



Australia Alopecia Areata Foundation Inc.

# ISSUE 8 MAY 2019

**Alopecia  
Areata  
Totalis  
Universalis**



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Front Cover: Tas Branch Manager- Jessica Farley  
Taken at larapuna, Bay of fires, Eddystone Point .

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Tammy Davey

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## PRESIDENT'S REPORT

Have you attended one of our pop up get togethers? Have you entered the sponsorship program? Have you submitted your art work for the Archie's Bald Art Exhibit? These are just a few opportunities being bought your way providing support, awareness, engagement and ultimately **#WinningAlopecia**.

With 18 submissions received in quarter one for the AAAF Sponsorship program and \$11,200 already granted, don't miss your opportunity to be involved.

No better answer to **#WinningAlopecia** than having 106 people from every state of Australia for a weekend of fun, friendship and support at the 2018 Kids Camp. If you missed the wrap-up visit [here](#).

Expressions of interest for this years camp is now open, see details in the Kids' Corner section.

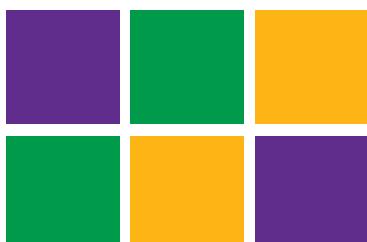
After many years of searching AAAF has welcomed our first Victorian Branch Manager – Helena. Helena and her son both have Alopecia . You can find more details about Helena and our other board members [here](#).

We would also like to announce two new support ambassadors. Stacey and Nadine. You can read more about their passions [here](#).

After five years at being the QLD Branch Manager Judy has resigned, to take on new adventures. In this time, she has grown this support group from just 80 members to nearly 300. Judy has also been a tireless volunteer on some of our biggest projects, including establishing the RAISE newsletter, creating our alopecia Christmas cards and calendar, the Crown Art Henna Project, expanding our Alopecia Support Group to far north QLD and the QLD south coast, and much, much more.

James, who has been with AAAF for eight years as a youth Ambassador, Support Ambassador has now taken on the role as the ACT Branch Manager Role.

If you live in the state of Queensland and are looking for an opportunity to voice your ideas and be part of our community, don't be shy and get in contact.



# MEET OUR COMMITTEE



## Stacey - Support Ambassador

My Alopecia appeared when I was nine years old. My first patch was discovered by my hairdresser; I remember being embarrassed that everyone was fussing about it. The patch itself did not bother me and I hated that it was being made to be a big deal, which at the time, I thought wasn't. I assumed that it would disappear after a short period of time; which was not the case.

Over the course of six years I had tried almost every available treatment for Alopecia. I persisted with a few treatments for several years with limited successful results. I had some success from steroid injections but the hair that grew back was not as strong as the hair I had before. The regrowth that I gained from the steroid injections fell out again once it reached a certain length. I always used to tell myself that it was just hair and that I was overreacting. I would relate this to people that have it a lot tougher than I do. In reality, everyone has difficult times of their life that they have to get through. Alopecia was just mine. I realised that it was okay to be sad, angry and upset about my situation as long as I didn't stay in that frame of mind for too long. I was healthy and that was something to be grateful for. I was lucky in a sense that my Alopecia developed quite slowly. I was able to disguise my bald patches with my own hair for over five years, until I had to start wearing beanies to hide the multiple patches.

Disguising my patches with my remaining hair was a constant battle, I would not leave the house until I was certain that every patch was hidden. Although my hairstyles were perceived to be 'perfect' not many people knew the necessary effort it took to complete them in order for me to feel comfortable enough to leave the house and go to school. I was governed by the fact that if people thought my hair looked nice, then I would have to maintain that standard as a distraction from my Alopecia. After coming to terms with my Alopecia, I now realise that it was unhealthy to rely so much on having hair as part of my identity.

I lived with Alopecia for six years before I decided to stop all treatments after convincing myself that it was okay to wear a wig. The day before going on holiday to Cairns, I chose to shave my remaining hair. It was such a good feeling knowing that I wouldn't have to watch my hair fall out anymore. It took a few days to get used to a shaved head, I would often scare myself in the mirror, not knowing who it was. I chose when I would lose all of my hair, instead of anticipating for the rest of it to fall out. I was relieved to regain some control over my Alopecia, which was difficult to do as the disease can be so unpredictable. Fortunately I was very grateful, and still am to this day to have supportive friends and family around me.

