



Australia Alopecia Areata Foundation Inc.

ISSUE 7 NOVEMBER 2018

Alopecia  
Areata  
Totalis  
Universalis

research R A I S E  
awareness R A I S E  
information R A I S E  
support R A I S E  
embrace R A I S E

research awareness information support embrace





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## PRESIDENT'S WELCOME

Are we **#WinningAlopecia**? I think so.

How about you? Looking back over my email trail and in 2010 the most common question into the foundation was "am I the only person with Alopecia"? Now the most common questions coming in is "how can I engage or where can I go to meet others with Alopecia", this certainly indicates that awareness into Alopecia Areata is growing. In 2018 alone, AAAF was represented on 12 TV airings. A big thank you to all that have provided their voice for Alopecia.

When AAAF run a survey earlier this year, gauging what our audience needs it was surprisingly an equal vote on running events and providing more opportunities or information on research. So, throughout 2019, expect to see Popup events with short notice from our committee members. As AAAF travel for work, holidays or other opportunities we will be doing a shout out to come and join us for a coffee. However, we also recognise we can't get to everywhere and cover all areas of Australia, so I encourage you to think about holding your own catch up as everyone needs to eat and we sure love our coffees.

As for research, look out for some big announcements coming early in 2019.

Building on from **#EmbracingAlopecia** & **#HealthyAlopecia**, AAAF Sponsorship Program, is a perfect fit in introducing **#WinningAlopecia**. This program has been developed to provide support by funding opportunities for skill development and participation in activities which grow confidence. We are especially looking for activities which support health and wellness of participants, both physical and mental. Activities which have an element of team or community participation are also encouraged.

Another exciting project that AAAF has been working on is an educational video to go into the hairdresser training schools, look out for snippets of the video on our YouTube channel.



# MEET OUR COMMITTEE

## Introducing our Tasmanian Branch Manager Jessica

"A crazy roller coaster of emotions" is my explanation for the past 12 months. This is the best way I can describe it and I think that truly sums it up.

On the 28th of November 2017, I was lying in bed and found my first patch of alopecia. Distraught, confused, scared, nervous and sick would be the best way to describe my feelings at that time. I had no idea what had caused this to happen and that was the scary part. There is no way I could have braced myself for the minutes, weeks or months to come. In a matter of just 6 weeks, my Alopecia took over completely. I was originally diagnosed with Alopecia Areata and progressed extremely quickly to Totalis. Then within about 3-4 months I found I was no longer producing any body hair what so ever, to which I learnt over time was referred to as Universalis.

I was unsure how to adjust to the new me. Sometimes I had found it had been days and I had not been outside my house or my yard. This become my safe haven; the one place I did not have to be anxious that people were studying me and my new appearance. It didn't take long for me to pull myself together. I found myself slowly accepting the new me and the fact I was finally accepting this isn't within my control. I soon learnt that those that mean something to me personally, will realise I am still the same person despite my change of appearance. Once I had learnt to accept myself, I found this new fire in me to strive to achieve anything I put my mind to. It was almost like I want to prove something to myself. To prove that I could transform this life experience into something that was positive and to see that I was not going to let Alopecia control me.

This new sense of drive was the fuel for me to push myself completely out of my comfort zone and this is never something those close to me would expect. Anxiety and Depression have been a big part of my life for approximately the last 7 years and the fact of standing out was the hardest part for me to come to terms with.

In the coming months, I completed a media release for The Examiner Newspaper and an interview for Win news to promote the Tasmanian Open Day with AAAF. It was through this process I was approached for an official title. These moments in the spotlight lead to me becoming the Tasmanian Branch Manager and attending but also speaking at the Tasmania Open Day.

I have since held multiple catch ups in Tasmania, have a support group of 56 currently and feel I am able to provide the support I was once given from others associated to the AAAF. I started to play netball weekly, using sleep meditations, learnt breathing techniques and reading my own emotions to ensure I can regulate them. I have started a new job to which I have worn my wig only a handful of times because I finally accept myself. I feel this is my reason for success.

I have the best support network, through family, friends and people I have met through the AAAF. Fast forward to now and most days I am completely comfortable in my own skin. Some days I am not and that's totally okay. But I have learnt not to hold onto that feeling for too long.

I am truly blessed to be given the opportunity to share my story again and I hope you find the confidence in yourself to strive to achieve. Whether that's a small win or a big win, it's still a win.

- Jessica.

