

GET INVOLVED FUNDRAISING

EVENTS



Histiocytosis UK

Introduction

Despite the misery it causes, Histiocytosis is too rare a disease to have generated substantial research in medical circles. Unfortunately, for every child or adult fighting for his or her life, the pain and suffering are just as severe for children and adults afflicted with other better known disorders receiving funding.

For the children and adults battling these illnesses, there is now reason to hope. To ensure the research continues, we ask for your help, to complete the funding puzzle.

Our awareness and research programmes provide a beacon of hope for the many children and adults battling Histiocytosis, to ensure this research continues we ask you to pledge your support.

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WHAT IS HISTIOCYTOSIS

What is Histiocytosis?

Histiocytosis is an umbrella term applied to a group of rare diseases, characterised by increased numbers of white blood cells called histiocytes in the blood and tissues. In all forms of histiocytosis, these cells, which are part of the protective immune system, begin to attack the body, targeting many organs of the body including the bone marrow, liver, spleen, lungs, skin, bone and brain.

The prognosis for patients varies greatly depending on the form of histiocytosis.

Please be advised that all the information you read in this document is not a replacement for the advice you will get from your consultant and their team.

Who we are?

Histiocytosis UK is a registered charity dedicated to promoting and funding scientific research into uncovering not only the causes of all histiocytic diseases, which include Langerhans Cell Histiocytosis and Haemophagocytic Lymphohistiocytosis, but also ensuring early diagnosis, effective treatment and a cure.

The Charity aims to support patients and their families by means of information and awareness as well as raise public and professional awareness of histiocytic disorders. Its team of Trustees include the UK's leading paediatric LCH and HLH specialists.

Histiocytosis UK Registered in England & Wales. Charity No. 1158789. Email: <u>Histio@HistioUK.org</u>. <u>www.histiouk.org</u>

ALL WAYS TO GET INVOLVED

All Ways to Get Involved

Now, more than ever, we need people like you to join our team and help us make sure no one faces histiocytosis alone.

We are indeed a rare community of patients, families, friends and doctors bound by the collective fight against histiocytic disorders. Our success is a direct result of the collaborative nature of this community and the desire and willingness of everyone to get involved in their own way.

There are limitless ways to get involved and make a difference in the lives of patients with histiocytic disorders.

Take action!

Gift Aid

Every gift you make to HistioUK - whatever its value - could be worth more at no extra cost to you just by choosing to Gift Aid it. Her Majesty's Revenue and Customs will add an extra 25p to every £1 you give to Histio UK.

How does Gift Aid work?

It is simple. As soon as you give your permission by completing a Gift Aid declaration form, we can claim the tax back on your donation. This means that a £10 donation will be worth £12.50 and for every £50 gift, we will actually receive £62.50.

Do I have to give regularly? No.

We can claim the tax back on a donation of any amount that has been made to us in the last four years. It doesn't matter whether you make a one off donation or set up a regular standing order or direct debit.

A single Gift Aid declaration will cover all future donations that you make to Histiocytosis UK if you are a UK tax payer.

Am I eligible to make a Gift Aid donation?

If you are a UK tax payer, yes.

Even if you are not employed, you are still eligible if you are paying tax on any of the following:

Personal or occupational pension

Stocks and shares

Bank and building society savings accounts

Rental income

Overseas and UK investment dividends.

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GIFT AID DECLARATION – for past, present and future donations
Please treat as Gift Aid donations all qualifying gifts of money made
today
in the past four years
in the future
Please tick all boxes you wish to apply
I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April to 5 April) that is a least equal to the amount of tax that all the charities or Community Amateur Sports Clubs (CASCs) that I donate to will reclaim on my gifts for that tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I give on or after 6 April 2008.
Donor's Details:
Title Initial (s) Surname
Home address
Postcode Date
Signature
Please notify Histiocytosis UK if you:
 Want to cancel this declaration Change your name or home address No longer pay sufficient tax on your income and/or capital gains
If you pay Income Tax at the higher or additional rate and want to receive the additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return or ask HM Revenue and Customs to adjust your tax code

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ORGANISED EVENTS

Look for an event to raise funds for us! Make a choice from our inspiring list!!

