

PNH Review

contents

Where Are They Now?

What You're Telling Us

Living Well with PNH

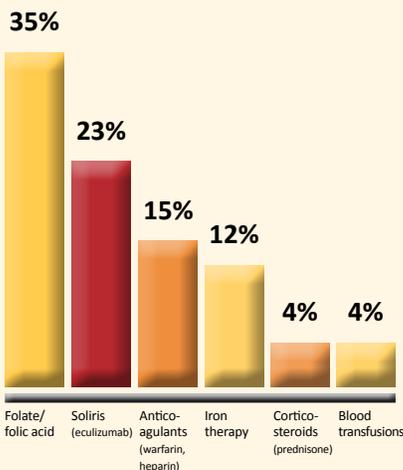
What's Happening?

Ask the Expert

What You're Telling Us

Our most recent poll question on www.pnhca.org asked respondents which treatments for PNH they are currently taking. Thirty-five per cent of patients are currently taking folate or folic acid, followed by 23% who are on Soliris (eculizumab). Next, 15% of respondents are on anticoagulants, like warfarin or heparin, followed by 12% of respondents who said they are on iron therapy. Blood transfusions and corticosteroids (like prednisone) were each mentioned by 4% of respondents.

We appreciate your responses to our survey questions, and we look forward to sharing our next poll question and results with you soon!



Where Are They Now?

Garrett Shakespeare was diagnosed with paroxysmal nocturnal hemoglobinuria (PNH) 15 years ago. Now 26, this rare and deadly disease took its toll on his body and major organs for more than half of his young life.

Once an avid hockey player, Garrett was forced to quit the sport due to the increasing risk of blood clots, and extreme fatigue and abdominal pain. He was prescribed a high dosage of steroids to manage his symptoms, but they were not effective and had countless negative side effects. Cataracts were severely affecting his field of vision, and in June 2011, he experienced a blood clot.

Garrett's doctor prescribed Soliris, but although the treatment was approved for PNH by Health Canada in 2009, he did not have access to this "miracle drug" under British Columbia's provincial drug plan. Like Garrett, many living with PNH were not funded through their province for treatment, and only some received Soliris through private health insurance. Without access to Soliris, Garrett knew his time was running out.



Garrett played a significant role in the fight for access to Soliris for PNH patients, as he urged the B.C. government to ensure that all PNH patients have access to Soliris through public funding. He met numerous times with his provincial government representatives, and shared his story with local and national media. On July 22, 2011, B.C. and all Canadian provinces announced that they would provide public access to Soliris for PNH patients. Days after his 23rd birthday, Garrett received his first infusion of the drug.

"A huge weight was lifted off my shoulders. I began to plan for the future again, instead of worrying about whether or not I would have a future," Garrett recalls. "I used to experience pain all over my body, and I would be so tired and lethargic. Now I play sports a lot more often, and everything is easier," he says of life on Soliris.

Though Garrett has experienced a remarkable transformation since beginning Soliris therapy, the transition to living well with PNH is not without its ups and downs. Garrett's tip for other patients starting their journey on Soliris? "Remember to slow down every once in a while. After I began to feel better, I thought I could do anything, and would often push myself too hard, work too many hours, and exhaust myself," he says. "It's okay to take a day to rest here and there."

Today, Garrett works as a DJ and in scheduling at his local recreation commission, and feels excited about what the future holds.

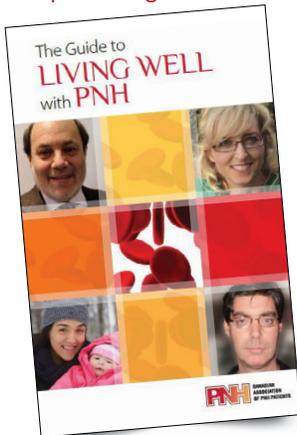
EDITOR'S NOTE: New patient stories needed! If you have been recently diagnosed with PNH and would like to share your story with the Canadian PNH community, we'd love to hear from you. Please email us at contact@pnhca.org today.

Living Well with PNH

Print copies of the PNH Guide
still available!

The Canadian Association of PNH Patients was thrilled to launch the *Guide to Living Well with PNH* earlier this year. We still have print copies of the *Guide* available to be mailed out to PNH patients and caregivers across Canada. This one-of-a-kind resource was developed by the Canadian Association of PNH Patients, and contains expert tips and contributions from patients, caregivers, nurses, and physicians.

To request a print copy (or copies), please send an email to guide@pnhca.org. To download a copy of the Guide, please visit www.pnhca.org.



What's Happening?

**COMING SOON: PNH meetings
in a region near you!**

The Canadian Association of PNH Patients is pleased to announce the launch of a series of regional group meetings for patients and families affected by PNH!

These informative and educational meetings will feature insights and presentations by a local PNH specialist, and information and discussion inspired by our *Guide to Living Well with PNH*. Discussion topics will include the physical, mental and emotional journey with PNH, and sharing personal experiences with the condition. There will also be a discussion on provincial access to PNH treatments, and special advocacy training provided to participants, with a goal of ensuring that PNH patients across Canada continue to have access to life-saving PNH medication.

The first meeting was held in Vancouver on Saturday, October 25, 2014. Thank you to the B.C. families who joined us for this event! We loved meeting you all, and appreciate the time we spent together sharing stories and experiences!

We are in the process of planning for our next sessions, and have scheduled our next regional meeting in Halifax, Nova Scotia on Saturday, January 17, 2015. We invite all PNH families in Atlantic Canada to mark their calendars and join us for this event! We will be joined by PNH expert Dr. Susan Robinson of the Queen Elizabeth II Health Sciences Centre. More to come on this meeting!

Stay tuned for more information on our next regional meetings, or send us an email at contact@pnhca.org! Travel subsidies will be available. If you would like us to hold a meeting in your city, please let us know by sending us an email.

ask the expert

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

To share your tips for coping with PNH and its symptoms, send your suggestions to contact@pnhca.org.

Can exercise play a role in PNH management?

Exercise should be incorporated into your daily routine as a part of maintaining a healthy lifestyle. It is important to find a form of physical activity that will help you live as well as possible with PNH. Before treatment with Soliris, the symptoms associated with PNH may have limited you to simple physical activities. Once you have started and responded to treatment, decreased fatigue and improved energy levels may allow you to increase your daily exercise regimen. Always discuss any new exercise plan with your doctor, and be respectful of your body's limits – particularly as you adjust to life on treatment.



When I start treatment with Soliris, will I get better right away?

Soliris has been shown to prevent the serious health consequences associated with PNH, such as reducing hemolysis and blood clots. Once on treatment with Soliris, patients' energy and overall quality of life can improve in as little as three weeks. It's important to remember, however, that the longer an individual has been living with PNH, the more severe the damage their body has sustained. Vital organs may need more time to restore themselves fully, so be patient and realistic about your recovery time.

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 contact@pnhca.org.