HISTIOCYTOSIS UK NEWS UPDATE

No-one should die of Histiocytosis

Together we will find a cure

Our sincere thanks to all of our supporters, fundraisers, partners, colleagues and friends that have contributed to our work to make this a milestone year for Histio UK.

THANK YOU ALL

UK Histiocytosis Registry Opens

At the beginning of September, we were advised that the Registry was now up and running and those who initially expressed interest in taking part are in process of being contacted.

NICE National Institute for Health and Care Excellence

SINGLE TECHNOLOGY APPRAISAL

Emapalumab for treating primary haemophagocytic lymphohistiocytosis [ID1438]

The Department of Health and Social Care has asked NICE to produce guidance on using the above technology in the NHS in England. This appraisal will be following the technology appraisal process published in April 2018. Histio UK, are invited to take part in the next stage of the process in 2020.

Public Health England

Histio UK are now represented on The National Disease Registration Service steering group for work funded by Histio UK.

5th Histio UK Forum

The 5th UK Histiocytosis Forum was held in November 2019. The meeting held in London was well received by health professional and patients with Keynote speaker Julien Haroche, the topics included:

Haemophagocytic Lymphohistiocytosis Histiocytosis
a) Involvement of the CNS in HLH - Claire Booth
b) UK Hyperferritinaemia audits - Ethan Sen
c) The UK HLH Across Specialty Collaboration (HASC) - Rachel Tattersall
d) Case-based discussion

LCH, ECD and the inflammatory myeloid neoplasms
a) Use of national electronic health data for epidemiologic research in histiocytosis- Joe West
b) ECD in the UK: initial report from the UKHR - Matthew Collin
c) d) Keynote address ‘Management of histiocytosis in adults’ Julien Haroche
e) Case-based discussion

Partnership Projects

UK Collaboration Haemophagocytosis across specialty collaboration (HASC) initiative.

In November 2019 over 50 Clinicians and Researchers drawn from multi-disciplinary backgrounds came from across the UK to share their knowledge of HLH. The collaboration drawn from adult and paediatric specialisms discussed wide ranging aspects in the research, diagnosis and treatment of HLH.

The group plan to hold the collaboration bi-annually in June and November 2020.

Share Your Voice

Our Mum Joan, her story - by Sharon & family.

We would like to share our story about our amazingly kind, polite, funny and oh so strong mum, who passed away peacefully surrounded by her 'chicks' (myself, my sister Diane and brother Andrew) in Barnsley District Hospital after a five week battle against this very cruel form of the disease - acquired **Haemophagocytic Lymphohistiocytosis,** (macrophage activation syndrome).

Mum first became ill on January 1st this year. She 'fell' on her way to the toilet in the early hours of new years day. She never drank more than a thimble full of alcohol, so we knew this was something serious. We were unable to reach her immediately and she was considered a 'long lay' and remained in hospital for a few weeks, before being transferred for rehabilitation. Her slow recovery was attributed to the 'long lay', as there was no obvious pathology…only non-specific raised serum ferritin and a slightly elevated liver marker identified on blood screening. Mum did return home to semi- independent living, but never returned to the level of health she had enjoyed before the 'fall'. In addition, mum lost her appetite and began having night sweats and had really no energy at all. Further visits by the GP led to further blood tests, which showed persistently elevated ferritin and also raised CA125, which led her down the route of ovarian cancer screening, but still no diagnosis. Mum 'fell' again on 15th May, but this time we got to her much sooner, following installation of a care button. She was on the floor, confused, as she had been on January 1st.

