

PNH Patient-Doctor Discussion Guide

Knowledge is key to taking control of your PNH

The more you know, the more you can help to successfully manage your PNH. Here are some questions you may want to ask when talking about PNH with your doctor. Use this guide to take notes on what you learn and things you want to know more about.

Here are some questions to help get you started learning about PNH:

- What is PNH? _____
- What is the underlying cause of PNH? _____
- How is PNH diagnosed? _____
- How is PNH monitored? What do you look for? _____

Your doctor has probably told you that hemolysis is the underlying cause of PNH and that controlling it is key to managing your PNH. Here are some questions to help you better understand the role of hemolysis in PNH:

- What is hemolysis? What does it have to do with PNH? _____
- What are the signs of hemolysis? _____
- How do you measure hemolysis? _____

PNH is a serious, progressive, and life-threatening disease. Here are some questions you can ask your doctor to better understand the effects of PNH:

- What does “PNH clone” mean? What is my PNH clone size? _____
- Can my disease get worse over time? _____
- Can PNH cause permanent damage? _____

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As part of working closely with your doctor and taking an active part in your health care, you may choose to ask your doctor these questions:

- I would like a copy of my lab test results. Would you please help me understand them?

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- How will I know if my PNH is getting worse or better? _____
 - How often will you order lab tests to help track the progression of my PNH? _____
 - What can I do to feel less tired? _____
 - What can I do to help reduce the health risks with PNH? _____
 - How many times will I need to see you each year? _____

These questions may help when talking with your doctor about your management options.

- What are my management options? _____
- What are the benefits of these management options? What does each one do? _____
- What are the risks and downsides of these management options? _____

Additional questions: _____

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Understanding PNH will help you live better with your PNH. Learn everything you can about this disease. Working closely with your physician is key to managing your PNH.

Alexion's OneSource™ program can help to answer your questions too. Just call 1.888.765.4747. Or visit www.PNHSource.com to learn more about PNH.