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## Palm Beacher named to Bush panel on disabilities

Fragile X foundation founder aims for treatment, awareness for disorder.

By DAVID ROGERS  
Daily News Staff Writer

President Bush has appointed Harris Hollin of Palm Beach, a former pharmaceutical company executive and founder of the Conquer Fragile X Foundation, to The President's Committee for People with Intellectual Disabilities.

Hollin joins 20 other civilian members, including researchers and academicians, and 13 members of the Cabinet, on the advisory committee. The board advises the president on intellectual disabilities and the needs of those with such conditions. Members are typically appointed for a year, then reappointed for a two-year term, he said.

Hollin, 74, said he wants to use the appointment to the national board to learn more about intellectual disabilities in general and to raise awareness of fragile X, the most common inherited cause of mental retardation. The committee meets quarterly, not including subcommittee meetings, he said.

Fragile X refers to a mutation on the X chromosome that causes it to overproduce a gene. The malfunction and the chemical reaction that halts it reduce the protein required for normal cell development. That in turn hinders memory

and the ability to learn.

A less severe form of the genetic malfunction is responsible for tremor-ataxia syndrome, which primarily affects men 50 and older, and for ovarian failure in women younger than 40.

### 'Happy child'

Doctors diagnosed fragile X-associated mental retardation in one of Hollin's grandsons, Matthew, when Matthew was 18 months old. Scientists had only identified the fragile X gene and created a test for it the previous year, in 1991.

Matthew, now 13, lives in Lower Merion Township, a suburb of Philadelphia, along with much of Hollin's immediate family. Matthew is full of joy and life, Hollin said.

"You can't help but feel good when you are around him," Hollin said. "You feel sad because he is so limited, and will be, unless we are able to help him. But he is a happy child in the scope of what he understands and what he can do."

Taking care of a child who has a developmental disability is not easy, but the experience has had a positive side, said Sande Hollin, Harris



Daily News Photo by Greer Gattuso

Harris Hollin, founder of the Conquer Fragile X Foundation, was appointed by President Bush to The President's Committee for People with Intellectual Disabilities. One of Hollin's grandsons was diagnosed with fragile X-associated mental retardation.

Hollin's wife and Matthew's grandmother.

"I think I have more understanding of what it means to be handicapped in this world and what a person struggles through, not just the child, but the whole family," Sande Hollin said. Schools are teaching children to understand disabilities, which helps create a more welcoming atmosphere for the disabled, she said.

### Aids research

Hollin founded the Conquer Fragile X Foundation in 1999. Its grants, typically between \$1,000 and \$30,000, help fund initial research so scientists can secure much larger federal grants. The foundation's grants have resulted in about \$8 million in fragile X research, he said.

Hollin said he would not have wished that a grandchild of his be mentally impaired, but said the situation is not a tragedy

when compared to other possible problems.

"Having said that, it does change your life and the life of your family forever, because these children live a normal life span, but they are a concern forever because they can't live independently," Hollin said. "Our goal with the research is at least to get the apparent children that have it to the point that they can live independently."

The foundation is broadening its scope by raising funds for fragile X research at Scripps Florida, in addition to funding projects elsewhere in the world, said Karen Fay, president of Conquer Fragile X ([www.cfx.org](http://www.cfx.org)).

Discoveries could lead to medication that greatly increases the cognitive ability of people who are mentally retarded as a result of fragile X, Fay said.

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