



Australia Alopecia Areata Foundation Inc.

ISSUE 13 NOVEMBER 2021

RAISE

research

awareness

information

support

embrace



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Front Cover: Christine Parin



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PRESIDENT'S WELCOME

- Chel Campbell

It feels like this year was gone in the blink of an eye! In our November newsletter, we bring you a summary of recent research, options for alopecia support and new competitions!

AAAF was once again not able to meet for our AGM, however our main focus for next year is to give, give, give. AAAF will be taking 13 of you to Alice Springs in 2022!

With over \$30,000 up for grabs in sponsorship opportunities will you be one of them! If taking on a sponsorship is not right for you, how about providing your advice to win one of 30 Hats with Hair we will be giving away.

AAAF said goodbye to Breanna and Stephanie in September this year. Breanna had been with AAAF for 3 years, as the NSW Branch Manager. Breanna is extending her family.

Stephanie assisted Breanna in executing events in NSW. Being a ICU nurse we can all appreciate how difficult this year has been for her. We wish them both the very best in their endeavours. We have found replacements in Carlo and Michelle and they are already up and running in holding their first event at the new Sydney Zoo.

AAAF takes your personal wellbeing seriously and we know that these are difficult times and that many of you may be feeling anxious. We have had lots of enquiries, asking if people with Alopecia Areata are at an increased risk of coronavirus (COVID-19) infection and questions relating to vaccines.

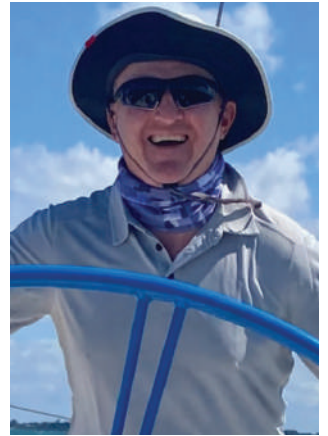
AAAF can only redirect you to a medical professional to answer these questions as each person's journey is unique.

For all the children attending the various state camps make new friends, have heaps of fun and take as many photos as you can to share!

"MEET OUR COMMITTEE"

BRISBANE BRANCH MANAGER

Greg



What are you reading or watching right now?

The Blacklist with my wife. Step by step to see where it ends. I love biographies and am reading Alex Ferguson (Football Manager).

Who's someone you admire or look up to?

Scott Morrison. A man with a difficult job right now.

What's something you want to learn?

Free diving. The thought of exploring greater depths on your own breath.

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

I used to wear a wig to my job with the ANZ bank then one day I decided, it was time for a change.

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

Knowing my luck it will be doing the dishes or washing some clothes for my other employer....my wife and family.



SOCIAL MEDIA OFFICER Sheridan

What are you reading or watching right now?

Reading: Happy Healthy Sexy - Ayurveda Wisdom for Modern Women! It's a requirement for an advanced Ayurveda training I am doing and very interesting so far!

Watching: Money Heist and Lucifer - absolutely in love with them & sad they are ending.

Who's someone you admire or look up to?

My partner, Ash - he is very smart, dedicated, and generous. Qualities I always admire.

What's something you want to learn?

I'd love to learn more about dance. I'd love to learn Bachata, Samba and Swing.

"MEET OUR COMMITTEE" -Continued

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

Becoming a widow at 25 years old in a foreign country, facing all of the emotional and logistical consequences and building a business at the same time!

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

I'd spend more time moving my body, going outside, going swimming, or just sleeping in!



NSW BRANCH MANAGER Carlo

Carlo joined the AAAF as a committee member in June 2017. Carlo is originally from Salford, UK and has been living in Australia since 2004. Carlo has had Alopecia Universalis since the age of 5. This has not stopped him in anyway, being a professional rugby league player in the UK Super League and coaching the Italian Rugby League in the World Cup in 2013.

Following on from his high performance life as a player and a coach Carlo has been employed in numerous executive positions using his expertise in high performance to assist with the growth of business's in different sectors.

