

VISION



#### **Can-SOLVE CKD Network Vision:**

By 2020, every Canadian with, or at high risk for, chronic kidney disease (CKD) will receive the best recommended care, experience optimal outcomes and have the opportunity to participate in studies with novel therapies, regardless of age, sex, gender, location or ethnicity.







#### The Patient Council is:

- Over 30 patients and family caregivers with lived experience of varying stages of chronic kidney disease and representative in age, ethnic and cultural backgrounds of Canadian population.
- All provinces and territories
- Working with the researchers in a 3-themed kidney research program towards 1 goal to impact kidney health and care

#### Vision:

A nationwide, representative group of active and passionate patient partners who bring their lived experience with chronic kidney disease (CKD) to researchers involved in the Can-SOLVE CKD Initiative. We will build a strong and collaborative kidney community in Canada and make a difference in health and care for future generations.

# NHO IS INVOLVEDS Indigenous peoples, Engagement

# Kondation of Canadal Kiames Get of Nephrology PATIENT COUNCIL

Can-SOLVE CED Steering Committee Patients & Caregivers 30+ members

#### **Goals:**

- Leading and guiding the Can-SOLVE CKD Initiative
- Creating and demonstrating the value and impact of patient partnership
- Working side by side with researchers within the Can-SOLVE CKD Network
- Championing for the kidney community across Canada

#### **Future Outcomes:**

- Increased research activities with results that are relevant & responsive to those living with kidney disease
- Increased awareness of the value of patient engagement in research
- A positive change in culture for patients & researchers
- Increased advocacy for access to research
- A strong and vibrant kidney patient-centred community
  - Improved lives of people impacted by kidney disease

## WORKING GROUPS







Measurement & Metrics

Researchers



### Figure **2**: Can-SOLVE CKD Network Partners

#### Universities:

- University of British Columbia
- University of Calgary
- University of Alberta
- University of Saskatchewan
- University of Manitoba
- University of Toronto
- McMaster University
- Western University
- University of Ottawa
- University of Montreal
- McGill University
- **Dalhousie University**
- Memorial University

#### **Research Centres/Groups:**

- Alberta Kidney Disease Network
- Improving Renal Complications in Adolescents with Type 2 Diabetes through Research Study (iCARE)
- Kidney, Dialysis & Transplantation Research Program
- All Provinces Project for Outcome Assessment in Coronary Heart disease (APPROACH),
- Alliance for Canadian Health Outcomes Research in Diabetes (ACHORD)
- British Columbia Alliance of Telehealth Policy and Research
- Canadian National Transplant Research Program (CNTRP)
- The Interdisciplinary Chronic Disease Collaboration
- Canadian Vascular Network

#### National Stakeholders:

- Canadian Organ Replacement Registry (CORR)
- . **KT** Canada
- Indigenous Physicians Association of Canada
- National Aboriginal Diabetes Association

#### International Research Groups:

- The Nephrotic Syndrome Study Network (NEPTUNE)
- Australian Kidney Trials Network
- Chronic Kidney Disease Prognosis Consortium (CKD-PC)
- Chronic Renal Insufficiency Network
- German CKD Cohort study

#### Provincial Renal Programs:

- British Columbia Renal Agency
- Alberta Renal Programs
- Manitoba Renal Program
- Saskatchewan Renal Program
- **Ontario Renal Network**
- Newfoundland Renal Program

#### Professional Associations:

- Canadian Society of Nephrology
- Canadian Association of Pediatric Nephrologists
- Canadian Society of Transplantation
- Canadian Association of Nephrology Administrators
- Canadian Association of Nephrology Nurses and Technologists
- Canadian Association of Nephrology Social Workers
- **Renal Pharmacists Network**
- Canadian Association of Nephrology Dieticians

#### **Training Programs:**

- Kidney Research Scientist Core Education and National Training Program (KRESCENT)
- University Based Nephrology Training Programs
- Patients as Partners (BC)
- Alberta SPOR Support Unit Patient Engagement Platform
- Centre for Aboriginal Health Education

#### **Patient Special Interest Groups:**

- Aboriginal Health Organizations
- KFOC (Provincial Kidney Foundation Branches)

#### **Existing Structures:**

- Canadian Kidney Knowledge Translation and **Generation Network** 
  - **Knowledge Translation Network**
  - Clinical Trial Group

#### **Biorepositories:**

- Donor Network Study
- CAN-PREDICT: : Canadian Study of Predicting Death, Dialysis and Cardiovascular events in CKD patients
- NEPTUNE
- CKD-PC
- iCare: Improving Renal Complications in Adolescents With Type 2 Diabetes Through the REsearch (iCARE)
- Adolescent Diabetes Intervention Trial

#### Industry:

- Amgen Canada
- Otsuka Baxter



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**Network** 





#### Can-SOLVE CKD Governance

- 1. Co-chairs: A Levin (researcher, clinical, policy & decision-maker), B Manns (researcher, clinical, health economist)
- 2. Chair: J Craig (reseacher, clinical)
- 3. Co-chairs: S Straus (researcher, clinical), R Harvey (policy & decision-maker)
- 4. Co-chairs: C Woods (patient, indigenous), K Huffman (patient), M McCormick (patient)
- 5. Co-chairs: E Adams (policy & decision-maker, indigenous) C Woods (patient, indigenous)
- 6. Co-chairs: K Burns (researcher, biomedical), N Rosenblum (researcher, biomedical, pediatric), N Fernandez (researcher, patient)
- 7. Chair: N Rosenblum (researcher, biomedical, pediatric)