



## The W. Maurice Young Centre for Applied Ethics is pleased to present: **Dr. Anne Townsend, Guest Speaker**



**Anne Townsend**, PhD received her doctorate, from the School of Social and Public Health Sciences, Medical Research Council Unit, at the University of Glasgow, UK in 2005. She was a Post-Doctoral Fellow in the CIHR Ethics of Health Research and Policy Training Program at the Maurice Young Centre for Applied Ethics from 2006-2009. She is now a Research Associate and Co-Investigator on the CIHR funded project 'Centring the Human Subject in Health Research' (Cox PI and McDonald Co-PI). She specializes in experiences of chronic illness, ethical issues in health research and health care and qualitative research.

### **Beyond Faith Hope and Charity: Becoming a Health Research Subject**

Paradoxically, while much research rests on systematic evidence building, research governance apparently does not. In consequence, we know very little about how individuals experience being human subjects in health research. This presentation draws on interview accounts from the first stage of a three-phase project: 'Centring the Human Subject in Health Research,' designed to investigate the experiences of subjects. We recruited 41 individuals (23 women, 18 men) through multiple strategies in order to gain a heterogeneous sample and explore diverse health research experiences (e.g. clinical trials, qualitative studies). Here we focus on reports of why people took part in health research. We applied a phenomenological approach to the data, which illuminated the dynamic and multi-dimensional 'lived experience' of becoming a subject. Participants reported a combination of circumstances and motivations that influenced their participation. Common factors included having trust in the system (faith), and anticipating personal health benefits (hope) or benefits to others (charity). Interest, education, a sense of social obligation, a sense of self, the practical circumstances of daily life, and the nature of research procedures also worked to encourage or discourage participation. One observation was how the relative significance of influencing factors changed according to illness status. The 'healthy' typically did not take part in clinical drug trials, whilst those reporting an illness condition often actively sought clinical trial participation because they considered it their only hope of effective treatment; they felt they had little choice. This raises concerns about the process of free and informed consent and forms of coercion. These findings contribute to an empirically based understanding of health research participation from the subject perspective, and have informed Phase II of the project.

**Room 325, Henry Angus Bldg., 2053 Main Mall, UBC  
February 8, 2010, 3:00-5:00pm.**

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