Department of Health and Human Services National Institutes of Health National Institute of Nursing Research Minutes of the National Advisory Council for Nursing Research

January 23-24, 2001

The 43rd meeting of the National Advisory Council for Nursing Research (NACNR) was convened on Tuesday, January 23, 2001, at 1:00 p.m., in Conference Room 6, Building 31, National Institutes of Health (NIH), Bethesda, Maryland. The meeting was open to the public from 1:00 p.m. until approximately 5:10 p.m. The open session of the meeting continued the next day, Wednesday, January 24, 2001, at 8:30 a.m. and continued until approximately 10:15 a.m. The closed session of the meeting, which included consideration of grant applications, continued immediately after the end of the open session until adjournment at 1:00 p.m. on the same day. Dr. Patricia A. Grady, Chair of the NACNR, presided over both sessions.

OPEN SESSION

I. CALL TO ORDER, OPENING REMARKS, COUNCIL PROCEDURES, AND RELATED MATTERS

Dr. Grady called the 43rd meeting of the NACNR to order, welcoming all Council members, visitors, and staff. She then introduced Dr. Betty Smith Williams, Professor, Department of Nursing at California State University at Long Beach, who was attending her first Council meeting. Dr. Williams is past president of the National Black Nurses Association and currently serves as president of the National Coalition of Ethnic Minority Nurse Associations.

Conflict of Interest and Confidentiality Statement

Dr. Mary Leveck, NACNR Executive Secretary, reminded attendees that the standard rules of conflict of interest applied throughout the Council meeting. She also reminded NACNR members of their status as special Federal employees while serving on the Council, and that the law prohibits the use of any funds to pay the salary or expenses of any Federal employee to influence State legislatures or Congress. Specific policies and procedures were reviewed in more detail at the beginning of the closed session and were available in Council notebooks.

Consideration of Minutes of Previous Meeting

Council members approved the minutes of the September 12-13, 2000, meeting by electronic mail. Dr. Grady thanked the Council members for their attention to the minutes, adding that she and her staff have received positive feedback regarding the posting and contents of the reports. The minutes from each NACNR meeting are posted on the National Institute of Nursing Research (NINR) Web Site (www.nih.gov/ninr/a_advisory.html).

Dates for Future Council Meetings

Dates for meetings in 2001 through 2002 have been approved and confirmed. Council members should contact either Dr. Grady or Dr. Leveck regarding any conflicts for dates in 2002.

<u>2001</u>

- May 22-23 (Tuesday-Wednesday)
- September 11-12 (Tuesday-Wednesday) 2002
- January 16-17 (Wednesday-Thursday)
- May 21-22 (Tuesday-Wednesday)
- September 17-18 (Tuesday-Wednesday)

II. REPORT OF THE DIRECTOR, NINR

Dr. Grady announced that her report would focus on providing updated budget information, along with a summary of the year's activities and updates for both the NIH and the NINR.

Budget Update

Dr. Grady reported that—while the NINR had not received news of its budget allocation until December 29, 2000, and there had been concern about what the actual figure might be—the news was excellent in that the NINR broke the \$100 million mark for the first time, with a budget allocation of \$104.3 million. This is considered a major breakthrough in that the NINR began 15 years ago as a Center with a \$16 million allocation. The NINR is delighted to be able to respond to the scientific areas of opportunity discussed last year by the Council, in addition to being able to respond to the many good scientific applications received and the needs identified.

The NINR's FY 2000 budget represented a record increase of 28.5 percent (compared to an overall NIH increase of 14.8 percent) over the previous year's budget. The FY 2001 budget allocation represents a 16.6 percent increase (compared to an overall NIH increase of 14 percent) over FY 2000, and was in fact the largest increase received by an Institute. Sustaining substantial increases such as these over a multiyear period is especially important in view of the NINR's average length of grant of 4 years. The delayed signing of this year's budget bill will result in delayed grant awards as well.

NIH Update

Dr. Grady noted that, with the change in the presidential administration, Department of Health and Human Services (DHHS) Secretary Donna Shalala has departed. The confirmation hearings for Secretary-designate Tommy Thompson have been going well, and his confirmation is expected shortly.

Dr. Grady announced that there are two new entities at the NIH. The National Institute of Biomedical Imaging and Bioengineering (NIBIB) does not have a budget yet, but has been legislated into existence. The National Center on Minority Health and Health Disparities (NCMHD) is a freestanding Center with its own grantmaking authority and its own appropriation and budget, currently at \$130 million. This previously was the Office of Research on Minority Health (ORMH) in the Office of the Director. The NINR had worked jointly on projects with this office and expects to continue to work with the new Center. The NCMHD also is accepting project applications.

Other recent changes at the NIH include the departure of Gerald Fischbach, M.D., as Director of the National Institute of Neurological Disorders and Stroke (NINDS), and the appointment of Paul Sieving, M.D., Ph.D., as Director of the National Eye Institute (NEI). John Ruffin, Ph.D., formerly director of the ORMH, has been named Director of the NCMHD. The NINR looks forward to increased collaborative efforts with this new entity. Finally, Carl Hunt, M.D., has been named Director of the National Center on Sleep Disorders Research (NCSDR), a Center within the National Heart, Lung, and Blood Institute (NHLBI).

NINR Update

Dr. Grady showed a graph depicting the total NINR budget for FY 2000 and the apportionment of funds to individual budget categories. She noted that the percentages were essentially unchanged from FY 1999, except for the Research Project Grant (RPG) line, which increased because of the large increase in funding. The vast majority of the budget is used to fund research in the extramural community including training, centers, and career development (91%). A small percentage of funds is used for intramural activities and support services, including staff and grants management support.

In comparing preliminary budget figures from FY 2000 and FY 2001, Dr. Grady noted that the Noncompeting Grant category is expected to increase from \$38.4 million in FY 2000 to \$53.7 million in FY 2001. This represents the "out years" for grants already funded. The Career Awards and Training budget lines are projected to increase significantly, and the Intramural line is essentially the same. The amount of individual training stipends will increase in FY 2001, which impacts on the total number of new trainees.

