



Alopecia
Areata
Totalis
Universalis

RAISE
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research awareness information support embrace

ISSUE 2 MAY 2016



Contents

President's Welcome

Meet our Committee

Haylee's Story

Research update

Did you Know?

Shopnate

Zonta International Project

Our Achievements

What's On?

Social Media

Kids Korner

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Photographer: Jess Morrison

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please click here.

PRESIDENT'S WELCOME

In RAISE we feature articles, hot topics, research within the field, upcoming events, and activities.

For more than five years, AAAF has been lobbying to have the GST removed on wigs for those who need them for a medical reason (eg Alopecia Areata). Successive governments have either not taken the time to understand the unfairness of the issue or have rejected any changes to the current GST ruling.

Another rejection recently by the Treasurer Scott Morrison will not deter AAAF from pursuing a change to this unfair situation. We need the Alopecia Areata community to get behind our online petition, together we can change this. [Click here.](#)

After 6 years of dedication to AAAF, Tracy resigned her position as Treasurer. We thank her for her tireless contribution. Vesna's determination to budget the books sees her transitioning into the treasurer role, and Georgia stepping into the Secretary role. With the expansion of the AAAF, a new role has been created and we have a vacancy on our Committee for a Victorian Branch Manager. We welcome all inquiries.

MEET OUR COMMITTEE

Introducing our QLD Branch Manager,
Judy Watson



My alopecia journey began when I was 24. I went to my hairdresser one Saturday morning and asked her to cut my hair very short. She told me that she wouldn't be able to cut it too short because of my bald spot to which I replied, "What bald spot?" She proceeded to give me a mirror and to my surprise, I saw a 15mm bald patch on the back of my scalp. Over the next couple of months, the hair grew back and I didn't think about it again.

Over the next couple of decades, my "bald patch" would come and go. I was 48 and just prior to Christmas I found another bald patch. By the end of February all my hair was gone. It was falling out in clumps, on my pillow, in the shower and I was afraid to brush it because I ended up with more in the brush than on my head. I went to work with a scarf on to try and hide the fact and a couple of young girls made some rude remarks about it, so I went into the city and bought my first wig.

My husband and I went to the doctor and he referred me to a specialist and I tried a number of different treatments stopping short of injections. I had been doing a bit of research and had drawn my own conclusion that it was not curable and that I would probably never re-grow my hair either. It was at this point that I started to wonder if it was hereditary and worried if my own daughter would also be a sufferer as my mother also had the condition.

One day a good friend pulled me aside and told me "Wake up to yourself – you're still the same person on the inside and it's not life threatening". Some times tough love is what you need and from that moment on, I decided to embrace my condition. I went online and found a support group. I went to workshops to learn how to draw on eyebrows and put on false eyelashes and started to feel a little more human again.

I then discovered cosmetic tattooing. I felt so good after I had my eyebrows done; they looked great and I even got eyeliner on both the top and bottom lids of my eyes. The eyeliner hurt a lot, but as they say – no pain, no gain.

Telling people about my condition was hard at first as I really didn't want them to know I was bald, but when you wear a wig, it's hard to do some of the things you used to do, like swimming, running and even going out on a windy day.

I hated the feeling of scratchy, itchy, hot wigs and the uncertainty of the weather blowing my wig off. I found Freedom suction wigs and decided this was for me. This was another positive step in my journey.

I decided to get involved supporting others with the condition and in January 2014, I took on the position of Branch Manager in Queensland for the Australia Alopecia Areata Foundation.

Haylee's Story



Malcolm

My son Malcolm was diagnosed with alopecia not long after his first birthday. It came as such a shock to us as his father and I have both come from fairly healthy families. It all started after he contracted parvo virus from a friend's little boy that I babysit and unfortunately, it sent his immune system into overdrive. It caused him some scary symptoms during that time and he had to have a bone marrow aspiration and an immunoglobulin infusion. For us it was petrifying as the doctors suspected leukaemia. Thankfully for our beautiful boy that was not the case.

Within 4 months of his first sign of hair loss he had lost every hair on his body. It was such an emotional time for us. Obviously being so young, Malcolm didn't understand what was happening. I was so sad and scared for him, potentially having to grow up being different from his peers was such a worry for me. It scared me a lot because when I first sat down to think about it, I thought about my high school experience, which wasn't all that positive. I was what I would call a normal person, yet I was still bullied to a point that it has affected my adult life. This is something that I won't tolerate for my child as I know how much it hurts.

