



## **The Global PNH Patient Registry**

### **Gift Card Incentives for Registry Participation- Frequently Asked Questions (FAQ)**

#### **What is the Gift Card Incentive Program?**

The Aplastic Anemia and MDS International Foundation (AAMDSIF) appreciates the time and effort that participants devote to updating their Registry surveys. This ongoing input is extremely valuable for researchers to understand all aspects of the PNH patient experience. For this reason, AAMDSIF is offering all eligible participants the option to receive digital gift cards. AAMDSIF is currently running two opportunities to receive gift cards:

1. **Thank You Gift Card:** After enrolling in the PNH Registry and completing all initial survey submissions, Participants may opt to receive a one-time gift card of \$150 USD.
2. **Survey Update Gift Card:** Upon completion of available survey retakes, Participants may opt to receive another gift card of \$150 USD up to two (2) times per calendar year.
  - a. To be eligible for this program, the Participant must upload a medical report confirming the diagnosis of PNH.

#### **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 Thank You 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 the Thank You Gift Card and if yes, you will be required to provide recipient information.

To receive a Survey Update Gift Card, you must complete all survey updates when they become available. We ask all Study Participants to retake the following surveys every 6 months: PNH Symptoms, Quality of Life (Part 1 and 2), Diagnosis, Medical History, Medication History, Additional Treatment Survey, and Medical Reports. You will also need to retake the Thank You Survey. Within this survey, you will be asked if you wish to receive the Survey Update gift card.

**How will I know when it's time to update my Registry surveys?**

You will receive automatic email reminders when surveys become available for retakes. The schedule is every 6 months based on the date each survey was first submitted. Additionally, 30 days prior to sending out Survey Update Gift Cards, we will send email reminders to all participants with surveys retakes currently available. The opportunity to receive Survey Update Gift Cards will be offered two times each calendar year.

**When will I get my digital gift card?**

We review Thank You Survey submissions on a monthly basis for the Thank You Gift Card opportunity. Once you have submitted the Thank You Survey, it may take 6-8 weeks to receive your Thank You Gift Card. 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.

Survey Retake Gift Cards will be sent out up to 2 times a year to all eligible participants. We will review the Thank You Survey and confirm your eligibility.

**How will I receive my digital gift card?**

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 other specific retailer. The value will be displayed 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 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 and we complete our review. If you have received the gift card email and are having trouble with redemption or using it locally, you may contact [help@tremendous.com](mailto: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 required surveys 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.

**What if I don't want to upload a medical report?**

If you do not want to upload a medical report, you can choose to opt out of receiving the gift card. You can continue participating in the Global PNH Patient Registry regardless of your participation in the Gift Card Incentive Program. 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](mailto: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 [pnhregistry@aamds.org](mailto:pnhregistry@aamds.org), or you may reach out to [iamrare-help@rarediseases.org](mailto:iamrare-help@rarediseases.org) with any questions.