



Australia Alopecia Areata Foundation Inc.

ISSUE 12 MAY 2021

# RAISE

research

awareness

information

support

embrace



# Contents

President's Welcome

Meet our Committee

Community Story

Advertise with us

Research Update

What's New?

Social Media

Did you Know?

What's On?

Kids Korner

Front Cover: Alopecia, It's life  
changing -by Kerri Weymouth



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# PRESIDENT'S WELCOME

## - Chel Campbell

How much self-care have you given yourself in the last 12 months. Self-care is anything that an individual does to take care of themselves and their physical, mental, emotional health and well being. Research shows that regularly taking time to care for yourself fosters resilience, which is the ability to adapt well in the face of adversity.

Life still feels frantic doesn't it! We remain in a constant state of re-adjustment as we find our way through COVID normal. It seems more of COVID interim as we take back those parts of our lives which were on hold. AAAF has also had to be very flexible and adaptive in how we engage and run events. I'll admit this has been challenging. Yes, AAAF have an ever growing audience and absolutely get great social media engagements, however, when it comes to individuals engaging in live videos or online events the attendance records are poor. This clearly showed to us that face to face interactions are preferred. This is why I'm delighted to announce that we are back running face to face events and the kids camps/events are back again this year. More information can be found in the kids' corner section.

You may have noticed a change in how our social media is being delivered in 2021. This is because Sheridan joined our team as our Social Media Manager in January. Sheridan resides in the A.C.T and has had Alopecia since childhood. Sheridan comes to us with many skills having graduated from Murdoch university with a degree in community development. Sheridan has a passion for personal and professional development with a strong focus on self-care.

We also said Goodbye to Georgia and Shea. Georgia had been with AAAF for 9 years, coming to us straight out of school, so it was time for her to try a new adventure. Shea had been with AAAF from day one, and although somewhat shy at first in expressing her ideas, blossomed into a powerful voice. We wish them both the very best in their endeavours.

We also welcomed in February two new members Jo (Support Ambassador) and Maddi (General Committee). We introduce them to you in meet our committee section.

The sponsorship program is back with the first round closing in 2021.

**[Click here for details.](#)**

Remember to keep in touch as AAAF is developing new support materials offering new services and running competitions every month.

# **“MEET OUR COMMITTEE”**

## **GENERAL COMMITTEE MEMBER Jo**



### **What are you reading or watching right now?**

Watching on SBS - shadow play

Reading- The Art of Racing in the Rain

### **Who's someone you admire or look up to?**

My brother- he is a doctor, who is very smart, dedicated and caring.

### **What's something you want to learn?**

My partner does a lot of surfing. He is very encouraging of me to join him. I would like to learn how to surf better. I am a beginner.

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

I just started my own business which was terrifying! I was very anxious and nervous! So far it is going well.

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

I would do more running- during Covid I started running and have really enjoyed it. I don't feel I have time to run anymore! I would also use the extra time to cook more banana bread for my work colleagues. I would also do more reading and mindfulness.



## **“MEET OUR COMMITTEE” -Continued**

### **GENERAL COMMITTEE MEMBER Maddi**

#### **What are you reading/watching right now?**

I have four unfinished books sitting on my bedside table at the moment. (How did that happen?!) The Alchemist, Man's search for meaning, Everything I know about love, and Women don't owe you pretty.

#### **Who's someone you admire or look up to?**

My best friends. I'm very fortunate to have an amazing, supportive and diverse group of friends who inspire me everyday.

#### **What's something you want to learn?**

Graphic Design! I've just started studying a Diploma of Graphic Design.

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

Moving from country VIC to Melbourne by myself when I was 18. Also, canyoneering in the Philippines and jumping off waterfalls.

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

I wish I could say I'd spend it exercising or studying, but if I'm being completely honest, I would probably spend it in bed - sleeping, reading, watching Netflix or drinking coffee. I love my bed.



