

**Statement of Paul W. Kincade, Ph.D.
President, Federation of American Societies for Experimental Biology (FASEB)
Council of the District of Columbia
Concerning Bill 15-52 "Human Rights Genetic Information Amendment Act of
2003"
July 7, 2004**

Thank you, Council members, for the opportunity to speak on this important and timely issue. My name is Dr. Paul Kincade, and I am the head of the Immunobiology and Cancer Program at the Oklahoma Medical Research Foundation, where my lab studies the development and daily replenishment of the immune system. In addition, I am President of the Federation of American Societies for Experimental Biology, or FASEB, the largest coalition organization of biomedical researchers in the nation. On behalf of FASEB, its 22 members Societies and the more than 65,000 scientists they represent, I am here to support legislative efforts to prevent genetic discrimination.

We exist in an exciting era of unprecedented biomedical research advancement. A major accomplishment of the 21st century has already been realized: the completion of the Human Genome Project, allowing complete access to the entirety of the human genetic code. Knowing the sequence of the human genome is an historic milestone in the path towards understanding the complexities of biological systems and how they interact at the molecular level. This wealth of information is an important tool in the effort to find treatments and cures for diseases, as well as leading towards the development of better detection and perhaps prevention of genetic disorders. The promise of gene-

based therapies and personalized medicine have already begun to be realized with the development of drugs such as Gleevec, which is used to treat chronic myelogenous leukemia, a form of leukemia that mainly impacts adults. Because scientists knew exactly which abnormal gene product caused the leukemia, they were able to specifically design a drug to stop it. Our understanding of the genetic underpinning of disease is growing at an exponential rate, and breakthroughs in human medicine seem both near and inevitable.

It is likely that one day the data from the Human Genome Project will reveal every person's predisposition to a variety of diseases and conditions. Unfortunately, such knowledge has the potential to be misused as a weapon to discriminate against individuals. Current law does not provide sufficient protection against job loss, health insurance cancellation or denial of coverage on the basis of genetic information. Such discrimination is patently unfair – from a scientific or medical viewpoint, it is mainly based on conjecture, because predisposition towards a disease is not the same as being inflicted with a disease. Using predictive genetic information, in the absence of a related medical diagnosis, to discriminate against a healthy individual is wrong, and should be prohibited.

Protection against genetic discrimination is of particular concern to biomedical researchers, because the absence of such protection is likely to have a chilling effect on clinical research, resulting in a devastating loss of scientific

knowledge. FASEB believes that a growing number of Americans will be discouraged from participating in vital research for fear of employment and health insurance-related consequences. As you know, biomedical advances are dependent on the willingness of individuals to participate in clinical research. In the absence of legal protections, it seems unfair to ask people to risk their livelihood or health insurance coverage, or even to live with the fear of that potential, and yet without such volunteers, the biomedical research enterprise will grind to a halt.

The United States Senate passed legislation protecting citizens against genetic discrimination in a nearly unanimous vote. The US House of Representatives has yet to consider a similar measure, leaving individuals without protection and allowing societal fear of genetic discrimination to drown out our ability to use genetic information to improve the health of our nation, to conduct the research needed to understand, treat and prevent gene-based diseases. It is critically important that we bridge this legislative gap and provide families and individuals with the protections they need and deserve. In the absence of federal law, state and local legislation, such as the bill under consideration by the DC Council, takes on greater significance.

FASEB has been consistently outspoken in our support of updating current law to prohibit discrimination based on genetic information. We are certainly not alone within the scientific and medical community in doing so.

FASEB has joined the Coalition for Genetic Fairness, an alliance of nearly 100 scientific, medical and patient advocacy groups, in calling for expedient passage of genetic nondiscrimination legislation. Dr. Francis Collins, Director of the National Human Genome Research Institute and member of 2 FASEB societies, has repeatedly and forcefully advocated for protections against genetic discrimination. On this issue, the scientific community appears to be in complete accord with policy makers: not only has the US Senate overwhelmingly supported such protections in a bipartisan manner, the White House has also called for prohibitions against the misuse of genetic information. Our hope today is that the DC Council will join this chorus of agreement, proactively protecting the citizens of Washington, DC. Genetic information holds great hope in our battle against disease – we must not let that hope be trampled by fear of discrimination. Thank you and I will be happy to answer any questions that the Council may have.