



KENYA

Hereditary Angio Edema-Kenya

Patricia Karani

HAEi Kenya Patient Representative



Hereditary Angioedema Kenya



My Kenya

- Location - East Africa
- Capital city - Nairobi
- Population - 47 million people
- Currency - Kenya Shilling
- Language – Swahili
- Anticipated HAE cases – 940



AMAZING KENYA



Image of Kenyan athletes in the steeplechase





My amazing Kenya

**The journey of a thousand miles begins with
one step**

[Images of Kenyan male and female athletes winning the Boston and London marathons respectively]

Management of HAE: Diagnosis and doctors

- **Number of cases:** 5 confirmed cases
 - Family – 4 cases
 - New cases – 1 gentleman
- **Knowledge rating of HAE among medical personnel**
 - Out of 10, I would rate the knowledge of our Kenyan doctors to be 1 which is dangerously low
- **Which doctor's see HAE patients?**
 - Physicians and general practitioners in urban areas . In rural areas clinical officers and nurses
- **Is there a specialist center for HAE?**
 - There is no specialist centre for HAE in the whole country nor are there HAE clinically trained medical personnel.



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Management of HAE: Diagnosis and doctors

- **How do patients get an accurate diagnosis?**
 - Dependent on labs with international affiliations such as Lancet group of labs.
 - Cost is a major limiting factor – 200 to 300 USD for C 1 esterase levels 100 to 150 USD for C4 levels.
- **How do HAE patients rate their care in comparison to how other rare diseases are managed?**
 - HAE currently has no Government recognition.
 - Rare diseases recognized by the government are
 - Muscular dystrophy
 - Multiple sclerosis
 - Albinism.

Management of HAE: Medications and treating attacks

- What HAE treatments have a license in your country:
 - Only Androgens are licensed in our country – Generic form.
 - Modern HAE medications are not available in our country
- How are rare diseases viewed in Kenya?
- Are they a priority?
 - Most rare diseases are neglected since the emphasis is on infectious diseases such as TB/ HIV and the growing pandemic of Non communicable disease - CVD and cancer.
 - A condition with a prevalence rate of more than 1 out of 5,000 is not given any priority in Kenya



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Management of HAE

- Treatments are not reimbursed by National Health insurance scheme or private insurance.
- Most modern HAE medications are not available in the hospitals other than Androgens - Danazol.
- No access to emergency treatments other than fresh frozen plasma.
- Rare diseases are a major challenge due to:
 - Limited clinical expertise
 - Diagnostics are a real challenge – cost and logistics.
 - No patient support system
 - Treatments and medication may not be covered by insurance



Management of HAE: Emergency situation

- What happens in an emergency situation?
- HAE is not easily recognized by doctors in the emergency room
- In case of attack
 - One is given antihistamines, hydrocortisone and adrenaline
 - However, my doctor is raising more awareness though doctors and nurses at the ER

HAE support

- We have HAE patient group called HAE-Kenya Support Group.
- It is normally attended by two patients namely me and my brother Francis, my physician, Dr. Eric Njenga and our international support member from HAEA, Karen Baird.
- We now have a new member who was recently diagnosed with HAE.
- We also wish to include HAE patients in our adjacent countries namely Uganda and Tanzania that have one confirmed case each.



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HAE support

Highlights of what HAE Kenya has achieved:

- HAE-Kenya website hosted by HAEi is up and running
- Plans are underway to incorporate HAE-Kenya as an NGO in Kenya.
- HAE Kenya facebook page: we link with other patients from other countries
- I am currently writing a small booklet for HAE Kenya which will highlight my life with HAE
- We have conducted various interviews with the local newspapers and they have put a HAE article in the newspapers
- We are establishing a “Aid my HAE’ campaign programme to seek medical funds for individual HAE patients who will be in need of financial assistance for their HAE therapy. This will be put up on the HAE Kenya website.



Future of HAE

What are your plans/dreams for HAE in your country

- I decided to speak out and fight for my life and decided not to hide anymore in my suffering.
- My goal is to get all those who are suffering silently, to be able to come out in the open and give them hope that HAE is a manageable condition.
- Robust NGO to facilitate advocacy creation that would enable HAE to gain government recognition.
- Access to Life saving medications in both Public and Tertiary referral hospital.
- Creation of a fund that will facilitate provision HAE treatment and training of Medical personnel to empower them with knowledge to effectively manage HAE.
- Enrolment of more HAE patients to our support group to create an ever growing advocacy voice.
- Funding of HAE medications and treatment by private medical schemes.



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HAE DAY :-)

- HAE day is dedicated to having HAE advocacy activities in the country.
- This year I used it as a day to have a meeting with the new HAE Kenyan patients as well as a HAE patient in Uganda.
- The agenda of the HAE day was:
 - Share our personal experiences with regard to living with HAE.
 - Discuss how to Harmonize the quality of HAE care in the region.
 - Discuss efforts of fostering HAE advocacy through various media campaigns.



Kenya



Stay in touch

Organization name: Hereditary Angio Edema- Kenya

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Organization contact details

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Special Vote of Thanks

HAEi President – Anthony Castaldo

HAEi – Henrik Boysen

HAEA- Karen Dorsett

HAE UK – Ann Price and Rachel Annals

HAEi United Arab Emirates Rep. – Rashad Matraji

HAE Kenya Doctor – Dr. Eric Njenga



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HAKUNA MATATA!



Hereditary Angioedema Kenya

