

Summer 2002

LINKS: Minority Research & Training



Karen Lowe Graham meets with Loyola University nuns.

Minority Recruiter Builds Trust Before African American Nuns Join AD Study

Out of more than 700 nuns, priests, and brothers who agreed to participate in a longitudinal study of aging and Alzheimer's disease (AD), only three African American clergy joined in its first 6 years. To improve recruitment results and expand the study, David A. Bennett, M.D., principal investigator for the Religious Orders Study (ROS), hired Karen Lowe Graham as the multicultural outreach director. Since then, Graham and her colleagues have recruited 70 African American nuns and priests to the ROS at the Rush Alzheimer's Disease Center and Rush-Presbyterian-St. Luke's Medical Center in Chicago, IL.

Recruitment of African Americans was deemed vital to the ROS, not only because they were underrepresented among the volunteers, but also because some research shows that African Americans may be at higher risk for developing AD than Caucasians and more likely to become physically disabled. Better efforts are needed to reach out to African American study participants if scientists are to develop a more complete understanding of AD. The recruitment process requires many months of groundwork conducting research, sharing study goals with influential gatekeepers, and presenting information about the study to national organizations, according to Graham.

Before she began recruiting, Graham contacted Sister (Sr.) Jamie Phelps, Ph.D., a well-connected and well-regarded African American nun from Loyola University. With Sr. Phelps on her side, others might be inclined to support the study, reasoned Graham.

(continued on page 3)

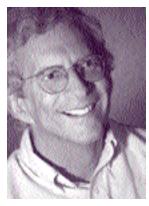
New Minority Aging Journal Provides Students a Venue to Publish, Review, and Advance

Undergraduate, graduate, and postdoctoral students may now review and publish articles that will advance minority aging research—and their careers—in the new online *Journal of Minority Aging for Young Investigators (JMAYI).* "Young researchers must publish before they go

into the job market, so it's important to help them develop journal article writing skills. The lack of publishing opportunities could delay young researchers' professional development," said Dr. Keith E. Whitfield, *JMAYI's* Supervising Editor and Associate Professor of Biobehavioral Health at the Pennsylvania State University.



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Richard J. Hodes. M.D.. Director

A Note from the Director

A portrait of an older America is beginning to emerge, and it is rife with inconsistencies. On one hand, data show that we are healthier and wealthier than ever before. A majority of us age 65 and older say our health is

good or excellent. Rates of disability and of several diseases are falling dramatically, despite a notable increase in the number of older people. Fewer of us live in nursing homes than did just a decade ago. And the poverty that used to accompany advancing old age has been greatly reduced.

On the other hand, good health and well-being are far from a universal reality. Disparities in major statistical health indicators among segments of the U.S. population, white and non-white groups, persist. In general, African American, American Indian, and Hispanic ethnic and racial groups are disadvantaged relative to whites on most health indices, whereas Asian Americans appear to be as healthy, if not healthier, than whites.

As a result, the NIA is increasing its emphasis on the study of gender, racial, and ethnic disparities in health and is making a concentrated effort to include more minorities in research and to train new minority scientists. To read the NIA's Strategic Plan To Address Health Disparities, go to our website at http://www.nia.nih.gov/ strat-planhd/2000-2005/. I also recommend to you "Portfolio for Progress" at http://nia.nih.gov/health/pubs/ portfolio/portfolio.pdf, a new NIA booklet outlining our research focus areas: the biology of aging, reducing disease and disability, Alzheimer's disease and cognitive changes, and the behavioral and social aspects of aging.

I would like to take this opportunity to introduce the new NIA Deputy Director, Judith A. Salerno M.D., M.S. Before joining us, Dr. Salerno developed policies to improve pain management, long-term care and end-of-life care as Chief Consultant for Geriatrics and Extended Care for the Veterans Health Administration (VHA).

At the VHA in Washington, D.C., Dr. Salerno set procedures to improve the diagnosis and treatment of dementia while forging relationships with the American Geriatrics Society, the Gerontological Society of America, and the National Chronic Care Consortium. Geriatric training is among Dr. Salerno's top priorities: at the VHA, she expanded the Geriatric Research, Education and Clinical Centers (GRECC) from 16 to 21 major centers.

