

# HI Fund

UK - Great Ormond Street



# The Children's Hyperinsulinism Fund

## Medical Team

Prof. Hussein

Clare Gilbert

Louise Hinchley

Kate Morgan

## Parents

Adrienne Burton

- Parent to Jessica
- Diffuse HI - pancreatectomy leading to diabetes

Helen Milne

- Parent to Charlie
- Focal HI - pancreatectomy curing HI but still unexplained hypoglycaemia

Matthew Hammond

- Parent to Scarlett
- Diffuse HI - on sirolimus

Laura Birnbaum

- Parent to David
- Focal HI - pancreatectomy curing HI

Michelle Walkley

- Parent to Alliza-Lily
- Diffuse HI - on diazoxide

# Beginnings

Started in 2003 by Adrienne and Julia along with members of the GOSH team.

A “sub-fund” of Great Ormond Street Hospital it allows people to donate to the specialist team through the hospital’s main charity.

Most of the funds go towards research including the employment of research assistants.

Other monies are used for the Christmas parties, running support meetings, travel expenses for staff and parent representatives

# **Fundraising - over £300,000 (410,000 €)**

## **What makes us so strong?**

- A medical team that have always supported us through ups and downs not only at the hospital but after we have gone home.
- Parents that are in contact with each other on a regular basis and have lots of excellent ideas to raise money.

## Big events supported by run-up events

Ronan's family raised £8,000 (10,800 €)

- quiz night, cycle ride, Belfast marathon

Charlie M's family raised £10,000 (13,500 €)

- quiz night, Thames walk

Charlie C's family raised £4,500 (6,100 €)

- psychic night, golf day, walk

Alliza-Lily's family raised £3,000 (4,100 €)

- sky dive, band night

Ellie and Sam's family raised £13,500 (18,100 €)

- 100 mile cycle ride



## Smaller regular events

Kirsty's family held a teddy bears' picnic.

Eloise's mum ran the Royal Parks Half Marathon

Scarlett's brother held a coffee and cake morning.

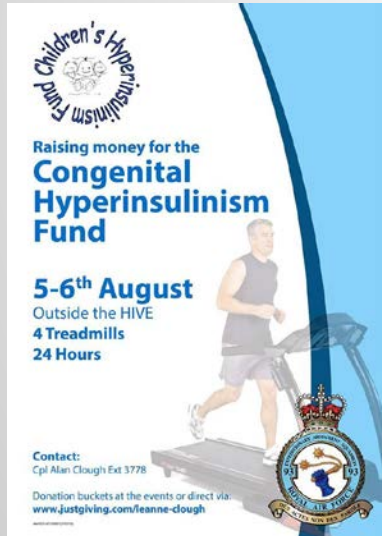
Nigel has run 3 half-marathon's for his son.





Amelia's family have raised over £8,500 (11,500 €) and still going strong

- Facebook craft page
- Parties with entrance fees
- Marathon
- Santa's post box
- Charity fashion shows
- 24hr run



# Where does the money go?

- Full time (almost) research person
- Research
  - Medications such as Sirolimus
  - Feeding difficulties
  - Long term neurological issues
  - Growth
  - Long term consequences of medical therapy
- Employment of a clinical assistant
- Christmas parties
- Parent information days

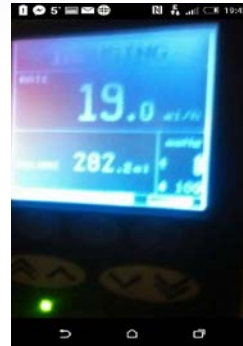




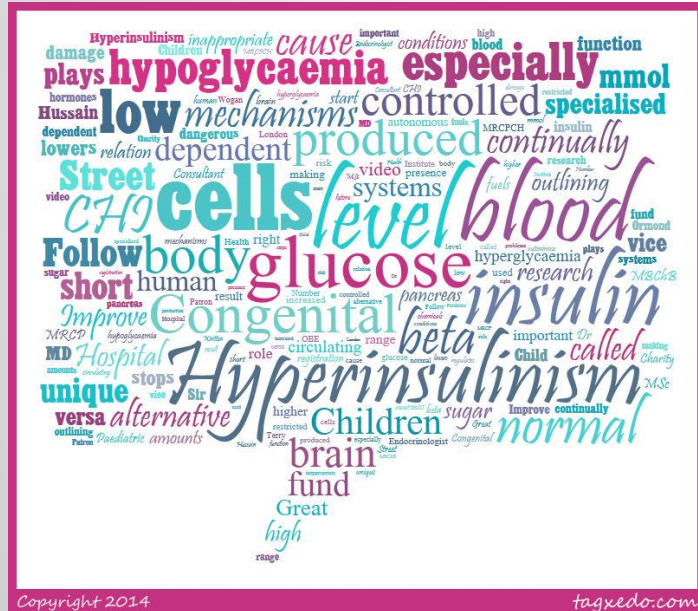
Saturday 5th December  
Lagoon Canteen,  
Great Ormond Street Hospital

# Facebook group - Children's Hyperinsulinism UK

# A place to literally share the highs and the lows!



Key role of admin is reminding our members that each child is unique and medical care should always be referred back to their medical team.





# Twitter group - Hyperinsulinism UK @HIFundUK

Where we share articles and patient stories.



By linking with famous people, groups and teams we hope to spread the word further.

A new charity is coming to the  
UK and Ireland

To raise awareness of CHI in  
UK and Ireland



Raising funds to sponsor  
and support families for  
education purposes  
at conferences in the UK

Supporting world  
class research



# Crowdfunding



- The new charity's first project is to raise £30,000 via a crowdfunding campaign which is set up and ready to go with many perks on offer including :
  - T-shirts, wrist bands, tote bags and many much bigger perks
- Monies raised will be for a variety of projects :
  - Further research into Sirolimus
  - Towards subsidising families to enable them to attend at a UK conference
  - Awareness raising
- We have been filming in London and writing our stories, so please watch out for our new charity's website and the crowdfunding links coming soon.

