

# ANNUAL REPORT

## 2022



**SPINA BIFIDA  
ASSOCIATION**



800-621-3141



[sbaa@sbaa.org](mailto:sbaa@sbaa.org)



[spinabifidaassociation.org](https://spinabifidaassociation.org)



1600 Wilson Blvd, Suite 800, Arlington, VA 22209

# From the CEO's Desk

Dear Friends:

I am excited to share this annual report with you and celebrate the progress you have made possible in improving the lives of the 166,000 people across the country living with Spina Bifida.

As you'll see in the report, we have been able to expand our outreach to people with Spina Bifida, their care partners, and clinicians. We've advanced our community-centered research agenda focused on addressing questions central to the quality of life of people in our community. We've secured critical public policy wins. And most importantly, we've made important strides in bringing quality, affordable clinical care to more people who need it.

One of our primary focuses in the past year has been on expanding our outreach to reach more individuals and families affected by Spina Bifida. In our pursuit of excellence, we recognized the importance of identifying research gaps to push forward advancements in treatment and care for people with Spina Bifida. Thanks to your generous contributions, we were able to fund and collaborate with esteemed researchers, working diligently to fill these gaps and further our understanding of the needs of Spina Bifida community.

So there is much to celebrate, and for that, I thank you. At the same time, there is still so much more work to do to make sure that every person living with Spina Bifida in the U.S. is able to access quality, affordable healthcare and has the means to achieve their full human potential.

As we look to the future, we will focus on the following areas:

- **Reducing clinical care gaps for adults with Spina Bifida.** Thanks to your support, we have the first generation of adults living with Spina Bifida. Yet we know many of those adults faced a care cliff as they transitioned from pediatric to adult care. We must do more to eliminate that cliff and ensure that this generation and the next generation of adults have the care they deserve.

# From the CEO's Desk

*continued*

- **Ensuring that all babies with Spina Bifida get off to a good start.** The Spina Bifida diagnosis experience for expectant parents is often traumatic and misinformed. We must make sure that doctors are equipped with the latest information to reduce the trauma expectant parents often face, and we must make sure that all newborns are connected to Spina Bifida care by three months.
- **Building a stronger, more supportive Spina Bifida community.** We will continue to build and nurture more peer-to-peer networks so that no one with Spina Bifida ever feels alone and unsupported ever again.
- **Closing evidence gaps.** We will focus intently on improving the availability of Spina Bifida patient data to enable research and will connect more researchers and funders to address questions identified in the research agenda we developed with the Spina Bifida community.
- **Raising awareness and educating key audiences.** Too many people still don't understand Spina Bifida and the challenges our community faces. We will redouble our efforts to educate clinicians, policymakers, and others who can help advance our agenda.

With your continued support, I am confident that together, we will achieve these goals and bring about meaningful change for those affected by Spina Bifida. The road ahead may present challenges, but with our collective dedication and determination, we can overcome any obstacle and make a lasting impact.

Once again, thank you for being an integral part of our mission. Together, we are making a difference and creating a brighter future for individuals living with Spina Bifida.

With heartfelt gratitude,



Sara Struwe  
CEO & President



**SPINA BIFIDA  
ASSOCIATION**

# We're On A Mission

To build a better and brighter future for all those impacted by Spina Bifida.



## Our Priorities

### Research

We identify the needs of people with Spina Bifida, bring health care professionals together to share the latest in treatment and care, identify clinics with the best outcomes, and inform and encourage future Spina Bifida research.

### Advocacy

In addition to advocating for funding for Spina Bifida programs at the CDC; disability rights; and affordable, accessible health care, we empower those with Spina Bifida to share their stories to create change in their communities.

