

Connecticut Fragile X Awareness Day Testimony

To: Members of the GAE Committee
From: Andrew Selinger
Subject: Connecticut Fragile X Awareness Day
Date: March 23, 2009

Madame Chair/Mr. Chairman and members of the committee, I am Andrew Selinger from West Hartford. I am here to support S. B. No. 337 which would establish an annual Fragile X Awareness Day on September 12. This year it will be on the day of the Fragile X Society of Connecticut's 2nd Annual Conference.

Fragile X gets its name from a fragile site on the X chromosome. Its impact can be anything from a mild learning disability to profound intellectual disability. The Fragile X-associated disorders encompass a spectrum of conditions that affect individuals and families throughout the life cycle. As many as 1 in 130 women and 1 in 700 men are estimated to be carriers of the Fragile X mutation.

Both my children, Jodi, 18, and Brian, 15, were diagnosed with Fragile X syndrome in 1994. We received their diagnoses within two weeks of each other. We are very fortunate to have received diagnosis for Jodi at 3-1/2 years old and for Brian at 9 months old. After diagnosing Jodi with autism, the developmental pediatrician/geneticist suggested testing for Fragile X because of the relationship between Fragile X and autism. This early diagnosis enabled us to give our children the opportunity to maximize their potential. Even with receiving early intervention and special education services throughout their lives, Brian and Jodi are extremely impacted and face many challenges daily. Jodi is now in a program learning vocational and life skills. Brian, being severely affected by Fragile X syndrome, has been a residential student at the New England Center for Children in Massachusetts since the age of 10.

A year after the diagnoses, in 1995, my wife and I reestablished the Fragile X Society of Connecticut. Although we were extremely impacted, we knew that we had to do whatever we could to get the word out about Fragile X. We feel so strongly about the need for awareness that we were the subjects of a Hartford Courant front page story about the impact of Fragile X on our family.

At the beginning of this month I traveled to Washington, DC along with five other Connecticut residents to advocate on Capitol Hill for funding for Fragile X. We joined 130 other advocates from 35 states in this effort. Attached to my written testimony you will see an article that was published in "The Hill" called "Addressing Fragile X" about Representative Gregg Harper's experience with Fragile X.

Increasing the awareness of Fragile X is critical. There are still too many people who say "Fragile What?"

Addressing Fragile X

By Betsy Rothstein

Posted: 03/02/09 04:50 PM [ET]

Rep. Gregg Harper (R-Miss.) and his wife, Sidney, weren't sure when they were going to start having babies.

They were married nearly 10 years when "we got pregnant." Harper likes to use the word "we" because, he says, "we" are in it together.

The delivery of their first child, Livingston, was normal. Everything seemed fine.

But soon, Harper and his wife noticed certain things about their son: his difficulty in walking; his hand-flapping; his rocking. At 11 months the parents expressed concern to the pediatrician that Livingston wasn't walking. At 12 months (the ordinary range is nine months to a year), he began.

"Over a period of time, all the milestones were at the end of the late-normal range and we didn't think a lot of them," says Harper in a phone interview from his district office in Pearl, Miss.

But four months after the birth of their second child came the wakeup call. The couple went out of town for a few days, and grandparents were caring for Livingston. He got sick and was taken to the pediatrician — and that's when the doctor discovered something was wrong.

The doctor, a friend, came over to the Harpers' home to deliver the news. The doctor couldn't say what specifically was wrong, just that something was.

"As you can imagine, it was a tough thing," Harper recalls.

Harper and his wife began taking Livingston to different doctors, experts and early intervention programs due to the developmental delays he was experiencing. At 20 months old, their son began weekly occupational and speech therapies. A local university hospital did a genetic test that came back with a misdiagnosis of cerebral palsy; the couple was told the child was a near-miss on autism.

When Livingston turned 4, Harper likes to say, a spiritual intervention occurred. A neighbor who headed all the special-education programs for the county public schools attended a seminar that included a session on children with Fragile X syndrome.

"She had no idea what it was, but her mouth fell open," Harper says. "She said, 'I think this is it.'"

Harper praises God, calling it "a little testimonial that God does indeed direct our path. I don't know that we would have ever stumbled across it."

Sure enough, a genetic test confirmed Livingston's condition. Doctors sent his blood for testing to a lab in South Carolina. They took him to Denver to a children's hospital to meet with Randi Hagerman, the leading pediatrician on Fragile X, who has written a textbook on the subject.

Harper says doctors have told him that Fragile X can often be confused for autism or Down syndrome. The children with it often exhibit speech delays and motor-skill problems, an

awkward walk and lack of coordination.

This Wednesday, Harper welcomes parents of children with Fragile X from around the nation to Capitol Hill. The purpose is to raise awareness on the illness and to put pressure on Congress to fund medical research for it. "We just want to make sure that when they are slicing up the pie that Fragile X is looked at, because it hasn't gotten as much as it needs," says Harper.

The congressman opposed the stimulus package. For philosophical reasons he opposes embryonic stem cell research. "That doesn't decrease the love I have for my son, but there are some things that are bigger than we are," he says.

At first, Harper struggled deeply with his son's condition. "On one hand you're glad to finally have a diagnosis, but you're pretty well devastated," says Harper, his voice breaking. "You cry a lot and you pray a lot. And then you get to work. We were determined we would live in a regular world."

They put Livingston into inclusion classes, a mix of regular and special-needs children.

Livingston, now 19, lives at home with his parents. He attends the local community college. In years to come the Harpers hope to have him living on his own with minor supervision.

They have raised him, in some ways, as they would have any other child. They have discovered his love of music. Harper says proudly that Livingston was the only special-needs student to sing in the high school choir.

"We have to work a little harder," says Harper. "He has to study harder. Sometimes he can get rather frustrated.

"He struggles," Harper adds. "Obviously, sports are something we don't do."

But the congressman couldn't be more touched by the presence of his son in his life. "He is a very loved young man. He is a blessing in everybody's life."

Harper brags about how his son works two nights a week in a restaurant busing tables. He has a cell phone with a keyboard and "has worn out the text message."

Among his favorite activities are football games, country and gospel music concerts and NASCAR races. Come April, Harper will take him to their fourth race at Talladega.

The congressman admits that having a child like Livingston can tear a couple apart, but says he and his wife have grown closer. He says his 17-year-old daughter, Maggie, who does not have Fragile X, could have gone two ways with Livingston. "My hat's off to my daughter," says Harper. "She has embraced it. She treats him just like a sister would, and they fuss and fight."

One of the many difficulties the family has experienced is Livingston having to go without health insurance for eight years because he couldn't be added to his father's health insurance.

For Harper, the toughest part was initially feeling alone. "It's still very emotional," he says. "It's hard for me to talk to you about it right now.

"I can't explain the depth of feelings for my son. I think it is the closest on earth that I can come to feeling how much our heavenly father loves us."