GLOW
The Global nLPHL One
Working Group

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Patient Advocate Incorporation Policy

Adopted for pilot by the GLOW Executive Committee on October 14, 2025

PURPOSE

In order to fulfill its mission of facilitating international collaboration aimed at optimizing the diagnosis, care, and outcomes for (and with) patients diagnosed with NLPHL worldwide, GLOW proposes the following guidelines for the incorporation and engagement of patient advocates in GLOW activities.

DEFINITION OF PATIENT ADVOCATE

For the purposes of this document, "patient advocate" refers to any of the following:

- A current or former patient diagnosed with NLPHL
- A parent, guardian, spouse, or child who has been a primary care partner during a NLPHL patient's diagnosis, treatment, and/or follow-up
- An employee or designated member of a national or international lymphoma advocacy organization

PATIENT ADVOCATE SELECTION & PREFERENCES

Executive Committee

The Executive Committee will aim to maintain 3-6 active patient advocate members for approximately 4 years per term. The chairs of the Executive Committee will be responsible for the approval and/or removal of patient advocates on the committee.

When possible, patient advocate selection will prioritize diversified patient advocate representation based on:

1. Age group at diagnosis
2. Stage at initial diagnosis
3. Care and/or treatment(s) received
4. Regional representation
5. Patient vs non-patient

Research Committees

Each research committee will aim to maintain 2-3 active patient advocate members for approximately 4 years per term. Research committee chairs will be responsible for the approval and/or removal of patient advocates on their respective committee.

When possible, patient advocate selection will prioritize diversified patient advocate representation based on:

1. Age group at diagnosis
2. Stage at initial diagnosis
3. Care and/or treatment(s) received
4. Regional representation
5. Patient vs non-patient

Patient advocates may simultaneously serve as a designated member on the Executive Committee and a research committee.

ROLES & RESPONSIBILITIES

It is anticipated that patient advocates will spend approximately 1-3 hours per month on the following GLOW activities as warranted:

- Attendance at committee meetings
- Follow-up on committee research, activities, and/or tasks
- Committee correspondence (via email)
- Collaboration on funding proposals and/or fundraising activities
- Collaboration on academic abstracts, publications, and/or presentations
- Completion of research and/or ethics training (if/as necessary)

Examples of anticipated activities include, but are not limited to, the following:

- **Contribute to research design, implementation, and outputs** Provide insights on research priorities, study design, study document development (e.g. consent forms, recruitment materials), recruitment strategies, analyses and interpretation, publications, and communication of research findings.
- **Assist in communication and education efforts** Help develop patient education materials, resources, and communication tools that are accurate, accessible, and culturally sensitive. Help share GLOW updates and research findings with NLPHL (and/or related) communities.
- **Promote patient and public involvement** Facilitate engagement of patients, families, and caregivers in discussions, feedback sessions, and awareness campaigns.
- **Bring feedback from the community** Collect and share lived NLPHL experiences, concerns, and priorities to inform GLOW research and outputs.
- **Ensure accessibility** Identify when GLOW protocols, outputs, or communications may be difficult for patients or caregivers to understand, and work with staff and researchers to implement improvements.
- **Advocate for equity** Identify opportunities for GLOW researchers and patient advocates to address disparities in access to NLPHL research, treatments, and/or appropriate care across geographies or demographics.

At this time, GLOW patient advocate advisory roles are served on a voluntary, unpaid basis. If, and when, funding is available to compensate patient advocate members' time, this guideline will be revisited. No travel will be required, and there are no anticipated expenses to be incurred by patient advocates.