Carlo has also been an ambassador for children's charities and was a trustee of Alopecia UK when he undertook a year contract helping a family business in the UK. Carlo is focused on the awareness of alopecia in the general public and providing support to the alopecia community especially children.

Carlo can be contacted on carlo@aaaf.org.au

Michelle Ogbonna has joined AAAF as the NSW Events Coordinator.

Michelle can be contacted at michelle@aaaf.org.au



CELEBRATING *10* years OF JAMES

AAAF is extremely grateful to James Miller for completing 10 years of service with us. We are so grateful to James for his continued service and how he open-heartedly welcomes new members of our community. He has been a pillar of our community and has served the AAAF starting of as a youth ambassador and now serving as the ACT Branch Manager. James has organised a multitude of events and promoted awareness through his cycling fundraisers. Through his dedication and commitment over time to our mission and population, he has stood out as a pillar of strength, especially with his work with our male population.



ADVERTISE WITH US

All you need is love

*and friendly specialists to guide you through
the journey. We help people just like you with
beautiful hair loss solutions*

Hair Patches (in salon only)

Hair Toppers

Hair Extensions

Custom & Premium Brand Wigs

Online & In Person Consultations

(Perth Wig Specialist in WA)

0481 747 113

info@australianwigcompany.com.au

www.australianwigcompany.com.au

THE AUSTRALIAN WIG COMPANY

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RESEARCH UPDATE

Trials produce treatment hope for alopecia areata patients

Professor Rod Sinclair of Sinclair Dermatology, Melbourne, has been the principal investigator and part of a global team investigating baricitinib as a possible treatment for AA. (Baricitinib is already available on the PBS as a treatment for rheumatoid arthritis.)

Some of the results are truly staggering, with completely bald patients regrowing a full head of hair.

Trials were carried out over 36 weeks on men aged between 18 and 60 and women between 18 and 70, with 2mg and 4mg doses being tested for efficacy against a placebo.

The trials used the SALT (severity of alopecia tool) measurement, which surveys the scalp in quadrants, with overall scores ranging from 0 (no hair loss) to 100 (complete hair loss).

A reduction in SALT score to less than 20 was the benchmark for positive response. This is called the primary endpoint.

Around a third of patients (35.2% in one group; 32.5% in the other) taking the 4mg dose achieved the primary endpoint with a reduction in SALT score to <20 at the 36-week stage.

A number of patients with a SALT score >95 at baseline recovered to SALT 0, with full scalp hair coverage.

The results in the 2mg cohort of patients were also superior to placebo with around one-fifth of patients achieving a reduction in SALT score to <20.

Trials are ongoing, and longer observation will help to assess potential delayed response, durability of clinical response, and long-term safety.

A Comprehensive Literature Review of JAK Inhibitors in Treatment of Alopecia Areata

With the advancement of pre-clinical and genetic studies, a greater understanding of the pathomechanisms involved in the development of AA has been uncovered. This has resulted in the introduction of targeted therapies that use small molecules to block specific pathways involved in AA pathophysiology. As such, the use of janus kinase (JAK) inhibitors for treatment of AA has emerged.

CLICK HERE to read the full article.

Therapeutic Agent in treatment of AA

At AAAF we are often contacted as to what is the most popular, effective, widely used treatment for the different categories of Alopecia Areata. It is worth noting that, to date, no specific treatment for AA exists. Current conventional treatment options for AA mostly include non-specific broad immunosuppressants that are administered either locally or systemically, with the most common approach involving the use of intralesional and topical steroids

Choosing therapeutic agents for AA are mostly based on empiric criteria which accounts for the patient's age, the disease progress (acute or chronic) and the percentage hair loss (< or >50%).

