

HISTIOCYTOSIS UK NEWS UPDATE

Together we will find a cure



IMPORTANT message from the Histo UK Team

We are immensely grateful to you all for making our research and information initiatives possible, without your continued support we would be unable to continue our work in histiocytosis.

“So please ensure that you do not leave us this way”

The General Data Protection Regulation (GDPR) is a set of EU regulations that will be enforceable from 25th May 2018. **This means we will be unable to send you further invitations to Conference, Newsletters and or information on the latest Histiocytic disease developments after this date unless you request to opt-in to receive them**

by contacting us via email, so reply **Yes** to this email or to Histo@histioUK.org, in the Subject box please enter

“Keep me on your list”

Thank you.



4th Histo UK Conference & Forum

Invitation to join Histo UK & the team at the 4th UK Histiocytosis Forum November 2018 London

Are you affected by Haemophagocytic lymphohistiocytosis (HLH)? If so, please register and book this date in your diary 8th November 2018 as the 4th Annual Forum on Histiocytosis will be taking place in London and places are limited. The meeting will include an update on targeted treatments for HLH, HSCT for primary HLH and controversies in the diagnosis and management of HLH in adults as well as the outcomes of a BMT post-transplant late effects study on HLH. To register your interest please contact: histio@histiouk.org.

13:15 Registration

Co-Chairs: **Prof. Mathew Collin** BM BCH DPhil MRCP FRCPath and **Dr Claire Booth** Honorary Consultant in Paediatric Immunology, Great Ormond Street Hospital.

13:30-An update on targeted treatments for HLH. **Dr Despina Eleftheriou**. Senior Lecturer in paediatric rheumatology. UCL Great Ormond St. Institute of Child Health

13:50-IFN γ neutralisation in HLH: the emapalumab clinical development. **Dr Cristina De Min**. CMO, Novimmune

14:10-Is cytokine profiling practical and useful? **Dr Kimberly Gilmour**. Clinical Scientist in Immunology, Great Ormond Street Hospital.

14:30-Discussion of topics raised

15:15-HSCT for Primary HLH – Outcomes and survival. **Dr Austen Worth**. Consultant Paediatric Immunologist, Great Ormond Street Hospital.

15:45-HLH in the adolescent population. **Dr Ben Carpenter**. Consultant Haematologist UCLH, London

16:05-Controversies in the diagnosis and management of HLH in adults. **Dr Nichola Cooper**. Consultant Immuno-haematologist, Hammersmith Hospital/Imperial College

16:35-BMT post-transplant late effects study on HLH. **Dr Kanchan Rao & Anupama Rao**. Gt Ormond St Hospital

17:05-Discussion of topics raised. **17:30**-Close



Partnership Projects

PRIMARY IMMUNODEFICIENCIES

This year we have partnered with Primary Immunodeficiency UK (PID UK) a division of Genetic Disorders UK in the production of a leaflet for **Paediatric HLH**.

PIDs stands for primary immunodeficiencies or primary immune deficiencies. People affected by PIDs have parts of their immune systems missing or not working. This leaves them with reduced or no natural defence against germs such as bacteria, fungi and viruses, which surround us every day.

The consequences are that people with PIDs get infections more often than is normal; they can take longer to get better when they have antibiotic treatment and even then, the infections can keep coming back.

CCLG

Partnership support promoting CCLG'S **Tissue Bank Pilot Grants for 2018** which includes **LCH**.

Share Your Voice

Because of Blake



In memory of our beautiful boy Blake who sadly lost his life to the most horrendous disease, Hemophagocytic lymphohistiocytosis or HLH.