### Education

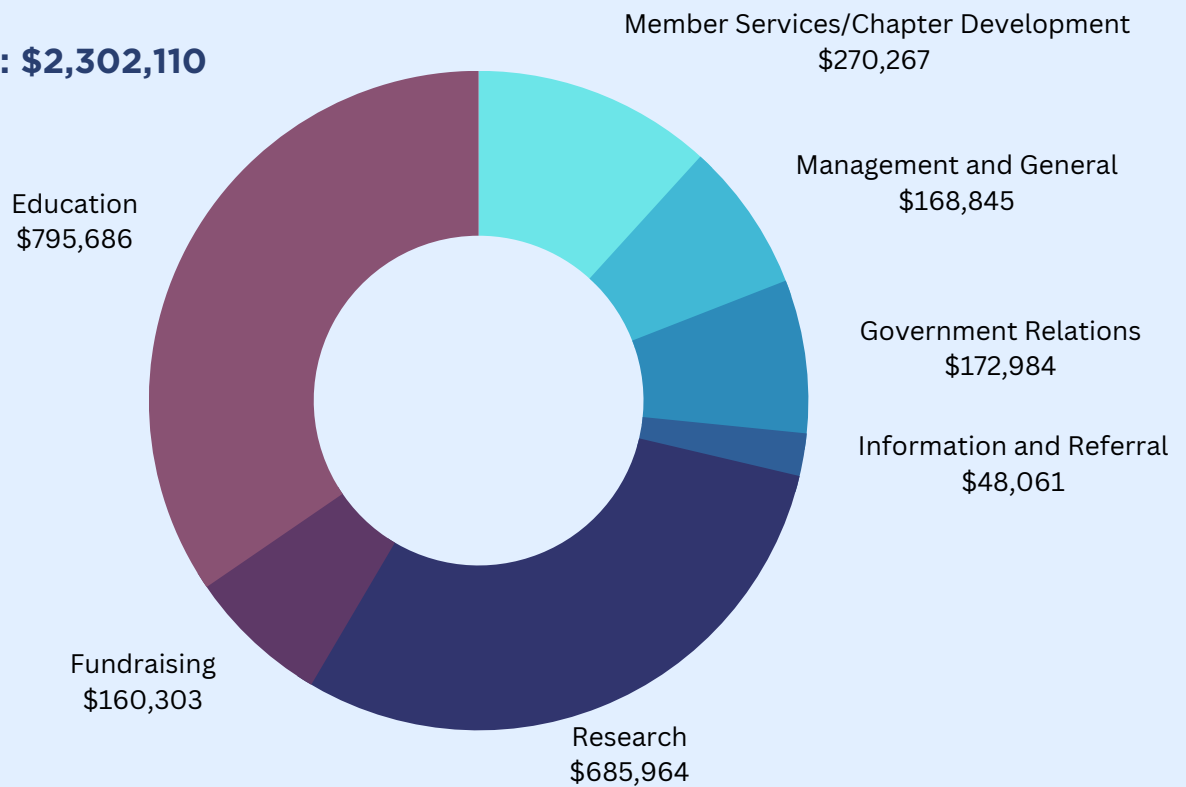
Through in-person and online education programs featuring medical experts, parents, and adults, we help individuals with Spina Bifida learn to live safely and successfully with a disability.

### Support

We provide resources and referrals in English and Spanish to individuals and families in need.