This table is an extract from the article referenced above providing general explanations on treatments:

Therapeutic Agent	Class	Modality	Studies	Efficacy	Adverse Effects
Steroids	Immuno-suppressant	-Topical - Intralesional -Systemic	Paediatric RCT; no RCT on intralesional steroids. ²⁴ Some studies included a Phase II clinical trial. ⁹	Collectively, there is no significant RCT evidence that suggests that steroids (topical/intralesional/systemic) are beneficial in AA. ²⁴ However, appears to be the most effective treatment among children with new hair growth by 6–8 wks. ⁹	Topical: atrophy of the skin, depigmentation (mostly in darker individuals), telangiectasias. Systemic: acne, weight gain, hyperglycemia, adrenal suppression, etc.
Ciclosporine	Immuno-suppressant/ Immuno-modulator	-Topical - Intralesional -Systemic	No RCTs on systemic and intralesional ciclosporine use; few trials on topical ciclosporine use. ²⁴	No significant/ acceptable hair growth observed within a 6 to12 month period. ²⁴	Topical: Hyperkeratosis and folliculitis
Methotrexate	Immuno-suppressant/ Immuno-modulator	Systemic	No RCTs; Retrospective study. ²⁵	More than 50% regrowth within a 3-month period. ²⁵	Myelosuppression / pancytopenia, rash, acne, mucositis, nausea, diarrhea, hepatotoxicity, etc.
Azathioprine	Immuno-suppressant/ Immuno-modulator	Systemic	No RCTs; Prospective study. ²⁶	Limited benefit; no significant hair growth within a 6-month period. ²⁶	Myelosuppression / pancytopenia, rash, nausea, diarrhea, hepatotoxicity, etc.
Retinoids	Vitamin A derivative	Topical	No RCTs. ⁹	Limited benefit but use is common in children. ⁹	Skin irritation and dermatitis (bexarotene).
Minoxidil	Hair growth stimulant	Topical: gel or foam	Few RCTs. ²⁴	Limited benefit; no significant hair growth within a 6 to12 month period. No benefit after treatment is discontinued. ²⁴	Dermatitis, pruritis (gel more than foam); hair growth at distant, non-affected sites.
Contact immunotherapy: DPCP and SADBE	Immuno-therapy	Topical	Retrospective study in children; ⁹ one RCT. ²⁴	Up to 70% response rate within a 3-month period. ⁹	Blistering, erythema, urticaria, dermatitis, pruritus, depigmentation and lymphadenopathy/ edema.
Anthralin	Immuno-therapy	Topical	No RCTs. ²⁴	Modest benefit within a 3-month period; use common in children. ⁹	Staining of skin, hair, and clothing in brown colour.
PUVA	Phototherapy/ Immuno-suppressant	Topical: Psoralens by mouth and UVA exposure	Few RCTs. ²⁴	No improvement seen that was cosmetically acceptable. ²⁴	Blistering, erythema, dryness, dermatitis, pruritus, nausea, headache, etc.

Abbreviations: PUVA, psoralen and ultraviolet A; RCTs, randomized controlled trials; SADBE, squaric acid dibutyl ester; DPCP, diphenylcyclopropenone.

WHAT'S NEW

HATS WITH HAIR

BECAUSE YOU DESERVE TO FEEL COMFORTABLE AND CONFIDENT EVERYDAY.

In a "joint initiative" AAAF brings Someone's Sunday Hats to our Alopecia Areata Community.

These hats are driven by simplicity and style, as such our products are sized to fit most people, and hair to sit naturally with your face. The hair length is 33cm, with ethically produced material with every product specifically designed for comfort, style, adaptability and breathability. All hair used is synthetic for ease of maintenance. Beanies, Cap's and Panama styles are available.

Learn more at www.aaaf.org.au and purchase from our store **here**.



HATS WITH HAIR
GIVEAWAY

WIN A HAT WITH HAIR

How to enter:

Email your advice for living with alopecia to info@aaaf.org.au

☑ Qualify for a *bonus entry* by posting your advice on social media and tagging @alopeciaaaf!



