

HAE HEALTHY MINDS

Improving the mental health of those affected by the rare and life-threatening disease, Hereditary Angioedema



HAE Australasia Ltd
Pre-Budget Submission for the
Australian Federal Budget 2017/2018

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Australian Federal Government
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THE CURRENT SITUATION - MENTAL HEALTH & HEREDITARY ANGIOEDEMA

Mental Health is the 3rd highest burden disease group in Australia (1). Sufferers of mental illnesses are commonly living with other conditions, or develop other high-burden diseases as a result of their poor mental health. It has been found that sufferers of rare and life-threatening diseases have a higher instance of poor physical and mental health when compared to the general population.

HAE Australasia's concern is for those that suffer from Hereditary Angioedema (HAE) - a chronic, rare, lifelong, genetic disease, with random and recurring symptoms that can be life threatening. Symptoms present as swelling of various parts of the body including face, tongue, airway (life-threatening), intestinal tract, arms, hands, legs, feet, torso, genitals. Based on worldwide statistics, there are estimated to be 480 patients in Australia (2).

HAE patients are more likely to have depressive symptoms when compared to the general population - a study (3) has found that HAE patients are 2.5 times higher on a depression scale than the general population, with over 40% of them reaching scores indicative of clinical depression.

The mental health and emotional wellbeing of HAE patients is affected by: (see also Appendix A: HAE Healthy Minds Pilot Workshops - Reports)

- Living with a disease that could threaten their life
- Not knowing when to expect an "attack" - HAE symptoms may or may not have triggers so a patient can never really know when they will suffer the symptoms of HAE
- Wondering how the next attack will affect them - will it make everyday tasks more challenging, will they be absent from a planned event, work or school, will they need to be bed-ridden due to severe pain, will they be fearing for their life?
- The hereditary nature of the disease and the potential for passing it onto children
- A feeling of guilt about how their own disease affects others (family, friends, employers etc)
- Concern that doctors do not have any or enough knowledge of the condition to appropriately treat the disease, particularly in an emergency situation - so who can they talk to?
- The potential of suffering side effects of medications that are prescribed to treat HAE
- Inability to travel or consider certain careers due the HAE impact on day to day living.

In addition to HAE patients, those caring for HAE patients (parents, partners, siblings, lived ones, friends) also suffer the same anxieties about the condition. Watching someone suffer the pain of HAE and hearing their anxieties can take a toll on the carer's mental health.

SOLUTION - HAE HEALTHY MINDS

To ensure that HAE patients and carers have access to mental health services tailored to their unique circumstances, HAE Australasia recommends the implementation of "HAE Healthy Minds" workshops. The proposed workshops, facilitated by clinical psychologists in a safe environment, are tailored to provide coping strategies for situations unique to HAE patients and carers as well as allowing the participants to feel heard and connected whilst meeting others with the rare disease.

HAE Australasia is requesting \$75,000 from the Australian Federal Government to fund 21 workshops around Australia during the next 3 years. The funding will cover the costs of the facilitating clinical psychologists, venue hire, attendee costs and associated resources.

These workshops will provide access to mental health support services for HAE patients and carers and, in the long term, improve their overall quality of life and reduce the burden on other health services.

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WHAT IS HEREDITARY ANGIOEDEMA?

Hereditary Angioedema (HAE) is a chronic, lifelong disease, with random and recurring symptoms that can be life threatening. The unpredictable nature of this disease can have a significant impact on a patient's emotional well-being leading to a series of mental health issues.

HAE is a rare, genetic, medical condition where patients have a deficiency or abnormal function of the protein C1 Inhibitor. This condition causes spontaneous episodes of swelling of various parts of the body, including:

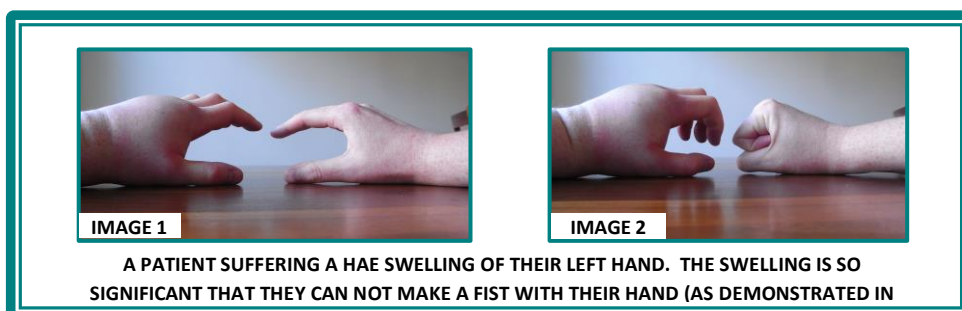
- Airway, tongue or face – these swellings, if not treated quickly or appropriately, can lead to asphyxiation.
- Intestinal swelling - causes intense pain, vomiting, diarrhoea and dehydration for days on end.
- Other areas of the body (hands, arms, shoulders, torso, genitals, legs, feet) - even though swelling in these areas may not be life threatening, the presence of a swelling is still a burden to the patient as the symptoms may prevent the patient from undertaking every day activities including work, education or caring for their family.



For patients without a HAE diagnosis, health care professionals may consider the above symptoms to be a result of allergies, abdominal complaints or injuries - treatments for these conditions do not relieve the HAE patient of their suffering. Unnecessary medical investigations may also be performed if HAE is not considered, all whilst the patient is still suffering through their HAE attack. Even if a patient does have a HAE diagnosis, ineffective treatments and unnecessary investigations are still performed in emergency situations where the patients are seen to by general medical staff that are unfamiliar with the disease - situations that increase a patient's anxiety about accessing emergency treatment.

Studies have revealed that approximately 50 – 75% of HAE patients suffer at least one life threatening attack at some point in their life (2). Some patients suffer airway attacks on a more frequent basis (weekly, monthly or yearly). Knowing that a life-threatening or debilitating HAE attack can spontaneously occur increases the risk of mental health issues such as anxiety or depressive disorders - patients and carers have a serious fear of what the next minutes, days, month or years may hold for them, they don't know if they can plan events or travel (just in case they become unwell due to HAE), or if treatment will be available in time to save their life. Life for HAE patients can have many unexpected and debilitating interruptions.

HAE is a rare condition – it may only affect approximately 480 people in Australia (2). However, these 480 people should still enjoy the same quality of life as those who were genetically given good health. Further information about patient experiences with HAE and how it affects their quality of life can be found in Appendix B: HAE & The Patient Experience.



HAE AUSTRALASIA – OUR SHORT HISTORY

Up until recently, the situation for Australian HAE patients was critical - they were faced with health care providers that had little to no knowledge of the condition, diagnosis was delayed and therefore patients endured years of suffering and treatment options were very limited.

However, in 2011, a group of 5 volunteers formed HAE Australia Ltd. Our vision was to enhance the quality of life for those living with HAE in Australia. Information about the Directors of HAE can be found in Appendix C: Team of HAE Australasia.



By 2013, we saw that the need of the 90 estimated New Zealand HAE patients was as urgent, if not more so, than Australia's and decided to include New Zealand in our activities. This led to a change of our organisations name – we are now known as HAE Australasia Ltd.

Our Mission:

To help Australian and New Zealand patients gain subsidised access to more treatment options, empowering patients through education about their condition, educating the medical and general community about HAE to ensure patients are recognised and diagnosed more quickly, and to connect patients and carers with our support network – they need to know that they are not alone.

See Appendix D: HAE Australasia's Mission, Vision, Objectives for further details

HAE Australasia's Achievements So Far

Prior to HAE Australasia, there was NO representative body in existence in Australia or New Zealand for HAE. HAE patients had almost no contact with anyone else with the condition and the information that they had may have been provided by a health care provider with little to no knowledge themselves of HAE. Patients were not receiving adequate care.

