



Australia Alopecia Areata Foundation Inc.

ISSUE 17 NOVEMBER 2023

RAISE

research

awareness

information

support

embrace



Contents

President's Welcome

Meet our Committee

Now Hiring

What's New?

Research Update

Advertise with us

What's On?

Dermal Therapy

Social Media

Did you Know?

Kids Korner

Front Cover: The Committe



If at any time you wish to unsubscribe,
please [click here](#).

PRESIDENT'S WELCOME

- Chel Campbell

November? Already? Surely not?! As you pull your favourite summer hat, allow me to fill you in on the latest news, research news, community blogs, support opportunities and more!

There are a number of research projects related to alopecia that are currently looking for people to take part. There are opportunities to participate in research seeking to understand the challenges people face, research that is developing support materials. For example, the GRIDD STUDY is currently looking for as many people as possible, with any skin condition, to complete their survey on the impact of their condition on quality of life. This global project will help provide evidence to decision makers on the need for more support and investment into dermatological services.

Earlier in the year AAAF did a shout out to participate in the MARISSA study aimed at assessing quality of life impact with 323 Adults, 50 Careers and 22 children participating in the study, AAAF thanks you for supporting these research opportunities. Another project, that might seem similar but is not, is evaluating the social, psychological, and economic burden of alopecia areata on adolescents and adults over the age of twelve which generates Quality Adjusted Life Years (QALYS), which allows the cost-benefit analysis of treating AA to be compared with other conditions, look out for participation on our social media channels.

We have published many great blogs on our website in the past.

<https://lovealopecia.wordpress.com/2021/02/26/remission-statistics-for-alopecia-areata/>

<https://lovealopecia.wordpress.com/2017/02/10/bald-girl-in-the-dating-world/>

<https://lovealopecia.wordpress.com/2017/05/19/managing-stress-alopecia/>

These are our top 3 blog posts and it is interesting that the themes are very different from understanding remission rates, to how to navigate dating to managing stress levels. You can find all these blogs, and more, on our website here (where you can also filter your blog search based on your interests).

AAAF is looking for an NSW Branch Manager. Carlo is not leaving AAAF, but is moving into the role of a Support Ambassador. The role of the Branch Manager is to build and develop their Alopecia Areata Community, whilst being the designated contact for their state, if this sound like you please email Chel@aaaf.org.au to obtain more information.

AAAF has joined the recycling buzz, see how you can help by recycling your cans.

“MEET OUR COMMITTEE”

SECRETARY - MICHELLE



Hello all!

I am Michelle, a final year medical student. I have been fortunate enough to join the AAAF community as the Secretary at the start of this year.

Despite having no lived experience of alopecia areata, I have always had a strong interest in autoimmune conditions both owing to personal reasons and a honed curiosity over my medical school journey. Through ongoing research in the dermatology field and clinical encounters with individuals with alopecia areata, I became acutely aware of the complex biopsychosocial factors contributing to the disease and its negative impact on an individual's quality-of-life. It also became apparent during my medical placements that there was a need for increased support of afflicted individuals, whether this be through raising awareness within the broader community, increased research, or advocacy – all of which aligned with AAAF's vision. As such, I intend to utilise my extensive volunteering experience, medical background, and passion for autoimmune conditions, including alopecia areata, in my role as Secretary to help improve the quality of care for individuals with alopecia areata in a holistic manner.



Should you have any questions, concerns, or just be in need of somebody to talk to, please do not hesitate to contact me at mich@aaaf.org.au.

Kind regards,

Michelle



THERE IS AN OPENING FOR A NEW BRANCH MANAGER FOR NSW!!!

**We can't wait to hear from you and
connect with the next community
member ready to support NSW.**

**Tag any one you think
could be a good fit.**

**Email chel@aaaf.org.au
to express your interest!**



@ALOPECIAAAAF



What's
new?

Support AAAF and the environment through recycling

We're in the process of registering with container deposit schemes across Australia, so you can support AAAF while recycling your empty beverage containers (bottles and cans).

Container deposit schemes incentivise the return of empty beverage containers in exchange for a 10c refund that has the option to be donated. The collected containers are then recycled contributing to a circular economy and reducing litter. Eligible containers will have a 10c mark on the label, often next to the barcode.

The funds raised through the container deposit schemes over the next 12 months will go towards next year's Alopecia Areata Adventure Camp for kids.

