SBA Update
2020

Sara Struve
President & CEO
The mission of the SBA is to build a better and brighter future for all those impacted by Spina Bifida.
COVID-19 Impact

• COVID-19 has not changed our mission. We look at the efforts around COVID-19 as a part of building a better and brighter future for people with Spina Bifida and the people who care for them.

• Our staff may now be 100% virtual, but they are 100% committed to the community and keeping it connected during such difficult times.
COVID-19 Impact

• We created a COVID-19 page on our website: https://www.spinabifidaassociation.org/covid19/

• It houses multiple resources for navigating this time.

• We update it when we vet information that we receive or find relating to COVID-19.
COVID-19 Impact

• We sent updates to our database periodically and will continue to do so during this pandemic.

• We used social media platforms to widely broadcast messages related to COVID-19 and we will continue to do so
COVID-19 Impact

We have moved to virtual events like:

- Teal on the Hill,
- Education Days,
- Walk-N-Rolls,
- Happy Hours,
- Check-ins and
- Chapter events.
COVID-19 Impact

We host periodic webinars on topics related to COVID-19:

• *Spina Bifida & COVID-19* (Held March 26, 2020 with over 800 people registered)

• *How is Coronavirus Affecting Your Mental Health* (Held April 9, 2020 with over 100 registered)

• *How Can I Help My Child with Spina Bifida Learn at Home* Held April 22, 2020 in conjunction with the SBA of Northeast New York).
COVID-19 Impact

We have identified other topics including:

• Impact of online learning for adolescents and young adults with Spina Bifida,

• Mental health issues that may be experienced by children during stay at home orders, and

• How parents and caregivers can take care of themselves.
COVID-19 Impact

Additional Plans:

• We plan to poll our social media followers to gain insight into emerging needs and what additional topics should be covered.

• We are creating written materials that will be on our website, covering the same topics and content as these webinars, and can be downloaded.
SBA Strategic Plan Core Principles

- Transparency
- Using Data to Drive Direction
- SB Community Involvement
Research: The Spina Bifida Association (SBA), through the *Spina Bifida Collaborative Care Network*, leads research to enhance the quality of life for people living with Spina Bifida.
How we’ll accomplish this:

- Create Research Agenda
- Support Translational Research
- Augment Research & Study Requests
- Conduct Research
- Summarize Research
Clinical Care: SBA spearheads, through the *Spina Bifida Collaborative Care Network*, efforts to improve clinical care for all people living with Spina Bifida.
How we’ll accomplish this:

- Clinics/Health Care Providers
- Translational Research
- Outcomes
- Transition Support
- Adult Care
- Partnership
Education & Support: SBA empowers members of the Spina Bifida community with information and support to improve their quality of life.
How we’ll accomplish this:

- Information & Support
- Education
- National Resource Center
Network Building: SBA serves as a hub to connect Chapters, clinics, and the broader community to improve the quality of life of people living with Spina Bifida.
How we’ll accomplish this:

• Chapters
• Communications
Advocacy: SBA advocates for positive change to the issues impacting the lives of people living with Spina Bifida.
How we’ll accomplish this:

• Appropriations
• Teal on the Hill Event
• Grassroots Advocacy
• Advocacy Coalitions
• State Advocacy
Fiscal Health: SBA raises funds from diverse streams and responsibly manages its financial resources to achieve organizational strategies.
How we’ll accomplish this:

- Fiscal Oversight
- Development
People & Operations: SBA aligns human, business, and operational resources to achieve organizational strategies.
How we’ll accomplish this:

- Staff
- Board
- Volunteers
• Chair: Mike Harty (mikehartyjr@gmail.com)
• Immediate Past Chair: Nicole Gower (ngower8875@gmail.com)
• Chair Elect: Maria Bournias (maria.bournias@gmail.com)
• Treasurer: Vacant
• Executive Committee At-Large: Marie Thoming (methoming@gmail.com)

• President & CEO: Sara Struwe (sstruwe@sbaa.org)
• Chief Operating Officer: Sheliah Roy (sroy@sbaa.org)
• Chief Financial Officer: GlenRae Brown (gbrown@sbaa.org)
Board Members

- Brad Dicianno, MD
- Nancy Gore
- David Morrissey
- Wilson Neyland
- Jason Ostrowski
- Chase Phillips
- Kathryn Smith, RN, MN, DrPH
- McKay Tolboe
- Anshul Varma
- John Wiener, MD
Advisors to the Board

Medical Director

Timothy J. Brei, MD, FAAP
Seattle Children’s Hospital

Legal Counsel

Stephanie P. Hales, Partner
Sidley Austin Brown & Wood LLP
A special THANK YOU to all of the many volunteers who make all of these activities happen!

We could not do any of this without your help!!!