

# CCMG PROFESSIONAL AND ETHICAL GUIDELINES

The CCMG was established to develop and ensure adherence to high standards in the delivery of medical genetics services in Canada. This includes standards for the training, competence and behaviour of those delivering these services.

Fellows of the CCMG have their own established codes of practice. The practice of medical genetics requires a specialized understanding of genetic mechanisms in basic biology and the impact of these not only on individuals but also on their offspring and the present and future population groups to which they belong. An appreciation of the limitations of this knowledge at any particular time is especially important.

In view of these considerations, the CCMG has approved the following guidelines for Fellows in relation to their responsibilities not only to patients but also to society as a whole, and to one another.

## Responsibilities to Patients

*Fellows of the CCMG should:*

1. Provide genetic services to individuals irrespective of sex, race, culture, sexual orientation or religious belief;
2. Take all reasonable measures to establish or ensure accuracy of diagnosis in patient or family;
3. Be alert to the limitations of their own expertise in interpreting results from specialized genetic or other investigations;
4. Be able to justify risk figures provided to the patient and other members of the family;
5. Have the patients' best interests in mind when conveying information and attempt to ensure an appropriate level of understanding of this information;
6. Disclose all clinically relevant information to patients unless specifically instructed not to do so by the patient;
7. Discuss with the family all options appropriate to their situation, bearing in mind that this will be influenced by level of risk, burden and age of onset;
8. Inform all patients if the Fellow's personal code of morality or religious conscience prevents them presenting all available options and, if so, refer to another qualified person;
9. Provide information in a supportive, unbiased, and non-directive way;
10. Appreciate when patients and families need referral to special support services;
11. Keep information obtained from patients in confidence unless written permission for release has been given, or unless it can be shown that doing so is likely to have significant detrimental effects of the health of other individuals, currently, or in the future;
12. Follow generally accepted guidelines in obtaining informed consent before including patients in research studies; and

13. Inform patients that it is their responsibility to maintain contact with the genetic centre in order to stay informed about the current status of their genetic disorder.

#### Responsibilities to Society

##### *Fellows of the CCMG should:*

1. Cooperate with the family to ensure contact and counselling of relatives at significant risk of high burden genetic disorders in the most appropriate manner available;
2. Encourage the establishment of screening programs for the detection of specific genetic disorders in population groups where such programs are appropriate and acceptable;
3. Strive to ensure equal access to genetic services by all segments of society;
4. Encourage any reasonable effort to extend and improve the education of the public on medical genetic matters; and
5. Ensure that their counsel is based on consideration of what implications such counsel would have for the individual rather than for society. They should assert, where appropriate, that counselling about the probability of recurrence of a disabling condition does not imply any devaluation of the worth of persons with disabilities.

#### Responsibilities to the Profession

##### *Fellows of the CCMG should:*

1. Take a responsible approach in the interpretation of personal research to the lay public. Normally, results of such medical genetics research should first be communicated to colleagues through recognized scientific channels to allow establishment of opinion as to its merits or validation of findings before presentation to the public or use in clinical service;
2. Recognize responsibility to give the generally held opinions of the profession when interpreting scientific knowledge to the public, and indicate when a personal opinion contrary to the generally held opinion of the profession is being presented;
3. Request the opinion of an appropriate colleague acceptable to the patient when diagnosis or treatment is difficult, or when requested by the patient;
4. Provide a written report containing details of findings and recommendations to a referring physician within reasonable time;
5. Cooperate with those individuals who, in the opinion of the Fellow, could assist in the care of the patient;
6. Make available to a colleague a report of the findings and counselling of a patient, on the written request of that patient;
7. Avoid any personal profit motive in initiating diagnostic procedures or treatments in any facility in which the Fellow has a financial interest;

8. As individuals, conduct themselves beyond reproach and act within their area of competence. They will report to the Board of the CCMG, conduct by a colleague that is considered unbecoming to the profession.