



Australia Alopecia Areata Foundation Inc.

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RAISE

research

awareness

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Front Cover: Kylie on her
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PRESIDENT'S WELCOME

- Chel Campbell

It has been another busy six months at AAAF. AAAF has partnered with several organisations to ramp up the collection of Quality Of Life (QOL) material, as after doing several investigative surveys to GP's, Pharmacies and Dermatologist the message was clear that more patient support perspective material was needed.

I want to say a big thank you to the support AAAF receives from you. You will see in this document we have pulled together an experience journey map. This is a result from the participation of individuals in a survey run late last year and has already been shared with multiple pharmaceutical companies and ACD.

There is a real buzz around the number of JAK inhibitors and the speed as to which they are coming to market. Hopefully you are keeping abreast of the new research opportunities being presented and the updates on the advancements with the JAK Inhibitors. If you have missed our updates, there is more information provided in this newsletter as well as on our research web page. Click [here](#) to find out more.

During this quarter we said Goodbye to Judy. Judy has been an active member on the AAAF committee for seven years, holding various positions. I can't say enough about all the time and effort that Judy invested in bringing a multitude of items and opportunities into the Alopecia Community.

Michelle has joined AAAF as our secretary. Michelle has keen interest in everything medical aiming to extend her career into immunology and dermatology.

AAAF is in the planning stages for 2023 Awareness Week activities, with the big ticket item already actioned. The EOI for the AAAdventure Camp 2023 has closed and positions offered with excitement around the camp being held in South Australia for the first time. Click [here](#) for more information.

If you would like to plan an event within Awareness Week being held from the 11th-18th of November, AAAF is keen to hear about. Let us know at info@aaaf.org.au

‘MEET OUR COMMITTEE’

NSW EVENTS MANAGER

Michelle



Hi I'm Michelle, I want to be involved with the AAAF as I developed Alopecia as a teenager and back then I struggled with a lot of depression and anxiety about the future. I want to be a source of hope for those who are struggling now. I've been organising catch ups for people with Alopecia for many years in SW Sydney and 2 years ago took up the role of Events Coordinator for AAAF NSW. Together with our NSW State Manager, Carlo, we have been working to establish small Catch Up groups in many parts of NSW so people can be connected with those in their area for mutual support. We would also like to start an online catch up for people who may be living in remote areas or prefer this mode of connection, we are seeking a volunteer to assist us in this role.

You can contact me at Michelle@aaaf.org.au .



What's new?

NSW have 9 Catch up groups operating in:

1. Central Coast / Newcastle
2. South Coast / Batemans Bay
3. Wollongong / Shellharbour
4. Hills District
5. Sydney Metro
6. Sutherland Shire
7. SW Sydney
8. Port Macquarie
9. North Shore

Contact Michelle for more details Michelle@aaaf.org.au



AAAF has a new secrerary - Please give Michelle Chen a warm welcome! She'll be taking care of our secretarial responsibilities behind the scenes and we are so lucky to have her.

RESEARCH UPDATE

Treatment Algorithm for Alopecia Areata

Statement from Professor Rodney Sinclair a Professor of Dermatology at the University of Melbourne and director of Epworth Dermatology.

We went pretty much 40 years without a single new treatment, and then in the past two or three years, we've probably got about 40 new emerging treatments. And this often happens in medicine, that once people make the fundamental breakthrough in science, molecular biology, then targeted treatments develop. And then once someone proves a targeted treatment works, then all the other pharmaceutical companies try and copy it, and develop modifications to it. And so the field moves very, very quickly.

We saw this at the turn of the century with psoriasis. We got the very first biologic treatments for psoriasis, and within a few years, we had about 20 new treatments. And as a consequence of that, all the psoriasis wards in the hospitals had to close because the patients were now being managed as outpatients with injectable treatments. I suspect we have seen similar changes in other diseases, with rheumatoid arthritis and perhaps even inflammatory bowel disease. I think we're on the cusp of seeing that emergence of a new paradigm shift in the treatment of alopecia on our doorstep.

How effective are the treatments?

