

WHAT PRICE AWARENESS?

As most of you know, the NFXF has been spreading awareness about Fragile X since its inception in 1984. Most of our efforts have been focused on medical, therapeutic, educational and counseling professionals. We have made great strides in reaching those professional groups. In most of the country we have moved beyond “Fragile what?” to “Fragile X, yes, I’ve heard of that.” (Or some such comment to indicate that the person has at least a vague awareness that Fragile X is a real and important condition that needs to be further assessed.) Rarely do we now hear of medical doctors who express total unawareness about the condition, or who are ordering outdated tests to determine whether a patient indeed has Fragile X.

We are certain that three recent efforts of ours have made a huge difference in awareness: 1) Every pediatrician in the U.S. has received a fragile X syndrome informational postcard from us; 2) Every neurologist has received a fragile X-associated tremor/ataxia syndrome postcard; 3) Every OB/GYN has received a fragile X-associated premature ovarian failure postcard. (These efforts, undertaken in conjunction with the CDC and the UC Davis M.I.N.D. Institute, have totaled more than 100,000 postcards!)

That said, general public awareness has been a harder nut to crack. Thousands of broadcasts of our public service announcements for television since 2000, equating to millions of viewers, have helped, but in a nation of 300 million (with nearly as many television channels!) and competition with hundreds of other conditions for viewers attention, it hasn’t been easy. Nonetheless, we have persevered. Your efforts, dear reader, have really helped, and Linda Sorensen’s “Focus on Volunteers” column on page 28 underscores that point.

But we never imagined the kind of awareness that came with the recent tragedy involving wrestler Chris Benoit and his wife and son. Like it or not, though, awareness is what we got. Gobs of it. As in 30,000 visitors to our website in three days. (A number typical for an entire month!) People tripping all over each other to report on the role that fragile X syndrome played in this terrible murder-suicide. Unfortunately, in most instances, they got it wrong. Once the first wave of sensational media accounts had passed, no reporter could find any evidence that Chris Benoit killed his wife and son and then himself because his son had fragile X syndrome. Chris Benoit did what he did for reasons far deeper and more complex than what having a child with a disability would ever cause. In short, Chris Benoit had his own, personal demons. (To this day, it is unclear whether his son even had FXS, and it will probably never be known.) But then, it really didn’t matter. The tabloid journalists and bloggers of the world had their

simplistic story: Disability = Hopelessness = Tragedy. A perfect formula, if they ever saw one, for attracting readers and the advertisers that follow them.

Whatever its shortcomings, once the Benoit story was out, all that was left for us was to respond to the best of our ability. As the story began to unfold in those first days, the NFXF issued a press release for national distribution, while my staff and I fielded questions from People magazine, Inside Edition and others. Throughout, we had one overriding goal: counter the perception that FXS is a hopeless condition. Yes, it can feel hopeless at times. Yes, it can be overwhelming. Yes, it can lead to sadness, depression, and feelings of anger. But it is not hopeless. Far from it, say the thousands of families who contact the NFXF each year. On the contrary, it is the love and pride that parents have for their son or daughter with FXS that comes through so clearly. It is the plans and dreams that they have for their children's futures that they want to tell us about.

So: awareness? Sure. We'll keep plugging away at that, now and in the future. But just as important, we'll be working for better treatments and improved access to care, greater self-determination, and more opportunities for involvement and success in this world.

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