



SPINA BIFIDA
ASSOCIATION

Stronger when
we stand together.

2025 Annual Report

Together, we expanded access to care, strengthened advocacy, advanced research, and empowered more individuals and families than ever before.



A Word From Our Leadership

Dear Spina Bifida Family,

As I reflect on the past year, I want to express my gratitude for the incredible community that makes the work of the Spina Bifida Association possible. Every milestone we reached in 2025 was made possible because of supporters like you—our donors, volunteers, advocates, healthcare partners, corporate sponsors, and families.

Together, we expanded education, strengthened clinical care, advanced research, and advocated for policies that improve the lives of people living with Spina Bifida. Through our virtual education series, National Resource Center, and Clinical Care Meeting, we equipped individuals, families, and healthcare professionals with the knowledge and resources needed to improve care and outcomes.

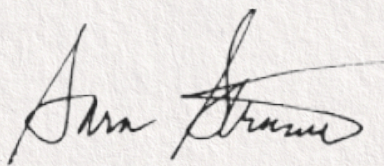
In addition to Teal on the Hill, SBA spearheaded a national coalition to protect access to medically necessary urological and ostomy supplies by opposing the expansion of Medicare's Competitive Bidding Program. Together, we amplified the voices of the Spina Bifida community and worked to ensure people receive the products that best meet their individual needs.

Just as importantly, we continued building connections that remind individuals and families they are never alone. Whether supporting expectant parents, advancing research, or creating opportunities to connect, we remain committed to improving lives at every stage.

Every accomplishment in this report reflects what is possible when compassionate people come together around a shared purpose. Your generosity fuels progress, strengthens advocacy, and creates hope for thousands of families across the country.

Thank you for believing in our mission and for helping build a future where every person living with Spina Bifida has the opportunity to thrive. We are stronger together.

With sincere gratitude,



Sara Struwe

**President & Chief Executive Officer
Spina Bifida Association**



Our Mission, Vision & Values

Our mission is to build a better and brighter future for all those impacted by Spina Bifida.

Research



We advocate for research that improves the lives of people living with Spina Bifida by advancing initiatives like the National Spina Bifida Patient Registry and the Urologic Protocol for Young Children with Spina Bifida, both housed at the CDC, and by collaborating with hundreds of healthcare professionals worldwide to update the Guidelines for the Care of People Living with Spina Bifida, identify research gaps, prioritize community-driven needs, encourage the use of NSBPR data, and secure funding to advance care.

Advocacy



We are dedicated to ensuring the voice of people with Spina Bifida is heard on Capitol Hill. Together, we can make a difference in the lives of those with Spina Bifida. We will not rest until every person has access to coordinated, affordable, comprehensive care.

Education & Support



Through the National Resource Center, the Spina Bifida Association provides personalized information and guidance for individuals, families, healthcare providers, and anyone impacted by Spina Bifida. SBA also offers in-person and virtual programs led by medical experts, parents, and adults with Spina Bifida, covering topics identified by and for the community.

Community Building



Whether you are living with Spina Bifida, expecting a child with Spina Bifida, supporting a loved one, or serving the community as a healthcare or service provider, SBA's staff and nationwide network of chapters, healthcare professionals, local advocates, families, and adults living with Spina Bifida are here to connect you with the information, resources, and support you need.



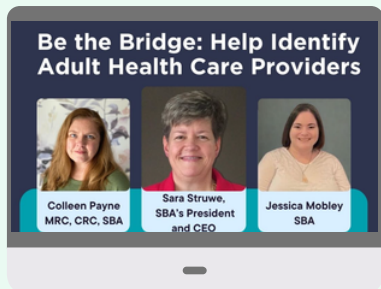


SPINA BIFIDA
ASSOCIATION

A Year of Progress. A Future of Possibility.

