

2019 IMPACT REPORT

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




NATIONAL FRAGILE X
FOUNDATION



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

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


\$10,000
in Summer Scholar
Research Grants

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

 participants
connected to
researchers
through
734 MyFXResearch
Portal

 families
signed up
to receive
400+ NFXF
research
updates

The FORWARD
natural history
study continues in
22 
US sites

 **4**
new peer-reviewed articles
published from FORWARD data

 **116%**
increase in collection of Parent
and Clinician form data
sets from Year 1 -Year 4
(from 188 to 406)

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