# COMMUNITY STORIES

## DOMINIQUE

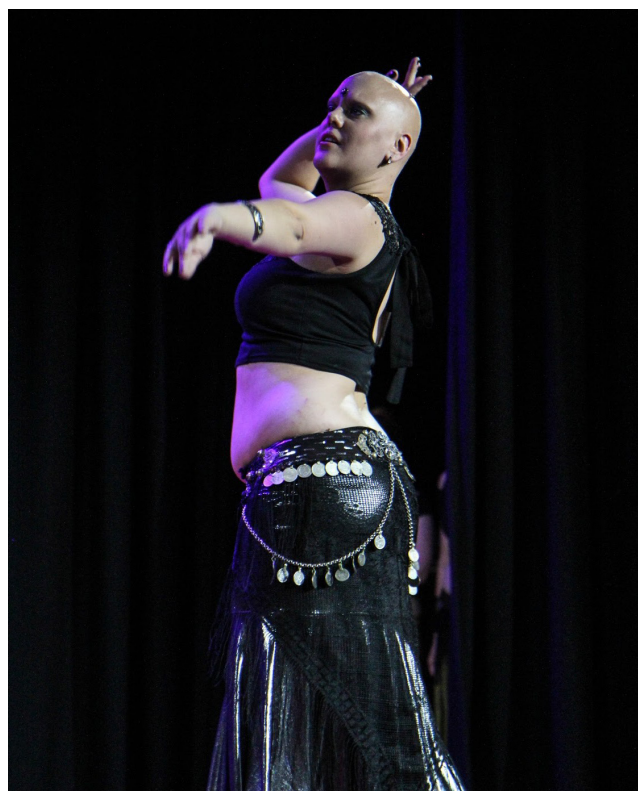
Dominique is an Intuitive Embodiment Coach. Certified in Feminine Embodiment and Akashic Record Reading, she is also a writer, intuitive, dancer and most importantly has 30 years of experience living as a bald woman. Certified by the School of Embodied Arts, which is an approved modality by IICT in Australia. Dominique is a avid Belly Dancer.

Her journey with alopecia has led her to all sorts of places, from hiding under hats throughout school to performing for audiences in the hundreds without a wig or covering up. Spending years of sitting outside the ideal of beauty norms, Dominique has reflected strongly on how this has impacted her life, and the lives of those around her.

Losing her sister to cancer in 2014, also gave her insight and filled in the missing piece of the role of grief in hair loss. The potential accompanying loss of identity, imagined futures, self-worth and femininity.

From feeling unlovable, unattractive and undesirable - she has spent years discovering how to live every day learning to love and accept yourself more and more, eventually uncovering her own Alopecia Superpower. Her passion lies now in changing the way the world perceives and prescribes beauty ideals, and supporting those who feel excluded by these narrow standards.

Her 1:1 Coaching Program: Alopecia Superpower launched early in 2021. Based on 4 pillars: Safety, Depth, Relaxation and Pleasure. Her mission is to guide Women with hair loss back into their own truth and authentic selves, uncovering their own Alopecia Superpower. Born and raised in Brisbane, Australia, Dominique has been a part of AAAF since conception and now lives in New York City, NY with her Husband.



## ADVERTISE WITH US



WIGS 4 U PERTH is a passion, not a business for Leslie.

Wigs 4 U Perth is a small WA business offering personal, professional service. You will look in the mirror & think... WOW is that me?!

You will love the sense of wellbeing & feel more confident when you are happy with how you appear to fit in.

"We have so many styles of synthetic, high quality, realistic wigs & accessories to complete your look! Regardless of the length of the wig, short, medium or long my starting price is from \$90.00. This is my hobby and I love that feeling of helping others to feel good - at a reasonable cost.

*I love it when I get feedback that resonates with my slogan to feel good. Just a few examples are: Went to my sister's after yours and she commented on how natural and good it looked: I have found a wig that I love. Thank you for having such nice wigs. You have me as a customer for life: I felt stunning over the festive season all thanks to YOUR personal touch. "*



### WIGS 4 U PERTH

PH: 0424 055 139

Website: <https://www.wigs4uperth.com/>

FACEBOOK: <https://www.facebook.com/WIGS4UPERTH/>



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# RESEARCH UPDATE

The 53rd Australasian Dermatologist conference was just held virtually from 9th April-13th April. AAAP every year attends these conferences and interacts with the dermatologist to find out any new developments.

AAAP is conscious that our audience believes little to no research is going into Alopecia Areata, however there is a lot of research around the world being conducted.

A summary of this can be found in the paper presented by Dr Charan Jeet Arora<sup>1</sup>, Prof Dee Dee Francis Murrell<sup>2</sup> associated with the Department of Dermatology St. George Hospital University of NSW Gray St, Kogarah, Sydney, Australia

## THE EFFECT OF ORAL AND TOPICAL JANUS KINASE INHIBITORS ON ALOPECIA AREATA – A SYSTEMATIC REVIEW

### Methodology

An electronic database search was carried out through PubMed, Ovid MEDLINE, Cochrane Library and Google Scholar, for articles published between 2000 and 2018. A manual search was also done, using reference lists of selected articles.