Dr. Grady highlighted the numbers of awards in FY 2000 versus estimated numbers of awards for FY 2001. The number of Noncompeting Grants is projected to increase from 136 to 156, while the number of Competing Grants is projected to decrease from 81 to 60. The numbers of Small Business Innovation Research (SBIR) and Small Business Technology Transfer Research (STTR) grants are projected to remain about the same. Full-Time Training Positions (FTTPs) are projected to increase from 219 to 259. The actual number may, in fact, be lower due to the planned increase in stipend size.

Dr. Grady discussed success rates as measured by the number of applications the NINR funds from those received. This measurement is somewhat controversial, but no other method has proved to be as useful so far. She displayed a graph that showed both NINR and NIH figures. In the past, the NINR and NIH success rates were usually close, although NINR was usually lower. In 1998 and 1999, however, increased competition for grants and budgetary constraints combined to lower the NINR success rate. In 2000, the NINR success rate, though still

preliminary, seems to have again come quite close to the overall NIH success rate. For 2001, both the NIH and the NINR are expected to be close to 32 percent. Dr. Grady then compared the difference between success rates for Type 1 (new) applications and those for Type 2 (continuing) applications. The trend has been for Type 2 applications to enjoy a higher success rate. This is true both at the NINR and throughout the NIH. The NINR receives more Type 2 applications now than it had in the past, which is a positive sign of sustained research programs.

Under the category of the numbers of different types of applications received by year, the overall trend is upward and fairly positive.

Training is a major part of the NINR's efforts. The Institute typically funds nearly the same number of trainees as researchers. Many of those who are entering the research field now appear to be remaining in research careers. This current trend is positive. In addition, the number of post-doctoral trainees is still small but growing, another indicator of positive growth of the research cadre.

Turning to average cost of grants and length of awards, Dr. Grady noted that the average cost of NINR grants is increasing, as is true throughout the NIH. The average cost of R01 grants is at \$344,000, and the average cost for RPGs stands at \$301,000. The average length of RPGs, including SBIR/STTR Awards, has increased as well, and is now at 3.77 years.

Four members are retiring from the NACNR and will be missed for their many contributions. They are Drs. Dorothy Brooten, Steven Finkler, Judith LaRosa, and Ada Lindsey. The four new members who will be added to the Council include Drs. Jacqueline M. Dunbar-Jacob, University of Pittsburgh; Mary D. Naylor, University of Pennsylvania; Joan L. Shaver, University of Illinois at Chicago; and David M. Ward, Medical University of South Carolina.

The NINR is pleased to announce that the second recipient of a Presidential Early Career Award for Scientists and Engineers, Dr. Leslie Ritter of the University of Arizona. Dr. Ritter's research is investigating leukocyte-platelet interactions and exploring ways to minimize brain injury for patients after stroke.

The Areas of Research Opportunity identified for FY 2001 have been developed into program announcements (PA) and Requests for Applications (RFA) have been issued, and applications are being submitted. Three broad areas are used to categorize them. The first area is <u>Chronic Illness or Conditions</u>, which includes *Self Management of Chronic Illness* (PA-00-109, 6/22/00) and *Diabetes Management in Minority Populations* (PA-00-113, 6/27/00). The second area is <u>Behavioral Changes and Interventions</u>, and includes *Telehealth Interventions to Improve Clinical Nursing Care* (PA-00-138, 9/22/00) and *Collaborative Clinical Trials Supplements* (RFA-NR-01-004, 1/16/01). The third area is <u>Responding to Compelling Public Health Concerns</u> and includes *Quality of Life for Individuals at the End of Life* (PA-00-127, 8/2/00); *Health Disparities, Centers, and Career Development* (RFAs on Developmental

Centers, Minority K01, Core Center Supplements, *NRSA Institutional Research Training Grants* [T32 notice for genetics/health disparities and early entry 1/12/01]), and an upcoming notice for Administrative Supplements for Postdoctoral Research Training in Genetics.

Recent RFAs in which the NINR is the primary sponsor of funds include the NINR Mentored Research Scientist Development Award for Minority Investigators (Minority K01, receipt 4/25/01), the NINR Career Transition Award (K22, receipt 5/11/01), and the Collaborative Clinical Trials Supplements (receipt 5/18/01). Recent RFAs that the NINR is cosponsoring include the International Initiatives to Prevent HIV/STD Infection; Prevention of Onset, Progression, and Disability of Osteoarthritis; the Planning Grant for Clinical Research Training in Minority Institutions; and Complementary/Alternative Medicine at the End of Life for Cancer and/or HIV/AIDS. Other recent PAs include Bioengineering Research Partnerships and Ethical, Legal, and Social Implications of Human Genetics/Genomic Research.

The NINR's strategic plan targeted better tracking of the publications that result from NINRfunded research. In FY 2000, 114 papers were published as a result of research funded by the NINR. These publications appeared in a variety of journals and addressed many topics. The NINR has compiled a list of these publications and will continue to do so in accordance with the strategic plan. In addition, synopses and results of NINR-funded research are now being published in at least three journals or newsletters with broad distribution in the nursing community, including *The American Journal of Nursing, Nursing Spectrum*, and *Medscape Nursing*.

With respect to trans-NIH activities, Dr. Grady drew the Council's attention to the NIH Consensus Development Conference on Adjuvant Therapy for Breast Cancer, which the NINR cosponsored with the National Cancer Institute (NCI) and the Office of Medical Applications of Research (OMAR). The NINR continues to be very active in transagency and trans-NIH activities in many areas, including women's health, the diabetes coordinating committee, rehabilitation, bone disease, and bioethics. The NINR, under the leadership of Dr. Ann Knebel, spearheaded a new NIH special interest group focusing on end-of-life issues. The group sponsored a community forum on November 14, 2000, to solicit community input on directions for future research in this area. The results of this forum are available on the NINR Web Site (www.nih.gov/ninr/i_publications.html).

