



Australia Alopecia Areata Foundation Inc.

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RAISE

research

awareness

information

support

embrace



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Front Cover: Ryan Campbell
in the Kimberleys



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PRESIDENT'S WELCOME

- Chel Campbell

AAAF AGM was held in October, the topic was raised on what is AAAF doing in the wider community? I thought this interesting being raised by one of our Committee members: but then took a moment to reflect and thought, wow I just do all this stuff and its behind closed doors, I need to be sharing this.

So in the last 6 months this is what AAAF has been up to:

- Run a Survey for GP's on their understanding on alopecia areata
- Joint partnered with an independent marketing company to better understand your experience of living with Alopecia Areata (Phase 1 for PBS)
- Working with 3rd party on ethics approval for (phase 2 for PBS) QOL survey
- Organised the AAADventure Camp
- Executed a Youtube explanation session with Pharmaceutical company explaining what AAAF does and how they can further assist.
- Feature article in Novembers addition of Retail Pharmacy Assistants emagazine
- Accompanied the Winners of our Beanie Competition to Alice Springs
- 3 Radio interviews
- Received a grant for W.A. to promote awareness into Alopecia Areata and the support we provide
- Awarded 22 Sponsorship grants
- Refreshed supporting material for 2022 content
- Attended the World Patient Conference (Virtual)

Not a bad list for someone who works full time!

Have you attended one of our pop up get togethers? Have you entered the sponsorship program? Will you showing your support to participate in our smiley face challenge as part of awareness week? These are just a few opportunities being bought your way providing support, awareness and engagement.

A focus going forward for AAAF will be in providing more focus on the status of the JAK Inhibitors. You will find in this newsletter a summary update.

We are also changing the way we are going to run events moving forward.

To create a greater reach for our support network. Create a process that can increase our informal and formal events on a social and reachable scale. Each state is a large area and the biggest problem is not enough events for all age groups to support people with Alopecia.

The aim of this plan is to split each state into regions and create sub committees or groups to assist with the organisation of informal events. More hands make light work. The duty of the AAAF appointed staff (Branch Manager, Events manager and Support ambassadors) is to oversee and authorise the sub-groups to be self-sufficient. We're all volunteers so there is no hierarchy. So if you would be interested in knowing more or being a part of running your own event in your own area, send an email into Chel@aaaf.org.au

“MEET OUR COMMITTEE”

SA BRANCH MANAGER- LIZ



Back in the late 1960's wigs started becoming fashionable. I was eighteen and decided one day to buy one, as a joke, to fool people into thinking I had cut my long hair. Fast forward 12 years and I wasn't wearing a wig to fool people but to cover up my hair loss.

After my son was born, I didn't notice that my skin and hair had changed from oily to dry. I didn't notice anything different with my hair after my eldest daughter was born either, but something happened just before her 1st birthday. I was getting ready to take the two children interstate to spend a couple of weeks with my parents when my husband noticed that I had a very thin patch of hair on my crown. I suppose I had noticed hair in the shower but never gave it another thought. By the time I returned home 2 weeks later I was wearing a scarf. A visit to my local GP and a follow up with a Dermatologist confirmed I had Alopecia Areata. I was prescribed Minoxidol tablets to be compounded into a lotion which I had to use on my scalp. I followed up with a second opinion, only to be told 'It's only hair'. I walked out of there bawling my eyes out and how I didn't have an accident driving home I'll never know. How can it be 'only hair' when there are advertisements all the time telling you how this or that shampoo will make your hair look healthy, shiny and beautiful. I remember an advertisement on TV, at the time, using a bald model telling everyone that if you used a certain shampoo, it would help your hair!

It took quite a while to accept my hair loss. My hair would grow back and then fall out again before reaching full head coverage. During those times I couldn't attend my gym as I couldn't face seeing all those females with hair. There were many tears shed as well. Eventually, I was able to accept that nothing was going to help regrow my hair. I had to pull myself together for the sake of my family, who supported me, and move forward. My Wig provider started asking if I would take calls from other people with Alopecia who were struggling. This, I suppose, was the beginning of offering support to people by listening to their stories and talking about mine.

