



SPINA BIFIDA
ASSOCIATION

SBA Update 2020

Sara Struwe
President & CEO

SBA's New Mission

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

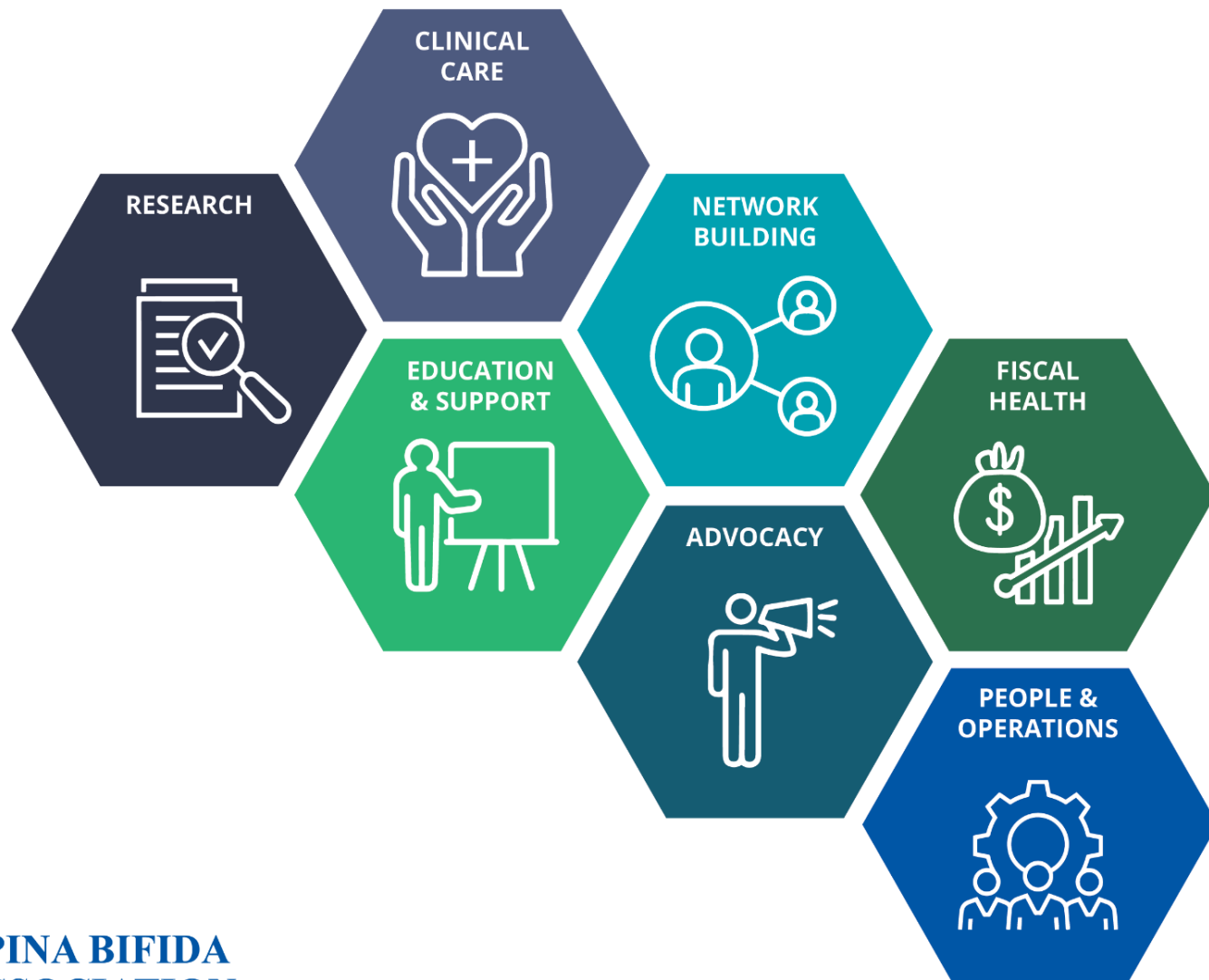
We have identified other topics including:

- 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:

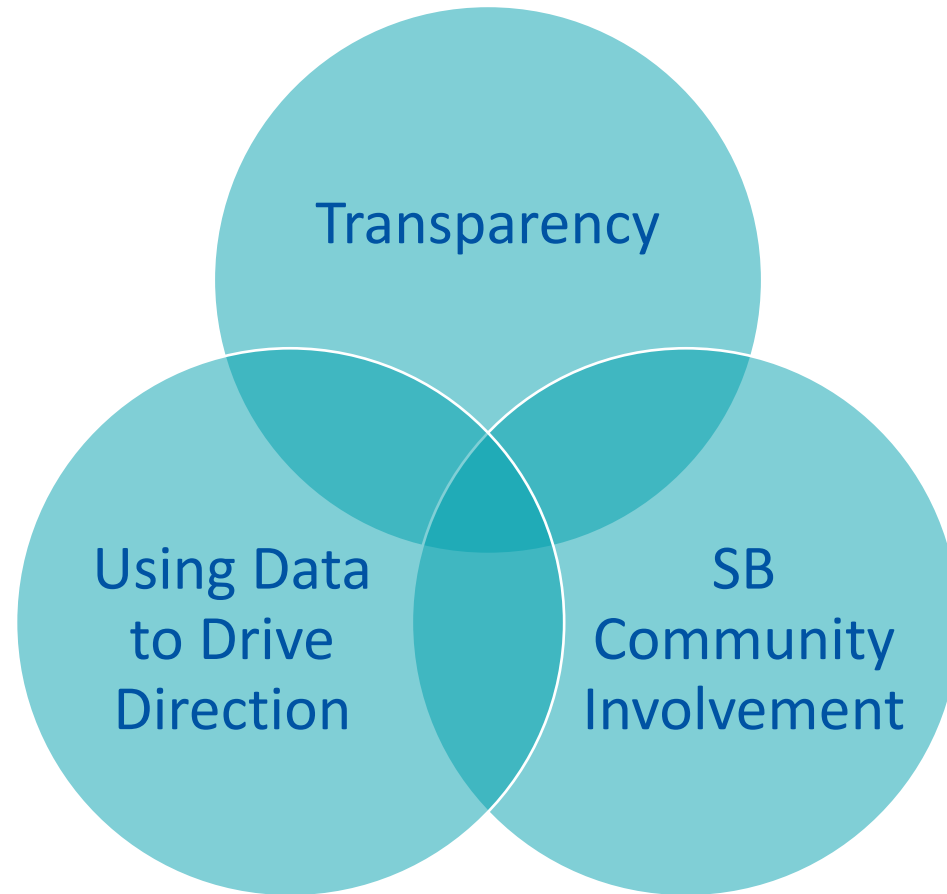
- We plan to poll our social media followers to gain insight into emerging needs and what additional topics should be covered.
- We are creating written materials that will be on our website, covering the same topics and content as these webinars, and can be downloaded.



STRATEGIC PLAN 2020-2022

<https://www.spinabifidaassociation.org/strategic-plan/>

SBA Strategic Plan Core Principles





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

Officers & Executive Committee

- 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

THANK YOU!

**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!!!**



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