RAISE AWARENESS

Whatever you do, big or small, <u>please let us know.</u> We would love to share your efforts with the Histio Community, and on our Facebook Histio Champions page. Some families are running around between doctor visits or are stuck in hospital rooms. Sharing your efforts gives them hope and lets them know that someone out there is fighting for them.

Get Histio on the move!

Where and what can you do to get "Histio on the move"?

10k Runs	BUPA London https://www.london10000.co.uk
Abseil	http://www.nationalabseilcentre.co.uk/
Climb a Mountain	http://www.skylineoverseas.co.uk/
Cycling	http://www.opencycling.com/ http://www.ukcyclingevents.co.uk/events/ http://www.bike-events.com/
Dirty Weekends	http://www.ratracedirtyweekend.com/ http://www.toughmudder.co.uk http://www.totalwarrior.co.uk/

Fun Runs	http://www.bigfunrun.com/				
	http://uk.runordye.com/locations				
Half Marathons	http://www.halfmarathonlist.co.uk				
Marathons	http://www.marathonrunnersdiary.com				
Miscellaneous					

ORGANISE YOUR OWN EVENT

Organise your own event Start at the very beginning and get the basics right!

You will need to have a think about a few practicalities to be sure your event will run smoothly.

What type of event should I organise?

There are a lots of tried and tested ways to fundraise in the community – you just need to find the right one for you. Check out some of the favourite ideas.

Is it a raffle or is it a lottery?

Holding a raffle? That is no problem, so long as the tickets are sold and drawn on the same day. If the tickets are sold before the day of the raffle, then you will need to obtain a lottery licence from your local authority.

What is the best time to hold your event?

Choose a date that is best for you and your friends and colleagues and remember that you will need plenty of time to organise it (it might take longer than you think). Try to avoid competition by finding out when other events may be happening around that time.

Where is the best place to hold your event?

Choose a venue that is large enough and has all the amenities you will need. If you would like to sell alcohol or have live music, make sure it has the necessary licence. (find out more in our tip 'Will it be alright on the night').

What is the budget?

You might want to dive straight in with organising your event, but it is important to work out a simple budget at the very start of your planning. Include all the costs you expect to incur (promotion, equipment, etc.) and estimate how much money will come in (tickets, sponsorship, etc.).

Can you reduce your costs? Perhaps through donated goods and volunteers' help? Might any local companies be interested in sponsoring your event or be willing to donate raffle prizes?

Set a review date before the event and do not forget to think about when things need to be paid.

Add the pizzazz

Stand out from the crowd with all the promotional materials and merchandise you need.

Make your own event posters and flyers

Download the Histio UK logo and make striking posters and flyers of your own.

If you are in need of any extra items, like T-shirts, balloons then contact the Office at Histio@HistioUK.org

The bigger the better!

Tell as many people as possible about your plans? You can get in touch with your friends, colleagues, the press and your local community, tell the Facebook page 'Histio Champions'

Get social

A great way to get the word out there is via social networking websites such as <u>Facebook</u> and <u>Twitter</u>. Set up your own social media page for your event. Why not get the conversation going by holding competitions, or offering special deals for your followers?

You can also use social media to keep people posted, share photos of your progress and generally boost the excitement about your event.

Help local media to tell your story

Promote your fundraising activity through local media. You could get in touch with news desks at local newspapers or try to get the local radio and television stations interested in your event. You could invite the local press to attend your event on the day – send an invitation at least two weeks in advance and do not forget an invitation for one of their photographers to come along.

After the Event

Write your own Press Release and send the local newspapers local radio and television stations the story of the event and a jpeg version of one or two photos.

Spread the word at work, school and among your friends

Use your contact lists and email contacts and internal websites, newsletters or noticeboards. Your friends, colleagues and employers will often be keen to hear your news, see pictures and follow your progress.

Good luck and we wish you lots of great coverage for your events.

How to Bank your money

Please have a look at the <u>Keep it safe and legal</u> section to make sure your event runs as smoothly as possible. Then, once all the hard work is done, all you need to do is pay in the money using one of the following methods:

Online

To make your donation go as far as it can, the best way to donate to Histio UK is to simply pay any cash into a bank account and then make an online donation. You can also set up an online sponsorship page with <u>JustGiving</u> or <u>Virgin Money Giving</u>, and we will receive all of your money directly from there.