I did have hair regrowth while I was pregnant with my third child which lasted for 6 months after the birth. I was determined to find a cause for my hair loss as I hadn't met anyone with Alopecia until in 2005, or so I thought, when I attended an Alopecia Areata open day in Victoria. After my eldest daughter was diagnosed with Alopecia Areata I remembered meeting my paternal Grandfather, on a previous overseas trip; he had no hair. I was fourteen at the time and saw him as an old man. I contacted my family overseas and they confirmed that he had suffered complete hair loss due to shock during World War II.

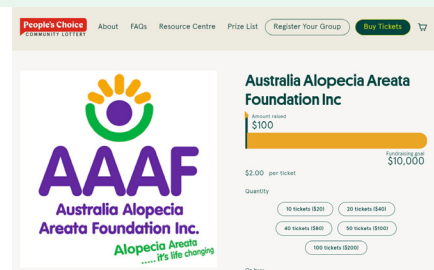
I had finally found my connection – genetics – but each of us has a different trigger.

Now I have accepted my hair loss I have quite a few wigs in different colours, lengths and styles which I wear just for fun. My wig journey has come full circle.



What's new?

AAAF and the People's Choice Community Lottery.



Did you know AAAF is 100% community funded?

We are a volunteer-run organisation with branches in every Australian state. We have been helping children and families have access to wigs, psychological and medical support, programs that aid them to develop and improve their passions and hobbies, and multiple other resources such as:

- * "No Hair We Care" packages
- * AAAdventure Camp for Kids
- * Wigs for Kids Grant Program
- * Wigs for Big Kids Special Program
- * Winning Alopecia Sponsorship Program
- * AA Advocate – School and community group educator
- * 1 full-time administrator
- * 1 dermatology nurse to provide telehealth services
- * 3 full-time program staff

Thanks to the amazing community we have built since our foundation back in 2010, we have also raised more than \$300,000 that have been invested in medical and psychological research for Alopecia Areata.

We have also hosted countless social and media campaigns, medical exhibitions, and specialist conferences with the sole aim of raising awareness and support for Alopecia Areata.

This is only possible due to the generous donations from people like you.

We rely on the kindness and love that we have drawn to the Alopecia Areata Community in order to keep operating and helping many others get through their journey as smoothly as possible.

One of our favourite ways of receiving donations is the People's Choice Community Lottery because you also go in the draw to win some awesome prizes.

There are 43 prizes on offer for the People's Choice Community Lottery, worth more than \$300,000. For next year's draw (winners to be revealed on Thursday, 9th of March of 2023) the prizes include:

- * a Toyota Kluger GX AWD Hybrid (RPP \$59,551)
- * a Toyota C-HR Hybrid GR-Sport Wagon (RRP \$42,306)
- * a Kozco Energy Solar Panel/Battery Package (RRP \$23,490)

If you want to take a look at the complete list of possible prizes, [click here!](#)

To participate, you can buy a raffle ticket for only \$2 and you can buy as many as you want by clicking [here!](#)

Please have in mind that your donations can really contribute to making a change. Here's a list of possibilities we can achieve with your support:

- ✓ \$5 can go towards providing classroom discussions at schools.
- ✓ \$25 can go towards supporting someone just diagnosed with this disease and linking them to a community network.
- ✓ \$50 can aid in creating resources to help a child educate a potential bully.
- ✓ \$400 can provide the funds to help a family purchase a wig for their child with Alopecia Areata.
- ✓ \$500 can help a researcher to go one step further towards finding a cure or acceptable treatment for Alopecia Areata.

Thanks to all the hard work and logistics implemented by People's Choice Community Lottery and their proud **business and media partners**, we get to keep a 100% of the donation made for every ticket!

Click [here](#) to support Alopecia Areata and AAAF and enter to win one of the amazing prizes.

WHAT IS THE RIGHT WIG FOR ME?

The Hair Piece world is so confusing!

Choosing a wig, hair piece or hair system can feel daunting as there are different options available, including different materials and attachment options.

Choosing the right wig to meet your needs can be a challenging journey. With so many types of wigs available, there is a lot of information to shift through and a lot of new terminology which can be confusing. The AAAF has put together these videos to help you understand a little more about the different types of wigs available, and answer some of the questions you may have about purchasing a wig.