# HEALTHY ALOPECIA STORY

## by Pearl



Growing up in today's society, hair is such a massive part of a girl, and to my, and my family's horror, I lost it all when I was only 7 years old. I'm forever thankful it was only my hair Alopecia effected, although at the time, it was the worst thing to ever happen to me. How was I supposed to grow my self-confidence when every time I looked in the mirror I hated what I saw? Or every time I went to school my peers tormented me? I wore a wig for a couple months although living in Cairns (30-degree heat!) It quickly knotted and became too hot to consistently wear every day. I can only imagine how hard it would have been for my mum. She constantly did her best to make me believe I was beautiful, buying me special Alopecia hats and scarfs, and in 2011 she organised my head to be painted and my photo was posted on the front page off The Cairns Post.

8 years on and I'm better than ever. After about three years of hatred for what had happened to me, I truly started to love myself. I moved schools, met a bunch of amazing people and grew as a person. I realised that I cannot change my circumstances, so I may as well embrace them. I've completely given up on wigs and hats as I don't really feel the need to wear them.

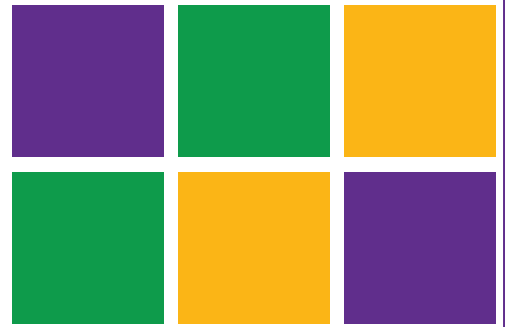
I'm fifteen years old and healthier than ever. I am a Muay Thai (kickboxing) fighter and train every day of the week except Sunday. I'm so passionate about health and fitness and wouldn't change my circumstances for the world. Muay Thai has really changed the way I see myself, and although I did love myself before, now I feel truly strong. And in my opinion, nothing can get in the way of a woman who feels truly strong. Every day I wake up thankful, as losing my hair was the biggest blessing in disguise I could ever receive. I would never have had the confidence to get in the ring, let alone be as exuberant and resilient as I am, if it weren't for the years of trial I dealt with. You never know how strong you are until being strong is the only option you'd have.

I have truly reached a point where I am not only mentally strong, but I am physically strong too. I put all my effort into training, as fighting is what I'm truly passionate about. I'm that person in my friend group that tells everyone that they're beautiful, because they are. A day never passes where I feel sad or resentful for what life has thrown at me because every single part of me is happy.





## RESEARCH UPDATE



### Medical Research

Rod Sinclair from Sinclair Dermatology has presented the initial results in Paris at the European Academy of Dermatology meeting for the Phase 2a, randomised placebo-controlled study evaluated the efficacy and safety of two drugs known as Janus Kinase (JAK) Inhibitors\*, PF-06651600 and PF 06700841, in alopecia areata over 24 weeks. The meeting was attended by over 10,000 dermatologists from around the world. Phase 3 trials due to start in the next six to twelve months. Patients can check their eligibility with their dermatologist. Both compounds performed significantly better than placebo in patients with Alopecia Totalis and Alopecia Universalis. Both JAK inhibitors were safe and well tolerated. With the most common adverse events were infections, gastrointestinal disorders, and skin and subcutaneous tissue disorders, and most were mild.

**Click here to watch the video.**

So many of our community comments on the inconsistency of treatment. AAAF has been working with the Dermatologists to rectify this. Treatment of Alopecia Areata: an Australian Expert Consensus Statement has also been accepted for publication. This consensus statement addresses the rationale for systemic treatment, the choice of systemic treatment, requirements for monitoring of systemic treatment, assessment of response to treatment, and appropriate cessation of therapy in AA.

### Psychological Research

*PALM Survey - Physical activity, quality of life, and mental health in Alopecia Areata individuals*  
This research is conducted with RMIT University and follows a previous study which found people with Alopecia Areata engage much less in physical activity and exercise than recommended, and also report high rates of mental health struggles. This follow up survey aims to understand why this is, and how individuals with AA can be better supported.  
In April and June 2018, an online survey recorded responses from people with Alopecia Areata both from within Australia and Internationally about their physical activity, quality of life and mental health.

