



50 YEARS

50 YEARS OF IMPACT: CELEBRATING MILESTONES & BUILDING FUTURES



2023

ANNUAL
REPORT

FROM THE CEO'S DESK

Dear SBA Community,

As we reflect on the accomplishments of 2023, I am filled with gratitude and pride for all that we have achieved together. It is with immense pleasure that I share with you the highlights of our collective efforts over the past year.

At the heart of our success lies our unwavering commitment to addressing the needs of individuals and families affected by Spina Bifida. Through the dedication of our donors, volunteers, and partners, we have made significant strides in advancing our mission and improving the lives of those we serve.

One of our proudest achievements this past year has been the expansion of our National Resource Center, which has enabled us to address more cases and provide vital support to individuals across the country. Through the tireless efforts of our team and the generosity of our supporters, we have been able to reach more individuals in need and provide them with the resources and assistance they require.

Our World Congress event brought together experts, professionals, and advocates from around the globe to share knowledge, collaborate, and inspire action. It served as a testament to the power of community and the importance of collective efforts in driving positive change.

In response to the feedback and input from our community, we have developed new programming as part of our Educational Series, ensuring that we are addressing the most pressing issues and providing relevant, timely information to those who need it most.

Our annual advocacy event, Teal on the Hill, saw increased participation and engagement, amplifying our collective voice and advocating for meaningful change on behalf of individuals with Spina Bifida.



FROM THE CEO'S DESK

Through our initiatives to educate healthcare professionals on the care of people with Spina Bifida, we have empowered countless individuals to provide better support and assistance to those in need. Our efforts have helped to improve the quality of care and enhance the lives of individuals with Spina Bifida.

The launch of our Expectant Parent Network, complete with trained mentors, has provided invaluable support and guidance to expectant parents facing the challenges of Spina Bifida diagnosis. This initiative underscores our commitment to supporting families at every stage of their journey.

Finally, our clinic care partners have experienced remarkable growth, expanding our network and increasing access to quality care for individuals with Spina Bifida across the country.

None of these achievements would have been possible without the dedication, generosity, and support of our donors, volunteers, and partners. It is through your unwavering commitment and collaboration that we have been able to make a meaningful difference in the lives of individuals and families impacted by Spina Bifida.

As we look ahead to the future, I am filled with optimism and excitement for what lies ahead. Together, we will continue to build on our successes, expand our impact, and work tirelessly to ensure that every individual affected by Spina Bifida receives the support, resources, and care they deserve.

Thank you for your continued support and dedication to our mission.

Warm regards,



Sara Struwe
CEO & President



We are proud to present the essence of the Spina Bifida Association (SBA) – our unwavering mission and core values. At SBA, our mission is to enhance the lives of individuals living with Spina Bifida and their families by providing support, resources, and advocacy. We are driven by a commitment to inclusivity, compassion, and empowerment, ensuring that every individual affected by Spina Bifida receives the care, support, and opportunities they deserve. As we reflect on the past year's accomplishments and look ahead to the future, our dedication to our mission and values remains steadfast, guiding us in our efforts to make a meaningful difference in the lives of those we serve.



