



Australia Alopecia Areata Foundation Inc.

ISSUE 14 MAY 2022

RAISE

research

awareness

information

support

embrace



#EmbraceAlopecia

AAAF



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**If at any time you wish to unsubscribe,
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PRESIDENT'S WELCOME - Chel Campbell

Wow what a beginning to 2022 we have had. We found ourselves pulled into a media storm. It has been an unusual time to be someone with Alopecia Areata when it has received such a large amount of public attention. What was really heart warming was the support AAAF received from our community. Within minutes of the incident occurring I had journalists on the phone, wanting that elusive "reaction comment", instead they got an education on what Alopecia Areata is. It just shows how far AAAF has come – they found us! And I found you. Yes 20 different opportunities created within 3 days and I had no trouble with finding individuals to go on TV, Radio Stations and appear in Newspaper, – so thank you for your support.

I'm delighted to announce that the kids camp will be national once again. This year it will be held in Sydney. Please refer to the kids corner for more details.

AAAF will also be taking nine people to the Beanie Festival in Alice Springs in June this year. AAAF will be donating 100 beanies into the local community. I am also hoping to purchase beanies with a difference for our NHWC packs.

Remember AAAF is always looking for ideas and opportunities to improve the lives of those affected by Alopecia Areata through our aims of Support, Awareness and Research.

As we move into normality it is time to get back to connecting. AAAF 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 and AAAF will be there to help promote your event, just let us know when and where it is happening.

Have you seen our new What to ask your doctor when considering treatment for Alopecia Areata infographic.

Click [here](#) to check it out.

“MEET OUR COMMITTEE”



SUPPORT AMBASSADOR - South Australia Mairead

What are you reading or watching right now?

The last book I read was *Light in the hidden places* by Sharon Cameron, a captivating recount of a heroic and brave young woman who helped shelter Jews during WW2. This book enraptured me from start to finish and I feel more wholesome having read it. I have also just finished watching *Bridgerton* on Netflix, and I can't wait for season 3!

Who's someone you admire or look up to?

I look up to my older sister, she inspires me everyday to be kind and compassionate and always true to myself. She reminds me of my strength and hold space for me to be authentic and unapologetically myself. My sister is my best friend and I am so thankful to have her in my life.

What's something you want to learn?

I would love to learn more holistic healing rituals, such as reiki energy healing, sound bowl therapy, horticulture and natural medicine. The thought of holistic healing therapies intrigues me as I love to be connected to nature and I am in touch with my energy and conscious of the energy around me. I have 2 singing bowls currently but struggle to play them both at once so just taking baby steps for now!

What's the bravest thing you've ever done?

The bravest thing I've ever done was one Christmas after a few too many cups of liquid courage, a friend and I walked to the end of the Glenelg jetty in our fancy Christmas dresses and jumped off! I am terrified of the ocean but have always wanted to jump in. We couldn't climb back up the ladder in our big dresses, so we ended up swimming back to shore only to be told that there had been a shark sighting earlier that day!

If you had 25 hours a day, how would you use your extra time?

I would spend more time moving my body, reading, practicing self care and cooking up a storm! I might even get up early enough for a sunrise as long as I can go back to bed with all my extra hours.



**What's
new?**

SPONSORSHIP OPPORTUNITY

**Are you interested in getting sponsored by
AAAF?**

**Our Sponsorship Program for 2022 is officially
OPEN!**

**You could receive
up to \$4,000 in
sponsorship!**

Want to know how?

**AAAF is opening its
doors to support
YOU with our
Sponsorship
Program**

What is it?

This Sponsorship Program aims to provide support for individuals and families living with Alopecia Areata, while also raising awareness of the condition and of AAAF, by getting connected to new communities.

What is it?

This program aims to provide support by funding opportunities for skill development and participation in activities which grow the stated outcomes of the individual.

What activities can be sponsored?

AAAF is especially looking for activities that support health and wellness of participants, both physical and mental. Activities which have an element of team or community participation are also encouraged.

Who is eligible?

Must have a form of Alopecia Areata

Must live in Australia

Must submit application by the due date and commit to requirements of the sponsorship level

Interested?

Applications open until
May 31.

