

Improving the outcomes of young people with cancer, one child at a time

This year over 700 Canadians from birth to 29 years of age will die of cancer. That is two children each day, every day of the year. Their cancers are refractory, relapsed, or metastatic. Common to them all is that the initial treatment did not work. Common to them all is that there is no cure.

Our Solution: Terry Fox PROFYLE

Together, we can change these stories. Advancements in molecular profiling and targeted drug therapies, over the last ten years make it possible to focus on relapsed, refractory, and metastatic cancer in young people.

Expected outcomes of the project

- Patients across Canada who are accepted for the program will have access to profiling that improves their treatment possibilities that may change the outcome of their cancer
- A new paradigm for cancer research in Canada will be developed; a national mixed based approach to address cancer for young people
- New methods are developed that will allow us to apply precision approaches to patients of all ages (new generation sequencing);
- New treatment options are developed for children and adults.

How Terry Fox PROFYLE will work

Advancements in molecular profiling and targeted drug therapies, over the last ten years make it possible to focus on relapsed, refractory, and metastatic cancer in young people. The information gathered from molecular profiling is used to identify and design therapies to target a specific cancer tumour profile. By targeting the specific genome of the cancer tumour, therapies promise to have less negative impact on the patient, resulting in both a better quality of life and longer life.

Advancing molecular profiling for a patient population that is dispersed across the country requires the collaboration of Canada's top researchers working in the top research facilities across the country. Under the leadership of The Terry Fox Research Institute, more than 50 of Canada's top researchers from fields as diverse as oncology, genomics, proteomics, biomarker analysis, pathology, biobanking, bioinformatics, drug development, clinical trials, regulatory affairs, patient advocacy, and bioethics are combining their renowned expertise to tackle this problem. Together they will build a common research platform for tissue bio-banking, disease modeling, and genomic sequencing that builds on and complements the expertise in hospitals and research facilities throughout Canada.

This new shared research infrastructure makes it possible to perform population-based studies on youth dispersed across the country. For the first time ever a young person anywhere in Canada will be able to access a pan-Canadian (i.e. national) network of expertise, diagnostic tools and treatments that otherwise would not be available to them.

In practice this means a hospitalized child in Manitoba, for example, will have a tissue sample taken of their cancer tumour that could be sequenced and profiled in British Columbia to discover the area most likely to respond to therapy. It could be clinicians in Toronto who advise on the best treatment, and scientists in Halifax who could model that tumour so that treatments and therapies can be developed and tested in Montreal.

The Potential of Terry Fox PROFYLE

This project could:

- transform the way children and young adults are diagnosed and treated in our nation's hospitals;
- make clinical trials available for pediatric and young adult population;
- translate to adults with cancer and improve cancer outcomes for all patients.

Terry Fox PROFYLE: Nodes of expertise

Terry Fox PROFYLE has recruited leaders in pediatric, adolescent and young adult cancer research and care from across Canada. Recognizing no geo-political boundaries, this remarkable collection of talent is driven by the sole purpose to improve the outcomes of young Canadians with high risk cancers. To harness the collective knowledge and expertise, our multidisciplinary team of over 50 investigators and collaborators has been structured into ten interconnected committees or nodes. Each committee, which oversees the execution of one or more specific research projects, is chaired by a member of the Program Executive Committee and ensures adherence to the project plan and timelines. The boundaries between the committees are fluid with several members sitting on more than one committee. These committees include biobanking, biomarkers, adolescent and young adults, genomics, clinical trials, program quality assurance, program ethics, proteomics and metabolomics, biobanking and the partnership node.

The **Biobanking Node**, led by Dr. Jennifer Chan will implement a national strategy for tissue collection, preparation, and storage. Jennifer is a neuropathologist and Assistant Professor of Pathology at the University of Calgary where she also directs the Brain and Pediatric Tumor Bank.

The **Biomarker Node**, led by Nada Jabado will develop profiling methods to allow for more accurate information about disease progression or regression, using less invasive and more frequent biopsies. The biomarker node will identify and validate biomarkers for refractory/relapsed pediatric and young adult cancers that can be used as surrogate diagnostic, prognostic, and therapeutic tools.

The **AYA Node**, led by Dr. David Eisenstat, will ensure seamless integration of patients whose ages are from 14 to 29 years into the program and will also establish a process to access AYA patient data, whose genomes have been sequenced as part of adult personalized oncology programs.

The **Genomics Node**, led by Dr. David Malkin, will oversee the planning and implementation of a national personalized medicine platform. Their focus is to provide real time sequencing to identify personalized epigenetic and/or genetic drivers as treatment targets in patient tumours. Sequencing for patients in Quebec and the eastern provinces will be done in Montreal, sequencing for patients in Ontario will be done in Toronto and sequencing for patients from Manitoba west will be done in Vancouver.

The **Clinical Trial Node**, led by Dr. Rebecca Dyell (Vancouver) and Dr. Henrique Bittencourt (Montreal) will initiate the development of new and innovative clinical trials for the underserved patient population that Terry Fox PROFYLE is focused on. In addition, Terry Fox PROFYLE has the potential to make inroads on making clinical trials available to the adolescent and young adult population.

The **Ethics Node** led by Conrad Fernandez, a professor at Dalhousie University and head, Division of Pediatric Hematology/Oncology, Department of Pediatrics and Bioethics at IWK Health Centre, will pioneer a national approach towards applying ethical guiding principles and processes to the PROFYLE program.

The **Proteomics and Metabolomics Node** will use the proteome to study disease and identify novel biomarker assays. This node is led by Poul Sorensen who is Johal Endowed Chair in Childhood Cancer Research and Professor of Pathology, University of British Columbia, Chair of the Translational Research Committee of COG and PI of the Genome Canada/CIHR/C17 Canadian pediatric cancer genome consortium which uses next-generation sequencing to identify drivers in high-risk childhood cancers.

The **Model System Node** will study disease markers in multiple organisms and initiate the development of new therapeutic compounds. This node is chaired by Dr. David Eisenstat, Professor in the Departments of Pediatrics and Medical Genetics at the University of Alberta and Division Director of the Pediatric Hematology/Oncology/Palliative Care at Stollery Children's Hospital.

The **Partnership and Advocacy Node** is engaged in raising funds, identifying partnership opportunities and providing important advocacy support. This node is led by Patrick Sullivan who is a passionate childhood cancer research advocate, President and founder of the Team Finn Foundation, a securities and corporate-commercial litigator, and board member with the Canadian Cancer Research Alliance.

Cost

This five-year project requires an initial investment of \$25 million. The Terry Fox Research Institute has committed \$5 million. On behalf of the entire project team and the patients we serve, thank-you for considering an investment in Terry Fox PROFYLE.