

Haemochromatosis • UK

Helping people live with iron overload

+Fe

David Head MBA
Chief Executive
Haemochromatosis UK

“In the UK approximately 10% of our north European and particularly Celtic populations (i.e. about 5,000,000 people) are genetic carriers with one copy of the haemochromatosis gene (HFE) and some 0.5% (i.e. about 250,000) have 2 copies of the HFE gene and are at risk of iron overload and iron related diseases.

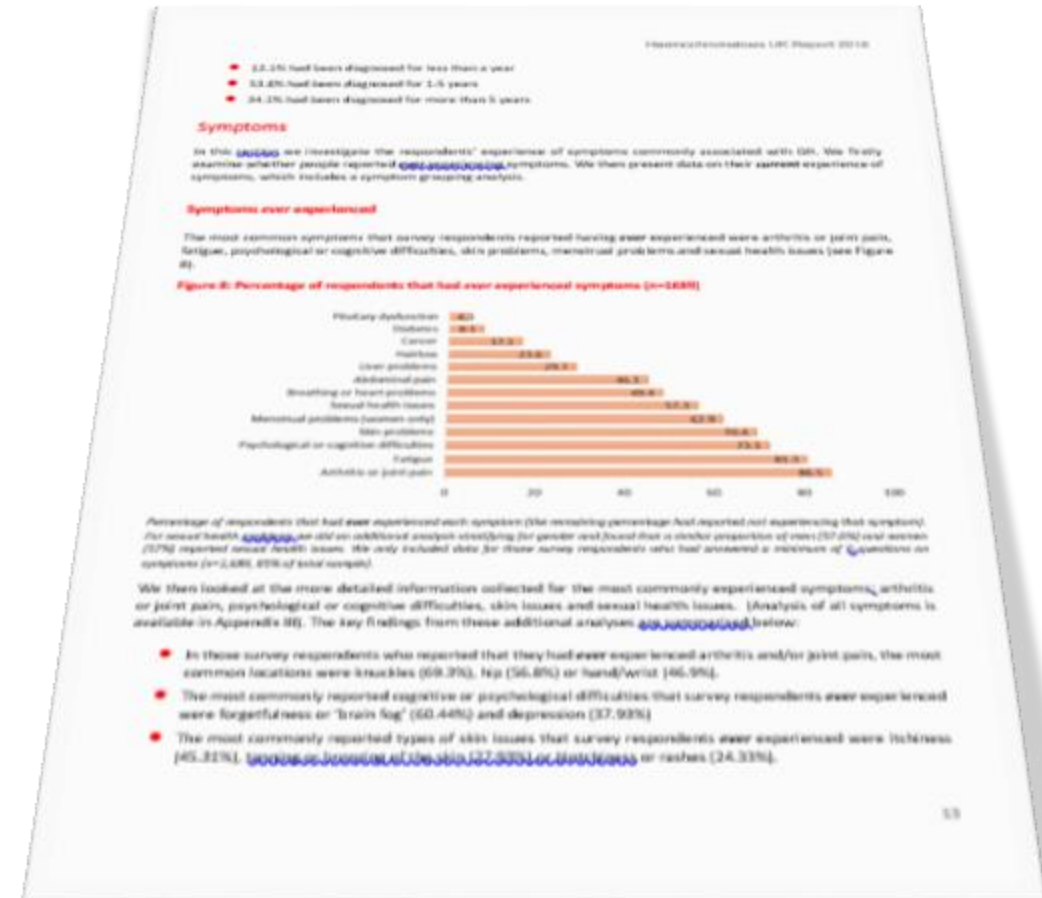
*Prof Edward (Ted) Fitzsimons
Consultant Haematologist
NHS Greater Glasgow and Clyde*

Patient Survey 2017

Data that provides evidence

Emphasis on quality of life issue

A chronic condition



The Iron Games:

Generating over £100,000

Irish firms
and families

Potentially repeating event



& Rushe



Assessments, Civils
RC Games
Air and Rail



TigerTurf
welcome to our world
be a good sport

JOY YO
Tiger



Haemochromatosis • UK • Fe
Helping people live with iron overload

THE IRON GAMES 2018

Teams

CAREYS WE CARE Tournen Group ECOL
GCL MITCHELLSON
DANNY SULLIVAN GROUP OLIVER CONNELL & SON LTD JRL
PC P.J. KEARY ADDINGTONS
MURPHY ASM METAL RECYCLING