AAAF is giving away 30 hats with hair for Alopecia Awareness Week in Australia!

Win a hat with hair by simply following the steps below!

"Hats with hair" are driven by simplicity and style, as such our products are sized to fit most people, and hair to sit naturally with your face. The hair length is 33cm, with ethically produced material with every product specifically designed for comfort, style, adaptability, and breathability. All hair used is synthetic for ease of maintenance.

Members of our community that live in Australia are free to enter to win a hat.

Entries close on Saturday 20 November

How to enter:

Email your advice for living with alopecia to info@aaaf.org.au

*Qualify for a *bonus entry* by posting your advice on social media and tagging @alopeciaaaf!

*must live in Australia

** giveaway for members of the alopecia areata community

*** each participant can only win one hat

**** giveaway is in no way sponsored by Facebook or Instagram

FUNDRAISING

Would you like to donate to AAAF and at the same time have the chance to win some great prizes?

The Peoples Choice Community Lottery gives you the opportunity to do just that.

By purchasing tickets, you are helping AAAF raise much needed funds.

Tickets are only \$2.00 each.

In 2021 we raised \$2300. Let's see if we can do better this year.

CLICK HERE to purchase tickets.



Australia Alopecia Areata Foundation Inc

Amount raised
\$2

Fundraising goal
\$10,000

\$2.00 per ticket

Quantity

10 tickets (\$20)

20 tickets (\$40)

40 tickets (\$80)

50 tickets (\$100)

100 tickets (\$200)

You could win!



1st Prize

Toyota Kluger GX AWD Hybrid (RRP \$59,537)



2nd Prize

Toyota Corolla Ascent Hybrid Hatch (RRP \$31,610)



3rd Prize

Harvey Norman Grand Home Package (RRP \$25,330)

Social Media

Top 3 youtube videos right now are:



5 tips for your mental health and alopecia.
[Click here to watch.](#)



Alopecia: How To Tell Your Friends.
[Click here to watch.](#)



Mental Health Meditation with Sheridan Ruth.
[Click here to watch.](#)

SOCIAL MEDIA LINKS

AAAF
Linkedin
Facebook

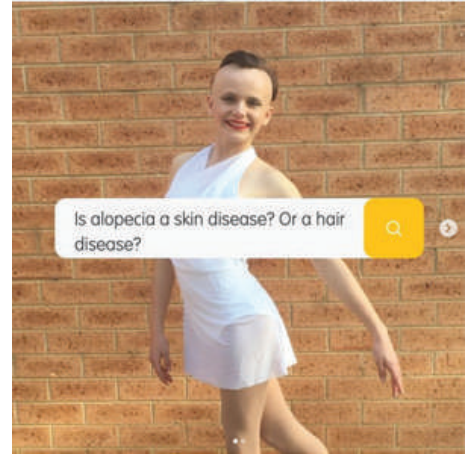
Instagram
You Tube
Go Fundraise

My Cause
Shopnate
Love Alopecia

Social Media



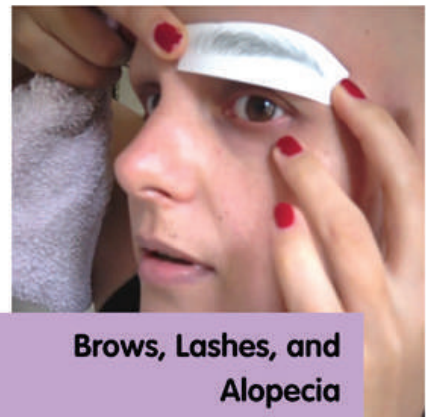
How to respond to comments about your alopecia.
[Click here to view.](#)



Learn about why alopecia areata is a skin disease
[Click here to view.](#)



Learn about the activities our sponsorship recipients have participated in.
[Click here to view.](#)



Read our blog on Brows, Lashes and Alopecia.
[Click here to read.](#)

BEANIE FESTIVAL GIVEAWAY



WIN A TRIP TO ALICE
SPRINGS BEANIE FEST

AAAF invites you to celebrate the 25th Anniversary of the Beanie Fest!