# Our Financials

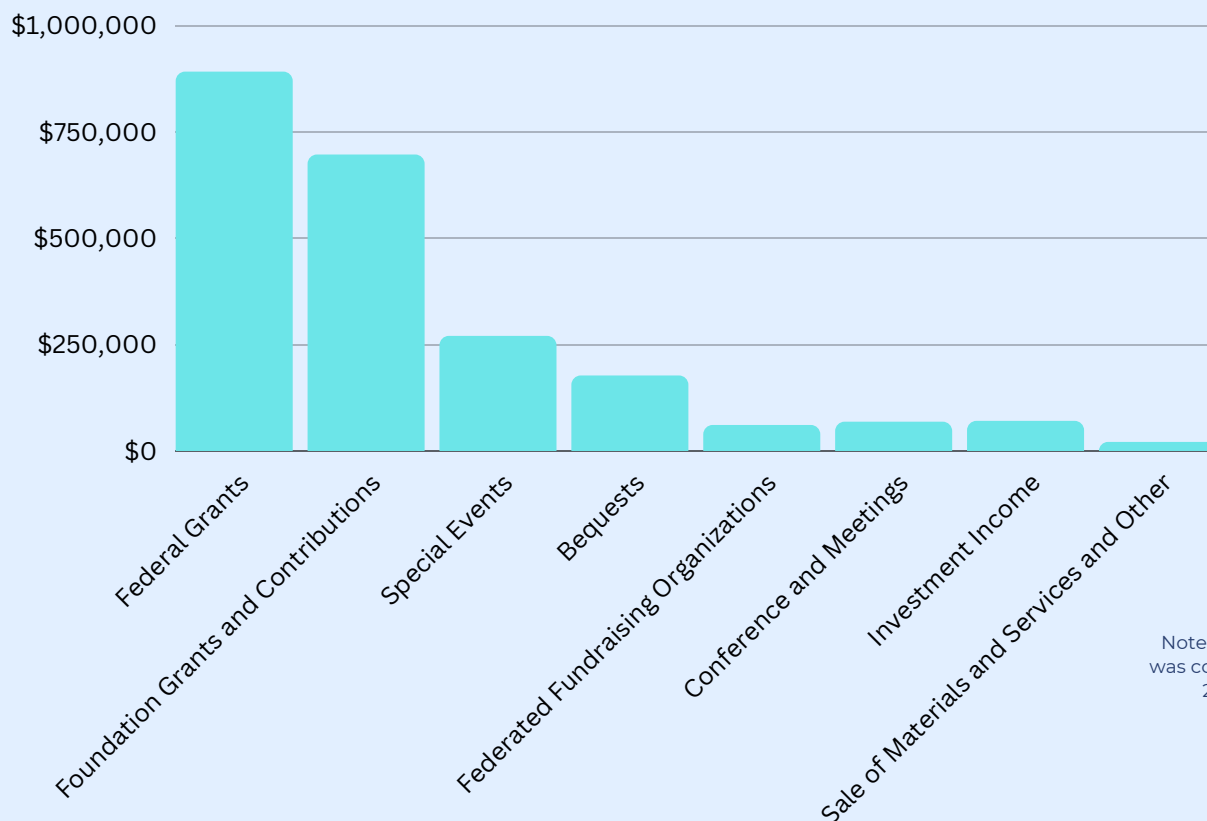
**Expenses: \$2,302,110**



**Net Assets Beginning of the Year:  
\$1,206,002**

**Income: \$2,110,333**

**Net Assets End of the Year:  
\$1,014,225**



Note: Financial information was compiled utilizing SBA's 2022 Audited Financial Statements.

# Our Board of Directors

Maria Bournias, Esq., CPA, Chair  
Michael Harty, Jr., Immediate Past Chair  
Nancy Gore, Chair-Elect  
Anshul Varma, Secretary/Treasurer  
Doug Burns  
Brad Dicianno, MD  
Tracy DiNunzio  
Wilson Neyland  
Chase Phillips  
Kathryn Ann Navarette Smith, RN, MN, DrPH  
Marie Thoming, PE  
Eric Tobin  
Dawne Widener-Burrows  
John Wiener, MD

## Advisors to the Board

Timothy J. Brei, MD, FAAP, Medical Director  
Stephanie P. Hales, Legal Counsel

## Our Staff

Sara Struwe, President & Chief Executive Officer  
GlenRae Brown, Chief Financial Officer  
Mike Wood, Chief Operating Officer  
Ryan Ben, National Director of Field Relations  
Jenna Brown, National Director of Development  
Leslie Holland, Financial Data Entry Specialist  
Sarah Hurst, Database Manager  
Stephanie Myers, Manager of Corporate & Individual Giving  
Jessica Palmeri, National Director of Marketing & Communications  
Juanita Panlener, National Resource Center Manager  
Libby Riordan, National Director of Special Events  
Kiki Setterlund, Manager of Special Events  
Giana Spear, Manager of Marketing & Communications  
Judy Thibadeau, National Director of Research & Programs



# Programmatic Highlights

---

## Connected More People to Resources & Support

- Updated the database of SBA clinics and healthcare providers on the SBA website
- Collected data and care plans from individual providers to share with adults who call into National Resource Center (NRC)
- Pushed new research, educational opportunities, and other information to health care professionals and researchers
- Addressed and reported 354 interactions from the National Resource Center that led to providing medical guidance and sharing health related materials to help families, health care professionals, and those living with Spina Bifida
- Held the highest attended Walk-N-Roll season

## Advanced Research Agenda

- Revamped the Professional Advisory Council to incorporate four committees aimed at enhancing the care and quality of life for individuals with Spina Bifida
- Prioritized 6 research topics through the Community-Centered Research Agenda: bowel incontinence, urinary incontinence, mental health, self-management, transition, weight management
- Reviewed and updated Guidelines for the Care of People with Spina Bifida
- Developed and presented Lifespan Bowel Management Protocol for the first time
- Planned 2023 World Congress on Spina Bifida Research and Care

# Programmatic Highlights

---

## Improved Quality of Care for People with Spina Bifida

- Established benchmarks for quality improvements with clinics in the National Spina Bifida Patient Registry
- Increased number of clinic care partners to 38
- Hosted 4 web-based SB-YOU educational programs by, for, and about adults with Spina Bifida with guidance from the Adult Advisory Council
- Marketed and recorded all educational programs to increase access
- Expanded Spina Bifida Occulta resources and developed a decision tree for finding the right provider
- Organized Clinical Care Meeting in partnership with Boston Children's Hospital

## Advanced Policy Reform

- Supported the “Work without Worry” Act
- Received a \$500,000 increase in funding for the CDC's National Spina Bifida Program
- Attended 87 congressional meetings to advocate for more federal Spina Bifida funding





# What's Ahead

## *2023-2025 Priorities*

---

### Address Adult Care Gaps

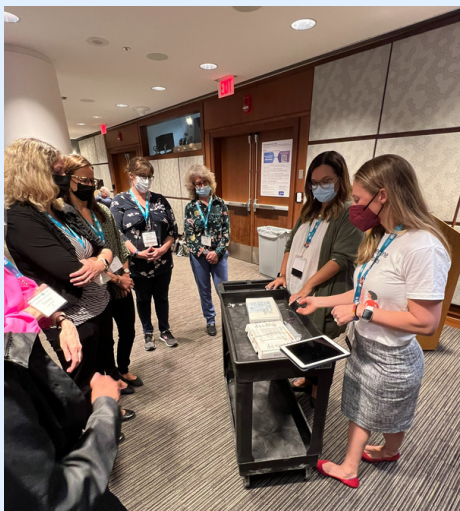
**People with Spina Bifida will have greater access to quality health care providers, equipment, medication, and supplies.**