Thank You To Our Sponsors

MCGEE Irish in Britain Pod-Trak
CUIRT FABRICATIONS LTD Irish Post

omello's all-ireland



THE IRON GAMES 2018

New Clinical Guidelines:

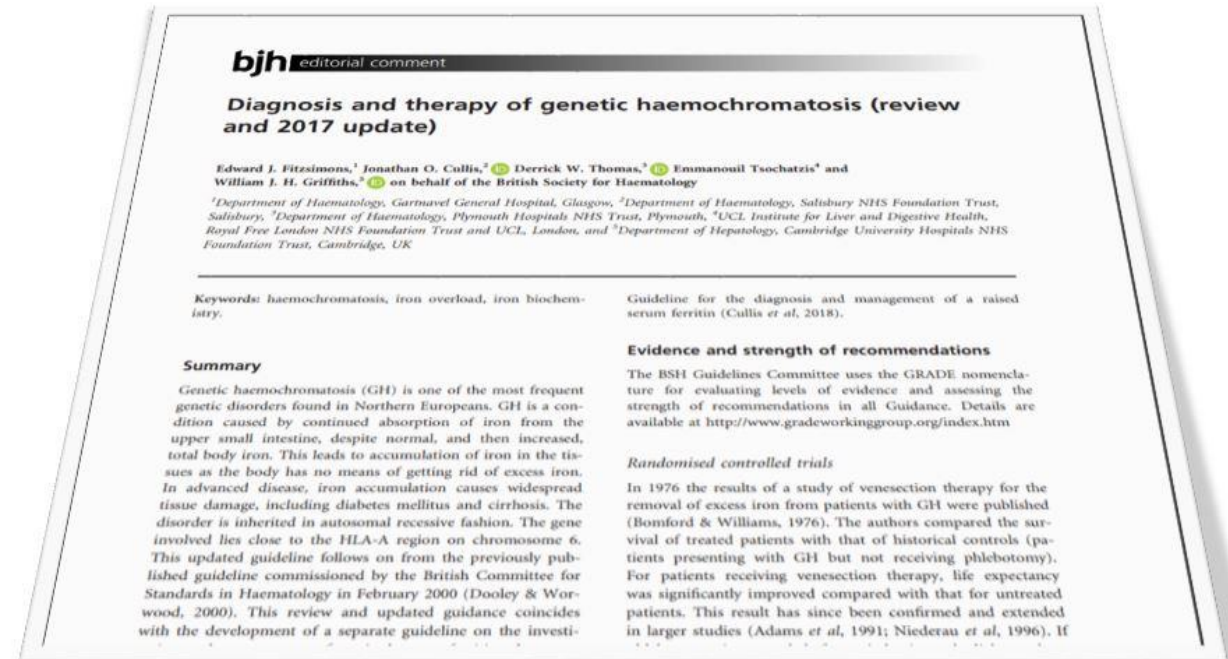
(British Society for Haematology)

Includes:

Family screening

Accessing testing

Accessing treatment



The Genetic Haemochromatosis Education Project (GHEP):

3 years / £330,000

Venesection, GPs, hospitals

Patient families and at-risk groups

Huge credibility and influence



EDUCATION
IS THE MOST
POWERFUL WEAPON
WE CAN USE
TO CHANGE THE WORLD

- NELSON MANDELA



Why is all this relevant

- We have evidence of need
- We have acceptance by Irish groups
- We have funding for education work
- We have clear guidelines

Irish Travellers

- At least 55,000 in England
- High level of risk
- Symptoms found in this group
- No information
- Little access to healthcare system
- Lack of trust in both directions



TRUST
IS KEY



Engaging with Travellers: so far

- Contact via trusted individual
- Credibility in being associated with Irish in Britain
- Meeting brokered and held

**Irish
in Britain**



TRUST
IS KEY



Engaging with Travellers: so far

- Cultural learning
- Agreed some next steps
- Working on materials
 - Video and audio
 - Travellers own voices
 - Differentiated reading materials
 - Social media
 - Short sharp “owned” messages

**Irish
in Britain**



TRUST
IS KEY



David Head MBA
Chief Executive
Haemochromatosis UK

(Did I mention that trust is key ?)