My involvement with AAAF began when I attended the Hobart open day in April of 2018. After I became a member of the Tasmanian support group I began to attend events and contribute my planning ideas for the future. I attended the AAAF Kids Camp in 2018 as a young adult helper to support others with their Alopecia. I completed media interviews in the lead up to the event to assist with the spread of Alopecia Awareness within my community. I became a support ambassador shortly after attending the AAAF Kids Camp. Having the chance to pass on my personal experiences makes me incredibly proud, as I am able to support people with Alopecia, who could be going through the same situation as I did.

Becoming a part of the AAAF community has been significantly important to me, as it has given me the opportunity to share my knowledge with other people who may be coming to terms with their Alopecia.

# COMMUNITY STORY

## By Georgia

*In many ways, I have been very lucky on my journey with this condition.*

*I was extremely young when I first presented with Alopecia Areata, so I don't really remember losing my hair and the stress that comes with that. I've just always been bald.*

*My Alopecia Areata has always developed and changed rather slowly, so I haven't had to experience the shock of losing all of my hair in a just a few weeks – or having it all grow back just as suddenly.*

*My mum is a doctor, so, when we found a specialist to speak to, we were able to understand the complicated medical information we were given and make a fully informed decision about treatment options.*

*I'm very lucky.*

*It has still been difficult.*

*In high school, I began hiding my hair loss and refusing to speak about my condition. I think I felt like if I didn't talk about it and people couldn't see it, then it wasn't real. Like ignoring it could make it go away and I wouldn't have to deal with it. Instead I started to become very anxious that people would find out. I was deeply concerned about my appearance and what others thought about it. I felt like I could only be acceptable if I hid this part of me away. It was very toxic and created a lot of negativity and stress.*

*I was always a good student and involved in music. Most of the adults in my life thought I was, in general, a pretty good kid. I started thinking, if only I had a different body, if I only I looked different, looked better, looked normal...*

*I was in a really bad place, mentally and emotionally.*

*In hindsight, it almost scares me to think about where I would be now if I hadn't started kenjutsu at my local karate club.*

*Kenjutsu is a Japanese style of martial arts which uses a katana sword. It's very physically demanding, and requires a lot of mental discipline as well.*

*To train, I couldn't wear my wig. I know that some people can engage in sports while wearing wigs, but I've never been able to mix the two. I get overheated and sweaty and my wig slips and I worry too much about my hair and not enough about the sword in my hands. So I stopped wearing them, and tied on a headscarf instead.*

*I remember training more vividly than I remember anything from high school. Three or four afternoons a week in was an old brick warehouse with no insulation, down behind the bowling club and the netball courts. It was freezing in winter and stuffy and humid in summer. The water treatment plant a few blocks up wasn't quite far enough away if the wind came in the wrong direction. It was sweaty and hard and I worked so hard to keep up with training and school and music.*

*But it was the first time I really started to love my body for what it could do. Sword in hand, I even loved how it looked. (However cool you think you look, you will be cooler with a sword. (Fact.)*



*During my final year of high school, the week before my final exams, I competed at the International Sport Karate Association's World Cup. I came third in my division.*

*Martial arts helped to turn my life around, and has been a huge impact on my journey to being comfortable and confident with my alopecia.*

*A year ago, I moved to Melbourne and started a new style of marital arts – German Longsword. The sense of community and the friendships I've built have been a huge help in settling into a new city so far from my family. I aim to compete in several tournaments this year.*

*I've also taken up another sporting activity – one completely out of my experience and comfort zone. Aerial hoop, also known as lyra, this is an incredibly challenging and fun type of circus art or aerial fitness. It requires strength, flexibility and stamina to perform a routine in aerial hoop.*

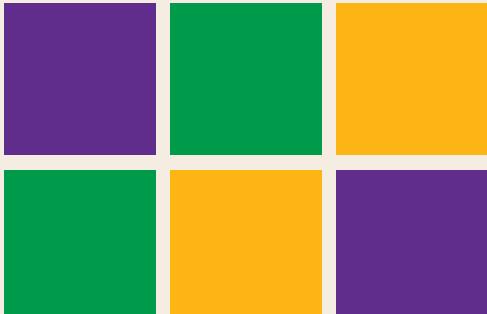
*These days I go full time without a wig, and rarely even bother with makeup. I'm comfortable that way, and in my day-to-day life my alopecia doesn't have much impact on me. Still, I do struggle with performance anxiety and feeling "looked at". Performing my first ever aerial hoop routine will be a big challenge, and I'm both terrified and excited.*

