

PERSONAL EXPLANATION

HON. ALLEN BOYD

OF FLORIDA

IN THE HOUSE OF REPRESENTATIVES

Wednesday, April 30, 2008

Mr. BOYD of Florida. Madam Speaker, last week, I missed the final vote on H.R. 2830, the Coast Guard Reauthorization Act. Had I been present, I would have voted as follows: H.R. 2830. Recorded vote. 24-Apr-2008, 3:13 p.m. Question: On Passage. Bill Title: Coast Guard Authorization for 2008.

"Aye" for Mr. F. Allen Boyd, Jr.

PERSONAL EXPLANATION

HON. KEITH ELLISON

OF MINNESOTA

IN THE HOUSE OF REPRESENTATIVES

Wednesday, April 30, 2008

Mr. ELLISON. Madam Speaker, on April 2, 2008, I inadvertently failed to vote on rollcall No. 155. Had I voted, I would have voted "aye" on rollcall Vote No. 155.

THE GENETIC INFORMATION
NONDISCRIMINATION ACT (GINA)**HON. SHEILA JACKSON-LEE**

OF TEXAS

IN THE HOUSE OF REPRESENTATIVES

Wednesday, April 30, 2008

Ms. JACKSON-LEE of Texas. Madam Speaker, I rise today in support of H.R. 493, "The Genetic Information Nondiscrimination Act, GINA." I would like to thank my colleague, Congresswoman LOUISE MCINTOSH SLAUGHTER, from New York for introducing this important legislation. I would also like to thank my colleagues on Energy and Commerce, Ways and Means, Education and Labor committees for their leadership in this highly contentious and complex health issue.

The Genetic Information Nondiscrimination Act, GINA, would restrict health insurers' (Title

I) and employers' (Title II) acquisition and use of genetic information in several ways. It is also supported by consumer groups, the medical profession, researchers, the medical products industry and pharmaceutical companies.

Since the first bills were introduced in the 103rd Congress, many of the arguments and positions supporting and opposing genetic nondiscrimination legislation have remained largely unchanged. The simple fact is without protection, people are apprehensive about seeking potentially beneficial genetic services or participating in much needed clinical research.

Alex Haley, the gifted author of *Roots*, stated on the front page of his book that "In all of us there is a hunger, marrow deep, to know our heritage—to know who we are and where we have come from. Without this enriching knowledge there is a hollow yearning. No matter what our attainment in life, there is still a vacuum, an emptiness and the most disquieting loneliness."

When author Alex Haley revealed his *Roots* in the late 1970's, everyone in the Nation, it seemed, wondered about their own great-great-grandparents. As a result, the genealogical quest fever spread, particularly among African Americans.

It took Haley more than a decade to trace back several generations, but as most Black people realize, not many of similar heritage will be able to unearth their lineage even that soon. That's because few, if any, reliable records of the centuries-long Atlantic slave trade remain to help in the search. That's what became all too apparent to rheumatologist Dr. Paul Plotz in 1992, when "a chance occurrence" pointed his research on a rare muscle disorder to West Africa and "the greatest undocumented migration of modern times."

As Haley pointed out, people have an inherent interest in knowing their heritage. Our investment in modern science, specifically the Human Genome Project, is poised not only to reveal medical truths about ourselves and our potential for health, but also to help us make that connection to our past.

While some of my colleagues are focused that GINA will provide further incentives and additional opportunities for litigation against employers, they seem to forget the very real

concern of individual protections. In an age where electronic databases are easily tampered with and private information is passed around like a bad cold, we must focus on the rights of individuals and their families when dealing with such a complex and contentious issue.

At a time when we want people to seek out preventative care and gain greater health literacy, we want to ensure them that they are safe and big brother is not selling their detailed information to the highest bidder.

Researchers at Penn State University have stated that from a medical viewpoint, African genetic diversity is important in understanding genetic diseases of African Americans and for finding treatment methods for contagious diseases that originated in Africa. These researchers have said that if they could identify the genetic changes that provided this protection, then they might be able to find treatment methods for the diseases.

These revolutionary discoveries are due to a diverse group of people feeling secure enough with their doctors, nurses, and health insurance companies that they participate in genetic testing and research studies.

We exclaim that we want better health care, greater incidences of prevention, better understanding of current diseases, and most importantly more cures to the illnesses of Americans. This is what genetic testing and research can do. If we allow employers and health insurance companies to manipulate the data to further restrict American's access to quality care, then we should not support this bill.

However, if we are for access to quality health care, if we are for greater understanding of infectious diseases and mutations, if we are for privacy protections in medical records and payment systems . . . then we must give our full support to this bill.

Thank you, Madam Speaker, for your leadership in the area of health care access, this is yet one more area that allows us to support an individual's right to care without fear of retribution by increased health insurance payments or even worse, denial of care altogether. Vote in support of access, understanding, and privacy.