

What is Primary Immune Deficiency?

Primary Immune deficiency is a pathological disorder corresponding to a failure or malfunction of one or several functions of the immune system. This can lead to an increased susceptibility to infections. More than 180 primary immunodeficiencies have been reported to date. Primary immunodeficiencies arise for the most part during childhood. However, certain immunodeficiencies affect patients during their third decade of the life⁽²⁾. The clinical presentation of primary immunodeficiencies is highly variable and can sometimes be likened to a relatively benign clinical disease among adults⁽²⁾.

Early detection of primary immune deficiencies is crucial to providing a proper therapeutic approach. Similarly, early screening can lead to a more in-depth and detailed genetic consultation. The latter is vitally important to family members of a newly diagnosed patient. Primary immunodeficiencies are still considered to be relatively rare and are not top-of-mind with clinicians; hence heightened awareness among health-care professionals is extremely important. The incidence of primary immunodeficiency varies according to the deficit itself. By grouping together all immunodeficiencies, it is estimated that the prevalence may be as common as 1:1200⁽³⁾ in the general population and 1:2000 in children⁽³⁾.

The treatment of primary immunodeficiency is complex and includes various therapeutic approaches and can vary depending on the particular type of primary immune deficiency. These approaches can include substitution or replacement of the missing part of a patient's immune system (immune globulin replacement), antibiotics or antifungal treatment, bone marrow transplants, and other forms of management⁽²⁾.

Ten warning signs of Primary Immunodeficiency

- 1 ≥ 4 ear infections per year
- 2 ≥ 2 sinusitis infections annually
- 3 2 pneumonias annually
- 4 ≥ 2 months of antibiotic treatment per year with little effect
- 5 the need for treatment with antibiotics intravenously (IV)
- 6 slow growth in children
- 7 persistent infection by fungi in the mouth or on the skin
- 8 deep and recurring abscesses on the skin or other organs
- 9 2 severe infections per year - hospitalization (e.g.: sepsis)
- 10 family history of primary immunodeficiency

* It should be noted that the clinical signs that can lead to a diagnosis of primary immunodeficiency in adults are similar to those of the child with close exceptions (1). Primary immunodeficiencies can have a highly variable clinical presentation. One or the other of these clinical indications may suggest primary immunodeficiency, without being systemic, however; other signs, such as autoimmune diseases can also lead to the diagnosis.



Contact us

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To leave a message in our voicemail

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To send us your suggestions and questions by email

www.cipo-apiq.ca

- For more information about the APIQ
- To find about our services
- To participate in our educational days and training
- To become a member
- To volunteer
- To donate*

* The APIQ is a registered charity to issue tax receipts to donors.



A BETTER life
for 700 existing patients
and for 700
still not known



Association des Patients
Immunodéficients du Québec

1 Notarangelo LD, Fischer A, Geha RS, et al.; International Union of Immunological Societies Expert Committee on Primary Immunodeficiencies. J Allergy Clin Immunol. 2010;125(3):771-773

2 McCusker and Warrington, Primary Immunodeficiency, Allergy, Asthma & Clinical Immunology, 2011:7 (sup 1):S11

3 Boyle JM, Buckley RH: Population prevalence of diagnosed primary immunodeficiency diseases in the United States. J Clin Immunol. 2007, 27:497-502.

1 Arkwright and Gennery, Ten warning signs of primary immunodeficiency: a new paradigm is needed for the 21st century, Ann. N.Y. Acad. Sci. 1238 (2011) 714

Our Mission

The goal of the Association des Patients Immunodéficients du Québec is to contribute to the improvement of health and quality of life of people with immunodeficiencies.

About the APIQ

APIQ is a non-profit organization that brings together patients with immune deficiencies as well as patients with hereditary angioedema, their families and health care professionals concerned with these diseases.

Our association was founded in 2004 as a result of the vision and dedication of patients with immune deficiencies, some of whom were to become the founding administrators of the Québec division of the Canadian Immune Deficiencies Patient Organization (CIPO). As a result of their sustained efforts and their firm desire to provide additional services to members, the group founded the Association des Patients Immunodéficients du Québec (APIQ) in 2012.

In short, the APIQ works with a Scientific Committee and other groups of patients around the world to raise awareness of immune deficiency and angioedema and to promote early diagnosis and to defend the interests of those affected.

Immune deficiency and hereditary angioedema are rare diseases with the common link of being deficient in a component of the immune system. In both cases, the treatment of these patients depends on blood-derived products.

Our goals and services

Inform

APIQ wants to offer to immunodeficient patients, families, and healthcare professionals, medical information on the causes, symptoms, and treatment of immune deficiencies through:

- our Web site
- our educational days
- our training workshops

Support

APIQ wants to provide patients and their families the support and sponsorship to allow them to better address their illness and achieve a better quality of life.

Defend

APIQ wants to educate the medical community, governments, suppliers of goods and services and the general public about the concerns of people affected by immunodeficiency and to defend their rights and access to treatment.

Join us!

The Association des Patients Immunodéficients du Québec provides support and services to the following people:

- people with immune deficiency;
- people with hereditary angioedema;
- the family and caregivers of people affected by this disease;
- health care professionals dedicated to the improvement and quality of life of people with immunodeficiencies.



Register on-line at
www.cipo-apiq.ca



Free Membership



Our Values

The Association des Patients Immunodéficients du Québec is determined to promote the following values:

Mutual assistance and solidarity

We want to make a difference in those who are affected by immunodeficiency; our intention is to achieve this through mutual assistance and solidarity projects.

Commitment and respect

We believe it is essential to be concerned for immunodeficient patients and their quality of life. This is why we are committed to keeping you informed, to offer you support services and to defend your rights with various decision-making bodies.