

# 2018 ANNUAL IMPACT REPORT

Accomplishing the mission to help all families living with Fragile X, today and tomorrow, always begins with you. Through your donations and volunteer work, the NFXF was, once again, able to accomplish our mission to provide unwavering support for every family affected by Fragile X, while relentlessly pursuing a cure.

We want you to know that every single one of our successes, both locally and nationally, happen because of your support. It is your donations, your volunteer work, and your continued participation in the Fragile X community that keeps the National Fragile X Foundation going strong. We could not do what we do without you – Together, We're Stronger!

This report highlights our impact in our three mission areas and our audited financial statement for 2018. View our financials, IRS 990, and download this report at fragilex.org/financials.



### **Community Support**

To assist and educate individuals and families living with Fragile X in all stages of life, through outreach and personal support.



**800+** family consults/ support provided



9 X Strides walks/runs



## 63 Community Support Network groups:

26 chapters, 9 community partners, and 28 parent contacts



Nearly **200** support, education, awareness, and fundraising events



**32** FXCRC Fragile X clinics



**164** Fly With Me Fund travel awards to assist families to travel to a Fragile X clinic.



## Education/Awareness /Advocacy

To educate Fragile X caregivers and medical providers, increase public and professional awareness of Fragile X, and to influence public policy to fund research and to improve the lives of those living with Fragile X and other intellectual and developmental disabilities.



**800+** Conference attendees, with **\$70K+** in scholarships



**1000+** on-demand viewers of Conference sessions



**168** Conference presentations/papers



**2,377** copies of Fragile X 101 ebooks delivered



**130** Congressional office visits during Advocacy Day



**66** STAR Local Advocates



**300K+** website visitors



**1M+ views** of Facebook posts during Awareness Month



#### Research

To fund and facilitate research that drives scientific and medical advances towards effective treatments and a cure.



**\$42M+** in federal investment for research in 2018; **\$493M+** since 2008



**\$7500** Summer Scholar Research Grants



**10** Junior Investigator awards to attend the Conference



**20** grants awarded to FXCRC clinics to support their services and research coordination



The FORWARD natural history study continues in 22 US sites. It is the largest resource of clinical and demographic data for the FXS population in the United States.



**25** trials and studies we helped market and recruit participants



Approximately **100** sets of Research Ready Material™ collected and stored in the NEXE Biobank