This is Dr. Salerno's second appointment at the



Judith A. Salerno M.D., M.S. Dr. Salerno received her Deputy Director

NIA. From 1989 to 1992, she served as Senior Clinical Investigator at the Laboratory of Neurosciences where she concentrated on clinical research in Alzheimer's disease and geriatric hypertension. From 1992 to 1995, she was an NIA guest researcher.

M.D. degree and a mas-

ter's degree in health policy and management from Harvard Medical School, followed by clinical and fellowship training in internal medicine at Georgetown University, The George Washington University, and the National Institutes of Health (NIH). Dr. Salerno, who is certified in geriatric medicine, has authored more than 50 publications related to the treatment of older people and age-associated diseases. We are very fortunate to have her join our research efforts as the NIA finds ways to lessen health disparities.

Cutard & Hodes

Richard J. Hodes, M.D. Director, National Institute on Aging

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Timeline for Multicultural Community Outreach for Religious Orders Study Conducted by Karen Lowe Graham and Her Colleagues

Date	Staff	Comments
6/97	Karen Graham	Dr. David Bennett asked Graham to find African American (AA) sites and get letters of support
12/97– 1/98	K. Graham, David Bennett	Received letters of support from 3 of the largest AA motherhouses as well as the National Black Sisters' Conference (NBSC) and National Black Catholic Clergy Caucus (NBCCC)
7/98	K. Graham, D. Bennett	Gave presentation at joint conference of NBSC and NBCCC
2/99	K. Graham, D. Bennett, Julie Bach	Gave recruitment talk to Franciscan Handmaids in NYC
4/99	K. Graham, D. Bennett, J. Bach	Gave recruitment talk to Oblate Sisters of Providence in Baltimore, MD
7/99	K. Graham, D. Bennett, J. Bach and Sr. Maria Goretti Mannix (Mother Superior of the Franciscan Handmaids)	Gave recruitment talk to Sisters of the Holy Family in New Orleans
4/00	K. Graham and Lisa Barnes	Gave study update to Franciscan Handmaids
6/00	K. Graham and L. Barnes	Gave study update to Sisters of Holy Family
7/00	K. Graham	Gave study update and recruitment talk to the Oblate Sisters
7/00	K. Graham	Gave update to NBSC and NBCCC at their joint conference
4/01	K. Graham, D. Bennett, J. Bach, and Maria Carrillo	Gave educational talks in English and Spanish to Latino sisters in San Antonio
7/01	K. Graham	Gave update at the NBSC conference

But first Graham, Bennett, and Jacob H. Fox, M.D., a co-investigator on the study, invited Sr. Phelps to lunch.

"Sr. Phelps asked us many questions. She wanted to make sure that Dr. Bennett wasn't going to exploit the nuns," Graham said of the meeting. "She wanted to know whether the study was going to make African Americans look less intelligent than Caucasians." Based on her positive impressions about the study, Sr. Phelps contacted the National Black Sisters' Conference (NBSC) and the National Black Catholic Clergy Caucus (NBCCC) and told them about the study. These organizations turned out to be very important to Graham's recruiting efforts.

Graham did a lot of time-intensive background work before setting up a meeting with the two influential groups. "We researched the organizations and identified our liaisons partly by having our ear to the ground and partly through visits with people," said Graham, who joined the NBSC as an associate member.

She met with Sr. Patricia Chappell, former NBSC president, who also asked her pointed questions and shared her own mixed experiences with medical researchers. Graham stressed the study's "give back" philosophy. "Instead of going to the meeting asking for something, we wanted to provide something. We offered free educational programs on AD and materials on caring for someone with AD. When the Sisters of the Holy Family wanted to start an AD unit at their nursing home in New Orleans, we provided materials and acted as a consultant for them."

When Sr. Chappell was satisfied with Graham's answers, she spoke on behalf of the ROS to the NBSC conference board. The NBSC and the NBCCC invited Graham and her colleagues to speak at a July 1998 joint conference in Charlotte, N.C.

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"We invited the boards of both groups to dinner and let them get to know us. Seven months later, we were able to move forward with our presentations to the individual communities."

In presentations to groups of nuns, Graham, Bennett, and Julie Bach, the study coordinator, discussed how the study requires participants to go through detailed physical and mental evaluations every year to help researchers better understand the effect of normal aging, AD, and other disorders of the brain.

