Diabetes Action Canada is now completing its first year of intensive planning and implementing the first stage of our patient-oriented research endeavours. Using our patients’ first lens our investigators are identifying major gaps in health care across Canada for individuals living with diabetes. Our core activities focus on establishing the most effective ways to identify those at risk and prevent blindness, amputations, cardiovascular and kidney disease. For individuals living with Type 1 diabetes (T1D), the most successful methods of improving glucose control is through technology-assisted glucose sensing and insulin delivery. This requires shared-decision making between the patient and a medical expert, generally located in tertiary referral clinical sites. For individuals living with Type 2 diabetes (T2D), who also suffer from multiple chronic conditions, community-based support is required from a professional team who can provide customized interventions to holistically address all health determinants. These approaches are supported by a high level of evidence in keeping with the Canadian and American diabetes guidelines.

As the first step in establishing these proven interventions to prevent diabetes complications, we must first identify individuals who are at risk. To this end, our Health Informatics group is now
working on establishing a diabetes repository in which individuals with diabetes can be registered for the purpose of connecting with their provincial health systems. In this newsletter, Frank Sullivan and Michelle Greiver, the group leads, describe this approach and the potential impact on identifying individuals with diabetes and their current health status. Concurrently, Diabetes Action Canada will be launching specific projects to improve interventions for individuals with both T1D and T2D. We feature one of our patient representatives, Doug Mumford, who has lived with T1D for 49 years and attests to the successful use of technology-assisted insulin treatment.

The second step is to increase the capacity of our patient-oriented research workforce in Canada to enable a continual learning environment where improvements in care for individuals living with diabetes is supported by best evidence. Our Training and Mentoring Group, under the leadership of Mathieu Bélanger and André Carpentier, has established a comprehensive program for graduate students, health professional students and post-doctoral students engaged in diabetes research summarized in this newsletter. We are most grateful to Diabetes Canada (formerly the Canadian Diabetes Association) for their generous support in partnering with Diabetes Action Canada to establish new joint postdoctoral fellowships in patient-oriented research commencing in 2017.

We look forward to accelerating all of our endeavours in 2017-18 that will be kicked off at our Annual Workshop in May where all of our patient representatives, investigators and stakeholder representatives will meet to evaluate progress to date and commit to next year’s strategic goals.

---

**Research:**

**Patients, Practices & Populations, Data Research Management System (PPPDRMS)**

Preventing the complications of diabetes will be achieved by increasing the use of existing knowledge as well as through the generation of new knowledge. Diabetes Action Canada is creating a health data system to support those efforts by using information that comes from and will be used by patients, practices and populations. The data will come from patients in practices
participating in the Canadian Primary Care Sentinel Surveillance Network (CPCSSN) or from those providing information via the health app bant. This means the system will use routinely collected health data from a variety of sources including Electronic Medical Records and information provided directly by patients who agree to take part. Having a register of individuals known to have diabetes will enable us to recall those who are due for appointments; this will help to ensure that patients obtain effective review of their diabetes care so that complications can be prevented or managed. Similar systems already work well in Canada for cancer screening. In many Western countries, entire populations are routinely screened for diabetes and its complications. Another advantage of our PPPDRMS will be a greater ability to identify patients, practices and populations that could contribute to research to generate new evidence. People with diabetes who might benefit from a new medicine to prevent complications like blindness will be offered information and invitations to participate in studies to determine if the new treatment works. Practices and populations will be invited into studies of new, potentially better ways of organizing care for people with diabetes. On its own a data management system cannot prevent complications but the patients, clinicians, researchers and policymakers who use it will do so by enabling improved shared decision-making and self-management.

The Training and Mentoring Program

The Diabetes Action Canada Training and Mentoring Program's main goal is to strengthen Patient-Oriented Research (POR) capacity in Canada for diabetes and its complications. Its primary focus is to prepare the next generation of diabetes researchers across Canada in POR methods. The training and mentoring program is geared towards diabetes research trainees from all fields of research and includes the offering of intensive training sessions, a mentoring exchange program, and funding to support training of postdoctoral fellows. Training opportunities are also provided to patients, healthcare providers, policy makers and administrators.