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BY THE NUMBERS

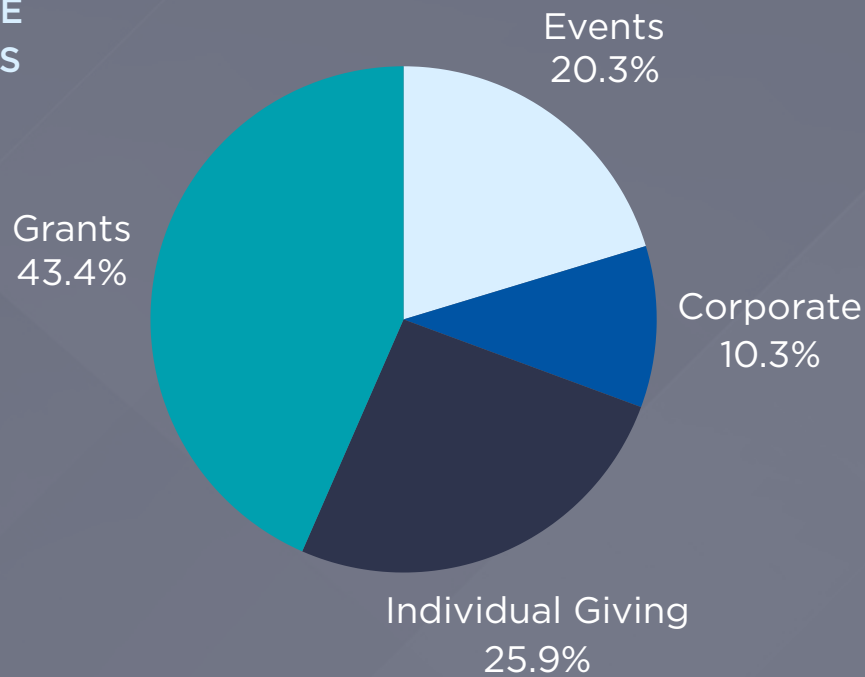


[Click here to watch a recap of our
2023 Supporter Impact Report.](#)



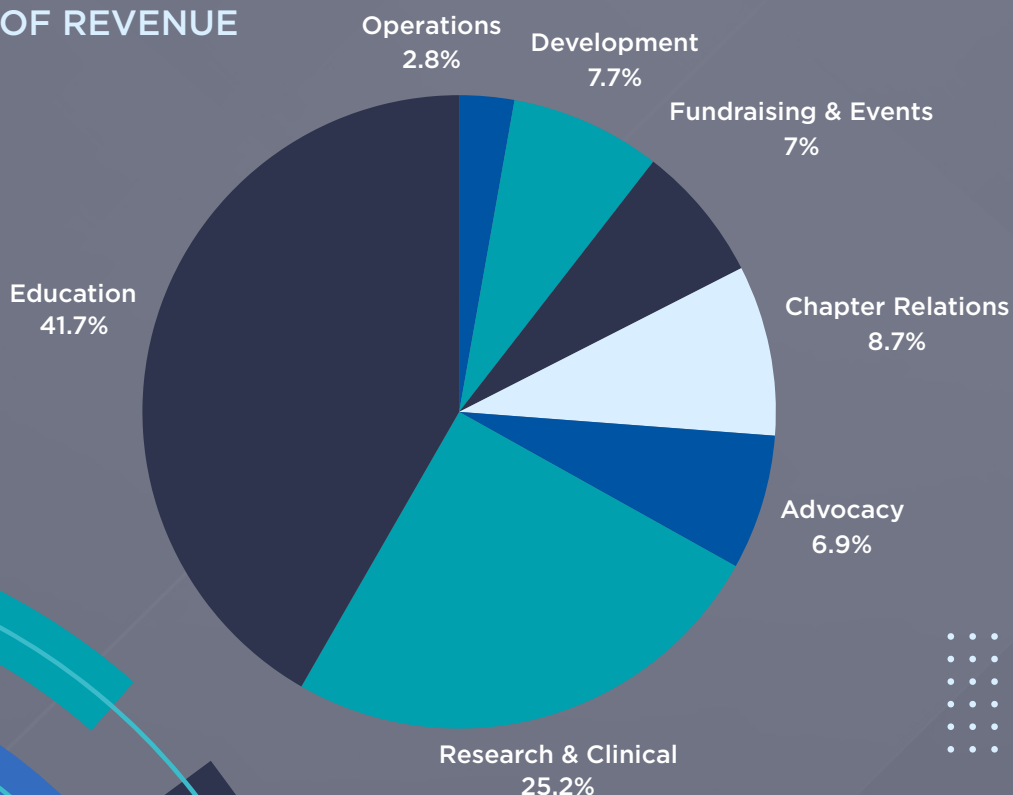
FINANCIAL IMPACT

REVENUE STREAMS



TOTAL REVENUE: \$3,213,534

DISTRIBUTION OF REVENUE



TOTAL EXPENSES: \$3,283,901

Please note, these financials have not yet been audited.

HADLEY & THE PETERSONS



Hadley was born with Spina Bifida and put up for adoption. She needed a forever family who wasn't afraid of the challenges she would face. Meanwhile Larry and Kelly Peterson desperately wanted to adopt a child... but since both of them have Spina Bifida, adoption agency after adoption agency told them, "No."