2025 By the Numbers

Empowering Through Education



42,531

YouTube
views
of SBA
content

1,972

webinar
participants

20

expert-led
webinars

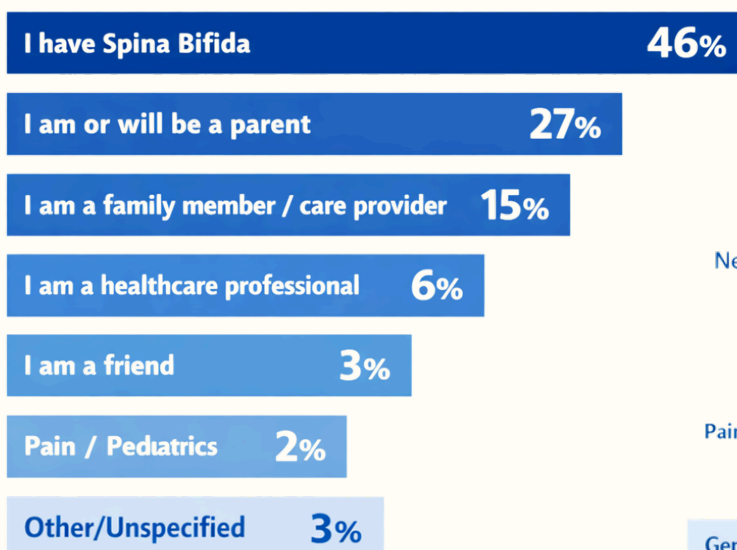
National Resource Center Highlights

281

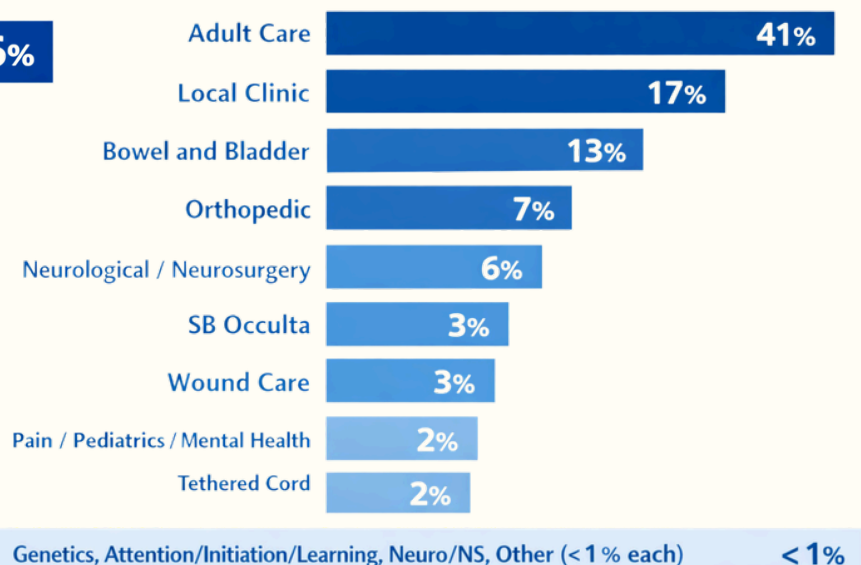
Individuals and
families received
personalized one-
on-one support
from SBA.

Every support request is unique. In 2025, SBA's National Resource Center provided personalized guidance, trusted information, and connections to resources for over 280 individuals and families. The charts below show who sought support and their relationship to Spina Bifida as well as the health topics they needed help navigating.

