

Member, BC Renal Autosomal Dominant Polycystic Kidney Disease (ADPKD) Advisory Group

Role description

The ADPKD Advisory Group helps improve care for people with ADPKD in BC Kidney Care Clinics (KCCs). This team reviews and updates provincial ADPKD best practice guidelines based on the latest national and international recommendations.

The group includes patient partners, clinical, and administrative leaders from provincial and regional health authorities and BC Renal. By sharing their perspectives, members work together to ensure high-quality care for people with ADPKD who are not on dialysis. Patient partners play a key role by working alongside kidney health professionals to ensure best outcomes and experiences for people living with ADPKD in BC.

Level of engagement

<u>Collaborate</u>: BC Renal will work together with all members in decision making, developing alternatives and solutions, and include your recommendations into each decision as much as possible.

Requirements

- Person (patients or family caregivers) who is diagnosed with ADPKD
- Currently receiving kidney care at a Kidney Care Clinic (i.e. not on dialysis or received a kidney transplant yet) in BC
- Experience working and sharing perspectives with diverse groups of people
- A strong interest in partnering and working together with health professionals to improve the quality of life of people living with ADPKD

We are hoping to recruit diverse voices and welcome patient partners of various ages, genders, kidney disease experiences, and cultural backgrounds from across the province.

Number of positions available

1

Commitment

- 1-hour meeting every 4-6 weeks via MS Teams
- Term membership will be for six months from January to June 2026 with possibility of extension.

Compensation

Expenses for travel and accommodation, if needed, will be reimbursed.

RSVP questions

Please respond to the following questions by email (<u>patientengagement@bcrenal.ca</u>) or phone (604-875-7340) by **December 31, 2025**

- 1. Why are you interested in being on this advisory group?
- 2. What skills and expertise would you bring to this advisory group?
- 3. Which renal program are/ were you or your family member in (i.e., Fraser Health, Interior Health, Island Health, Northern Health, Providence Health Care, Vancouver Coastal Health or BC Children's Hospital)?