

Productivity and Effectiveness Submission to the House of Commons Standing Committee on Finance

Pre-Budget Submission 2018

The Kidney Foundation of Canada

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Ms. Elizabeth Myles National Executive Director 310-5160 Decarie Blvd Montreal QC H3X 2H9 The Kidney Foundation of Canada is pleased to submit recommendations to the House of Commons Standing Committee on Finance concerning Budget 2018.

The Kidney Foundation of Canada

In Canada, health charities play an essential role to people affected by health conditions by providing expertise and support. The Kidney Foundation of Canada faithfully supports and serves people with kidney disease and their families. The Foundation, through its volunteers and employees, is committed to understanding the needs of our community and to providing services and programs which are meaningful and effective for people with kidney disease and those at risk.

Since its inception in 1964, the Foundation has consistently and significantly invested in research funds in order to have a positive impact on the outcomes of kidney disease. Research projects have been supported across a wide spectrum of topics, from understanding diagnosis to preventing or delaying the onset of kidney disease to the treatment options available, and dedicated to discoveries about specific types of kidney disease, and its psychosocial impacts.

The Kidney Foundation of Canada respectfully submits the following recommendations for the 2018 federal budget:

- The federal government should identify and implement strategies to lessen the
 economic impact of kidney disease that is often experienced by people with end-stage
 kidney disease.
- 2. The federal government should invest in systems to improve transplantation rates, as transplantation is the preferred and most cost-effective treatment for kidney disease
- 3. The federal government should follow the recommendations of the Fundamental Science Review Report and ensure that a fair and reasonable share of these needed new funds will be allocated to the Canadian Institutes of Health Research.

Introduction

Kidney disease is a complex and life-altering condition. 1 in 10 Canadians have kidney disease and millions more are at risk.

In addition to having a shorter than average life expectancy, people with end-stage kidney disease are more likely to experience losses of short-term and long-term productivityⁱ. People on dialysis, the most common form of treatment, often experience sustained, long-term effects on their ability to work.

Another treatment option available for people with end-stage kidney disease is transplantation. A kidney transplant is considered the best way to treat kidney failure for many people. From an economic viewpoint, kidney transplantation lessens the burden on the healthcare system. The quality of life of those with functioning transplants is relatively comparable to the general populationⁱⁱ, but many more people are waiting for an organ than are available.

Background

The main causes of kidney failure in Canada are diabetes (39%), high blood pressure and a family history of kidney disease. These conditions can affect anyone, from newborns to the elderly and every age in between. People of Indigenous, Asian, South Asian, Pacific Island, African/Caribbean and Hispanic descent are at a higher risk of chronic kidney disease (CKD).

The prevalence of kidney disease continues to grow at an alarming rate, with the number of Canadians living with end-stage kidney disease increasing by 36% from 2006 to 2015. An average of 15 people each day are told that their kidneys have failed. In 2015, 36,251 Canadians were being treated for kidney failure, with 58.5% on dialysis and 41.5% living with a functioning kidney transplant. The most common treatment for people starting renal replacement therapy for kidney failure is dialysis, with the average cost per patient per year of \$92,000.

Often considered a disease which largely impacts the elderly, statistics show a different story: nearly half of those starting renal replacement therapy -47% – are under age 65^{iii} .

Treatment options include hemodialysis (in-centre or at home), peritoneal dialysis and transplant.

People with kidney disease often need multiple medications to help manage their condition, need dietary and fluid restrictions, and depending on the stage of the disease, they may require dialysis or transplantation. Additionally, there are many doctor and clinic visits, surgery may be needed for dialysis access, transplantation or complications of the disease itself.

 The federal government should identify and implement strategies to lessen the economic impact of kidney disease that is often experienced by people with end-stage kidney disease.

This life-altering condition affects many aspects of a person's life but can reach further to their family and friends. The disease can take a physical, emotional, social and financial toll. Travel to dialysis and medical appointments, the inability to work in many cases, cost of medication, travel limitations such as inability to find or afford holiday dialysis space or cost of travel insurance, escalating costs of electricity and water for home dialysis, extra equipment costs, e.g. blood pressure monitors or scales and nutritional supplements, can all have a significant and detrimental impact on individuals living with kidney disease.

In addition to having shorter than average life expectancy, people with end-stage kidney disease are more likely to experience losses of short-term and long-term productivity^{iv}. People on dialysis often experience sustained, long-term effects on their ability to work or perform other activities. Morbidity and premature mortality also impose a considerable burden on society^v.

Each hemodialysis treatment normally takes 4 to 5 hours, 3 times per week, so transportation to and from dialysis can be significant and costly challenge. While home-based therapies can increase flexibility and reduce the burden of transportation, there can be other barriers such as lack of adequate housing and increased water and energy costs.

A survey conducted in 2015-6 found that nearly 50% of people on dialysis report that their annual incomes have decreased since starting dialysis. Further to this, people reported that they have missed doctors' appointments and dialysis sessions due to financial barriers. Unacceptably, nearly 20% of respondents missed purchasing medications or went without food or basic necessities due to financial barriers associated with end-stage kidney disease^{vi}.

A national strategy addressing the financial impacts of kidney disease is needed to help people living with kidney disease overcome the significant financial burdens that they experience as a result of their disease.

