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“Contemplating the duty to disclose genetics research results to research participants – the case of autism genetics.”

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*Wednesday, 27 February 2008, 4:10 – 5:00 pm
Great Hall, Joint Centre for Bioethics, 88 College St.*

Abstract: Research ethicists have recently declared a new ethical imperative: that researchers should communicate the results of research to participants. For some analysts, the obligation is restricted to the communication of the general findings or conclusions of the study. However, some analysts extend the obligation to the disclosure of individual research results, especially when these results are perceived to have clinical relevance. The obligation to disclose individual results is argued most forcefully in the case of research-based genetic test results, but increasingly the obligation is suggested for other types of clinical research, such as unblinding at the conclusion of trials and the reporting of relevant individual-level clinical data to participants. Several scholars have advanced cogent critiques of the putative obligation to disclose individual research results. They question whether the obligation is adequately specified, whether ethical goals are served by disclosure or violated by non-disclosure, and whether the communication of research results respects ethically salient differences between research practices and clinical care. This talk will examine this debate through the lens of autism genetics research.

The Ontario Genomics Institute - University of Toronto Joint Centre for Bioethics Benchside Ethics Seminar Series is a part of the JCB Bioethics Seminar Series and is an accredited continuing education activity under CFPC and RCPSC programs.

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