Click [here](#) to watch our video on choosing the right wig for you.

Click [here](#) to watch our video on frequently asked questions.



SOME HELPFUL INFORMATION

TERMINOLOGY

Alternative hair terminology can differ from place to place, but here are the most commonly used terms.
WIG: Covers the entire head by way of a full 'cap'. Suitable for those with a number of bald patches or total hair loss

HAIR PIECE/TOUPEE/TOPPER: A smaller piece that is designed to cover a smaller area of hair loss rather than the whole head. These are most commonly used by men with androgenic alopecia, also known as male pattern baldness.

HAIR SYSTEM: This is generally used to refer to hair options that are fixed to the scalp. Hair systems are sometimes referred to as permanent solutions but this doesn't mean permanent in the sense of 'forever'. Hair systems are not removed in the same way as a wig or clip in hair piece, they can be worn for months at a time and you can do your everyday activities in a hair system such as showering and swimming. The hair system requires regular maintenance, and you need to discuss what this entails with a hair replacement specialist.

READY TO WEAR: A wig, hairpiece or hair system that is ready to go straight from the box.

CUSTOM MADE: A wig, hairpiece, or hair system that is made bespoke for your individual needs.

WHAT IS THE RIGHT WIG FOR ME?

TYPES OF ATTACHMENT

Alternative hair options can be attached in several ways:

GLUE: Can last up to 6 weeks. You can usually swim, play sport and carry out daily activities. You will need to be skin tested for this method to check for any allergies to the glue. For the best results it is recommend having one hair piece to wash and one hair piece to wear. If you have a system glued, you will need to have your stylist take off the piece and replace it with the clean one. The removed hair piece will be cleaned before your next appointment, usually 4-6 weeks. Glue should only be used on areas with no hair. Some people learn the skills required to maintain at home with the correct aftercare, such as de-bonder.

TAPE: Can last up to 4 weeks. For best results change at least once a week. Tape should only be used on areas with no hair.

CLIPS: These are clipped into any existing hair to create an anchor.

TYPES OF HAIR MATERIAL

Alternative hair options are available in the following materials:

SYNTHETIC FIBRE: This mimics hair, however it's man-made fibre. You cannot usually use heat on synthetic fibre. It doesn't colour fade and requires little to no styling; however, can be prone to 'friction frizz' as the piece gets older which can mean it looks worn and unnatural toward the end of its shelf-life, which will vary depending on regularity of use, care and conditions exposed to.

HIGH HEAT FIBRE/CYBER: Life-like synthetic fibre that you can use a mild heat on to style. Usually no colour fade, however, can be prone to some 'friction frizz' when the piece gets older. These are great for grey styles, or styles with a grey percentage.

HUMAN HAIR: Different human hair types from around the world. The hair varies in quality and price, depending on how it is sourced and treated. Human hair requires more styling than synthetic fibre.

WRAP UP

Please keep in mind that all wigs, hairpieces and systems require maintenance to keep them looking their best. This can include colouring, cutting, styling, adding hair, conditioning treatments and more. It is important to get the best advice you can before choosing the option for you, considering your lifestyle, time and budget. Ensure you gain a clear understanding of any ongoing maintenance costs, if applicable, so you are not surprised by unexpected costs.

RESEARCH UPDATE

JAKs - Where are we now and where might we be heading?

Janus Kinase Inhibitors (JAK inhibitors) are a hot topic within our community peer support spaces, and is clearly the number 1 repeated questions being asked into the AAAF team, so we wanted to provide an update regarding the current position re JAK inhibitor drugs as a potential treatment for alopecia areata.

Firstly, what is a JAK inhibitor and why are they being explored as a treatment option for alopecia areata?

JAK inhibitors are a type of drug that suppress the activity or response of one or more of the Janus Kinase enzymes, also known as JAK1, JAK2, JAK3 and TYK2. JAK enzymes are known contributors to the autoimmune process. In a nutshell, JAK inhibitors could block the inflammatory pathways that occur in active alopecia areata, reducing the inflammation that occurs around the hair follicles and allowing hair to grow once again.

What is happening with clinical trials for JAK inhibitors for alopecia areata?