With the goal of maximising impact, Diabetes Action Canada recently finalised an agreement with Diabetes Canada to co-fund five two-year Patient-Oriented Research postdoctoral fellowships in diabetes research. Aligned with the mission of Diabetes Action Canada, this is a demonstration of key partnership with the aim of transforming the health outcomes of people with diabetes and its related complications. To be considered, candidates need to apply through the regular Diabetes Canada competition and specify how their proposed research fits with our vision of Patient-Oriented Research.

Announcements:

Our new Steering Council Chair and Vice Chairs:

The Steering Council of Diabetes Action Canada, is our highest level of governance and provides the Network with the necessary guidance and oversight on all aspects of our Network activities.
We are delighted to announce our new Steering Council Chair is Malcolm King. Malcolm led the CIHR Institute of Aboriginal Peoples’ Health as its Scientific Director for the past 8 years, and has devoted many years to improving wellness and achieving health equity for Indigenous Peoples through his tireless efforts in promoting meaningful research and strategic collaboration. We are privileged to be able to tap Malcolm’s invaluable leadership and wealth of experience.

Provided below for your information, are links to Malcolm’s profile and the Steering Council webpage of the Diabetes Action Canada website.

- [https://www.sfu.ca/fhs/people/profiles/malcolm-king.html](https://www.sfu.ca/fhs/people/profiles/malcolm-king.html)
- [http://diabetesaction.ca/about/](http://diabetesaction.ca/about/)

Terry Sullivan and Ross Gray have very kindly agreed to accept the invitation to be the Chairs of the Nomination/Governance and Finance/Audit Standing Committees, respectively.

As Chair of the Nomination/Governance Standing Committee, Terry leads the Committee in the recruitment of members for the Steering Council and Standing Committees, as well, organize the performance evaluation for the Steering Council and our leadership of the SPOR Network. Ross, in his capacity as Chair of the Finance/Audit Standing Committee, will lead the Committee in providing oversight of the budget plannings, financial reporting and audits for the Network.

Dr. Terrence Sullivan currently serves on a number of governance and advisory roles in health services and health policy. He is the Chair of CADTH’s Board of Directors, the Quality Committee of the Hospital for Sick Children, and the Governance Committee for Exactis Innovation (a federal Network Centre of Excellence focused on new therapeutics for cancer).

Ross Gray is currently a Patient Representative advising Diabetes Action Canada. He is a semi-retired Real Estate developer who has been a member of the Rotary Club of Bolton for over 25 years. He has held many Executive positions within several corporates and charitable organizations. Also, Mr. Gray is actively involved in major charitable endeavors (both locally and nationally) including the Banting & Best Cabinet. He has been supporting Diabetes Research for around 10 years and has been greatly involved with Dr. Gary Lewis.

Diabetes Action Canada is delighted to have members with such outstanding skills serving on our Steering Council.
Featured Members:

Dr. Frank Sullivan

Dr. Frank Sullivan is an academic family physician at the University of Toronto with clinical appointment at North York General Hospital and is the director of the University of Toronto’s Practice Based Research Network. Before coming to Canada, he was involved in developing the Scottish Care Information – Diabetes Collaboration (SCI-DC), which tracks real-time clinical information on all 300,000 people with Type 1 and Type 2 diabetes in Scotland. Data in this system are used for research and quality improvement as well as clinical care. Some of the lessons learnt over fifteen years developing the Scottish system may be applicable in Canada. Many of the new and exciting approaches being developed in Canada may be beneficial to people in Scotland with diabetes.