**Apply now using the
link**

<https://aaaf.org.au/sponsorship-program/>



MENTAL HEALTH RESOURCES

The Emotions Of Alopecia Areata

People who have Alopecia Areata and their family members often experience a variety of emotions:

- Feeling alone, withdrawn, and isolated
- Loss and grief
- Fear that others may find out you have the disease
- Scared that others may find out that you wear a wig
- Sadness and depression
- Anger
- Embarrassment
- Guilt or self-blame that you somehow brought the disease on yourself
- Guilt related to how the disease is affecting family members and loved ones
- Helpless in regard to searching for answers or cures (going to extremes)

For parents:

- Guilt that they may have genetically contributed to their child's disease
- For siblings and other family members, shame and hurt because the disease has also affected their lives.

These emotions are very normal but can have a negative impact on the lives of individuals if not addressed. If you need help or support, we recommend reaching out to the following organisations.

Beyond Blue

Kids Help Line

Headspace

Australian Psychological Society

SUPPORT FOR PARENTS

Did you know that you can access a Parent's Pack? A 26 page online document that will help parents of those with alopecia areata navigate the disease. Even if you've been around alopecia areata for a while now, we recommend you have a look at the information and inspiring stories included.

Access here

How to Explain Alopecia to Young Children

Alopecia can be difficult enough to explain to adults, so explaining the complexities of how autoimmune conditions work to children can feel daunting.

However, AAAP believes that it is very important for children with Alopecia Areata to understand what is happening to their body as much as is possible for their age. Understanding the condition will help children to feel more in control of what's going on and more confident, and help to combat feelings of fear or anxiety.

Below is an example which may help you to explain the condition to children.

- Everyone has a system in their body which helps to keep them healthy. It works like a troop of very tiny soldiers, which receives orders from your brain when you are sick or injured. These soldiers (called the immune system) seek out the things that might make you sick and attack them, like germs or viruses, in order to keep you healthy. Sometimes, these soldiers get confused by the orders they get from your brain, and instead of attacking germs or viruses they attack parts of your own body. This is what happens with alopecia. Your soldiers don't understand their orders, and they begin to attack your hair follicles – the place your hair grows from. This is what makes the hair fall out.

Kaylene:

You will be okay. All that matters is that you have confidence in yourself. Love yourself because you have many family and friends that love you too.



ADVERTISE WITH US



Zen Wigs is an Australian online wig boutique specialising in human hair wigs for clients with medical hair loss. We pride ourselves on providing comfortable, natural looking, quality wigs.

We are excited to bring the internationally renowned iWig by Erica Luxembourg to Australia. The iWig Solace Cap™ has a lace front, silk top, with an incredibly soft lining, along with silicone strips around the perimeter and silicone ear tabs for grip. The cap is designed with comfort in mind, and is suitable for everyone but perfect for people suffering from medical hair loss. The hair used is premium quality with European texture and a healthy, silky feel. The Medium size tends to fit the majority of people, while the Small is suitable for petite and younger wearers. If you are looking for the ultimate in comfort and quality, then the iWig could be your answer.

www.zenwigs.com.au

AAAF Special - Use Coupon Code AAAF-FRIENDS at checkout for an additional \$100 discount on In-Stock Wigs

Email: zenwigs@gmail.com
PO Box 1090, Tamworth NSW 2340



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RESEARCH UPDATE

Professor Angela Christiano is a Professor of Dermatology and a Professor of Genetics and Development at Columbia University's Irving Medical Center. The major focus of Prof Christiano's work is the study of inherited skin and hair disorders to develop genetic and cell-based therapies for skin and hair diseases.

As Professor Christiano is an alopecia patient herself, she has a unique connection.

