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Living Well with PNH

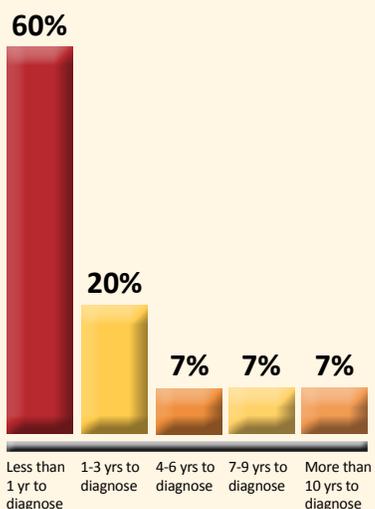
What's Happening?

Ask the Expert

What You're Telling Us

Our latest poll question on www.pnhca.org asked **how long it took individuals to be diagnosed with PNH after first experiencing symptoms. Most patients (60%) were diagnosed in under a year. Next, 20% of respondents took one to three years to be diagnosed.** It took the remainder of respondents over four years to be diagnosed: 7% of patients took four to six years, 7% took seven to nine years, and 7% more than 10 years to be diagnosed after exhibiting symptoms, respectively.

Thank you again to those who responded to this survey question. Your votes are helping us to better understand the PNH community in Canada! Please check pnhca.org for our next poll question, and cast your vote today!



Where Are They Now?

When Niagara Falls native Carrie Richards was 18, she was diagnosed with Aplastic Anemia. After living with crippling fatigue and enduring regular blood transfusions, she was rushed to hospital, unable to swallow foods or fluids without severe discomfort. Shortly after this 2005 episode, she was diagnosed with PNH.

Carrie began to feel the effect of the disease on her body, experiencing lower back pain, bloating, depression, indigestion, jaundice, discoloured urine and kidney infections. Her condition deteriorating, she was hospitalized numerous times and she began to realize that her body was shutting down.

When Carrie was first introduced to Soliris, the Ontario government did not fund the life-saving treatment through its public drug plan. At this time, patients without private health insurance were unable to receive the drug through public funding, and only some patients had access to the drug through private coverage. Fortunately, in November 2009, Carrie received her first infusion of Soliris.



The impact of the treatment on her health was immediate and dramatic. "My health almost instantly improved before the end of my first infusion," Carrie recalls. Despite experiencing headaches during the first few days of therapy (a common but temporary side effect of Soliris infusions), she required fewer blood transfusions over time, and even went three years without a single transfusion. Her skin colour returned to a healthy, normal hue and her hemolysis disappeared. "I felt like I could do pretty much anything."

Carrie played a key role in the fight for access to Soliris for PNH patients, as she met with her MPP several times, and shared her story with local media to spread awareness of the issue and put pressure on government decision-makers. In July 2011, provincial governments across Canada made a landmark decision to fund Soliris through their public drug programs. "Ontario announced funding for Soliris on the day before my 29th birthday – it was the best gift I could have ever imagined. I finally felt safe."

More positive life changes came for Carrie in 2013. She gave birth to a beautiful, healthy baby girl named Ava Leigh Morgan by C-section on September 9, 2013 at McMaster University Hospital. Throughout her pregnancy, Carrie continued to receive regular infusions of Soliris at an increased dose, as well as bi-weekly blood transfusions and blood thinners as precautions. "The baby needed more blood than I could provide on my own," Carrie says

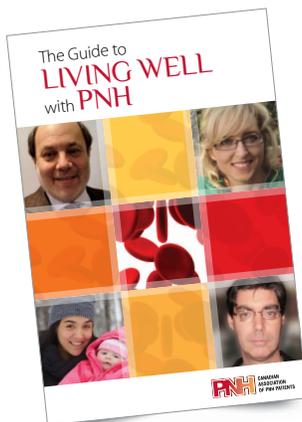
Though Carrie's pregnancy was successful, it didn't come without its challenges. Carrie recalls her pregnancy taking a toll mentally and physically, but a positive attitude helped her manage the condition while pregnant. "Try to keep your head up and know that it gets better." She also credits her partner and family members for their steadfast support. *(continued)*

EDITOR'S NOTE: New Patient Stories Needed! If you have been recently diagnosed with PNH and would like to share your story with the Canadian PNH community, we'd love to hear from you. Please email us at info@pnhca.org today.