*But mostly, I just feel lucky.*

*I'm so grateful to AAAF for the sponsorship I've been awarded to help me on my journey with these two weird, crazy, amazing sports. I hope sharing my story and progress will help other people with alopecia to try something new. Even if you're not a traditionally sporty person, there are so many non-traditional and special sports out there, and they have the most amazingly supportive communities. It's never too late to get involved and to try something new.*

*AAAF's Sponsorship Program aims to support people with any form of Alopecia Areata to reach their goals in sport and the arts. Sponsorships range from \$500-\$4000. To find out more about the Sponsorship Program, and how to get involved, [visit here](#).*

*Click [here](#) to watch Georgia in action.*





# RESEARCH UPDATE

## Road Map for Diagnosis –

Major step in the treatment of Alopecia Areata

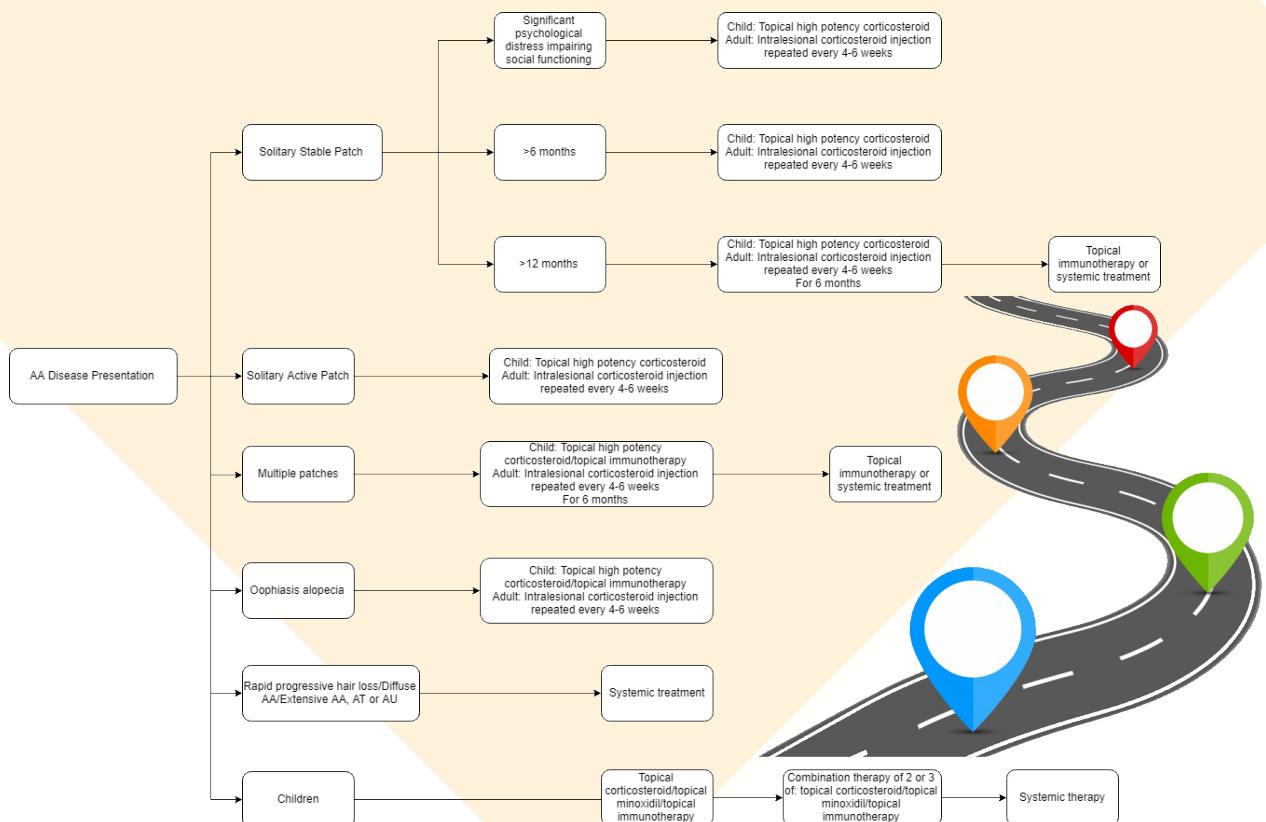
The purpose of this roadmap is for the diagnosis and treatment of Alopecia Areata and represents a major step in the treatment of Alopecia Areata. Currently, there is no standard treatment pathway for people with Alopecia Areata. This Road Map will provide an important resource for dermatologists around Australia, and aims to improve the care and outcomes for those with Alopecia Areata.

