

March 2020

Volume 8, Issue 1

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

Save the Dates:

May 3, 2020:
Spina Bifida Family Fun Day at CHOP

May 31, 2020:
Spina Bifida Walk n Roll

October 2020:
Spina Bifida Awareness Month

October 17, 2020:
5K Run, Walk or Roll

December 13, 2020:
Holiday Party

It's Time For Walk n Roll!



Please join us for our Walk or Roll
on Sunday, May 31st
at Everybody's Playgroud
540 Dresher Road
Horsham, PA 19044

Start Fundraising and Building Teams At:
<https://walkandroll2020.everydayhero.do>

SBADV Has A New Office!

Thanks to the generous donation of office space made by Old City Millwork, the Association now has a designated Accessible office. Our new address is:
6935 Airport Hwy Lane, Office 1, Pennsauken, NJ 08109.

This new space will enable us to receive mail directly and store our supplies and materials. We will no longer need to rent a post office box or storage space.

2019 5K Run, Walk or Roll in Philadelphia, PA 10/18/2019



We'd like to express our gratitude to all who came out to Run, Walk, or Roll to support SBADV at our annual 5k fundraiser on October 20, 2019. Special thanks also go out to those families and organizations who organized teams for the event. Thank you for bringing your spirit, enthusiasm and support to the event! The teams participating in the event were:

The Episcopal Academy

The PCOM Running Club

CarMax

A Moment of Magic

Fearless Finn - The Herman Family

Kim's Wildbunch – The Patton Family

Nate's Ninja's – The Panusky Family

Rolling with Pedro – The Miranda Family

Sofia Sparkles – The Alphonse Family

The J-WalkErs – The Doughty, Rafter and Kadyszewski Families

We'd like to thank our sponsors for supporting the SBADV annual 5k. Your sponsorship has helped the SBADV gained valuable tools and resources to support our SBADV community. A special thanks to the volunteers from the Philadelphia Parks and Recreation staff for their help and support in planning and carrying out this event.

Platinum:

Gerald Kessler- Wells Fargo Advisors
Philadelphia Parks & Recreation
D'Lauro & Rodgers
The Riff Group

Silver:

Coloplast
Gerald Regni and Associates
Lakash
Sping Garden Construction
La Finestra Restonrante

Mile Markers:

The Case Family
First Trust Bank
Samantha & Stuart Greenberg
John and Lindsey Swartz – ReMax
The Herman Family

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

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.

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Editor:
Alicia Alphonse

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

Champion of the Community

The Spina Bifida Association of Delaware Valley has awarded Jeanne Melchionni with the Champion of the Community Award. Jeanne Melchionni has been a life-long advocate for those living with Spina Bifida. She has been a dedicated and passionate champion to the CHOP community for the past 42 years. When Jeanne began her employment with the Spina Bifida clinic, Jeanne worked with Dr. Mary Ames, who, in 1964, started the first Spina Bifida Program in the country. THE FIRST! At the time, Jeanne and Mary had only about 150 patients. CHOP's Spina Bifida program has now expanded to over 550 patients of all ages and nationalities.

Currently, Jeanne is the coordinator of the clinic and is working on beginning a multidisciplinary program for adults at Penn using the CHOP Program as a model.

Jeanne was awarded The Caroline Langstadter Award for Excellence in Nursing at CHOP in 1995 and the even-closer-to-her-heart "Forget Me Not" award from the Spina Bifida Association of Delaware Valley.

She has been a part of numerous publications over the years in which she has collaborated with many colleagues in all divisions of Children's Hospital. These articles and essays have aided in advancing the care of our kids for the future.

The Herman family stated, "Jeanne has been a constant in our lives ever since my son's birth in 2016. She has always greeted my family to the clinic with a warm, welcoming smile. When I have questions about what to do with Finn, she's quick to email me back and give sage advice. But, mostly, Jeanne is THERE for us in both our triumphs and failures. She celebrates our victories and holds us up in our defeats. She is a constant, someone who has dedicated her life to helping others, and, ultimately, seeing the divine essence in every single human being."

The SBADV thanks Jeanne for all she has done for so many families. CHOP wouldn't be the same without her and her tireless support of others is something we should all look to do and look to be. We are forever grateful!



This year we held our annual Holiday Party at Galdo's in Philadelphia. The holiday season was filled with close friends and family. We joined together to spend some good old fashion quality time and shopping from a few vendors (Mary Kay, DoTerra Oils and Thirty One). The kids enjoyed a visit and gift from Santa while doing holiday crafts. Thank you to all who attended. We are looking forward to a great year!





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

Lucy DiFelice Kohler, Mother of Mary Kohler

Patricia Iacono

Robert F. Ferguson, Sr., Uncle of Kim Patton

and

Margaret W. Long

We are grateful for the donation to the Association made in
their honor.

**SPINA BIFIDA ASSOCIATION OF
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