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SPECIAL REPORT

Global nLPHL One Working Group (GLOW) Research Roadmap for Nodular Lymphocyte-Predominant Hodgkin Lymphoma

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ABSTRACT

Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) is a rare, indolent lymphoma lacking an evidence-based standard of care. NLPHL research has been challenging due to its classification, unique features, and rarity. The Global nLPHL One Working Group (GLOW) launched in 2020 to accelerate NLPHL research internationally across all ages and stages and to establish a global standard of care. GLOW identified six core aims and 19 activities in its strategic roadmap to overcome historical research challenges, establish a research pipeline to inform a global standard of care, and disseminate findings. Once its prospective trials launch, GLOW will leverage this roadmap to study other rare lymphomas.

1 | Background

Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) is a rare, indolent subtype of lymphoma that, to date, lacks sufficient data to inform an evidence-based standard of care approach. NLPHL occurs across the age continuum and accounts for approximately 0.3%–1.7% of lymphoma diagnoses, equating to an approximate global incidence of 2500–5800 cases annually [1–5]. It is more often diagnosed in males and at early stages, has a risk for late relapse with a risk for transformation to aggressive lymphoma, and does not typically express CD30 [6, 7].

Historically, patients with NLPHL have been treated on regimens developed for classic Hodgkin lymphoma (cHL), but recent

Abbreviations: cHL, classic Hodgkin lymphoma; COG, Children's Oncology Group; EuroNet-PHL, European Network on Pediatric Hodgkin Lymphoma; GHSG, German Hodgkin Study Group; GLOW, Global nLPHL One Working Group; HL, Hodgkin lymphoma; IAP, immunoarchitectural patterns; LP-IPS, Lymphocyte-Predominant International Prognostic Score; NLPBL, nodular lymphocyte-predominant B-cell lymphoma; NLPHL, nodular lymphocyte-predominant Hodgkin lymphoma; REAL, Revised European–American Classification of Lymphoid Neoplasms; US, United States of America; WHO, World Health Organization.

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research consistently highlights excellent event-free survival and overall survival [3] for patients with NLPHL, indicating an opportunity to explore tailored treatment approaches to spare excessive late effects. Significant variation in therapeutic approaches, systemic therapy regimen intensity, and utilization of radiation therapy (RT) exists globally for patients of all ages. There is a need to better adapt treatment approaches given its indolent nature, frequency of relapses regardless of the intensity of frontline therapy, and associated risks of avoidable, cumulative therapy-related late toxicities [8–10].

To date, there is no standard of care approach for NLPHL due to a lack of robust, uniform prospective data across the age continuum and current exclusion from frontline clinical trials. Age-related outcomes, risk for relapse, and potential for transformation to aggressive lymphoma more than 20 years after initial diagnosis [11–14] have been previously described, but the underlying pathobiology of these clinical observations is poorly understood, and diagnosis remains a challenge [15, 16]. Long-term follow-up data for patients of all ages is needed to inform and balance multiple goals: treatment efficacy, late effects of treatments, and risks for late relapse and transformation throughout the life course.

2 | Historical Research Challenges

2.1 | Classification

As shown in Figure 1, NLPHL has had several classification changes since Hodgkin lymphoma was first described in 1832 [17]. In 1944, after decades of discussions of histological subtypes of HL, Jackson and Parker first described Hodgkin's paragranuloma, now known as NLPHL. This classification marked the first recognition of NLPHL as a distinct clinical entity rather than "early Hodgkin's" [18] and was followed by Lukes and Butler's classification system [19], which serves as the modern basis for HL classification. In 1994, the International Lymphoma Study Group Revised the European–American Classification of Lymphoid Neoplasms (REAL) recognized NLPHL as a distinct subtype [20], and the World Health Organization (WHO) adopted the REAL classification system in 1997 [21]. In 2003, Fan et al. identified and characterized six immunoarchitectural patterns (IAP) of NLPHL [22], thus enabling new lines of research into outcomes. The debate over classification remains, with the International Consensus Classification Clinical Advisory Committee reclassifying NLPHL to NLPBL in 2022 [23], while the WHO maintains the term NLPHL [10, 24].

