

the head, face or neck using any part of the body or equipment.

“The campaign is certainly bringing awareness to the fact that we should not be making any contact to the head in minor hockey,” says Todd Jackson, senior manager of membership services of Hockey Canada. “I call it a campaign because it is much more than just a rule change. ... It includes promotion, it includes awareness, and it includes education for everyone involved in minor hockey.”

The latter includes online dissemination of concussion awareness resources, as well as specific instruction and training for parents, officials, coaches and players alike. Teams are now required to have a “safety person” at facilities, who must be trained on how to identify concussions, be familiar with risk management protocols and be able to provide treatment. The campaign also includes a six-step process (first established in 1995) for determining when players can return to the ice surface.

In order, the six steps are:

- Complete rest until all symptoms disappear
- Light aerobic exercise such as walking or light stationary cycling but no resistance or weight training
- Hockey specific training, such as skating
- Non-contact drills and light resistance training
- Body contact drills but only after

reassessment and clearance from a physician has occurred

- Return to play.

Also introducing new concussion protocols this year was the government of Ontario, which will require teachers, coaches and others in the education system to follow guidelines governing how “a pupil who is suspected of having sustained a concussion is to be removed from or prevented from further participating in intramural or inter-school athletics or any part of the health and physical education curriculum” (www.ontla.on.ca/web/bills/bills_detail.do?locale=en&Intranet=&BillID=2584). The legislation compels school boards to follow provincial standards for identifying and managing concussions.

But Therien says such initiatives are inadequate.

“So, what,” he says of Hockey Canada’s changes. “It’s just patchwork. They aren’t dealing with the problem at hand.”

Therien, whose son Chris had his 12-year NHL career end after a head injury in 2005–06, says Hockey Canada has failed to adequately address safety issues in the game. Citing a study indicating that teams in Alberta minor league hockey which allowed bodychecking experience three times as many injuries as those in Quebec, which do not, (*JAMA* 2010;303[22]:2265-72), Therien says “there are all these evidence-based studies that are showing how unsafe the

game is. Hockey Canada doesn’t even acknowledge them; they just bury them.”

But Hockey Canada counters that it is giving youngsters a choice and has made it a priority to encourage associations to offer noncontact options. “Every association across the country looks at ways to give kids the choice to play with bodychecking or without bodychecking,” says Paul Carson, vice-president for hockey development at Hockey Canada. He notes that a league in lower mainland British Columbia will join its counterparts in the rest of the province next season by eliminating bodychecking at the house league level, while Hockey Calgary decided to eliminate bodychecking for the forthcoming season at the pee-wee level after a poll indicated 73% of parents wanted a change.

Therien says media coverage alone does not explain the decline in hockey registration. Other factors may also be responsible, including the growing variety of sports and recreational activities available to children, as well as the costs associated with playing the game, in comparison to those associated with such sports as soccer and basketball. But he predicts there will be an ongoing exodus from the game as a result of safety concerns, forecasting a registration “free fall” that will result in participation numbers on the order of 200 000 within a decade. — Chris Hemond, Ottawa, Ont.

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The downside of genetic screening

There is universal screening, sub-population screening and targeted screening. There is screening of embryos, newborns and those within a specific age range. There is screening of people according to their weight, race or family history. There is screening for HIV, genetic abnormalities, various cancers and numerous other illnesses and health risks.

There is, in short, a whole lot of screening happening in medicine. And there will likely be even more happening as genetic testing technologies continue to advance, enabling the discovery

of previously undetectable health risks.

On the surface, screening certain populations for health risks seems like a practice with many pros and few cons. It provides benefits in preventive medicine, family planning, medical research, diagnosing illnesses and other areas of health. There is, however, a downside to screening. Identifying risk is one thing. Deciding which course of action to take in view of that risk is a more complicated matter.