HAE Australasia is governed by a board of 5 women who are either HAE patients or carers. We all volunteer our time outside of work and family commitments and are very passionate about making a difference. This is evidenced by the phenomenal achievements that have been made in the short time since our organisation was formed which include establishing a support network, developing a dedicated HAE website, playing a pivotal role in seeing new treatments becoming accessible to patients and assisting with HAE research (see Appendix E: HAE Australasia Projects & Outcomes).

Despite these successes, there is still a long way to go to see that HAE patients' quality of life is improved, particularly in regards to the emotional well-being and mental health of patients and carers. With a relatively modest investment of funds from the Australian Federal Government, we at HAE Australasia believe we have the skills and networks to achieve significant improvements over the present situation.

THE ISSUE – POOR MENTAL HEALTH OF HAE PATIENTS & CARERS

The Australian Burden of Disease Study (published in 2011) (1) analysed the burden of living with ill health and also the burden of dying pre-maturely due to ill health. This study demonstrated that Mental Health is the 3rd highest burden disease and an area of priority for the Australian Government.

Anxiety disorders, depressive disorders and other mental health issues were identified in this study as being in the top 5 leading causes of total burden in males aged in the 5 - 44 age groups and in females aged in the 5 - 64 age groups. People that are within these age groups include school age children, adults in higher education, and those that are active within the community and workforce. To have mental illnesses affecting the population at pivotal points in their life can have a significant and long-lasting effect on the overall community.

Within the population, there are those that are affected by the rare disease HAE. It has been found (3) that, when compared to the general population, HAE patients reported poorer health-related quality of life and poorer mental health conditions.

HAE patients were 2.5 times higher on a depression scale than the general population - they scored 8.1 on the Hamilton Depression Inventory Short Form (HDI-SF) versus 3.1 of the general population. 42.5% of the HAE patients reached scores of 8.5 or more which suggests the patients need for evaluation for clinical depression.

This study also noted that, due to their most recent HAE attack, workers lost an average of 3.3 days and students lost an average of 1.9 days. This reduction in productivity affects employers and the education of HAE students. This can have a significant financial and emotional impact on patients and their families.

The life experiences of patients and carers that are in contact with HAE Australasia reflect those demonstrated in the above listed study. They have said that their mental health and emotional wellbeing is effected by:

- Living with a disease that could threaten their life
- Not knowing when to expect an “attack” - HAE symptoms may or may not have triggers so a patient can never really know when they will suffer the symptoms of HAE
- Wondering how the next attack will affect them - will it make everyday tasks more challenging, will they be absent from a planned event, work or school, will they need to be bed-ridden due to severe pain, will they be fearing for their life?
- The hereditary nature of the disease and the potential for passing it onto children
- A feeling of guilt about how their own disease affects others (family, friends, employers etc)
- Concern that doctors do not have any or enough knowledge of the condition to appropriately treat the disease, particularly in an emergency situation - so who can they talk to?
- The potential of suffering side effects of medications that are prescribed to treat HAE
- Not being able to travel or consider certain careers due the HAE impact on day to day living.

OUR RECOMMENDATION - HAE HEALTHY MINDS

Patients and carers need to be given the opportunity to recognise they are suffering from different forms of mental health issues. Living with such a chronic, rare and life-threatening disease can leave people feeling quite helpless - the disease may have affected their education and job productivity, therefore leaving them under financial stress as well. Being able to source HAE specific help for their mental health would be of significant benefit to them, their family and community.

Our organisation would like to provide a support service to our HAE patients and carers to:

- Ensure that they are provided appropriate guidance from specialists in the HAE area - HAE has a unique set of mental health issues that need to be focussed on
- Give them the strategies and tools needed to cope with living with HAE
- Gives them an opportunity to support others, share ideas and ways of overcoming their issues.
- Give them a safe space to speak about issues that are troubling them, and an opportunity to network and keep in contact with others that understand what they are going through
- Give them tools to use every day to overcome anxiety, depression and stress not just relating to HAE
- Give carers tools to use, also a platform to discuss how they are feeling about caring for someone with a rare disease with or without mental health complications

How The Workshops Will Function:

This support service would be in the form of our HAE Healthy Minds workshops which would operate as follows:

- Free of charge to attendees to ensure this vital support is accessible to all HAE patients and carers
- Facilitated by clinical psychologists
- Workshops will have two separate groups - one for adults and one for children and adolescents - this will ensure that the specific needs are met utilising methods tailored for each group
- Each workshop:
 - o Duration: 3-5 hours (depending on number of participants) with a short break
 - o Process:
 - Introduction from members of the group
 - Guidelines for the group articulated
 - Selection of topics to be covered chosen by participants
 - A short list of topics thoroughly discussed. The facilitator:
 - ensuring equal contribution from participants
 - keeping the discussion on track and positive
 - encourage sharing of strategies that participants have found helpful
 - provide summaries of discussions
 - selectively provide input where needed
 - Feedback of the activity
 - Determine any recommendations for future workshops

Outcome of Pilot Workshops:

HAE Australasia have trialled these workshops to determine if this method of providing mental health support to HAE patients and carers would be appropriate. The pilot workshops have been very well received by participants and the feedback documented by the facilitating clinical psychologists has reflected this (see below). Australian Federal Government funding would ensure that HAE patients and carers can have access to mental health services facilitated by clinical psychologists knowledgeable with HAE. Please refer to Appendix A: HAE Healthy Minds Pilot Workshops - Reports for further reports.

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16th January 2017

Fiona Wardman
HAE Australia
PO Box 285
Narre Warren VIC 3805

Dear Fiona

RE: Funding for future HAE groups

I would like to take the opportunity to make a few comments about the small support groups that we have been providing in anticipation of your application for further funding.

As you know from the reports, the attendees benefit from the opportunity to learn from each other, feel connected, form enduring relationships and have a discussion about coping facilitated by a mental health professional very helpful. The setting and structure of the groups means that they provide some positive elements that the larger seminars and forums cannot. One comment in our evaluation form said "Definitely worthwhile in combination with the bigger forums, as it did ensure positive outcomes and talking about worries rather than just being informational".

We have received positive feedback. The only constructive criticism was in fact for us to provide more structured content within the group, where we had left it open for group discussion. Other comments and feedback have included "I found it useful to have an opportunity to discuss how hard things are for me but not be caught up in loads of sympathy", "Very useful day" and "A good opportunity".

The limitations that we have discovered pertain to finding mental health professionals in each capital city who are familiar with coping with rare diseases. This is needed as Maria Milic and I cannot afford to volunteer frequently to travel. A combination of some funding and ongoing networking efforts may help to manage this.

In summary, these groups constitute a unique and powerful way to help people affected by HAE in a cost-effective way. A little capital can help a lot of people. Based on other illnesses, I predict that the focus on empowering oneself with information and using consumer network can reduce the use of and burden on specialist health care.

Yours sincerely,



Dr Christopher Basten (M.Psychol.; PhD.)
Clinical Psychologist

Who Can Benefit From The HAE Healthy Minds Workshops?

These workshops will be available to Australian HAE patients and carers. Funding from the Australian Federal Government would allow us to hold these workshops around Australia - 7 per year, for 3 years. This would provide HAE patients and carers with an opportunity to attend one or more workshops which would be of significant benefit to them as they will be able to build on the coping strategies that they develop.

It is estimated that there are 480 HAE patients in Australia in addition to the carers that support them. 150 Australian patients and carers currently access other services of HAE Australasia. Our organisation has a number of projects underway to locate the remaining patients and provide access to vital HAE support.

