



NEWS UPDATE

Together we will find a cure

Our sincere thanks to all our supporters, fundraisers, partners, colleagues, and friends that have contributed to our work.

THANK YOU ALL

Grant Awards 2020

A UK & European multi centre project: -

MUTANT BRAF ALLELE BURDEN IN RELATION TO CLINICAL OUTCOME

Aim 1: bio banked and prospectively collected peripheral blood samples will be used to assess which of the two available assays (cell-free DNA isolated from plasma or DNA extracted from bulk blood cells) correctly reflects (changes in) disease burden. These results will lay the basis for a non-invasive monitoring protocol for improved clinical management of patients.

Aim 2: will analyse which type(s) of lineage cells in the blood actually express mutant BRAF alleles. This part of the project delivers data which help to further unravel the pathophysiology of LCH.



We know that all Histo journeys come with unique challenges and we would like to hear about how we can best help **you**.

Can you help us try meet your needs with helpful information and programs through your histio journey?

However you found us here at Histo UK whether you come to us newly diagnosed or have been with us for years, your input will guide us in providing the information you and many others may need in our Histo Community.

Keep a look out in 2021 for our new Let's Talk & Connect Forum UK.



Contact us at: LetsTalk@HistoUKConnect.org

Let's Talk-Histio UK Connect

Across Continents an Awareness Initiative for all Histiocytic disorders.

Let's Talk-Histio UK Connect – The Let's Talk Project has gathered together with Parent and Patient associations from across the continents via online discussion media.

In partnership with the USA, Canada, Greece, Italy, Spain, France, Argentina, and Brazil discussions will continue with a view to advance Patient and Parent support, information provision and knowledge sharing at local and international levels.



6th Histio UK Forum

Held on the 19th November 2020 Histio UK hosted leading Researchers and Clinical practitioners in the fields of Langerhans Cell Histiocytosis (LCH) and Haemophagocytic Lymphohistiocytosis (HLH) *via webinar.*

With over 100 Professionals Parents and Patients in the audience.

Speakers included:

HLH Introduced by - Dr Claire Booth:

Paediatric HLH

Dr Anupama Rao: *Speaking on:* Post HSCT outcomes in children with primary (genetic) HLH treated on Emapalumab

Dr Alasdair Bamford *Speaking on:* PIMS-TS/COVID related hyperinflammation in children.

HLH Adult:

Dr. Jessica Manson *Speaking on:* COVID 19, HLH and hyperinflammation & HLH where are we now and where are we going?

LCH Introduced by - Prof. Matthew Collin

Dr Paul Milne – *Speaking on:* Advances in molecular diagnostics

Dr Jean Donadieu – *Speaking on:* Targeted inhibitors

2021

Histiocytosis 7

The 7th Annual UK Histiocytosis Forum

Hosted by Histio UK

Thursday, 18th November 2021

Selected histiocytosis cases for education and collaborative consultation

MDT audits and registry activity

Specialist Trainee best case presentation

Let's Talk - Share your Voice - My Story
dedicated to patients and families



Partnership Projects

UK Collaboration Hyperinflammation & HLH Across Specialty Initiative

On November 18th, the HASC group convened with over 204 members for its annual AGM.

The group Co-Chaired by Dr Jessica Manson and Dr Rachel Tattersall draws its membership from multi-disciplinary backgrounds.

The meeting held via webinar joined its members from across the UK to share their knowledge of Hyperinflammation and HLH.

The collaboration is made up of both Adult and Paediatric specialists discussed wide ranging aspects in the research, diagnosis and treatment of HLH.

NHS

Histio UK has been invited to participate in the Rheumatology Clinical Reference Group

NHS England Specialised Commissioning will be conducting a 2-week period of stakeholder testing from next week on a policy statement proposal for Anakinra in HLH.

Share Your Voice

Violets in Bloom by Kerry

A Beautiful Baby Girl

Violet Lilian Mornington was born on 3rd June 2008 at Samuel Johnson Hospital in Lichfield to Kerry and Ivan. A happy, healthy, sometimes very silly and a tiny bit naughty little girl, she completely rocked her Mummy and Daddy's world. 'Life was never boring with Vi, she was into everything, always on the go and making us laugh'.

Violet had so many friends firstly through her Nursery, Animal Crackers and then when she started school in September 2012 at St Stephens in Fradley, where she lived. She loved school and she loved her friends.

