

THE UNIVERSITY OF BRITISH COLUMBIA



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Anth 428 / 519
Medicine, Culture, and Society
Prof. William McKellin
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It is important for both members of the public and health researchers to understand the impact of genetic and chronic illnesses on individuals and their families. Would you and your organization be willing to identify individuals who would be willing to be interviewed by students in medical anthropology about the impact of genetic and chronic illness on themselves and or their family members as part of a 4th year / graduate course Anth 428 / 519 Medicine, Culture, and Society?

We hope that you could identify 3 or 4 individuals or families in the Vancouver area, who are connected with your organization and are willing to be interviewed in their homes between October 15, and November. 15th. The interview should be about 1 to 1 ½ hours. It will cover such topics as individuals' basic biographies, their experience of the condition, how it has affected their family and social life, and their experiences with health professionals, medical institutions, and service agencies. Participants are encouraged to offer any other information that they believe is important to understanding their condition. Also, if students ask questions that they believe are inappropriate, I hope that the person interviewed will explain why it is inappropriate.

Each student will provide a brief oral report to the class accompanied by a brief written report about the interview. They will also write a term paper about the familial and social aspects of the genetic condition, chronic illness, or disability based their interviews and library research. Because students will be using the interviews as the basis of a course assignment, they may ask permission to tape record the interview. Students may also use their papers as the basis for developing additional academic material. Students will maintain interviewee's confidentiality by using pseudonyms in their oral and written reports and papers, and will not use information that will identify individuals or their family members. You will have the choice of using or not using the names of health care practitioners, institutions and organizations during the interviews. Students will provide a copy of their report to the individual they interviewed.

Once you are able to find some volunteers please provide them with a copy of this letter describing the interview, either have the individuals contact me directly, or you may collect their names, addresses and phone numbers, and pass them on to me. In some instances two students may work together to interview the same individual. I will select the students who will contact your volunteer to arrange a date and time for the interview.

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Thank you for your willingness to assist us in this important educational activity. If you have any questions or concerns either now, or once the interviews begin, don't hesitate to call or email me. If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Ethics at (604) 822-8598.

Sincerely,

William H. McKellin, PhD
Assistant Professor