The articles were screened for relevance. Only articles that reported on the therapeutic use of Janus Kinase Inhibitors for alopecia in humans were included. All original research, including case reports, case series, and case-control studies were included and extrapolated onto a data extraction sheet.

The following parameters were recorded:

- \* type of study and number of patients evaluated
- \* age and sex of the patients
- \* the drug used
- \* dosage and route of administration
- \* duration of drug therapy.

### Results

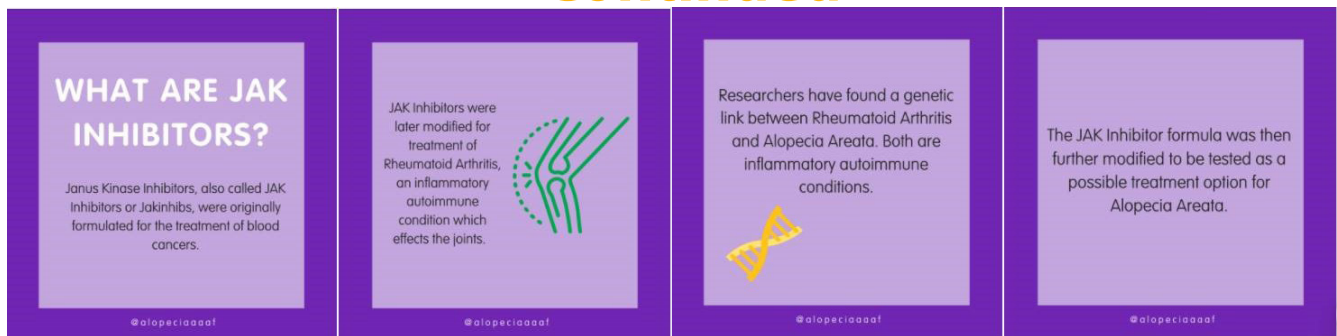
Identified through manual search, 40 articles were identified as being relevant to the topic. A total of 297 patients were evaluated in the above articles. Only 11 studies reported results based on percentage change in SALT scoring, the rest were observational. Based on Liu et al's scale of response to therapy, 60 patients had complete response (20.2%), 89 patients had intermediate response (30%), 49 patients had moderate response (16.5%), and 59 patients did not respond to treatment (19.9%). Three patients were described as responders, who relapsed subsequently despite continuing medication (1%). In 18 patients (6%), the extent of response could not be assessed, but was described by the authors as 'partial growth'.

### Conclusion

The current literature shows that both topical and systemic JKIs have reasonable efficacy in management of alopecia areata, particularly those which are refractive to other forms of therapy. The adverse effects are minimal and mostly related to infections. Future studies are required to establish whether the oral JKIs can be used as first-line therapy in patients with alopecia areata, alopecia totalis and alopecia universalis.

# RESEARCH UPDATE

## - Continued



### What is new in the JAK Inhibitors.

A phase 2a randomized, placebo-controlled study to evaluate the efficacy and safety of the oral Janus kinase inhibitors ritlecitinib and brepocitinib in alopecia areata: 24-week results

### Background

Alopecia areata (AA) is an autoimmune form of hair loss with limited treatments.

### Objective

To evaluate the efficacy and safety of the Janus kinase inhibitors ritlecitinib and brepocitinib in patients who have AA with  $\geq 50\%$  scalp hair loss.

### Methods

Patients were randomized to once-daily ritlecitinib, brepocitinib, or placebo. The primary efficacy endpoint was a 24-week change from baseline in the Severity of Alopecia Tool (SALT) score. The key secondary efficacy endpoint was the proportion of patients achieving 30% improvement in SALT score (SALT30).

### Results

The ritlecitinib, brepocitinib, and placebo groups included 48, 47, and 47 patients, respectively. At week 24, least-squares mean difference from placebo in SALT score change from baseline was 31.1 (95% confidence interval [CI], 18.8-43.5) for ritlecitinib and 49.2 (95% CI, 36.6-61.7) for brepocitinib ( $P < .0001$  for both comparisons with placebo). SALT30 was achieved by 50% (90% CI, 38%-62%) of patients receiving ritlecitinib, 64% (90% CI, 51%-75%) receiving brepocitinib, and 2% (90% CI, 0%-9%) receiving placebo. Two patients experienced a serious adverse event (rhabdomyolysis) in the brepocitinib group only.