Relationship to SB



Specific Health Topics Discussed

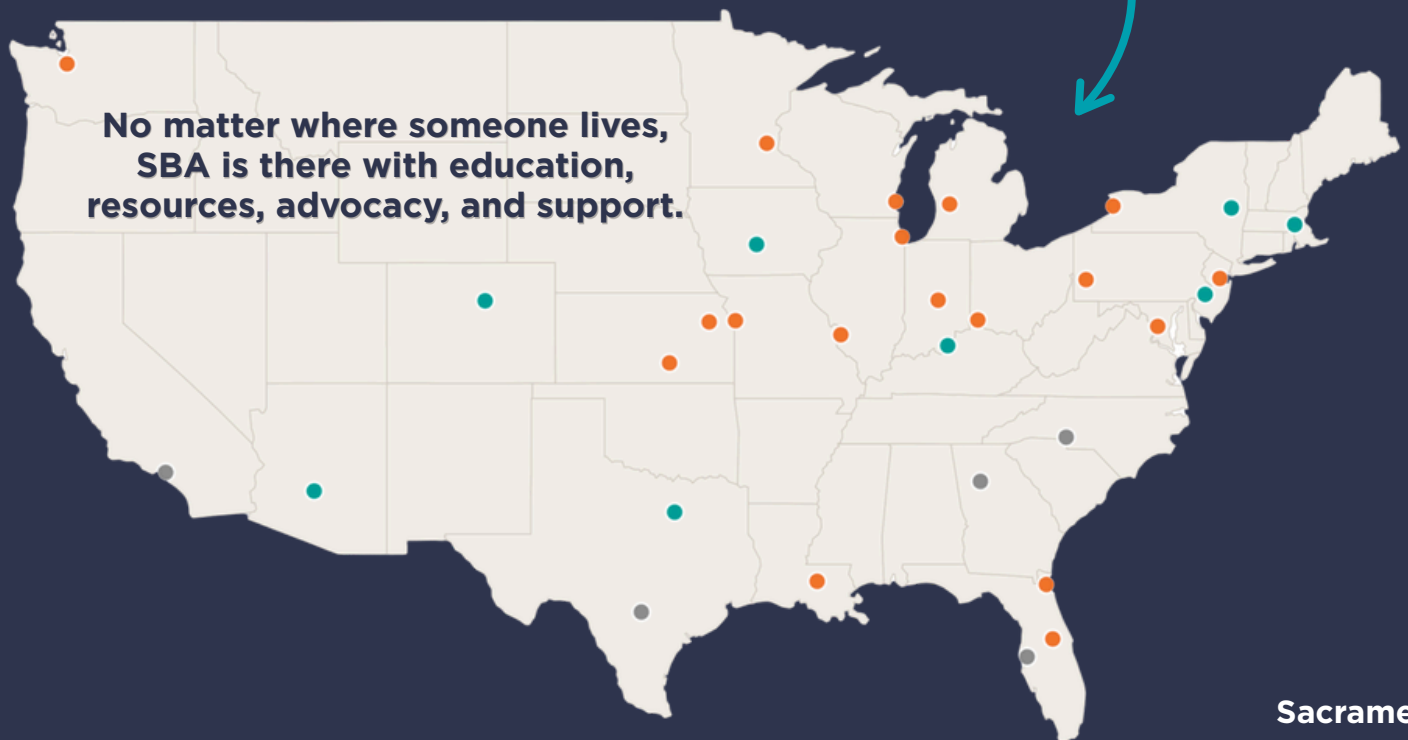


Our National Reach

SBA's Footprint

SBA chapters and community support groups across the U.S.

● Corporate chapter ● Affiliate chapter ● Community support group



Community Impact & Events



Teal on the Hill: **WE ADVOCATED**

Through Teal on the Hill, advocates, families, healthcare professionals, and self-advocates meet directly with lawmakers to champion policies that improve the lives of people living with Spina Bifida.

“I am a 42-year-old man with Spina Bifida and a longtime advocate, but this was my first Teal on the Hill. I have never felt a greater urgency to take action. In our first meeting, a staffer urged us not only to seek increased CDC funding for the National Spina Bifida Registry but also to push federal leaders to allocate it properly. It was a powerful experience to fight alongside passionate advocates for our community's future, and I couldn't be more proud.”