There are lots of stages of research, starting out with basic research and pilot studies before moving into clinical trials. Clinical trials for JAK inhibitors as a treatment for alopecia areata are currently underway across the world with at least 4 pharmaceutical companies. Clinical trials can be a lengthy process as they need to rigorously test the drugs, first to check they are safe for use and then to see if they are effective, and monitor any side-effects. These trials have been in operation since 2015.

Can I get JAK inhibitor drugs for my alopecia areata privately?

We are aware that some people are choosing to source JAK inhibitors themselves. Because JAK inhibitors are licensed for treating rheumatoid arthritis and atopic dermatitis (eczema), some dermatologists are prepared to prescribe JAK inhibitors for patients with alopecia areata 'off-label'. This can be at a great cost for the drugs, this will be determined by supplier.

What is the position with any approval of JAK inhibitors for the treatment of alopecia areata?

The US Food and Drug Administration (FDA) approved a JAK inhibitor on 14 June 2022, history was made, marking the first FDA-approved treatment for the condition. The drug called Baricitinib (brand name Olumiant™) for the treatment of alopecia areata, In addition, in September 2022 the FDA accepted a New Drug Application for a JAK inhibitor called 'Ritlecitinib' for adults and adolescents 12 years and older with alopecia areata. The FDA decision is expected by mid-2023. AAAF will be representing the patient voice for the JAK inhibitor drugs - Baricitinib (Eli Lilly) and Ritlecitinib (Pfizer).

RESEARCH UPDATE

- Continued

So the question then comes which drug will be best suited to my form of hair loss. Baricitinib is under consultation for the treatment of severe alopecia areata in adults and Ritlecitinib is under consultation for the treatment of moderate to severe alopecia areata in people aged 12 years and over. It is unlikely that it will be offered to patients with small patches of alopecia areata. We are unclear at this point what the criteria will be in terms of what is determined 'severe' or 'moderate' hair loss.

Next phase is listing the JAK inhibitors for the treatment of Alopecia Areata onto the PBS

To understand the work involved to get a drug listed on the Pharmaceutical Benefits Scheme (PBS) you can familiarise yourself here. <https://www.pbs.gov.au/pbs/industry/listing/listing-steps> AAAF is participating in conjunction with third parties, to obtain the vital inputs into the lodgements need by the pharmaceutical companies.

Managing Expectations?

It is important that anyone embarking on these treatments, goes in with open eyes and realistic expectations. Whilst these JAK inhibitor drugs are a giant leap forward in the treatment of alopecia areata, they do not represent the cure that many are hoping for.

Research

In August AAAF in partnership with Pfizer and InSites Consulting (InSites Consulting is a well established, independent research organisation) run a new patient-focused research study about Alopecia Areata.

The goal of the research is to better understand what it's like to live with Alopecia Areata on a day-to-day basis. This means that AAAF can help identify ways in which Pfizer can better support patients and healthcare professionals to manage the condition.

We would like to thank the 50 people that took the time to provide their stories for this vital research.



ADVERTISE WITH US



Arch Beauty



Cosmetic tattoo studio **located** in Riverhills, Brisbane, offering eyebrow tattooing (as well as lip and eyeliner).

I **love** being able to give my clients the brows they have always wanted and to help them feel their most confident versions of **themselves**.

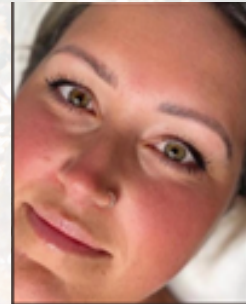
Clients can choose from three different types of eyebrow tattooing. **All** tattooing techniques are semi-permanent and use pigment, not ink. Numbing cream is used to make sure you are **comfortable** throughout and I take a very gentle, reassuring approach to each client's concerns. A follow-up appointment at 6 weeks is also needed to go back over the initial tattoo to **ensure** the pigment lasts.

Microblading (also known as feather touch): creates a natural look using a small blade to make hair-like strokes. Lasts 1-1.5 years depending on the individual.