### Limitations

Only a single-dosage regimen of each study drug was included.

### Conclusion

Treatment with ritlecitinib or brepocitinib for 24 weeks was efficacious and generally well tolerated.



AAAF is excited to be able to share more alopecia stories, advice and lessons.



Introducing Kieranpal, whose mindset and use of gratitude helps him manage his hair loss and demanding uni schedule.

[Click here to watch Kieranpal's story.](#)

**Now, it's your turn!**

We would love to feature you and your story in a video similar to Kieranpal's.

If you are interested, please email [sheridan@aaaf.org.au](mailto:sheridan@aaaf.org.au)

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## *Self Care*

Self care is such an important part of becoming resilient and AAAF would like to support your self care journey by offering a discount code for Yoga for Alopecia classes with Sheridan Ruth.

**USE THIS COUPON CODE for 25% off: AAAF.**

Access the website by clicking on the image below. here:



# 20 things to do when you are having a bad day

"Actually realising it's ok to have a bad day. And just roll with it and know that when the sun rises the next day it could be different." - Toni

"I have a go-to cap and not bother about styling up a wig to go "out"" - Helen

"I drink a big cup of coffee and have a little phrase I say to myself "whack on your wig and smile .... you can do it" - Michelle

"Music can help sometimes but if it a tired exhausted bad day, it's rest and retreat that I need" Amy

"After allowing the miseries for a bit, Say 'shut up head'. It is my self talk that really brings me down, after a hurtful event, so shut them up, and change the channel to include the above!" - Amanda

"I put on makeup eyelashes and curl my hair, I always feel fabulous when I do that! I have to have red lipstick as well!" - Bek

"Meditation. Focusing on gratitude for what I have. Making a nourishing meal. A cuddle from my kids or dog. Exercise. Seeing/swimming in the ocean if I can get there." - Emma

"I look myself in the mirror and I say 'You are more than just hair, hair is an insignificant part of who you are as a person.'" - Naomi

"Going for a massage " - Amy

"I speak with my girlfriend, she's always a good ear ." - Michael

"Do my face and put on great shoes!" - Sally

"I focus on my family and what is good in my life" - Jack

"When I feel like it's a crappy day I'll try to have a day off, drink tea lie in bed and binge-watch something on Netflix." - Amanda

"I have a instagram account and sometimes look at the men on Instagram who are bald, that helps."" - Nick

"Swim laps at the local pool. Phone someone you know who lives alone. Watch some Louis Armstrong, Chuck Berry, Aretha Franklin or James Brown YouTube" - Andrew

"I like to practise gratitude." - Kieranpal

"I have a special "bad day" music playlist with songs that make me feel good. Listening to that while going for a walk usually helps!" - Breanna

"I get lost in the world of video games where I have a character that has beautiful hair" - Fernando

"Reading about shared experiences." - Tiffany



# Social Media

A lot has been going on over on our social media! Here are some of our favorite posts from the year so far:

Copy the links into your browsers to read more:



Applying Eyelashes and Eyebrows

<https://www.facebook.com/watch/?v=229805538831012>



Men and Boys

<https://www.instagram.com/p/CNEHP6ahAHT/>



Jessie donates her hair

[https://www.instagram.com/p/CM-80HPH\\_dn/](https://www.instagram.com/p/CM-80HPH_dn/)

<https://www.instagram.com/p/CLhwM4pgtzr/>

One of our favorite parts of social media is community. Over the next few months, we will be highlighting empowering stories from people with alopecia and we would love to feature YOU.

Would you like to share your alopecia story and what you have learnt?

Please email [sheridan@aaaf.org.au](mailto:sheridan@aaaf.org.au) to learn about being featured.

## SOCIAL MEDIA LINKS

AAAF  
Linkedin  
Facebook

Instagram  
You Tube  
Go Fundraise

My Cause  
Shopnate  
Love Alopecia

# *Did you know?*

A 3300 year old wig.

Yes you read that right!

This is the wig of Merit, wife of Kha, found in the tomb of the couple (TT8) in Thebes, present-day Luxor, Egypt.

The wig was beautifully constructed of human hair. The wig can now be seen in the Museo Egizio, Torino, Italy.