Now a proud mother, and enjoying a fulfilling career as a social worker, Carrie has returned to the regular dose of Soliris and her health is back on track. "I'm feeling better than I have in a decade." Carrie's advice to others living with PNH? "Enjoy life and count your blessings daily. Take notice of the world around you, spend your time with positive people, ignore negativity and cherish every day." She describes her future in one word: optimistic. We wish you a happy and healthy future with your family, Carrie!

PNH Guide Now Available!

The Canadian Association of PNH Patients is thrilled to announce the launch of the *Guide to Living Well with PNH*! This important resource, developed by the Canadian Association of PNH Patients, is now available in digital and print formats. Our association would like to sincerely thank the members of the Canadian PNH community (including patients, families, physicians and nurses) for their many contributions to this one-of-a-kind publication! To download a copy of the Guide, please visit www.pnhca.org. Or, to request a hard copy (or copies), please send an email to guide@pnhca.org.



What's Happening?

New Brunswick Catastrophic Drug Program Revealed!

On Tuesday, December 10, the New Brunswick government introduced a bill that will ensure that all PNH patients in the province have access to the life-saving medication Soliris. Bill 27, titled "The Prescription and Catastrophic Drug Insurance Act," will serve as a lifeline to the few PNH patients who had previously fallen between the cracks, left anxiously awaiting a Soliris funding solution from the province.

The new plan will cover drugs listed on the New Brunswick Prescription Drug Program formulary, including Soliris. The plan will be rolled out in two phases – the first being in May 2014, and the second in April 2015. The Canadian Association of PNH Patients applauds the Government of New Brunswick for following through on its promise and introducing this bill, and is eager to see it implemented properly and in a timely manner.

With the enactment of Bill 27, all PNH patients across Canada will have publicly funded access to Soliris – thanks to the relentless efforts of the Canadian Association of PNH Patients and advocates from coast-to-coast, including New Brunswickers Mark Brennan, Gordon Manuel and his son, Justin.

To see the full bill, click [here](#).

New data in PNH patients presented at ASH

In November 2013, the annual meeting of the American Society of Hematology (ASH) featured presentations of new data on patients with PNH, which is helping to improve understanding of the disease. Researchers presented data from a prospective Korean PNH registry, which shows that non-transfused patients (similar to transfused patients) also suffered from elevated hemolysis, debilitating clinical symptoms of PNH, chronic kidney disease, and other life-threatening complications. In a Japanese poster presentation, data from an observational clinical study showed the importance of high sensitivity flow cytometry to enable the reliable detection of PNH cells in suspected PNH patients, and patients with other bone marrow failure syndromes. Finally, researchers established the importance of regular clone size monitoring in PNH patients, in order to detect possible expansion of pre-existing PNH clones.

For more information on these findings, click [here](#).

ask the expert

We've added new questions to the Ask the Expert feature on the PNH website – click [here](#) to see them!

I'm a woman with PNH. Can I have children one day?

While it is possible for women with PNH to become pregnant, it can be dangerous for both the mother and infant. If you have PNH and wish to become pregnant, you should discuss this with your partner, your PNH specialist and an obstetrician who specializes in high-risk pregnancies. It is important to understand the risks before you become pregnant. If you do become pregnant, you should be very closely monitored by your doctors.

If I become pregnant, will my child inherit my PNH?

PNH results from a genetic mutation in a bone marrow stem cell, is not inherited, and therefore it cannot be passed down to children.

This information was prepared by the Canadian Association of PNH Patients and reviewed by: Dr. Richard A. Wells MD, D.Phil., FRCP(C) Hematologist, Sunnybrook Health Sciences Centre and assistant professor, Department of Medical Biophysics, University of Toronto

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