HISTIOCYTOSIS UK

No-one should die of Histiocytosis

Volunteering Opportunity

Histiocytosis UK are seeking Expressions of Interest from Parents, Patients and Professionals for positions on the Advisory Panel to the Board of Trustees.

Advisory Panel Members are appointed for one year, attending a minimum of 2 meetings (one in person and one virtual). Their role is to help steer the charity to ensure that no one should die of histiocytosis and to represent patients and professionals in the histiocytosis field. Advisory Panel members can apply to join the Board of Trustees (for two years). The current vacancies have arisen because some members have come to the end of their terms of service.

The APM appointments are to the General Portfolio Team, we would also be particularly interested to hear from those who would be happy to take up either Financial/Banking or Scientific Research Portfolios should they be offered the opportunity to join the Board of Trustees.

Who are HistioUK?

Since thelaunch of Histio UK in September 2014, we have developed into a successful Research & Information Support network. We aim to help health professionals with diagnosis and treatment awareness of histiocytosis in children, young people and adults and foster a network of clinical champions. We also support people with histiocytosis as well as their families and supporters.

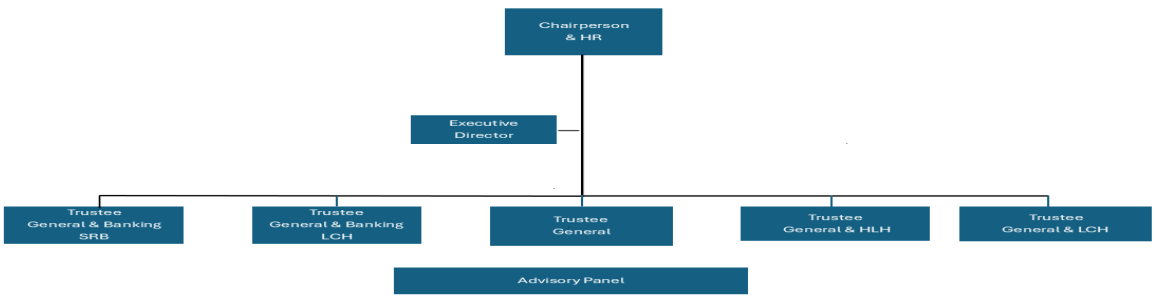
Histiocytosis UK is part of the international campaign for the promotion of awareness, research and medical knowledge globally. ***No one should die of Histiocytosis***

We are growing a network of volunteers around the country who are increasing awareness information to schools, GP surgeries and hospital waiting rooms.

We want to develop our growing number of volunteers into a more cohesive force and recruit Histio Champions around the country to complement the work of the Clinical Champions already in place.

Our Structure

We are a Charitable Incorporated Organisation registered in England & Wales Reg No,158789.
Our responsible Officer is the Executive Director and we are governed by our Trustees who are led by our Chairperson & Deputy Chairperson. Research is scrutinised and recommended by our Scientific Research Board.



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Meet Our Current Trustees:

Paul Kontoyannis, Chair - Paul established The Histiocytosis Research Trust with Dr Jon Pritchard in 1991. The two men met in 1982 when Paul took his 40-day old son, Nikolas, to Great Ormond Street Hospital. Nikolas was diagnosed with multi-system LCH and given only a 30% chance of survival.

Professor Peter Beverley, Vice-Chair and Chair SRB. - Peter trained as a physician but carries out research in immunology. His research focuses on understanding immunological memory and how the properties of memory cells contribute to protective immunity and disease pathogenesis. He trained at the National Institute for Medical Research in London and after postdoctoral work at Sloan Kettering Institute in New York, joined the Imperial Cancer Research Fund Tumour Immunology Unit in 1973, becoming Director in 1992. From 1995-2005 he was the Scientific Head of the Edward Jenner Institute for Vaccine Research at Compton in Berkshire and subsequently worked on immunity to tuberculosis at Oxford University until 2014. He is currently a Visiting Professor at Imperial College London. He has published over 200 papers in refereed journals and served on committees of the Medical Research Council, the Wellcome Trust, several other UK medical charities and international bodies. He has been involved with the Nikolas Symposia on the Histiocytoses as organiser and advisor since 1989 and has been a Trustee of the Histiocytosis Research Trust, now Histiocytosis UK, since its inception. He was elected a Fellow of the Society of Biology in 2003 and the Academy of Medical Science in 2003.