— Dennis Carmody, MPH, CCRP

2025 Impact:

- 148 advocates **raised their voices on Capitol Hill**
- 87 congressional meetings **advanced policies that support the Spina Bifida community**
- Through countless personal stories, **SBA advocates educated lawmakers and inspired action toward a healthier, more equitable future**



Clinical Care Meeting:

Improving the quality of care for individuals living with Spina Bifida begins with bringing healthcare professionals together to **learn, collaborate, and innovate**. Each year, SBA's Clinical Care Meeting (CCM) provides a forum where multidisciplinary teams **share the latest research, exchange best practices, and strengthen the partnerships that lead to better lifelong outcomes**. In 2025, CCM was held in partnership with the University of Alabama at Birmingham (UAB), bringing together healthcare providers from across the country to **advance evidence-based care and improve the future of Spina Bifida care**.

WE ADVANCED CARE



“By investing in education and collaboration, SBA is helping build a stronger network of providers equipped to deliver high-quality, coordinated care for every stage of life.”

2025 Impact

- 20 clinics represented across 15 states
- 125+ healthcare professionals trained in the latest best practices
- 25 educational sessions where collaboration, innovation, and new ideas were sparked



Walk-N-Roll:

WE CONNECTED OUR COMMUNITY



Number of Events:

13



Participants

2,800+



Funds raised:

\$288K



A Message From Our Board Chair

Dear Friends,

Looking back on 2025, I'm inspired by all that our community accomplished together. **Every milestone in this report reflects the generosity, dedication, and determination of people who believe in creating a brighter future** for individuals and families living with Spina Bifida.

Throughout the year, we witnessed the power of coming together. **Advocates met with lawmakers on Capitol Hill** to champion policies that improve lives. **Healthcare professionals collaborated to strengthen clinical care** and share best practices. **Families found trusted resources and meaningful connections**, and **generous supporters invested in programs that create lasting impact across the country.**

Serving as the 2025 Board Chair was a true privilege. I had the opportunity to witness firsthand the passion of our volunteers, the expertise of our staff, and the unwavering commitment of our donors, partners, and advocates. **Together, you helped expand access to care, advance research and education, strengthen our community, and ensure more individuals with Spina Bifida have the resources they need to thrive.**

While my term as Board Chair has concluded, my commitment to the Spina Bifida Association and this remarkable community remains as strong as ever. **Thank you for making 2025 a year of meaningful progress.** Together, we are creating lasting change and expanding opportunities for generations to come.

With gratitude,



Nancy Gore
2025 Chair, Board of Directors



“Together, we are creating lasting change and expanding opportunities for generations to come...”