From the moment our son Blake was born he flooded our hearts with love. As a baby he was so cuddly and adorable. As a toddler he was so bright, cheerful and adventurous and when he started school he came into his own, showing how fantastic he was at everything he did. But at five years old Blake was diagnosed with Acute Lymphoblastic Leukaemia. His treatment started straight away, with six months of intensive chemotherapy and a planned further three years of maintenance chemotherapy. There were a few initial complications, but Blake responded well to the treatment and went into remission really quickly. In September 2017, part way through his maintenance treatment, Blake started to get progressively ill. He always struggled with vomiting through treatment, but this worsened along with shingles, nose bleeds, total loss of appetite and an unstoppable thirst. He was finally hospitalised at the beginning of November 2017 when his temperature spiked. His illness baffled the doctors and consultants, he was tested for everything they could think of including diabetes insipidus, but nothing of note came back apart from he tested positive for rhinovirus. Within one week at hospital he became seriously ill and his liver started to fail. He was, at this point, transferred to intensive care and put on life support. Here he was diagnosed with Hemophagocytic lymphohistiocytosis (HLH). We had never heard of this life-threatening disease. We were told that it was highly unlikely that Blake would survive this as he was so seriously ill. He needed dialysis as he was storing fluid all over his body. His blood pressure medication was at the highest dose. He needed constant blood products as his blood was not clotting. He also had a CT scan which showed small bleeds on his brain. Blake was given all the treatment that was available. Firstly steroids, and then chemotherapy. Blake did not respond to any of the treatment he was given and needed the maximum level of life support. It was too big a fight for Blake. Our perfect boy sadly passed away on 30 November 2017, seven years old, to this terrible disease. It is an understatement to say our world has been shattered and our hearts have been truly broken, words cannot express the pain and heartache we are going through.

To help us keep going and honour our beautiful boy we are fundraising for Histo UK. We want to help the charity to support patients and their families and also raise awareness, especially for HLH. This illness is so rare and so deadly we feel Histo UK needs our support to be able to help save the lives of other children who are so unlucky to be struck by HLH. This deadly disease needs to be stopped!

So, what are we going to do?

To raise money for Histo UK we plan to fundraise every year. This year a core group of Blake's family and friends are doing 'The Big Eight' as it would be Blake's eighth birthday. This means eight gruelling events between a core team of eight people. This will include A Cyclothon, A Swimathon, The Three Yorkshire Peaks, The Three National Peaks (in 24 hours), Total Warrior, A Total Wipe Out Style Obstacle Course, A Walk to Barnsley Hospital Tied Together and The Hedgehog Half Marathon. All the events will have a meaningful link to Blake and details are continually posted on our Facebook page [Because.Of.Blake](#)

We are also holding a charity evening which will be a meal, auction and raffle.

These events are seriously pushing us out of our comfort zone. We need to support Hystio UK – no child should ever have to go through what Blake did. Support this charity, Support Blake.

If you would like to donate, please visit Just Giving and search for Because of Blake.

Thank you from the bottom of our hearts
The Holdsworths

Our thanks to you all!

Here are just some of the activities you have taken part in:

Awareness & Fundraising

Here are just some of our Hystio Champions who have raised funds and awareness of for us this year.

(Do not forget to post to your events and activities to our Facebook page).

Poppy & Evie Fun Day	Team Astro Jack-Rock & Roll Marathon	Motors for Max
Amy's Cathedral Abseil	Because of Blake	Team Cookson
Team Tebbs	Team Holdsworth	Kili Climb for Albie
Team Heaton	Lara's Gift Free Birthday	British Airways Entertainment Society
Winchester Bridge Club	Donlevy 10k'ers	Wallington Crafts
Jamieson 10k'ers	Michelle's Charity Ball	Oliver-No Sweets please and colour run.
Diane's 10k	Briony's London Land Mark 10k	Darren's Birmingham Velo100
Steve's Ultra MMA	Camilla's Chain Runner	Vincent's Football for Ottie
Southend Colourthon Team	Port Sunlight Team dual 5/10k	George - Ironman UK
Olivia runs the Paris Marathon	The Video Team	Cardiff Half Marathon

Our thanks go to everyone raising awareness and funds.

To our Corporate, Regular, Anonymous, Community and On-Line supporters

Thank You All!

Support Services

contact

support families, bring families together and help families take action for others.
We are here for all families, whoever they are and whatever their child's condition, helpline 0808 808 3555 www.contact.org.uk.

MacMillan in your area: <https://www.macmillan.org.uk/in-your-area/choose-location.html>

Carers UK: Offers advice and support for carers, including benefits checks and help with finances. www.carersuk.org
0808 8087777

Together for Short Lives: Charity for children & Young people. www.togetherforshortlives.org.uk 0808 8088100

Family Fund: Grants to parents of children who are disabled or ill. www.familyfund.org.uk 01904 550055

Disability living allowance helpline: 0345 712 3456

Fundraising Ideas

GoRaise

Are you looking for Gifts, Retail Therapy, Everyday Shopping or Business Supplies?