Project - HAE Healthy Minds Workshops

Details of Project/Purpose of Funding:

To provide HAE patients and carers with free access to tailored mental health workshops where they will be given the tools and coping strategies to live life with the rare and life threatening disease, HAE. See Appendix A: HAE Healthy Minds Pilot Workshops - Reports for outcomes from our pilot workshops.

Budget for Project:

Workshop Costs (Venue Hire, Catering, Travel, Psychologists Fees)	\$3,500
Number of Workshops per Year (various locations around Australia)	<u>7</u>
	\$24,500
Additional Supporting Materials and Resources	<u>\$500</u>
Total Cost per Year	\$25,000

We are requesting projecting funding support from the Australian Government for **3 years**.

Total amount requested from the Australian Federal Government \$75,000
to be provided by Quarter 1, 2017/2018

Government Legislation Changes Required?

No - HAE Australasia's activities simply need to be considered as part of the 2017/2018 Australian Federal Budget.

Measuring The Project's Success:

HAE Australasia is strongly focussed on monitoring progress and improving processes wherever possible. Feedback will be provided to the facilitating clinical psychologists at the end of workshops and reported back to HAE Australasia. Also, HAE Australasia, in conjunction with our Medical Advisor, conducts Quality of Life (Q.o.L) surveys. Survey results will identify changes to the mental health issues identified by patients and carers. These reports will indicate the success of the workshops in regards to the improvement of patient and carers mental health. The most recent Q.o.L survey results can be found in Appendix G: HAE in Australia 2015 (Quality of Life).

Other indicators (including quantitative statistics and financial measures) will also be monitored, analysed and actioned to ensure continued improvement in the provision of the HAE Healthy Minds Workshops.

Where funds will be sourced after the proposed Government support:

HAE Australasia has strong relationships with existing funding providers. Funds currently sourced from these resources (and for the next 3 years) have been directed to projects dedicated to:

- increasing awareness of the condition amongst health care providers to ensure quicker diagnosis and treatment of HAE
- educational events and resources for diagnosed patients
- strengthening the support network for diagnosed patients and carers

Funding for a dedicated mental health program is required from the Australian Government as soon as possible to ensure that tailored HAE mental health services are expedited to HAE patients and carers.

After the initial 3 year period, it is expected that funding for the HAE Healthy Minds program will be sourced from other funding providers.

“One can only imagine the progress this energetic and capable group could make in key areas such as patient identification, education, diagnosis, and research if they had access to more funding sources.”

“It is remarkable that this intrepid group of dedicated volunteers has made such great strides in transforming the lives of a very sick and neglected patient population with relatively scarce financial resources.”

Our Recommendations Align with Current Government Policies

Department of Health Goals - Outcome 1 - Population health

We aim to improve the mental health of those living with HAE. This would lead the HAE community to becoming more actively involved in education, employment and the community.

Department of Health Goal - Outcome 5 - Primary Health Care

Gives HAE patients and carers access to specifically tailored mental health services that do not currently exist for this group. The workshops will provide guidance and help to manage the mental health issues that surround living with a chronic, rare and life-threatening disease.

“Feelings vary from deep sadness and depression, to a sense of gratitude and satisfaction to family, friends and self for the ability to keep on keeping on.”

“[By sharing coping strategies with others] I don't feel so isolated or alone. It helps me overcome insecurities and gain positive valuable effective information.”

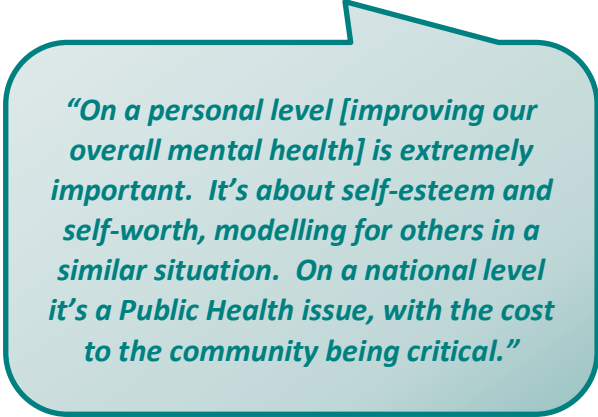
CONCLUSION...

Hereditary Angioedema (HAE) is a rare, chronic, lifelong disease, with random and recurring symptoms that can be life threatening.

This document discusses a recommendation of how the Australian Federal Government can support HAE Australasia to implement a program of HAE Healthy Minds Workshops which is vital to improving the mental health of those living with HAE, either as a patient or carer.

HAE Australasia is requesting \$75,000 from the Australian Federal Government which is vital for the implementation of these workshops. These funds will provide for 21 workshops over 3 years. Each workshop will have an adult and a child/adolescent group facilitated by clinical psychologists.

Together, HAE Australasia and the Australian Federal Government can help to significantly improve the mental health of HAE patients and carers, which can help them to achieve an improved quality of life and enable an increased participation in their community and the economy.



“On a personal level [improving our overall mental health] is extremely important. It’s about self-esteem and self-worth, modelling for others in a similar situation. On a national level it’s a Public Health issue, with the cost to the community being critical.”

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4th July

Fiona Wardman
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Dear Fiona,

Re: Summary of the HAE support group facilitation.

I write with a summary of the support group that was held on Saturday 18th June.

Purpose and Aims:

The planned main aims were to provide a small group format that would (a) help people to share effective coping strategies and resources for common problems associates with HAE, (b) to feel heard and connected and (c) meet others with HAE.

Structure:

- The group ran from 1pm to 4pm, with a 25 minute refreshment break in the middle.
- Two parallel groups were organised: one for adults and one for children and teens.
- Participants were required to register in advance so that the number of people and who would come was known.
- People with HAE and their family and carers were included and participated.

Materials and Venue:

- The Sydney venue was a community centre that had several adjacent meeting rooms, chosen for its proximity to public transport, parking and fairly central location.
- The materials for adults included name badges and one printed sheet to use as a prompt for discussions (appended).

Attendees:

Eight adult and two children attended. Both children had HAE. Five adults had HAE and three were partners.

Process (Children):

This group was exceptional (may not be the same in other places when done again) in as much as there were only two present and they were siblings. The process involved the group leader having some age-appropriate games to play that permitted all the engage with each other and to have a non-verbal activity to focus on while some discussions were had. Open questions were used to start a conversation about difficulties and to explore coping with these difficulties.

Given some issues that were raised, the group leader sought permission to give feedback to a parent, which was done.

Process (Adults):

1. An introduction process was used to commence whereby people briefly introduced themselves using four prompts suggested by the facilitator and given in writing.
2. Guidelines for the group were articulated: (1) *respect* for others, as shown through no interrupting, no criticism or negating a point of view, (2) *confidentiality* – we all needed to promise that nothing would be repeated outside the room after the group, and (3) *positivity* – while it was expected that problems and challenges would be discussed, the focus was to remain on how people adapted and coped and managed in order to avoid the sense that HAE was awful or that it was a day of complaining.
3. Selection of topics was undertaken by asking participants to select the six main issues that they wanted to discuss off a list (the list is attached). Initially, just to get started immediately, participants read out the three topics of greatest interest and the common themes were noted and discussion started. During the break a longer list of challenges was identified by the facilitator who read through participants' rankings of the issues.

The topics that were rated as most important for discussion were:

Ranked 1 to 5	Ranked 6 to 10
Fear of a major health crisis (e.g. airway closing)	Impact on close relationships
Pain	Impact on work, career and/or education
Unpredictability of attacks and future pain	Doctors do not understand
Strong feelings about children and hereditary nature of HAE	Family and friends do not understand
Feeling 'guilty' for the impact on others	Medication side-effects

4. Discussion leadership. The facilitator suggested a topic to start with (which was 'coping with fear of a major health crisis'). After a very brief orientation and reminder of the group guidelines, the participants were asked to comment. Participants who said the least were asked questions or invited to comment.

