2019 IMPACT REPORT

A summary of the highlights of our impact in 2019, made possible with the support of our generous donors.

COMMUNITY

1,000+ family consults provided

CSN groups

20 Chapters

10 Community Partners

150 number of community events

94 Fly With Me Fund travel awards to assist families to travel to a Fragile X clinic

10 “Anything for Fragile X” Fundraisers raised $87,544

6 X Strides walk events raised $81,221

64 Facebook birthday fundraisers raised $69,952

RESEARCH FACILITATION

$10,000 in Summer Scholar Research Grants

$38.5M+ in federal investment for research in 2019, $531.5M+ since 2008

participants connected to researchers through MyFXResearch Portal

41 trials, studies, and surveys for which the NFXF helped market and recruit participants

734 families signed up to receive NFXF research updates

The FORWARD natural history study continues in new peer-reviewed articles published from FORWARD data

400+ in collection of Parent and Clinician form data sets from Year 1-Year 4 (from 188 to 406)

22 US sites

116% increase

Launch of two new initiatives: MyFXResearch Portal and the NFXF Research Readiness Program™

EDUCATION & AWARENESS

7 educational webinars

1700 copies of Fragile X 1010 delivered

250K number of website visitors

117 number of Congressional office visits during Advocacy Day

1.4M number of social media impressions during Awareness Month