# WHAT'S ON?

## Sponsorship Program 2021-2022

**\*OPEN\***

First round closes 31st May 2021 – awarded by 14th June  
Second Round closes 31st July 2021 – awarded by 16th August  
Third round closes 31st October 2021– awarded by 19th November  
Fourth round closes 31st January 2022 – awarded by 11th February



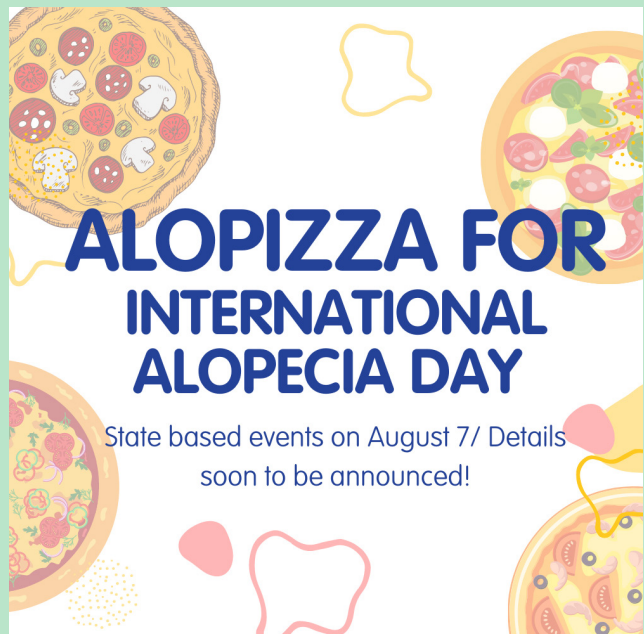
South Australia -

"Come One Come All" – Welcome to AAAF's circus celebration!

When? 1-3 pm, Sunday, 13/6/2021 details posted on FB and website.

AAAF will be holding state based events on International Alopecia Day August 7th. This years theme will be Alopizza.

Each state will announce the location and time in July.



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

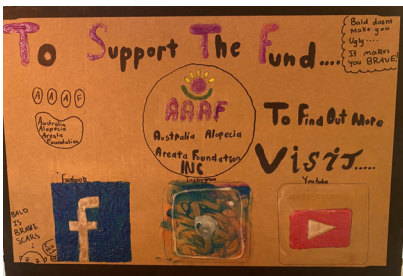
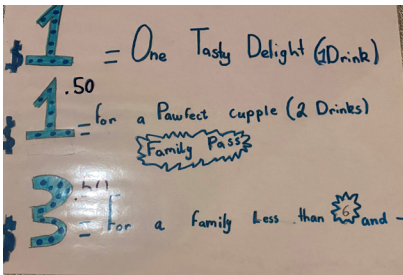
## Kids Korner



Ava is 10 years old and has set up a lemonade stand to raise money for the AAAF. She sold home made lemonade and people donated money .

Ava decided to do this all on her own accord and has made signs to advertise the stand.

Ava made \$187 from her lemonade stand and over \$1,200.00 with family and friend donations.



## Congratulations to the winners of our Barbie Doll competition



# Kids Korner - Continued

## Alopecia Areata Adventure Camp in 2021.

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

The Alopecia Areata Adventure Camp is a fantastic opportunity for kids living with Alopecia to make friends, learn about the condition and – most importantly – have a very fun time.

AAAF is delighted to be holding a variation on the Alopecia Areata Adventure Camp in 2021. Each state will be holding an event through awareness week. Due to the difference in numbers in each state, the events will vary. If you are interested in attending the event in your state and you haven't already expressed your interest, please send an email to [info@aaaf.org.au](mailto:info@aaaf.org.au) with your state, child's name, child's age and gender, and further information will be provided.

**A.C.T – Saturday 20th November to Sunday 21st November at GreenHills Centre**

**N.S.W Saturday 20th November at new Sydney Zoo at Bungaribee.**

**QLD - Saturday 20th November to Sunday 21st November at Maranatha Recreation and Education Camp**

**S.A – To Be Confirmed**

**Tasmania - To Be Confirmed**

**Victoria – Saturday 20th November to Sunday 21st November at YMCA Anglesea Recreation Camp**

**W.A. Friday 12th November to Sunday 14th November 2021 at Eagle Bay**

**Please note: Limited spaces are available at all camps so please get your interest in early.**

