

ANNUAL REPORT

2012



OUR MISSION

Since 1973, the Spina Bifida Association (SBA) has been the only national voluntary health agency dedicated solely to promoting the prevention of Spina Bifida and enhancing the lives of all affected.

PROGRAMMATIC HIGHLIGHTS

Thanks to the generosity of our supporters during 2012, SBA was able to:



During Spina Bifida Awareness Month, reach more than one million people with information about Spina Bifida, its challenges, and the life-saving effects of folic acid.



Through our National Resource Center, provide high quality, confidential information, resources, and/or referrals to more than 120,000 individuals and families whose lives have been touched by Spina Bifida.



Play host to more than 700 children and adults with Spina Bifida, their families, physicians, and other health professionals at Gearing Up for the Future, our 39th National Conference, held in Indianapolis, IN.



Convene 400 scientists and clinicians from more than 20 countries at the Second World Congress on Spina Bifida Research & Care to discuss neurosurgery, neurology, urology, developmental pediatrics, orthopedics, epidemiology and the role each plays in the future of Spina Bifida. Michele Polfuss, PhD, RN, APBP-AC/PC presented her research on how to accurately measure body composition in children with Spina Bifida, which will lead to interventions to prevent or reduce obesity. Dr. Theresa Crytzer, DPT, ATP presented her findings on whether pulmonary function or cardiac function is the leading factor limiting exercise in individuals with Spina Bifida. Both are recipients of SBA's 2011 Young Investigator Research Awards.



In recognition of Birth Defects Prevention Month and Folic Acid Awareness Week, conduct a month-long campaign to kick-start healthy habits for the SB community, posting daily tips and resources on social media; debuting a new SB University session titled Food & Folic Acid: What Every Woman Should Know (developed in partnership with the Grain Foods Foundation); producing new health information sheets on osteoporosis and SB and pain as it relates to chronic health conditions; and launching Team Spina Bifida, a new endurance program allowing individuals to compete in athletic events while helping to raise funds for Spina Bifida education, advocacy, research, and support.

Award six scholarships to students living with Spina Bifida to pursue secondary education – Emily Wheeler of Morgantown, NC; Ryan Minks of Nesbit, MS; Hannah Harkness of Elkhorn, WI; Jordan Coughlin of Point Pleasant, NJ; Emma Shreve of Charlottesville, VA; and Morgan Graham of Portland, OR.



Create Beyond Crayons, a program aimed at creating healthy school environments for students with Spina Bifida, and hold several webinars on topics such as understanding the difference between Individualized Education Programs and 504 Plans; preventing and addressing bullying; and being an effective advocate for your child.



With partner groups, develop a citizen's petition to the Food & Drug Administration seeking a review of the fortification of corn masa – a staple of the Hispanic diet – with folic acid.



Through Chapter-led and online activities, begin providing youth and young adults with Spina Bifida with valuable guidance and resources to help them navigate the challenges of transitioning to adult life through our Journey Program. Setting goals, pursuing higher education, searching for employment, building healthy relationships, and managing health and finances were just a few of the topics addressed.



Based on feedback from the SB community and health care providers, launch our new National Website at www.spinabifidaassociation.org.

