Special Precautions for PNH

Patients PNH patients need to take a few special precautions including:

Airplane Travel and High Altitudes

These activities can cause a shortage of oxygen which can result in chest pain. Patients with low platelet counts can have bleeding issues when cabin pressure changes. There is also an increased risk of viral infections from recirculated air. Prior to flying or going to regions with high altitude, talk to your PNH doctor. Be sure to drink plenty of water, walk around frequently, and discuss blood thinners for long flights.

Pregnancy

PNH patients can successfully get pregnant and maintain the pregnancy, however there are increased risks for both the fetus and pregnant patient. The pregnant PNH patient may need red blood cell transfusions more frequently and are more likely to get blood clots. Additionally, a patient should be under the care of a high-risk obstetrician and their PNH doctor should be fully informed about all of the possible risks and treatment restrictions. Some PNH treatments can continue throughout pregnancy, however PNH patients should consult with their healthcare team to develop a specific treatment plan which will include increased monitoring. Eculizumab and ravulizumab have been shown to decrease complications during pregnancy.

Surgery

Surgery can make the complement system more active, which can cause hemolysis, increase the risk of blood clots, and can cause serious bleeding in PNH patients with a low platelet count. Surgical patients may need transfusions before surgery. Be sure that your PNH doctor coordinates with the surgeon and their staff before scheduling the surgery. Nearly all PNH patients on treatment should stay on the medications through surgery and if the patient is not on treatment, they should be on an anticoagulant as soon as possible after surgery.