In NINR staff news, Dr. Grady formally announced the appointment of Dr. Mary Leveck as Deputy Director of the NINR. This marks the first time in the history of the NINR that the Office of Personnel Management has allotted a staff position for a Deputy Director for NINR. She also noted the departure of three NINR staff. Michael J. ("Jeff") Carow, Grants Management Officer, retired. Cynthia McDermott, who had been second in command in that office, has been appointed to replace him. The NINR welcomes her to that position. Dr. Annette Wysocki left the Division of Intramural Research and is now a staff scientist in the National Institute of Dental and Craniofacial Research. Dr. Anne Thomas, intramural clinical director, returned to her former employment in Indiana. Upcoming NINR events include the second Summer Genetics Institute, which is scheduled for June–July 2001. The application deadline is March 1, 2001. This is an 8-week, intense course that will accommodate approximately 14 students. Also in July (July 17–20, 2001), the NINR will conduct the sixth annual Research Training: Developing Nurse Scientists. This course generally receives many more applications than can be admitted, but the NINR is working to expand availability of the content via a website. Further information on both of these courses is available on the NINR Web Site (www.nih.gov/ninr/i_meetings.html).

In closing, Dr. Grady noted that the NINR will celebrate its 15th Anniversary this year. We will have a national symposium on campus to mark this event. The date for the symposium is September 20–21, 2001, with the annual Friends of NINR gala scheduled for the evening of September 20. Finally, she drew the Council's attention to the NINR Web Site (www.nih.gov/ninr) and invited feedback about its form and content.

Questions/Comments

A council member remarked that "the word on the street" is that it is extremely difficult to get a competing continuation funded by the NINR. She urged that attempts be made to better publicize the figures that counter this view. Another member commented favorably on the summer institute on Research Training for Developing Nurse Scientists and asked whether undergraduates might be considered for participation in the institute. Dr. Grady noted that they are not included, but that other programs will target undergraduates and that the summer institute eventually may include them as well. A council member asked whether the NINR's programs were influencing curricula, and Dr. Grady noted their effect.

III. NIH UPDATE ON HEALTH DISPARITIES ACTIVITIES

Dr. Grady introduced Dr. Yvonne Maddox, Acting Deputy Director, NIH, to provide a broad picture of health disparities activities within the NIH. Dr. Maddox noted that the NIH has a long history in the areas of health disparities and minority health research, with the ORMH having celebrated its 10th anniversary last summer.

On February 21, 1998, President Clinton announced his initiative to eliminate racial and ethnic health disparities by the year 2010. Federal agencies were directed to develop plans to make this a reality. The DHHS, under Dr. Shalala, was expected to have a major role in carrying out this initiative and decided to focus on six areas: infant mortality, cancer screening and management, cardiovascular disease, diabetes, HIV/AIDS, and immunization. Chairpersons were appointed to oversee the work on each of these areas. The NIH had cochairs on all of these committees except immunization, which was targeted mainly to the Centers for Disease Control and Prevention (CDC). Thus, the NIH had early and broad experience in the health disparities area.

In September 1999, NIH Director Dr. Harold Varmus established a working group to develop a strategic plan for addressing health disparities. The group defined health disparities as the difference in the incidence, prevalence, mortality, burden of disease, and other adverse health conditions that exist among specific population groups in the United States. The working group also emphasized that, while there are many special populations within the country, for the purpose of this initiative the NIH would focus on racial and ethnic populations, including African Americans, Asians/Pacific Islanders, Hispanics/Latinos, Native Americans, and Alaska Natives. The working group also emphasized the relevance of socioeconomic factors to health disparities. The group presented its recommendations to Dr. Varmus in December 1999.

In January 2000, Dr. Ruth L. Kirschstein was appointed as NIH Acting Director. She reconstituted the working group to include all of the directors of the 25 NIH Institutes. Dr. Anthony S. Fauci, Director of the National Institute of Allergy and Infectious Diseases (NIAID), and Dr. Maddox were named as Co-chairs. They decided that the working group's plan would set the priorities for addressing health disparities for the NIH as a whole, but that each Institute also would be responsible for developing its own strategic plan.

The group felt that it needed to make clear to the public and to various communities what the existing health disparities were and seek their input in developing its strategic plan. Dr. Maddox provided several examples of disparities that exist in incidence, mortality, and morbidity between various special population groups for diseases such as HIV/AIDS, prostrate cancer, breast cancer, and asthma, along with infant mortality in general. The following goals were set for the plan: to develop a 5-year Strategic Research Agenda; to focus on recruiting and training minority investigators; to advance community outreach activities; to maintain and form new partnerships with minority institutions as well as industry, private foundations, professional organizations, and others; to better identify and define what is meant by health disparities research and to better analyze and evaluate such research; and to enhance public awareness of health disparities issues.

To date, many NIH Institutes have developed their own strategic plans for addressing health disparities issues and have posted these plans on their Web sites. In June 2000, the working group presented a draft plan with preliminary budget figures for FY 2002 to Dr. Kirschstein. The new National Center on Minority Health and Health Disparities (NCMHD) is expected to coordinate the health disparities efforts and activities among the various Institutes. Its own \$130 million allocation is to be used for special initiatives above and beyond those of the Institutes.

Questions/Comments

In response to a question about coordination, Dr. Maddox indicated that the NIH Strategic Plan was placed on the NIH Web Site (www.nih.gov) in October 2000 and that public comment has been vigorous. When the NCMHD was established, it took over the job of implementing the plan. The Center extended the public comment period and has been collecting and organizing the comments received to finalize the Plan and implement it in time for the FY 2002 budget process.

