

Patient and Caregiver Storytellers



Are you keen to tell your story about your journey with immunodeficiency? Do you have good verbal communication skills and an outgoing nature? Are you comfortable in front of an audience or video camera? If so, there is always a demand for patients, parents and caregivers to tell their stories about PI! You might be answering questions about your experiences during diagnosis, what it is like to live with or care for someone with a PI, or the impact that appropriate treatment has had on your life.

Mission

We empower Canadians impacted by immunodeficiency disorders to live well through education, support, advocacy, community-building, and research.

Vision

All Canadians with immunodeficiency disorders have access to the resources they need to thrive.



Values

Our values are: community, equity, inclusiveness, empowerment, excellence and innovation.

Volunteer Philosophy

Volunteers are a key element and vital part of the Primary Immunodeficiency community and ImmUnity Canada. You have been integral to our organization from the very start, helping to shape our present and future needs. Collaborating together, our volunteers help us to create a community where everyone feels welcomed, heard, supported and empowered to live their best life possible. We welcome volunteers from all walks of life, and will help you to overcome barriers to feel included in our community.

Position Description

Our Patient and Caregiver Storytellers verbally narrate their stories to grow awareness about immunodeficiency and the experience of living with a rare disorder. We are looking for people to share their stories during our conferences and education days, for our website and social media, as well as to go into a storybank for future use. Volunteers might also give public talks, participate in video interviews and webinars or even take part in a live television/radio interview. These positions are based on our need for presenters, and demand from media and other organizations, so may be ad-hoc in nature.

Core Experiences

Working as a volunteer storyteller, you might be:

- ★ Using your verbal communication skills to share your story in person, on Zoom or on live television/radio
- ★ Helping ImUnity Canada to create a patient and caregiver storybank for use on social media, our website and for advocacy purposes
- ★ Growing awareness about immunodeficiency and how it impacts people's lives
- ★ Representing ImmUnity Canada as a volunteer leader
- ★ Collaborating with staff via telephone, email and virtual platforms

Experience, skills, qualities and equipment needed

To be able to complete these tasks with ease, you should:



- ★ Be willing to share your immunodeficiency story in the public domain
- ★ Be outgoing, confident and friendly
- ★ Feel comfortable using your communication skills to talk to media, the public and others
- ★ Be over 18 years of age or accompanied by a parent/guardian
- ★ Have access to your own transport, a stable internet connection and a cellphone

Onboarding/Training Provided

As a new volunteer, we will take you through an orientation to ImmUnity Canada and your role. You will also receive an ImmUnity Canada volunteer handbook, which contains some useful information about the organization, our policies and your rights and responsibilities. We will further provide you with a guidebook for Patient and Caregiver `Storytellers, which comprises your training. ImmUnity Canada staff will also provide support as you need it and be available for questions related to your position.

Benefits to you as a Volunteer

At ImmUnity Canada, we gain a great deal from the work of our volunteers and hope that as one of our storytellers, you will feel appreciated. We offer a personal reference to all volunteers and hope the experience will also benefit you in the following ways:

- ★ Have the opportunity to be in the spotlight!
- ★ Improve your communication and public speaking skills
- ★ Develop and practice your story-telling skills
- ★ Get out-and-about and make new connections
- ★ Gain satisfaction from using your own knowledge and experiences to promote awareness of immunodeficiency and ImmUnity Canada

Location

Wherever you are needed across Canada and virtual platforms such as Zoom.

Time Commitment

- ★ Hours will be as required
- ★ You should be able to commit for a minimum of 1 year or more



Application Process

Application form, email and resume, followed by an informal interview by telephone or over Zoom.

Please fill out an online application form, and submit your resume with an email explaining why you are interested in this role, to Fiona, the Project and Volunteer Coordinator:

volunteer@immunitycanada.org