



TUSKEGEE
UNIVERSITY

*National Center for Bioethics
in Research and Health Care*



**Community-Campus
Partnerships for Health**
Transforming Communities & Higher Education



Conference Call Series on Institutional Review Boards (IRBs) and Ethical Issues in Research

Call #2: Highlighting the Importance of the Non-Affiliated (Community) IRB Member

Telspan, the conference call operator, will call the speakers and moderator at 11:30 a.m. PST in preparation for the call. We will speak as a group regarding last-minute details and receive instruction from the operator.

March 14, 2007, 12:00 to 1:30 pm PST

Welcome, overview of call series	12:00 to 12:05
Introduction of moderator and instructions for participants Kristine Wong, Program Director, CCPH	
Introduction of today's call topic and speakers by moderator Vanessa Northington Gamble, Director of the Bioethics Center	12:05 to 12:10
History and role of community members on IRBs, current snapshot of non-affiliated IRB representation, focus group results, and challenges in representing the community Elda Railey and Mary Lou Smith, Co-Founders, Research Advocacy Network	12:10 to 12:30
Sharing of experience as an IRB community member, including challenges and coping strategies. Lucille Webb, IRB Non-Affiliated (Community) Member & Director, Strengthening the Black Family	12:30 to 12:45
Sharing of experience as an IRB community member, ways to strengthen the role of the community member, and strategies for recruitment, training, and retention of non-affiliated members Gigi McMillan, IRB Non-Affiliated (Community) Member & Executive Director, We Can Pediatric Brain Tumor Network	12:45 to 1:00
Q & A for all speakers <i>Vanessa asks the operator to open the call for questions</i> Moderated by Vanessa Northington Gamble	1:00 to 1:20
Closing Remarks regarding call content Vanessa Northington Gamble	1:20 to 1:25
Thank you and brief announcement Kristine Wong	1:25 to 1:30

Call description:

Highlighting the Importance of the Non-Affiliated (Community) IRB Member

Elda Railey and Mary Lou Smith of Research Advocacy Network will discuss the history and role of community (non-affiliated and non-scientific) members on IRBs. They will provide the results of focus groups of IRB administrators and community members that demonstrate the value of having community members on IRBs and the challenges they face in representing the community. Lucille Webb will demonstrate the benefits of the lay perspective through discussion of her experience as an IRB community member with North Carolina State Department of Public Health. Gigi McMillan will also discuss her role as a community IRB member at University of California, Los Angeles, and she will highlight her efforts to create support systems and ongoing training opportunities that strengthen the role of the community member.

Moderator:

Vanessa Northington Gamble, Director, Tuskegee University National Center for Bioethics in Research and Health Care, Tuskegee, Alabama

Vanessa Northington Gamble, M.D., Ph.D., is director of the Tuskegee University National Center for Bioethics in Research and Health Care. The Center, the only bioethics center at a historically black college university, focuses on bioethics, minority health, and public health. The Center was established in 1999 as a result of President Clinton's apology for the United States Public Health Syphilis Study. Dr. Gamble chaired the committee that took the lead role in the campaign to obtain the apology. At Tuskegee, Dr. Gamble is also a professor of bioethics in the College of Veterinary Medicine, Nursing and Allied Health at Tuskegee University. A physician and medical historian, she is an internationally recognized expert on the history of race and racism in American medicine, racial and ethnic disparities in health and health care, cultural competence, diversity, and bioethics. Dr. Gamble is a member of the Institute of Medicine, National Academy of Sciences.

Speakers:

Elda Railey, Co-Founder, Research Advocacy Network, Arlington Heights, Illinois

Elda Railey, co-founder of the Research Advocacy Network and director of their Advocate Institute™, was formerly with the Susan G. Komen Breast Cancer Foundation as Director of Grants. Elda's interests include education programs to enhance access for people of all backgrounds and socioeconomic status to quality healthcare. She specializes in collaborations and equipping advocates for more effective integration in research and patient advocacy.

She is a member of the Intercultural Cancer Council, the External Advisory Board of the University of California San Francisco Breast Cancer SPORE (Specialized Program of Research Excellence), Redes En Accion, EDICT (Eliminating Disparities in Clinical Trials) and has reviewed for Komen, Avon-NCI (National Cancer Institute) Partners in Progress, Centers for Disease Control and Prevention (CDC) and formerly served on the Patient Advocate Committee for ACOSOG (American College of Surgeons Oncology Group).

Mary Lou Smith, Co-Founder, Research Advocacy Network, Arlington Heights, Illinois

Mary Lou Smith is a Co-founder of the Research Advocacy Network. She is currently serving as co-chair of the Eastern Cooperative Oncology Group (ECOG) Patient Representative Committee and the Radiation Therapy Oncology Group Patient Advocate Committee and as a community

member of the IRB at Rush University Medical Center. She serves on the National Comprehensive Cancer Network (NCCN) Breast Cancer Screening and Treatment Guidelines Committees, the North Central Cancer Treatment Group (NCCTG) Patient Advocacy Committee and on the Advocate Core of the Department of Defense Center of Excellence for Individualization of Therapy for Breast Cancer at Indiana University. Mary Lou is past president of Y-ME National Breast Cancer Organization and has served on the Cancer Leadership Council and the National Breast Cancer Coalition's Board of Directors. She is a 20-year breast cancer survivor.

Mary Lou has spent over 20 years in health care. Before becoming involved in advocacy efforts she developed managed care products for the Blue Cross and Blue Shield Association, including a "centers of excellence" network for pediatric oncology, a women's health initiative, clinical trials program, transplant medical review service, national second opinion consulting panel, case management network and a national utilization management capacity. Mary Lou has a Juris Doctorate with a Health Law Certification and a master's degree in Business Administration.

Lucille Webb, Director, Strengthening the Black Family, Raleigh, North Carolina and North Carolina State Department of Public Health IRB Non-Affiliated (Community) Member

As a founding member of Strengthening the Black Family, Inc. and president of its board of directors, Webb has spent the past 20 years as a community health advocate and volunteer, devoting countless hours to helping others. Through her work with this organization, which she founded in 1981, she focuses on developing programs and partnerships that lead to greater economic, health, employment, and educational opportunities for all families. Her vision for this non-profit coalition came out of a conference in which she brought eight community organizations together to collaborate about ways to help African American families optimally utilize existing community resources.

Her work on various boards, commissions, task forces and organizations has directly led to planning and implementing programs that impact health, family life and education across Wake County. The retired social studies teacher and personnel administrator for the Wake County Public School System, currently chairs the executive committee of Project DIRECT (Diabetes Intervention Reaching and Educating Communities Together), a CDC-funded diabetes research development project.

Gigi McMillan, Executive Director, We Can Pediatric Brain Tumor Network, Los Angeles, California and University of California - Los Angeles IRB Non-Affiliated (Community) Member

Gigi McMillan is Co-Founder and Executive Director of We Can, Pediatric Brain Tumor Network. We Can offers information and support to families whose children have brain tumors. Programs include support group meetings, Parent Education Nights, Teen Groups, Sibling Workshops, Family Camp and one-on-one mentoring by trained volunteers. Gigi is a Community Member and Subject Representative for University of California Los Angeles Medical IRBs and a Patient Advocate for the NCI's Pediatric Central IRB. She also sits on the Sub-Part A Sub-Committee for the US Department of Health and Human Services Secretary's Advisory Committee on Human Research Protections. She is the mother of four lovely children, one of whom is a brain tumor survivor.