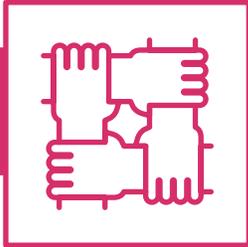


NATIONAL **FRAGILE X**  
FOUNDATION

# 2019-2023

## STRATEGIC PRIORITIES

The National Fragile X Foundation (NFXF) Strategic Priorities serve as our roadmap for guiding the organization in executing its mission to provide unwavering support to the Fragile X community while relentlessly pursuing a cure.



## #1 STRATEGIC PRIORITY: COMMUNITY

### WHY DO WE DO IT?

The NFXF recognizes that the often-unexpected Fragile X journey can be challenging at every stage of life. We know from 35 years of experience serving the FX Community, that the individuals and families who successfully navigate this journey do so by committing to learning and understanding everything from managing behavior to the underlying science of FX-associated disorders. Our goal is to serve as the premier hub of engagement, education, information, and support for the global Fragile X community.

### WHAT DO WE DO?

The NFXF commits to achieving this goal by focusing our resources on these Community-related activities:



Connecting families with one another and with academia, media, clinical, research, and industry groups and education, financial, and local resources



Maintaining a robust and comprehensive online presence, publishing and sharing information important to the entire community across the lifespan



Engaging our constituents to “pay it forward” ensuring that the services and support they received will be available for the future newly diagnosed families



Supporting a national network of chapters, parent contacts, community partners and volunteers to extend our reach by delivering our mission on a local level



Developing a professional certification program to attract and grow interest of treatment practitioners and educators to continue their knowledge and understanding of FX



Connecting distinct interest groups, including self-advocates, parents, and siblings, scientific, clinical, and research professionals, pharma and bio-medical industry, and government through access and information

### WHO WE DO IT WITH?

To achieve this goal, the NFXF engages these important stakeholders to achieve the sense of community necessary to master the knowledge and experience to stand up to Fragile X.



Families



Volunteers



Donors



Educators



Community Support Chapter & Regional leaders



Self-advocates & Siblings



Community Partners



Government



Basic & Clinical Research Scientists



Pharma Industry Partners

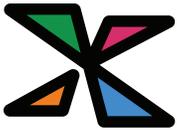


Medical & Clinical Professionals

### HOW WE MEASURE SUCCESS?

We will know that we have been effective at maintaining and growing the FX Community by:

- Growing the number of engaged chapters & community partners
- Growing the relationships with government representatives
- Creating opportunities for engagement with the community



## #2 STRATEGIC PRIORITY: RESEARCH FACILITATION

### WHY DO WE DO IT?

The NFXF recognizes that research studies play the most important role in identifying effective treatment options for all FX-associated disorders. While a cure for FX is also important, our goal is to ensure we do everything possible to facilitate research that will make life with FX better today and after a cure is discovered.

### WHAT DO WE DO?

The NFXF commits to achieving this goal by focusing our resources on these Research Facilitation initiatives:

- 1** Establishing proactive partnerships to solidify business opportunities with pharma & other Industry partners
  - Create process for clinical trial consultations to ensure positive and successful research outcomes for families and researchers
  - Develop new program to inform and educate patients and families about the importance of research studies and their valuable role in the process
  - Marketing services for research studies to various segments of the FX community
- 2** Partnering with other organizations to take advantage of federal funding opportunities
  - CDC FORWARD Longitudinal Database & Registry; increasing the number of peer-reviewed research publications
  - NIH Rare Diseases Consortium application
- 3** Funding grants to FX Clinics nationwide to ensure access to and effectiveness of FX treatments in addition to supporting the development of research-ready sites
- 4** Funding the NFXF Biobank designed to efficiently/effectively advance the research timeline
  - Leveraging an intellectual property strategy to provide a "return on investment" option for financially beneficial research discoveries
- 5** Funding research grants to post-doctoral and junior scientists to further develop their work in the field of FX

### WHO WE DO IT WITH?

To achieve this goal, the NFXF engages these important stakeholders to effectively facilitate research:



Families



Medical & Clinical Professionals



Donors



Pharma Industry Partners

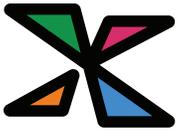


Basic & Clinical Research Scientists

### HOW WE MEASURE SUCCESS?

We will know that we have been successful at facilitating research by accomplishing these objectives:

- Developing Pharma and other Industry as meaningful business partners
- Increasing our financial investment in FXCRC clinics to support their infrastructure
- Increasing opportunities to partner with other FX organizations to facilitate research
- Confirming accurate prevalence numbers for FXS
- Increasing numbers of researchers committed to the field



## #3 STRATEGIC PRIORITY: EDUCATION AND AWARENESS

### WHY DO WE DO IT?

The NFXF recognizes that general public awareness of FX-associated disorders can be helpful in achieving acceptance, dedicated resources and support in education, jobs and independent living as well as empathy and understanding for families caring for loved ones living with Fragile X. In addition, the NFXF recognizes that improving professional awareness of FX is imperative for early diagnosis.

Our goals are to increase professional awareness – medical providers, genetic counselors, neurologists, educators and therapists to improve the rate/accuracy of diagnosis. And to serve as the voice of Fragile X, promoting awareness through local and national education and advocacy efforts.

### WHAT DO WE DO?

The NFXF commits to achieving this goal by focusing our resources on these Research Facilitation initiatives:

- 1 Facilitating training programs to develop the next generation of knowledgeable FX treatment practitioners
- 2 Growing and maintaining the NFXF website as a source of quality educational content
  - Creating/curating and regularly updating evidence and consensus-based educational and informational content for website publication
  - Increasing access to FX information and resources through an expanded menu of online webinars and local educational events
- 3 Supporting the efforts of CSN chapters to deliver local/regional educational events for families and professionals
- 4 Driving local and national advocacy efforts, including annual Advocacy Day to ensure continuance of federal spending for FX research
  - Continuing effective government relations efforts to grow opportunities to increase effective public policy for the intellectual disability community
- 5 Increased collaborations with international parent support groups and FX Clinics

### WHO WE DO IT WITH?

To achieve these goals, the NFXF engages these important stakeholders to effectively increase awareness:

- |   |   |
|---|---|
|  Medical & Clinical Professionals      |  Educators       |
|  Pharma Industry Partners              |  Media Relations |
|  CSN Regional and Chapter leadership |  Families      |
|  Community Partners                  |  Donors        |
|  Members of Congress                 |   |

### HOW WE MEASURE SUCCESS?

We will know that we have been successful at creating awareness by accomplishing these objectives:

- Increased educational content and resources
- Additional educational opportunities via current and new technologies
- Improved access to in-person educational opportunities
- Lowering the age of diagnosis for FXS
- Ensuring that FXCRC member clinics are providing the full spectrum of care
- Improved network of global support & treatment opportunities