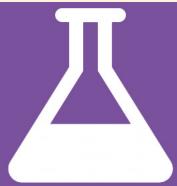
This consensus statement outlines a treatment algorithm for AA, including the indications for systemic treatment, appropriate choice of systemic treatment and the satisfactory outcome measures and when to discontinue successful or unsuccessful treatment.

AAAF would like to thank all of those involved in dedicating their time and expertise for this important outcome.

[Click here to download the Australian Expert Consensus Statement.](#)

[Click here to download the Road Map for Diagnosis.](#)





## RESEARCH UPDATE

Continued

Associations between physical activity, quality of life (QoL) and mental health in patients with Alopecia Areata: The Physical Activity, quality of Life and Mental health (PALM) study.

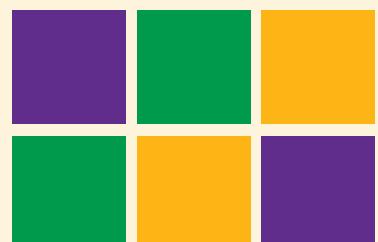
AAAF has been working with researchers at RMIT University on understanding the connection between physical health and mental health in people with Alopecia Areata. This research will ultimately help us towards our goals in seeking government support and funding for future treatment options for this condition.

The next stage in our research looks into physical and emotional barriers to physical activity experienced by people with Alopecia Areata, and aims to identify solutions to these barriers.

In the latest development, two of our papers have been accepted as poster presentation at the International Society of Behavioral, Nutrition and Physical Activity Conference 2019, in Prague, Czech Republic. This is a fantastic opportunity, and we thank our research partners at RMIT University.

### Cyclosprine Study Completed Last Year -

For those interested in reading about our research published in JAAD -(journal of American Academy of Dermatologists), please click [here](#).



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## *False Eyebrows & Eyelashes*

Hi, I'm Violeta Addamo and I've had Alopecia Universalis for over 20 years. As a sports enthusiast with a huge love for life, I decided I needed products to support my lifestyle. So, I specialised in the supply of false human hair eyebrows. I hope you enjoy wearing them as much as I do!



I don't need to tell you how hard it can be to stay positive and feel beautiful every day when you have Alopecia. Finding products that stay on can be challenging. Especially, if you love fitness, as a hobby, like I do. You can still look beautiful and turn some heads with a little extra help, should you want it!

Please feel free to contact me if you need help with your product or just need to chat.

Request a free e-book on the "Ultimate Ten Traits" to self-love and happiness.

[www.whitecat.com.au](http://www.whitecat.com.au)

**WHITECAT**

[info@whitecat.com.au](mailto:info@whitecat.com.au)