Historical treatment for alopecia was prednisone. Prednisolone worked in about 80% of patients, but many people had to continue taking it and then they started to accumulate all the side effects

associated with prolonged prednisone use. It's a steroid and so that steroid treatment gave the treatment a bad name because many people were either intolerant of the side effects or made a decision that the side effects were worse than the disease itself. That's now changed with these new treatments. They belong to a family of medications called Janus Kinase Inhibitors (JAK).

JAK's were actually invented at the Walter and Eliza Hall here in Melbourne. A fellow called Andrew Wilks who basically set the whole ball in motion, spoke at one of the conferences we ran in Melbourne, he was saying that globally there's over \$20 billion in annual sales of these Janus kinase inhibitors for the treatment of a whole range of diseases, of which alopecia areata is probably the newest one added to the list.

And what we've just seen in the last few months is the first of these medications has now got FDA approval in the United States, and so that's now being widely prescribed throughout America. It's got approval in Europe through what's called the EMA, which is their equivalent, the equivalent in Japan. And it's now under consideration by the TGA. And so, when you think about all these regulatory bodies around the world, the FDA is probably the highest bar that you've got to get over, and this medication is now an FDA approved treatment for alopecia.

RESEARCH UPDATE - Continued

Does the hair stop growing when people stop taking JAK's

We've been fortunate enough to have patients enrolled in clinical trials using these medications for the past six years now at our centre, and had a number of patients who have been able to stop the treatments, and they've managed to continue to keep their hair. But there are also patients who when you stop the treatment, it relapses. And a little bit of that depends on how long they've had the disease before they have the treatment. Patients who might have had the disease for 10 or 15 years, they're more likely to require ongoing treatment. However, patients who are newly diagnosed tend to have a better prognosis, and many of them can stop the treatments without a problem. But ongoing treatment is not necessarily a problem because in diseases like rheumatoid arthritis, for which some of these drugs were originally designed, it was always the intention that people would take it lifelong, and so the safety profile for these medications, when they were being developed, was designed for people to take it lifelong. In alopecia areata, I think we're going to be fortunate that many patients will be able to stop the treatment after a period of time.

If you're having this treatment for life, and are there side effects that accumulate?

There doesn't appear to be side effects that accumulate. It tends to be very well tolerated. With the one medication that's been approved by the FDA in the United States, that's one called Baricitinib, the main side effect that we tend to see is a little bit of mild acne that we can manage with some topical antibiotic ointment. We sometimes see a mild elevation in their cholesterol but it's not enough to require treatment and, on the whole, it's a really well tolerated treatment.



RESEARCH UPDATE - Continued

Seeking Participation:

Assessing the Impact of Alopecia Areata from Patients' and Caregivers' Perspective in Australia (MARISSA).

Have you been diagnosed with Alopecia Areata (AA) by a doctor?

If so, you are invited to help improve research and contribute to a greater understanding of how AA affects day-to-day life!

Currently, there is limited evidence about Australians living with AA, especially surrounding quality of life, school/work productivity and treatment satisfaction, among others.

Pfizer Australia Pty Ltd, is collecting meaningful data to help improve the lives of people living with AA and their families across Australia.

The online survey should take no more than 25-30 minutes to complete and can be done from the comfort of your own home. You will remain anonymous, and all data collected with be de-identified.

We understand life gets busy, so as compensation for your time, your bank details will be requested so you can be reimbursed \$150 within 10 business days of survey completion.

If you are interested in taking part, check your eligibility by clicking this link **Marissa Survey Study** or simply scanning the QR code attached.

Have you been diagnosed with Alopecia Areata (AA) by a doctor?
We would like to hear from you!

Currently, there is not enough information on how AA affects your life.

Please help us improve research by participating in an online survey.

This is an online study so there's no need to disrupt your day-to-day.

To check if you can take part, click the below link or scan this QR code.

RESEARCH UPDATE - Continued

Seeking Participation for a Clinical Trial:

Currently seeking adult participants for clinical trial in subjects with moderate to severe alopecia areata

A clinical trial evaluating at a multicytokine inhibitor medication as a new potential treatment for alopecia areata is currently recruiting volunteers across multiple sites in Australia. We are seeking adult participants who have had moderate to severe hair loss due to Alopecia Areata for a minimum duration of 6 months.