*In October 2018, a focus group met at RMIT University to workshop and discuss barriers to physical activity and exercise. The discussions aim to find out how being diagnosed with AA affected exercise, and what factors motivated and stopped people from engaging in physical activity.*

*The survey is currently ongoing and we look forward to sharing the findings with you all. This research forms part of a broader plan to better understand the impact AA has on quality of life. In time, we hope to use this data to seek government support for this condition.*

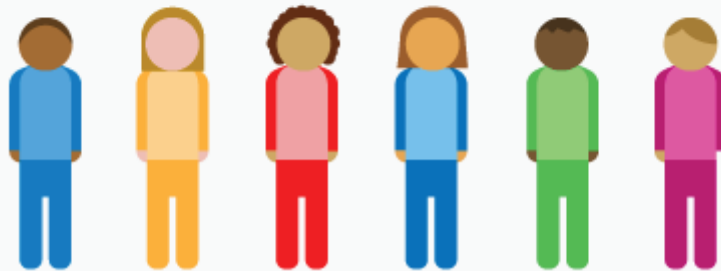




## RESEARCH UPDATE

*Continued*

# Clinical Trials



## **For Victoria ONLY** **Seeking participants for New Clinical Trials for JAK Inhibitors**

Sinclair Dermatology has secured 2 new trials. Pre-screening has opened up for the trials to run next year. One of these trial conditions will cater for children over 12.

Pre-screening visits are bulk billed so there is no cost to the patients. Patients need to have stable alopecia areata affecting 50% or more of their scalp. The current episode should be no longer than 10 years.

If you are interested please contact Sinclair Dermatology directly on: **03 90130099** or **[clinicaltrials@sinclairdermatology.com.au](mailto:clinicaltrials@sinclairdermatology.com.au)** to schedule a screening visit.

# VOLUNTEERS *with a heart*

## Volunteer of the Year

Volunteer of the Year is an award AAAF provides to community members who have gone above and beyond to support people with Alopecia Areata and to assist AAAF. We couldn't be more grateful to all our supporters and volunteers, and to everyone who gives their time to assist others.

We would like to express our thanks to the following nominees:

**Beverley May (SA)** - For organising videoing of a segment on wig hair knotting/repairs with Marguerite Bowman. She has also allowed the AAAF use of videoing she has had done on wig washing

**Marguerite Bowman (SA)** – For filming a video segment on wig knitting hair knitting/repairs

**Michelle Edwards (SA)** - For hosting events for SA Support Group and running several fundraisers on behalf of AAAF.

**Holly Faller (SA)** – For creating a series of live videos for the SA Alopecia Support Group, explaining several elements of Alopecia styling techniques, and general feel-good chats.

**Sharalynne Robertson (QLD)** – For giving her time and experience in photographing many of our functions in QLD. Many of her images featured in the AAAF 2018 calendar.

**Michelle Ogbonna (NSW)** - For organising numerous events for the NSW Support Group, as well as being a very active member of the NSW Alopecia Support group and meeting people in her own time.

**Nicole Dematos (VIC)** – for being actively engaged within our community, attending events and working with committee members to enhance her knowledge on Alopecia Areata

**Erin Tutty (Vic)**– For her ongoing support of the Hair donation program and assistance with thank you certificates.

**And a special thank you and congratulations to our winner:**

**Amy Thomas from WA!** Amy has single-handedly organised WA boldest morning teas during Alopecia Awareness Week for three years running and has been instrumental in forming a strong sub-group of twenty-something girls who provide great support for each other.

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**3/12 Executive Drive, Burleigh Waters, QLD**  
**<http://thebeautyspot.net.au>**  
**(07) 5593 5359**

Internationally recognized and accredited artist Debbie LaBes is the founder, director and head cosmetic artist of the Beauty Spot Cosmetic & Skin Clinic. Debbie has more than 10 years experience in cosmetic tattooing and close to 30 years in Aesthetics. She is an advanced skin therapist with qualifications in dermal science, light physics and beauty therapy.



Debbie specializes in a technique called micro-blading or feather touch brows. This technique creates the appearance of individual hair strokes and looks very natural for people who have lost their brows through alopecia. Cosmetic tattooing can also be used to create an eyeliner effect which enhances the eyes, never smudges, and doesn't need to be reapplied. Debbie is very experienced at working with clients with alopecia and understands the condition well. She strives to create a friendly and understanding environment and positive experience.

"I have always held the firm belief that it's not just about appearances, and that your true beauty should be able to shine through. However, sometimes we sabotage ourselves with low self-esteem or lack of confidence. My dream is to be able to help people recreate themselves, which will allow the very best version of their inner-self to be illuminated."



The Beauty Spot also provide a range of other beauty and wellbeing services, including skincare and facials, tanning, teeth whitening and more.



## WHAT'S NEW?

### Sponsorship Program.

Over the last two years, AAAF has been campaigning to **#EmbraceAlopecia** and to support **#HealthyAlopecia**. We're very proud to empower our community to find confidence with their alopecia and to manage their alopecia journey in a way that promotes their physical and mental wellbeing.

Continuing to build on the success of these campaigns, AAAF is proud to announce our new Sponsorship Program.