The nuns were particularly concerned about the study's requirement to donate their brains. "This was a great barrier to recruitment," Graham said. "I had one nun ask me, 'What will it mean when I go

to heaven without a brain?" Religious communities tend to be altruistic, but most people do not want to donate their brains. "We talked about the legacy their participation would provide to their grand nieces and nephews," she said.

At every 3 hour presentation, Graham was asked questions about the Tuskegee Syphilis Study in which 400 low-income African American males were infected with syphilis and monitored for 40 years without treatment.

"They wanted to find out how we were going to make sure their bodies were going to be respected and that the research would be truly useful. We addressed their concerns head on. Dr. Bennett and I talked about how our study is different [from the Tuskegee study] because of Institutional Review Boards, which protect people from those kinds of abuses," Graham said.

Recruitment efforts were greatly helped when the Mother Superiors of the Oblate Sisters of Providence, the Franciscan Handmaids of Mary in New York City, and the Sisters of the Holy Family in New Orleans signed up for the study. Since then, Graham has had very low drop-out rates in part because she stays in frequent contact with the nuns. Study participants also were reassured to know that people of color were analyzing and presenting the data from the ROS.

Dr. Lisa Barnes, an African American cognitive neuroscientist and co-investigator on the ROS, has

coauthored many publications based on the study and has presented data from the ROS at national meetings.

Study executives attended every presentation so the nuns could get to know and trust them, but the Sisters often directed their questions and comments to Graham. "It's important that a multicultural recruiter is someone of color who speaks the community's language and who is a full member of the team. You need to be able to communicate and

"African Americans are an oral people. We talk to each other." Karen Lowe Graham feel comfortable going to different parts of the city. It also helps to have some diversity among researchers and study administrators," she said.

Graham is also charged with educating and sensitizing

researchers. At workshops, she coaches researchers on what to say and what not to say before they ever set foot in the community. Graham accompanies them into the field to make sure they are conducting themselves with sensitivity. She helps them avoid such common mistakes as failing to inform the community about the study results. "If the researcher comes in with the attitude of, 'I'm going to get mine and go on' they will alienate not only the volunteers but the volunteers' relatives and neighbors. African Americans are an oral people. We talk to each other."

Graham's success with the ROS resulted in her being asked to help recruit for several other studies being conducted at Rush. Presently, Graham is reaching out to Spanish-speaking communities with the help of Dr. Maria Carrillo, Assistant Professor of the Department of Neurological Sciences at Rush Neuroscience Institute. To surmount language barriers, Graham is hiring a Spanish-speaking recruiter to make presentations, administer tests, and translate materials.

The Rush AD Center is one of 29 NIA-supported AD centers across the U.S., which conduct basic, clinical, and social and behavioral research on dementia, and AD. NIA also sponsors the Alzheimer's Disease Education and Referral (ADEAR) Center, which provides information on AD research to the public, health professionals, and the media. \clubsuit

Gap in Reading Levels May Explain Apparent Differences in Cognitive Testing

The research of Jennifer Manly, Ph.D., and colleagues at Columbia University suggests that methodological and analytical approaches, not actual racial or ethnic disparities in cognitive test performance, may in some cases help explain differences between older African Americans and non-Hispanic whites on cognitive tests.

The Columbia group's findings, published in the March 2002 Journal of the International Neuropsychological Society offer a powerful new tool—adjusting test results for quality of education—as one way to make cognitive testing of older people more culturally neutral. In the study, when test scores of participants with similar quality of education, measured by reading level, were compared, differences in test scores between the two racial groups mostly disappeared.

The report challenges a standard approach used in research on cognition and dementia. Because differences in education might affect test scores or health status, most studies that have adjusted for the number of years of schooling still found that older African Americans did not score as well on cognitive tests as non-Hispanic whites. Manly's work looks instead at the quality of education. Inequalities in the educational experience of those who grew up in an era of segregated schools, Manly reasons, might be attributed to less funding and resources for such schools as well as fewer days per year that schools in the agrarian South were open for instruction. These discrepancies in early education, Manly suggests, have the potential to persist throughout life, as indicated in differences in reading levels between older African Americans and non-Hispanic whites.

