

Synergizing Epidemiology Research on Rare Cancers Meeting

Summary

EGRP Grantees Meet To Stimulate Research on Rare Cancers

EGRP and NIH's Office of Rare Diseases (ORD) cosponsored a workshop to stimulate epidemiologic research on rare cancers in May on the NIH Campus in Bethesda, MD. Many current and former EGRP grantees expert in epidemiologic research on rare cancers attended along with scientists from the National Cancer Institute (NCI) and other components of NIH, survivors of rare cancers, and representatives of foundations devoted to supporting research and education on these cancers.

“We appreciate the difficulties that investigators focusing on rare cancers encounter in recruiting sufficient numbers of patients quickly in the face of often rapidly lethal disease and want to see what we can do to facilitate research on understudied rare cancers,” said Isis S. Mikhail, M.D., M.P.H., Dr.P.H., Acting Chief of EGRP's Clinical and Translational Epidemiology Branch.

The workshop's goals were to suggest ideas to synergize the development of collaborations and consortia in epidemiologic research on understudied rare cancers, address best practices and successful models to aid in collaborations, and explore mechanisms to promote further research aimed at investigating the etiology of these understudied and often rapidly fatal cancers.

Rare cancers were defined as those cancers for which the incidence rate is less than 15 cases per 100,000 population or fewer than 40,000 new cases per year in the United States. Although these numbers are relatively small, all rare cancers combined account for 27 percent of cancers diagnosed each year and 25 percent of cancer-related deaths, and the morbidity and mortality that they cause are increasing.

Working groups spent time focusing on specific cancers that are underrepresented in EGRP's grant portfolio, including sarcoma, multiple myeloma, and esophageal and liver cancer, and on discussing methods and strategies for stimulating overall research on rare cancers.

Invited speakers described a variety of consortia as models for collaborations to pool data, expertise, and other resources to more effectively study rare cancers. To begin the meeting, Julie Ross, Ph.D., M.P.H., of the University of Minnesota, gave a presentation on the Childhood Cancer Research Network (CCRN), which is a unique project to establish a national research registry of children with cancer, including a tissue bank for tumor and blood specimens, to use to identify environmental and other causes of childhood cancer. The project is part of the NCI-funded Children's Oncology Group (COG).

Melissa Bondy, Ph.D., of the University of Texas M.D. Anderson Cancer Center, described the establishment of the International Study of Familial Glioma (Gliogene) Consortia, which has been funded by EGRP since 2006 along with other support provided by the American Brain Tumor Association, National Brain Tumor Foundation, and the Tug McGraw Foundation.

Bob Graham, a survivor of carcinoid syndrome, spoke eloquently about his experiences as a patient and his perspective on improving patient participation in epidemiologic research.

Among the workshop recommendations, participants encouraged the development of mechanisms to support and facilitate data sharing, such as creation of central data management or coordinating centers, standardized exposure collection questionnaires, and guidelines to assist pre- and post-doctoral researchers and trainees become involved in rare cancer research and consortia; development of new Web-based tools to pool existing data; conducting symposia about methodological research for study of rare cancers at national cancer meetings; and greater collaboration between investigators and community or advocacy groups and concerned foundations to improve enrollment in studies.

“The enthusiasm and interest of the investigators attending this workshop were remarkable. Scientists are ready to work together to further the study of rare cancers. We expect to build on the momentum of this meeting,” said Dr. Mikhail. Plans now are under way to publish a summary of the proceedings and to consider possible funding mechanisms or initiatives based on the input from the workshop in order to solicit new research proposals. The speakers’ PowerPoint presentations also will be made available on EGRP’s Web site.

“Synergizing Epidemiologic Research on Rare Cancers” was organized by Dr. Mikhail and Rashmi Gopal-Srivastava, Ph.D., Director, Extramural Research Program, ORD. Other members of the organizing committee were Dr. Winn, EGRP Acting Associate Director; Patricia Hartge, Sc.D., Office of the Director, DCCPS; Shelia Zahm, Sc.D., Deputy Director, Division of Cancer Epidemiology and Genetics (DCEG); and Nonye Harvey, M.P.H., and Scott Rogers, M.P.H., Program Analysts, Office of the EGRP Associate Director.