Dr. Maddox indicated that, although the specifics of the Plan may be revised, few changes are expected in the broad areas it addresses. The working group had outlined three broad areas of focus: a research agenda, the research infrastructure (e.g., developing new scientists and investigators for the field, improving laboratories), and community outreach, including information dissemination. A comment was made about the importance of taking what is learned and getting it out to the community. Dr. Maddox acknowledged the importance of this, as well as the importance of getting the information out in a form that a specific community will understand and to which it will respond.

Another comment emphasized the need for a long-term commitment (10 to 20 years) to solving health disparities problems, versus short-term funding. Dr. Maddox acknowledged the need for a broad effort in this area and noted recent activities of private organizations, including major foundations that have instituted fellowships and lecture series on the topic. She cited the need for the health disparities problem area to "become institutionalized," and said that there are positive signs that this is occurring.

A final comment noted the need for an all-inclusive approach that focuses on health disparities among a broad range of groups, including gays and lesbians, for example. Dr. Maddox noted that no one is to be excluded, and that a broad definition of minority populations and underserved groups is being employed.

IV. NINR RESEARCH ACTIVITIES: "MINORITY HEALTH RESEARCH"

Dr. Grady welcomed five students who were in attendance from a Yale/Howard University program designed to encourage minority undergraduate students to enter the field of nursing research. She then introduced Dr. Janice Phillips, who directs the NINR's extramural minority health research activities.

Dr. Phillips noted that the NINR's Strategic Plan for Reducing Health Disparities focuses on three components: research, infrastructure, and outreach. The Plan delineates goals for each of these areas. The first research goal focuses on soliciting research applications related to health disparities, and the NINR has issued several PAs in this area. In 1999, the PA dealt with Low Birth Weight in Minority Populations, and the year 2000 PA focused on Diabetes Self Management in Minority Populations. Additional PAs are forthcoming, and the goal is to have at least one area of research opportunity each year that addresses health disparities.

The second research goal focuses on supporting investigator-initiated research proposals that address health disparities. Research initiated under this goal has already produced significant findings. For example, one researcher has shown that home visits by nurse practitioners and community outreach workers to inner city males in Baltimore, MD, have had a positive effect in significantly reducing systolic blood pressure readings . Another investigator has found that telephone calls to pregnant African American women are a low-cost, low technology way of improving pregnancy outcomes. These calls address such topics as smoking, substance abuse, and nutrition.

Dr. Phillips outlined the rest of the health disparities strategic plan; the first infrastructure goal focuses on enhancing infrastructure for an increased emphasis on health disparities. The second infrastructure goal focuses on enhancing mentorship, training, and research opportunities for minority students and researchers.

Three outreach goals are included in the Plan. The first is to maintain involvement with minority nursing organizations such as the National Coalition of Ethnic Minority Nurse Associations. The NINR's collaboration with this group will be discussed later during this meeting and includes efforts to develop minority nurse investigators and to establish priorities for minority health research. A second outreach goal focuses on enhancing communication and dissemination activities and emphasizes disseminating findings from the NINR's extramural research. The third outreach goal is to continue sponsorship of special programs and initiatives.

Dr. Phillips highlighted NINR research activities in three selected research areas: child health, women's health, and HIV/AIDS. Some minority health work exists in all of the NINR's portfolios. Typically, NINR spends approximately 20% of the overall budget on minority health research, career development, and training. In FY2000 there were 109 awards. Examples of projects in the area of child health include one that is exploring ways in which parents can reduce growth deficiencies among Mexican-American children. Another project is targeting lead exposure among African American children in Philadelphia. A Chicago project is focusing on strategies to enhance interaction and communication skills among parents, teachers, and children, with the long-term goal of reducing behavioral problems in inner city Hispanic and African American children.

Examples of projects supported by the NINR in the area of women's health include validation of a weight management model for postpartal African American, Hispanic, and Caucasian women. Another project promotes exercise among inactive African American women ages 35 to 45. A third project is a 5-year longitudinal study of biobehavioral health in midlife Mexican American, African American, and Caucasian women. HIV/AIDS projects include culturally sensitive interventions for Pacific Islander adolescents and for Latina women ages 18 to 40. A third project is targeting reducing HIV risk among Latino youth ages 13 to 18.

Turning to NINR Core Centers, Dr. Phillips noted that this mechanism (P30) is used to support the research infrastructure at schools of nursing. The NINR currently is supporting 10 Core Centers, 8 of which focus on health disparities and minority health. These Centers are located in the states of California, Indiana, North Carolina, Pennsylvania, South Carolina, Texas, and Washington. They target such areas as chronic conditions, vulnerable populations, women's health, health promotion and disease prevention, quality of life, and outcomes research.

Last year, Core Center program directors had the opportunity to submit an application for supplemental funds to further their research efforts in the area of health disparities. The NINR also supports Institutional Research Training Grants (T32). Applicants for these grants are required to develop a plan for recruiting and retaining underrepresented minority trainees. The

implementation of this plan is monitored annually. In 2000 and 2001, program directors and T32 administrators were encouraged to include a focus on health disparities in their projects.

The NINR also has a long tradition of supporting research supplements for underrepresented minorities. These supplements are awarded to investigators who receive NIH funding and are devoted toward helping minority students (high school and above) and faculty members develop their research careers. Many similar supplements are awarded, and the projects they fund address a wide variety of topics.

The NINR also supports Mentored Research Scientist Development Awards for Minority Investigators (K01). These awards are designed to support the career development training of minority faculty members. In 1997, 12 such applications were received, and 4 were funded, with ORMH having funded 75 percent of these projects. In 1998, 11 applications were received and 2 were funded, with no ORMH support. In 1999, 4 of 7 applications were funded, again with 75 percent support from the ORMH. In 2000, 3 of 9 applications were funded, with 75 percent ORMH support. Dr. Phillips noted that the NINR would like to receive more applications and is encouraging those whose previous applications were not successful to apply again. She asked the Council to assist in the effort to encourage more K01 applications. Dr. Phillips concluded by referring attendees to the NINR's Web Site, www.nih.gov/ninr, for more information.