At the NIA, racial and ethnic differences in cognitive function and dementia are an increased focus of research. "Several studies have reported racial and ethnic differences in cognitive performance in older adults and in the prevalence of Alzheimer's disease," notes Molly Wagster, Ph.D., Program Director for Neuropsychology of Aging Research and project officer for the Manly study. "Because cultural, educational, or other differences might affect performance on this type of testing, there have been questions about whether measurement techniques are as culturally neutral as they could be."

Participants were drawn from a community-based study of cognitive aging in New York City's ethnically diverse neighborhoods of northern Manhattan. Random sampling was used to select 192 African Americans and 192 non-Hispanic whites age 65 and older. The two groups were matched in age, sex, and number of years of education. Participants were given medical evaluations at the start of the study to confirm that they did not have dementia and that they had no problems with daily activities. A battery of neuropsychological tests was then administered to examine memory, learning, and thinking abilities. Older people with low levels of reading ability could only name letters or read short, common words. Those with higher reading levels were able to pronounce complex, less common words, out of context.

The African American group scored lower on the neuropsychological test battery overall as compared to non-Hispanic whites. But when reading scores were factored in, most differences between the groups were no longer statistically significant. The exceptions were category fluency (a test in which people must name objects in a category during a set period of time) and a drawing test, where differences between racial groups were observed even after adjusting for reading level. More information is needed to explain the persistent differences on those two measures, the researchers said.

Manly recommended further research to sort out methodological and analytical approaches, such as accounting for quality of education, from real racial or ethnic disparities in cognitive test performance. Such problems in methodology and analysis make it difficult to establish whether one group or another truly may have greater rates of cognitive decline and may cause misdiagnosis of cognitive decline and dementia in minority groups. "We need to develop measures designed to assess cognitive abilities in a way that is compatible with African American and other cultures," she notes. "With these, we will have greater confidence in any measures which show—or do not show—differences in cognitive health and

New Journal (continued from page 1)



Dr. Keith E. Whitfield

The decision to launch the online journal grew from a roundtable discussion on the impact of race on the science of aging hosted by the Gerontological Society of America's (GSA) Task Force on Minority Issues at last year's annual meeting. Many

of the 60 participants cited the need for more minority research publishing venues to help bring attention to important research. Junior investigators, in particular, need more publishing venues, participants said. From this discussion, *JMAYI* was born, said Whitfield, who is also the GSA task force chair.

The journal will be edited and reviewed entirely by students, and as students graduate, others will have the opportunity to take a turn at the helm, he said. Students will also have the opportunity to publish journal articles that are based on presentations made at professional conferences, he said.

Journal editors will consider papers from disciplines including (but not limited to) psychology, biology, public policy, sociology, social work, nursing, medicine, anthropology, education, health education, and public health. Research on minority aging submitted to the journal should include human subjects from ethnic groups including (but not limited to) Latinos, Asians, African Americans, American Indians, and Pacific Islanders. *JMAYI* articles will be archived in PDF files and can be accessed for free.

New investigators should try to get their research published in peer-reviewed journals that are listed in PubMed Central (for example, *American Journal of Public Health, Ethnicity and Disease, Minority Health Today, Journal of the National Medical Association*) in order to have the greatest influence on the research field. *JMAYI* is a good venue to learn the publishing process and bring to fruition a piece of research work that has not found acceptance in the established journals of the field, commented Dr. Dan Longo, the NIA scientific director.

In its early stages, an advisory board will help provide guidance, encourage student editors and submitters, and spread the word about the new journal. Later, *JMAYI* editors will forge formal connections with professional organizations and arrange mini-conferences at gerontology meetings.

The need to increase the number and preparedness of researchers studying minority aging is getting attention and gaining momentum. On March 26, 2002, the Institute of Medicine issued a 562-page report titled, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care" that spelled out how lower quality health care can contribute to minorities' higher death rates and shorter lifespans. A day after the IOM report was released, NIA's Behavioral and Social Research Program sponsored a 2 day workshop on Ethnic Disparities in Aging Health at the National Academy of Sciences (NAS). The NAS experts' reports, due next fall, will help determine the future direction of NIA research.

