

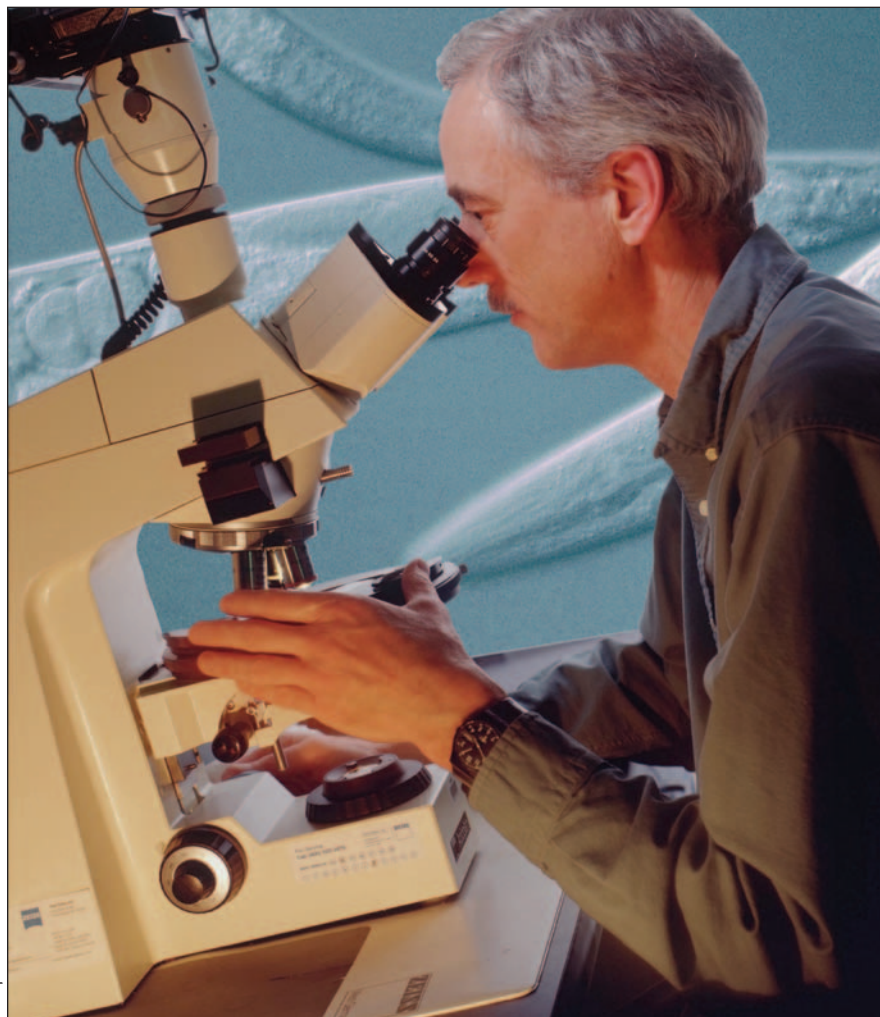
## The wide gap between genetic research and clinical needs

Canada has invested heavily in genetic research, reaping notable payoffs in important scientific discoveries that, in turn, are increasing demand for patient services. But resources to address this growing need are not being similarly invested, and already legions of patients are in limbo because of long wait times for consultations with clinical geneticists.

The shortage of health care professionals with specialty training in genetics is “a huge concern,” says Dr. Diane Allingham-Hawkins, past president of the Canadian College of Medical Geneticists and director of molecular genetics at North York General Hospital in Toronto. Canada does well when it comes to delivering timely results for urgent genetic tests, such as for prenatal diagnosis or testing newborns for treatable metabolic disorders. But across the country, patients seeking a routine clinical consultation — for example, for a 5-year-old with developmental delays — can wait anywhere from a couple of months to over 2 years.

There is a “huge disparity” in waiting times depending on where you live in Canada, says Dr. Gail Graham, chair of the Royal College of Physicians and Surgeons of Canada (RCPSC) Specialty Committee in Medical Genetics. For example, patients in Ottawa may wait 2 or 3 months for a non-urgent consultation, whereas in Quebec waits can be a year or 2, and in the 3 maritime provinces (served until recently by only 2 clinical geneticists) wait times can exceed 2 years.

“We hear that some physicians don’t even bother to refer, the wait time is so long,” says Dr. Sarah Dyack, who works at the Isaac Walton Killam Health Centre in Halifax. Dyack notes that there is government funding to



Canapress

Canada has invested heavily in genetic research but not in the training of clinical geneticists to meet growing demand.

hire another geneticist, but “we can’t recruit. We just haven’t been able to fill our positions.”

Allingham-Hawkins points to the stress and anxiety created by long wait times for test results and consultations, as well as the fact that they can lead to a delay in helpful interventions or treatments. Early and accurate diagnosis may also change parents’ reproductive plans or allow some couples the option of a prenatal diagnosis before a second child is born.

The situation is unlikely to improve soon because the number of training positions has not kept pace with de-

mand and the pool of patients is growing as researchers are discovering more about the genetic component of conditions that develop in adults, such as problems with iron storage and increased risk of blood clotting. As well, people born with genetic conditions are living much longer than in the past and requiring ongoing care.

