

PRESIDENT'S NOTES

Don Bailey



Full Speed Ahead on FX Family Survey

In the fall of 2006 the Centers for Disease Control funded a two-year project at Research Triangle Institute (RTI) International in North Carolina, where I now conduct research on Fragile X. The project involves a national assessment of the needs of families that include children with fragile X syndrome. This is the first national survey of such families, and it has provided us with an exciting opportunity to learn more about FXS so that the information can be used to shape future policy and improve practice.

Because we did not have a large database of family names, we had to rely on organizations and researchers to help. The National Fragile X Foundation, FRAXA Research Foundation, Conquer Fragile X, and several researchers around the country agreed to send information about the survey to families on their mailing lists. For confidentiality reasons, names could not be given directly to RTI, so many of you probably got several announcements. (Sorry!)


The fall of 2007 was the enrollment phase of the study. Families could enroll online or call a toll-free number. During enrollment, families were asked to provide general information about their family as a whole, and also specific information about each family member. The response was great—nearly 1,300 families agreed to participate in the survey!

In the spring of 2008, we developed and distributed the full survey. Using feedback from researchers, clinicians, and families, we formulated several topic areas that were addressed by a series of questions. We organized the

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topics into three sections. The first section focused on family needs and how FXS affects family life. The second section focused on the skills, strengths, services, and needs of children with FXS. The last section asked families their opinions on issues such as newborn screening and participation in clinical trials.

As I write this column, more than 400 families have already completed the full survey. By May, we collected enough data to begin our analyses. We plan to summarize the major findings at the International Conference in St. Louis. However, it is still not too late to help us get the fullest possible picture on the important questions in this survey. If you have not yet enrolled and would like to do so, please go to <https://fragilex.rti.org>. The national picture we develop from this and other surveys will help guide research, practice, and policy recommendations over the next few years.

I would like to thank all of the families who have taken the time to participate. Although many studies have been conducted with families of children with FXS, this is the first to survey a very large number of families. Most families agreed to allow their names to be kept in a confidential survey research registry, so that they can be invited to participate in future studies. 

Don Bailey, PhD, is president of the NFXF Board of Directors and distinguished fellow at RTI International in Research Triangle Park, NC. He will be a presenter at the NFXF International Conference in July. Email: dbailey@rti.org

