

Build it and they will come: the UK HLH network

Rachel S Tattersall ¹ Matthew Collin ² Jessica J Manson ³

1. **Sheffield Teaching Hospitals NHSFT and University of Sheffield, UK**
 2. **Institute of Clinical and Translational Research, Newcastle University, UK**
 3. **University College Hospitals NHSFT and University College London, UK**
- Corresponding author: rachel.tattersall@nhs.net

1. Background

People with Haemophagocytic lymphohistiocytosis (HLH) can present to any medical service. Inequity of access to specialist services, under-recognition, lack of standardised care and a poor evidence base contribute to high mortality. The UK National Health Service (NHS) provides care free at the point of access to 67.5 million population. The NHS is a resource-limited structure but one that provides opportunities to implement uniform practice and to audit real world outcomes in rare diseases.

2. Aims and Methods

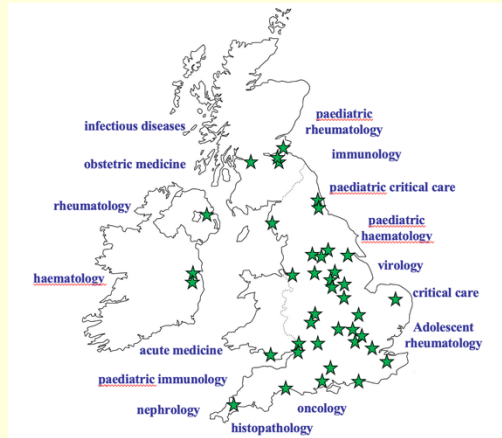
The formation of a multiprofessional, multidisciplinary clinical network - the **Hyperinflammation and HLH Across specialty Collaboration (HiHASC)** www.hihasc.org - enabled its members to work together to drive a national advisory panel (NAP) for real time clinical support, to design a nationally agreed service development strategy, to create a UK-wide education program and to drive a matched research strategy

3. Conclusions

Here we describe a real-world approach to the development of HLH services in the UK universal healthcare system. The work has been done by interested clinicians volunteering their time. Further work is needed to prospectively evaluate and refine this approach

The professional Network - HiHASC

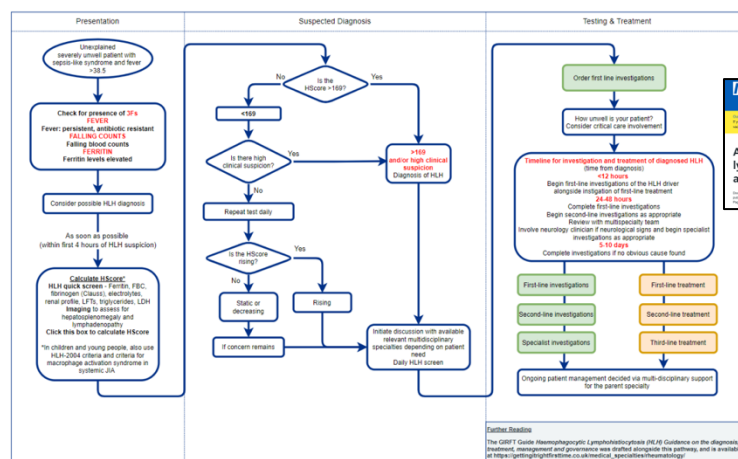
Over 6 years, HiHASC membership increased fifteenfold (currently 228 members) with multiprofessional, all-age representation. It is supported by the charity Histiouk - www.hihasc.org. Bimonthly virtual meetings deliver accessible education and professional networking with small group working to drive specific projects.



Influencing UK Strategy for people with HLH

GETTING IT RIGHT FIRST TIME : GIRFT pathway for managing HLH in the NHS

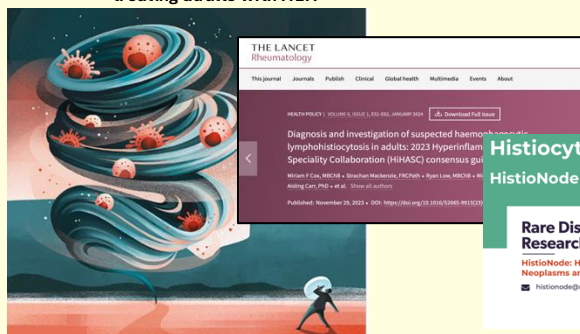
Available at: <https://gettingitrightfirsttime.co.uk/wp-content/uploads/2024/07/HLH-Pathway-FINAL-V1-1-July-2024.html>



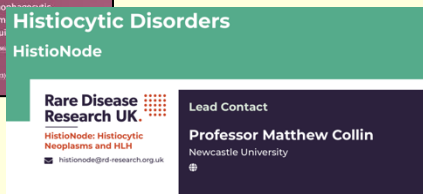
HiHASC has delivered the NHS "Getting It Right First Time" program for people with HLH, a national pathway that mandates care, signposts additional resources, summarises evidence and confirms medicines availability.

Improving the Evidence Base: Guidelines and Histonode Research

HiHASC has delivered evidence based guidelines for treating adults with HLH



HiHASC facilitated the research collaboration HistoNode with successful £1.2 million funding with a focus on multi-site, national patient recruitment to set up a biobank and nested studies.



The HLH National Advisory Panel (NAP)

Through collaboration between two specialist centres, terms of reference and governance procedures were developed to deliver a multi-disciplinary HLH NAP. Meeting frequency increasing from monthly to weekly over a 5-year period due to high demand. The NAP is open to any clinician and provides emergency advice between meetings. Referrals continue to climb; 83 patients discussed in 2022 and 111 in 2023

References

Getting It Right First Time. Haemophagocytic Lymphohistiocytosis (HLH) Guidance on the diagnosis, treatment, management and governance. Getting It Right First Time, 2024 <https://gettingitrightfirsttime.co.uk/wp-content/uploads/2024/07/HLH-Guide-final-version-v1.1-1-July-2024.pdf> (accessed Sept 23, 2024).

Cox MF, Mackenzie S, Low R, et al. Diagnosis and investigation of suspected haemophagocytic lymphohistiocytosis in adults: 2023 Hyperinflammation and HLH Across Specialty Collaboration (HiHASC) consensus guideline. *Lancet Rheumatol* 2024; Jan 6(1):51-62