5. After some time of thorough discussion, the facilitator suggested that the group move on to discuss the issue that emerged as the next most popular choice, which was 'coping with pain'. This merged naturally with an associated topic – managing unpredictability and future attacks with or without pain.

The facilitator's roles included:

- ice-breaking, introductions, establish ground-rules
- help the group select themes for discussion
- ensure roughly equal contribution
- keep people on track and keep the tone positive (can use guiding questions such as "that sounds challenging; tell us about how you cope and what you have learned to do about this issue that helps you?")
- invite the sharing of strategies that people have found helpful

- watch out for invalidation from participants and direct the conversation to be inclusive and non-judging (not necessary with this group)
- provide summaries at the end of a reasonable discussion
- then move the discussion onto another topic
- selectively provide some input on the ways that others cope and coping theory (two people said they were expecting more expert input)

Feedback (adult group only):

A brief informal feedback sheet was used and seven of eight provided feedback. This is summarised in an appendix.

Recommendations for future groups:

- Three hours was quite good. Could possibly make it four.
- Consider having 20 to 30 minutes devoted to a structured talk on coping and adapting to chronic illness (especially if using a 3.5 or 4.0 hour format).
- Name tags are good
- The prompt sheet seemed to work well
- Establish expectations about the nature and format prior to the group (e.g. when advertising)
- Need to bring pens for people to jot down notes
- Consider evaluating outcomes and effectiveness more thoroughly.
-

It was a pleasure to help facilitate the group and I am happy to share advice with future facilitators.

Yours faithfully,

Christopher Basten
(M.Psychol.; PhD.)
Clinical Psychologist

Review and Feedback: The number of responses in each category is summarised below

0 = not at all; 1 = disagree; 2 = agree; 3 = agree strongly

<u>Feedback question</u>	<u>N° of people giving each rating for this question</u>	<u>average</u>
I felt more connected with others	0 0 1 0 2 3 3 4	2.6
I am planning on staying in touch with someone from the group that I just met	0 0 1 0 2 5 3 2	2.3
I now feel better equipped to keep living with HAE	0 0 1 0 2 4 3 3	2.4
The group discussions were too unstructured	0 4 1 1 2 1 3 1	0.9
The group discussions were open enough to let us talk about relevant issues	0 0 1 0 2 3 3 4	2.6
The venue was appropriate	0 0 1 0 2 3 3 4	2.6
It was worth my trouble coming	0 0 1 0 2 1 3 6	2.7
"I found it useful to have an opportunity to discuss how hard things are for me but not be caught up in loads of sympathy." "Definitely worthwhile in combination with the bigger forums, as it did ensure positive outcomes and talking about worries rather than just being informational". Maybe one hour longer and a bit more education/strategies on coping with chronic illness". "I did expect part to be more structured". "Very useful day".	COMMENTS	

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24th September 2016

Fiona Wardman
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Dear Fiona,

Re: Summary of the HAE support group facilitation.

I write with a summary of the support group that was held on Saturday 17th September.

Purpose and Aims:

As with the last group, the stated aims were to provide a small group format that would (a) help people to share effective coping strategies and resources for common problems associates with HAE, (b) to feel heard and connected and (c) meet others with HAE.

Structure:

- The group ran from 1pm to 4:30pm, with a 30 minute refreshment break in the middle.
- Two parallel groups were organised: one for adults and one for children and teens.
- Participants registered in advance
-

Materials and Venue:

- The Brisbane venue was a meeting room in a hotel, previously used by HAE Aust.
- Adults: The materials for adults included a printed sheet to use as a prompt for discussions and some pens.
- Children / teens: Maria used some 'Strengths Cards' and drawing paper with textas.

Attendees:

Nine adults and two children attended. Both children had HAE. Two of the adults were partners for the affected person.

Process (Children):

The same two teenager siblings who attended the Sydney group enrolled again. This is a testimony to the perceived helpfulness of these sessions. Maria Milic ran the teen group and engaged them in a series of exercises to help them (a) establish their various feelings, (b) work out their strengths that they already possess that will help them deal with known challenges, (c) decide what coping strategies are best for different challenges, and (d) help them to respect each other's differences in the way that they cope and manage their illness.

Process (Adults):

1. An introduction process was used to commence whereby people briefly introduced themselves using four prompts suggested by the facilitator and given in writing.
2. Guidelines for the group were articulated: (1) *respect* for others, as shown through no interrupting, no criticism or negating a point of view, (2) *confidentiality* – we all needed to promise that nothing would be repeated outside the room after the group, and (3) *positivity* – while it was expected that problems and challenges would be discussed, the focus was to remain on how people adapted and coped and managed in order to avoid the sense that HAE was awful or that it was a day of complaining.
3. Selection of topics was undertaken by asking participants to select the six main issues that they wanted to discuss off a list (the list is attached). Initially, just to get started immediately, participants read out the three topics of greatest interest and the common themes were noted and discussion started. During the break a longer list of challenges was identified by the facilitator who read through participants' rankings of the issues.

The topics that were rated as most important for discussion were (in order):

1. Fear of a major health crisis (e.g. airway closing)
2. Doctors do not understand
3. Pain
4. Strong feelings about children and the hereditary nature of HAE
5. Impact on work, career and study
6. Feeling guilty for the impact on others

4. Discussion leadership. The facilitator suggested a topic to start with (which was 'coping with fear of a major health crisis'). After a very brief orientation and reminder of the group guidelines, the participants were asked to comment. Participants who said the least were asked questions or invited to comment.

5. After some time of thorough discussion, the facilitator suggested that the group move on to discuss the issue that emerged as the next most popular choice, which was 'fear of major health crisis'. This naturally led into discussions about accessing hospital and medications, which led to the next most common topic that was selected for discussion: "Doctors do not understand". Several participants reported having been dismissed and doubted, both before and after diagnosis.

The facilitator's roles included:

- ice-breaking, introductions, establish ground-rules
- help the group select themes for discussion
- ensure roughly equal contribution
- keep people on track and keep the tone positive (can use guiding questions such as "that sounds challenging, tell us about how you cope and what you have learned to do about this issue that helps you?")
- invite the sharing of strategies that people have found helpful
- watch out for invalidation from participants and direct the conversation to be inclusive and non-judging (not necessary with this group)
- provide summaries at the end of a reasonable discussion
- then move the discussion onto another topic
- selectively provide some input on the ways that others cope and coping theory (two people said they were expecting more expert input)

Feedback (adult group only):

A brief informal feedback sheet was used and all nine provided feedback. This is summarised in an appendix.

Recommendations for future groups:

- Three and a half hours was appropriate. It could be possible to do it in three (as in Sydney). The teens probably needed to finish after **three hours**.
- The groups coped well without name tags
- The prompt-sheet seemed to work well as a way to promote discussion.

Yours faithfully,



Christopher Basten
(M.Psychol.; PhD.)
Clinical Psychologist

Review and Feedback: Sept 2016

The number of responses in each category is summarised below

0 = not at all; 1 = disagree; 2 = agree; 3 agree strongly

<u>Feedback question</u>	N° of people giving each rating for this question	<u>average</u>
I felt more connected with others	0 0 1 0 2 0 3 9	3
I am planning on staying in touch with someone from the group that I just met	0 0 1 0 2 2 3 7	2.78
I now feel better equipped to keep living with HAE	0 0 1 0 2 1 3 8	2.89
The group discussions were too unstructured	0 7 1 2 2 0 3 0	0.22
The group discussions were open enough to let us talk about relevant issues	0 0 1 0 2 1 3 8	2.89
The venue was appropriate	0 0 1 0 2 2 3 7	2.78
It was worth my trouble coming	0 0 1 0 2 3	3
"That was great" "A good opportunity"	COMMENTS	

APPENDIX B: HAE & THE PATIENT EXPERIENCE

HAE swelling attacks are usually spontaneous

Even though the cause of HAE is known, what triggers a swelling attack varies from patient to patient and also, within a patient's own experience. What may have caused an attack at one time may not the next time. Often there is no apparent trigger.