After about 6 months, we were quite used to him having alopecia and it didn't bother us as much as it had previously, but the older he got, the more noticeable it was that he didn't have hair. At a young age children can get away with being bald and it is often seen as normal. As he got closer to 2 people started to ask questions and make comments. Children were touching and rubbing his head all the time. He got sympathetic looks and comments about cancer or chemo. All of those feelings I had about sadness and fear towards this disorder came flooding back. It started to remind me that yes he was different and he started to realise it too. One morning when I was doing my make up, he was sitting on the bathroom counter pretending to do his. He watched me do my mascara and tried to copy me. Seeing him look from my eyelashes to the place where his should be and noticing that confused look on his face instantly broke my heart. A couple of days later, I had a lady come up to me and tell me how brave he is and how brave I am as his mother, and I thought this beautiful boy may have to deal with this for the rest of his life. Realizing that, was a bit of a shock to me. This is when Warrick and I decided to shave our heads. We thought that if he's going to have to struggle with judgment (even if it's coming from a caring and genuine place) the least we can do is show him that we support him 100%. So on the 4th April, we did a fundraiser for alopecia and we shaved our heads.

It's been a month now since we did the shave and after living a life with no hair for this short month, my heart goes out to all the people living with alopecia. When I shaved my hair, I knew mine would grow back, so I could handle the looks and the questions and comments, but for so many of you, this is something you deal with on a daily basis. Until you or someone close to you has had experience with alopecia, it is really hard to understand just how much of an emotional journey it can be.

You are all so brave and beautiful!!



Alopecia areata (AA) clinical trial using topical Janus Kinase (JAK) Inhibitors

Janus Kinase (JAK) inhibitors inhibit the activity of the JAK enzymes. These JAK enzymes are involved in signal transduction, which plays a role in cytokine signalling. Cytokine signalling controls the growth of cells and the immune response. It is this immune response that causes AA.

To date, there have not been any studies that look at whether the JAK inhibitor ointments, when applied to the skin, work for Alopecia Areata Totalis. However, studies investigating efficacy of JAK inhibitors, taken in tablet form, show excellent results in clinic. Our study looked at the effectiveness of topical Janus Kinase (JAK) inhibitors, specifically Ruxolitinib and Tofacitinib in potentially regrowing hair. This study is a double-blind placebo controlled, prospective clinical trial comparing 1% Ruxolitinib ointment, 2% Tofacitinib ointment, 0.05% betamethasone dipropionate (an ultra-potent topical corticosteroid) ointment-to-ointment base. A total of four ointments, including a base ointment, was provided to participants in 1 gram unlabelled tubes (Tube A,B,C & D) to apply twice daily for 12 weeks. Applications were on four different areas: left and right eyebrows as well as left and right parietal scalp (above the ears).

Our preliminary results suggest promising outcomes for the use of JAK inhibitors in regrowing hair. A total of sixteen patients were successfully recruited into the trial and put on medication. 30% of patients reported spontaneous hair regrowth in both treatment areas and scalp. One patient reported complete regrowth of scalp hair and eyebrows. Regrowth is maintained 12 weeks after medication have completed. Areas treated with 2% Tofacitinib have demonstrated marginally better regrowth in comparison to 1% Ruxolitinib. In addition, 0.05% Betamethasone dipropionate (corticosteroid) have shown to result in hair regrowth in some of these patients. We are currently in the final stages of the study and in the process of analysing results.

DID YOU KNOW?

AAAF runs a Wigs For Kids program all year round? Since 2011 we have granted over \$92,000 and financially helped 125 families! Are you one of those? Our latest derivative of this program – Wigs for the BIGGEST Kids saw AAAF give out 56 grants at a total of \$37210.

A note from Elma

A big thank you to the AAAF for their latest initiative – Wigs for Biggest Kids. It is great that different age groups have been invited to apply for grants towards a wig purchase over the last couple of years. I used my grant towards the purchase of a human hair wig from Hairific at the RAH. The service I received from Christine was outstanding. I am so pleased with it and have had many favourable comments.



You can help us to lobby to have GST removed from medical wigs - Click here to sign and share our petition.



Most of us shop online at some point. Imagine being able to make a donation to the Australia Alopecia Areata Foundation Inc. every time you shop online and **at no extra cost to you!**

Well that's exactly how Shopnate works.