Questions/Comments

A question was raised about whether any formal efforts are being made to bring K01 recipients together so that they can support one another and encourage further applications. Dr. Phillips noted that the NINR has talked about this and hopes to move forward in a concrete way soon. Dr. Grady noted that efforts are underway to bring various fundees together at a workshop in the near future. The comment was made that the regional research meetings might be a good venue to begin this process. Dr. Grady indicated that this was a good idea and that perhaps the process could begin at this year's regional meetings. Another comment was made that some fundees have, in fact, requested time on the agenda of the upcoming Baltimore meeting for this purpose.

Another commenter noted that the sample list of projects that Dr. Phillips had presented was very impressive and made her interested in seeing the whole roster of projects. Dr. Phillips indicated that such a list could be made available.

V. CAREER DEVELOPMENT AWARD: "DETERMINANTS OF HEALTHY BEHAVIORS IN ADOLESCENTS"

Dr. Grady introduced Dr. Constance Hendricks of the University of South Carolina at Columbia. She is an NINR minority career development grantee and directs a project entitled "Determinants of Healthy Behaviors in Adolescents." Her original K01 had two proposed phases: the first phase was a qualitative component, and the second phase involved retesting the expanded model. She developed the Hendricks Perceptual Health Promotion Determinants Model as part of her doctoral work and has been working since then to refine it. She found that her original model was able to explain 23 percent of the variance found, and she is continuing her efforts in this area.

The original model was developed with 1,036 seventh and eighth graders in rural Alabama. She subsequently tested the model with a second group of 1,408 Alabama young people and found that the model continued to hold and explained up to 33 percent of the variance found. Her goal was to focus on the health promotion aspects and to devise a means for early intervention with adolescents, before they engaged in negative health behaviors.

Her K01 grant enabled her to continue her studies in qualitative analysis. She conducted focus groups and individual interviews with teens to collect additional data. Her content analyses of the qualitative data posed the question, "What do you/your friends do to stay healthy?" She asked what made them decide to participate in risky behaviors such as smoking, drinking, and sexual activity. She grouped their answers into three areas: health-promoting behaviors, avoiding unhealthy behaviors, and factors influencing healthy decision-making.

She then conducted a pilot study in which she used community-based organizations, rather than schools, to help her gain access to adolescents. She tested scales she had not tested before with 55 youth ages 11 to 17 at a summer sports camp program. The instruments she tested proved to be quite reliable, and she is still analyzing the data compiled from this pilot. In addition, she began piloting various instruments with fifth and sixth graders in a school setting in South Carolina. The instruments proved reliable in this pilot as well.

Dr. Hendricks noted that the positive aspects of having a K01 grant include having dedicated time to focus on research, access to and being able to consult with multidisciplinary research teams, the opportunity to work with faculty researchers, the chance to develop productive relationships with other researchers, the affirmation of continued learning, support and guidance in her research goals, the opportunity to display and share her work, opportunities to publish, and the opportunity to consult and collaborate with other researchers and content experts. She stated that one of the most challenging aspects of the K01 experience, for her and for other researchers she has spoken with, has been the difficulty in identifying appropriate mentors. Once a mentor is found, whether they are at the same facility or at a distant facility there are additional challenges. Having a mentor onsite and another mentor at a different institution has worked well for her.

Questions/Comments

A question was raised about sex education in schools and whether it reinforced avoiding the types of behaviors that Dr. Hendricks was concerned about with adolescents. Dr. Hendricks noted that, unfortunately, many parents do not want their children to have formalized sex education in schools. Another questioner expressed surprise at the low levels of sexual activity that were reported by the respondents in the pilot studies. Dr. Hendricks noted that, in the intervention phase, the focus would be on fourth and fifth graders to provide them

with information *before* they become sexually active. Another questioner asked what steps Dr. Hendricks had taken to develop a rapport with the youth she spoke with and how she assessed whether they were being truthful in their responses. Dr. Hendricks acknowledged that researchers often confront the problem of respondents providing answers that they think the investigator wants to hear. She noted that, in addition to her research, she provides the community with community nursing services as a way of establishing herself and gaining credibility there. In response to a further comment about the need to ensure the validity of the answers she receives, she noted that she feels she can develop a good rapport with the respondents quickly, but that she is vigilant about the validity issue and will remain cognizant of it as she continues her research.

VI. REPORT OF NINR CONFERENCE: MINORITY HEALTH RESEARCH DEVELOPMENT FOR NURSE INVESTIGATORS

Dr. Grady acknowledged the previous reference to the National Coalition of Ethnic Minority Nurse Associations. She thought it would be valuable for the Council to hear from some of the principals involved in the development of this Coalition. Dr. Betty Smith Williams is President of the Coalition, and Dr. Antonia M. Villarruel is its Vice President.

Dr. Williams noted that the Coalition's members include the Asian American/Pacific Islander Nurses Association, the National Alaska/Native American Indian Nurses Association, the National Association of Hispanic Nurses, the National Black Nurses Association, and the Philippine Nurses Association of America. In 1996, the presidents of the above groups (except for the Philippine Nurses Association) attended a leadership conference in Denver, where the idea of these groups working together emerged.

In 1998, the group incorporated as the nonprofit National Coalition of Ethnic Minority Nurse Associations. The Coalition received support from a pharmaceutical association and other organizations. The group determined that its members would consist of national ethnic nurse organizations, with the seated presidents of these organizations serving as the voting representatives. The Philippine Nurses Association of America sought membership shortly after the Coalition was formed. The combined membership of the organizations in the Coalition totals approximately 350,000 nurses. The Coalition is supported by its members' dues.