The symptoms are often mistaken for allergies or abdominal complaints and are therefore, in the first instance, treated with inappropriate medical investigations or medications that either amplify the symptoms or are not effective and the patient continues to suffer. Patients MUST receive specific HAE treatments to reduce or prevent their symptoms.

Having HAE can severely affect a person's way of life (4)

Where there is a family history of the condition, patients can be diagnosed early in life and can work with their doctor to put a medical action plan in place. It is often the case that the family doctor's only HAE experience is from other family members and may not be up to date with HAE best practice.

For the many where the condition hasn't been diagnosed, the patient may suffer decades of unexplained and debilitating swelling episodes that were either not treated correctly or resulted in unnecessary investigative procedures.

Delay in Diagnosis

On average, it takes 13 to 21 years (2) from the time a patient first experiences symptoms to the time a diagnosis is made. Even when a diagnosis is made, patients often encounter health care providers that have limited or no knowledge of the condition and therefore do not treat the patients with HAE specific medications. Significant improvements are required in this area to ensure that patients are not suffering or enduring unnecessary medical investigations which may only worsen their symptoms.

"Doctors being unable to provide much support due to lack of awareness of HAE or expertise"

"[Patients have had] distressing experience at [ED]. ... Lengthy delays, misdiagnosis, wrong treatment, anxiety"

Living with the threat of life-threatening or major attacks

Once a diagnosis is made, patients live with the threat that a life-threatening or major HAE attack is about to occur. This results in severe anxieties and other mental health issues as well as a low participation in activities. Everyday occurrences that the general population take for granted can be an issue for HAE patients.

"[There is a] negative impact on mental state Causing feelings of anxiety, depression, mood swings, inability to cope, relationship issues"

"Inability to plan in life; due to the degree of uncertainty and the unknown about attacks ... not joining clubs or classes, not planning longer term for activities or events, not taking up training or education"

"Periods of childhood or adolescence severely impact[ed] teasing, missing school, not being able to join in teams, not attending social events, minimising suffering and bravado. Detrimental impact on education"

"Restriction on [the] ability to travel to regional areas or overseas"

"Career limitation Not being able to work, taking a lesser career path"

"A curtailment of social life and an inability to participate fully in outside interest[s] Not being able to form friendships or attend functions"

APPENDIX C: TEAM OF HAE AUSTRALASIA

Our team of 5 directors tirelessly volunteer time outside of family, work and other commitments. They co-ordinate all projects of HAE Australasia. Due to our own previous HAE experience and enthusiasm to improve HAE patients' quality of life, we are all committed to adhering to best practice standards. We are very proud of the strong team that we have representing HAE in Australia and New Zealand. Our dedication is reflected in our successes and in the feedback we have received from HAE patients, carers and health care providers (see Appendix H: Testimonials).

President - Fiona Wardman (Director)

Qualifications / Experience: Office & Operations Manager
Over 20 years' experience in Office & Project Management

Fiona's HAE diagnosis came in her 30's after years of unexplained swellings from the age of 9 which progressively worsened as she got older. No one else in Fiona's family has HAE. Fiona is proud to be part of an organisation that is making a difference to patients with HAE in Australia and New Zealand.



Vice President - Anne Wilkinson (Director)

Qualifications / Experience: Qualified Pharmacist
Over 30 years' experience in the field

Anne is married, has four adult children and lives in Melbourne. Anne was not diagnosed as having HAE until her late forties. Her diagnosis led to a diagnosis of other family members.



Treasurer - Louise Ridout (Director)

Qualifications / Experience: CPA Accountant, Registered Tax Agent & Registered Financial Planner
Over 10 years in public practice

Louise lives in Melbourne with her partner and young daughters. Louise was diagnosed with HAE when she was a baby as HAE was known in her family. She is passionate about raising awareness of HAE and keen to see better treatment options available for patients.



Secretary - Amanda Tionisio (Director)

Qualifications / Experience: Office Manager for over 15 years

Amanda lives in Western Australia with her husband and 4 young children. She has a long family history of HAE and is particularly passionate about assisting children with HAE as she has two daughters with the condition.



NZ Representative - Olivia Willard (Director)

Qualifications / Experience: Ecommerce Manager
Over 12 years' experience

Olivia is based in Auckland, New Zealand and represents the interests of our New Zealand patients. She is passionate about New Zealand patients receiving and having access to the same treatment and care as patients in Australia and the rest of the world.



Medical Advisor - Professor Connie Katelaris

Dr Katelaris is the Medical Advisor to HAE Australasia. She is Professor, Immunology & Allergy, University of Western Sydney, Head of Department and Senior Staff Specialist at Campbelltown Hospital. She is convenor of the Graduate Certificate in Allergic Diseases, the first postgraduate course in the Faculty of Medicine, University of Western Sydney. She is a past President of Asian Pacific Association of Allergy, Asthma and Clinical Immunology and a past president of the Australasian Society of Clinical Immunology and Allergy.

APPENDIX D: HAE AUSTRALASIA'S MISSION, VISION, OBJECTIVES



HAE Australasia Ltd is a non-government, not for profit, health promotion charity that was established in 2011 as there was a need to increase the awareness of Hereditary Angioedema (HAE) in Australia and New Zealand.

Vision of HAE Australasia

HAE Australasia Ltd.'s vision is to enhance the quality of life for those living with Hereditary Angioedema (HAE) in Australia & New Zealand.

Mission Statement

To achieve this vision, HAE Australasia Ltd aims to help patients gain subsidised access to more treatment options, empowering patients through education about their condition, educating the medical and general community about HAE to ensure patients are recognised and diagnosed more quickly, and to connect patients and carers with our support network – they need to know that they are not alone.

Operational Objectives

The objectives of HAE Australasia Ltd are to:

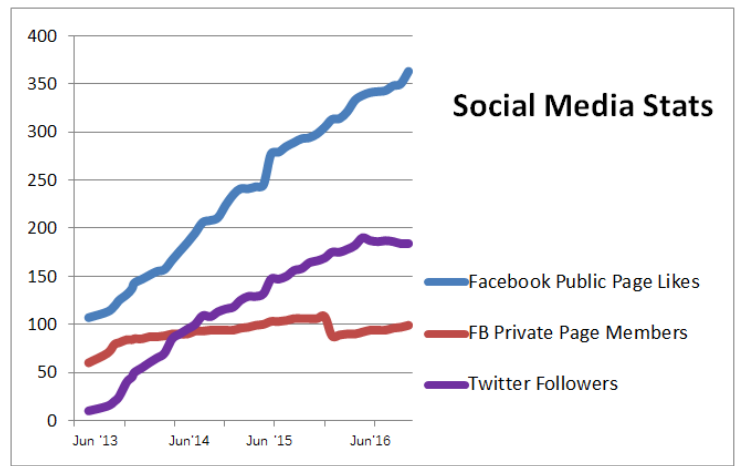
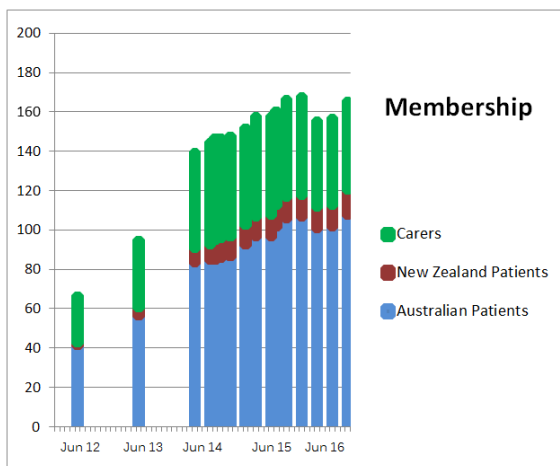
- Enhance the support and quality of life for people with HAE and their carers
- Provide a support group for people affected by HAE and allow patients and carers to communicate with each other to discuss their experiences. They need to know that they are not alone.
- Provide up to date and broad based education to:
 - o HAE patients to help them better understand their condition and treatment options available.
 - o HAE Carers to enable them to appropriately support individuals suffering from HAE
 - o Health care providers to enable them to appropriately recognise & support individuals suffering from HAE
- Engaging in activities to raise community awareness of HAE (to help undiagnosed patients access appropriate treatment and to help the community understand what it's like to live with the life-threatening and debilitating condition)
- Look at ways to make treatments and medications more accessible and subsidised for patients with HAE
- Assist research organisations with medical research into the causes, prevention and treatment of HAE
- Provide prompt and reliable responses in a professional manner to any HAE query
- Be considered by patients, carers, health care providers and the wider community to be a professional, reliable, courageous and compassionate organisation.

