

# History of HAE Australasia:

In 2011 a group of patients and carers living with the medical condition Hereditary Angioedema (HAE) were brought together in a joint effort by HAEi (the International Patient Organization for C1 Inhibitor Deficiencies) and the Australasian Society of Clinical Immunology and Allergy (ASCI) to discuss the current state of HAE in Australia and what could be done to improve the quality of life for sufferers of HAE in the future. From that meeting, a group of 5 women volunteered their time outside of work and family commitments to establish and operate HAE Australasia Ltd (formerly HAE Australia Ltd) - an Australian, not-for profit, health promotion charity. The passion that the board of directors has for the cause is evidenced by the phenomenal achievements made in such a short space of time including expanding operations to include New Zealand. HAE patients and carers have seen a significant change in the HAE landscape during this period. And it's just the beginning!

## Our Objectives:

Provide a support network for those with HAE - they need to know they are not alone.

Provide HAE education to patients, carers & health care providers

Raise awareness of HAE in the medical & general communities

Assist research organisations with their studies into the causes, prevention & treatment of HAE

Look at ways to make treatment/ medications more accessible and affordable for patients

## Stay In Touch:

### **Become a Member:**

To ensure you are up to date with news & events, go to

[www.haeaustralasia.org.au/become-member](http://www.haeaustralasia.org.au/become-member)

### **Join Us On Facebook for Exclusive Member Only Access to Our Support Network:**

Available to members only (see "Become a Member" above)



Get your friends & family to support us on Facebook: [www.facebook.com/HAEAustralasia](http://www.facebook.com/HAEAustralasia)  
"HAE Australasia Awareness & Support"

Follow us on Twitter: @HAEAustralasia

### **Donate to HAE Australasia:**

Go to [www.haeaustralasia.org.au/donate-now](http://www.haeaustralasia.org.au/donate-now)

### **Are you an EveryDay Hero? Fundraise for a Great Cause!**

Go to the following link & become a supporter!  
[www.everydayhero.com.au/charity/view?charity=4093](http://www.everydayhero.com.au/charity/view?charity=4093)

Visit our website: [www.haeaustralasia.org.au](http://www.haeaustralasia.org.au)

Send us an email: [info@haeaustralasia.org.au](mailto:info@haeaustralasia.org.au)



A.B.N. 34 152 887 440.

HAE Australasia Ltd is an endorsed Australian Deductible Gift Recipient  
PO Box 285 Webb Street NARRE WARREN VIC 3805 AUSTRALIA



## **Our Mission:**

*To enhance the quality of life  
for those living with  
Hereditary Angioedema (HAE)  
in Australia and New Zealand.*



## **Information About HAE Australasia**

# Hope

*Giving hope to patients by providing support and letting them know they are not alone*



## Our Activities:

### Private Forum for Patient & Carer Discussions

Providing a support network of HAE patients and carers to share experiences, ask questions of each other and to provide a sympathetic ear when needed.

### HAE Meet Up's

Local, educational, but informal meetings for HAE patients and carers to get together and strengthen the support network

### Connecting with Patients

Strengthening the network between our organisation, patients and health care providers to encourage referrals of newly diagnosed HAE patients to HAE Australasia and for connections to be made with those that have been previously diagnosed.

# Advocacy

*Providing a voice to HAE patients to raise awareness about this rare medical condition & the issues that surround it*



## Our Activities:

### Engaging with Governments

Discussing treatment options (current & potential) and medication availability with Government departments to encourage subsidisation for much needed therapies.

### Engaging with Medical Professionals

Giving a patients perspective of the condition to medical professionals and pharmaceutical representatives during their training sessions

### Patient Advocacy

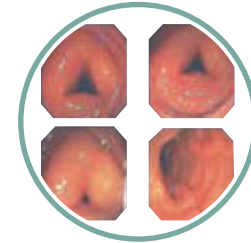
Talking to medical professionals on behalf of patients where needed.

### Finding Global Best Practice for Our Patients

Representing Australian & New Zealand patients at Global HAE Conferences to ensure that we are aware of the best practice HAE treatments that we need to strive for.

# Education

*Educating patients, care givers, health care providers & the general community about HAE to help improve the HAE patient's quality of life*



## Our Activities:

### Annual Patient & Carer Meetings

Educating patients and carers about HAE, current research and progress with medication.

### Educating & Raising Awareness with HCP's

Participating in medical conferences to increase the awareness of HAE & HAE Australasia in the medical community

### Furthering HAE Research

Assisting research organisations with various studies to increase the knowledge of HAE and connecting potential participants with researchers.

### Dedicated Australian & New Zealand HAE Website

Developed & maintain a dedicated HAE website containing quality information from reputable sources

### Educating Patient, Carers & General Community

Regular updates to HAE patients, carers, & the general community via the website, newsletters, Facebook & Twitter.