The Coalition's purpose is to improve the provision of health care to ethnic/minority populations in the Nation. Its goals include advocating for accessible, affordable health care through culturally-competent providers; promoting research to develop culturally- competent models of care; increasing the number of ethnic/minority nurses to reflect the Nation's diversity; increasing the number of ethnic nurse leaders who can influence issues in health policy, practice, education, and research; promoting the professional advancement of ethnic/minority nurses; and serving as a clearinghouse for the dissemination of information on education, practice, policy, research, and leadership. Because the five member associations have been working with health disparity issues for many years, the Coalition is confident it can provide leadership in this area. The NINR and the Coalition agree on the importance of reaching minority populations, and recognize past efforts have not all been successful. The Coalition will work to help discover what drives human health behaviors so that these findings can be implemented to improve the health of ethnic/minority populations.

Dr. Villarruel noted that the conference on Minority Health Research Development for Nurse Investigators held June 5-6, 2000, was an important step in this direction. This invitational conference brought together 27 minority nurse investigators and minority nursing association officers, as well as NIH and NINR staff, to discuss key issues for minority health nursing research and career development for minority nurses. The conference was sponsored by the Coalition, the NINR, and the NIH Office of Research on Minority Health (now the National Center on Minority Health and Health Disparities).

Each of the five Coalition organizations presented a paper that described the history and background of their ethnic group, a summary of the health status of the ethnic group, and specific areas appropriate for research, with an emphasis on future minority health nursing research. These papers are to be published in *Nursing Outlook*.

The conference participants identified several research issues common to all groups that should be considered in developing future minority health nursing research: diversity, appropriateness of research methods, the need for community-based research, and the importance of broad dissemination of research findings. Areas of research opportunity for minority health were identified under the broad topics of health promotion, illness management, and lifespan issues. The group also made recommendations about career development for minority nurse investigators in the areas of grantsmanship training, research training, funding, mentoring, and peer review.

Further details on this conference can be found in the meeting's Executive Summary, which is posted on the NINR Web Site (www.nih.gov/ninr/i_publications.html). Dr. Williams indicated that the next steps for the Coalition are to develop program and policy initiatives by working the NINR, the NIH, and other organizations.

Questions/Comments

A question was raised about how the group was addressing recruitment issues and how research could help in this area. Dr. Villarruel indicated that nursing recruitment in general is difficult and that minority recruitment is even more difficult. Each Coalition organization has its own recruitment program, and appropriate steps should be taken in each community to address these issues. Dr. Grady commented that recruitment for minorities could be incorporated into the overall efforts that will be made to address the Nation's nursing shortage. Other comments addressed the need for developing a model for community organizations to be a part of the funding mechanism for minority nursing research, and the importance of the Coalition's members reaching consensus on these important issues.

VII. DISCUSSION OF FY 2003 AREAS OF OPPORTUNITY

Dr. Grady explained that this session would focus on reviewing and commenting on the draft descriptions of the Areas of Opportunity as proposed for FY 2003.

Symptom Management of Neurological Mobility Disorders – Drs. Cammermeyer and Hanley, Discussants

Dr. Cammermeyer observed that this area of opportunity seeks to improve quality of life for individuals affected by limited mobility, and addresses a very important topic. She questioned why the focus was on neurological problems rather than mobility impairment in general, and suggested that the purpose be defined more clearly. Dr. Hanley also suggested focusing on the whole patient and including any disorder that limits mobility. He agreed that the idea of identifying interventions to maintain physical functioning is important for persons with limited mobility.

When originally drafted, this topic was broadly defined, but it was then narrowed to neurological problems in order to provide greater focus. In addition, little work has been done in the area of the neurological aspects of mobility impairment. Dr. Grady indicated that finding a middle ground may be the best strategy, and suggested examining what mobility issues were being covered in current or planned initiatives on stroke and osteoarthritis. She also noted that more than one initiative might be needed for this topic area. However, a broad initiative focused on symptom management of individuals with mobility disorders may attract investigators with expertise in a range of specific diseases or conditions.

<u>Research on Clinical Bioethical Decision Making – Drs. Hanley and Powell, Discussants</u> Dr. Grady announced that Dr. Powell had to leave but that she had concurred with the proposed initiative. Dr. Hanley stated that this research area was good, and that substitute decision-making and advance care planning were particularly bold topics. He noted that this description highlights observational opportunities, but NINR may wish to consider including intervention studies such as those related to community decision making. Dr. Grady indicated that the NINR has had a small program in bioethics for years; now may be good time to reenergize it. Informed consent, right to privacy, and end of life are some of the specific topics that NINR anticipates will be addressed by this initiative.

Discussion addressed the fact that informed consent is an excellent area of study for nurse researchers. The importance and timeliness of trying to ascertain what people think is important for informed-consent decision-making was mentioned, including community-based approaches. It was noted that the Department of Veteran's Affairs will conduct a state-of-the-art conference on this topic in April 2001.

<u>Increasing Nursing Collaboration in AIDS International Research Programs – Dr. Patton and</u> <u>Mr. Blumenreich, Discussants</u> Nurse scientists are well positioned to provide research expertise for international HIV/AIDS research, particularly in the areas of symptom management and research training. This initiative would facilitate a workshop for nurse researchers and others in order to foster international collaborations. Dr. Patton supported this initiative, indicating that it could be expanded beyond tuberculosis and AIDS research. He also noted that identifying countries, groups, and resources abroad could be added to the workshop objectives. In addition, he suggested adding a special leadership role for nurse scientists in the areas of adherence, symptom management, prevention, and vulnerable populations – topics for which our research base is very strong. Mr. Blumenreich concurred that this topic is important, and noted the need to emphasize how this research would affect the health of the U.S.

<u>Clinical Intervention Research:</u> Prevention, Screening, and Early Treatment of COPD –Dr. Lindsey and Ms. Sanford, Discussants

Although most research to date has focused on dealing with managing the symptoms of COPD as a chronic disease, this initiative shifts the focus to screening for COPD in order to help prevent its long-term consequences. Dr. Lindsey concurred that this proposed area of opportunity is timely and significant, and that a focus on preventive strategies, particularly smoking, is very important in advancing the science. She also suggested adding the use of new technologies in home health care. Ms. Sanford agreed, and suggested that attention be paid to the addiction component in early screening.