By bank transfer

We can also send out our bank details and a unique reference number for you to make your donation by BACS transfer. All we need to know is your full address and as much detail as possible about how the money has been raised.

By paying-in-slip

Alternatively, we can send you out a paying-in-slip which you can use to deposit both cash and cheques at any HSBC. Again, all we need to know is your full address and as much detail as possible about how the money has been raised.

By post

If you have sponsorship forms, Gift Aid forms or cheques that you wish to send to us, you can post them along with a covering letter stating your details and the reason for your donation. Please email or telephone for the address.

Whichever way you choose; we will send out a thank you to you over email or in the post. But if you would prefer not to receive one, let us know and we will save our postage stamps for next time.

Will it be alright on the night?

Try to think of all possible scenarios, and you will be ready to enjoy your event, whatever happens.

Before any event

- Equipment What do you need? Write a list so you do not forget anything.
- Helpers How many do you need? Remember to ask them in plenty of time
- Contingency plans What if it rains? Do you have a Plan B? Are there extra resources
 or emergency cash available on the day? Don't be afraid of cancelling or
 postponing an event if necessary.

On the day

Do you have a checklist of all the things you need to do so you do not forget anything? Double check your equipment, brief your volunteers and arrange some refreshments. Decorate the event venue with posters and balloons and display any merchandise you have.

If possible, announce the anticipated amount to be raised from the event, reminding everyone why the money is being raised and say a big 'Thank you'.

After the event

Do not forget to thank everyone who helped out on the day. Then count up the money raised and send it, bank it or donate it. Do not forget to declare Gift Aid when possible and help your contribution grow.

And most of all, a BIG thank you.

EVENT IDEAS

A	Aerobics Workout, All Our Yesterdays, Air Walk, Are you ready for Awareness Month September, Auction,	Z	Nights in by the telly with friends, Nominate a friend, Nominate a Histio Champion,
В	Balloon Race, Barbecue, Beard Shave, Bring and Buy Sale, Book Sale, Bad Taste Day (wear something gauche), Bath in Beans, Big Bucket Day,	0	Office photo caption competition Open your garden,
С	Car Wash, Car Boot Sale, Cheese and Wine Party, Coffee Morning, Cricket Tournament, Camping, Charity Auction	p	Pop Star Party hold one on: Pancake Day, Valentine's Day, Picnic In the Park,
D	Dress up or Dress down day, Darts Competition, Disco, Dinner Party, Dine in for Two,	Q	Quiz Night, Quit Day, Quiet Day,
E	Easter Egg Hunt, Egg & Spoon Race, Egomania Day,	R	Raffle, Rugby tournament, Retiring collection - If you are retiring and feeling generous you could request that a donation is

			made to Histio UK in lieu of a
			leaving gift,
F	Family Fun Day, Football Tournament, Fuel the Cure,	S	Show Time - This is an annual UK wide fundraising event where everyone of any age can show off their talents. It is easy and fun to take part in whatever your talent:
			Act, Cook, Dance, play an
			Instrument, Recite
			Poetry, Sing, Jest or Juggle.
			The Floor is yours!!
			Sponsored walk, cycle, run, swim, head shave, Shopping evening, Speaker WHEN Spoken to Day, Skydiving, Shush day,
			September Awareness Month
G	Golf Day, Garden Party, Go Sober, Go without, Gym,	Т	Teddy Bear's Picnic, Tango Night, Tea and Toast Day, Tea @Three, The big Buzz (shave it off), Tell Jokes,
Н	Head-shave, Hair disaster Day. Histio Hatters - Is an annual event held during Histio Awareness Month of September or you may hold your	U	Under the duvet day a, OR Sponsored Sleep over,
	own Histio Hatters day at any time!		

