

ADVOCATING FOR CHANGE

#MAKELUPUSVISIBLE #LETSTALKLUPUS



Together let's make lupus visible!

THE IMPACT OF LUPUS AT WORK AND IN DAILY LIFE

44%

Reported lupus impacting their daily life, including the ability to care for themselves or their family

23%

Had to be away from work for more than 25 days due to lupus

36%

Experienced between 1 and 3 flares in a 12 month period

48%

Family members had to take time off work to help care for their loved one living with lupus

EMOTIONAL IMPACT OF LUPUS

FRUSTRATION

Before a diagnosis was established, patients were often labelled hypochondriacs, lazy, or just tired by their family and GPs. Patients felt frustrated, misunderstood, and mislabelled.

UNHELPFUL GP'S

Patients who were diagnosed by their GPs complained about a lack of empathy and disease knowledge. They expected an expert who could tell them exactly what was wrong.

RUNNING AROUND TO SPECIALISTS

They felt they were waiting for appointments for specialists and being tossed around the healthcare system until a firm diagnosis was made.

LACK OF EFFECTIVE TREATMENT

Once diagnosed, patients were often told that the treatment they were on may or may not work. There was a perception that lupus does not get enough attention in research and drug development despite a lack of treatments.



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Patients with lupus face a large emotional burden due to the chronic nature of their disease.

ANXIETY & DEPRESSION

Most physicians mentioned an underlying depression in their patients because of the chronic nature of lupus.

WORRY

Often patients "complain" to the rheumatologist about pains and concerns. Due to the amorphous characteristic of the disease, they worry everything new is their lupus becoming active.

UNCERTAINTY

Unlike rheumatoid arthritis where some level of disease progression can be expected, lupus is unpredictable and patients must deal with the uncertainty of their prognosis.

TREATMENT & PATIENT EQUITY

For the first time ever there has been advancement in the lupus treatment development space which is great news! with these new treatments comes new challenges. We believe...

All Canadian lupus patients should have easy and equitable access to lupus specific drugs.

PATIENT
EQUITY

Coverage and access to treatment is critical to ensure Canadians living with lupus are able to maintain productivity.

PATIENT
CARE

Delays to access for patients can be detrimental to their health and therefore drug reviews need to be conducted in a timely manner.

PATIENT
RIGHTS