_ Newsletter (suggest and write articles for our newsletter)
- \_\_\_\_\_ New Parent Outreach (be a resource to answer questions for parents with a child newly diagnosed with Spina Bifida)
- \_\_\_\_\_ Database (help enter new information into our database or create a membership directory)
- \_\_\_\_\_ Finance Committee (utilize your investment knowledge to help SBADV grow)
- \_\_\_\_\_ Donor Management and Correspondence (write thank you and acknowledgement letters to donors and sponsors)
- \_\_\_\_\_ Holiday Party (serve on the committee to plan activities for our party)
- \_\_\_\_\_ Event Help at Fundraisers