Each State and Territory operate their scheme differently. Discover below how to donate your 10c refund to AAAF in your area and keep an eye out on social media for updates.

NSW - Return and Earn Program



We have successfully registered as a charity partner with Return and Earn. Donate your 10c refund(s) to AAAF from any Return and Earn machines located near you using the Return and Earn app.

1. Download the Return and Earn app (available from your App store)
2. Look us up by searching "Alopecia" under the "Charities" menu and press "Set as payout"
3. Scan the app, return containers and press "TRANSFER" on the screen when finished!

To find your closest machine visit: returnandearn.org.au/return-points/

VICTORIA - CDS Vic Program



From 1 November 2023, people in Victoria can exchange eligible beverage containers for 10c refund(s). CDS VIC has three zones with three different operators. We have registered for all three zones as a charity partner.

Depending where you are located you will need to download either the CDS Vic East, CDS Vic West or CDS Vic North app (available from your App store).

At the refund point you will be able to choose to donate your refund to AAAF through the app. Look us up by searching "Alopecia" under "donations".

To find out more about the new CDS Vic scheme and a break down of the zones visit:
cdsvic.org.au/how-to-make-a-return

ACT, QUEENSLAND & WESTERN AUSTRALIA

We are currently in the process of registering with Return-It and Containers for Change in ACT, QLD and WA. Please keep an eye out on socials for updates.

SOUTH AUSTRALIA & NORTHERN TERRITORY

Both SA and NT run container deposit schemes, however there is not currently an app or option to register as a charity partner with one organisation. The best way to fundraise in SA and NT is by organising an event such as a collection drive and returning the containers to a return point. Businesses or sporting clubs can also consider providing bins in the workplace for staff. Funds raised can then be donated directly to AAAF.

Envirobank operates in NT and can assist with clubs and sporting teams to raise money. To find out how it works visit here: envirobank.com.au/fundraising/clubs/

For details on how to donate to AAAF visit: aaaf.org.au/donate-funds/

TASMANIA - Recycle Rewards Program

Tasmania's scheme is scheduled to commence in 2024. For more information visit:
nre.tas.gov.au/environment/recycle-rewards

RESEARCH UPDATE

GRIDD Project.

The Global Research on the Impact of Dermatological Diseases (GRIDD) project is the first global patient impact project in the history of dermatology. It aims to collect global data on the impact of dermatological diseases directly from patients. AAAF has previously supported earlier phases of this study, in which the researchers interviewed people with skin conditions to develop a tool to measure the true impact of skin conditions. In the current phase, they are trying to gather data on the impact of skin diseases from 10,000 people with all different skin conditions, from all countries.

The GRIDD data will support local, national, and international advocacy work for more research, better treatments and healthcare policies, and, ultimately, will improve the lives of dermatology patients. For the first time, dermatology patients around the world and from all disease types will contribute to a dataset that measures the true impact of living with their diseases. The dermatology community, including patients, patient organisations, health care professionals, researchers and industry will be empowered with verifiable, patient-derived data and supportive advocacy tools, training, and resources to collectively take action for a better future for patients.

The Patient-Reported Impact of Dermatological Diseases (PRIDD) measure was developed because no existing measurement tool is capable of comprehensively capturing the full impact of dermatological conditions on patients' lives. PRIDD was developed in partnership with 2,490 patients representing 90 conditions from 61 countries and according to best practices in new measure development.

The GRIDD Study will be live from June 5 through December 31. The primary goal of the study is to capture responses from 10,000 dermatology patients from as many regions and dermatological conditions as possible. The Study will be comprised of an online survey available on a dedicated mobile-friendly website and will take approximately 10-20 minutes for patients to complete. The survey is available in 17 languages.

The study is open to adults aged >18 years, who have any skin condition (including any type of alopecia).

The participant information sheet contains further detailed information about the study

https://globalskin.org/images/GRIDD_Study_Launch/PIS_Docs/ENG_PIS_v1.pdf.

To participate in this research please follow this link:

<https://globalskin.org/GRIDDStudy>

RESEARCH UPDATE

The social, psychological, and economic burden of alopecia areata on adolescents and adults over the age of twelve-survey and questionnaire

The study is investigating the socio-economic burden of Alopecia Areata (AA) on adolescents, adults, and their caregivers/partners. This analysis will be used to generate Quality-Adjusted Life Years, a quantitative measure for how patient's lives are impacted, which may facilitate assessments for the TGA and potential reimbursement through the PBS by detailing cost-effectiveness of AA treatment. Information about caregiver/partner impact can be used as evidence that the burden of AA extends to the caregiver/partner.