Dr. Michelle Greiver

Dr. Michelle Greiver is an academic family physician at the University of Toronto with clinical appointment at North York General Hospital. She has been involved with the inception and development of Canadian Primary Care Sentinel Surveillance system. She is also involved in studying Electronic Medical Record implementation and its effect on preventive services. Dr. Greiver believes that the lack of data standards and problematic data quality in EMRs are holding back quality improvement efforts in a range of long-term health problems, including diabetes. She
is involved in studies looking at improving EMR data quality and is the deputy director of the University of Toronto’s Practice Based Research Network.

Doug Mumford

Doug Mumford has had diabetes since 1968. Initially with only urine testing and animal insulins, control was difficult to achieve and Doug feels lucky and grateful that he is still around and healthy forty-nine years later!

In 2009 he volunteered in a clinical trial to determine whether a Sensor Augmented Insulin Pump could enable patients to lower their A1C. A measurement and control engineer, Doug took to Continuous Glucose Monitoring (CGM) like a duck to water, seeing it as a tool to finally enable control of blood glucose (BG) levels. As Doug says, “If you cannot measure something, you cannot hope to control it”. His A1C fell from 8.5% to 6.5% during the trial and has remained below that, and more importantly Doug now lives life as he chooses. That freedom was impossible before.

Dr. Bruce Perkins was the research clinician for that trial and Doug switched to him for ongoing care. Believing he could help others with diabetes, Doug became a volunteer and has been active in that role ever since. He has been instrumental in developing a Diabetes Patient Portal website which will soon go live. With a nurse colleague, he also developed software to show graphically how insulin pump complex boluses actually affect BG over their duration. Patients have found this tool very helpful.

Dr. Perkins suggested that Doug get involved in the SPOR initiative and after reading everything he could find on-line, Doug volunteered and was selected as a member of the General Patient Council. Within days they realized Doug was a good fit for the Diabetes Action Canada Health Informatics project and drafted him to its Technical Committee where he has contributed both by representing the patient viewpoint and as someone knowledgeable in data and systems.

News & Alerts

Congratulations Dr. Paul Fernyhough!

Congratulations Dr. Paul Fernyhough for publishing your paper, *Selective antagonism of muscarinic receptors is neuroprotective in peripheral neuropathy*, on the Journal for Clinical Investigation!
Dr. Paul Fernyhough is a Principal Investigator in the Clinical Trials and New Therapies Goal Group at Diabetes Action Canada. Dr. Fernyhough has completed his B.Sc. degree in Biological Sciences at the University of Essex and performed his PhD in biochemistry at University of Sheffield in the UK. He also performed postdoctoral research at Colorado State University, Kings College London and as a Wellcome Trust Postdoctoral Fellow at St Bartholomew’s Medical College. Dr. Fernyhough subsequently worked as a fully tenured lecturer in the School of Biological Sciences (now the Faculty of Life Sciences) at the University of Manchester. Dr. Fernyhough’s general research interest is in the cell biology underlying neurodegenerative disorders of the peripheral and central nervous systems.

His recent paper on the Journal for Clinical Investigation focuses on the identification of a novel endogenous pathway in adult neurons that regulates nerve fiber growth. Normally this pathway suppresses growth of nerve fibers but by the use of antagonist drugs against a key receptor in the pathway, fibers can be released from this constraint and permit higher levels of growth. This allows specific drugs to drive nerve fiber regeneration and repair in disease states such as diabetes and chemotherapy where there is irreversible nerve damage. An exciting aspect of the work is that the drugs being used are old drugs for new uses. These drugs have been used in humans for over 20 years with no serious side effects. This class of drugs is currently being used to treat myopia in children, highlighting the excellent safety profile of these compounds. Therefore, phase 1 trials are expected to progress smoothly; phase 2 trials have been arranged and are already funded for 2017. Also, an interesting component of this drug development work is that these drugs can be applied in a topical formulation. This approach restricts side effects and permits application via patch or cream. Commercialization is proceeding rapidly with a company, WinSanTor Inc, supporting drug development through NIH funding and preparing for clinical trials in 2017-2018.

To read more about Dr. Fernyhough’s paper, please click here: http://www.jci.org/articles/view/88321

Once again, well done Dr. Paul Fernyhough. Diabetes Action Canada wishes you all the best in your future endeavours!

