

## LETTERS TO THE EDITOR

---

Am. J. Hum. Genet. 64:329, 1999

### Reply to Niermeijer

To the Editor:

We thank Prof. Niermeijer for his response to and comments on our letter to the editor, regarding health, life, and disability insurance in hereditary nonpolyposis colorectal cancer (HNPCC). As stated in our letter, our survey respondents probably represented <5% of insurance policies sold in the United States. We agree with Prof. Niermeijer that “the silence of the majority of the insurance companies in the U.S. study by Rodriguez-Bigas et al. (1998) reflects the general neglect of this subject in discussions between governments of the major economic countries and the regulators of the insurance and underwriter’s system.” However, we were encouraged to find, as stated in our earlier letter, that “the majority of health, life, and disability insurance providers with an opinion would be willing to sell insurance to HNPCC gene carriers and at risk-individuals” (Rodriguez-Bigas et al. 1998, p. 737). This apparent dichotomy in our survey reflects the need for legislative bodies, insurance providers, health-care providers (including geneticists and counselors), as well as members of affected kindreds, to enter into dialogues so that further steps can be taken for public and professional education, as well as for prevention of genetic discrimination in our societies.

Similar to what has occurred in the Netherlands, legislative action has been undertaken in the United States, with regard to potential genetic discrimination. The Health Insurance Portability and Accountability Act of 1996, which went into effect on July 1, 1997, includes provisions that deal with genetic discrimination as it relates to the use of genetic information on individuals who have or who are eligible for health insurance under a group health plan offered by an employer. Under this law, genetic information is included in the list of “health status-related factors” that an insurer is prohibited from using to deny, cancel, or refuse to renew insurance coverage. The law also states that genetic information may not be treated as a preexisting condition, without a diagnosis of the condition related to this information. An-

other provision provides that the health status of an individual or his or her dependents cannot be used to charge premium rates different from those applied to other, similarly situated individuals within the group.

Although this law addresses some potential health insurance–discrimination concerns, it does not apply to individuals ineligible for group health-insurance policies. Furthermore, this law does not restrict the use of individual genetic information for the purpose of setting a particular group premium. These “gaps” in protection demonstrate that, although legislation such as this has been enacted, all issues related to potential health-insurance discrimination regarding individuals affected with and/or at risk for genetic conditions such as HNPCC have yet to be remedied. There is ongoing activity, on both the federal and the state levels, to address these “gaps” and other societal issues associated with genetic status. In the meantime, it is the policy at our institution, as it is in many other centers in the United States and elsewhere, to provide risk assessment and genetic consultation in order to address the exact issues raised by Prof. Niermeijer.

MIGUEL A. RODRIGUEZ-BIGAS,<sup>1</sup> MARY-  
JO T. ROSENBLATT,<sup>2</sup> AND CAROLYN FARRELL<sup>2</sup>  
<sup>1</sup>*Division of Surgical Oncology and* <sup>2</sup>*Clinical Genetic  
Services, Roswell Park Cancer Institute, Buffalo*

### Reference

Rodriguez-Bigas MA, Vasen HFA, O’Malley L, Rosenblatt M-JT, Farrell C, Weber TK, Petrelli NJ (1998) Health, life, and disability insurance and hereditary nonpolyposis colorectal cancer. *Am J Hum Genet* 62:736–737

Address for correspondence and reprints: Dr. Miguel A. Rodriguez-Bigas, Division of Surgical Oncology, Roswell Park Cancer Institute, Elm & Carlton Streets, Buffalo, NY, 14243. E-mail: mrodriguez@SC3101.med.buffalo.edu

© 1999 by The American Society of Human Genetics. All rights reserved.  
0002-9297/99/6401-0048\$02.00