Sinclair Dermatology are looking to recruit both adolescents aged 13-17 and adults 18+. Participants will be asked to fill out an expression of interest form online to register your interest. If eligible, you will be asked to complete a series of questionnaires/surveys. Participants will be reimbursed \$30. Those that complete the questionnaires will be invited to take part in a structured 30-45 min long interview conducted by a medical doctor. The interview covers loss of time from employment/education and cost of treatment/concealment. Participants will be reimbursed \$50 for taking part in the interview. Caregivers/partners will also be invited to partake in one questionnaire and the interview, although this is not mandatory for participation in the study.

QALYs and the financial loss-of-earnings information acquired in the interview allows the study, and hopefully the government, to compare the value of paying for AA treatment to the value of paying for other treatments. By comparing the QALY of different conditions, it outlines the 'reward' of resource allocation to AA explicitly. We all know AA has an impact on quality of life, but the financial impact is less well substantiated.

Inclusion/exclusion criteria for this study is less strict than for other studies. Participants must have AA/AT/AU, be over the age of 13, be an Australian resident, and have been diagnosed at least 6 months ago. Participants will not be eligible if they have other types of alopecia (pattern hair loss, FFA, etc) or have a comorbid psychiatric disorder that they do not think is related to their AA. If the participant believes that their psychiatric disorder is due to or related to alopecia, they are still eligible for the study.

If you want any further information about the study or your involvement in the study, you can contact Dr Huw Rees on (03) 9013 0099 or

huw.rees@sinclairdermatology.com.au



RESEARCH UPDATE

RESEARCH UPDATE

Why has a boxed warning been put on JAK Inhibitors and how should this be interpreted?

Based on the results of a large safety study on the JAK inhibitor tofacitinib for rheumatoid arthritis, it was found that tofacitinib demonstrated an increased risk of major cardiovascular problems (e.g., myocardial infarction), malignancies (especially lung cancers, lymphomas, and non-melanoma skin cancers), serious infections, and death compared to tumour necrosis factor inhibitors.

Given that the other JAK inhibitors (e.g., baricitinib, upadacitinib) share similar mechanisms of action to tofacitinib, warnings about the aforementioned risks have been issued for all JAK inhibitors (e.g., in the form of Boxed Warnings by the FDA in the US, and updates to the Product Information by the TGA in Australia). These warnings recommend that JAK inhibitors be used with caution for people:

- with a history of cardiovascular disease (eg. heart attack or stroke)
- at increased risk of cardiovascular problems (eg. current or past long-time smokers)
- at increased risk of cancer
- aged 65 years and over

In terms of how we interpret these warnings as a consumer, it is important to keep in mind (1) the applicability of these results to individuals with alopecia areata, and (2) that research on the safety of JAK inhibitors is still ongoing and not yet fully elucidated.

So first and foremost, the patient population included in the study is not entirely congruent with individuals in the alopecia areata community. The study recruited patients aged 50 years old and above, with active moderate-severe rheumatoid arthritis inadequately controlled on methotrexate monotherapy. The patients also needed to have had at least one additional cardiovascular risk factor (e.g., current cigarette smoker, hypertension, high-density lipoprotein cholesterol level of <40 mg per deciliter, diabetes mellitus, family history of premature coronary heart disease, extraarticular rheumatoid arthritis, or history of coronary artery disease).

Full list of inclusion and exclusion found [here from pg 9-17](#).

Second, is that it is always paramount for you to be consulting your treating medical professional for personalised medical advice. This is made more crucial by the uncertainty surrounding these newer drugs. Having a warning, does not make the drug an inappropriate or ineffective management option for a condition. Its potential risks must be weighed against its benefits, and taken in consideration of your individualised circumstances and medical history. This should be a conversation and decision between you and your treating physician.

Please note that any information that AAAP disseminates should not be taken as medical information or advice in any shape or form.

ADVERTISE WITH US

SMP HQ

SCALP MICROPIGMENTATION

Scalp Micropigmentation (SMP) is a highly effective, non-surgical cosmetic procedure designed to provide the illusion of a closely shaved or buzz-cut hairstyle. It is a specialized form of tattooing where tiny, precision-placed pigment deposits replicate the appearance of hair follicles on the scalp.

