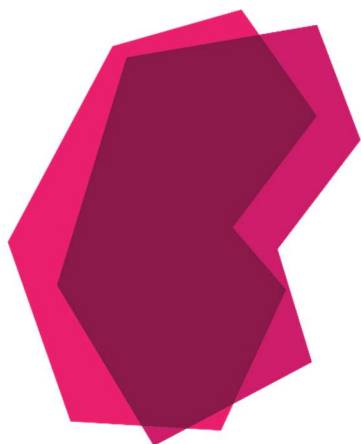


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Submission to the House of Commons Standing Committee on Finance

Pre-Budget Submission 2021

The Kidney Foundation of Canada

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The Kidney Foundation of Canada respectfully submits the following recommendations for the 2021 federal budget:

The federal government, working in collaboration with the provincial/territory governments, to ensure equitable access to treatment options for Canadians with a chronic illness, particularly those with chronic kidney disease by:

- Addressing the financial burden of kidney disease via
 - Subsidized transportation costs and expanded access to travel grants, particularly for people in rural areas,
 - Minimized disparities in accessing medications for people with kidney disease and developing mechanisms to offset costs equitably across jurisdictions,
 - Adequate support for home dialysis through reimbursement of utility costs and consideration of the financial and health literacy of patients when operationalizing “home first” policies;
- Implementing a national strategy and oversight to ensure every potential deceased donor is identified and referred, and that every person awaiting transplant has equitable access to organ transplantation across the country.

Introduction

Kidney disease is a complex and life-threatening condition. 1 in 10 Canadians, approximately 4 million people have kidney disease and millions more are at riskⁱ. More than 50, 000 Canadians are being treated for kidney failureⁱⁱ. It is the 10th leading cause of death in Canada, and there is no cure.

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

The only other 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 population, but many more people are waiting for an organ than are available.

Being on dialysis or having a kidney transplant can place significant financial strain on patients and families due to loss of income and increased out-of-pocket treatment related expenses.

Living with Kidney Disease

Kidney disease changes peoples' lives forever. There is no cure for kidney disease. Once diagnosed with kidney failure, an individual will require life-sustaining dialysis treatments three to four times a week for the rest of his/her life, unless they are eligible for and fortunate enough to have a transplant. For those with end-stage kidney disease, 58% are on dialysis and 42.5% have a functioning transplantⁱⁱ. Of the people on dialysis, only 11% are on the waiting list for a transplant^{iv}.

People living with kidney failure and their families often face substantial financial hardships because of the manner in which symptoms of their chronic illness impact their physical, emotional and psychological wellbeing. This is compounded by the demands of their dialysis treatment, which has great impacts on their productivity level both at home and in the

ⁱ Manns, Braden et al. "The Financial Impact of Advanced Kidney Disease on Canada Pension Plan and Private Disability Insurance Costs" Canadian journal of kidney health and disease vol. 4

2054358117703986. 17 Apr. 2017, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5406196/>

ⁱⁱ Organ replacement in Canada: CORR annual statistics, 2019, <https://www.cihi.ca/en/organ-replacement-in-canada-corr-annual-statistics-2019>, supplemented with data collected by the Quebec Branch of The Kidney Foundation of Canada as provided by renal units.

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

^{iv} CORR e-Statistics on Organ Transplants, Waiting Lists and Donors 2018, <http://www.cihi.ca/sites/default/files/document/corr-eststatistics-2018-en-web.xlsx>

workforce as patients undergo treatment three to six times a week, depending on the form of dialysis. Many people living with kidney disease frequently experience significant financial challenges related to loss of income, combined with increased costs for transportation and medication.

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, must maintain strict dietary and fluid restrictions and, depending on the stage of the disease, they may require dialysis or transplantation. Additionally, costs are impacted by numerous medical appointments for matters beyond treatment; surgery may be needed for dialysis access, testing and processes for transplantation or matters arising from complications of the disease.

Addressing the Financial Burden of Kidney Disease

Canadians with kidney failure and their families face significant financial challenges as a result of their dialysis treatment. Starting dialysis often results in a decrease of income at the same time that out-of-pocket costs increase. Government coverage and financial support for people on dialysis varies, resulting in inequalities across jurisdictions.

Being on dialysis or having a kidney transplant can place significant financial strain on patients and families due to loss of income and increased out-of-pocket treatment related expenses. Treatment-related, out-of-pocket costs can include:

- Transportation to and from dialysis treatments, attending frequent medical tests and procedures, especially those that may not be available locally.
- Travel costs for home dialysis training.
- Loss of employment income during home dialysis training.
- Travel costs for patients and their caregivers who do not live within a close proximity to the regional transplant centres for assessments, accommodations for transplant surgery, and post-transplant follow-up appointments.
- Increased water, electricity and garbage disposal fees for home dialysis.
- Disparities in accessing medications across jurisdictions.
- Nutritional supplements and special diet requirements which are not covered.
- Relocation from remote communities to access medical care.
- While there is an increased push for home dialysis therapies to optimize health, these therapies transfer the cost savings from the health care system onto the patient and their families to endure.

Examining the Financial Burden of Kidney Disease

In 2016, The Kidney Foundation of Canada and the Canadian Association of Nephrology Social Workers (CANSW) conducted a Canadian study to determine the extent of the financial burden which patients and families experience living with kidney disease.