2. The federal government should invest in systems to improve transplantation rates, as transplantation is the preferred and most cost-effective treatment for kidney disease

Health services account for most of the economic burden of kidney disease services. Dialysis is the most common treatment for kidney failure and costs the healthcare system between \$56,000 and \$107,000 per patient per year^{vii}. Home based therapies, such as peritoneal dialysis (\$56,000 per year on average) and home hemodialysis (\$71,000-\$90,000 per year on average), are less costly for the health care system^{viii}.

From a macroeconomic viewpoint, kidney transplantation lessens the burden on the healthcare system. Importantly, it is also the best treatment option for people with kidney failure and provides a quality of life that is relatively comparable to the general population . The cost of a kidney transplant, including donor costs, is approximately \$100,000 initially, decreasing to \$20,000 in care costs for the second year and further decreasing annually each year thereafter.

Many more people are waiting for organs than are available. In 2015, there were 3,471 patients waiting for a transplant as of Dec. 31; throughout 2015, a total of 1,513 patients received a transplant and 73 died while waiting. The median wait time for a deceased donor transplant is 4 years, with the longest waits being in Saskatchewan (5.4 years) and Manitoba (5.3 years)^{xi}.

Kidneys for transplant can come from living or deceased donors. The number of deceased donors (all organs) has increased by 42 per cent from 460 in 2006 to 649 in 2015; however, a growing number of people require transplants and the supply remains inadequate. Canada's deceased donation rate remains well below those of many leading countries internationally.

In order to improve transplantation rates, it is vital that there are health practices and policies in place to optimize organ donation in Canada. A comprehensive, coordinated and sustainable national strategy that includes national practice standards/guidelines, data management systems, integrated organ donation programs in hospital structures, professional training and public education should be developed and implemented.

3. The federal government should follow the recommendations of the Fundamental Science Review Report and ensure that a fair and reasonable share of these needed new funds will be allocated to the Canadian Institutes of Health Research.

In May 2017, the kidney community met to discuss the steps that could be taken to continue to pursue excellence in kidney research, and improved lives for Canadians living with kidney disease. The workshop was titled "HORIZONS 2022" and as one of the action steps, the group felt it was important to

write a letter to congratulate the Government on the Fundamental Science Review, and to express our sincere support for the recommendations contained therein. This is an extraordinary period in the history of biological research, particularly human biologic research with massive payoffs guided by genomics and the future integration of such things as stem cell organ reproduction with 3D printing. Canada cannot afford to fall behind or lose a generation of young health researchers. We are therefore counting on the government to take action; following not only the governance and oversight recommendations of the review panel's report but also to ensure that a fair and reasonable share of these needed new funds will be allocated to the Canadian Institutes of Health Research (CIHR).

Furthermore, the Kidney Foundation of Canada supports the submissions of the Health Charities Coalition of Canada (HCCC) and the Chronic Disease Prevention Alliance of Canada (CDPAC). The Health Charities Coalition of Canada (HCCC) is a member-based organization comprised of 27 national health charities who represent the voice of patients at all levels of the health continuum. The collective members translate knowledge gathered through research to advocate for better public policy and better health outcomes for Canadians. As a member of HCCC, we support their recommendations for greater access to medicines for all Canadians and for the investment in research that will provide jobs and stimulate the economy, setting the stage for improved prosperity and innovation in the future. Additionally, we support the recommendation for the Government of Canada to establish a formal mechanism for meaningfully and continuously engaging patient representatives in its decision making and regulatory processes on issues related to health and health research.

Additionally, we support CDPAC's recommendation that the Government of Canada strengthen its support for healthy living and chronic disease prevention by adopting a levy on the manufacturers of sugary drinks to reduce consumption and to partially recover related health care costs.

We hope that the above recommendations are considered and we would be pleased to provide further information and evidence to support them.

ⁱ Zelmer, JL. The economic burden of end-stage renal disease in Canada. Kidney International (2007) 72, 1122-1129

^{II} Zelmer, JL. The economic burden of end-stage renal disease in Canada. Kidney International (2007) 72, 1122-1129

iii Annual Statistics on Organ Replacement in Canada: Dialysis, Transplantation and Donation, 2006 to 2015, www.cihi.ca

[™] Zelmer, JL. The economic burden of end-stage renal disease in Canada. Kidney International (2007) 72, 1122-1129

^v Zelmer, JL. The economic burden of end-stage renal disease in Canada. *Kidney International* (2007) **72**, 1122-1129

vi Kidney Foundation of Canada. 2017. The Economic Impact of End-Stage Kidney Disease. Unpublished data.

vii Dialysis patients younger than 18 have the highest risk of being hospitalized, https://www.cihi.ca/en/types-of-care/specialized-services/organreplacements/dialysis-patients-younger-than-18-have-the

viii Chronic Kidney Disease in Manitoba: Can We Change the Future?, http://mchp-appserv.cpe.umanitoba.ca/reference//ckd_4_page_summary.pdf

ix Zelmer, JL. The economic burden of end-stage renal disease in Canada. Kidney International (2007) 72, 1122-1129

^{*} Prevalence of Severe Kidney Disease and Use of Dialysis and Transplantation Across Alberta from 2004-2013,

http://www.albertahealthservices.ca/assets/about/scn/ahs-scn-kh-annual-kidney-care-2015.pdf

xi Annual Statistics on Organ Replacement in Canada: Dialysis, Transplantation and Donation, 2006 to 2015, www.cihi.ca