APPENDIX E: HAE AUSTRALASIA PROJECTS & OUTCOMES

Established an Australian & New Zealand support network of HAE patients & carers.

"We support each other, because we know what it is like to have HAE."

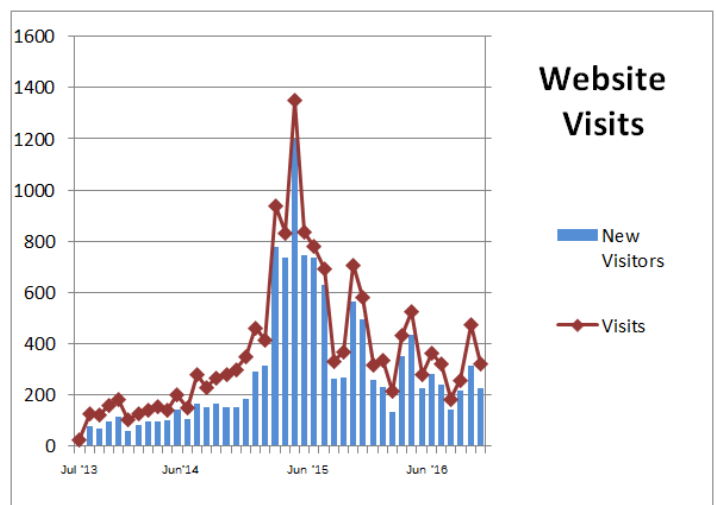
"I don't feel so alone or isolated knowing there is an organisation and people in that organisation that understands and has knowledge about this awful disease that I live with every day."



HAE Australasia Website - www.haeaustralasia.org.au.

The aim is for this website to be the go-to place for all Australian and New Zealand HAE patients, carers, health care providers and supporters.

"When I last saw my specialist for my check up, he used the HAE Australasia website to get resources that I needed."



Assisted new treatments becoming subsidised

We were actively involved and provided invaluable input into the applications of new treatments becoming subsidised. These treatments' becoming more accessible for patients was a major turning point for HAE patients in Australia and New Zealand - they began to feel that they could actually live a life. The following treatments are now subsidised (for specific uses):

- Firazyr (Icatibant) - Australia (2012)
- Firazyr (Icatibant) - New Zealand (2016), Berinert (C1 Inhibitor) - Australia (2016)

"I have been involved in the introduction of new innovative therapies for HAE in Australia and negotiation with authorities can be difficult. Participation of an organized patient group facilitates such negotiation and can clarify the importance of new therapies to those with a poor understanding of the condition"

"I can now afford to medicate myself and therefore have greatly enhanced my life. I no longer need to attend the emergency department of my local hospital, for treatment that lasts between a few hours to a couple of days, depending on the severity of the attack. I have done this at least once sometimes twice a month over the last 30 years or so. Which would of been of great cost to The Health System and the community."

"Since the availability of Firazyr [Icatibant] for me which was October 2012 I have not attended the hospital for any medical treatment connected to my HAE. Thanks to the assistance of HAE Australasia."

"Having Firazyr available has lifted any anxieties I had about travelling away from a hospital that I knew had other emergency treatment. Thank you so much HAE Australasia for being my voice!"

Assisted with HAE Research

HAE Australasia has connected research organisations with patients to conduct desperately needed HAE research and clinical trials. The quality of life and other issues surrounding HAE was discussed by patients in a recent research paper that our organisation helped locate participants for. Various responses to this research can be found in Appendix F: Sample of responses from Research on the Australian HAE Treatment Landscape.

Increased awareness in the medical community

There has been a significant increase in the number of doctors that now know about HAE due to our activities. This helps to identify potentially undiagnosed patients and allows patients diagnosed with HAE be able to access appropriate treatments quicker.

"There are now many more hospitals who are not only well educated about HAE but they also stock the correct medication."

Held Patient Meetings, HAE Meet Ups & HAE Healthy Minds Workshops

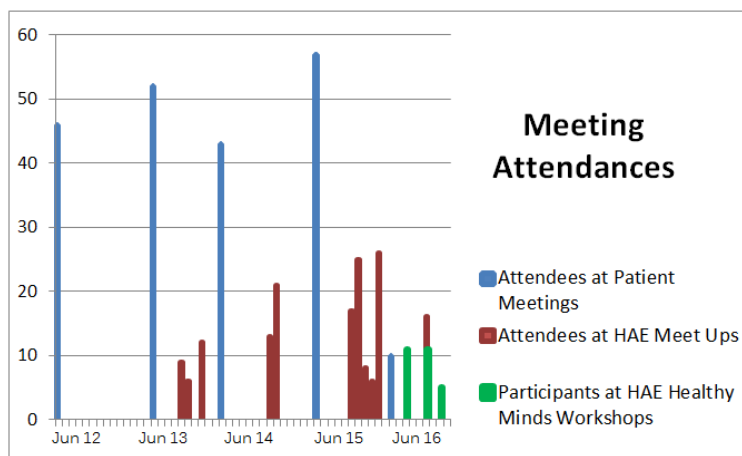
Patient Meetings (conferences) educate patients and their carers about HAE, current research and new treatment availabilities. "HAE Meet Ups" strengthen the local HAE support networks. "HAE Healthy Minds" Workshops have been piloted to determine if this project can help improve the mental health of patients and carers (as discussed throughout this submission).

"Having HAE Australasia organising Patient Meet Ups has been invaluable for my self-esteem and feeling connected."

"Whilst attending a HAE Australasia Patient meeting, I found out that the father of a toddler with HAE works in my building! What are the chances with so few HAE patients in Australia! It's good to know others are close by that I can talk to"

"Coming into contact with the HAE Australasia team has been life changing to say the least. They have given me the knowledge and the confidence to seek out the best medical treatment available"

"Having been educated at HAE conferences and Forums I have attended over the years, for me knowledge is power and power is strength. Strength to carry on and live a happy, well and valuable life with this insidious disease."



Empowerment of Patients

"I really don't know how I got on without HAE Australasia."

"I would like to give my thanks and sincere appreciation to those involved with HAE AUSTRALASIA, as you have given me hope and an expectation for a better future."

"HAE Australasia is an important organization for the support and education of people with HAE and those associated with them, and for the furtherance of research and understanding of this condition"

"I hold the HAE Australasia team in very high regard and I have absolutely no doubt that they saved my life, in more ways than one."