Scalp Micropigmentation is the perfect option for people who want the appearance of a full head of hair. Firstly, it's a non-invasive, safe, and effective solution. Unlike surgical options, SMP doesn't require any downtime, and the results are immediate.

Secondly, Scalp Micropigmentation is versatile. Whether you have partial or complete hair loss, it can be tailored to your specific needs. Every treatment is customized to suit your unique requirements, ensuring that you achieve the look that reflects your personality and style.

SMP is a long-lasting solution that requires minimal maintenance. It offers a natural-looking, permanent alternative to more invasive procedures like hair transplants or topical solutions.

When performed by a skilled practitioner like Ryan at SMP HQ Scalp Micropigmentation Clinic, it can be a life-changing confidence booster. SMP HQ Scalp Micropigmentation clinic is an owner/operator-run business in Melbourne CBD by Ryan Anderson who has also has Scalp Micropigmentation too!

Brandon P - Review

"Ryan is hands down one of the best SMP artists out there! His passion for his craft is evident in his ability to connect with his clients and understand their unique needs and his work speaks for itself.

But what sets him apart is his ability to truly transform lives. He's helped me regain my confidence and self-esteem in a way that I never thought was possible. I'm so grateful to have found Ryan and would highly recommend him to anyone looking for an SMP artist who is not only talented but also truly cares about his clients. Thank you, Ryan!"



Contact details:

SMP HQ Scalp Micropigmentation Clinic
Level 8, 94 Elizabeth Street, Melbourne CBD

Website: <https://smphq.com.au/>

Phone: +61 0478 876 747

Book a FREE consultation:
<https://smphq.com.au/contact/>

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

WHAT'S ON:

November brings with it Alopecia Awareness Week 2023 and lots of wonderful events!

We can't wait to share an amazing week celebrating and championing awareness with you all! On social media we'll be sharing stories, and a special giveaway for \$100.

Additionally, there will be events you can host and participate in!

**Alopecia Awareness Week
runs November 11-18.**



@ALOPECIAAAAF

November 11-12: AAAdventure Camp

What is the AAAdventure camp?

- Super Fun
- Full of memorable experiences
- A chance to meet other kids with alopecia
- And have a great time!

Where is the camp in 2023?

2023's camp will take place at Mylor Adventure Camp – 32 Wingrove Road, Mylor SA 5153, Australia

What will we do?

- Activities like Flying Fox, Bouldering Shed, Low Ropes, Archery, Challenge Course (Slide and mud fun), Leap of Faith and more
- Workshops to build confidence and resilience
- All overseen by highly trained and award-winning staff.

Join us at Mylor Adventure Camp on November 11th and 12th 2023.

This camp is open to kids aged 6-18. All costs for kids with Alopecia Areaata covered by AAAF! That includes flights, accommodation, catering and activities.



@ALOPECIAAAAF

November 15: Baldest Morning Tea

One way that you can help raise awareness of alopecia is to host a morning tea at your workplace, school or community group.

This can be a fantastic way to support a friend or loved one with alopecia, or to raise funds for research about Alopecia Areaata. A morning tea at your workplace, school or community group.

Here's how it works:

- Just set a date
- Pick the place
- Spread the word to your community telling them to join you
- Invite those who attend to bring a plate and make a donation.

While we host our "official" Boldest Bald Brunch during Awareness Week, businesses and organisations are able to get involved all year round.

We invite you to get inspired and host one in your community.



@ALOPECIAAAAF

November 17: Crazy Hair Day

Join us for Crazy Hair Day!!

We're looking to get schools and community groups across Australia involved in this campaign to improve awareness of alopecia, combat bullying, and funds for research. Whether you're involved at kinder, primary, secondary or even in university, this is a great opportunity to have some fun and in the process inform others about this disease.

November 19: Victoria Open Day

Want to hear from Experts in Hair and Dermatology? Gain updated information from experts at our Open Day!

When: Sunday 19th November between 10am to 2pm.

Where: Temple Society Australia, 152 Tucker Road Benteigh VIC

Details to come via email and social media.



@ALOPECIAAAAF

WHAT'S ON:

Raging Waters
Sydney

AAAF
Australia Alopecia Areata Foundation Inc.
Alopecia Areata
..... it's life changing

AAAF COMMUNITY EVENT
Annual Major Community Event
End of Year Celebration!

Raging Waters Water Park
Sunday December 3rd 2023

Tickets \$40 per person (special charity rate)
People with Alopecia and Kids under 3 are
FREE!

