

May 1, 2001 Meeting Minutes

5th Meeting of the Director's Council of Public Representatives

Tuesday, May 1, 2001

8:30 a.m.

Building 31C, Conference Room 6

National Institutes of Health

Bethesda, Maryland

The Council of Public Representatives convened its fifth meeting at 8:30 a.m., Tuesday, May 1, Building 31C, Conference Room 6, National Institutes of Health,

Health and Health Disparities Research, a new program to better enable 24 states to improve their infrastructures and make them more competitive for NIH grants; several efforts to explain to the public and Congress how NIH is allocating the funding it receives from Congress; and initial plans for establishing the recently mandated new NIH National Institute for Biomedical Imaging and Bioengineering. She also summarized several personnel changes among key NIH administrators.

Dr. Kirschstein said that the first meeting of the special NIH review committee, Human Pluripotent Stem Cell Review Group (HPSCRG), was postponed, pending a review of this entire area of research by the Department of Health and Human Services (HHS). She also said that she recently testified on this issue before Congress, reminding them that if such research is restricted to the private sector, it will not be subject to federal oversight.

COPR members presented a series of brief reports describing their recent NIH-related individual and working group activities on a range of topics, including efforts to make NIH Web sites more accessible to the visually impaired, efforts to coordinate NIH site visits in Tennessee and Hawaii, efforts to identify ways of streamlining regulatory burdens while strengthening protections for those who participate in clinical trials, and efforts to evaluate the overall performance of the directors of the NIH National Institute of Environmental Health Sciences (NIEHS) and the National Institute for Nursing Research (NINR).

Dr. Patricia Grady, Director of the NIH NINR, described her Institute's programs and priorities, including research focusing on chronic illnesses, end of life, genetics, and health disparities; completion of a strategic plan for the Institute, which emphasizes supporting research opportunities, disseminating findings, and training nurse researchers; and other targeted studies, such as low birth-weight babies, coping with chronic illness among teenagers, helping the elderly return home following hospital care, and developing bilingual tools for communicating with Hispanic populations. NINR's Division of Intramural Research sponsors several training programs each year, including one in human genetics and another to train nurses on how to launch their scientific careers.

Dr. Allen Spiegel, Director of the NIH National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), said that the Institute sponsors research in diabetes and six additional areas, adhering to a strategic plan that was developed following a public meeting held in October 1999. Noting that some 16 million individuals have diabetes and the high toll that it exacts in medical costs—which is estimated at \$100 billion per year—this disease has a high priority within the Institute, according to Dr. Spiegel, who summarized a number of the complications associated with type 1 and type 2 diabetes and research efforts aimed at better

Formal appropriations hearings were scheduled for May 16 in the House of Representatives and May 23 in the Senate, according to Dr. Kirschstein. Among highlighted NIH programs and achievements are the completion of a full draft sequence of the human genome; rapid progress in efforts to sequence genomes of other organisms such as the mouse and rat; heightened emphasis on clinical research programs, including authorizing legislation from December 2000 that provides career development awards and also enables NIH to repay loans at a level of \$35,000 per year (plus ancillary expenses) for medical students while they are being trained to conduct clinical research; new emphasis on infrastructure and enabling technologies, including support of 36,000 grants, the highest number in NIH history; and research on health disparities and underserved populations, including an increase in the proposed budget for the new NIH National Center for Minority and Health Disparities by 20 percent to \$158 million.

Dr. Kirschstein said that NIH will begin the Biomedical Research Infrastructure Network (BRIN) Program in FY 2001 that is aimed at bolstering institutions in 24 states that receive relatively little funding from NIH to support research. The new program provides funding to help institutions within those states form consortia and take other steps to make future biomedical research proposals more competitive. NIH also recently increased stipends for predoctoral and postdoctoral researchers by 10 percent, and is developing a plan for adjusting those stipends systematically during the next .0Tw -56.ioe6frasM1(tisform cS[y r494274ID 3 BdC -0.0003 Tc 0.

patient advocacy and other elements for assisting research participants to be better in

investigators overseeing particular protocols. Ms. Lappin said that only about 25 percent of IRBs require investigators to disclose such information, but she was not

NBAC—National Bioethics Advisory Commission

NCI—National Cancer Institute