# WHAT'S NEW?

## Online Support Group

**Calling all young people with Alopecia - We've created a new on-line support group just for you!**

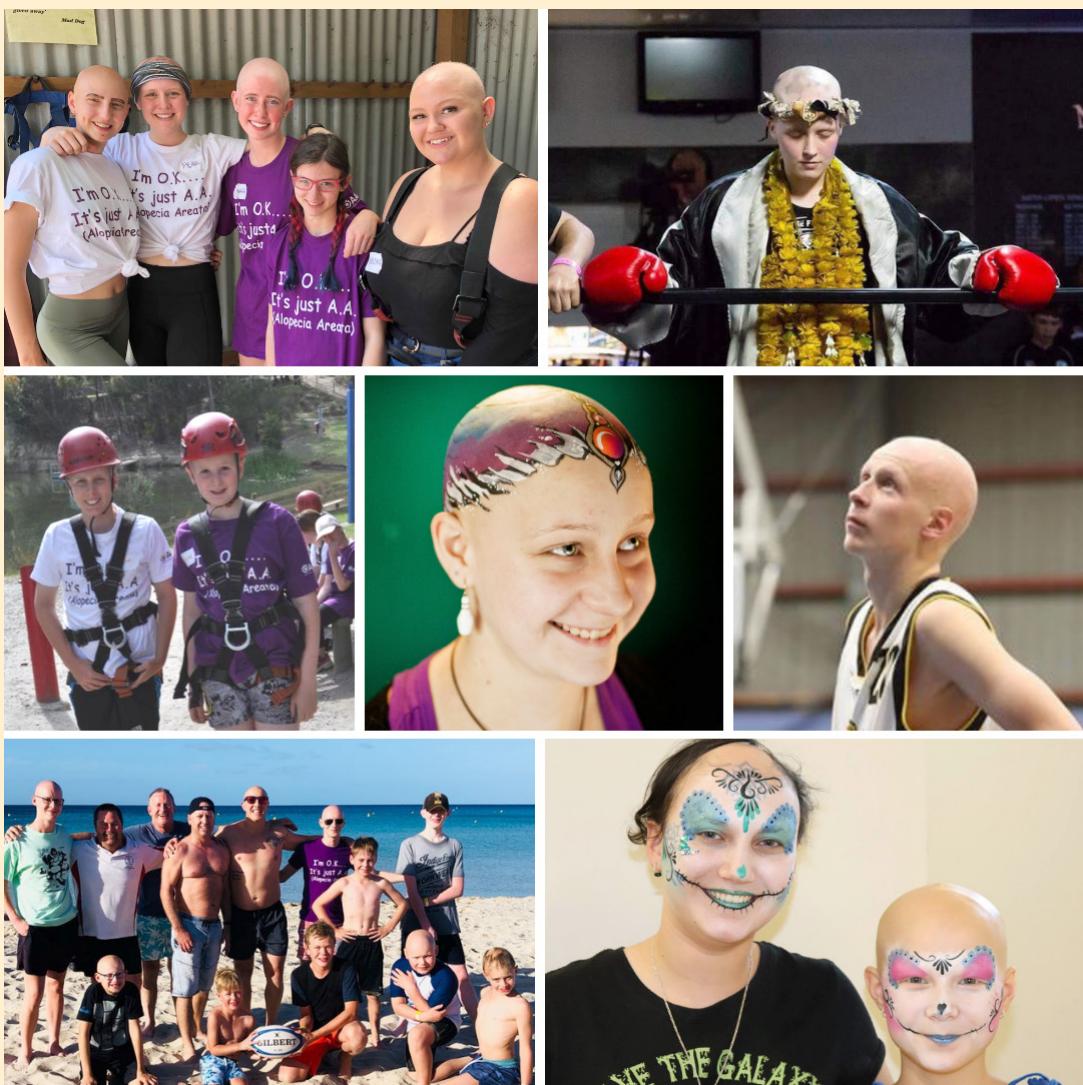
**This group is a private space for young people aged 13-23 with alopecia to connect, make friends and share experiences.**

**Please note that parents of young people with alopecia will not be accepted into this group. Parents and family members are very welcome in all our state-based support groups.**

**[Click here to join.](#)**

**We also have a new page on our website which collects many of our fantastic resources for young people living with Alopecia Areata into one place.**