Progress is being made to a long-term cure for alopecia areata. Below are some takeaways from her latest seminar:

- There was originally a bias that assumed alopecia areata would have most in common with other skin inflammatory conditions. But starting with genetics studies a decade ago, Christiano showed that alopecia areata involves pathways which have more in common with rheumatoid arthritis, coeliac disease and type 1 diabetes, than with inflammatory skin conditions such as eczema and psoriasis. It strengthens the case for specialities to work together and share knowledge and make collaborative decisions as treatments become available. We see this already in rheumatology, gastroenterology, and paediatrics, when treating patients with other inflammatory diseases.
- Secondly, with no JAK inhibitor yet licenced in the Australia for the treatment of alopecia areata, many people are driven to extreme lengths to access JAK inhibitors such as Xeljanz (tofacitinib). Christiano's more recent research paves the way for the development of a new generation of JAK inhibitors, which are more targeted. Her studies in a strain of mice that naturally develops alopecia, show that treatment with just a JAK3 inhibitor alone, or a JAK1 inhibitor alone, was sufficient to reverse alopecia and reduce inflammation in the skin, but that JAK2 inhibition was not required. We are waiting to hear more details of the clinical trials now taking place, but hopefully these more narrowly selective JAK inhibitors may become the drugs of choice for dermatologists to prescribe. We can hope that further clinical studies in people will get us closer to a more refined approach to reversing alopecia areata with JAK inhibitors, and that the prospect of licensing JAK inhibitors is gaining momentum.
- For the one-third of non-responders to JAK inhibitors, Professor Christiano's research does not ignore these patients. The studies extend to showing that white blood cells called CD8 T cells move from blood vessels in the skin into the innermost part of the hair follicle where they destroy hair producing cells. This opens the possibility of using new small molecule inhibitor drugs aimed at the signals that T cells depend on to do their damage. There is already a drug which can block a protein called LFA-1, which guides T cells in the skin and makes them competent to target the hair follicle. This drug is approved as a topical treatment for dry eye disease, and more investigations are needed to test in alopecia in the future.

RESEARCH UPDATE

- Continued

- The research is also moving closer to identifying a trigger of alopecia areata. This provides huge empowerment to those with the condition and has personally had a huge impact on my mental health. It was interesting to hear that a single gene, for a type of keratin in hair called KRT82, is associated with alopecia areata, and it does not seem to be responsible for pitted/weak nails. This is a revelation as so many people link them together. This is an important development that shines new light on previous studies from several years ago that keratins may be the elusive autoantigen for alopecia – at least for some patients - and provides a focus for further investigation. Conversely, it may turn out that there are many other genes involved, and we await further research to help reveal their different roles.
- Professor Christiano's next goal is to investigate long-term reversal of alopecia areata. Currently many patients experience flares once treatment with JAK inhibitors is stopped. Christiano's team have shown that some of the T cells which invade the hair follicle remain there during treatment, as 'resident memory T cells'. These are 'the enemy' in Christiano's words, which could explain the recurrence of alopecia when treatment stops. It's a challenging area but being investigated nonetheless to find ways to block these cells using single-cell 'barcodes' of their unique T cell receptors. Certainly, next stages will focus on both the ongoing immune response, as well as protecting the integrity of the subsequent hair follicle.



WHAT'S ON?

Things are opening up around the country and we have been getting busy with events!

You'll find more on the events page of our website or in the state support groups, but here is a rundown of a few events:

AAAF is getting things organised for this year's AAAdventure Camp! We are so grateful to our volunteers who make this possible.

More details for the camp can be found in the Kids Korner section of the newsletter.

NEW SOUTH WALES:

May 15th, Hills District catch up
May 18th, 12pm Ladies lunch catch up



LADIES ONLY ALOPECIA LUNCH

When? May 18, 12pm - 2.15pm

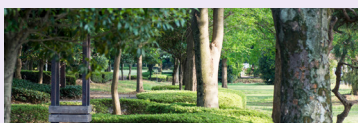
What? You're invited to a daytime event targeting mature aged ladies who have any form of alopecia, and who may have grown or school aged children.

You can expect a relaxed catch up over food and drink.

How much? Expect to spend approximately \$15- \$30 for lunch and a drink.

Where? Moorebank Sports Club - (Sporties), Indulge Brasserie - inside, through the foyer, to the left. Look for the table with a reservation card for Michelle. This is along Heathcote Road Hammondville.

We can't wait to see you!
Please RSVP michelle@aaaf.org.au



HILLS DISTRICT CATCH UP

When? May 15, 12pm - 3pm

What? Catch up at Fagan Park in Galston. There are walking trails, kid's play area, a lake with ducks, the pathway for bikes, bbq area if needed. A great way for new parents/children to get to know each other and who live near by.

Where? Fagan's Park (38-48 Arcadia Road, Galston) near the B&Q's.

