Canadian Pemphigus and Pemphigoid Foundation

The CPPF is a newly established organization that helps Canadians with pemphigus or pemphigoid achieve a better quality of life.

Our activities include:

- Establishing and maintaining caring and compassionate support groups for patients and their families across the country;
- Providing up-to-date information on effective treatment and coping strategies, and relevant research activities in Canada and around the world;
- Educating and informing the medical community, the Canadian public, government, and other key stakeholders on issues impacting pemphigus and pemphigoid patients and their caregivers in Canada.

CPPF Support Groups

Toronto Pemphigus and Pemphigoid Support Group
Group Leaders: Karen Wong (kw_pemphigus@sympatico.ca) and Rena Sky (rsky@rogers.com)

Ottawa Pemphigus and Pemphigoid Support Group
Group Leader: Victoria Carlan (vc_pemphigus@istar.ca)

Support groups will soon be established in Montreal and Calgary.

For more information on how we can help you, please contact:

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Or visit www.pemphigus.ca.

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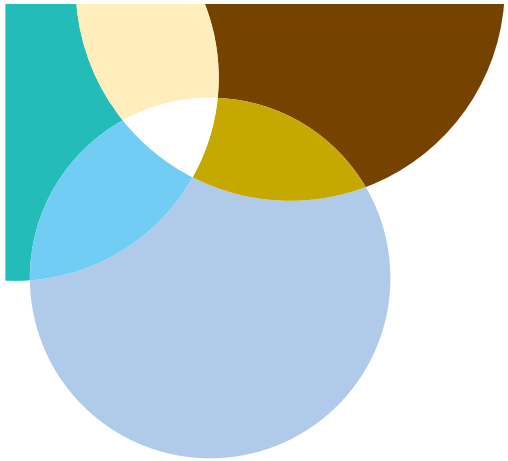
Talecris BIOTHERAPEUTICS

The canadian pemphigus and pemphigoid foundation

An organization supporting patients, caregivers and the healthcare community.



About Pemphigus and Pemphigoid

Pemphigus is a group of rare, autoimmune diseases of the skin and mucous membranes. Auto-antibodies are produced and attack desmoglein - the "glue" of the epidermis that keeps the skin intact. When this happens, the skin cells become separated from each other. This causes burn-like lesions or blisters that do not heal. In some cases, these blisters can cover a large area of the body. It can be fatal if left untreated and the blisters spread and become infected. Early diagnosis is important and aggressive treatment strategies are often needed.

There are several different types of pemphigus including Pemphigus Vulgaris (most common), Pemphigus Foliaceus and Paraneoplastic Pemphigus (rarest).

Pemphigoid is also a group of rare, autoimmune blistering diseases. There are two major forms – Bullous Pemphigoid and Cicatricial Pemphigoid. The type of pemphigoid one has depends on which auto-antibodies are produced and in which layer of the skin blisters occur.

Bullous Pemphigoid patients have itching that may be painful with blisters appearing mostly on the abdomen, back, arms and legs. Cicatricial Pemphigoid lesions usually occur on mucous membrane surfaces. The gums are commonly affected and eye epithelium (cornea and conjunctiva) is affected in up to one third of cases.

Pemphigoid is usually seen in the elderly. As with pemphigus, if left untreated it can be fatal.

What are autoimmune diseases?

Our immune system protects us from infection and disease. However, if you have an autoimmune disease the antibodies that your immune system produces to fight off bacteria, viruses etc., are attacking the body's own cells by mistake. Autoimmune diseases are chronic and the course they take is often unpredictable.

Diagnosis

In general, a diagnosis will be based on the presentation of important features (i.e., 'blistering' lesions) and a skin biopsy. A special immune test, known as direct immunofluorescence, is taken from a separate skin biopsy and is useful to confirm the diagnosis. Sometimes, the antibody titre count is also used to confirm the level of activity of the disease. The antibody titre count is a blood test that measures the level of the protein that is causing the condition. Once diagnosed, the patient can begin working with their healthcare professional to determine the best treatment plan for them.

Treatment Options

There are a number of medications and therapies available to patients:

- Corticosteroids (e.g., prednisone) are most often used to get the disease "under control". It is not uncommon to use it in combination with other treatment options in order to reduce the dose of this medication. If used for prolonged periods of time, the side effects can be severe.
- Immunosuppessants such as azathioprine (Imuran®), mycophenolate mofetil (CellCept®), mycophenolic acid (Myfortic®), cyclophosphamide (Cyotxan®), and cyclosporine (Neoral®) are also used. These drugs help suppress the part of the immune system that triggers the production of auto-antibodies. While it takes time for these medications to work, they have been successful with many patients.
- Other therapies used include intravenous immunoglobulin (IVIG), plasmapheresis and a select number of biologics such as rituximab, infliximab, and etanercept.
- Other drugs used with varying degrees of success include dapsone, gold injections, methotrexate, tetracycline, minocycline, doxycycline and niacinamide.

To date, there is no single medication or combination of medications and therapies that will guarantee remission. (Remission is defined as a state in which a patient has had no lesions while off all therapies for at least two months.) What works for one person, might not work for another. It is, therefore, important that patients become knowledgeable about their options and work with their dermatologist and other healthcare professionals to determine the most appropriate strategy.