

2020 IMPACT REPORT



– Turning challenges into opportunities

In 2020, our community rallied together. Because of you, our small but mighty organization was well-positioned to quickly respond to the uncertainty and upheaval the pandemic introduced into our community's lives. We responded with new and timely resources related to the changes in routines (a daunting task for families in the best of times) and tools to help manage a whole new set of stressful situations. Thank you for making this invaluable work possible... you made a real difference in the lives of everyone living with Fragile X this past year!

OUR DONORS, VOLUNTEERS, PROFESSIONALS, AND FUNDRAISERS MAKE WHAT WE DO POSSIBLE!

- 1,000+** Volunteers
- 2,270** Donors
- 229** Facebook and Anything for Fragile X Fundraisers
- 1,545** Facebook Donors
- 560** X Strides supporters from 31 states and 5 countries
- 130** Authors, Conference & Webinar Presenters



Here are some highlights of the impact you made possible in 2020:

FACILITATING RESEARCH & TREATMENTS

\$38.5M+

\$38.5M+ in federal investment for research in 2020, **\$505.5M+** since 2008 – thanks to 140+ advocacy meetings with members of Congress in 2020!

10

NFXF Research Readiness Program™ consultations to provide every researcher the opportunity to engage with experts and families to ensure proposed research studies are scientifically sound, relevant, and patient-centric

421

Participants connected to researchers through MyFXResearch, moving research forward

337

Registrants with the International Fragile X Premutation Registry, a key step in advancing research for FX-associated disorders

22

Sites participating in the FORWARD natural history study

3,752

Participants have enrolled into the FORWARD Registry

BUILDING COMMUNITY

1,000+

Family consults provided

16

Community Support Network Coffee Talk webinars

29

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

MONTHLY

Siblings and Self Advocates Dance Parties, Chats and Virtual Graduation

40+

Community Support Network virtual events

322

X Strides participants, 12 chapters, from 31 states and 5 countries

12

Community Virtual Happy Hour and Conference Meet-Ups

CREATING AWARENESS & PROVIDING EDUCATION

98

First Virtual International Fragile X Conference: 98 presentations over 5 days – many thanks to our presenters who enthusiastically embraced Zoom technology!

2,796

E-books delivered – FXS 101 and Adults with FXS

23

Articles and videos on Covid resources

3,684

On-demand conference video viewers

2,367

Webinar attendees