2.2 | Lack of Funding for Frontline NLPHL Clinical Trials

Increasing understanding of differences in clinical outcomes between (rare) NLPHL and (more common) cHL, as well as a difference in the expression of cell surface antigens, led to the exclusion of patients with NLPHL from frontline HL clinical trials. The introduction of the antibody–drug conjugate brentuximab vedotin, targeting CD30, into clinical trials in the 2000s and its accelerated approval by the United States (US) Food and Drug Administration in 2011 [25, 26] further contributed to the exclusion of patients with NLPHL in contemporary randomized global trials, as cHL expresses CD30 and NLPHL does not. Attempts to open large NLPHL clinical trials, such as the 2011 European Network on Pediatric Hodgkin Lymphoma (EuroNet-PHL)-LP2 study design and the 2016 AllStAGEs study [27], have been unable to launch since 2010. In 2023, a small, randomized Phase II NLPHL trial for adults (NCT05886036) was opened at MD Anderson Cancer Center to compare progression-free survival of mosunetuzumab in patients with NLPHL with that

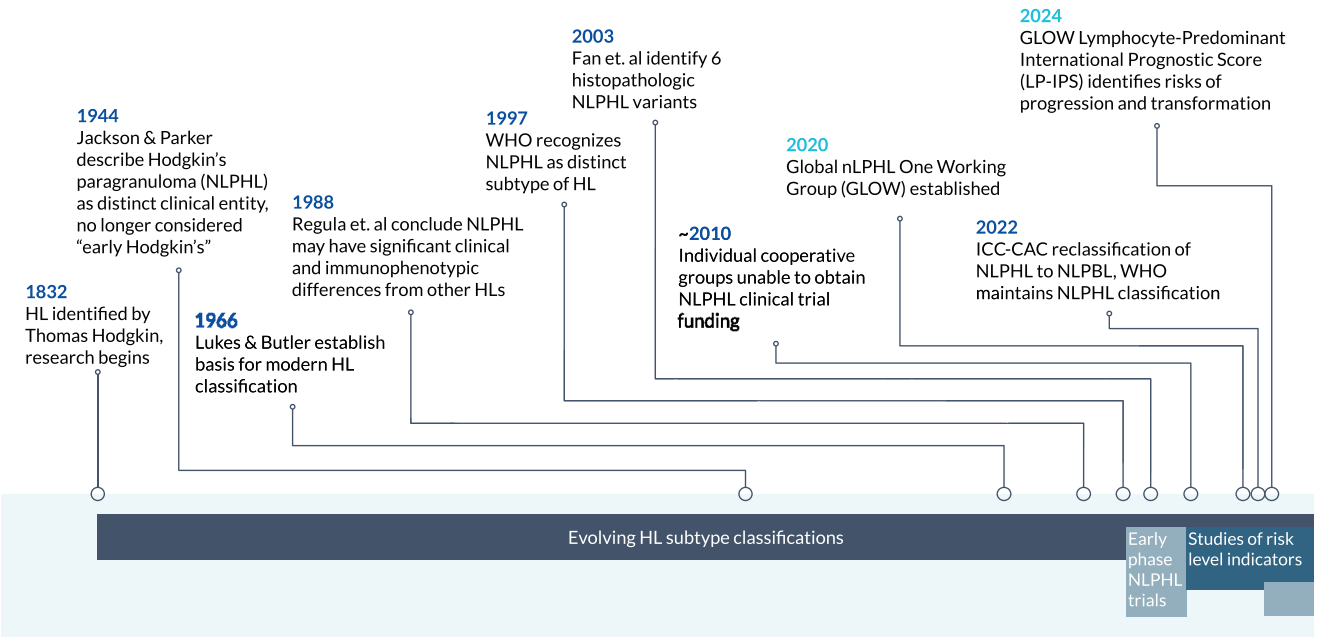

FIGURE 1 | Historical milestones in NLPHL research. Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) has undergone multiple phases of classification within lymphoma classification systems. These classifications and additional understanding of NLPHL have impacted the course of NLPHL research.

of rituximab. As such, the vast majority of patients with NLPHL remain unable to participate in any form of clinical research.