The Petersons refused to give up. The Spina Bifida Association and kind people like you stood behind them... and, in the nick of time, the Petersons were able to adopt Hadley!

SBA is leading the way in helping adults with Spina Bifida explore parenting options, including finding resources from diagnosis to birth and connecting them to the specialized Spina Bifida care their child requires.

"Who better to parent this child than two people who have a deep understanding of the issues she is facing and will face in the future?"

They were right. Now Kelly and Larry have all the joys — and challenges — of parenting.



ANSHUL & FAITH

Anshul is proud to wear many hats: consultant, SBA board member, Texan, and husband. But for the last twenty years, his most important role has been 'DAD.'

As he contemplated fatherhood through adoption, Anshul recalls the feelings of fear and doubt.

"I was very, very scared. I did not know what to expect. I could only think about all the things that could go wrong and the limitations of what I may be able to offer as a father."

But after 20 years of forming an unbreakable bond, he offers these words that deeply resonate:

"My biggest piece of advice is don't be that person. Children are incredibly resilient. They are incredibly creative and smart. And they will figure out ways to do things with you that are going to form your bond. It's going to be your own special unique bond."

Your support ensures that individuals like Anshul can thrive as parents, and families affected by Spina Bifida can embrace a future filled with hope, resilience, and endless possibilities.



COLLEEN & NATE



This year alone, Colleen has seen four adult friends with Spina Bifida die early from preventable problems. Now she is scared the same will happen to her son, Nate.

The “care cliff” is deadly for adults – and it doesn’t have to be this way.

“It’s not fair that young adults don’t get a longer life because of lack of specialized care. They are somebody’s son, friend, and brother – with the same hopes, dreams, goals, and relationships as everyone else.” -Colleen, mother to Nate, a young adult with Spina Bifida

SBA is actively working to educate physicians in the care of adults with Spina Bifida. But the need is overwhelming.

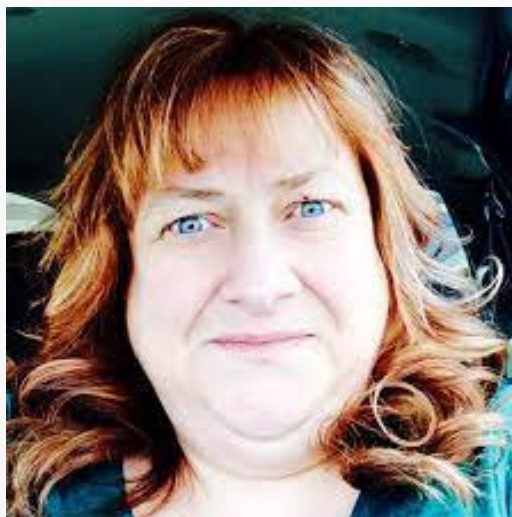
MONICA STILL

Monica Still of Pittsburgh, PA is a mother, a grandmother, a nurse, and has navigated living with Spina Bifida for 58 years...

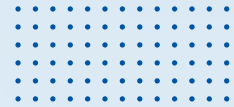
...but one shortsighted policy that denies her a basic treatment called TAI is destroying her life. In fact, the lack of TAI caused Monica to be fired from her job.

“Lack of effective bowel treatments quickly leads to constipation, which causes UTIs, which impact neurogenic bladders causing further damage to the kidneys, liver and bladder. If you can’t go to the bathroom it can lead to surgery or death if not treated.”

SBA is in full swing executing a three-part advocacy plan to collect, analyze and deliver key data to decision makers at the Centers for Medicare and Medicaid to push for the procedure to be covered. And insurance companies often follow Medicare’s lead for standards of service!