Congratulations Dr. Gillian Booth!

Congratulations to Dr. Gillian Booth for having her research selected by the American Heart Association’s Lifestyle and Cardiometabolic Health Council as one of the most impactful papers of 2016.
Dr. Booth is a Scientist in the Centre for Urban Health Solutions (C-UHS) in the Keenan Research Centre located at the Li Ka Shing Knowledge Institute of St. Michael’s Hospital in Toronto. She is also an Adjunct Scientist at the Institute for Clinical Evaluative Sciences (ICES) and an Associate Professor in the Department of Medicine and Institute of Health Policy, Management and Evaluation at the University of Toronto. Dr. Booth’s research focuses on environmental, socioeconomic, and health care factors influencing the risk of diabetes and related chronic diseases. A major thrust of her research focuses on effects of the built environment on health, which is supported by a 7-year CIHR Foundation Grant.

Dr. Booth and her team published a highly impactful research paper entitled “Association of neighborhood walkability with change in overweight, obesity, and diabetes” in JAMA. This study found that urban neighbourhoods with highly walkable urban designs had a stable prevalence of overweight and obesity and declining diabetes incidence during a 12-year period (2001-2012). Throughout this period, rates of each of these conditions were significantly lower in these highly walkable neighbourhoods compared with less walkable areas, in which levels of obesity had continued to increase.

For further information on this research, please see:  
http://jamanetwork.com/journals/jama/fullarticle/2524191

The T1International Type 1 Diabetes Access Charter

T1International believes in a world where everyone with type 1 diabetes – no matter where they live – has everything they need to survive and achieve their dreams. This organization works towards ensuring people with type 1 diabetes have adequate access to insulin, diabetes supplies, medical care and diabetes education. T1International does this by raising awareness, campaigning and collaborating with existing initiatives, and supporting individuals and organisations on the ground that are working to make life better for people with type 1 diabetes.
The T1 International Type 1 Diabetes Access Charter was created to take a stand against the outrageous lack of access to life-saving essentials that people with type 1 diabetes around the world face every day. Many people with type 1 diabetes are dying or suffering expensive complications because insulin, and the supplies and education to manage diabetes, remain out of reach. This Charter will be used to bolster type 1 diabetes advocacy efforts worldwide. It will show the world that there are many voices united in support of these rights. It can be used to influence the actions of governments and organizations so that policies can be changed and the rights of people with type 1 diabetes can be prioritized.

By signing this Charter, you agree that everyone with type 1 diabetes has the following rights:

1. The right to insulin
2. The right to manage blood sugar
3. The right to diabetes education
4. The right to healthcare
5. The right to live a life free from discrimination

Read more and sign the charter by visiting this link: https://www.t1international.com/get-involved/

Events:

Annual Diabetes Action Canada Workshop, May 26, 27

Our Diabetes Action Canada Scientific Leads, Principal Investigators, Co-Investigators, patient representatives and key stakeholder representatives will convene in Toronto at our an annual workshop on May 26, 27.
The purpose of this face-to-face meeting is to evaluate our progress to date and advance strategic planning for the next year and beyond. This networking experience is critically important for the development of new opportunities to build collaborative relationships. We aim to better understand how our major projects can be integrated for optimal outcomes including translation of knowledge into practical solutions for individuals living with diabetes. After a year of start-up and much progress, our workshop will highlight all of our projects in Patient-Engagement, Indigenous Health, Retinopathy Screening, Health Informatics, Clinical Trials, Teaching and Mentoring, Knowledge Translation, Sex & Gender - focused on impact. In advance of the two day workshop, our Patient Councils will meet and prepare to advise our deliberations during the visioning and strategic planning of our research and capacity building. As part of our proceedings, the Steering Council and the Standing Committee on Strategic Partnering and Innovations will meet and then advise us during our workshop deliberations. We look forward to this exciting opportunity to network with all those engaged in Diabetes Action Canada.