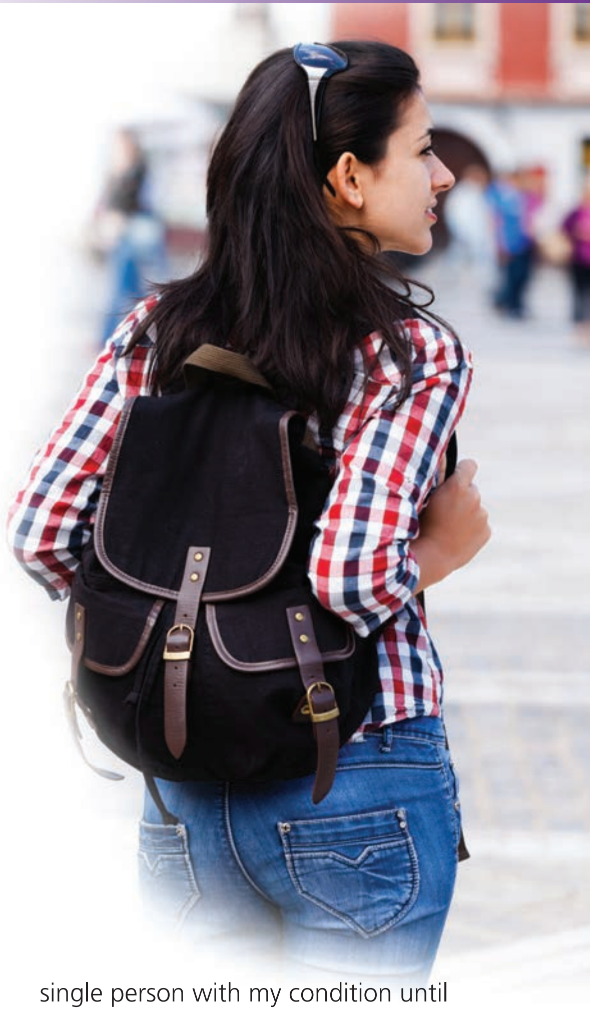
Kayla's story:

Living with chronic idiopathic urticaria

Meet Kayla, a bright 20-year-old university student living with chronic idiopathic urticaria (CIU), a dermatological condition that affects one per cent of the population. CIU is defined as the prolonged occurrence of wheals, hives and itching with no obvious cause.

Interview by Sheri Pilon



Tell us about yourself and where you live.

I grew up in Pictou County, Nova Scotia, but I am living in Antigonish while attending St. Francis Xavier University. I enjoy being active and advocating for patients with CIU.

How do you manage your condition?

I have lived with CIU since I was six years old. I was diagnosed at the age of 10 and was prescribed antihistamines, and now also use an immune-suppression medication as well as antibody injections. I eat healthily and avoid foods that are high in histamine.

How does your condition influence daily living and personal relationships?

I get tired easily when I am having a flare, which is a result of the combination of medications, having hives and not being able to sleep. My family and friends have been impacted, as activities as simple as a road trip need to be carefully planned in case of a medical emergency. The most difficult aspect of my life is building friendships, since you can be labelled as "unreliable" due to the spontaneity of CIU. It is also hard to commit to a job or school.

Have you ever been on the receiving end of stares?

I have been stared at and tormented many times. Some CIU patients, like me, suffer from angioedema (rapid swelling of the skin), which can be disfiguring and embarrassing.

Tell us about the education and support you have received.

At first, I had to pursue counselling on my own. Today, I have an amazing, supportive allergist who is genuinely interested in educating patients and helping them develop a healthy quality of life!

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The CSPA says you are skin warrior. When and why did you decide to speak out about your condition?

CIU causes financial difficulties, mental pain, constant physical pain and significant loss of relationships. I began speaking out about CIU when it began taking over my life. After a semester of university, I had to take a medical leave to regain my physical health and also to focus on my mental health. University can be hard, and when you throw a disabling chronic illness into the mix, your life can become a mess! I didn't know a single person with my condition until I was 18. Afterwards, I decided it was time to start building awareness to perhaps prevent others from having the same struggles.

Tell me about a time when CIU got in the way of doing what you wanted.

CIU has prevented me from doing many "normal" things. Simply going to the beach can be difficult, since the heat is a major trigger for me. My medication also prevents me from staying in the sun for long periods.

Where do you see yourself in 10 years from now?

I would like to have completed my masters in either social work or public health. I hope to host a national CIU conference, establish a non-profit organization to support CIU patients and have a career that I love. CS