2.3 | Fragmented Research Groups

Historically, pediatric and adult research consortia have conducted clinical trials largely independent of one another, resulting in disparate data collection practices and small, fragmented data sets for this already rare entity [37]. In pediatrics, nonrandomized NLPHL studies were conducted by the French Society of Pediatric Oncology [28], the EuroNet-PHL [29], the Children's Oncology Group (COG) [30], and a British and French collaboration [31] accruing only 27, 58, 183, and 55 patients, respectively. In prior pediatric HL studies such as the COG CCG-5492, patients with NLPHL represented a minority of participants in the trial; CCG-5492 [32–34] accrued 78 patients with NLPHL. Adult research groups have experienced similar challenges in accruing sizable patient populations. Between 1993 and 2009, the German Hodgkin Study Group (GHSG) accrued 108 patients diagnosed with NLPHL in total on its HD7-HD9 trials, 168 in the HD10-HD12 trials, and 195 in the HD13-HD15 trials [9]. Additional Phase II, single-agent studies of rituximab by the GHSG from 2006 to 2007 and Stanford University and Washington University Medical Center from 1999 to 2006 enrolled 29 and 39 patients, respectively [35, 36].

Recent collaborations between pediatric and adult consortia are beginning to bridge this historic separation, and prospective clinical trials across the age continuum would overcome many of the remaining barriers to accruing necessary prospective patient cohorts.

2.4 | Inclusion of Patient Advocates in Agenda-Setting

There has been no formal evaluation of patient advocates' NLPHL care priorities and preferences nor inclusion of patients, care partners, or their research and care priorities in historical NLPHL trial designs. The significance of patient and care partner partnerships in agenda-setting, research, and evaluation processes has been increasingly documented in research, medical, and public health settings in the past 20 years [38–49]. Historical NLPHL research protocols were developed independent of patient and care partner involvement, representing a missed opportunity for advancement in both patient outcomes and in research, though recent (non-NLPHL) lymphoma clinical trial development has successfully included patient advocates. Given the long survival of patients with NLPHL and the variation in risks and benefits with different treatment approaches (e.g., risk of relapse and/or transformation vs. risk for late effects), it is critical to understand patient and care partners' treatment priorities and values and to partner with them in research and clinical agenda-setting. Beyond the need to partner with patients and care partners to effectively establish a standard of care that aligns with patient values, needs, and preferences across the age continuum, the inclusion of patient advocates in research planning and analyses is increasingly a standard requirement by funding agencies, including the US National Cancer Institute.

2.5 | Rare Disease Research

Researchers of rare cancers, particularly in pediatric populations with low overall cancer incidence, encounter unique challenges [50, 51]. First, researchers must collaborate across institutions and internationally to accrue sufficient sample sizes [37]. Inability to overcome sample size limitations may affect the accuracy and and generalizability of findings as well as the number and type of feasible research questions that can be pursued. Likewise, limited biological specimens require researchers to be more selective in the research they pursue.

Second, collaborative research involves planning, coordination, and communication. Before research begins, rare disease researchers must dedicate considerable time to identify collaborators, align objectives and corresponding data elements, execute data use agreements that incorporate local, national, and regional data privacy laws, clean data, and harmonize data. These opportunities for timeline lag multiply considerably with each additional collaborating site. Although the formation of regional cooperative research groups reduces *some* administrative burdens in pooling available cases, rare diseases like NLPHL spanning across pediatric and adult age groups entail significant coordination and communication between and within research groups around the world.

Third, these increased operational and logistical needs require resources. Researchers must budget funds for the shipment and storage of biological specimens and for utilization of participating centers' core resources, which are again multiplied by the number of centers required. Dedicated project management staff and tools are necessary to engage, coordinate, and inform stakeholders as well as to track activities and to effectively communicate findings. As rare disease researchers are able to incorporate wider community engagement, education, and advocacy efforts, and to expand the scope or scale of research projects, it is increasingly prudent to include staff with experience in program management.