This was the true start of her decline. Ferritin was still high, and a couple of other non-specific markers were slightly raised, but nothing else. She soon became extremely unwell with suspected sepsis. Mum’s temperature spikes were becoming more and more frequent and difficult to control, but the underlying cause was still unknown. We were trying to remain positive, hoping that when we had a diagnosis, mum could get some treatment and would get better, but the doctors were baffled. Gradually, other blood markers manifested as abnormal, including the detection of antibodies to Epstein Barr Virus, and the decision was made to perform a bone marrow, following which mum was diagnosed with acquired HLH. By this time, she had become almost completely bed-bound. She was transferred to the haematology/chemotherapy ward and was initiated on high dose steroid therapy, while further tests were carried out to try to identify the underlying cause of the aHLH. After a small, initial response to steroids, mum had a further bone marrow, with trephine this time, and many more tests also followed. Unfortunately, the steroid response was inadequate and short-lived and mum deteriorated disturbingly quickly, with increasing loss of function and severity of blood parameters. On 18th June, we were given a diagnosis of aggressive lymphoma in her bone marrow. Mum died the following morning.

For me, this has been particularly tough to accept, as I am a clinical scientist working in a specialist haematological malignancy diagnostic unit, and my specialty is aggressive lymphoma. Knowing there was something quite wrong with mum, but not being able to make the diagnosis in time to save her was extremely difficult to accept. Acquired HLH is extremely rare, with most doctors seeing only a handful of cases in a career. It is difficult to diagnose, and more often than not, once the diagnosis is made, there is no way back, no chance of cure. Earlier, more accurate screening and diagnosis and increased awareness of the potential diagnosis are essential to reduce deaths from this cruel disease in the future. There is limited government funding for rare diseases, and therefore the only way this can improve is if research is funded by charitable donations. RIP Joan Crosland 13/10/1941-19/6/2019

My Mum Anita, her story - by Barry Skinner

In mid-August 2018, my mum, Anita (71), fell ill following a trip to London.

She initially had an upset stomach and high temperature. My mum's GP assumed a virus and asked her to go home, rest and it should pass in a few days. Anita continued to feel more unwell, several more visits to the GP all resulted in her being told it was just a virus that needed to run its course. About 10 days after starting to feel unwell Anita was admitted to a respiratory ward at Royal Bolton hospital in a very poorly state with breathing difficulties. The doctors suspected pneumonia and placed her on high dose antibiotics. After 4 days and no response to the antibiotics, Anita started to have large spikes in her temperature (swinging fever as the doctors called it). Every 8 hours her temperature would spike and she needed IV paracetamol to bring it under control. The temperature spikes started to get closer together, so close in fact she had to try and ride them out because sufficient time had not passed for her to have more paracetamol.

None of the treatment was working and my mum was very sick and had been in hospital for 10 days now. A bone marrow biopsy was taken, and they put her on steroids. The steroids gave her instant respite, her temperature spikes stopped and as a family we were able to spend a little bit of quality time with her. 3 days later the bone marrow results came back which indicated HLH.

We had never heard of it, but the doctors gave us the awful news that it would take our mum very quickly. Anita was too old for a bone marrow transplant and too poorly for Chemotherapy, she died on the 21st September 2018**, 9 days after the HLH diagnosis and about 5 weeks after falling ill.**

This condition is so rare that doctors are not able to diagnose it quickly I hope that by providing more information the awareness increases and doctors are able to diagnose sooner so that more patients have a better chance to beat this devastating disease.

Oliver Chapman – by Mum Danielle Eaves

Oliver was diagnosed with multi system Langerhans Cell Histiocytosis when he was 20 months old, back in 2014.

The LCH had attacked Oliver's bone, skin and gut and he started chemotherapy and had a port-a-cath fitted at Addenbrookes Hospital. Oliver had 3 different chemotherapy courses, trying different ones but the LCH was still very active and spread to his eye sockets.

In 2015 he started a clinical drug trial at Great Ormond Street Hospital, which targets the B-RAF gene in which Oliver was found to have a mutation. Oliver is still on these medications 4 years later and we are not sure what the long term plan will be.

Isobel the Griscelli Supergirl by Mum

Clippers Diagnosis

Isobel was 9 when a routine optician test showed there was an issue at the back of her right eye. Where the synapses meet at the back of the eye instead of a smooth oval there was a raised bump. Regular eye check-ups over 18 months showed no change in growth, there were no headaches or problems with vision and as she was not in pain, it was agreed that she would be discharged at the next appointment. However, 4 weeks before that appointment Isobel started to complain of having double vision. 2 weeks before the appointment her right eye turned in. At the appointment, she was booked in for a 20-minute MRI.