The AAAF Sponsorship Program will run for the next 12 months providing support for individuals living with Alopecia Areata whilst raising awareness directly into your community by empowering you to reach your goals in sports and the arts. Successful sponsorship applicants will receive between \$500 and \$4000 to help you achieve your objectives in activities which benefit your overall wellbeing.

Sponsorships are available at Bronze, Silver or Gold level and can assist with things like training fees and lessons, competition and performance entry fees.

Sponsorships are available for individuals with any form of Alopecia Areata living in Australia for solo or team participation.

Applications will be open from December 2018 to September 2019. There will be three application review dates – March 31st 2019, June 30th 2019 and September 30th 2019.

Further information will be released when the application period window opens. To stay up to date, make sure you are following AAAF on Facebook and are registered with us for email updates.

[Link to Facebook here](#)

[Link to Email updates here](#)

## DID YOU KNOW



- *AAAF attended the first ever Youth Health Forum, Consumer Health Forum of Australia in September?*
- *AAAF is working with Sustainable Salons Australia to educate hairdressers about Alopecia Areata and Hair Donation?*
- *AAAF attended the national Come Together Conference hosted by our friends at the Canadian Alopecia Areata Foundation?*

# WHAT'S ON?

## QLD Open Day

Saturday November 17th – 10.00-3.00pm

North Lakes Community Center

10 The Corso, North Lakes, QLD

RSVP – [judy@aaaf.org.au](mailto:judy@aaaf.org.au)



## Launceston Picnic – TAS

Sunday November 18th – 11.00-2.00

Cataract Gorge Reserve, Launceston, TAS

RSVP – [jessica@aaaf.org.au](mailto:jessica@aaaf.org.au)

## Perth Family Picnic

Sunday November 18th – 11.30-3.30

Shoak Lawn, May Drive Parkland, Kings Park WA

RSVP – [greg@aaaf.org.au](mailto:greg@aaaf.org.au)



## SA Picnic Lunch

Sunday November 18th – 12noon

Tusmore Park, Stirling Street, Tusmore, SA

RSVP – [liz@aaaf.org.au](mailto:liz@aaaf.org.au)

## Wet'N'Wild Community Day

Saturday December 8th – 10.00-4.00pm

Discounted rate of \$33 per person, and AAFA to cover costs for people with Alopecia Areata to attend

Access the booking form by clicking [here](#).

RSVP – [carlo@aaaf.org.au](mailto:carlo@aaaf.org.au)



## VICTORIA Christmas Picnic

Sunday December 2nd - 10.30am-3.00pm

The Basin Triangle Park

1310 Mountain Hwy, The Basin, VIC

RSVP – [vesna@aaaf.org.au](mailto:vesna@aaaf.org.au)

# SOCIAL MEDIA



## #HealthyAlopecia Blog Competition

November is the very last chance to get involved in our #HealthyAlopecia Blog competition!  
**Click here to find out how.**

You can win \$2000 towards a healthier you. Looking to join a gym or take up a new sport? Feel like you'd feel more confident with a new wig or brows? Want to see a specialist or talk to a councillor, but are worried about the costs? This program can help with any of these items, and more.

Our final draw will be on the 30th of November.

We have already had 11 lucky winners receive \$2000 towards improving their health and wellbeing. You could be number 12!

**Read our previous winners stories here.**

## Love, Alopecia

Did you catch these popular posts on the AAAF blog, Love, Alopecia?

**Click on the images to read the posts.**

Raising Kids with Alopecia  
(From an ex-kid with Alopecia)  
– by Georgia:



Bald Girl in the Dating World  
– by Bianca:



*Bald Girl*  
in the  
DATING WORLD

Dear Alopecia Diary –  
Teagan's Story:



## SOCIAL MEDIA LINKS

**AAAF**  
**Linkedin**  
**Facebook**

**Instagram**  
**You Tube**  
**Go Fundraise**

**My Cause**  
**Shopnate**  
**Love Alopecia**



# Kids Korner

The AAAdventure Camp 2019 will be hosted on the *Gold Coast in Queensland!*

Next year the camp will take place on the *9th and 10th of November*, so be sure to save those dates if you're keen to join us!

We're aiming to have even more kids attend than ever join us in 2019 for an amazing weekend of confidence-building activities, new friends, and of course some fun at the theme parks!

What an amazing way to kick off the start of Alopecia Awareness Week!



## WIG GRANTS

**Have you applied for your wig grant yet?**

AAAF's Wigs for Kids program provides funding for wigs for anyone with any form of Alopecia Areata aged 18 and under! Variety - the Children's Charity also run a wig grant program.

**Don't miss out! Apply today!**



**Apply here: AAAF Wigs for kids or here: Variety**