

# 2016 ANNUAL REPORT



**SPINA BIFIDA  
ASSOCIATION**



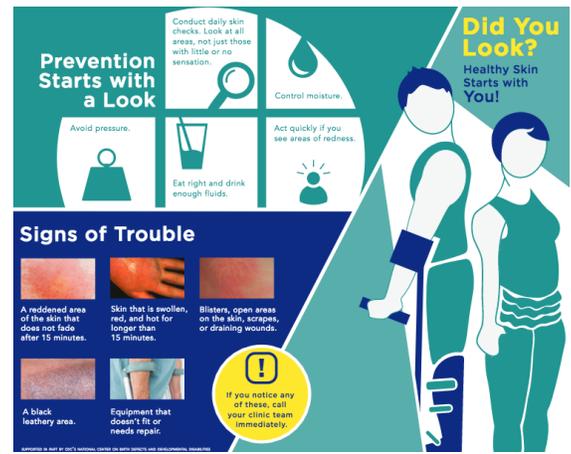
# MISSION

**The Spina Bifida Association  
promotes the prevention of Spina Bifida  
and enhances the lives of all affected.**

# ACCOMPLISHMENTS

## RESEARCH

- In partnership with the Centers for Disease Control & Prevention (CDC) and with a generous grant from Smith & Nephew, the Spina Bifida Association (SBA) completed the development of its provider and patient wound care education campaign called Did You Look?



Select clinics in the National Spina Bifida Patient Registry began sharing these materials with patients with a goal of reducing the incidence of life threatening wounds in the Spina Bifida community.

- SBA launched its Adult Spina Bifida Survey, which collected demographic, behavioral, and health care information from more than 1,000 respondents. We know that adults living with Spina Bifida struggle to find appropriate services and care, but there have been no statistics to back up those claims. Now that we have this data, we can use it to develop the plans necessary to improve care for adults living with Spina Bifida.
- SBA conducted focus groups with parents of young children and adults with Spina Bifida to gather feedback on the ongoing revisions to the Health Care Guidelines for Individuals Living with Spina Bifida across the lifespan.

# ADVOCACY

- In partnership with the March of Dimes, the National Council of La Raza, the American Academy of Pediatrics, and Gruma, SBA successfully completed its multi-year efforts to get the Food and Drug Administration to add folic acid to corn masa flour, a staple of the Hispanic diet. Hispanic women have a 30-40 percent higher risk of having a child born with a brain or spine defect, so we are hopeful that this fortification will result in fewer cases of Spina Bifida in that population.
- SBA helped secure level funding for the National Center on Birth Defects and Developmental Disabilities, which houses the National Spina Bifida Program and the National Spina Bifida Patient Registry. Data coming out of the Registry has helped launch several research studies, including the development and dissemination of urological protocols for children from birth to five years. They are now being tested in select clinics across the nation to help curb renal failure later in life.



# EDUCATION

- SBA and its corporate Chapters provided more than \$45,000 in scholarship assistance to needy families, enabling them to attend SBA's 41st National Conference in Bloomington, MN. The event, attended by more than 700 individuals with Spina Bifida and their families as well as health care professionals, Chapter



leaders, and vendors, provided attendees with the latest information on Spina Bifida treatment and care.

- SBA held another successful Spina Bifida Awareness Month in October, reaching more than 1.96 million unique users with its #BeyondAllLimits campaign and increasing awareness about health care needs, support opportunities, and advancements in research important to the Spina Bifida community.



