

The Global PNH Patient Registry

Thank You Gift Card - Frequently Asked Questions (FAQ)

What is the Thank You Gift Card?

The Aplastic Anemia and MDS International Foundation (AAMDSIF) wants to thank all participants in the Global PNH Patient Registry for their time and the effort they put into completing the Registry surveys. For this reason, AAMDSIF is offering all eligible participants who complete the baseline surveys the option to select to receive one digital gift card totaling \$75 USD.

How can I earn a gift card?

To participate in the Registry, you must have a diagnosis of Paroxysmal Nocturnal Hemoglobinuria (PNH). To receive a gift card, you must register for the Global PNH Patient Registry and submit each of the baseline surveys: Getting Started, Demographics, PNH Symptoms, Quality of Life (Part 1 and 2), Diagnosis, Medical History, Medication History, Additional Treatment Survey, and Medical Reports. You do not need to complete all of the surveys at one time. You can save your progress as you go and answer the questions at your own pace. Please note, required questions within each survey are marked with a red asterisk (*). Once you have submitted the baseline surveys, the Thank You Survey will become available. Within this survey, you will be asked if you wish to receive this gift and if yes, you will be required to provide recipient information.

When and how will I get my digital gift card?

Once you have submitted the Thank You Survey, it may take 6-8 weeks to receive your gift card. We will be reviewing Thank You Survey submissions on a monthly basis. Once we have reviewed your submission and confirmed your eligibility, we will send the gift card to the email you indicate within the Thank You Survey. The email will come from "The Global PNH Patient Registry via Tremendous" and you may add "rewards@reward.tremendous.com" to your safe sender list to avoid it being caught by a spam or junk filter. Once you get the email, you will click the "View Reward" button, which will open a secure online portal. There, you will be able to select from a list of available gift card options, which vary based on your location. Most recipients will have the option to redeem their gift card as a Virtual Visa (or Virtual Visa International) or other specific retailer. The value will display in both USD and your local currency.

I do not live in the United States. Is the gift card available internationally?

Yes! Using Tremendous, we are able to send digital gift cards to participants in over 200 regions. When you redeem your gift card, the browser will automatically detect your region and display the gift card options available to you. Most recipients will have the option to select Virtual Visa International or other specific retailers, depending on location. The value will display in both USD and your local currency. Please note, there are certain countries that we are unable to send digital rewards to because of government regulations or other legalities. If you live in a country that does not allow for digital gift cards, we will notify you via email after you submit the Thank You Survey. If you have received the gift card email and are having trouble with redemption or using it locally, you may contact help@tremendous.com directly for assistance.

I am the Legally Authorized Representative (Parent/Caregiver) for a person with PNH. Who will receive the gift card?

Once the baseline surveys and Thank You Survey are submitted, the gift card will be issued in the name of the Study Participant and sent to the email specified within the Thank You Survey. If there is more than one Study Participant in one account (e.g. Adult Self-Participant AND Dependent Participant), each participant will be eligible to receive their own gift card (subject to availability in your country of residence).

What if I don't want to receive a gift card?

You are still welcome to participate in the Global PNH Patient Registry. You may choose to volunteer your information and not accept any compensation from the Aplastic Anemia and MDS International Foundation. You will have the opportunity to indicate your preference in the Thank You Survey.

I'd like to join! How do I enroll in the Registry?

Great! To get started, register here: <https://pnh.iamrare.org/>

You will then have the chance to review the full informed consent document and submit your survey responses. If you are already registered, you may log in to your account here: <https://pnh.iamrare.org/>

I received the email but I'm having trouble redeeming the reward. What should I do?

Please contact help@tremendous.com directly with any problems or questions with the gift card redemption process.

What if I have more questions about the Thank You survey or the Global PNH Patient Registry?

You may contact AAMDSIF at (800)747-2820 or email help@aamds.org, or you may reach out to nordregistry@rarediseases.org with any questions.