Shopnate donations will help Australia Alopecia Areata Foundation Inc.. just by shopping online.

Shopnate works with hundreds of leading stores that have signed up to donate a commission on every online purchase to the charity of your choice. This commission is already included in the price of what you're buying, so you can support your favourite cause, at no extra cost to you.

More information can be found by clicking this link.

Why don't you consider joining Shopnate now-

- 1. You Shop – shop with the same big name brands on Shopnate without paying a cent more.**
- 2. They Donate – retailers pay a commission that it is given automatically to your chosen charity.**
- 3. Everyone Smiles – the charity now has extra funds to do their great work and you can feel good.**



Liz our South Australian branch Manager is very excited to advise that the Zonta Club of Mt Barker has approved funding for a project named , 'Zonta Empowering Teens with Alopecia'.

For the next 12 months, Liz will be looking for 6 teenage girls aged between 13 and 18 to attend a personalized make-up workshop with Kiara Brewer of Athelstone in South Australia.

Kiara is a qualified make-up artist aged 20 years old, is warm and compassionate and very excited to be part this pilot program in SA.

Her facebook page is KBMUA \ Kiara Brewer Makeup Artistry.

The make-up workshop will be 1.5 hours conducted in Kiara's Athelstone home. The appointment is coordinated directly by the family with Kiara. The girls are encouraged to bring their own make-up to learn how best to apply it, but Kiara has a full make-up kit and brushes etc available to use on the day and for purchase if required after the workshop. The teen's mother or primary care giver is also invited to have a makeover as a thank you for their support. A set of eyelashes and a face chart for notes is included to take home. In the workshop Kiara will demonstrate on half the face and then let the teen copy application on the other side to ensure a real hands-on learning experience.

Bookings can be made by contacting Liz at liz@aaaf.org.au or completing the form at <http://www.mtbarkerzonta.org.au/contact.html>

Also available are up to 10 of the AAAF DVD's - "Alopecia Areata - Why does my hair fall out" to go out to schools. If you would like to request one of these DVD for your school, please use the link below:

<http://www.mtbarkerzonta.org.au/contact.html>



Our Achievements

AAAF supporting your journey



Research	Support	Awareness
<ul style="list-style-type: none"> • Involvement with Fusion Hair Trial • Grant for Psychology Research into coping techniques • The psychological impact of AA on young people • AAAF grant to Australia Dermatologists College for yearly research paper • Grant for Skin resident memory T cells in AA • Grant for Viviscal Trial • AA on women's self-esteem, mood states and coping • Grant for Psychological research into impact of AA over time • Grant for Psychosocial research into AA impact on the family unit • Grant for Treatment of AA with topical Janus Kinase (JAK) inhibitors 	<ul style="list-style-type: none"> • Establishing AAAF state branches in SA, ACT, QLD, WA and NSW • Launch Wigs For Kids Program • Annual open days - rotating states • Facebook accounts • Creation of Support Ambassador Roles • Launch of No GST on Wigs campaign • Creation of the AAAF online store • Launch of Instagram • Establish closed Facebook groups • Wigs for Big Kids - Uni students Program • Grief paper - Click here • Brochures - Click here • Kids Informational Video "Alopecia Areata: Why does my hair fall out?" Watch the video here • Informational videos for helping people with AA • Launch of AAAF newsletter R.A.I.S.E. • Wigs for Biggest Kids -over age 55 Program 	<ul style="list-style-type: none"> • Launch Donate Hair Program - Download the details here • Launch of the annual Awareness Week • Creation of School Pack - Download here • Hair Expo 2011 • Village Cinema Ad • C31 TV Ad • Establish Crazy Hair Day Fundraiser • Annual Trivia Nights – state based • Collaboration with band Redwoods on song "All The Strands" You can download it for only \$1.69 by clicking here • Launch of the Turning Heads Project • Verbatim play and DVD "Bald Heads and Blue Stars" Purchase the DVD here • Establish LinkedIn profile • Boldest Bald Tea • Radio advertising - Donate Hair - Listen here • Launch of Bald Canvas Initiative

What's On

- * Brisbane Support Group - Sunshine Coast picnic day, Saturday 11th June 11.00am Mooloolabah Beach QLD
- * Victoria Support Group - Mega Wig sale, 18th June 11.00am Temple Society 152 Tucker Road, Bentleigh Vic
- * Brisbane Support Group - Gold Coast picnic day, Saturday 18th June 11.00am Broadwater Parklands, Gold Coast QLD
- * Victoria Support Group - Charity Trivia night, 18th June 6.30pm Temple Society 152 Tucker Road, Bentleigh Vic