10 days later, we received an evening phone call that no parent wants to have. There was a problem with the MRI, which showed inflammation spots scattered throughout Isobel's brain, particularly behind the right eye and at the top of her spine. The doctors were unsure what it was, and we needed to come in the next day for more tests to be done on a children's ward. Isobel, now 11, had a barrage of tests, including a 50-minute contrast MRI and a lumbar puncture. Within 3 days, thanks to a sharp-eyed radiographer, we had a diagnosis of Clippers, an auto-immune illness of the brain and one of only 60 known cases in the world. Isobel has tried various medicines over the last 2 years and the inflammation responds well to steroids, which she is still on; without them her balance and vision are severely affected.

Griscelli and HLH Diagnosis

Our wonderful Clippers specialist has been working closely with Great Ormond Street Hospital (GOSH) on Isobel's case and over the last 2 years there has been genetic research to show that Clippers is not an illness in itself but a symptom of an underlying cause. Isobel, now age 14, went to GOSH to meet the team, have bloods taken and a lock of her hair to test for various genes. Recently we received the dreaded news that Isobel has tested positive for a very rare hereditary genetic condition called Griscelli, under the umbrella of **HLH**, a life-threatening auto-immune illness of the blood. there are 60 known cases of Griscelli in the world. The only hope of a cure is chemotherapy and a bone marrow transplant.

Over summer 2019 Isobel has had numerous tests, appointments and treatment discussions. She has been further diagnosed with **'isolated neurological HLH'** one of 11 known cases in Europe as her **HLH** symptoms are so rare. Doctors say they have never seen anyone "so well" with this illness despite inflammation spots presenting in her brain and spine. Further treatment has been hotly debated between GOSH and Birmingham Children's Hospital and they finally agree that she will continue to be closely monitored and the search for a donor match will go on. It is expected her symptoms won't always respond so well to steroids and doctors want to be ready to move quickly if and when necessary. For now, we feel that we have had a reprieve and can plan some future events with family and friends without worrying we will get 'the call' for a Bone Marrow Transplant. Further donor events are in the pipeline for Isobel and for so many others in more dire need of a BMT.

Isobel isn't the only one who has had tests! Kev and I had the results of our genetic tests. Everyone has 2 working Griscelli genes (RAB27A) which carry melatonin around the body. Amazingly Kev and I have only 1 functioning gene each and have passed on the non-working gene to poor Isobel. The chances of us both being affected were millions to one, the chance of passing it on were 1in 4. Myles is now having testing and genetic counselling to see if he is a carrier and to see if he could be a possible donor for Isobel.

GRISCELLI

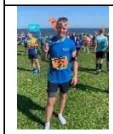
People have commented on Isobel's unusual colouring- white blonde hair and olive- toned skin since she was a baby- just like her elder brother. When the GOSH team wanted to test her for Griscelli (a genetic abnormality in gene RAB27) we were convinced she couldn't have it, as Griscelli children are described as having very pale, translucent skin and Griscelli is under the albino umbrella. We were stunned when she tested positive. Griscelli is considered life threatening but Isobel is currently classed as atypical as the illness hasn't attacked her body as it seems to in others.

Awareness & Fundraising Our thanks to you all!

Team Astro Jack – Reach their target, just after the photo was taken, Jack turned to his Mum Rachel and asked:

What's next are we going to £100,000?