Cost? Parking is approx \$6 per car, a gold coin for the BBQ's if needed.

We can't wait to see you!
Please RSVP kellykinsella@gmail.com



QUEENSLAND:

May 14th, Brisbane South Catch up
May 28th, Brisbane North Catch up



BRISBANE NORTH CATCH-UP

When May 28th, 2022 from 10 am

Gather together for a catch up for the Brisbane North Members!

Where? Endeavour Park Endeavour Esplanade Newport. The helium filled purple and white balloons will be easily seen. There is a cafe for purchases and we will have games and more!

We can't wait to see you!
Please RSVP greg@aaaf.org.au



BRISBANE SOUTH CATCH-UP - CORSO FAIRFIELD

When May 14th, 2022 from 10 am

Gather together for a catch up by the Brisbane River at The Corso Fairfield.

There will be games and more!

Where? The Brisbane Corso Park, Fairfield. Along the river bank at the white and purple balloons. We will be located near the mobile cafe in the park.

We can't wait to see you!
Please RSVP greg@aaaf.org.au



VICTORIA:

28th May, AAAF Stock Clearance Sale
28th May, Trivia Night



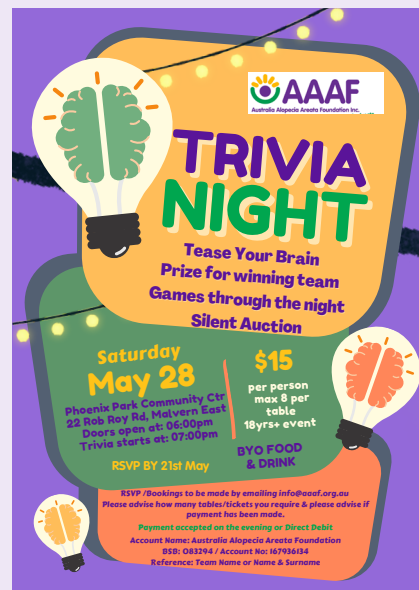
AAAF STOCK CLEARANCE SALE

When May 28 2022, 2-4 pm

AAAF is hosting a stock clearance sale. 1 (one) Free Synthetic Wig for each person up for grabs.

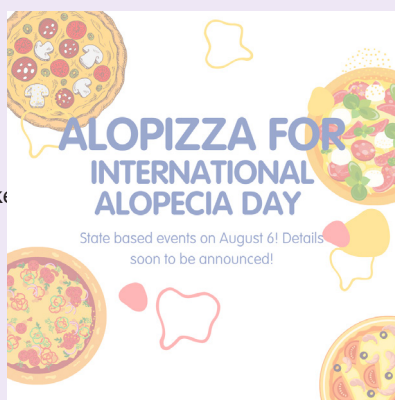
Wigs, Wigs Stands, Wig brushes, Eyelashes, Eyebrow tattoos, Hats with Hair other head coverage items will all be available at cost or below price.

Located in: Phoenix Park Playground
Address: 22 Rob Roy Rd, Malvern East VIC 3145



August 6th - International Alopecia Day

Each state will be holding an Alopizza Night. Make sure you are following us on Facebook, LinkedIn, and Instagram, in your state/territory Facebook group, or register [here](#) to receive information!



24th - 27th June - Alice Springs Beanie Festival
AAAF will be taking 10 individuals with a form of alopecia areata to the Alice Springs Beanie Festival!

Friday, June 24, 2022 - Monday 27, 2022

The Alice Springs Beanie Festival is a community-based event that began in 1997 and is now a fun event where Aboriginal and non-Aboriginal artists share their culture and exhibit together. The festival is unique because of the incredible amount of community participation and our unique ties with local Aboriginal organisations. The festival's aims have always been to develop Aboriginal women's textiles, promote women's culture and the beanie as a regional art form, as well as promote handmade textile arts.



Click [here](#) to view all our upcoming events.

Social Media

So in reviewing a multitude of posts this quarter, it seems there is a common question being asked.

Is it normal to experience itchiness and or soreness with Alopecia Areata?

Hair loss often occurs without any discomfort however some can experience different sensations when hair is lost. As such it is hard to define what is 'normal'. If you experience discomfort at the point of losing hair, such as feelings of itchiness, soreness, burning or aching, you are certainly not alone.