# SUPPORT

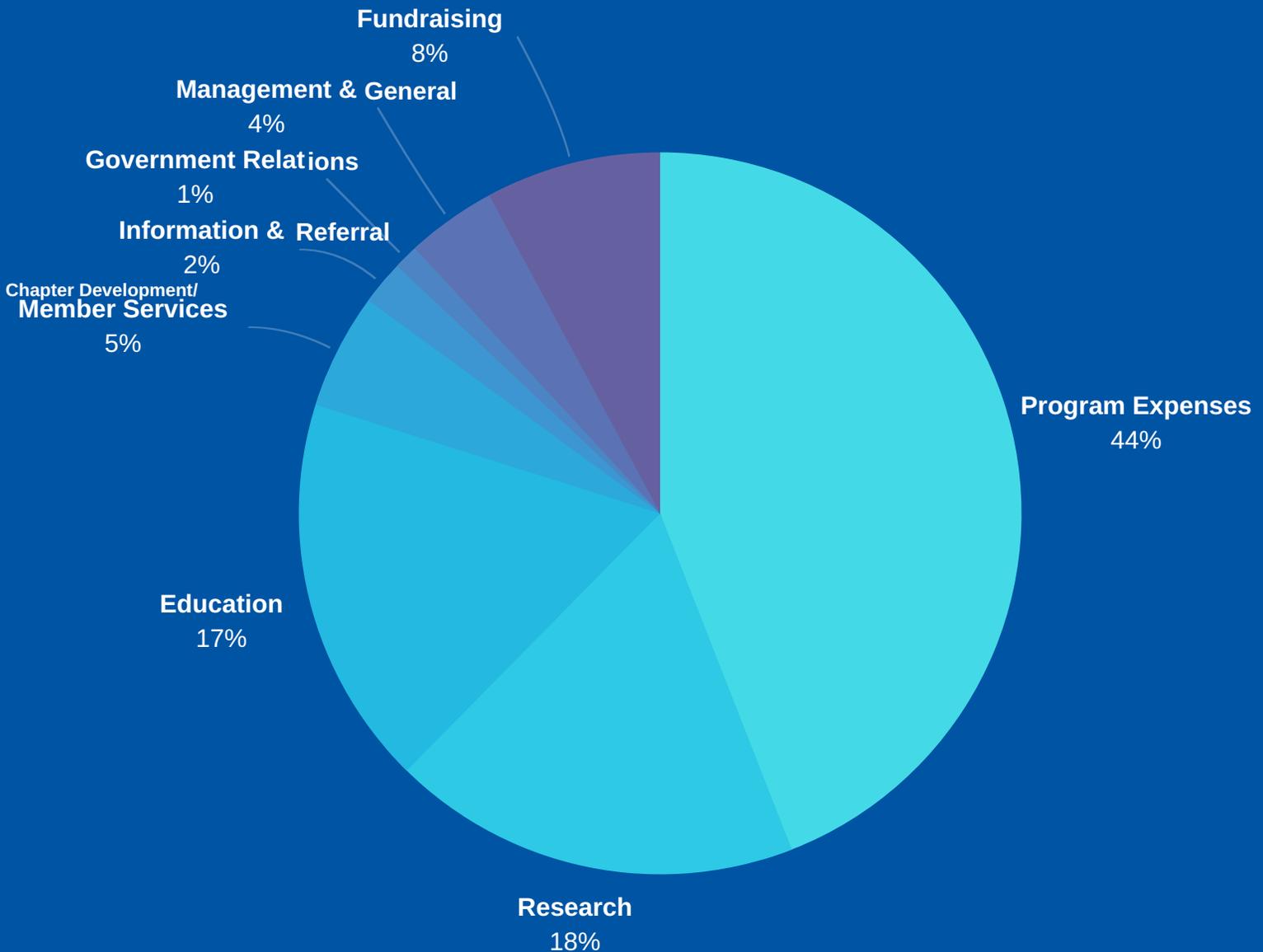
- In June, we welcomed 150 children to Kids!Camp, the only national camp specifically designed for children with Spina Bifida and their siblings. Like any other camp, Kids!Camp provides an opportunity for young people to learn new things, meet new people, and participate in physical activities, while also promoting creativity, self-esteem, and independence. It's a place where children with Spina Bifida can just be kids-not "the kid in the wheelchair" or "the kid who is different."
- SBA's National Resource Center responded to thousands of emails, phone calls, and social media messages from family members, adults, social service and health care providers, researchers, and others seeking information about services, care, and support related to living with Spina Bifida.
- SBA Chapters held 15 networking events throughout the U.S, bringing together close to 1,000 Spina Bifida community members across the country.



