



# HISTIOCYTOSIS UK NEWS UPDATE

Together we will find a cure



The UK Histiocytosis Registry has been submitted to the Integrated Research Assessment System for ethical approval. This final stage normally takes 60 days. Review by IRAS is required to endorse the consent forms and information sheets that will be used to register patients and to allow access to pathology samples for research tests. UKHR will be open to patients with histiocytosis of all ages. Information in the registry will be used to drive NHS policy to improve services for patients, to improve diagnostic tests and to join international registries dealing with rare histiocytosis: The Erdheim Chester Disease Global Alliance Registry, based in New York and the International Rare Histiocytic Disorders Registry based in Toronto. We thank everyone for their patience while we have been negotiating the regulatory obstacles!

**Histio UK can now take via email, your expression of interest to be included in this valuable registry.**

**Email: [Histio@HistioUK.org](mailto:Histio@HistioUK.org), in the subject line: EoI- Inc. UKHR and the Patient Name**

**PLEASE DO NOT submit to Histio UK any other patient information or content. Thank You.**

**Important: By submitting your Name/Patient Name by email to [Histio@HistioUK.org](mailto:Histio@HistioUK.org) you are agreeing that Histio UK may transfer the names and email addresses to the UKHR administrator who will contact you direct once the UKHR is open.**



## 4th Histio UK Conference & Forum

The 4<sup>th</sup> UK Histiocytosis Forum was held on the 8<sup>th</sup> November 2018. The meeting included updates 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. Over 60 clinicians, researchers, patients and parents attended.



## Partnership Projects



National Institute for Health Research

Histio UK is made a non-commercial partner of the **National Institute for Health Research**

**18<sup>th</sup> July 2018** - It was confirmed today that appropriate research studies funded through Histio UK's eligible funding streams (Research Project Grants) are now automatically eligible for NIHR Clinical Research Network (CRN) support and therefore entitled to access NHS support via the NIHR Clinical Research Network.

**NICE** National Institute for Health and Care Excellence

**Histio UK receives 1<sup>st</sup> invitation to participate:** Proposed Highly Specialised Technology Evaluation Emopalumab for treating primary haemophagocytic lymphohistiocytosis.

## PRIMARY IMMUNODEFICIENCIES

[http://www.histiouk.org/wp-content/uploads/2018/06/PIDUK\\_booklet22\\_HLH\\_AW.pdf](http://www.histiouk.org/wp-content/uploads/2018/06/PIDUK_booklet22_HLH_AW.pdf)

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

## Share Your Voice



### Our Friend Ottie by Olivia Ellis

My friend and I decided to run the Paris marathon in April 2018 after our best friend Ottie tragically died from HLH in October 2017. Ottie was the person who put a smile on everyone's face whenever they saw her. She was incredibly warm and caring and always put her family and friends first. Ottie lived a life full of laughter and fun and loved a challenge so we decided this would be a great way to honour her as well as focusing us during a difficult time. Despite the training being rather gruelling at times (especially during the freak snow fall we had!) the overall experience was incredibly rewarding.

A group of 15 of us including Ottie's parents and many of her friends travelled to Paris to watch on the day. I'm certain I wouldn't have crossed the finish line without their unfaltering support – they managed to see me 5 times around the course on an amazingly hot day! It felt fantastic to be able to raise over £3000 for HistoUK in memory of our wonderful Ottie.

A devastating disease like HLH which can be fatal in those so young needs greater awareness and support, so it can be further understood, with the ultimate aim of finding a cure.

A large group of Ottie's friends and family will be running the Oxford half marathon in October 2018 to remember her and raise more money for HistoUK in her name. Ottie would have been at the forefront of any challenge to raise money for such an important cause and I know she will be enthusiastically cheering us all on.



### Ottie's Mega Babes - The Team Story

On the 7th October, 'Ottie's Mega Babes' ran the Oxford Half Marathon in memory of their incredible friend Ottie. She loved a challenge but also adored nothing more than having fun and being with her friends, so bringing everyone together to run 21km seemed only appropriate! **A true testament to Ottie's phenomenal popularity, over 80 runners in our team running the Oxford Half together!!!**

October marked a year since we sadly lost Ottie's to an extremely rare autoimmune disease, which as a consequence, does not have enough substantial research behind its diagnosis and treatment. Therefore, we are raising money for Histo UK, a small charity, where the funds raised will make a massive difference to the vital research needed to help both the individuals and families of those who suffer from this devastating disease.

Ottie was a hugely inspirational girl who changed and influenced all our lives. 'Mega babe' was one of her favourite descriptive phrases and such was Ottie's infectiously friendly nature, most people fell under this category - both friends and family! We are all incredibly honoured to be running together in memory of our beautiful, amazing friend.