Friends and Family Welcome
Closing Date - Friday 24th November 7pm

BOOK HERE



THANK YOU TO DERMAL THERAPY FOR YOUR CONTRIBUTION TO THE NO HAIR WE CARE PACKS!



These products include lip balms for sensitive lips and SFP 50+ for sun protection, very dry face cream for dry skin, Sensitive skin wash and lotion, Sweat control spray and roll-on with 100% natural actives and aluminium free, Anti-itch relief cream and lotion, and specialised shampoos and conditioners for dry, itchy scalp and hair loss.

Our No Hair We Care Packs are for people with a form of Alopecia Areata. Each care package is only \$15 (+GST) and contains \$150 worth of items, including headwear, skincare, books, DVDs, makeup, jewellery, games and more. The packs also include information and resources to support you on your journey.



'Dermal Therapy is one of Australia's fastest growing, clinically proven and dermatologist recommended skincare brands. Proudly Australian made and Owned the multi-award-winning head-to-toe range has a solution for all skin types at an affordable price point. Dermal Therapy take pride in developing innovative and efficacious products for their community delivering visible results in just 1 day across many products within the range. Serious about offering 'seriously good skincare' Dermal Therapy offers skincare solutions that do work and the brand prides itself on the efficacy and the science behind their products and truly believe that their products speak for themselves (and not to mention the clinical studies and thousands of customer reviews!)

You can learn more about Dermal Therapy at <https://dermaltherapy.com.au/>



Social Media



After reviewing our popular posts this quarter, we have encountered raising interest in different types of content. We'll share the highlights below, including links to our different platforms so you can have positive, educative and supportive content on your social media apps.

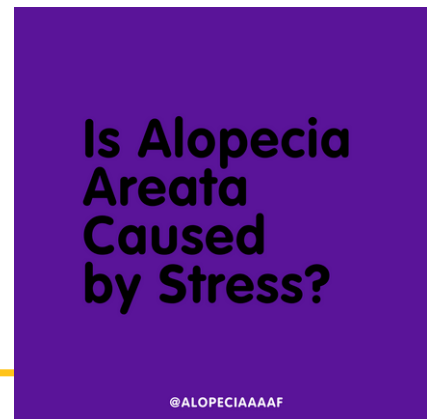
One question that often comes up is: Is Alopecia Caused by Stress?

Everyone's experience with alopecia and stress is unique. Taking care of your physical and emotional health can make a significant difference. [Click here to view the post.](#)



Piper excels in taekwondo, enjoys dancing, and cherishes her time with her lovely dog. Most importantly, she embodies amazingness every day!

Piper is a recipient of our sponsorship program and has graciously shared her inspiring journey with us. Read her full story at www.lovealopecia.wordpress.com

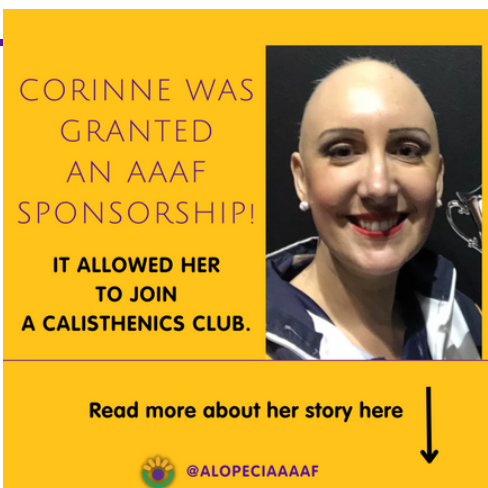


The Sponsorship Program offers financial aid to those affected by Alopecia Areata, promoting awareness about the condition.

Successful applicants will receive funding for skill development and participation in health-oriented activities.

Activities emphasizing teamwork and community engagement are preferred. The program aims to raise awareness by featuring sponsored individuals' content on social and traditional media.

AAAF encourages participants to engage in PR and media endeavors while spreading information about Alopecia Areata and AAAF within their communities. [Click here for more information.](#)



SOCIAL MEDIA LINKS

AAAF
Linkedin
Facebook

Instagram
You Tube
Go Fundraise

My Cause
Shopnate
Love Alopecia

Did you know?

Did you know Alopecia Areata can go into spontaneous remission?