- * Clinics participating in Victoria, WA, NSW and QLD .
- * Study duration is 33 weeks and will require 27 visits to the study
- * Click [here](#) for more information

To register your interest in this research, or to learn more about the full eligibility criteria, please contact the State contact below:

Victoria

Sinclair Dermatology - Dr Evelyn Loh evelyn.loh@sinclairdermatology.com.au
Ph 03 9013 0099

New South Wales

Premier Specialists - Dr Corey Stone premierdermatologytrials@gmail.com
Ph 0416 502 017

Queensland

Veracity Clinical Research - Dr Lynda Spelman
Ph 07 3039 1311

Western Australia

Freemantle Dermatology - FULL



COMMUNITY STORY

Meet Jess-James Ferguson

On a very exciting and positive note, after many painstaking years where I wanted to give up repeatedly, I finally attained my last 2 tags necessary in order to grade for my black belt at TaeKwonDo and that is happening at the end of this month so I will be sharing pics and video of that once it happens. I really want to thank AAAF for the support and sponsorship that has made my journey to black belt a reality and honestly, I couldn't wish for a better ending to my sponsorship period as I approach the last quarter.

My journey with alopecia has been a lot like my journey with martial arts, finally getting to try a medication that has given many people hope and success is in essence a parallel with achieving every stage leading up to my black belt...the finish line is so close, I can hardly believe I'm actually at this point. It has taught me a lot about life in general and perseverance. I've watched my younger brother go through the fashion trend of getting a mullet to fit in at school and I still shake my head and wonder how these kids can take their hair for granted so much that they deliberately go out and pay for one of the least appealing hairstyles known in history, second only to a skullet or Edgar...look them up if you're unsure, ha, ha. I actually love my brother deep down, way deep down.

I have come out of my shell so to speak in that I also started an outdoor phys ed class at school and every Monday before school our class goes to the beach and snorkels or goes bodyboarding...something I had never done before nor wanted to expose myself to as it meant the likelihood of someone seeing me without my hat, but I have actually loved every minute of it and ask Mum to take me to the beach on weekends, something I never thought my alopecia would "let" me do.

Each week, I'm mindful of the person I'm developing into and the headway I've made (if you'll pardon the pun.)





If you've **lost** your eyebrows and want them back, My Two Brows Temporary Eyebrow Tattoos can help restore your confidence with **stunningly** realistic eyebrows, custom fit the perfect size, style and colour combination for your unique face.

This eyebrow replacement solution is super quick and easy to apply, **100%** waterproof, and can last up to 3 days per use. We've got eyebrow sizes & styles for men, women, and kids of all ages. **Nobody** will be able to tell they aren't your real brows!

Their realistic look comes in 11 colours, 5 styles and 5 sizes, so everybody can aspire to get their **perfect** fit.

Hanah. H - Review.

Amazing product!

Easy to use, long-lasting, incredibly realistic, and so beautiful! I am thrilled that I came across this company, my **self-confidence** is at a whole new level.

Customer service is amazing, all of my questions were answered on the same day. Could not be **happier** with this and I wholeheartedly recommend this product.

Hop onto our **website** to grab your free sample pack now and put your brow problems behind you!

