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# University Hospital News: November 6, 1989

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November 6, 1989

Dear Member of the Media,

Several Boston University School of Medicine (BUSM) researchers will present information at the annual meeting of the American Society of Human Genetics (ASHG), which will be held in Baltimore on November 11-15.

Enclosed is a news release, written by the ASHG, on a study indicating that Alzheimer's disease is caused by multiple mechanisms. Lindsay Farrer, Ph.D., an assistant professor of neurology and public health at BUSM, will present this information on Tuesday, November 14, at 9:45 a.m. The story is embargoed until that time. Farrer's primary appointment is with BUSM, but he holds appointments in the Harvard system as well.

In addition, Dorothy C. Wertz, Ph.D., a research professor of public health at Boston University School of Public Health, is first author on a poster session on DNA Testing for Cystic Fibrosis (CF): Psychosocial Factors Affecting Utilization by New England Families.

Since 1985, genetic testing has been available to relatives of persons with CF to identify carriers of CF and to diagnose the condition prenatally. Wertz and researchers from Massachusetts General Hospital and the Eunice Kennedy Shriver Center for Mental Retardation evaluated the psychosocial factors that influence family decision making with regard to prenatal diagnosis.

Anonymous questionnaires were distributed in six New England states. Of the 305 responses, 88 were from adults with CF, 217 were from parents of children with CF. In general, the researchers found that prenatal DNA testing for CF--a genetic disease of the mucus glands that results in pulmonary disease, usually strikes in childhood, and whose victims often die at a young age--is underutilized. The reasons cited for not seeking DNA testing included: no additional children were intended; the families were optimistic regarding the present and future health of their affected child; and personal opposition to abortion for CF. Those intending to use prenatal diagnosis were most likely to have received genetic counseling.

The researchers also found that the reproductive plans of parents with affected children were dramatically altered because of the possibility of having more children with CF. The majority did not intend to have more children. In fact, 52 percent had been surgically sterilized; 61 percent of this group reported that having a child with CF affected their decision to become sterilized. Among the fertile couples at risk for having a child with CF, 51 percent were planning more children. Fifty-eight percent of parents responding stated they would alter their reproductive plans if they could be certain that future offspring would not be affected. Fifty-six percent said they would have an abortion for severe mental retardation, but only 20 percent said they would abort for CF.

If you are interested in interviewing either of the researchers, give me a call at (617) 638-8491.

Sincerely,

Betty Russell

Director, Media Relations  
Boston University Medical Center