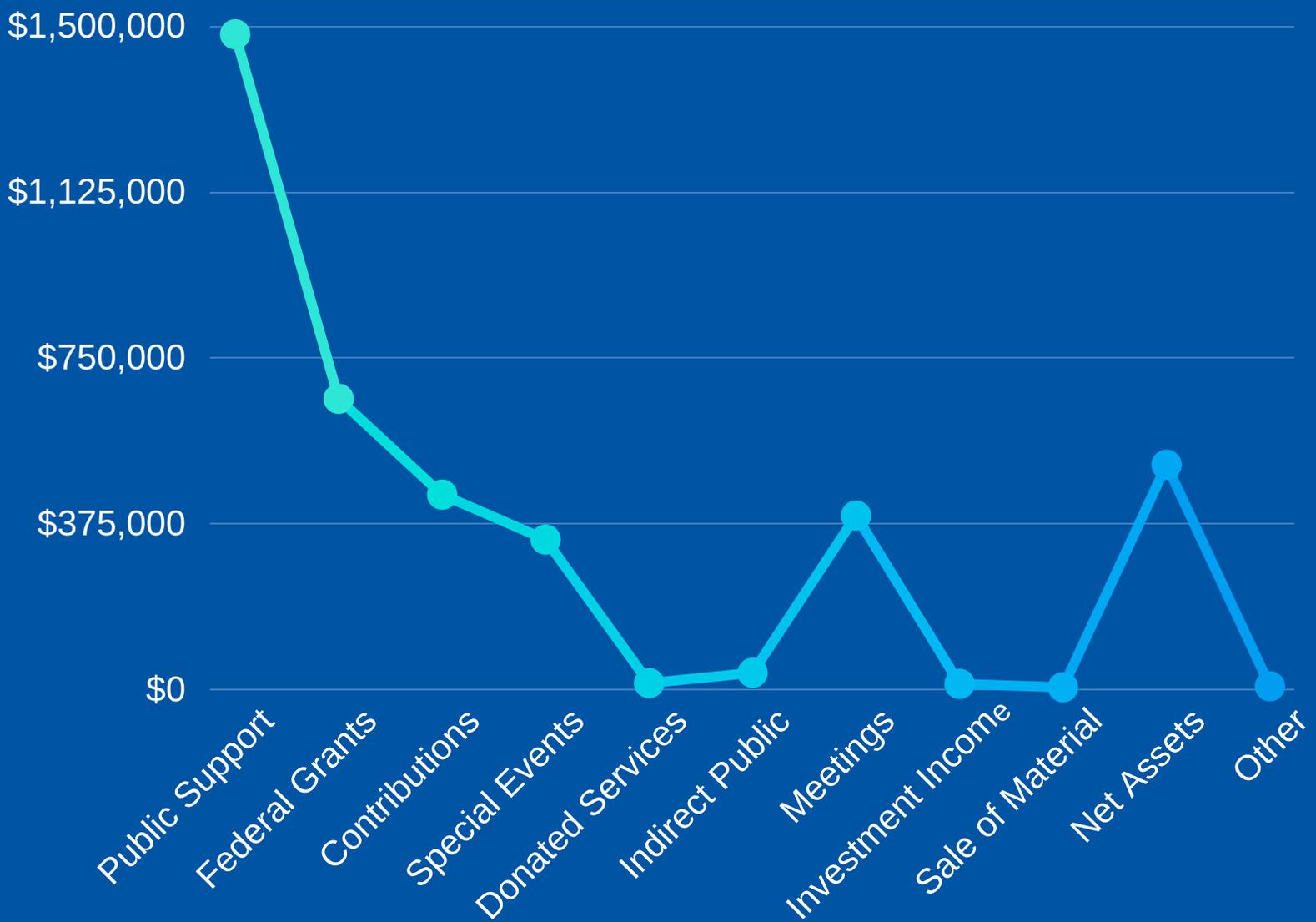


# OUR FINANCIALS

## EXPENSES: \$2,090,603



# REVENUE: \$2,397,676



# EXPENSES: \$2,090,603

Program Services: \$1,618,346  
Research - \$672,691  
Education - \$642,348  
Information & Referral - \$72,403  
Government Relations - \$40,669  
Member Services/Chapter Development - \$190,235  
Management & General: \$184,245  
Fundraising: \$288,012

# REVENUE: \$2,397,676

Public Support: \$1,480,340  
Federal Grants - \$655,708  
Foundation Grants and Contributions - \$438,883  
Special Events - \$337,231  
Donated Services - \$12,604  
Indirect Public Support (Federated Fundraising Orgs): \$35,914  
Management & General: \$184,245  
Fundraising: \$288,012  
Conferences and Meetings: \$391,556  
Investment Income: \$10,725  
Sale of Materials/Services: \$3,125  
Net Assets Released from Restrictions: \$506,470  
Other Revenue: \$5,460

Net Assets Beginning of Year: \$199,530  
Net Assets End of Year: \$506,603

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# OUR SUPPORTERS

We thank the many individuals, corporations, and foundations who supported our work in 2016, and our Board of Directors, Advisory Councils, and volunteers who donated their time and energy.

SBA is a 501(c)(3) charitable nonprofit organization, and we depend on your donations. Your tax-deductible gifts allow us to provide research, advocacy, education, and support to the more than 177,000 individuals living in the United States today with Spina Bifida and their families.

To use resources wisely, we have opted not to publish a list of our supporters in this report. If you have questions or concerns or would like information on ways to give, please contact Elizabeth Merck, Director of Development, at [emerck@sbaa.org](mailto:emerck@sbaa.org) or (202) 618-4754.

## OUR CONTACT INFO

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