

Advancing the Personalized Health Care In

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Health, Education, and Human Services (HEHS) Fellows Scott Boyle and Kristin Brinner worked for two years in the Department of Health and Human Services (HHS) in the Immediate Office of the Secretary, where their main responsibility was the Personalized Health Care (PHC) Initiative, one of former HHS Secretary Michael O. Leavitt's priority areas.

They were involved in the initiative at the highest levels of the federal government, and were tapped to work with industry, academia, and government leaders to communicate the "big-systems view" and how PHC implementation manifests changes in other programs and policies. Their significant access was facilitated by Dr. Gregory Downing, program director of the PHC initiative. He was formerly at NIH where he had supervised numerous AAAS Fellows.

"It's important to have smart, highly motivated people applying their energies, talents and vision to this critical process" says Dr. Downing. "Scott and Kristin did exemplary work helping to frame complex issues."

Gene-based or personalized medicine can help individuals identify their particular susceptibilities to disease while they are well and take effective preventive steps. In the future, it will help detect the onset of disease much earlier, enabling treatment to prevent disease progression, and can help bring about medical products that are tailored more precisely to the needs of each individual. The PHC Initiative involves developing policies, supporting scientific advancement in understanding individual aspects of disease and disease prevention, and developing standards for interoperable

electronic health record systems.

Kristin and Scott applied their scientific and analytical skills to reviewing regulations and assessing reimbursement of molecular diagnostic tests; examining policies regarding access to NIH databases containing genetic and related health information; preparing plans for implementation of legislation; and monitoring new areas relating to personalized medicine.

Kristin helped lead the PHC work group of the HHS American Health Information Community (AHIC), a federal advisory body chartered in 2005 to make recommendations to the HHS Secretary on ways to accelerate the development and adoption of health information technology. Under her coordination, they focused on establishing standards for reporting and incorporating common medical genetic/genomic tests and family health history data into electronic health records, and providing incentives for adoption across the country. Kristin co-published two white papers on the work group's activities for the *Journal of the American Medical Informatics Association*.

She also was a major contributor to three subgroups of the PHC work group that made recommendations to the Secretary on genetic/genomic tests, family history and newborn screening. She led another subgroup focused on confidentiality, privacy and security issues surrounding genetic information, which developed a white paper published by the American College of Medical Genetics.

Scott coordinated a workshop on consumer genomics – the controversial emerging market where companies provide

initiative

access to genetic testing and relay the information directly to the consumer. The July 2008 event concentrated on understanding consumers' interest in genetic testing services and identifying the information consumers need to make best use of such services. More than 150 physicians attended, in addition to representatives from genetic testing companies, consumer and health care advocates, and others interested in consumer-oriented, genome-based health information services and personalized medicine.

"We brought together groups that had been talking past one another," Scott explains. In addition to developing the agenda and discussion topics, he wrote the executive summary of the meeting.

Scott, in collaboration with Kristin, also led a subgroup on pharmacogenomic clinical trials. Its recommendations were made to the Secretary in June 2008.

Secretary Leavitt suggested that "a generation of effort lies before us" in achieving the goal of personalized health care – "perhaps one of the most complex science-based endeavors in our history." Both Kristin and Scott would like to continue to be involved in that endeavor.

Kristin noted that the two years as a S&T Policy Fellow significantly broadened her perspective on career paths. "I know now I have many more options than if I'd remained in research." She also knew there would be time to explore those possibilities in the future. At the conclusion of her fellowship, Kristin and her husband launched a year-long adventure driving a modified hybrid vehicle through Central and South America. They have developed an online resource for like-minded travelers and are documenting the progress of their trip on their blog.

Scott also emphasized that his experience in Washington, DC, "changed the trajectory" of his career. At the close of his fellowship he pursued a more traditional route than Kristin, and returned to his graduate alma mater, Yale University, where for several months he was a postdoctoral associate helping with a spin-off project from his

graduate work in molecular and biophysics and biochemistry. Scott then accepted a contract as a science policy writer to create the *Consumer's Guide to DNA-based Health Information Testing*, which directly related to his activities at HHS. The document can be found on the PMC website: <http://www.personalizedmedicinecoalition.org/objects/docs/PMC-Consumer'sGuide-Shared.doc>. Scott is now a Presidential Postdoctoral Fellow at Novartis, a pharmaceuticals company.