Smoking Cessation Targeted in Youth—Preventing Cardiovascular Disease – Drs. Grey and LaRosa, Discussants

Dr. Grey characterized this area of research as "enormously important," and urged making this area a major priority. While other population groups are quitting smoking, children are starting—and they will smoke for a long time. She recommended that the focus of this initiative be broadened to emphasizing how to help youth stop smoking, rather than just preventing cardiovascular disease. Dr. LaRosa concurred, indicating that this initiative and the proposed area of opportunity on Enhancing Adolescent Health Promotion Across Multiple High-Risk Behaviors are crucially important. More research is needed on smoking prevention in adolescents, and young girls—especially young black girls—who are particularly at risk of starting smoking. Both discussants suggested that NINR examine whether additional initiatives beyond a Program Announcement might be warranted for this crucial topic.

Long-Term Care Recipients: Health Care Needs and Interventions – Drs. Buckwalter and Finkler, Discussants

Dr. Buckwalter characterized this area as enormously important, and noted the specific need for translational research. Although considerable research data exists about effective interventions for some problems, these findings aren't routinely implemented in the current care delivery

system. She suggested that NINR consider ways to study the identified research gaps, and to test what strategies can work given the constraints of our current health care delivery system. She also recommended adding a component to test popular new "in vogue" approaches (e.g., the Eden alternative) for which outcome data on effectiveness are lacking, and adding an emphasis on assisted living arrangements. Partnering with Patient Safety Centers on such problems as medication management and falls may be beneficial. Dr. Finkler supported Dr. Buckwalter's comments, noting that the problems for long-term care recipients are multifaceted, and include dissemination, enforcement, policy, coordination, and financial components.

Community-Partnered Interventions To Eliminate Health Disparities – Drs. Powell and Patton, Discussants

Dr. Grady noted that this topic had been widely discussed already, but asked if there were any additional comments. Dr. Patton characterized this initiative as a unique opportunity to create partnerships and to learn from the communities. He highlighted the fact that this topic is consistent with Dr. Maddox's earlier presentation and thought it would be supported by the NCMHD as well.

Enhancing Adolescent Health Promotion Across Multiple High-Risk Behaviors – Drs. LaRosa and Grey, Discussants

Dr. Grady noted that this area, too, had been discussed previously. This proposed area of opportunity is unique in targeting multiple high-risk behaviors of adolescents. Drs. Grey and LaRosa reiterated that the NINR should take the lead in this area and that smoking should be included in the topics examined.

<u>End-of-Life:</u> Bridging Life and Death – Drs. Buckwalter and Lindsey, Discussants NINR has been the leader at NIH on end-of-life issues, having recently issued a Program Announcement on the quality of life at the end of life and launched an NIH-wide research interest group on the topic. Dr. Buckwalter noted the importance of building on this momentum and expressed her support for this initiative. She suggested expanding it in four areas: health status of the caregiver; communication, especially soliciting family and patient preferences; developing new models of palliative care, e.g., in rural areas; and capacity for decision making by partially autonomous patients. Dr. Lindsey concurred about the importance and timeliness of this topic. She suggested including such areas as decreasing caregiver burden; management of physical symptoms, cognitive problems, and psychosocial distress; dependence issues; and cultural/ethnic preferences.

Program Director Dr. Ann Knebel noted that the NINR is planning a state-of-the-science conference on end-of-life issues for October 2001. The proposed format includes white papers on specific topic authored by investigators. The conference will have a focus on end-of-life issues in the aging population, and will be a collaborative effort involving the National Institute

on Aging (NIA), the National Cancer Institute (NCI), and the National Center for Complementary and Alternative Medicine (NCCAM).

Dr. Grady thanked the Council members for their comments and effort in reviewing these areas of opportunity.

VIII. REVIEW OF STRATEGIC PLAN PROGRESS INDICATORS FOR YEAR 01

Dr. Grady explained that the five-year NINR strategic plan had been reviewed carefully and progress indicators identified to assess the degree to which we are meeting the goals. This activity was developed with significant council input. At this council meeting, it was time to examine the outcomes of the first year indicators as compared to the baseline year of FY1999.

Council noted that in all but a very few instances, the goals were met and were frequently exceeded. Only a few points were briefly discussed to further refine the process. Council commented on how useful this exercise is and complimented the staff on putting together the summary document.

- In the section on identifying the increase in funding selected research areas, Dr. Buckwalter noted that it would be valuable to also look at data that result from counting each research grant only one time.
- Target indicators need to be revised for the intramural program in outlying years. This will be an ongoing process.
- With regard to the NINR Website usage, the question of what should be tracked arose. Suggestions were made to make data more comparable across years. Search engines will also be checked to see that the NINR is cited prominently when users look for information on nursing research. Proper targeting of words and the amount of time people spend on the Website also were discussed.
- There is a positive trend in the increase of pre- and postdoctoral candidates, but the increase in actual numbers of trainees was not as high as was hoped for. The increase in individual stipends was a significant reason since the dollars were increased to the target level.
- The timeframe for evaluating the plan was confirmed. NIH funds may be sought to conduct this evaluation.
- The targeted number of 32 career development awards was reached, but at a lower funding level. This is due to some of these awards having been cofunded by other offices.
- There is a need to develop separate evaluation plans for the P20s and P30s because their expressed missions are different.
- It was noted that the 114 articles published with NINR support was higher than expected. It was suggested that it was not a good idea to change target levels annually, even if a target is exceeded in a given year. A longer-term perspective generally is more useful.

• One council member urged that the publications be identified as "peer reviewed" and that we look at including how often these publications are cited by others, even though there would be a time lag associated with these data.

Council noted the importance of sharing NINR's successes with the scientific community. The usefulness of this instrument and the idea of circulating it to other NIH components as a model was suggested.

Dr. Grady thanked the staff for having prepared the summary document and the Council members for their input.

