



Australia & New Zealand HAE Australasia

Fiona, Anne & Olivia

HAE Australasia Board Members

About Australasia

- Support patients and carers in Australia & New Zealand
- Population:
 - Australia - 24.3 million
 - New Zealand - 4.6 million
- HAE patient population in Australasia
 - #'s by prevalence: Australia - 450
 - New Zealand - 50

 - #'s of known patients: Australia - 110
 - New Zealand - 14



Management of HAE in Australasia: Diagnosis and doctors

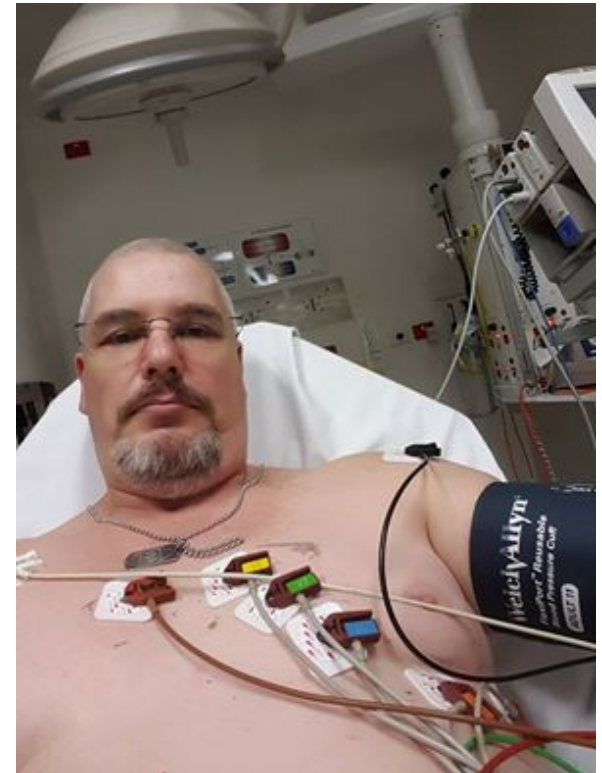
- HAE patients are cared for by Immunologists in both Australia and New Zealand
- We have knowledgeable Doctors in major cities of both countries
- General Practitioners are lacking in knowledge and awareness of HAE
- Accurate diagnosis is by blood tests
- HAE care is ‘hit and miss’ depending on their Doctor and hospital they attend

Management of HAE: Medication and treating attacks

- Australia:
 - Danazol Reimbursed
 - Tranexamic Acid Reimbursed
 - Firazyr (icatibant) Reimbursed (some restrictions)
 - C1 Esterase Soon to be reimbursed with restrictions, in hospital
- New Zealand:
 - Danazol Reimbursed
 - Tranexamic Acid Reimbursed
 - Firazyr (icatibant) Reimbursed (some restrictions)
 - C1 Esterase In hospital (some special use)
- Rare diseases are not a high priority in Australia or New Zealand

Management of HAE: An emergency situation

- Some hospitals Emergency Rooms with regular HAE patients recognize symptoms and treat patients as necessary
- Medication is not always available or administered promptly
- Often patients go through unnecessary tests and procedures



HAE Support



- We are a member organization of HAEi
- We have 167 members
- Website: www.haeaustralasia.org.au
- Closed Facebook page for patients and carers
- Open Facebook page for awareness
- Twitter
- Bi-monthly newsletter
- Bi-annual Australasian meetings
- Regular 'Meet Ups' around Australia and New Zealand
- Other educational meetings for patients, carers and medical professionals

HAE Australasia education and awareness events



HAE AUSTRALASIA INVITES YOU TO ATTEND THE

WA HAE PATIENTS
& CARERS
MEET-UP

28TH NOVEMBER 2015
10AM - 2PM
EAST FREMANTLE YACHT CLUB

FREE INFORMAL EVENT TO MEET OTHER PATIENTS &
CARERS PLUS HEAR FROM GUEST SPEAKERS!
MORNING TEA, LUNCH, TEA/COFFEE PROVIDED.

RSVPS ESSENTIAL -
AMANDA@HAEAUSTRALASIA.ORG.AU



HAE awareness and fundraising activities



Jeff and Abi run for HAE
Sydney Half Marathon 2015



Printed and online media



A family curse

From left: Dad, Jess and me during an attack

Treasuring the GOOD DAYS

We could all die in our sleep, but we don't dwell on it

Tania Bogoyevitch, 45, Sunnybank Hills, Qld.

One of my earliest memories is riding my bicycle with my older brother. Suddenly, I lost my balance and fell face first onto the handlebars. "Are you all right?" my dad asked, helping me up. I nodded, trying to be brave. I was only four. The next morning, I woke up and couldn't open my eyes. I started screaming. "Your eyes are swollen, sweetie," Dad said. "Remember you fell off your bicycle yesterday?" Mom said. A realisation dawned on me. "You like Daddy?" I asked. My father suffered from a strange condition where his face swelled up. "It looks that way," Mom replied, sadly. It began to happen regularly. I'd knock my hands or feet somewhere and they'd end up swelling. We didn't have a name for it, but Dad knew from experience that the swelling lasted for a day or so before it went down again. A year later, I was helping Mom change my baby brother Matthew's nappy when we noticed that his feet were swollen. "It's got it, too," I said. Within five days the swelling had spread through his whole body. Our doctor had no idea what it was. It never seemed to affect my older brother, but Dad, Matthew and I got it all the time. Once, when I was nine, Dad's face swelled up like a balloon. I watched in horror as he tried to sip his tea, but his lips were so swollen it dribbled straight out his mouth. His tongue was hanging out and he started gapping for breath. He couldn't speak and his face was pain. "Dad's always so closing," Mom said, panicking. She reached for the phone to call an ambulance but Dad shook his head forcefully. He didn't like going to the hospital.

After several hours, the swelling went down. "That was scary," he said, when he could finally talk. Then, when I was 18, Dad found an immunologist who'd heard about similar cases in America. Matthew, Dad and I got tested and were all diagnosed with a rare blood condition called hereditary angioedema or HAE. We're missing a protein in our blood, which causes swelling all over our body. If our throat or lungs swell up too much, we could die. There was no known cure or prevention, only medicine to reduce the swelling. Stress or knocks could trigger an episode. Once an attack came, it could last from 12 hours to several days. My dad's family got tested and none of them had it, so doctors thought it started with a mutation in his genes when he was conceived. It was a pretty shocking diagnosis, but we tried not to let it rule our lives. One morning, I woke up with a tight feeling in my throat. Mom and Dad took me straight to hospital. Because worrying made it worse, I was lying there with my eyes closed, trying to relax when I overheard a doctor. "If she can't make a sound in the next 10 minutes, we'll perform a tracheostomy."

"There was no known cure"

OUR DEARLY SEAS A rising nearly stole my girl


OUR big day went up in flames

28 **Take5**



Future of HAE

- Find more patients in our region
- Gain better access to all available HAE treatments
- Create more awareness of HAE
- Better education of Medical Professionals for quicker diagnosis



hae day :-) is creating global
community awareness

Many Faces One Family



Stay in touch

- HAE Australasia
 - Fiona Wardman - President
 - Anne Wilkinson – Vice President
 - Louise Ridout - Treasurer
 - Olivia Worthington – Board Member & New Zealand Rep
 - Amanda Tionisio - Secretary

- Contact details
 - www.haeaustralasia.org.au
 - HAE Australasia (closed Facebook page)
 - HAE Australasia Awareness and Support (open Facebook page)
 - @HAEAustralasia

Australasia: Australia & New Zealand

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MANY FACES
ONE FAMILY