When hair loss occurs, there is inflammation around the hair follicles. It is this inflammation that can cause discomfort. Some people with Alopecia Areata report similar sensations when their hair is growing back.

Taking anti-inflammatories or antihistamines might help to ease symptoms. Applying a cold or warm compress to the affected areas can also provide some relief. Discuss your symptoms with your GP and/or dermatologist as some physical symptoms are more typical of particular types of Alopecia Areata so it is helpful for your doctor to fully understand what symptoms you are experiencing.

Check out our Top 3 Social Media posts:

Decades of studies have been dedicated to finding the root cause of alopecia, and the only things that all doctors can agree on is that there is currently no cure, it is unique to the individual, it is based on a complex gene interaction, and it is not the individual's fault. - Click [here](#)

Alex is enjoying a lot of vitamin D in her Hat with Hair. The perfect summer companion. Click [here](#)

Alopecia areata can take many forms. What do they all have in common? Though there is still lots of research to do, we know they are all due to an auto-immune response. Click [here](#)

SOCIAL MEDIA LINKS

AAAF
Linkedin
Facebook

Instagram
You Tube
Go Fundraise

My Cause
Shopnate
Love Alopecia

Did you know?

Alopecia Areata is known as a “polygenic disease”. This means that, unlike a single-gene disease, both parents must contribute a number of specific genes in order for a child to develop it. Because of this, most parents will not pass Alopecia Areata along to their children. With identical twins – who share all the same genes – there’s only a 55% chance that if one has Alopecia Areata, the other will too. This is why scientist believe that it takes more than just genetics to cause the disease and that other environmental factors also contribute.



Did you also know?

Hair is being used for groundbreaking research at QUT?!

Researcher Amandeep Singh Pannu, a material scientist at QUT and his team are tapping into the potential of human hair as a cutting-edge sustainable future resource.

For the first time in the world, the QUT team were able to create luminescent hair that could one day help power tv's and smartwatches. In fact, the technology is now being used in solar panels to help make them more stable and efficient.

Kids Korner

Have you heard of our Wigs For Kids program?

Do you know a child who may need help getting a wig? They could be eligible to receive a grant from the AAAF Wigs for Kids program!

Children 17 years and younger who have a form of Alopecia Areata are eligible to apply.

They could receive a grant of \$400 to help them purchase a wig or anything that will be used to care for it (wig stand, hair brush, specialty shampoos and conditioners).

First, choose a Wig Provider in your state. Before deciding on a wig, it is best to do some research on the best type and style of wig for the child.

Once the application is approved, the recipient will receive a voucher that they can present to the Wig Provider when they get their wig!

It's as simple as that!

AAAF is on a mission to support children with Alopecia Areata and their families get wigs if they need help!

If this is you, click [HERE](#) to access the application form.



Alessandro's Alopecia Story



Click [here](#) to watch Alessandro discuss his Alopecia journey

Kids Korner - Continued

TRY SOMETHING NEW.

AAADVENTURE CAMP FOR KIDS



Nov 12 -13 2022 | Sydney NSW

Expressions of Interest Now Open for the Alopecia Areata Adventure Camp 2022!

The Alopecia Areata Adventure Camp is an opportunity for kids aged from 6 to 18 with any form of Alopecia Areata to come together for an exciting weekend. The camp is free for kids with any form of Alopecia Areata, including flights, meals, accommodation and activities.

This year we will be hosting our camp in Sydney, NSW on November 12th and 13th.

Where? YMCA Camp Yarramundi - 316 Springwood Rd, Yarramundi, NSW, 2753

The Alopecia Areata Adventure Camp will be a fantastic opportunity for kids living with Alopecia to make friends, learn about the condition and – most importantly – have a very fun time. This year we will be exploring activities such as abseiling, alpine rescue, archery, bushcraft, camp out, flying fox, giant swing, GPS orienteering, high ropes course, rock climbing, night activities, different sports and group challenges.

Head to our website to learn more about the 2022 Alopecia Areata Adventure Camp.

<https://aaaf.org.au/aaadventure-camp/>

Email info@aaaf.org.au

Click [here](#) to complete an Expression of Interest form.