We would like to sponsor 13 lucky people to take a trip to the wonderful Beanie Fest accompanying several AAAF Committee members!

Together, we can enjoy the warmth, colour and joy that everyone brings to our unique Central Australian event.



Festival details:

Friday, June 25, 2022 - Monday 29, 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 womens' culture and the beanie as a regional art form, as well as promote handmade textile arts.

How to enter:

Get creative and make 2 beanies (1 for NHWC and 1 to be voted on by our community and then donated to the festival) and send your most creative beanies to AAAF, PO Box 5029, FRANKSTON SOUTH VIC 3199 The beanie for AAAF should be a beanie you would be comfortable wearing day-to-day. The festival beanie should be creative and fun! The beanies can be made out of anything, such as felt, they can be knitted or sewn. Let your imagination run wild.

You can find patterns at <https://beaniefest.org/get-involved/free-patterns>

To be eligible you must:

Live in Australia

Have a form of Alopecia Areata (including Totalis and Universalis)

Be 18+

Be able to travel on the festival dates (Friday, June 25, 2022 - Monday 29, 2022)

Make 1 beanie for AAAF and a minimum of 5 for the festival

Important dates:

By November 30: Please email an expression of interest to sheridan@aaaf.org.au

By March 31st: AAAF must have received the AAAF Beanie and the Beanie that the individual would like to get voted on.

The winner will be chosen by our community, the most popular, most creative beanie will be voted on to win.

WHAT'S ON?

AAAF is doing everything we can to run the camps in each state this year. Getting things organised and adapting to the changes from covid-19 restrictions has been a team effort!

We are so grateful to our volunteers who make this possible. All camps are fully organised and camp goers advised. We thank Variety for their support in making these camps possible.



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

N.S.W – Saturday 20th November at new Sydney Zoo at Bungarribee. – Younger NSW children.

Queensland – Saturday 20th November to Sunday 21st November at Maranatha Recreation and Education Camp Sunshine Coast.

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

Tasmania – Saturday 13-Nov-2021 to Sunday 14-Nov-2021 – Lea Scout Centre Tasmania Gilwell Dr, Kingston TAS 7050

New South Wales

Due to Covid, this year we are holding an adventure day trip to Sydney Zoo (Western Sydney). This is open to all Kids young or old. With alopecia or Without alopecia. Please fill in all details per person. Kids will be paid for, Adults need to pay via the AAAF Account. Once completed please transfer monies to the AAAF Bank account. \$40 per Adult. Any person (Adult or Child) must be named in this form. If anyone is not added will have to pay the full price at the gate.

Click this link for the Booking Form (Google).



Continued Over



PICNIC IN THE PARK

SUNDAY 14TH
NOVEMBER

12 NOON
TUSMORE PARK

South Australia

Picnic in the Park Sunday 14th November Tusmore Park. Adelaide. S.A. BBQ facilities available for use or bring a picnic lunch. Tennis courts will be booked for a couple of hours.

Queensland

Join us for a sunny, fun day with the alopecia community! We have set up bocce, frisbee throwing and other games so we can all meet and kick off December with some fun!

Christmas Morning Tea at the Gold Coast Regional Botanic Gardens, Rosser Park
Saturday December 4th 2021 9.30am .

Christmas Afternoon Tea at Victoria Park (Old Golf Club)
Saturday December 11th 2021 2pm .

Both are BYO Tea/coffee and snacks.



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



Did you know?

AAAF HAS A SPONSORSHIP PROGRAM

2021 has been such a fantastic year for our sponsorship participants! We have supported our community through drawing lessons, Bridgeneering, basketball, gymnastics, horse-riding, exercise classes, meditation, calisthenics and much more. We have learnt a lot about each individuals experience with alopecia, and found them very inspiring. You can see all the alopecia stories on our blog: Love, Alopecia.