Professor Matthew Collin, Vice-Chair Scientific Review Board
Graduated from Oxford University Medical School in 1995, having obtained a DPhil in Immunology in 1992. Completed specialist training in Haematology and Transplantation in Newcastle in 2004 and was appointed as a Consultant Haematologist in 2006. He has followed a combined clinical and research career initially funded by Leukaemia and Lymphoma Research through a Clinician Scientist award (2002) and Bennett Senior Fellowship in Experimental Haematology (2006). Since 2006 he has been a Clinical Senior Lecturer at Newcastle University. He became Professor of Haematology and Director of Adult Bone Marrow Transplantation in 2010.

Peter Bienenstock - As a baby, Peter's daughter, Lea was diagnosed with multi-system LCH and also developed haemophagocytic syndrome. After a year of chemotherapy, there was little hope but doctors at the Nikolas Symposium in Greece developed a salvage therapy which was successful. Within weeks, Lea had left hospital. Now a healthy adult, Lea's story shows the value of working together to find treatments and ultimately a cure for all histiocytosis patients.

Dr Vasanta Rao Nanduri MBBS, DCH, MRCP, FRCPCH, MD (research)
Dr Nanduri is a Consultant Paediatric Oncologist and Endocrinologist in the UK.
She is recognized internationally as an expert in histiocytic disorders with special expertise in the long-term consequences of Langerhans cell Histiocytosis including endocrine deficiencies, neurodegeneration and the impact on Quality of life.
Dr Nanduri has authored over 45 peer-reviewed publications, >100 abstracts and several book chapters.
She has been a Guest speaker at several international conferences and been invited to participate in the Nikolas Symposium.
Dr Nanduri is the incoming 2025 President of the international Histiocyte Society.
She has previously been on the Education and LCH Steering Committees and Member-at-Large and Treasurer on the Board of the Histiocyte Society.

She is the Chief Investigator for UK for the LCH IV trial, Lead for Stratum VII and was UK CI for HLH 2004.
She is a Trustee and Medical Advisor for Histio UK and a Board member of ECHO (European Consortium for Histiocytoses) and is on the UK National Histiocytosis Advisory Panel.

Dr Rachel Tattersall - is an Adolescent Rheumatologist working across both Sheffield Children's Hospital and Sheffield Teaching Hospitals She is passionate about improving the diagnosis, treatment and research about haemophagocytic lymphohistiocytosis (HLH)across the life course and co-chairs and delivers the UK HLH Network an award winning multi-professional network providing HLH care UK-wide She qualified in Medicine in 1995, trained in adult rheumatology in Yorkshire and in paediatric rheumatology in Nottingham taking up consultant post in Sheffield in 2008.

- **If I am interested, what do I need to do?**

Just complete the Volunteer form follow this link**:** **https://www.histiocytosisuk.org/volunteer/**

Closing time & date for this round is **16th December 2025** We will notify you of your application and outcome.

This will be a two-interview process:

1st Interview via video 10th February 2026 AM & **2nd** Interview in person London 17th March 2026 AM

Restrictions:

- You must be over 16years of age.
- You must not act as a trustee if you are disqualified. Disqualifications included:
- being bankrupt or having an individual voluntary arrangement (IVA)
- having an unspent conviction for certain offences (including any that involve dishonesty or deception)
- being on the sex offenders' register
- **What qualities do Advisory Panel Members need?**

A commitment and empathy for patients of these terrible disorders and a willingness to ensure that NO-ONE should die of Histiocytosis. Good meeting attendance and a willingness to actively be involved.

- **Can I claim expenses?**

These roles are unpaid, reasonable expenses can be claimed for attendance at meetings at: Standard 2nd Class rail travel and mileage at HMRC rates.

We look forward to hearing from YOU!