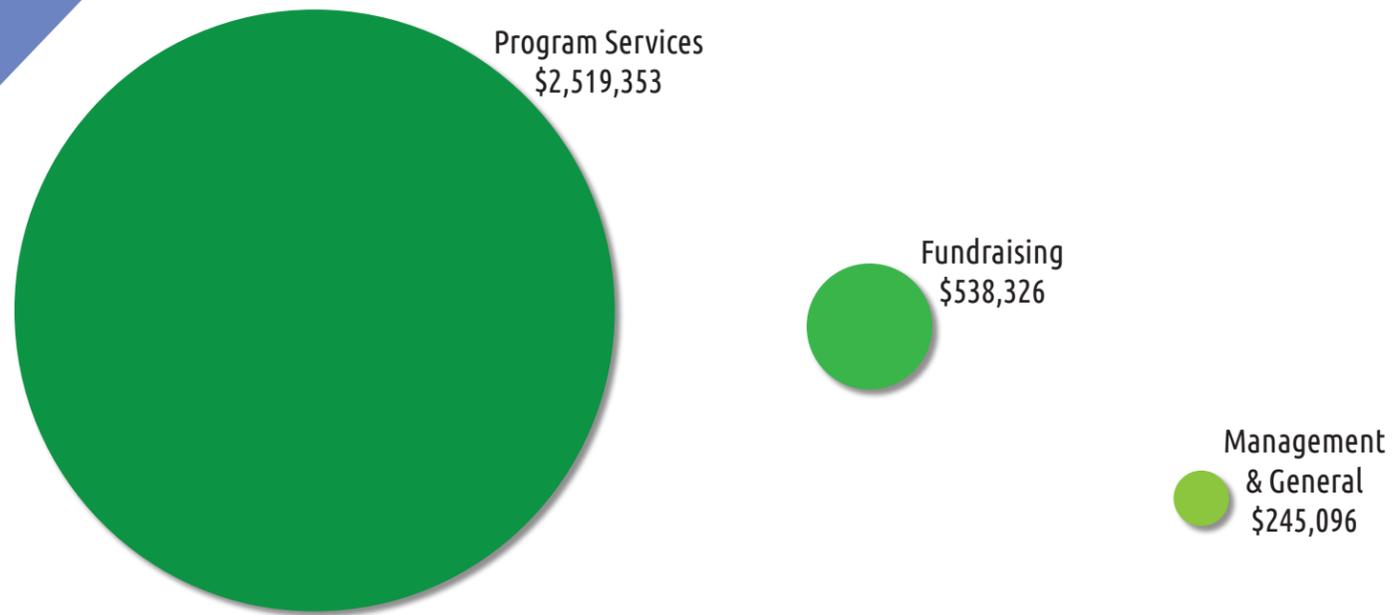


Join a Centers for Disease Control and Prevention (CDC) sponsored working group made up of leaders in the field of pediatric urological care and management tasked with identifying best practices to protect the kidneys of children from birth to 5 years and developing protocols that can be adopted by clinics across the nation, leading to improved outcomes for young – and eventually all – patients. SBA will play a pivotal role in bringing awareness to the project and encouraging the adoption of the protocols by clinics across the nation.

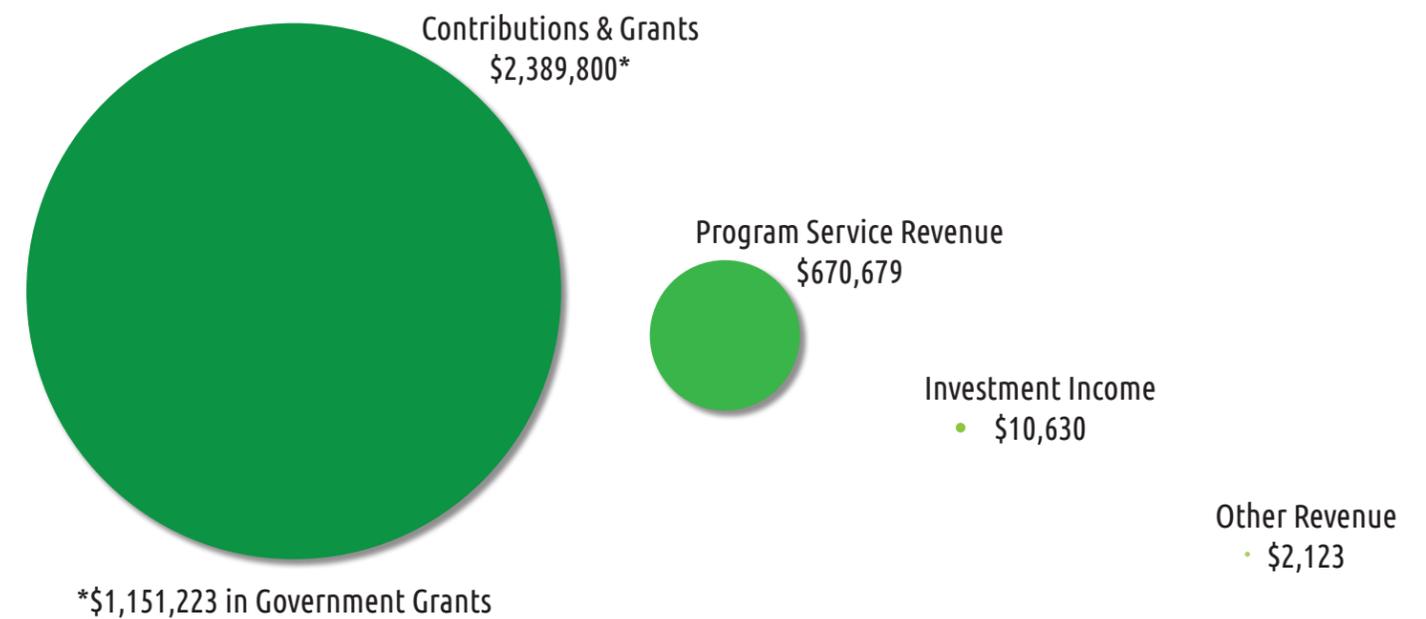


OUR FINANCIALS

EXPENSES \$3,302,775



REVENUE \$3,073,232



NET ASSETS

Beginning of Year: \$1,871,501
End of Year: \$1,633,112

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A THANK YOU TO OUR SUPPORTERS

SBA gratefully acknowledges the many individuals, corporations, and foundations who supported our work in 2012. We could not have done it without you! For more information on ways to give, please contact our Development Department at (202) 944-3285 x23 or development@sbaa.org.



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