- Increase the number of adult providers available who are knowledgeable in the care of individuals with Spina Bifida across the lifespan
- Advocate for reform of insurance payment policies to make equipment, medications, and supplies more affordable
- Collect and share information about providers and equipment to provide effective and speedy referrals and connections for families and individuals with Spina Bifida

### Improve Diagnosis Experience

**Expectant families of children with Spina Bifida will get off to the right start.**

- Improve the way the diagnosis of Spina Bifida is delivered to reduce maternal/family stress and ensure potential parents have all the options available
- Connect more newborns with Spina Bifida to qualified clinical care



# What's Ahead

## 2023-2025 Priorities

---

### Develop Better Evidence

**The Spina Bifida community will have access to better quality, more comprehensive, community-centered research and data.**

- Expand data gathering efforts to supplement the CDC Spina Bifida Patient Registry and support additional research
- Generate funded research that advances the SBA community-centered research agenda
- Facilitate robust sharing and dissemination of research at conferences, in online resources, and with other outreach activities

### Build Community

**People with Spina Bifida, their families, and care partners will be better connected to one another for support, education, and access to resources.**

- Connect more individuals with Spina Bifida and their care partners to peer groups for to information, education, and support
- Increase the sharing of information, research, and support within and across Spina Bifida peer groups



# Their Stories Are Your Stories

## Giving Tuesday

### The Kirby Family

Alone in a dark room, Jordan heard the words, “Your baby has Spina Bifida.” Jordan could sense panic as the technician frantically printed pictures, shared no words and was then quickly shuttled to a sterile room, where she waited with anticipation.

Eager to hear updates on her fraternal twins, the obstetrician unsympathetically delivered the news that the baby boy had a “lemon sign that signifies Spina Bifida,” but would not provide any further information. She was inaccurately told the Maternal Fetal Medicine Clinic would not see her for another 3-4 weeks, because the obstetrician felt the babies needed to grow. After this excruciating period of time, she was left with one option—carry to term, while awaiting results to determine her son’s level of Spina Bifida and plan of care.



### Eric Tobin

*"There's no information for me. There's just guessing. But with your help, we can create the roadmap to the best care for individuals with Spina Bifida. Pave the health pathway today!"*



# Hear Their Stories

## Appeals

---

### Maria Bournias

*"Throughout my whole life I suppressed the thought of motherhood. My yearning for a family was always met with someone guiding and persuading me to place my sights elsewhere. I was told motherhood was not a possibility. I did not know any women who*

*simultaneously had biological children and Spina Bifida. But, one day that all changed. I registered to attend a conference in Cincinnati hosted by the Spina Bifida Association. Upon arriving, I was nervous and anxious but very quickly met a woman with Spina Bifida—a mother who had given birth to her children. My mind was blown. 'Wait. You have Spina Bifida, and you have children? How is that possible?' Here I was in my 30s, a successful adult from a loving and supportive family, and I was just now discovering newfound territory that I had no clue how to navigate."*



### The Clegg Family

The Cleggs went through fertility treatments for three years, and they finally found out Nicole was pregnant—with twins! But what should have been a joyful occasion at her 19-week ultrasound was marred by the realization that “Baby A” had Spina Bifida. Instead of learning about all her options and getting an accurate picture of what life could be like if she chose to continue the

pregnancy, she instead heard phrases like “mentally different,” “severely delayed,” “dependent on a ventilator,” “probably,” and “never.”

According to Nicole, “There was a stigma placed on me that day. I’ve never been able to let go of it. I was made to believe the only reason why babies are born with a neural tube defect was from something I did wrong.”

# Thank You YOU make our mission possible.

Thank you to our amazing supporters, who donated their time, treasure, and talent. Together, we're building a better and brighter future for all those impacted by Spina Bifida.

SBA is a 501(c)(3) charitable nonprofit organization, and we depend on your donations. Your tax-deductible gifts allow us to serve the more than 166,000 individuals living in the United States today with Spina Bifida, their families, and the health care professionals who care for them.

Thank you again for providing comprehensive support, medical advancements, and opportunities for people impacted by Spina Bifida.

## Join Us

If you have additional questions or would like information on ways to give: visit [www.spinabifidaassociation.org](http://www.spinabifidaassociation.org) or contact Jenna Brown, National Director of Development, at [jbrown@sbaa.org](mailto:jbrown@sbaa.org).

EIN: 58-1342181