In some cases, without any specific treatment, hair can spontaneously regrow in areas affected by Alopecia Areata. This encouraging aspect of the condition shows that the body has the potential to heal itself, and hair can return even after experiencing hair loss. While the reasons for spontaneous remission are not entirely understood, it brings hope to those dealing with this condition, emphasizing the body's resilience and capacity for recovery.



COMPETITION RULES

Enter for a chance to win 1 of 5 \$100 giftcards!!!

- These are the eyes of famous individuals, all with Alopecia Areata.
- Each post has 6 clues, to help people identify the mystery person.
- The task is to guess the famous person's identity based solely on the provided clues and their eye image.
- Clues may vary in difficulty, from personal anecdotes to professional achievements, leading everyone to an intriguing journey of discovery.
- The competition is running between November 13-17, submit your guesses to info@aaaf.org.au on the corresponding day stated for the clues.
- The winner's name will be drawn from a barrel and announced each day. Goodluck!

1 enter 13/11/2023



FACT 1

I started my television career in children's TV, before branching out into modelling and presenting mainstream TV

FACT 2

In 2005 I developed alopecia totalis, losing my hair.

FACT 3

In 2008 to 2011, I was a regular panelist on Channel 5's The Wright Stuff

FACT 4

I became a guest editor of Fashion Plus magazine

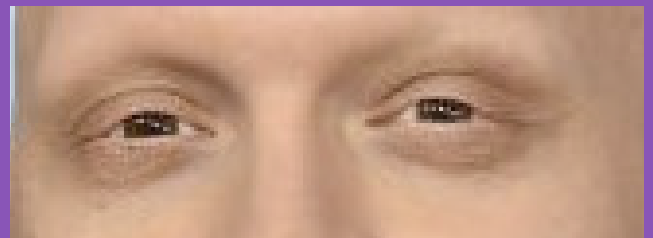
FACT 5

I became an ambassador for a charity that provides wigs to children with hair loss

FACT 6

I studied for a BTEC HND in media production at West Herts College

2 enter 14/11/2023



FACT 1

Since childhood, I have had alopecia areata, an autoimmune disease that causes hair loss

FACT 2

I am married to a professional chess player

FACT 3

I am an advocate for both body positivity and human rights

FACT 4

I was nominated three times for the Primetime Emmy Award for Outstanding Supporting Actor in a Comedy Series

FACT 5

I studied acting at Carnegie Mellon University

FACT 6

I have Irish, English, one quarter Portuguese Azorean, and more distant Polish and Welsh ancestry



Kids Korner-Continued

3 enter 15/11/2023



FACT 1

My family is Jewish, and my mother's family fled Nazi Germany just before the Second World War.

FACT 2

I've had alopecia since childhood, and I lost all of my hair at the age of 6 in 1980.

FACT 3

I started an undergraduate degree in Theatre, Film and Television at the University of Bristol in 1993.

FACT 4

I am 1.69 m in height

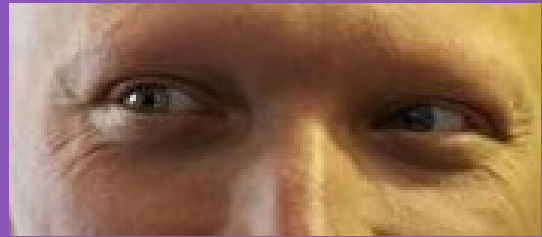
FACT 5

In the mid-90s, I appeared in the comedy gameshow and played the role of a giant baby.

FACT 6

In 2020, I spent my spare time in lockdown rewriting a song that became an instant hit, with all proceeds from sales going to a charity.

4 enter 16/11/2023



FACT 1

I was the inaugural winner of the second-tier V8 Supercar development series in 2000.

FACT 2

In 2003, I was diagnosed with Alopecia Universalis

FACT 3

I run a performance driving school and undertake driver coaching and TV and film work.

FACT 4

I joined 156 races

FACT 5

In 2019, I competed in my 21st Bathurst 1000

FACT 6

I was the first to become a multiple-champion in the Supercar Development series

5 enter 17/11/2023



FACT 1

My career started in the Queensland police force

FACT 2

I hold a Bachelor of Business

FACT 3

In May 27, 2022 I announced that I had Alopecia Totalis on Channel 9's Today Show

FACT 4

I support the Brisbane Broncos

FACT 5

I have been a member of Parliament since 2001

FACT 6

I am the eldest of five children, with one brother and three sisters.



@ALOPECIAAAAF