

## Parent or Professional Contact Information

Welcome to the network of Parent and Professionals Contacts affiliated with The National Fragile X Foundation. The more local contacts we have, the better able we are to put people in touch with those "who have been there".

**Parent Contacts** are parents who agree to have their contact information made available to other parents and or individuals in their area, especially those with newly diagnosed children.

**Professional Contacts** including physicians, therapists, educators, and counselors as well as their respective institutions also agree to have their contact information made available to anyone in their area contacting the NFXF.

### Our obligation to you:

- ④ To refer all parents and or individuals to you, from your area, who contact the National Fragile X Foundation seeking information regarding local community resources or just someone to talk who is familiar with FX
- ④ To maintain our toll-free 800 number, email and website [www.FragileX.org](http://www.FragileX.org) so that families can contact us at no cost and be referred to you
- ④ To keep you regularly informed on the latest activities at the NFXF and in the FX Community; all Parent and Professional contacts receive complimentary issues of the *Foundation Quarterly* journal and our monthly eNews *Fragile Xtras*

### Your responsibilities to the NFXF:

- ④ To support The National Fragile X Foundation's mission of increasing awareness and education by encouraging families to become members of the foundation.
- ④ To assemble and keep current a listing of physicians, therapists, test centers, education consultants and support groups with expertise in FX, as well as other local referral information
- ④ To refrain from disseminating information under the "auspices" of the NFXF contrary to NFXF policy (i.e. untested treatment ideas, "cures", solicitation for groups other than the NFXF or your group, junk science, etc.)
- ④ To refrain from giving advice one is not qualified to give (i.e. medical advice unless one is a physician etc.).
- ④ To keep the NFXF informed of any change in your status as a Parent Contact or Professional Contact and any changes to your contact information.
- ④ To maintain an active membership with the NFXF; free one year memberships available upon request.