Whitfield is well-prepared to launch this multidisciplinary journal. He serves as faculty for four different NIA-supported summer institutes designed to promote the development of junior faculty and students. He also is Chair of the Advisory Committee for the Minority Aging Networks in Psychology program for the American Psychological Association; a member of the APA Minority Fellowship Advisory Board, and a member of the National Advisory Board for the Center for Urban African American Aging Research at the University of Michigan.

For more information about the journal, please go to: http://www.personal.psu.edu/faculty/k/e/kew5/jmayi.htm

For Dr. Whitfield's *Secrets of Successful Publishing*, please go to page 7.

LET US HEAR FROM YOU!

We are always interested in hearing from minority program faculty, alumni, and students. Please drop us a line and let us know where you are and what you are doing.

Work Group on Minority Aging Office of the Director National Institutes of Health National Institute on Aging Building 31, Room 5C35 Bethesda, MD 20892-2292 Phone: 301-496-0765

Secrets to Successful Publishing

Dr. Keith E. Whitfield, Supervising Editor of the new *Journal of Minority Aging for Young Investigators* (JMAYI) and Associate Professor of Biobehavioral Health at the Pennsylvania State University, provides these tips to young researchers who want to publish in professional journals. Whitfield rates the importance of the tips on a scale of 1 (least crucial) to 10 (most crucial).

- Always have someone read your article before submission. Your goal is to convey your point about minority aging research. If your reader can repeat to you what you wanted to convey, you'll know you're on track. [rated 10]
- Use your research results to convey your unique point of view on minority aging. There is no one truth. The field of minority aging research needs lots of insights and lots of different minds. It takes time and practice to be good at conducting and publishing research. Your thinking will become refined as you test and integrate other ideas. [rated 10]
- Spend time on your first sentence and first paragraph because they set the whole tone for the paper. They should be dramatic, high impact, and strongly identify an important issue. An example of a good first sentence is "African Americans have the highest rate of hypertension in the world." [rated 8]
- The paper should be neat, organized, and read like a novel. There's no excuse for spelling errors. You should review and tell the story of the existing literature and explain how you arrived at your own hypothesis. Explain how you conducted your study. Present both the findings and the implications. [rated 8]
- One error young researchers make in the discussion section is to restate the results of the study. Instead, you should interpret your results. You want to point out how your results support the existing literature or differ from it, and how your research takes the literature a step further. [rated 8]
- Follow exactly the 'Instructions to the Author' section. If you don't follow the format, it is bothersome to the editors and reviewers. By following the reference format for footnotes and instructions on headers, it will be a clearer and better paper. Unfortunately, people who haven't been on editorial boards often don't attend to these important details. [rated 7]
- Submit your articles to the most appropriate and best journals you can find. Review past copies of the journals and talk to your senior faculty or mentor to determine which are most appropriate and best. You can also check the *Social Science Citation Index* to see how many times a journal is cited. Communicate with the journal editor that you're thinking about submitting an article and ask whether he/she thinks your manuscript would be a good fit. [rated 7]
- Even if you haven't seen a certain type of article in a journal, if you think it is appropriate, you should make the effort to get it published. [rated 7]

dementia among various groups." Manly pursues such research as a neuropsychologist at the NIAsupported Alzheimer's Disease Center at Columbia University. Part of Manly's focus at the Center concentrates on research to improve the accuracy in diagnosing cognitive impairment and decline over time.

Researchers at Columbia are now adding tests of reading levels to their assessments of cognitive ability and are looking to see how accounting for quality of education might affect previous findings on levels of cognitive performance and rates of dementia among different groups in the community. In addition, Manly and her colleagues are carrying out further research on the effect of quality of education and literacy among Spanish-speaking Caribbean Hispanics through a pilot grant from the Columbia Center for the Active Life of Minority Elders (CALME), a Resource Center for Minority Aging Research (RCMAR) funded by the NIA and the National Institute of Nursing Research. \clubsuit

Remember! August 1st Deadline for Technical Assistance Workshop

NIA will sponsor a Technical Assistance Workshop Nov. 20 and 21, 2002 in conjunction with the Gerontological Society of America's annual meeting in Boston, MA. Applications are due by August 1, 2002. For information and an application, please contact Mrs. Nenomie Palmer at 301-496-0765; email: palmerne@nia.nih.gov.

LINKS: MINORITY RESEARCH & TRAINING

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