“We rarely in medicine do unalloyed good,” says Dr. James Evans, editor-in-chief of *Genetics in Medicine* and Bryson Distinguished Professor of

Genetics and Medicine at the University of North Carolina in Chapel Hill. “Some of the tools we employ in modern medicine are blunt. They are primitive. There are mastectomies, and there are drugs with side effects. Because of the bluntness of these tools, you better have great information and a clear-cut situation before you employ them.”

Situations often arise in medicine, however, that aren’t clear cut, and screening is no exception. For example, screening can detect some types of breast cancer that will progress to invasive cancer in some women but not in others. Prob-

lem is, there is no way of knowing which group any given patient will fall into.

“It’s not that I’m arguing we are doing the wrong thing, but there is a penalty for picking up on some things,” says Evans. “A substantial number of women will undergo surgery and radiation that they don’t need. We have to overtreat to prevent harm in that other subset that will develop it.”

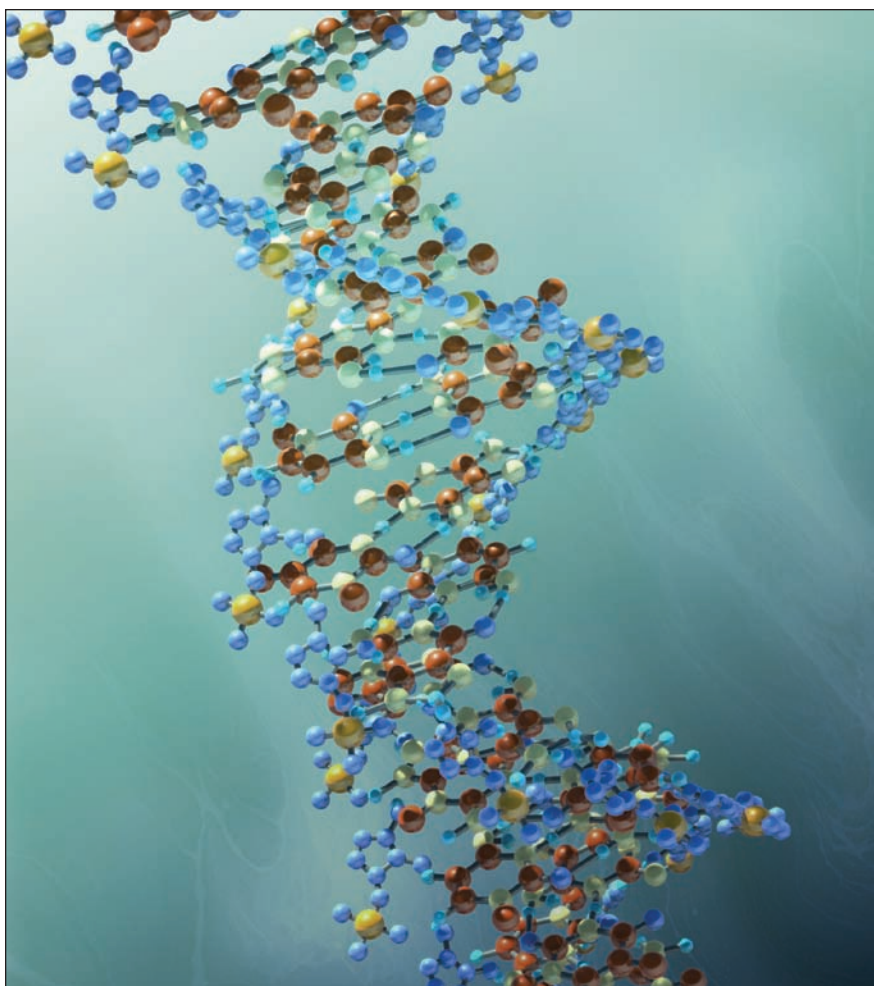
When the topic of genetic screening comes up, people tend to think of prenatal screening, for conditions such as trisomy 21, or newborn screening for early treatment of illnesses, such as sickle cell disease. But technological advances now “allow multiple genetic risks to be ascertained simultaneously and offer new genetic screening opportunities — for example, the potential to detect genetic susceptibilities to common diseases at a level far exceeding that of conventional family history assessment,” according to a recent overview of genetic screening practices (*Epidemiol Rev* 2011;33:148-64).