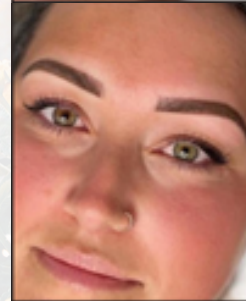
Powder Brow: very similar to powder makeup and creates a soft powder effect. This technique is done with a shading technique similar to a tattoo gun. Lasts 2-3 years depending on the individual.

Combination: combine both techniques listed above, with microblading at the front of the brow and powder brow through to the tail of the brow.

Before



After



Before



After



Instagram- @archbeautyau

Facebook- Arch Beauty Au

Email- archbeautyau@gmail.com



This content is a sponsored advertisement. To find out more about AAAF's advertising policy, Email info@aaaf.org.au.



Whats on?



Every month, we make sure to launch and host multiple events so our community is always engaged and present for our processes and ideas. Take a look at some of the upcoming events for the next two months!

Brisbane Community Event - November 19, 2022.

12:00 pm - 2:00 pm. Join us for an afternoon of fun at the White Hill Parkland Reserve!

AAAF Community Event - December 3, 2022. Cost: 40\$ p/p.
9:30 am (or tickets will be left at the ticket office) - 5:00 pm.
Every year the AAAF holds a community event in partnership with Raging Waters Sydney. The last event in 2019 we had over 130 attendees! This is open to all; kids and adults, young or old, with or without alopecia.



AAAdventure Camp - November 12, 2022- 13/11/2022
12:00 am. This year we will be hosting our camp in Sydney, NSW on November 12th and 13th.

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 many fun activities. Click [here](#) to learn more about the 2022 Alopecia Areata Adventure Camp.

We are inviting you to participate in our smiley face challenge :)

It'll take you about 90 seconds - here's what to do:

1. Draw the AAAF smiley face logo on your wrist
2. Take a picture
3. Post it to your social media with the hashtag #AAAF so that we can share, like and comment!



Learn about Awareness Week 12th-20th November

[Click here](#)





Social Media



After reviewing our **popular** posts this quarter, we have encountered raising interest in different types of content. We will talk a bit more about each particular one next up, but this is also a great opportunity to recommend to you one of our most informative (and liked) videos on YouTube! By **clicking** here, you will find 5 tips from a psychologist for protecting your mental health when beginning your **Alopecia** journey!

One of **AAAF's** biggest purposes, since it was created back in 2010, has been raising **awareness** and spreading information about Alopecia Areata with the intention of improving the lives of everybody that is going through their Alopecia **journey**. The most liked post in this category (**information**) was this post about supporting loved ones with Alopecia. You can read the full information by clicking **here!**

HOW TO SUPPORT SIBLINGS OF CHILDREN WITH ALOPECIA AREATA

@ALOPECIAAAAF



That's one of the reasons why I don't wear a wig – I think if a child or teenager sees me confidently walking around with my little bald head, maybe I can inspire them to do the same!? -Kate

@ALOPECIAAAAF

Sponsorships and Alopecia Support Stories are some of the most **vital** things AAAF focuses on, due to many reasons. Alopecia's exposure to the media and mainstream **increases**, families get support for their loved ones, people get resources to keep **developing** their talents and we get to keep **fulfilling** our mission and vision of helping people with Alopecia through their **journeys!** The most liked post in this category (**Alopecia Stories**) was **this one** from Kate's story. Truly amazing words!

AAAF operates 100% on donations and community support. This is not only **true** for the financial aspect of the foundation but also for our workforce, which is built up entirely by volunteers. **Many** of these and others that are not a part of AAAF's workforce **donate** their hair to programs like **Wigs for Kids** and **No Hair We Care**; the most liked post for this category (**donations**) was **Milla's**. Thank you so much to all of the donors as well!



Thank you Milla!

@ALOPECIAAAAF

SOCIAL MEDIA LINKS

AAAF
Linkedin
Facebook

Instagram
You Tube
Go Fundraise

My Cause
Shopnate
Love Alopecia

Did you know?



That AAFF runs surveys to understand the level of knowledge amongst our General Practitioners. In the survey undertaken in September 2022, we asked the following question -

Which of the following would lead you to refer a suspected alopecia areata patient to a dermatologist?

| ANSWER CHOICES | RESPONSES |
|---------------------------------------|-----------|
| Small or localised patch of hair loss | 22.73% |
| Progressive hair loss | 81.82% |
| Extensive hair loss | 90.91% |
| Treatment-refractory | 86.36% |
| Other | 9.09% |

This information is very powerful as it helps AAFF to target specific areas of knowledge sharing.