3 | NLPHL Strategic Research Roadmap

The Global nLPHL One Working Group (GLOW) launched as a coordinated international NLPHL research hub in 2020 to mobilize NLPHL researchers and advocates to overcome historical challenges in NLPHL research, to study NLPHL across all ages and stages, and to establish a standard of care for all patients diagnosed with NLPHL. As outlined in Table 1, international experts in NLPHL have identified six core aims and 19 activities necessary to address these challenges, to create a coordinated global NLPHL research hub, to establish a comprehensive research pipeline that will inform a global NLPHL standard of care, and to disseminate findings to patients, care partners, healthcare practitioners, researchers, and patient support organizations. These aims and activities were developed collaboratively by NLPHL researchers, patients and care partners, GLOW research committee chairs, and the GLOW Executive Committee with the guidance of GLOW Senior Advisors who are recognized world leaders in lymphoma research. Detailed rationale and progress to date for each core aim and activity are reported in the Supporting Information and Figure S1.

TABLE 1 | Global nLPHL One Working Group (GLOW) NLPHL research roadmap and current status.

Aim	2025 Status
1. Establish a coordinated NLPHL research network	**Complete**
1.1. Establish GLOW	Complete
1.2. Determine GLOW identity, structure, and governance	Complete
1.3. Build scaffolding for GLOW infrastructure	Complete
1.4. Engage NLPHL researchers, patients, and care partners	Ongoing
1.5. Identify funding sources	Ongoing
2. Improve NLPHL diagnostic accuracy	**In progress**
2.1. Create and maintain tissue bank	Ongoing
2.2. Conduct pathology research to improve diagnostic accuracy	Ongoing
3. Standardize core NLPHL research processes	**In progress**
3.1. Harmonize retrospective NLPHL data from pediatric and adult cooperative groups	Ongoing
3.2. Facilitate standardized prospective data collection, central pathology review, and central imaging review	Planning
4. Determine research priorities and strategy	**In progress**
4.1. Understand patient and care partner needs, priorities, and preferences	Ongoing
4.2. Understand the needs and priorities of researchers and healthcare practitioners	Ongoing
4.3. Convene key stakeholders to prioritize research objectives	Ongoing
5. Establish a global standard of care	**In progress**
5.1. Study risk stratification and predictive factors across the age continuum	Ongoing
5.2. Develop and test an NLPHL patient decision aid	Ongoing
5.3. Launch international prospective trials and registry for all ages	Planning
5.4. Investigate longitudinal patient-reported outcomes and quality of life in patients with NLPHL	Ongoing
5.5. Create a global standard of care	On deck
6. Communicate GLOW research findings	**In progress**
6.1. Disseminate NLPHL publications and clinical resources	Ongoing
6.2. Collaborate with advocacy and support groups to create and update resources for patients and care partners	Ongoing

4 | Conclusions

Research in recent decades highlights the need to tailor care approaches for patients with NLPHL, but there is a lack of prospective trial data to inform a global standard of care for both pediatric and adult patients. GLOW addresses previous challenges to conducting necessary research in NLPHL. We hope that the strategic work plan presented in this paper can serve as a roadmap for other international collaborative groups seeking to advance research in their respective fields.

GLOW presents an opportunity to unite critical stakeholders across the world to accelerate progress and establish a standard of care for patients of all ages worldwide with NLPHL. Once the first NLPHL prospective clinical trials are in progress, GLOW seeks to leverage this strategic roadmap, network of lymphoma researchers, and infrastructure to study other rare lymphomas.

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Conflicts of Interest

Graham P. Collins: Honoraria for consultancy and speaker work from: Roche, Takeda, Kite/Gilead, Sobi, Astra Zeneca, SecuraBio, Abvie, ADC Therapeutics, Beigene. Research support from: Beigene, Pfizer, BMS, Amgen, Astra Zeneca. Kara M. Kelly: Served as a nonpaid advisory board member for Seagen and BMS; the institution has received research support from the Children's Oncology Group for its role as scientific steering committee member for a Merck-sponsored study. The remaining authors declare no conflicts of interest.

Data Availability Statement

Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.