**[Click here to access.](#)**

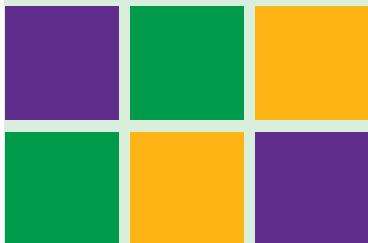
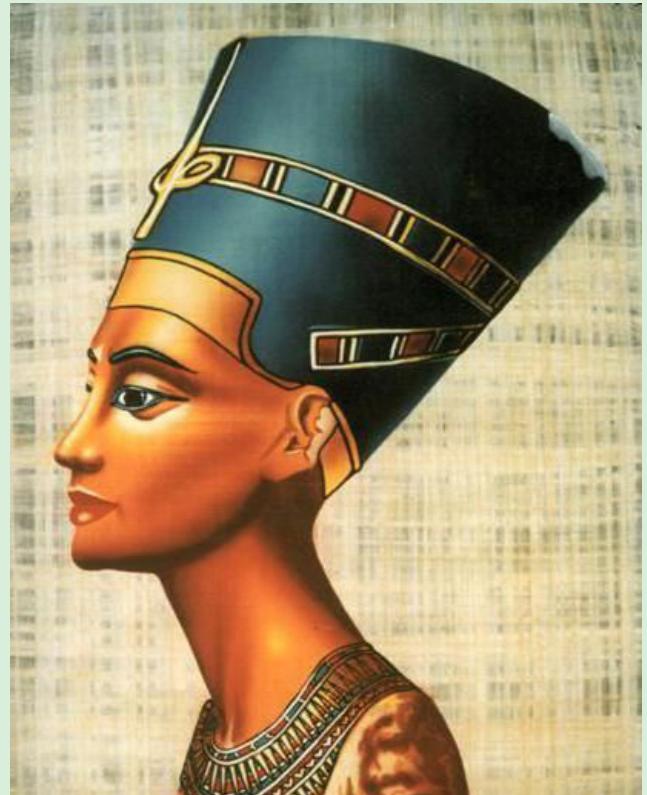
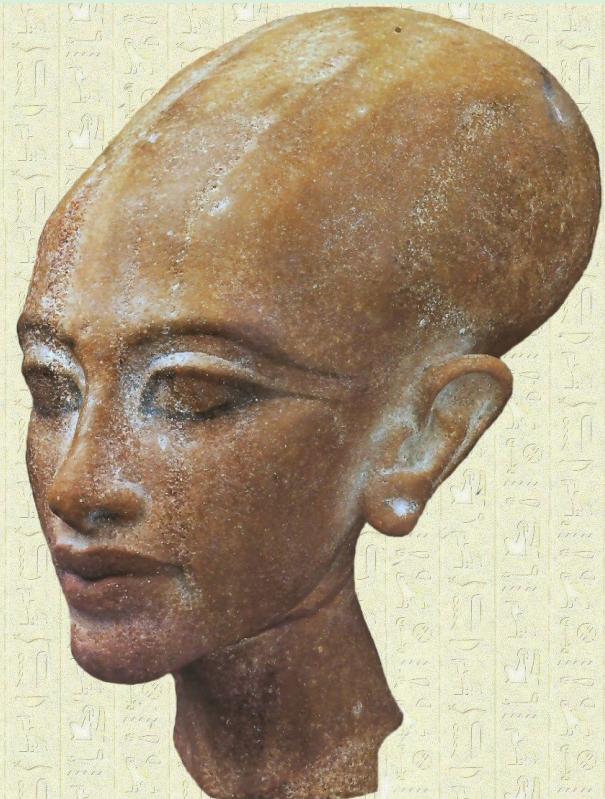


# DID YOU KNOW THAT... ?

In Egypt around 1500 B.C., a shaved head was considered the ultimate in feminine beauty.

Egyptian women removed every hair from their heads with special gold tweezers and polished their scalps to a high sheen with buffing cloths.

## The Bald Beauty of Nefertiti



# WHAT'S ON?

This information is subject to change, check website for latest event information [here](#).

## WESTERN AUSTRALIA

### Family Pizza Day

Saturday 3/8/19

Theo and Co, Albany Highway , East Vic Park



## TASMANIA

### Family Bowling Day

Saturday 22/6/19

Launceston Lanes, 24 Innocent St,  
Kings Meadows



## TASMANIA

### Hair Donation Cut

Saturday 22/6/19

Kameleon Hair and Beauty

18 Hobart Road, Youngtown.



## VICTORIA -

### Family Day

Sunday 4/8/19

11am - 4pm

Knox Garden Community Hall



## SOCIAL MEDIA



**Throughout 2019, AAAF is running a monthly live chat discussing different aspects about living with Alopecia Areata. We've already hosted talks on explaining Alopecia Areata, dating, trichology and what Alopecia Areata is like for men and boys.**

**You can follow us on Facebook for notifications about our next live chats, or view past chats on our YouTube channel.**

**Are you in our latest update on what Alopecia is?**

**Click here to watch our latest video.**

## SOCIAL MEDIA LINKS

**AAAF  
Linkedin  
Facebook**

**Instagram  
You Tube  
Go Fundraise**

**My Cause  
Shopnate  
Love Alopecia**

# Kids Korner



**EXPRESSIONS OF INTEREST NOW OPEN!**  
**ADVENTURE CAMP 2019**



**Expressions of Interest are now open for the Variety Alopecia Areata Camp 2019!**

**The Camp is an opportunity for kids aged 18 and under with any form of Alopecia Areata to come together for an exciting weekend. This year, the camp will be held on November 9th and 10th in the Gold Coast, QLD.**

**Thanks to the generous support of Variety - the Children's Charity NSW/ACT, this camp is completely free for kids with Alopecia Areata - including flights, meals, accommodation and amazing activities.**

**To find out more about the Camp 2019 and how to register your interest,**

**[click here.](#)**