This Sponsorship Program provides financial support for individuals and families living with Alopecia Areata, while also raising awareness of the condition.

AAAF will provide funding for successful applicants for skill development and participation in activities. We are especially looking for activities that support the health and wellness of participants, both physical and mental. Activities which have an element of team or community participation are also encouraged.

The program will raise awareness for alopecia areata by collecting and sharing content from sponsorship recipients on social and traditional media. AAAF encourages participants to seek and take part in PR and media activities, and to share information about Alopecia Areata and AAAF with their local communities.

It's not too late to apply for this year.

Third round closes 31st October 2021 – awarded by 19th November 2021

Fourth round closes 31st January 2022 – awarded by 11th February 2022

APPLY HERE.

CURRENT SPONSORSHIP RECIPIENTS

Name	State	Activity	Awarded
Frankie	QLD	Drawing lessons	Bronze \$500 3 months
Corinne	VIC	Calisthenics	Bronze \$500 3 months
Thomas	WA	Basketball	Bronze \$500 3 months
Isabella	SA	Gymnastics	Silver \$1500 6 months
Kate	NSW	Campdrafting is horse riding	Gold \$4000 12 months
Emma	SA	Gymnastics	Silver \$1500 6 months
Sheridan	ACT	Meditation	Silver \$1500 6 months
Alessandro	VIC	Boxing	Gold \$4000 12 months
Tristan	VIC	Boxing	Gold \$4000 12 months
Alex	QLD	Bridge Building	Bronze \$500 3 months
Simone	NSW	Basketball	Silver \$1500 6 months
Christine	WA	MOAM Fitness	Silver \$1500 6 months

Kids Korner



Alex's Alopecia Story!

Alex is one of the 2021 recipients of our Sponsorship Program and we are so proud of his wonderful story! Read his alopecia story below.

Hi, my name is Alex. I am eight years old and I have had alopecia forever (Mum says I was one when I started to lose my hair). I used to have no hair on my head when I was two and I loved wearing beanies in winter. My favourite beanie was a strawberry one but then we met a really nice friend who knitted me a frog beanie.

Frogs are my favourite animal so that's my favourite beanie now. When I had no hair, people often looked at me a lot and thought I was sick. But I'm not sick, I just have alopecia.

Ever since I was a little kid, I have liked figuring out how things work. Even before I could walk, I used to like spinning the wheels on bikes, toy prams and cars and watching what happened. I also love the sandpit and play in it for hours, building great tunnels, waterways, towers and bridges. My Dad is an engineer and I want to be an engineer too. When I was in kindy, my favourite thing to do was play with the water course and design channels that let me control the flow of water. My hair started to grow back then, when I was in kindy, so I began to grow it long. My hair is really long now and I am trying to grow it long enough to donate it to wigs for kids so kids with no hair can have long hair too. I still have to make sure I put suncream on my patches when I go out, or wear a hat.

I've always loved engineering. That's why I want to go to the engineering class and learn how to build the best bridges. I think having alopecia makes me really lucky because I get to do engineering classes. One day, I'm going to be a great engineer.

What can I do if I feel upset because of my alopecia?

It's perfectly normal to feel upset from time to time. Many of us feel sad at times because of our alopecia. We all deal with things differently. Some of us like to talk to others, some of us prefer some time on our own. It is your choice.

It is usually best to share your feelings with others. Perhaps a friend, a parent, a teacher, a grandparent. Remember, a problem shared is a problem halved. Bottling up how we're feeling can be exhausting. It can really help to get our feelings and thoughts out. Writing a diary or journal can be a good idea.

It can help to develop a motto or mantra to remind ourselves on bad days. Here are some suggestions:

"I am ok just the way I am"

"I have alopecia. Alopecia doesn't have me"

"Alopecia doesn't change who I am"

"I can deal with what alopecia throws at me because I am stronger than I think"