Just some of the team: Lucy Rogers, Georgie Burgoyne, Joanne Scott, Lydia Uden, Annabelle Massy-Collier, Ellie Lister, Julian Lavender, Sophie Lavender, Lucy Dowling, Emma Walsh, Sophie Puddick, Isabel Glover, Charlotte Goosey, Sophie Conway, Ellie Howard, Lucy Matthews, Charlotte Wilson, Chris P-Slater, Will Englander, Gemma Sarre, Felicity Parker, Isabel Sherman, Alice Berry, Eloise Johnson, Emma Gregory, Eliza Tracey, Olivia Ellis, Ava Daruwalla, Milly Belcher, William van Klaveren, Ellie Hillier, Freddie Chalmers, Helen Gibson, Lucy Morgan, Ben Whitman, Grace Knudsen, Zoë Cocks, Hannah Bray, Briony Venn, Veronica Clarke, James Archdeacon, Isobel Murray, Charlie Adam, Flora Brown, Lucy Lukic, Elen Wyatt, Ben Booker, Laura Morris, Scarlett Tankard, Hattie Coleman, Minty Culley, Laura Toolan, Laura Gordon Lennox, Lottie Little.

## Awareness & Fundraising **Our thanks to you all!**

**Here are just some of the activities you, our Histo Champions have taken part in raising Awareness and Funds 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	Dauids Cardiff Half Marathon
Pen & Parchment Fun Day	Layla's Rainbow	Manchester to Blackpool Cycle
Bev's 1 <sup>st</sup> Half Marathon	Thames Path Challengers	Bath Half Marathon
Cheltenham Half Marathon	Ottie's Mega Babes Oxford Half Team of 84 Savills UK Ltd	3 Peaks and a Half
24 Football Soccerdome	James's Brave the Shave Challenge	Over 260 walkers support research into LCH at the Forest Part Castlewellan near Kilcoo Northern Ireland
Much Hadham Pre School Charity Ball	Olivia Owletts Dublin 23	Clarks Shoes Carrier Bag Tax – Emma Royale
Liam's Zumberthon	Hattie & Sophie St Helens & St Katherine Lacrosse Tournament	Damar Training
Beacon Foods	Billy & Sam's Mammoth 2019 challenge	Shelleys Half Marathon
Margaret's - Perkins Run Marsh & McLennan	Jagruti, Akshaya and Vissal. In Memory	Wallace - In Memory
Knox - Golf Day	Corptel	RPC Group
Jack Daley Fundraising	Alex Heaton Fundraising	Linklaters
Canada Life	Cheshire Cats	Eversheds
Merseyside Police Federation	Crondall Baptist Church	Cotswold Morris Dancers
Wakefield District Housing		All our In Memory Fundraisers not wishing to be named
Individual Donors not wishing to be named	Our Corporate Donors not wishing to be named	Regular Donors not wishing to be named
Our Anonymous Donors	Our Give As You Earn Donors	Our Match Funders
Our Craft and Festival Supporters	Isabel's Half Marathon Etton	

**Our thanks go to everyone raising awareness and funds.**

**Thank You All!**

# Support Services

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## 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](http://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](http://www.carersuk.org)  
0808 8087777

**Together for Short Lives:** Charity for children & Young people. [www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk) 0808 8088100

**Family Fund:** Grants to parents of children who are disabled or ill. [www.familyfund.org.uk](http://www.familyfund.org.uk) 01904 550055

**Disability living allowance helpline:** 0345 712 3456

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# Fundraising Ideas & Tools

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Amazon donates 0.5% of the net purchase price (excluding VAT, returns and shipping fees) of eligible purchases to the charitable organisation of your choice. AmazonSmile is the same Amazon you know. Same products, same prices, same service. Support Histio UK by starting your shopping at [smile.amazon.co.uk](http://smile.amazon.co.uk)



**Are you looking for things to sell at your Fundraising Event or just to raise funds for Histio UK?**

**Charity Calendars – For Fundraising Events - an Easy to Use Online Calendar Designer**

- any quantity can be ordered from 1 upwards
- Spiral Wall, Premium Lay Flat Spiral Booklet, Desk or Stapled Booklet Calendars
- 10% Discount to Schools and Charities
- all our calendars now have Bank Holiday and Notable dates on for England, Scotland, Wales, Northern Ireland & Ireland.
- everything printed and lovingly hand made by us at our family run factory in Suffolk
- the LOWEST prices in the UK, and we aim to beat any other price by 10%

Just make contact or visit the website, choose your template and start a design yourself today at [www.askcalendars.co.uk](http://www.askcalendars.co.uk)



PayPal Giving Fund donations are funds raised through the giving programmes powered by PayPal Giving Fund on PayPal, eBay, Humble Bumble and other platforms.



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 HistoUK 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 Histo UK when you book through ChariTable Bookings at numerous restaurants across the UK at no cost to you.

[www.charitablebookings.org](http://www.charitablebookings.org)



**Easy Fundraising**

Thank you to our amazing supporters shopping online with easyfundraising. Your support really does make a difference, so don't forget there's 3,300 shops and sites you can raise free donations with. Please make sure you shop the easyfundraising way every time you buy something online:

<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](#)



## Facebook

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

@: "Histiocytosis UK - LCH" community support

@: "Histiocytosis UK - HLH" - community support

**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](mailto:histio@histiouk.org) w: [www.histiouk.org](http://www.histiouk.org)

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*To unsubscribe please email [HISTIO@HISTIOUK.ORG](mailto:HISTIO@HISTIOUK.ORG) with UNSUBSCRIBE in the subject box*