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

HCB Park Woodline - Jill	Richard – Cardiff Half Marathon	HCB Park Woodfine LLP
Giddo's Gift	Wakefield Methodist Church	In memory of Tom - English Open F3f event, Radio control glider racing
All Saints Primary Stockport	Blue Fin	Dunsmore Lodge
Louise and Team on 19th Great North Run	Spence - Bank Holiday Fun	Julie – Tea in the Garden
Tracey - Lunch & Learn	Oliver Chapmans Fund	Sue – Team Isobel-Griscelli-Supergirl
 Daniel Great North Run	 Games Maker Choir – Cake Break	 Astro Jack reaches his Target
Emily's 10k run for Joan	Layla's Rainbow	 Sue -Team Isobel Nottingham Half Marathon
Louise Great North Run	Thomas Tatton Park	Katy Hever Castle
Hugo - Daisy's Fund	Team SOBI -Scarfel Pyke	Joe Hell Runner
In Lieu of Golden Wedding Gifts	Emma- Bath Half	Canada Life -Team
Our Corporate Donors	All our anonymous Donors	All our In-Memory Fundraisers
Individual Donors	Our Give as You Earn Donors	Regular Donors

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.

CancerCare (LCH Adults) North Lancaster & South Cumbria.
They do a variety of things 1:1 like counselling, reiki, aromatherapy massage, and Alexander technique, and also group things like Tai Chi, jewellery making and other creative stuff!. **https://cancercare.org.uk 01524 381 820.**

MacMillan in your area**: https://www.macmillan.org.uk/in-your-area/choose-location.html 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 & Tools

Easy earners

Whether you run these as well as or instead of a full-blown event, here are a few fundraising ideas that will ensure a guaranteed source of income for very little effort!

Cake sales: a recipe for success!

Cake stalls or bake sales don't take too much organisation and are always a popular fundraising activity with both charities and supporters! If you're running a cake stall and want to increase profits, read our tips for success...

Bake sales, cake stalls, or afternoon teas are popular fundraising activities, that require very little planning, but how can you make them a success?

Publicise your Cake Sale

A bake sale isn't something that supporters need to prepare for, so plan your marketing to begin far enough in advance to pique interest, but not too early that people will have forgotten about it by the time the date arrives! Decide on the date and location of your sale and think about drawing up some marketing material. How long will it last? What refreshments will be available?

Once the date and format are agreed, start telling people about it! Depending on the scale of your event, place posters in local nursery schools, GP surgeries, supermarkets, businesses and shops. Explain what you're raising money for, so that supporters know the impact their contribution will have.

Use your Facebook page, Twitter page, email and any other social media to tell people about your sale. Send out reminders as the event gets closer, using language that implies a growing sense of urgency: 'NEXT Friday, come and eat cake!

Request Cake Donations

To ensure maximum profit on the day, try to get as many cakes donated as possible. Appeal to supporters of your charity - mums, dads, grandparents, children, and your neighbours. Do not ask for too much, if everyone supplies ten cupcakes each, you'll be well on the way. Ask donors to provide a list of ingredients along with their cakes for people with allergies. For the competitive bakers out there, you could introduce a bake-off style competition, with local celebrities judging the best cakes in different categories, such as 'cupcake connoisseur' or 'brilliant bread'!

To pull in potential donors, use our cake poem examples - stick the poems on a plate or advertise it across social media/on posters to grab their attention.

Increase cake donations with poetry!.......

By getting treats donated, your cake stall sales become pure profit. But how can you make sure your request gets noticed? Print poems onto stickers, attach to paper plates and send them out to supporters!

Cake stalls make a popular feature at fundraising events or can be run as a standalone activity to draw in extra funds. Posters or request letters might not catch the attention of your supporters, so our fundraising friends on Facebook suggested this great tried-and-tested method of sending out a paper plate with a cake poem attached!

The paper plate is intended as a prompt, so don't be offended if cakes are handed in without the plate (bulk packets of paper plates can be picked up very cheaply)! So, choose or better still write a poem, print onto stickers, put onto plates and hand them out.

Pricing

You do not want to empty people's pockets but remember you're there to raise money. Price cakes according to size and intricacy bake. For a rough guide, 30p for small cupcakes decorated by children, 75p for a large slice of cake, £1 for fancy cupcakes. Consider running a pop-up cafe, selling tea and coffee too. You could also have a cake decorating table for children, with plain fairy cakes, different coloured icing in squeezy bottles and a choice of toppings from silver balls to dolly mixtures.

