AS THE SPRING LEGISLATIVE SESSION APPROACHES, the Alliance is receiving increasing numbers of requests for review of genetic privacy legislative proposals. The 105th Congress promises to be unusually worthy of attention on both the Federal and state levels, and Alliance staff is straining to manage the growing numbers of the timely demands. Yet, oversight by genetics consumers and professionals is critical to the process. The Alliance membership, so rich in untapped expertise, legislative experience and critical judgment, holds a promising solution. We are developing a Public Policy Consumer Network which will focus on legislative issues. We are looking for individuals, both consumers and professionals, to review legislative proposals and to consult on questions about genetics and bioethics as they relate to specific legislation. Watch the Alert for more information as this exciting grassroots network takes shape.

THE PARTNERSHIP FOR GENETIC SERVICES, the Alliance’s newest consumer-professional collaborative project, proudly announces an award of $35,000 from The Robert Wood Johnson Foundation. The Partnership Project will impact the quality of genetic services through educational and service/resource interventions designed to promote better understanding of the needs, interests, skills, and resources of consumers. This grant will support Alliance efforts within the Mid-Atlantic Regional Human Genetics Network (MARHGN) to foster relationships with primary care providers (PCPs) in managed care organizations and to prepare consumer orientation materials that will also be tested in two additional Regional Networks.

To reach PCPs, we plan to work with managed care organizations, where increasing numbers of PCPs are delivering services to families with specialized medical needs. We will also work with medical schools where the diagnostic and clinical skills of future PCPs are being developed. Efforts directed to managed care organizations in the Pacific Northwest Regional Genetics Network (PacNoRGG) and to medical schools in the Great Lakes Regional Genetics Group (GLaRGG) will be initiated during the same time as the pilot in MARHGN. The Alliance will form educational teams of trained consumers, clinical genetics professionals and primary care providers in all three Regions. Using consumer quality guidelines, these teams will evaluate current genetic services, plan educational and service/resource interventions and assess subsequent improvements in service delivery. The Alliance is deeply appreciative of The Robert Wood Johnson Foundation and our other sponsors, who have recognized the merit of this landmark project.

NEWSWEEK ARTICLE QUOTES THE ALLIANCE. Check out the December 23 issue of NEWSWEEK Magazine and the cover article on cancer. In a companion piece entitled, "Flunk the gene test and lose your insurance," Martha Volner, speaking for the Alliance, is quoted, saying, "This is bigger than race or sexual orientation. Genetic discrimination is the civil-rights issues of the 21st century."