IX. REVIEW OF COUNCIL DOCUMENTS

Biennial Data for Gender and Minorities

Dr. Leveck introduced Dr. Carole Hudgings to lead the discussion on the 2001 Biennial NINR Report to NACNR on Compliance With Inclusion Guidelines. Other documents were also provided for council, including the NIH report on Monitoring Adherence to the NIH Policy on the Inclusion of Women and Minorities as Subjects in Clinical Research for FY 1997 and FY 1998. This document highlights the background and the Congressional mandate to include women and minorities in clinical research and describes the peer-review process ensuring the inclusion of these groups. It also provides an update on the May 2000 General Accounting Office (GAO) report on women's health and including women in clinical research.

Dr. Hudgings stated that the NINR is required to report to the Council every other year on its process for reviewing applications for the inclusion of women and minorities in clinical research, and the resultant data. The current report covers data for FY 1998 and FY 1999. In FY 1998, just under 50 percent of all subjects in NINR-funded clinical research studies were White (compared with an NIH-wide figure of approximately 55 %). Thus, slightly more than 50 percent of subjects represented the categories of American Indian, Asian, Black, Hispanic, and other. The NINR exceeded the overall NIH average in representation of Blacks and Hispanics in FY 1998. The NINR's percentage of males and females enrolled (36% male, 61% female) also compares favorably with NIH figures.

Data for FY 1999 showed little change, with about 54 percent of the subjects in NINRsupported clinical research studies reported as White, and the remaining percentage distributed among the other ethnic categories. Fifty-seven percent of subjects were female, and 29 percent were male. NIH-wide data for Fiscal 1999 were not available for comparison at the time this report was prepared.

Annual Statement of Understanding

Dr. Leveck called the Council's attention to the January 2001 Statement of Understanding Between the Staff of the NINR and the NACNR. She noted that the document was unchanged from the previous year, except for the addition of the expedited En Bloc Concurrence process. Based on Council comments, the process now includes primary and secondary reviewers. Future changes will reflect modifications being made to the electronic Council book. The document was approved as circulated.

Dr. Grady noted that the Open Session of this Council meeting was now concluded. She thanked all present for their time and participation.

X. REVIEW OF APPLICATIONS

The members of the National Advisory Council for Nursing Research considered 105 research and training grant applications requesting \$77,567,260 in total costs. The Council recommended 69 applications with a total cost of \$57,620,345.

XI. OTHER ITEMS FOR CLOSED SESSION: EXECUTIVE SESSION

The closed session concluded with a discussion of personnel and proprietary items.

XII. ADJOURNMENT

The 43rd meeting of the NACNR was adjourned at 1:00 PM on January 24, 2001.

CERTIFICATION

I hereby certify that the foregoing minutes are accurate and complete.

Patricia A. Grady, Ph.D., R.N., F.A.A.N.Mary D. Leveck, Ph.D., R.N.ChairExecutive SecretaryNational Advisory Council for Nursing
ResearchNational Advisory Council for Nursing

MEMBERS PRESENT

Dr. Patricia A. Grady, Chair Mr. Gene Blumenreich Dr. Kathleen C. Buckwalter Dr. Margarethe Cammermeyer Dr. Steven Finkler Dr. Margaret Grey Dr. David Hanley Dr. Judith LaRosa Dr. Ada M. Lindsey Dr. Curtis L. Patton Dr. Dorothy Powell Ms. Sarah Sanford Dr. Betty Smith Williams Dr. Paulette Cournoyer, *Ex Officio* Dr. Catherine Schempp (LTC), *Ex Officio* Dr. Mary Leveck, Executive Secretary, NINR

MEMBERS OF THE PUBLIC PRESENT

Dr. Jean Anthony, Howard University Ms. Gia Belton, Howard University Dr. Doris Bloch, Window on Nursing, Maryland Ms. Joanne Brodsky, The Scientific Consulting Group, Maryland Dr. Carolyn Cochrane, American Psychiatric Nurses Association Ms. Annette Conley, Howard University Hospital Dr. Constance Hendricks, University of South Carolina Ms. Erica Jones, Howard University Ms. Nicole Laing, Howard University Ms. Martha Mohler, National Committee to Preserve Social Security and Medicare Ms. Pam Moore, Capitol Publications/Aspen Publishers Dr. Cornelia Porter, University of Michigan Ms. Angela Sharpe, Consortium of Social Science Organizations Ms. Sabrina Singleton, Howard University Dr. Anne Thomas, Family Practice Center, Terre Haute, Indiana Dr. Antonia Villaruel, University of Michigan Dr. Grace Willard, WESTAT, Rockville, MD

FEDERAL EMPLOYEES PRESENT

Dr. Nell Armstrong, NINR/NIH Mr. Ray Bingham, NINR/NIH Ms. Linda Cook, NINR/NIH Ms. Janet Craigie, NHLBI/NIH Ms. Marianne Duffy, NINR/NIH Ms. Robin Gruber, NINR/NIH Dr. Clare Hastings, Clinical Center/NIH Dr. Karin Helmers, NINR/NIH Dr. Carole Hudgings, NINR/NIH Dr. Ann Knebel, NINR/NIH Dr. Yvonne Maddox, OD & NICHD/NIH Ms. Cindy McDermott, OD/NIH Ms. Tara Mowery, NHLBI/NIH Mr. Daniel O'Neal, NINR/NIH Mr. Eddie Rivera, NINR/NIH Mr. William Rosano, NINR/NIH Dr. Hilary Sigmon, NINR/NIH Ms. Arlene Simmons, NINR/NIH Dr. Mary Stephens-Frazier, NINR/NIH

Mr. Robert Tarwater, NINR/NIH Ms. Kimberly Witherspoon, NINR/NIH Ms. Sally York, NINR/NIH

ROSTER: NATIONAL ADVISORY COUNCIL FOR NURSING RESEARCH

(Terms expire on January 31 of the indicated year)

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