



United Kingdom

HAE UK

Laura Szutowicz Chief Executive Officer

Rachel Annals Executive Officer

About our country

- United Kingdom (total population around 64m)
 - England (>54m)
 - Scotland (5.3m)
 - Wales (3.06m)
 - Northern Ireland (1.8m)
- Estimated 1,500-2,000 HAE patients in the UK
 - Numbers known to HAE UK around 1,000- but duplication?
 - Wales; if incidence 1;50,000 there should be over 60 HAE patients in Wales



About our country

- Therefore can make reasonable assumption that HAE is HUGELY under-diagnosed
- WHY?
- Family history often concealed/misdiagnosed/incorrect referrals/sporadic nature of condition/many other factors

Management of HAE: Diagnosis and doctors

- General Practitioners (GP, family doctors) will rarely see more than one HAE patient in their lifetime
- Diagnosis tends to take a long time
 - First time presentations often referred to GI, allergy, dermatology, gynae...
- Most Immunology Centres now also deal with allergy so majority HAE patients should now be under Immunology
- There are around 30 specialist Immunology Centres in UK
- Referral is from GP to Immunology Centre (ideal!) but often via other specialities...

Management of HAE: Medication and treating attacks

- All HAE treatment is under Specialised Commissioning (some 70 therapy areas)
 - Directly funded by NHS England/national funding
- Many patients are successfully treated with low-dose androgens to prevent attacks
 - NHS England consensus document 2013
- Home Therapy is ‘Gold standard’
- However, still some clinicians unaware of funding process!
 - Free service not taken up...patients only allowed ‘one attack’

Management of HAE: Medication and treating attacks

- Strong advocate voices in Clinical Reference Groups
 - e.g. protocol for substituting oxandrolone for stanozolol
- Awareness amongst treating clinicians/specialist nurses very high
- However...patients frequently do not attend, lack of compliance, failure to engage...don't always understand difference between treatments and need for soonest possibly action...

Management of HAE: An emergency situation

- Typical A&E reaction:

We'll try half
the dose and
see what
happens

I've never
heard of it

I can't get
hold of
immunology!

You're
behaving
hysterically!

- Many patients hold supply of C1-INH and take it with them to A&E but.....delays.....ignorance.....'looks like an allergic reaction'
- Hence our A&E cards! Emergency phone line etc

HAE UK Support

- HAE UK formed as an NMO in 2010 and is now a registered charity
- Over 400 members
- Closed Facebook group
- Annual meetings
- Quarterly newsletters
- Fundraising

Our recent projects

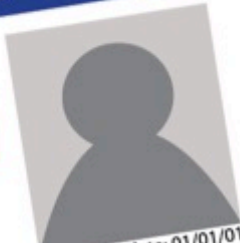
- HAE Lorry
- Annual Patient Day
- HAE UK Logo / rebranding
- HAE UK Youth Ambassador
- A&E cards



This patient suffers from Hereditary Angioedema (HAE)

Episodes can be life threatening and require urgent attention: consider emergency airway management

Name: John Johns
Date of birth: 01/01/1001
NHS number: 12345678
This patient is under the care of:
Name: Dr Simon Simons
Speciality: Immunology
Hospital: Manchester Hospital
Telephone: 01234 567890



Card issue date: 01/01/01



This patient suffers from Hereditary Angioedema (HAE)

Adrenaline / steroids / antihistamines are NOT effective

Administer: **C1 Inhibitor** or **Bradykinin B2 receptor antagonist (Icatibant)**

- Use in accordance with local HAE management protocol
- See BNF if no protocol available
- Stocked by many emergency departments. Patients may hold own supply. Source drug from hospital pharmacy, blood bank or regional holding centre depending on local arrangement if required
- Consider FFP if C1 Inhibitor / Icatibant is not available



For further information about HAE see: www.haeuk.org

Our future projects

- We are updating our website
 - Member area
 - Youth section
- First Scottish Patient Day on 1st October
- Annual Patient Day on 19th November
- We will continue to raise awareness – media campaigns, HAE unit visits and meetings



hae day :-)

- **hae day :-)** is about raising awareness, sharing information
- We used social media to share brief statements about HAE
- HAE UK poster campaign
- Joining in the Global HAE Walk

Keep in touch

- HAE UK

Laura Szutowicz (Chief Executive Officer)

Rachel Annals (Executive Officer)

Alex Graham (Youth Ambassador)

- www.haeuk.org
- support@haeuk.org
- Facebook – ‘HAE UK Association’



United Kingdom

hae
day :-)

MANY FACES
ONE FAMILY