Canadian governments have stepped up funding to genetic research in the past 6 to 10 years through a variety of channels, most notably Genome Canada with its \$600 million in public funding. Because grant recipients must find matching dollars, that funding has

leveraged hundreds of millions of dollars from other public bodies, foundations and the private sector.

But Canada, with a population of more than 30 million, has only 218 medical geneticists and, at most, only about 80 who are clinical geneticists — that is, medical doctors with specialty training who work actively with patients. The balance of these college members are PhDs or medical doctors with further training who work in laboratories, work out of the country or are retired, Allingham-Hawkins says.

The RCPSC accredits 7 universities to provide residency training in medical genetics. Each year, 6–10 doctors begin the training, though some of those positions are filled by foreign-trained doctors who might not stay in Canada, Graham says. The numbers represent a modest increase over the past 5 years, but still not nearly enough for an adequate supply of specialists to “fill the gaps we have now and expect to have in the future.” There is also a serious shortage of PhD medical geneticists to direct genetic laboratories (Ontario, for example, funds only 2 such PhD training positions each year) and of technologists to work in them. In addition, there is a huge need for continuing education about genetics for family doctors and medical specialists, who are taking on aspects of genetic counselling.

The landmark 2002 Ontario report,<sup>1</sup> *Genetics, Testing and Gene Patenting: Charting New Territory in Health Care*, documented the relative shortage of genetic specialists and observed that it

“will only become more pressing as new tests and interventions are introduced.” That report had called for a cross-jurisdictional framework that would increase opportunities for the education and training of health professionals in genetics and new genetic medicine.

But Canada has not put a priority on nor significantly ramped up education and training in these fields, unlike some other countries. Several years ago, the United Kingdom’s National Health Service developed a plan to double the number of genetic medical specialists within 5 years. And in 1997, a US initiative was launched to address looming shortages.

Genetic counsellors, who work with clinical geneticists, are also already in short supply, with a projected future shortage in the field: only 18 new genetic counsellors will be graduating each year from the 4 university programs in Canada, says Jennifer Fitzpatrick, past president of the Canadian Association of Genetic Counsellors. Fitzpatrick is impatient with the high priority given to research while families continue to wait for services. “We’re asked to participate in all sorts of clinical trials, all sorts of research, yet we can’t meet the most basic needs of our patients.” Meanwhile, the Canadian Institutes for Health Research, Institute of Genetics, commissioned an inventory of clinical research in genetics in response to concerns that “research that has direct application to the care of patients was being underfunded.” The inventory report generally supported those concerns

and suggested that “the possibility of systematic biases against the funding of patient-oriented research should be evaluated.”<sup>2</sup>

Compounding the problem of present and future shortages of health professionals working in the field is the wide variation across the provinces in funding for genetic testing. “Wait lists for some appropriate and clinically indicated genetic tests can be up to 3 years ... and some genetic tests are not funded at all,” says Dr. Albert Chudley, president of the Canadian College of Medical Geneticists. “This is one of the most pressing issues with respect to access to care.” But there is no powerful patient advocacy group to help push for more clinical resources, probably because there are about 2500 different genetic syndromes, says Chudley. — Ann Silversides, Toronto

**Acknowledgements:** Research for this article was supported in part by an Atkinson Foundation Fellowship in Public Policy.

## REFERENCES

1. *Report to the Provinces and Territories. Genetics, testing and gene patenting: charting new territory in healthcare.* Ontario Report to Premiers. Toronto: Ontario Ministry of Health and Long-Term Care; 2002. Available: [www.health.gov.on.ca/english/public/pub/ministry\\_reports/geneticsrepo2/report\\_e.pdf](http://www.health.gov.on.ca/english/public/pub/ministry_reports/geneticsrepo2/report_e.pdf) (accessed 2006 Dec. 20).
2. Evans, J. *Clinical genetics research in Canada: an inventory and annotated bibliography.* Ottawa: Canadian Institutes of Health Research, Institute of Genetics; 2004. Available: [www.cihr-irsc.gc.ca/e/24625.html](http://www.cihr-irsc.gc.ca/e/24625.html) (accessed 2006 Dec. 20).

Ann Silversides is a Toronto-based freelance journalist specializing in health and social-policy issues.

## Canadian Adverse Reaction Newsletter Bulletin canadien des effets indésirables

To receive the Newsletter and health product Advisories free by email, join Health Canada’s **MedEffect** mailing list.

Go to [www.bc-sc.gc.ca/dhp-mps/medeff/subscribe-abonnement/index\\_e.html](http://www.bc-sc.gc.ca/dhp-mps/medeff/subscribe-abonnement/index_e.html).

Inscrivez-vous à la liste **MedEffet** de Santé Canada pour recevoir gratuitement par courriel le Bulletin et les Avis au sujet des produits de santé. Rendez-vous à l’adresse [www.bc-sc.gc.ca/dhp-mps/medeff/subscribe-abonnement/index\\_f.html](http://www.bc-sc.gc.ca/dhp-mps/medeff/subscribe-abonnement/index_f.html).

**Report adverse reactions toll free to Health Canada  
Signaler sans frais des effets indésirables à Santé Canada**

Tel./Tél. : 866 234-2345 • Fax/Télec. : 866 678-6789

Canada