APPENDIX F: SAMPLE OF RESPONSES FROM RESEARCH ON THE AUSTRALIAN HAE TREATMENT LANDSCAPE (2)

- Patients reported that the top 3 sources of information were their specialist, online sources (including the HAE Australasia Facebook Page) and other family members
- There was a severe negative impact on the quality of life over the long term reported by HAE patients. Some of the issues that were identified included:
 - o “Periods of childhood or adolescence severely impact e.g. teasing, missing school, not being able to join in teams, not attending social events, minimising suffering and bravado. Detrimental impact on education”
 - o “Distressing experience at [ED]. e.g. Lengthy delays, misdiagnosis, wrong treatment, anxiety”
 - o “Doctors being unable to provide much support due to lack of awareness of HAE or expertise”
 - o “Career limitation e.g. Not being able to work, taking a lesser career path
 - o “A severe impact on other family members. E.g. anxiety, impact on ability to work, disruption of childhood, necessity to care for grandchildren when a parent is ill”
 - o “The restriction on ability to travel to regional areas or overseas”
 - o “A curtailment of social life and an inability to participate fully in outside interest e.g. Not being able to form friendships or attend functions”
 - o “The inability to plan in life; due to the degree of uncertainty and the unknown about attacks e.g. not joining clubs or classes, not planning longer term for activities or events, not taking up training or education”
 - o “The decision not to have children (2 patients)”
 - o “Negative impact on mental state (not a discussion point but did emerge) e.g. Causing feelings of anxiety, depression, mood swings, inability to cope, relationship issues”
- “Stoicism is likely to have contributed to:
 - o Some limitations by some patients on their use of treatment e.g. because they have grown accustomed to dealing with attacks and one’s behaviour can be difficult to change.
 - o They may not feel an attack is severe enough in relation to other attacks they can have, even though most of the population might consider the same attack to be severe.
 - o They may not have discussed the true impact on life of their less severe attacks with specialists”
- Research found that, when determining the severity of attacks, not only were patients considering things like the impact on their airway, pain level, the location of the attack, the need to attend the emergency department, but they would also consider the impact that the attack had on their daily life, if they were able to continue looking after children or go to work. There were also instances where their specialist advice was in contradiction to the Australasian Society of Clinical Immunology and Allergy action plan and therefore wouldn’t treat an attack that may have been recommended by Australasian Society of Clinical Immunology and Allergy (or vice versa).

APPENDIX G: HAE IN AUSTRALIA 2015 (QUALITY OF LIFE)

HAE in Australia in 2015: results of HAE Australasia survey.

Although the situation for those living with HAE has improved, the recent HAE Australasia Patient Survey reveals the continuing burden of living with this condition.

Twenty two participants at the annual conference in May 2015 gave consent and completed a questionnaire. As this year's meeting was held in Sydney, it was to be expected that the majority of those answering the questions lived in NSW or Victoria. Not surprisingly, the majority had other family members affected by this genetic disorder; only 4/22 had no family history of HAE.

Nearly half those responding to the survey stated that their diagnosis was made because of an affected family member; one "lucky" person was diagnosed correctly after the very first angioedema attack; eleven people waited many years for a correct diagnosis.

HAE attacks are very debilitating and interfere with daily life. Half the survey group stated they experienced one attack per month on average, while six people experienced more than one attack a fortnight and one person averaged two attacks per week. In the last 12 months, most people had missed days from work as a direct consequence of HAE; seven respondents had lost 5 days and only one had not missed work because of HAE.

The advent of self-management and the availability of "on demand" treatment has definitely impacted positively on the lives and well-being of those living with HAE and this is reflected in the marked reduction in the number of visits needed to the emergency department in the last 12 months. Only five people had made more than one visit to an ED; eight had not had any visits. This is in marked contrast to the results of the first HAE survey in Australia where 50% of people had experienced 10 or more visits to an ED.

Those living with HAE continue to nominate "stress" as the single most common cause precipitating an attack (15/22); trauma was nominated by 14; infection by eight and menstrual period a trigger in

five people. One third of those answering the questionnaire volunteered depression and anxiety as a co morbidity. According to Sane Australia, during a one-year period, anxiety disorders will affect 14% of the population and depression will affect 6%, thus those living with the burden of HAE have a much greater risk of these debilitating disorders and this gives HAE Australasia an opportunity to explore interventions to alleviate this burden among its members.

The survey explored members' use of HAE medication. Both tranexamic acid (50%) and danazol (75%) had been used by many respondents. Not surprisingly in this adult population, most had found danazol more effective than tranexamic acid. Firazyr (icatibant) had been used by 15 of 19 who replied to this question; one person had not found it effective and one was unsure regarding its effectiveness but all others had found it effective. In the last 6 months, the number of injections used ranged from once (3 respondents) to more than five times (8 respondents) and all stated that having this medication had prevented hospitalisation.

C1 inhibitor concentrate (Berinert or Cinryze) had been accessed by 9/19 respondents, four of these occasions had been for pre-operative prophylaxis.

This survey, as did the previous one of Australians living with HAE, has shed light on the continuing burden of having this disorder and while the situation has definitely improved, there is still more to be done.

Finally, we thank all those who took the time to participate in this survey. It is only by knowing about the burden faced by those with HAE and their continuing difficulties that we can hope to advocate for improvements in management.

Prof CH Katelaris

Medical advisor, HAE Australasia

Mrs Fiona Wardman, [President] HAE Australasia

APPENDIX H: TESTIMONIALS

1. Patient - Shane Burke (Australia/New Zealand)

HAE Australasia and me

January 2014 my daughter sent me an email saying she was going to apply for a travel grant to the HAE conference in Washington DC, and would I like to go too.

I looked at the application and found I was still in time to apply for a travel grant, and was able to get one. Without the grant, I would not have been able to attend. My daughter didn't attend due to other issues.

At the conference, I was sought out by the HAE Australasia people, as they knew I was attending, but I had not joined HAE Australasia. I would meet one person and then they said "you must meet this person". They were very passionate and made me feel special.

The conference was really an eye opener for me and I learnt so much.

- The president of HAEi (the international parent body), personally went around meeting everyone.*
- Doctors gave me their contact details should I have issues (I went there on a fact finding mission to help my daughters' condition).*
- I spoke to other patients from Australia and NZ...and around the world*

Fiona [Wardman] told me I should be under an immunologist to manage my condition. I didn't fully understand this at the time as I have been on the same medication for over 30 years and had no issues. I followed her advice and discovered that one of the side effects of Danazol, is ischaemic heart disease and liver damage. I knew I had to get my liver functions tested, but never knew why. I now take a third of my original medication and have access to [Firazyr] in the event of an attack.

The information I have obtained, directly as a result of being a member of HAE Australasia is amazing. I have not only passed this onto my immediate family, but also other lines of my family.

My dad has seen a specialist and his medication has been reduced by half. He has recently had a triple bypass. I can't help thinking that maybe if we had made contact with HAE Australasia earlier and learnt more about HAE, then this may not have been necessary.

Now getting back to my fact finding mission for my daughter. She lives in Christchurch and up until last year, was a 2nd year law student. She has had her life turned upside down due to HAE. She is a member of HAE Australasia and has been supported by them. It wasn't until August last year that I realised how dire her situation was. She was depressed and had given up on life. I was so concerned that I flew to Christchurch from Melbourne to sort out her issues. Olivia [Worthington], HAE Australasia NZ Director, put me in touch with Dr Jordan, an immunologist in Auckland. I arranged for a doctors referral for my daughter to see him. Olivia arranged a patient meet-up for NZ, in Auckland. Dr Jordan organised an appointment a few days before the meet-up and HAE Australasia gave her a travel grant to fly up to Auckland. She stayed with my dad in Hamilton and they both travelled to the meet-up together. At the meet-up she met a young lady, also treated by Dr Jordan, and they compared notes.