- **Many Canadians report a drop in household income as a result of starting dialysis.**
Nearly 50% of respondents indicated that their annual household income decreased since starting dialysis. Of those who said their income decreased, more than half said it had decreased by 40% or more.
- **The proportion of patients on dialysis who are below Canada's Low Income Cut-Off (LICO) is much higher than the general population.**
Of all respondents, 41% are below the Canadian Low Income Cut-Off (LICO), compared to 8-14% of the general Canadian population.
- **Out-of-pocket costs related to dialysis treatment are a significant burden.**
The reported annual average out-of-pocket costs related to dialysis treatment ranged from \$1,400 to \$2,500 (depending on treatment modality).ⁱ

This is significant when you consider that:

- 55% of respondents reported an annual household income of less than \$35,000; and
- 23% of respondents reported an annual household income of less than \$20,000.

The burden of these out-of-pocket costs is substantial. Of all respondents, 21% reported going without food or basic necessities in the last six months due to the financial burden of dialysis treatment.

The impact of poverty as a social determinant of health is significant when:

- 27% of respondents who fall below the LICO indicated that they missed purchasing medication in the last 6 months due to a financial barrier.
- 21% of all respondents indicated that they had gone without food or necessities in the last 6 months due to financial barriers.

The consequence of going without required medications or maintain an appropriate specialized renal diet can have significant impact on their health. A slight change can result in hospitalization.

ⁱ Non-response was interpreted as having a \$0 value for many of the sections, and therefore it is likely that the results here systematically underestimate true costs, especially monthly out-of-pocket costs.

Organ Donation and Transplantation

Since 2011, the number of deceased donors in Canada has increased steadily. Despite the advances in the number of transplants over the last few years, Canada is not meeting the needs of thousands of Canadians awaiting life-saving transplantation as the number of recipients is still much greater than the number of organ donors. There is an urgent need to improve our organ donation and transplantation system to save the lives of this under-served population. 75% of the 4,300 Canadians on the waiting list for an organ transplant are waiting for a kidney^{iv}. In 2018, there were only 1709 kidney transplants. 223 people died while waiting for a transplant, of which 94 were waiting for a kidney in 2018ⁱⁱⁱ.

Dialysis has an annual mortality rate of nearly 16%. Just 44% of people on dialysis are alive after five-years^{vii}. Increasing transplantation rates is a matter of life and death for people with kidney failure.

Not only does a transplant have better health outcomes and improved quality of life, but it is also a less costly option for the health care system than dialysis. The total annual cost of dialysis ranges from \$56,000 to \$107,000 per patient. The cost of a transplant is \$66,000 in the first year, then \$23,000 in subsequent years. Therefore, the healthcare system annually saves up to \$84,000 per patient transplanted^{viii}. The need for kidneys continues to exceed the supply of donor kidneys. Although 1,709 kidney transplants were performed in 2018^{vi} there are nearly twice as many people still waiting for a kidney.

Recommendation

The Kidney Foundation of Canada calls upon the Federal/Provincial/Territorial Conference of Health Ministers to implement a national strategy and oversight to ensure every potential deceased donor is identified and referred, and that every person awaiting transplant has equitable access to organ transplantation across the country. This includes implementation and monitoring of best practices, public and professional education, and the development and coordination of an advanced inter-provincial organ sharing and data monitoring system. The strategy should be developed in collaboration with a broad range of stakeholders including government, health care, and the public and voluntary sector.

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

^{iv} e-Statistics Report on Transplant, Waiting List and Donor Statistics. Canadian Organ Replacement Register, Canadian Institute for Health Information, 2019.

^{vii} Canadian Institute for Health Information. Treatment of End-Stage Organ Failure in Canada, Canadian Organ Replacement Register, 2009 to 2018: End-Stage Kidney Disease and Kidney Transplants — Data Tables. Ottawa, ON: CIHI; 2019.

^{viii} 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-kidneycare-2015.pdf>.

Supporting Other Submissions

Furthermore, The Kidney Foundation of Canada supports the submissions of the Health Charities Coalition of Canada (HCCC), the Chronic Disease Prevention Alliance (CDPAC) and the Canadian Quality End of Life Care Coalition of Canada (QELCCC).

Canadian health charities have seen a 50% drop in revenue compared to this time last year due to the COVID-19 pandemic. At the same time, demand for services has increased and research initiatives have been put at risk, jeopardizing years of work and hundreds of millions of dollars of investment. This is why members of the Health Charities Coalition of Canada are seeking the government's support for up to \$28 million per month, so that national health charities can support Canadians living with disease and continue to fund vital research.

Recommendation: Following the same structures and principles of other government funding programs, that the Government of Canada provide direct financial support to health charities of up to \$28 million per month as health charities recover from the impact of COVID-19 so that they can continue to develop and offer programs to support patients, families and caregivers.

About the Kidney Foundation of Canada

The Foundation is the national volunteer organization committed to eliminating the burden of kidney disease through:

- Funding and stimulating innovative research for better treatments and a cure;
- Providing education and support to prevent kidney disease in those at risk and empower those with kidney disease to optimize their health status;
- Advocating for improved access to high quality health care;
- Increasing public awareness and commitment to advancing kidney health and organ donation.