I	Inspire your self-day or be inspired!	V	VE Day a 40's Theme Night
	International Day - contact		Variety show - You know that your
	friend and colleagues		pupils are talented, so why not let
	overseas,		them share that with the world? As part of the school day or after
			school with parents, this is a fun
			way to build pupils' confidence
			while raising funds.
			Volunteering
J	Jumble Sale, Juggle, Jym!! ,	W	Wear Blue for Histio Month, Who dunnit night! Walk the
	Just do it!		Walk,
			·
K	Klimb! Kilimanjaro !	X	Xtreme Sports!
7	Killis Killianjaro :	^	Attraction oper to:
	Keep Quiet Day!		X-Factor singing competition
	Kamping!!		Xmas card recycling
L	Lunch Celebrations:	У	Yoyo & Hula Hoop day,
	Anything on Toast! Cheesy eh!		Yoddle, Yahoo it,
	Ladies Who do not Lunch!		
	Laughing Day,		
M	Mexican night- sombreros	Z	Zzzzz's you must be tired by now!
	chilli and tequila (in		
	moderation) of course, Mid Morning Snack, Mums Meet,		
	Morning Shack, Munis Meet,		

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Fundraising FAQ

I want to fundraise for HISTIO UK

How do I get involved?

We are very happy that you should want to fundraise for us. Your amazing efforts really will help us to make sure that our work continues. There are so many ways you can get involved – why not take a look at our events ideas for some inspiration?

Can I hold my own event for Histio UK?

Yes, if you are doing your own thing, be it LAZYING in a bath of beans, holding a quiz night or masterminding a charity auction, do not forget to post it on the Facebook Champions page. Of course. If you are looking for a pre-arranged event such as a walk, a run or a cycling challenge, all you need to do is head to the specific events page for that category.

How will you use the funds I have raised?

Your money will help us to provide a variety of information services and fund vital research into seeking a cure for Histiocytosis.

Keep it safe and legal

Make sure your event Measures up!

Do not let anything stand in the way of your event being a huge success. Take a bit of time to have a look through some of these practical things to consider.

Health and safety and risk assessment

Follow the professional advice of equipment manufacturers and staff supervising any facilities.

Events need to be adequately risk-assessed to find, reduce and control the risk to all those taking part and members of the public who may be attending.

Histiocytosis UK cannot accept liability for any loss, damage or injury suffered by yourself or anyone else as a result of taking part in a fundraising event organised in aid of Histiocytosis UK.

Some useful information on organising your own event can be found at the <u>Institute of Fundraising</u>.

For guidance on how to run an event safely go to the <u>Health and Safety Executive at http://www.hse.gov.uk/event-safety/running.htm.</u>

Food hygiene

This is vitally important. Please take great care when handling food and work to basic rules for safe preparation, storage, display and cooking. The <u>Food Standards Agency</u>. Produces a number of booklets.

1. Food Standards Agency - I'm a volunteer that sells food at ...

... I'm a volunteer that sells **food** at charity events. Do I need a **food hygiene certificate**? No. **Food hygiene certificates** are not a legal requirement. ...

http://food.gov.uk/business-industry/caterers/food-hygiene/charity-community-groups/food-hygiene-certificate

Data protection

Make sure any electronic or paper record you keep about people involved in a fundraising event complies with the Data Protection Act. As a rule of thumb, don't keep information about people any longer than you have to, and don't share information or data about someone without their permission. More information can be found at the <u>Information Commissioner's Office</u>. http://ico.org.uk/

Insurance

By organising your own fundraising event in aid of Histiocytosis UK, you are responsible for taking adequate steps to make sure that the event poses no risk to others. Check that any buildings or equipment that you hire are covered. Insurance is often included in the hire fee but not always.

You may need to consider arranging public liability cover for some events, which will protect you against claims made by third parties for injury or property damage as a result of negligence. In most cases, for public and/or hazardous events, you may need public liability cover in place. For private events this may not be necessary.

Alcohol and public entertainment license

If your event involves the sale of alcohol and/or live or recorded music, dancing, showing of a film or performance of a play, an indoor sporting event (including a boxing or wrestling match), or any entertainment of a similar nature, you may need a licence. Speak with your local authority, the police and other relevant parties as necessary.

Collections

Public collections take place in a public space. Public collections are governed by strict legal requirements and must be licensed by the Local Authority. Some popular premises for public collections, such as supermarkets, train stations, etc. may require you to arrange public liability insurance. It is worth checking with your location contact beforehand.

Private collections take place on private premises and do not need the permission of the local authority. If you are organising a private collection you only need the permission of the owner of the premises.

Raffles, lotteries and prize draws

There are strict legal requirements about the organisation of raffles, lotteries and prize draws. More information about these rules can be found at the <u>Gambling Commission</u>.