Is Genetics Reshaping the Physician’s Duty to Patients – Updates from an Evening with the Medico-Legal Society of Toronto and Dr. Ronald D. Cohn

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The Medico-Legal Society of Toronto hosted an engaging dinner on January 22, 2013, with guest speaker Dr. Ronald D. Cohn. Lonny Rosen of Rosen Sunshine LLP introduced Bill Carter of Borden Ladner Gervais LLP, who moderated the program. Dr. Cohn has recently joined the Hospital for Sick Children as the Chief of the Division of Clinical and Metabolic Genetics, Co-Director of the Centre for Genetic Medicine and Senior Scientist.

Dr. Cohn began by exploring the developments in genetic research and application since the human genome was first sequenced. He presented a series of case studies highlighting the ethical and legal issues arising out of the developments and application. One case study focused on the disclosure of unexpected findings. The case involved a 4-year-old male patient enrolled in a genomic research study concerning autism. Ten years later, researchers discovered a deletion in the child’s genome, completely unrelated to the autism study. This unexpected finding had medical implications not only for the child, but also potentially for his mother, siblings and aunts.

Dr. Cohn asked the audience whether the researchers and physicians had an ethical or legal duty to disclose such unexpected findings. The case study raised interesting practical issues as well. For instance, it was noted that Canada’s legal protections for individuals with a genetic diagnosis have not kept pace with the research and testing. Instead of being proactive, the law is reactive.

A second case study highlighted the difficulties associated with gene expression. While an individual may have a potentially significant genetic finding, the extent to which the genetic finding will be expressed is often difficult to predict. Since knowing about a potentially significant genetic finding may inform a patient’s behaviour and interactions, providing a patient with this information without knowing the extent to which the patient will be affected raises ethical and legal concerns.

Dr. Cohn discussed a number of potential solutions to the ethical and legal dilemmas posed by the developments in genetic research. One such solution is to carefully establish patient expectations at the outset of a genetic study. By asking patients before testing is conducted what he or she would like to know, researchers and physicians have more guidance on what steps to take when there are unexpected findings. Dr. Cohn also discussed the importance of developing new consent forms and revising consent discussions to reflect the complex ethical and legal issues posed by genetics.
The evening concluded with an interesting discussion about the differences between personalized and individualized medicine. Physicians currently practice personalized medicine, which is medicine that attempts to apply universal principles to individual patients. Genetics will soon allow physicians to treat patients on a truly individual basis according to their unique genome, thereby practicing individualized medicine. Dr. Cohn highlighted the need to merge evidence-based medicine with individualized medicine, allowing physicians to provide a new level of care to patients. While these developments present an exciting new chapter in medicine, the medical and legal community must also address the new set of ethical and legal issues posed by this progress.

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