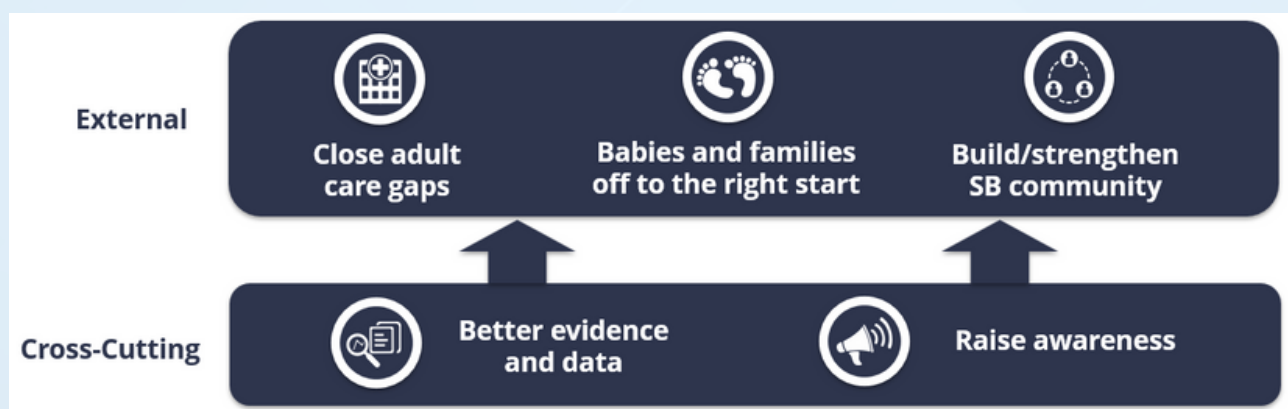


VISION



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

THE WORK CONTINUES: STRATEGIC PRIORITIES



Major Donors



Recurring Donors

Corporate Donors



OUR PARTNERS

Tom Baroch Advocacy Award

Millie Gonzalez

Congressional Champion Award

Representative Kevin Hern

Lifetime Achievement Award

Honoree Dr. Godfrey Oakley

Judy Thibadeau Award

Paula Ruth Peterson

Young Investigators Award

Melinda Rocchi

Arthi Hannallah

James Rague

AWARDS

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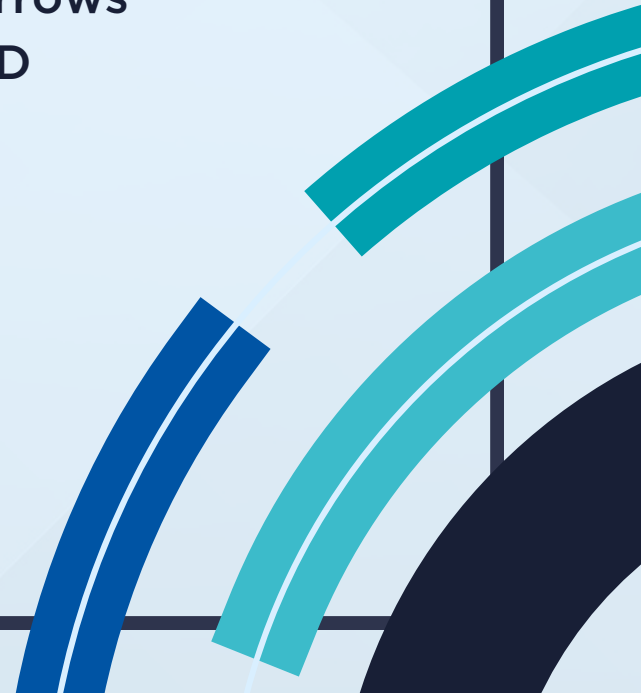
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THANK YOU!



As we reflect on the past year, we are overwhelmed with gratitude for your unwavering support of the Spina Bifida Association. Your dedication and generosity have been instrumental in advancing our mission and providing vital support to individuals and families impacted by Spina Bifida.

Our volunteers are the heart of our organization. Their time, energy, and passion drive our programs and initiatives forward, making a meaningful difference in the lives of those we serve. Their commitment to service inspires us all.

To our donors, your generosity fuels our work and enables us to provide essential resources, support services, and advocacy efforts for the Spina Bifida community. Your contributions are truly life-changing, and we are profoundly grateful for your partnership.

As we look to the future, we recognize that our success depends on you—our dedicated volunteers and generous donors. Together, we can continue to make a positive impact, empower individuals with Spina Bifida, and advocate for a better and brighter future.

Thank you for your invaluable support. We are honored to have you by our side.

[Click here to watch a recap of our 2023 Supporter Impact Report.](#)





SPINA BIFIDA
ASSOCIATION

50 YEARS

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