

## What are the responsibilities of NFXF LINKS Leaders?

LINKS Groups are defined as one or more individuals united by the common mission of providing support, creating awareness and educational opportunities and participating in advocacy efforts. To accomplish this mission, LINKS Leaders are expected to:

### Establish and Maintain a Vital Group

- ☞ Actively recruit new members and publicize group contact information and activities
- ☞ Develop and maintain communication systems to retain and keep members informed
- ☞ Establish and maintain a contact directory of group members
- ☞ Keep records of all new member inquiries received and schedule periodic follow-up calls/emails
- ☞ Hold regular group meetings by phone or in person – quarterly at minimum
- ☞ Include mention of your group name on your home answering machine
- ☞ Work with the NFXF on outreach efforts to other families in your area
- ☞ Respond in a timely manner to all requests for information made by the NFXF
- ☞ Keep the NFXF informed of any change in your status as a group or your contact information

### Provide Support

- ☞ Coordinate and implement at least one social and/or family event per calendar year
- ☞ Assemble and maintain current a directory of physicians, therapists, FX Clinics, education consultants and support groups with expertise in FX, as well as other local referral information
- ☞ Establish a good working knowledge of access to special education services in your area
- ☞ Refrain from giving advice one is not qualified to give (i.e. medical advice unless one is a physician etc.)
- ☞ Refrain from disseminating information under the “auspices” of the NFXF contrary to NFXF policy (i.e. untested treatment ideas, "cures", solicitation for organizations other than the NFXF or your group, junk science, etc.)
- ☞ Establish and maintain a strong working relationship with the Fragile X clinic in your area or help identify potential clinic sites

### Create Awareness

- ☞ Use the National Fragile X Foundation name, contact information and logo on all group publications
- ☞ Establish relationships with local media outlets for dissemination of NFXF press releases, PSA,s or personal stories

### Educate Yourself and Others

- ☞ Regularly read the Foundation Quarterly journal
- ☞ Participate in quarterly conference calls with national or regional program coordinator
- ☞ Attend biennial international FX Conference and related LINKS events i.e. luncheon, training meeting, etc. (*Scholarship assistance may be available*)
- ☞ Organize educational events in your area utilizing local and/or national FX experts

### Raise Money

- ☞ Organize fundraising activities in support of local group activities and NFXF programs
- ☞ Encourage contributions to NFXF at either an individual level or as part of organized fundraising activities
- ☞ Maintain current membership status with the NFXF; encourage group members to become &/or renew their NFXF memberships. Current members receive significant discounts to the biennial International FX conferences.

### Advocacy

- ☞ Become a registered Advocate
- ☞ Respond appropriately to all Advocacy Alerts
- ☞ Attempt to attend an annual Advocacy Day in DC

**What should LINKS Leaders expect from the NFXF?** The NFXF is committed to supporting the efforts of all volunteer leaders in the following ways:

### Establish and Maintain a Vital Group

- ④ Refer all new diagnosis/new member's contacts residing in your area.
- ④ Help with the development of an NFXF-hosted group website
- ④ Provide a complete resource library of FX books and multimedia
- ④ Provide a regular supply of special topics brochures, flyers, and *Foundation Quarterly* journals as needed
- ④ Help with the design/edit/ review all group mailings
- ④ Conduct mailings on your behalf announcing group events and activities to NFXF database records in your area
- ④ Provide customized labels (*group name and contact information*) for the FXD brochure upon request
- ④ Maintain an accurate and up-to-date NFXF LINKS website directory
- ④ Provide assistance with establishing and maintaining a strong working relationship with your local FX Clinic
- ④ Provide access to LINKS Online Toolbox with how- to guidelines for support, awareness, education, fundraising, advocacy and FX clinics activities

### Provide Support

- ④ Maintain an up-to-date website with recent and accurate information about all Fragile X-associated disorders
- ④ Provide toll-free phone and email support for consultations regarding diagnosis and treatment issues

### Create Awareness

- ④ Publicize group activities and results on the NFXF website calendar and in the *Foundation Quarterly* &/or in the *ConneXions* e-News

### Educate Yourself and Others

- ④ Subscription to *ConneXions* monthly e-Newsletter for NFXF LINKS groups
- ④ Complimentary issues for distribution to group members of the *Foundation Quarterly* journal
- ④ Provide up-to-date information on the latest findings/happenings in the FX community
- ④ Provide regular leadership development opportunities

### Raise Money

- ④ Provide consultation and assistance with planning group events and activities.
- ④ Provide Managed Account Services for receipt on tax-deductible donations on your group's behalf

### Advocacy

- ④ Organize Washington DC based advocacy effort annually to influence federal government support for FX
- ④ Communicate year-long advocacy efforts and results in a timely manner

## L.I.N.K.S

*Linking Individuals in Knowledge and Support*

a program of the



The National **Fragile X** Foundation