

PNH Review

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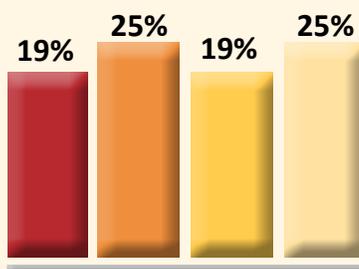
Ask the Expert

What You're Telling Us

Our new poll feature on pnhca.org has been taking the pulse of the Canadian PNH community for the past few months. Our first question asked what features you're looking for on our website. The majority of readers are looking to share their experiences living with PNH, as well as receive information on treatment options. Tips from experts on how to live well with PNH were also requested, as well as the option to act as a mentor to newly-diagnosed PNH patients.

We are grateful for your feedback, and look forward to continuing to grow the website into a useful tool for everyone in the PNH community.

Stay tuned for next month's poll!



Tips from experts on how to live well with PNH

Sharing my experience living with PNH with others

Acting as a mentor to newly-diagnosed PNH patients

Info on treatment options for PNH

Where are they now?

We recently caught up with Toronto resident Hilary Handley, over one year after starting treatment for PNH.

Toronto resident Hilary Handley is among an estimated 90 Canadians living with PNH (paroxysmal nocturnal haemoglobinuria). After the initial onset of symptoms, Hilary began to feel her body deteriorate and her quality of life diminish. Due to haemolysis, her red blood cell levels decreased and caused extreme fatigue and shortness of breath. Hilary lived every day in fear of having a stroke, heart attack, organ failure, or dying of a blood clot.

A life-saving but costly treatment for PNH called Soliris was approved by Health Canada in 2009. A lucky few patients received funding for the drug through private insurance or through exceptional access programs, but most patients – including Hilary – did not have access to Soliris, either through private insurance or through their provincial drug plans. But she couldn't just stand by and wait for something to happen, so with her family beside her, she became an advocate.

Starting in June of 2010 and throughout 2011, Hilary and many others urged the Ontario government to act immediately to ensure that all PNH patients had access to Soliris through provincial funding. In July of 2011, all provinces (except for Quebec) signed a groundbreaking agreement to provide Soliris to all Canadians with PNH. Hilary received her first infusion of the drug the following month. "I was thrilled and relieved when I heard the news. I haven't really stopped smiling!" Hilary recalls.

Today, Hilary says she feels great. She is now able to work full-time, and even is taking an intensive cardio exercise class. "My life has pretty much gone back to normal, I consider myself a lucky person," Hilary says. "I now just live my regular life."

Looking back on her fight for access to Soliris, Hilary expresses her appreciation for the support of her husband, family, friends and all the people in her neighbourhood who wrote letters and signed petitions. Her husband practically stopped working to search for ways to help her, and her close friends accompanied her to appointments and blood transfusions. "You really need a supportive network of people to talk to, someone to go to the doctors with you, and listen to you."

When it came to adjusting to life on treatment, Hilary expected to feel better instantly. While she did feel the effects of treatment right away, it took some time for the physical benefits to catch up with the psychological "high" of being on treatment she knew would save her life.

"After about six months of treatments, I felt that I was on track again." Looking ahead, Hilary says she's excited about the future.



EDITOR'S NOTE: If you (or someone you know) have PNH and are having trouble accessing treatment through either private or public funding, please contact us at info@pnhca.org.

Living Well with PNH

We asked our PNH expert, Dr. Richard Wells, how Canadians living with PNH can best cope with their condition.

Here's what he had to say...

To enjoy a better quality of life with PNH, some specialists advise living as healthy a lifestyle as possible, by eating a healthy diet and drinking lots of water. Listen to your body and rest when you need to. Pay attention to your symptoms, and if your condition changes or worsens, contact your physician.

One of the best coping mechanisms for patients is talking about your disease. Try not to be afraid of talking about PNH with your family or friends. Once those close to you have a better understanding of the disease, they can provide emotional support, as well as help with your everyday tasks.

To share your tips for coping with PNH and its symptoms, send your suggestions to info@pnhca.org or [join our forum](#).



In the coming months, we will be introducing a special **Guide to Living Well with PNH!** We would appreciate submissions in the form of tips, advice or personal experiences.

PLEASE NOTE: The information in this newsletter is intended for general knowledge only and is not to be substituted for medical advice. Please consult with your medical practitioner for further information regarding your personal circumstances.

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What's Happening?

Website Updates

The Canadian Association of PNH Patients website has been refreshed! Our **online home** has been updated with new content and exciting exclusive features, including this eNewsletter and a discussion forum where you can connect with others in the community and share your experiences with PNH. Be sure to check the site regularly for new patient stories, Q&As with Canadian PNH doctors, and much more. If you have a story to share, please [contact us](#).

Support New Zealand PNH Patients

In New Zealand, PNH patients are being denied access to innovative drugs like Soliris, putting lives at risk. To build awareness and support for New Zealanders living with PNH, an online petition has been created, with a goal of reaching 25,000 signatures. Your urgent help is needed to pressure the New Zealand government to provide immediate and lifelong access to Soliris for PNH patients who need it! Please take a minute to sign the petition by [clicking here](#) and sending the link to your own network.

ask the expert

We've added an Ask the Expert feature to the PNH website! [Click here to see it!](#)

Can my PNH be cured?

The only known curative treatment is a bone marrow transplant. However, well-matched donors are often difficult to find, and the procedure carries a significant risk with half the patients dying and at least another third suffering from rejection complications.

There is, however, a treatment for PNH that effectively prevents the premature destruction of red blood cells and thereby significantly reduces the development of life-threatening complications such as blood clots (strokes, heart attacks) and kidney failure. Eculizumab (Soliris) allows a patient's life expectancy to return to that of a healthy person. Soliris is administered by infusion every 14 days by a licensed health care professional at a health care clinic, physician's office or infusion clinic, or even the patient's own home for the duration of the patient's life.

Questions, comments or ideas for the next issue? Please send us an email at info@pnhca.org.