Did you also know?

Health funds can help to cover the cost of non PBS medication?

The eligibility criteria or conditions around what kinds of non-PBS medication can be claimed, waiting periods, annual limits and individual item benefits varies across each health fund. It is important to check with your health fund what is available to you. Benefits for non-PBS items are usually included under Extras or otherwise known as General Treatment cover.

Styling Options for Men

Losing your hair and coming to terms with a new appearance can have a big impact on your confidence. You might feel less like yourselves and not feel as attractive as you did. It can be tough getting used to looking different. The following tips may be things to consider for getting some confidence back.

1. Consider a new style/expand your wardrobe

Some men use their alopecia as an opportunity for switching up their style or focusing more on the clothes they wear than they've ever done before. New clothes can lift us, give us that much-needed boost, and make us feel good about ourselves.

2. Hats, hats, hats!

Until you start exploring hats, you may not even know of the MANY styles of hats that are available; baseball caps, beanies, bucket hats, Fedoras, flat caps, Panama hats, to name a few! Hats are much more fashionable now than they were 15 years ago. Hats can help to cover your hair loss if your alopecia is not something you're comfortable with. But more than that, hats can also offer warmth in cold weather, protect scalps from sunburn in hot weather or just finish off an outfit and add some style. If you are not a regular hat wearer, you may need to experiment and try on different styles to find the perfect one for you.

3. Framing features

Men who lose their eyebrows to alopecia tell us that they feel like their face has been 'wiped out'. The loss of facial hair can make a huge difference to your appearance. One way to give your face some definition back without going for the more permanent brow options, is to use spectacles/glasses. Over the years, many men with alopecia who wear glasses have told us that they have switched their glasses style to a bolder, darker frame as this can make the lack of eyebrows less obvious. Not a spectacles wearer? Don't worry! Did you know that you can buy non-prescription clear lens glasses? Some people have always worn glasses for fashion reasons rather than necessity. Some men in the alopecia community wear clear lens glasses to help to frame their face. As with hats, it's about finding the right style for you.

Another option for framing the face are piercings (or fake ones). Nose rings and an earring/s can help frame the face as well and add something extra that can take the emphasis from the hair loss.

4. Looking good starts with feeling good

Before we can start to think about looking good, it can really help to firstly focus on the things that can help us to feel good! The following are things that other men have told us have helped them to feel good at points when they've felt low:

1. Exercise – going for a run, walk, swim, cycle or joining a gym can all help to release the endorphins
2. Team activities – whether it be joining a sports team or a pub quiz team, getting together with others can help to keep improve our mood
3. Taking time for yourself – life can be BUSY and full on. It is important to take some time for yourself to relax, whether that be participating in some mindfulness/meditation, or simply making some time to enjoy something you really love
4. Talk to your guy friends about confidence – everyone has hang-ups about their appearance, even those who don't have alopecia and it can help to normalise some of your concerns. If you would rather speak to other men with alopecia you can join our Facebook group for men and ask how others manage their confidence. Click [here](#) to find the group.

Kids Korner


Fighting crime and fighting for a kinder, better world will remain your task, even now that you have Alopecia!

We have created an amazing new collection of T-shirts so you can write your own stories while wearing a reminder that Alopecia cannot stop you!


Here's the link to our store! Click [here](#) and check the new designs we've got for you.




**Our new AAAF T-Shirts are
HERE!**

**NOW'S THE TIME TO BE A WARRIOR!**

Alopecia can't get in your way of slaying dragons and aiding those in need! We have launched this amazing line of T-shirts as a reminder.

**NOT ALL SUPERHEROES WEAR HAIR!**

Fighting for a kinder, more informed and aware world will remain your task, especially now that you have Alopecia! Check our store to buy yours!

**BEING BEAUTIFUL ISN'T RELATED TO YOUR HAIR**

Make a statement and remind others that a princess doesn't need hair to wear a powerful, shiny crown, by wearing this fashionable T-Shirt.

www.aaaf.org.au