In 2013, Violet was coming on in leaps and bounds with her reading and writing, she had learnt to swim at her swimming lessons and mum and dad were planning on taking the stabilisers off her bike ready for the Summer. Things were good and Violet's most favourite things in the whole world were her books and her teddy bears.

It all changed

On her 5th Birthday (03 June 2013) this all changed when Violet came home from school feeling a little unwell. We thought maybe she was a bit over excited about her birthday'. When Violet didn't seem to pick up after few days and after several trips to the doctors, Violet was taken to A&E where she was immediately transferred to Birmingham Children's Hospital where for several weeks she left Doctors baffled as to what was wrong.

Doctors ruled out Leukaemia and other weird and wonderful viruses, but they were completely stumped. They could not figure out why Violet's bloods were so 'bonkers', as they put it.

They couldn't understand why she was having raging temperatures up to six times each day, why her spleen had doubled in size and why she was too tired to even get out of bed to have a little play in the playroom.

Diagnosis

Finally, after three weeks in hospital, they diagnosed Epstein Barr Virus associated Hodgkin's Lymphoma and set about her first lot of treatment. However, it soon transpired that there was something more sinister going on with poor Violet and they suspected a rare blood disorder called HLH (Hemophagocytic Lymphohistiocytosis), a potentially fatal disease of the blood if not diagnosed and treated in time.

Despite starting chemotherapy treatment, the disease had gotten hold of Violet and on Saturday 20th July she started to have severe respiratory problems. After 24 hours of fighting so hard to stay with us, little Violet sadly lost her fight and she passed away on 21st July 2013. She died peacefully in the arms of her Mommy and Daddy.

Violet will be remembered and loved by everyone who knew her for her sense of humour, her beautiful smile, her strong personality, for her individuality and for the amazing courage and bravery she showed during her illness.

Awareness & Fundraising

It has indeed been a difficult year for all, and it is with these difficult times in mind that we extend

Our special thanks to you all!

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

Hannah 's 2.6 Challenge	Maria's 50 Miles in May	Chloe's Fundraising
Simons Head Shave	Alana's Fund Raising	Seb's 5k a day through August
Rebecca's Massive Hair Cut	Claire's run to France	SOBI – Match Fund
Ian's fundraising	Jay's Marathon	Andy
Violets in Bloom	Joe's Cycling	Claire's Bike Ride to France
Alanna	Nicola's Virtual Marathon	Giddo's Gift
	All our individual and anonymous supporters	

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.

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



Want to help us raise even more for FREE? Well, now you can just by shopping via Give as you Live Online!

When you shop at over 4,000 top stores including John Lewis & Partners, Expedia and Marks & Spencer via Give as you Live Online, they'll turn a percentage of your spend into free funds for us!

Simply sign up, search for the retailer and start shopping. It's that simple!

Get started today!

https://www.giveasyoulive.com/join/histiocytosisresearch?utm_source=charitytoolkit&utm_medium=post&utm_campaign=CTJoinLink



Shop with heart - Every fundraising page on Virgin Money Giving can be hooked up with Kindred, so you can turn everyday online shopping into a way to generate free donations for Histio UK. **Kindred**, everyday online shopping can help you fundraise raise **EVEN** more.

Hook up YOUR fundraising page to Kindred and shop with heart!

You will earn Histio UK free donations of up to 40% when you or your friends' shop.



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.



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
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PayPal Giving Fund

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

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 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

CharitableBookings.com. SIGN UP or LOGIN today and enjoy up to 95% cheaper room rates than other major booking platforms, FREE lifestyle benefits, a £250 Welcome Gift and 30% of the net commission from all your hotel bookings donated to your favourite charity at absolutely no cost to you.



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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:

THREE EASY WAYS to use easyfundraising and raise money for us whenever you shop online:

1. Download the **Mobile App** and raise when shop from your mobile or tablet
2. Get the **Donation Reminder** for your laptop or PC and get alerted when the retailer you're shopping with will donate
3. Or simply login www.easyfundraising.org.uk and start shopping

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



Facebook

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

@:" Histiocytosis UK - LCH "community support

@:" Histiocytosis UK - HLH" community support



Twitter: @histiouk.



HISTIOCYTOSIS UK

No-one should die of Histiocytosis

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