affect a tiny number of people, especially compared with high blood pressure, diabetes or heart disease. The attention these rare disorders receive from pharmaceutical programmes, the medical community and academic research has historically been correspondingly small, despite the significant disease burden they bring to the health-care systems of many countries.

Perhaps up to one-fifth of paediatric hospital admissions worldwide are the result of Mendelian disorders — uncommon diseases that follow inheritance patterns outlined by Mendel in the nineteenth century, usually caused by mutations in a single gene. If not deadly, these conditions often demand expensive life-long care.

Beyond the economic factors are the harrowing stories of parents trying to find treatment or even a diagnosis for a child with an exceptional problem. For rare diseases for which there are perhaps only one or two experts in the world, it typically takes a broad network of parents working together for the families to find help, or even information.

The rapid rise of genome sequencing and its increasing use in paediatric clinics offers some hope. Children with known diseases can be diagnosed faster than before, and those with previously unknown syndromes might be able to get a better understanding of the reason for their illness.

Rare disorders have conventionally been used to sharpen the tools of genetic medicine. Diseases that affect several families are prime targets for unpicking and understanding the effects of human gene mutations. With the development of better tools, researchers are now equipped to tackle even the rarest disorders. As the price of sequencing drops and analysis tools become more sophisticated, fewer individuals are needed to pin down the common genetic cause.

As the News Feature on page 20 highlights, one small clinic serving Amish and Mennonite communities in the United States is at the forefront of these efforts. Through sequencing and other tools, the paediatricians there estimate that they can discover 5–15 new disorders per year. They think that about half should be treatable if the underlying cause is identified early.

"Genetic disease has a long history of teaching scientists about normal biological processes."

The clinic is in an exceptional position, however. The communities it serves come from small founder populations, have a good knowledge of family history and a high rate of intermarriage. All of this makes unravelling the genetics of disease easier than in a more diverse population. But there are two reasons to treasure these exceptions. First, genetic disease has a long history of teaching scientists about normal biological processes, and can sometimes give insight into the processes that go awry in other, more common diseases. Liddle syndrome, for example, is one of several genetic disorders in which high blood pressure is a major defining factor. Tangier disease causes low levels of 'good' cholesterol in the blood, and many of those affected have premature atherosclerosis.

The second reason relates to a growing appreciation of the heterogeneity of 'common' diseases. Projects that sequence tumour genomes from dozens of patients — who by standard diagnostic measures have the same cancer, and thus the same disease — have revealed that each tumour has unique and divergent genetic properties. Indeed, the real work may begin once we realize that every case is an exception. ■

Frozen out

Canada's government should free its scientists to speak to the press, as its US counterpart has.

Media interactions with government scientists have undergone a reversal across North America during the past six years. In the United States, President Barack Obama's administration has directed federal science agencies to develop integrity policies with clear guidelines for scientists who are approached by journalists.

In December, agencies including the US National Science Foundation (NSF) and the US National Oceanic and Atmospheric Administration (NOAA) issued guidelines that promote openness with the press. For instance, NOAA and NSF-funded scientists and staff are free to speak to journalists without first seeking the approval of a public-affairs officer. The NSF's policy states that researchers are free to express their personal views as long as they make clear that they are not speaking on behalf of the agency. And scientists also have right of review over agency publications and press releases that claim to represent their expert opinions. Such policies may not be implemented successfully in all cases, but they show that attitudes have evolved encouragingly since 2006, when charges that then-president George W. Bush's administration had silenced US government researchers made front-page news.

Over the same period, Canada has moved in the opposite direction. Since Prime Minister Stephen Harper's Conservative Party won power in 2006, there has been a gradual tightening of media protocols for federal scientists and other government workers. Researchers who once would have felt comfortable responding freely and promptly to journalists are now required to direct inquiries to a media-relations office, which demands written questions in advance, and might not permit scientists to speak. Canadian journalists have documented several instances in which prominent researchers have been prevented from discussing published, peer-reviewed literature. Policy directives and e-mails obtained from the government through freedom of information reveal a confused and Byzantine approach to the press, prioritizing message control and showing little understanding of the importance of the free flow of scientific knowledge.

The Harper government's poor record on openness has been raised by this publication before (see K. O'Hara *Nature* **467,** 501; 2010), and *Nature*'s news reporters, who have an obvious interest in access to scientific information and expert opinion, have experienced directly the cumbersome approval process that stalls or prevents meaningful contact with Canada's publicly funded scientists. Little has changed in the past two years: rather than address the matter, the Canadian government seems inclined to stick with its restrictive course and ride out all objections.

That position is coming under increasing pressure as a result of the scientific-integrity policies taking shape across the border. The clarity of the US guidelines undercuts the Canadian government's assertion that its own media policies are adequate and have simply been misunderstood. If the Harper government truly embraces public access to publicly funded scientific expertise, then it should do what the Canadian Science Writers' Association and several other organizations have called for in a letter sent to the prime minister on 16 February: "implement a policy of timely and transparent communication" like those used by NOAA and the NSF.

The letter coincided with a symposium, 'Unmuzzling Government Scientists: How to Re-open the Debate', which was held last week at the meeting of the American Association for the Advancement of Science in Vancouver, Canada. With the country taking centre stage as the meeting's host, the Harper government found its media policies in the international spotlight. Scientists and other visitors from around the globe discovered, to their surprise, that Canada's generally positive foreign reputation as a progressive, scientific nation masks some startlingly poor behaviour. The way forward is clear: it is time for the Canadian government to set its scientists free. ■

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