We have a great new way to help us raise funds. Go Raise: <https://www.goraise.co.uk/histiocytosis-uk>

Whenever you buy online for yourself, family, friends or colleagues, if you are booking travel and hotels or are looking for business suppliers/services, stationery, office equipment, couriers, insurance hundreds of business suppliers and services will make a free donation to Histiocytosis UK as a thank you, and at no extra cost to you or your company or organisation!

You could help us raise £1000s in extra funding this year, just with your routine or business purchases.

How does it work?

Simply visit <https://www.goraise.co.uk/histiocytosis-uk> and sign up for free access, to great offers from hundreds of business suppliers and services. Generate free donations with any purchase, order or booking and these are passed on to us by Go Raise. Simple.

<https://www.goraise.co.uk/histiocytosis-uk>

Get your free donations now!

John Lewis Unbeatable Price Matching and 100's of offers across categories

Raise up to 3.5%, Argos **Raise up to 1%**, M&S Free delivery when you spend over £50 **Raise up to 1.5%**, Sainsbury's Your weekly grocery shop could raise £26 per year **Raise £0.50 for every completed shop**, Expedia Unreal deals, Escape sale and lots more offers **Raise up to 6%**, House of Fraser Up to 40% off your favourite brands, across the store **Raise up to 2%**, Groupon Amazing cut-price deals **Raise up to 6%**, Hotels.com Save up to 40% in their Winter Sale **Raise up to 3%**, Debenhams VAT free fragrance and incredible offers across the site! **Raise up to 1.5%**, Boots 3 for 2 mix and match deals **Raise up to 2%**.

With over 3,000 retailers to choose from, next time you Go Shopping don't forget to GoRaise.

[Go Raise Everyday shopping, Extraordinary giving!](#)



ChariTable Bookings

WHAT'S THE BIG IDEA?

The exciting new way to book tables and support HistiioUK at no cost to you.

You can enjoy dining at your favourite restaurants while happily knowing you are making a difference at the same time.

£1 for every diner will be donated by the restaurant to Histiio UK when you book through ChariTable Bookings at numerous restaurants across the UK at no cost to you.

www.charitablebookings.org



The **CHARITABLE BOOKINGS** Signature Dish is a premium recipe book with **365 main courses** from **365** leading UK chefs.

In addition to the **CHARITABLE BOOKINGS** free philanthropic [restaurant booking platform](#) the **CHARITABLE BOOKINGS** Signature Dish recipe book is a fundraiser to support Histiio UK.

For every book purchased, **CHARITABLE BOOKINGS** will make a donation of **£5** to Histiio UK. At **£40.00**, the **CHARITABLE BOOKINGS** Signature Dish recipe book is a **754** page, **3.6kg** hard back book with limited edition slip case that makes the perfect gift for yourself, friends or a family member whilst in addition giving back to a charity close to your heart.

<https://charitablebookings.com/store/checkout>



Easy Fundraising

<https://www.easyfundraising.org.uk/causes/histiocytosis>

How do you shop with easyfundraising?

Using the Donation Reminder

If you have our Donation Reminder it won't automatically send you an alert when you shop on these sites. You must activate it yourself. Follow these three simple steps to ensure you always collect donations for **Histiocytosis UK**.



1. Empty your shopping basket

If you're shopping with Amazon, eBay, Expedia or Hotels.com, always make sure your basket is empty before you start shopping.



2. Use your Donation Reminder

Open up your web browser on your PC or laptop and click the easyfundraising logo at the top right-hand corner.



3. Click on Amazon, eBay, Expedia or Hotels.com

Click on the retailer logos and we'll take you through to their website.



4. Go shop as normal

Go shopping as normal and when you check out, you'll collect your free donation! Easy.

[Get the Donation Reminder](#)

Fundraising Stamps



If you are collecting stamps this service will close on 30th April 2018
Please send them in quickly. www.fundraisingstamps.com



Facebook

@ "Histio Champions" - celebrating patients, families and champions of all Histio Awareness

@: "Histio Champions Support UK" - a discussion forum page

@: "Histio Champions LCH" - LCH community



Twitter: @histiouk.

Text HIST00 £5 to 70070 or THRT13 £5 to 70070 to donate to Histiocytosis research and make a difference today.



Histiocytosis UK Registered in England & Wales No. 1158789.

t: 07850 740241

e: histio@histiouk.org

w: www.histiouk.org

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To unsubscribe please email HISTIO@HISTIOUK.ORG with UNSUBSCRIBE in the subject box