Meet Our SBA Board Members



JAMES ARMIJO



ROBIN M. BOWMAN, MD



JOSEPH EVANS



ELLEN FREMION, MD



NANCY GORE



SHELIAH ROY



**KATHRYN ANN NAVARETTE
SMITH, RN, MN, DPH**



HEIDI SIEGEL



DOUGLAS SOROCO



MARIE THOMING, PE



ERIC TOBIN



ANSHUL VARMA



BRYAN VODICKA



**DAWNE WIDENER-
BURROWS**



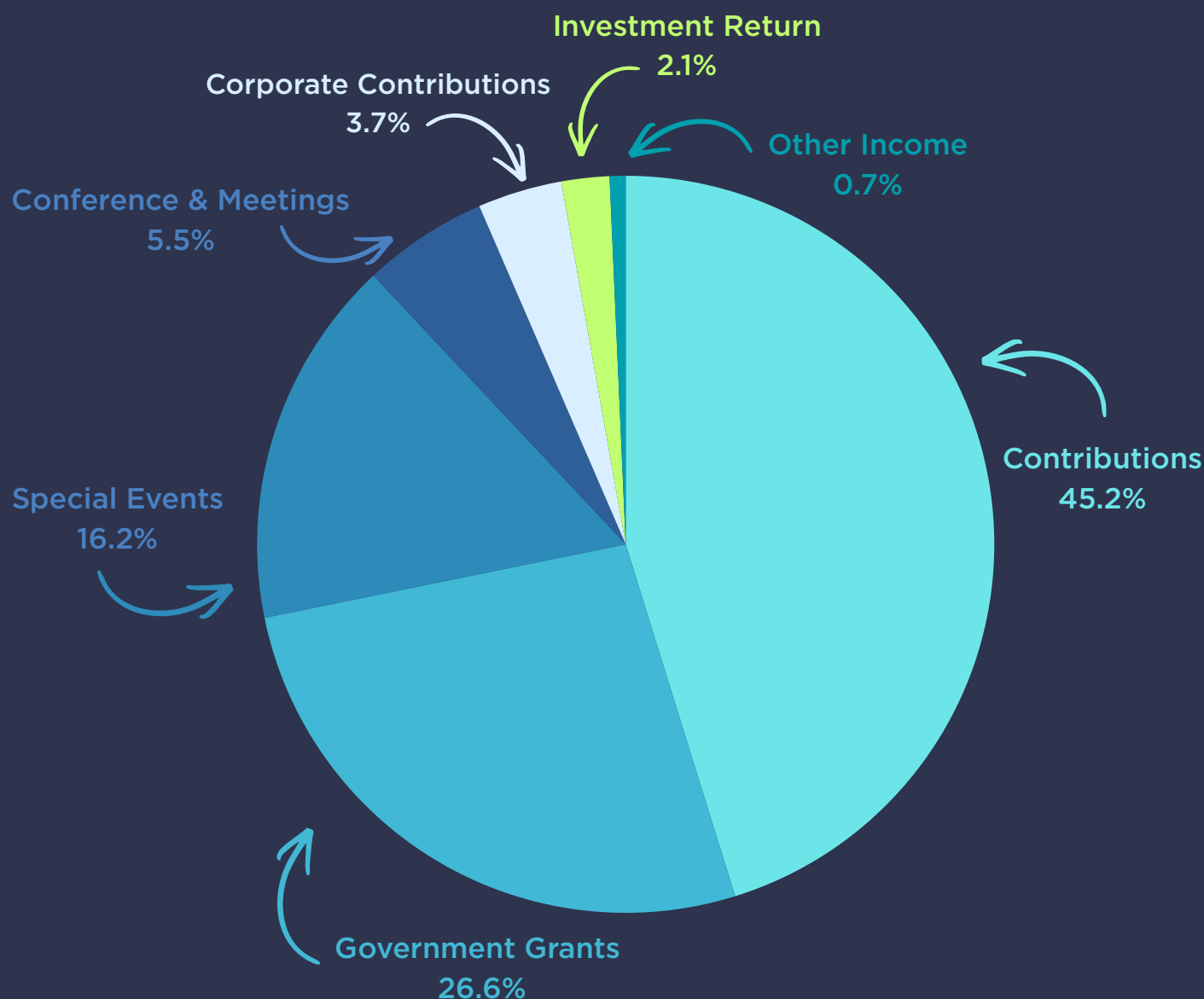
MELISSA WIEGEL



JOHN WIENER, MD

Financial Stewardship

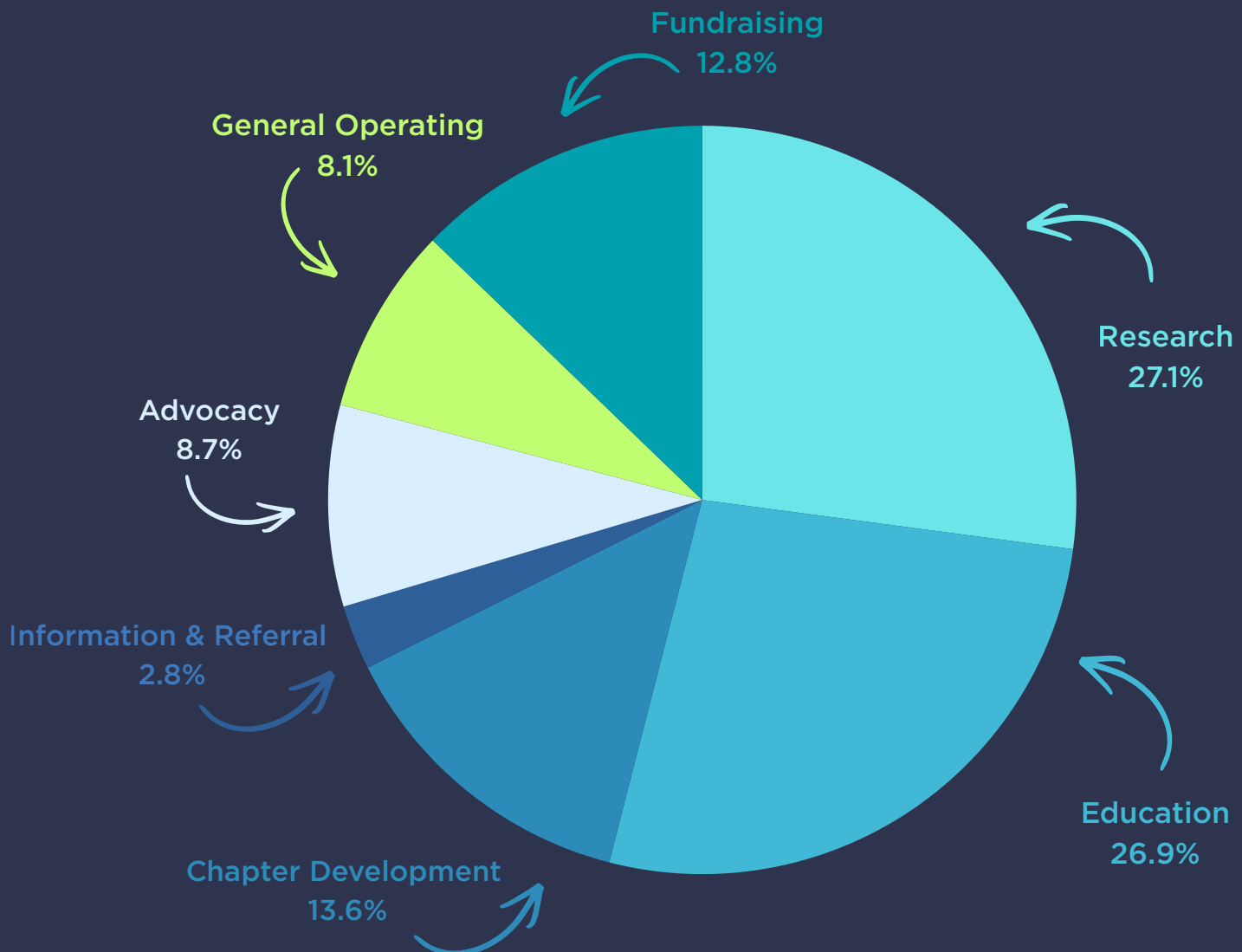
Revenue Sources



FY2025 TOTAL REVENUE: \$1.94 MILLION

We remain committed to **using every contribution responsibly and transparently**, and to directing it where it can make **the greatest impact** for those living with Spina Bifida.

Financial Stewardship Expenses



FY2025 TOTAL EXPENSES: \$1,858,898

Your generosity is stewarded with care. In 2025, nearly **79% of every dollar spent directly supported SBA's mission** through research, education, advocacy, chapter development, and information & referral services.



Thank You

Because of You...

Families found support. Providers received education.
Advocates raised their voices. Research and care moved forward.
Hope reached more people impacted by Spina Bifida.

Donate



SPINA BIFIDA
ASSOCIATION

Spina Bifida Association
2000 Duke Street, Suite 300
Alexandria, VA 22314