It became apparent that my daughter's HAE management is not being managed well (at all).

At a recent visit to Christchurch hospital, she woke up in ICU with a target on her throat showing the location for an emergency tracheostomy. She was given the wrong medication, and not enough of the medication she needed. I am on my way to Christchurch to meet with the department heads at Christchurch hospital to sort this out.

Without the help, support and guidance that HAE Australasia has given my family, I would not be equipped with the information required to help my daughter and she probably would not be with us today.

I am able to suggest that the hospital emergency staff get some training on HAE, and offer the help and resources of HAE Australasia to do this.

HAE Australasia, via their face book page, gives me access to patient forums where I can compare notes with other patients. We support each other, because we know what it is like to have HAE.

Via the HAE Australasia website, there are a wealth of resources to help us deal with any situation. We can get instant help via the forums or by emailing one of the team from HAE Australasia.

As you can imagine the worry I have about my daughters' condition, but HAE Australasia has been with me all the way with advice and support.

I really don't know how I got on without HAE Australasia.

Regards

Shane Burke

2. Patient - Maureen Hutchinson (Australia)

To whom it may concern,

This TESTAMONIAL may be used, along with my name, for any reason by HAE AUSTRALASIA.

The following is a part of how my life has been improved by being a member of HAE AUSTRALASIA.

I don't feel so alone or isolated knowing there is an organisation and people in that organisation that understands and has knowledge about this awful disease that I live with every day.

The fact that HAE AUSTRALASIA has been involved in the process of getting my medication on the PBS has greatly improved my life.

I can now afford to medicate myself and therefore have greatly enhanced my life.

I no longer need to attend the emergency department of my local hospital, for treatment that lasts between a few hours to a couple of days, depending on the severity of the attack. I have done this at least once sometimes twice a month over the last 30 years or so. Which would of been of great cost to The Health System and the community.

Since the availability of FIRAZYR For me which was October 2012 I have not attended the hospital for any medical treatment connected to my HAE. Thanks to the assistance of HAE AUSTRALASIA.

Having been educated at HAE conferences and Forums I have attended over the years, for me knowledge is power and power is strength. Strength to carry on and live a happy, well and valuable life with this insidious disease.

Having HAE AUSTRALASIA Organising Patient Meet Ups has been invaluable for my self-esteem and feeling connected.

Being one of the senior members of the HAE Community, I have been able to pass onto the younger members some of the knowledge and awareness I have gained through these meetings.

For individuals we have no hope of consulting with government departments, health bodies and drug companies regarding research, development and funding for potential new treatments.

Without the Doctors, committee and supporters of HAE AUSTRALASIA who give their time willingly our lives would be very different.

I would like to give my thanks and sincere appreciation to those involved with HAE AUSTRALASIA, as you have given me hope and an expectation for a better future.

Yours sincerely,

Maureen Hutchinson

3. Patient - Cindy Hughes (Australia)

Just a few years ago I was a patient in a very remote location living with a rare, life threatening disease, had no effective medication on hand, knew very little information about my disease and my health care providers didn't seem to be able to give me any answers either.

I felt isolated, helpless and was a ticking time bomb waiting to go off. It was very much a case of "you don't know what you don't know".

Coming into contact with the HAE Australasia team has been life changing to say the least. They have given me the knowledge and the confidence to seek out the best medical treatment available. I have learned that when you have a rare condition like HAE it is vital to be an expert on your own condition and not rely on health care providers to know what's best, as this is not always the case.

The education of the patients has had a massive flow on effect to many medical professionals as well. There are now many more hospitals who are not only well educated about HAE but they also stock the correct medication.

This is all thanks to the power of an organisation doing the talking, rather than coming from just one person. As a group they have been able to assist in the progress of new HAE medications being considered and also subsidised.

The development of the website has made important information and documents such as the Action Plan more readily accessible. The online support group and yearly patient meet ups play an important role of making patients feel understood and that they are not alone, this in itself is a very powerful thing as many patients have never met another person with the same condition.

I hold the HAE Australasia team in very high regard and I have absolutely no doubt that they saved my life, in more ways than one.

4. Anonymous Patient Testimonials & Quotes

"[By sharing coping strategies with others] I don't feel so isolated or alone. It helps me overcome insecurities and gain positive valuable effective information."

"On a personal level [improving our overall mental health] is extremely important. It's about self-esteem and self-worth, modelling for others in a similar situation. On a national level it's a Public Health issue, with the cost to the community being critical."

"I don't make plans with friends or family, just in case I'm sick again and I end up disappointing them - again"

"Feelings ... vary from deep sadness and depression, to a sense of gratitude and satisfaction to family, friends and self for the ability to keep on keeping on."

"I don't travel anywhere that is more than an hour from a hospital that I KNOW has C1 Inhibitor - just in case I need it"

"Having Firazyr available has lifted any anxieties I had about travelling away from a hospital that I knew had other emergency treatment. Thank you so much HAE Australasia for being my voice!"

"When I last saw my specialist for my check up, he used the HAE Australasia website to get resources that I needed."

"Whilst attending a HAE Australasia Patient meeting, I found out that the father of a toddler with HAE works in my building! What are the chances with so few HAE patients in Australia! It's good to know others are close by that I can talk to"

5. *HAEi (International) President / HAEA (USA) President - Anthony Castaldo,*

My name is Anthony Castaldo and I serve as the President of HAE International—the umbrella organization that represents the world’s HAE patient group. I am also the President of the United States HAE Association.

I have the great privilege of interacting with leaders and members of HAE patient organizations from throughout the world. I must say that the HAE Australasia group and their leadership stand out as one of the most well organized, energetic, and effective of all our member organizations.

The progress HAE Australasia has made in serving the HAE patient community since its relatively recent inception is nothing short of extraordinary. With limited resources, this “can do” organization has made great strides in identifying patients and helping otherwise sick people receive desperately needed treatment. This is no small accomplishment because HAE is a rare, difficult to diagnose disease that is not only debilitating, but potentially fatal.

It is remarkable that this intrepid group of dedicated volunteers has made such great strides in transforming the lives of a very sick and neglected patient population with relatively scarce financial resources.

One can only imagine the progress this energetic and capable group could make in key areas such as patient identification, education, diagnosis, and research if they had access to more funding sources.

Sincerely.

Anthony J. Castaldo

President



www.haei.org

Email: a.j.castaldo@haei.org

Cell: +1 202 247 8619

6. Immunology Senior Consultant – Dr William Smith



Government of South Australia
SA Health

29 January 2014

To Whom It May Concern:

RE: HAE Australasia

I am a medical immunologist working at the Royal Adelaide Hospital and in private practice. I am consulted by people who have HAE to provide medical management and medical advice.

I have found HAE Australasia to be an excellent organization, well organized and enthusiastically run. It has been very useful in providing high-quality information and support for people with HAE. The newsletters have been very effective in providing information on developments and events in the world of HAE. HAE Australasia seems to be well linked and integrated with equivalent international organisations.

I and my colleagues have from time to time carried out research with the purpose of improving management and conditions for people with HAE. This research will be greatly facilitated by HAE Australasia in terms of reaching people who might be interested in participating in research, in particular if a register were established this would be extremely effective for that purpose. The HAE community is diverse and dispersed and individuals can be hard to reach but a register would facilitate contact and communication.

I have been involved in the introduction of new innovative therapies for HAE in Australia and negotiation with authorities can be difficult. Participation of an organized patient group facilitates such negotiation and can clarify the importance of new therapies to those with a poor understanding of the condition.

In my opinion, HAE Australasia is an important organization for the support and education of people with HAE and those associated with them, and for the furtherance of research and understanding of this condition.

Yours sincerely

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