The paper warns, however, that there is a need for “careful deliberation about the use of genome-scale screening on the part of all concerned, including genomic researchers, clinicians, public health officials, health care payers, and, most importantly, potential recipients of this novel screening approach.”

There are several reasons for caution when implementing a screening program. For one, it is inevitable that a certain portion of test results will yield false positives, which may lead to anxiety and retesting. Test results can also be ambiguous and of unclear significance, leaving patients wondering if they are well or sick and need treatment.

Overdiagnosis is another inevitability of screening. Estimates of overdiagnosis in mammography screening, for instance, have ranged from barely at all (1%) to more than half (54%), depending on the predictive models used to perform the calculation (*Epidemiol Rev* 2011;33:1-6). Overdiagnosis is also a problem of screening for other types of cancer, including lung cancer, melanoma and kidney cancer (*J Natl Cancer Inst* 2010; 102:605-13).

The natural companion to overdiagnosis is overtreatment, and any treatment, be it surgical or pharmaceutical,



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DNA-based tests are being used to diagnose vulnerabilities to a host of inherited diseases.

carries its own risks. For example, in any population of children screened for the neurodegenerative disorder Krabbe disease, there will be some who test positive but will remain asymptomatic. This is a concern considering that the treatment, a bone marrow transplant, can itself be life-threatening.

Screening will also yield incidental findings, identifying genetic markers that were not part of the program’s goal. This may be news that some people would rather not have received, especially if for a condition which has no treatment. There are also times when high-, low- and no-risk individuals end up lumped together in a category that has been referred to as “predisease,” which leads some people to seek further testing and medical interventions, actions not justified by their actual risk levels.

Screening an entire ethnic group can also lead to inadvertent harm, such as creating the impression that an entire

population is genetically cursed, which can lead to fear and anxiety. Ashkenazi Jewish women, for instance, are at higher risk than the general female population of developing breast cancer from mutations in *BRCA1* (BRest Cancer gene one) or *BRCA2* (BRest Cancer gene two), but that doesn’t mean they all must undergo genetic testing, says Dr. Ellen Warner, a medical oncologist at Sunnybrook Health Sciences Centre in Toronto, Ontario.

“I’m not saying it’s a good thing or a bad thing, just that we have to be careful who we offer testing to. The test has saved many lives but it has also created a lot of unnecessary anxiety,” says Warner. “We have created patients that didn’t exist before.”

A woman should undergo genetic testing only if she really wants to, and not because of cultural pressures or the insistence of relatives, adds Warner. “Sometimes women are tested because

of family pressure. That is not appropriate. A lot of women don't understand what testing means and are shocked when they get the results. Or they think they have to immediately run out and get rid of their breasts and have their ovaries removed, and that's not true."

Screening for diseases and health risks, in general, may have more potential harms than people realize, suggests a recent overview of the practice (*Epidemiol Rev* 2011;33:1-6). "It may be that we are learning that the magnitude of benefit from screening is less than we hoped, and the harms may be greater than we thought," the paper states. "Perhaps we should not think of screening as our primary prevention strategy but rather use screening to make a real, but limited, contribution to population health for a few conditions." — Roger Collier, *CMAJ*

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Editor's note: Ninth of a multipart series on genetic testing.

Part 1: **Separating hype from reality in the era of the affordable genome** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4143).

Part 2: **Popping the genetics bubble** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4142).

Part 3: **Who should hold the keys to your DNA?** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4141).

Part 4: **A race-based detour to personalized medicine** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4133).

Part 5: **Race and genetics in the doctor's office** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4134).

Part 6: **Predisposed to risk but not change** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4157).

Part 7: **Unhealthy behaviours influenced by genes and environment** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4162).

Part 8: **Young women with breast cancer genes face tough choices** (www.cmaj.ca/lookup/doi/10.1503/cmaj.109-4168).