



*What Does it Mean to Represent the Community?
A Primer on Community Participation in Research*

**The Gaylord Opryland Resort & Convention Center • Nashville, TN
November 13, 2009**

Program Description

This is a full-day program that will focus on the role of institutional review board (IRB) non-scientific, un-affiliated members (Community Members) and members of community research advisory boards (CRABs). The morning session will review the history of research, how abuse has shaped federal regulations governing human subjects research, and current accepted practice. Attendees will then choose one of two afternoon sessions that further explore the professional development needs of Community Members or CRABs. The **Community Members** session will address questions such as: *What, exactly, is a community member? Who do they represent? What are their educational needs? and How can they enhance the work that they do ?* The **CRABs** session will describe the innovative development of a CRAB as a model for building better partnerships between minority communities and research investigators. By the end of this afternoon session, attendees will be able to describe the role and purpose of a CRAB; determine the benefits and challenges of a CRAB; and identify steps in the development of a CRAB.

*Agenda**

Morning Session: All registrants will attend this portion of the program.

7:00 AM	Registration
7:00-8:30 AM	Continental breakfast
8:30-8:45 AM	Why We are Here? The Role and Power of Community Involvement in Research <i>Stephen Thomas, PhD, University of Pittsburgh Graduate School of Public Health</i>
8:45-9:15 AM	History of Abuses in Human Subjects Research <i>Stephen Thomas, PhD, University of Pittsburgh Graduate School of Public Health</i>
9:15-9:30 AM	<i>Break</i>
9:30-10:00 AM	The Ethical Principles of Belmont <i>Don Workman, PhD, Northwestern University</i>
10:00-10:30 AM	The IRB Regulations <i>Don Workman, PhD, Northwestern University</i>
10:30-11:00 AM	The Privacy Rule and Research <i>Don Workman, PhD, Northwestern University</i>
11:00-11:30 AM	The Role of the Non-Scientist in Reviewing Scientific Protocols <i>Gigi McMillan, BA, Children's Brain Tumor Foundation</i>
11:30 AM-12:30 PM	<i>Boxed Lunch</i>

Afternoon sessions: Registrants will select ONE of the following sessions:

Option #1: Community Members

12:30-1:15 PM	The Role of the Unaffiliated Member in the IRB <i>Gigi McMillan, BA, Children's Brain Tumor Foundation</i>
1:15-2:00 PM	Specific Strategies for a Non-Scientist Reviewing a Protocol <i>Gigi McMillan, BA, Children's Brain Tumor Foundation</i>
2:00-2:45 PM	The Psychology of an IRB Meeting <i>Don Workman, PhD, Northwestern University</i>
2:45-3:00 PM	<i>Break</i>
3:00-3:45 PM	Advanced Topics in Informed Consent/Assent <i>Gigi McMillan, BA, Children's Brain Tumor Foundation and Don Workman, PhD, Northwestern University</i>
3:45-4:30 PM	Case Studies <i>Don Workman, PhD, Northwestern University</i>
4:30-5:00 PM	Questions, answers, and discussion
5:00 PM	Adjournment

Option #2: CRABs

12:30-1:15 PM	What is a CRAB and How Does it Differ from Community Advisory Boards? <i>Sandra Quinn, PhD and Stephen B. Thomas, PhD; The University of Pittsburgh</i>
1:15-2:00 PM	The Mission, Values, and Core Philosophy of CRABs <i>Sandra Quinn, PhD and Stephen B. Thomas, PhD; The University of Pittsburgh</i>
2:00-2:45 PM	Recruitment and Composition of the Board <i>Sandra Quinn, PhD and Stephen B. Thomas, PhD; The University of Pittsburgh</i>
2:45-3:00 PM	<i>Break</i>
3:00-3:45 PM	Operating Procedures and Policies <i>Sandra Quinn, PhD and Stephen B. Thomas, PhD; The University of Pittsburgh</i>
3:45-4:30 PM	Benefits and Challenges of Serving on a CRAB <i>Sandra Quinn, PhD and Stephen B. Thomas, PhD; The University of Pittsburgh</i>
4:30-5:00 PM	Questions, answers, and discussion
5:00 PM	Adjournment

**Please note the agenda is subject to change.*