International Alopecia Day - Saturday August 6th

- * International Alopecia Day - WEST V'S REST 8.00am - 5.30pm
Create your own event. [Click here for details of how to get involved.](#)

- * Western Australia Support Group - Annual Quiz Night at the Victoria Park Bowling Club 18 Kent St, East Victoria Park WA



Alopecia Areata Awareness Week - November 14-19

- * Boldest Bald Tea – Wednesday 16th November 2016 – See the information sheet here. You can join in by hosting your own Boldest Bald Tea or join other tea parties and fundraise as a team.
- * Crazy Hair Day – Friday 18th November 2016 – See the Flyer here. Whether you're at kinder, primary, secondary or even in university, get involved, have some fun and in the process, inform others about this disease. Send your interest to info@aaaf.org.au and we will provide you with helpful details for your school. Our youth ambassadors can also assist in their home states.

Brisbane Support Group Henna Head Tattooing and Face Painting - Saturday 19th November 2016 - details to be finalised.

[Click here to find all our current scheduled events.](#)





From April 15-30, AAAF held an Instagram competition. We asked you and your families to create an Alopecia - inspired meme and post it to your Instagram account with the hashtag #AAAFmemecomp.

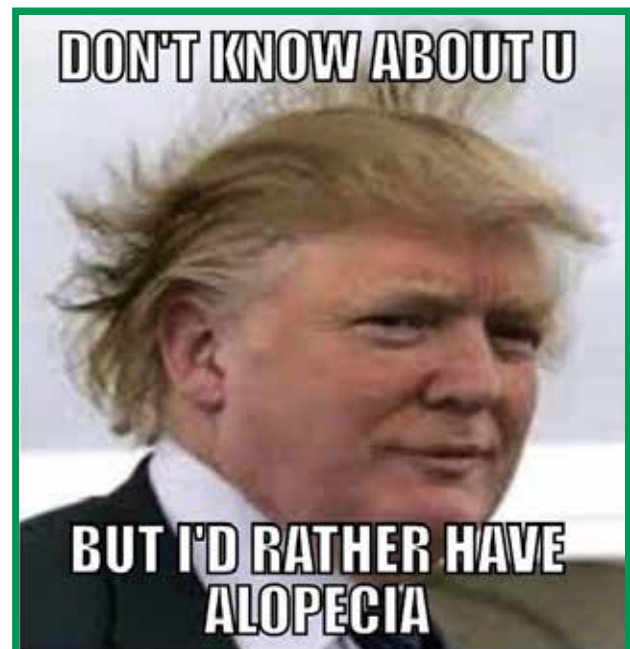
INSTAGRAM COMPETITION

Thank you to all those who took the time to enter the competition.

Take a look at the entries on Instagram using the hash tag #AAAFmemecomp.



Congratulations Emma, you have won a \$100 Visa Gift Card.



SOCIAL MEDIA LINKS

AAAF

Linkedin

Facebook

Instagram

You Tube

Go Fundraise

My Cause

Shopnate

Kids Korner

Word Search

TOTALISQNORMALG
 WAUNWIGTTBAJJFZ
 ZVNDAMAJVBXJBZN
 AZIWLPDFEELINGS
 HXVEOQQIIMJMHNA
 ACEOPPQRFHFPAVT
 PMRCEFPFMFZVIFA
 PESNCBUCHHEBRVD
 YSABIRABAEPRNFR
 RSLFANLLLAEEUQ
 FRIENDSODHTLYNW
 CUSHSRRNXACYTZT
 XHTKSVHCJTHKXHN
 TDGJYKMRZREQFOY
 EYEBROWSBUSFZUH

Answers



universalis	different	feelings	eyebrows
alopecia	patches	normal	friends
hair	totalis	bald	wig
healthy	happy	hat	fun

Alopecia Areata – Why does my hair fall out?

Jamie is just your ordinary kid, until one day, he loses his hair. Join Jamie, and thousands of other kids like him, as he learns about hairloss and Alopecia Areata.

This video was produced by the Australia Alopecia Areata Foundation to help kids aged 4-12 to understand and explain their alopecia.

Watch the video here