Before



After

Before



After



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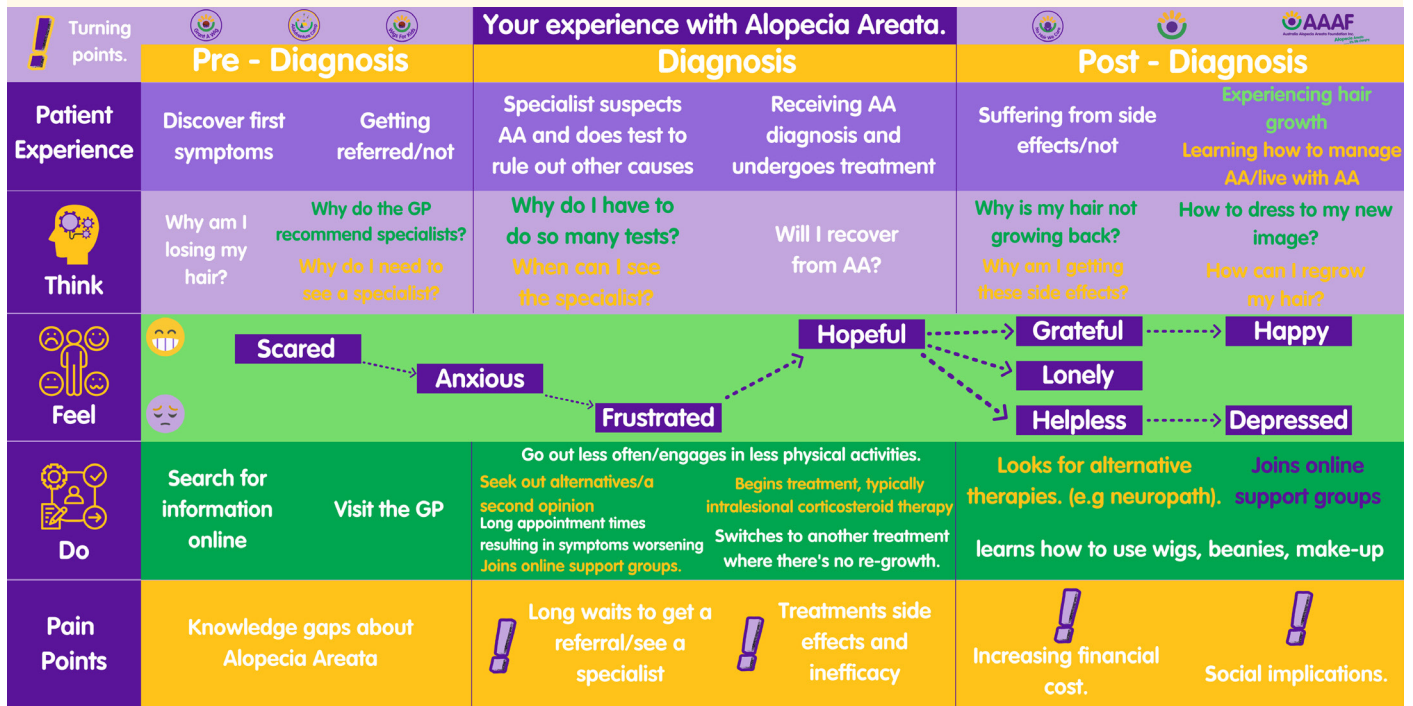
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Did you know?

Your experience with Alopecia Areata.

Did you know that AAAF is sharing your journey thoughts with GP's and Dermatologists.



Did you also know?

Designer Thomas Vailly created a human hair bioplastic that “resembles leather” and could be a useful alternative to other single-use plastics.





INTERNATIONAL ALOPECIA DAY IS AUGUST 5TH

These states will be holding an Alo-Pizza night – TAS, WA, SA, QLD and VIC

W.A -Geraldton will be holding an event on Saturday 13th May.

Contact your Branch Manager for more information.

TAS: - Jess jessica@aaaf.org.au

WA: - Greg greg@aaaf.org.au

SA: - Liz liz@aaaf.org.au or 0409892021

QLD: - Greg Gregt@aaaf.org.au

VIC: - Helena helena@aaaf.org.au



Kids Korner



I am Amy, the mother of piper who is 9. In November, I decided to rally my community and organised a big raffle, obtaining over \$9000 of prizes donated by our local community. I set about an online raffle page and asked everyone I knew to buy a raffle ticket.

I did this because The Australia Alopecia Areata Foundation has been a wonderful support and continue to be, to both our family and most of all our daughter. I'm so grateful for everyone who supported this idea as we netted over \$15,000 for AAAF.

In addition to our effort, Mailey, also jumped onboard raising just shy of \$5000.00 See her story below:



Hi, my name is Mailey and I am 8 years old my best friend is Piper and we have been friends our whole lives. 2 years ago, Piper was diagnosed with Alopecia.

This month I have decided to cut my hair and donate it to make a wig for someone just like Piper. I have been trying hard to grow my hair long enough to cut it, so I am able to donate.

I'm hoping along with all your help, to raise money for Australia Alopecia Areata Foundation to help with research, the making of Wigs and hopefully find a cure.

Because I believe that Piper and everyone else living with Alopecia deserves to feel beautiful,

Love Mailey