Display

Make your display look as enticing as possible... Seek out a variety of different cake stands of varying heights - not only does this make it easier to fit more on the table, but people will also be drawn in by all your mouth-watering goodies as they approach!

Try to label your cakes, making it easier for visitors to choose - this won't take long, just some cut-up card and a marker pen to make some stand-up labels.

Give your sale a vintage twist by sourcing old-fashioned cups and saucers from charity shops, popping a moist muffin in the cup, and wrapping these in cellophane. Your price can increase to cover the cost of the crockery!

Having material/posters detailing your cause, and anything specific you are raising money for will remind people who are donating or buying where their money will be going! You never know, it might make them dig a little deeper into their pockets!

Timings

Inform donors where and when they need to deliver their cakes. Set up your stall at least an hour before the sale starts. Run the cake sale for between one-to-two hours, or shorter if the cakes go fast, and allow some time to clean up afterwards.

CASH For Trash: Recycling Fundraisers

There are a range of fundraising recycling schemes that will generate cash for your organisation, you just need to choose which one suits you!

Clothing & Textile Recycling

80% of clothing thrown away in the UK can be reused, because the quality is so high. Some companies give a price per bag while others pay by weight (Rags2Riches4Schools pay 40p per kilo!). The more you collect, the more you earn. Items accepted vary between companies, but many take shoes, handbags and children's toys as well as clothing.

The collecting companies should provide all the necessary resources, and don't worry about storage space - just arrange for donations to be delivered the same day as the recycler collects. This way the clothes can be loaded straight into the collecting company's van, rather than building up in a storeroom or corridor. Many companies offer resources, including posters and letters for you to download, print and distribute as well as collection bags.

TIP: You will have more success if you run a campaign in spring or autumn, when people are changing from summer to winter clothes or vice versa.

Printer cartridge recycling

You can raise around £1 per recyclable cartridge - some companies pay a flat rate, others have a price list showing all the cartridges they accept. **Empties Please** estimate that each household six cartridges each year.

Apart from publicising the idea, all you need to do is collect the cartridges. A large cardboard box or plastic dustbin is the ideal collection bank. Be aware that some designs of cartridge can leak residual ink, even after the printer has decided they are empty. Make sure any collection bin is capable of containing such leaks. Many companies will supply you with a recycle bin and charity starter pack, posters to display in and around your charity and offices

TIP: Could local businesses support your cause? They could display a recycling bin in their offices to collect on your behalf.

Currency, Notes and foreign coins.

According to British Airways, Britain alone hordes foreign coins worth more than £30 million every year, because banks and bureaux de change won't exchange them.

Cash 4 coins accept any currency from all corners of the globe, including notes! They even change old UK, Irish and pre-euro European coins. This means that while stashes of currency that your supporters have may appear worthless to them, it could be worth something to you! They also provide envelopes to go out to supporters, press releases for local radio, etc.

If you collect 5kg or more delivery/collection is free. Your coins are checked, and an offer is made within 3-14 days.

TIP: To maximise support, promote this just before and after school holidays and around ski season when people are most likely to travel.

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smile.amazon.co.uk

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

Also, don't forget to use our unique charity link, enabling you to select Histio UK on smile.amazon.co.uk with just one click:

https://smile.amazon.co.uk/ch/1158789-0

If you are an AmazonSmile customer, you can now support Histiocytosis UK in the Amazon shopping app on your Android device! Simply follow these instructions to turn on AmazonSmile and start generating donations.

1. *If you have the latest version of the Amazon Shopping App, open the App on your Android device.*
2. *View Settings and select AmazonSmile.*
3. *Follow the in App instructions to complete the process.*

If you do not have the latest version of the Amazon Shopping App, update your App.

askprint

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

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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!

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Go Raise Everyday shopping, Extraordinary giving!

ChariTable Bookings WHAT'S THE BIG IDEA?

The exciting new way to book tables and support HistioUK 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 Histio UK when you book through ChariTable Bookings at numerous restaurants across the UK at no cost to you.
www.charitablebookings.org

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

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