



**Alopecia
Areata
Totalis
Universalis**

A word cloud graphic featuring the words "research", "awareness", "information", "support", and "embrace" repeated multiple times. The words are arranged in a grid-like pattern, with each word appearing in a different color (purple, green, orange, grey, and blue) and orientation (horizontal and vertical). The background is a light blue sky with white clouds.



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Front Cover: AAAF AGM
October 2019



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PRESIDENT'S WELCOME

Did you know AAAF is turning Ten (10).

What made me decide ten years ago to found AAAF? I don't have Alopecia Areata, my experiences with doctors was not at all overly positive, but I did have a huge passion for promoting awareness into Alopecia Areata and to make things happen you have to get involved.

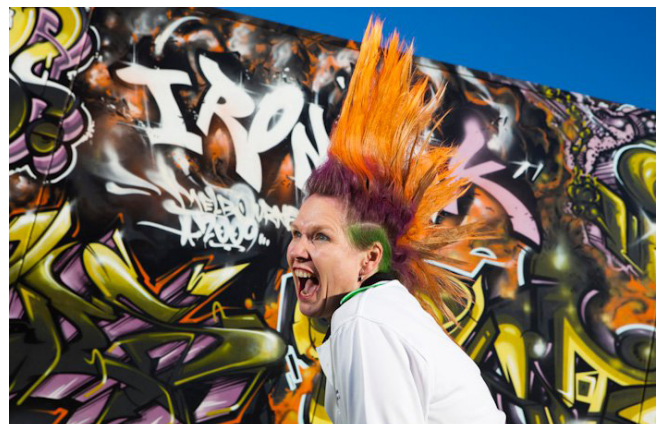
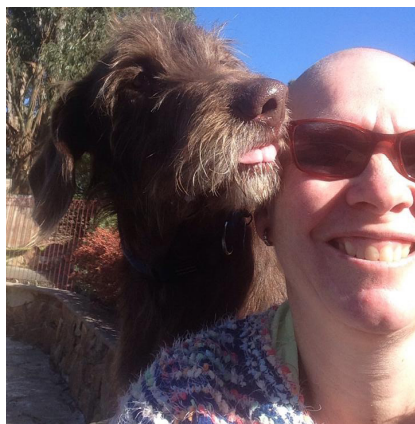
Running a not-for-profit charity is a huge amount of work for our team of volunteers. Take a moment to think about all the work this great team does to provide support, research opportunities and promote awareness into the greater community. 200+ emails a week get answered; 100+ support posts get actioned; creation of support material, social media discussion forum; fundraising initiatives, events, the website management and this is handled by individuals that have families and full-time jobs.

AAAF is here to share information that you want. I think we can all agree that Alopecia Areata.....it's life changing..... to me it's feeling and appearing a lot more positive.

Alopecia Areata is Isolating – I needed to know I l'm no on my own. I thought I was the only person who had lost their hair. This was the number one question I was hearing in 2009, and now I'm rarely ever asked this. This proves AAAF has made an impact by reaching out and seeing who else is out there, first by our website and now through various channels of social media.

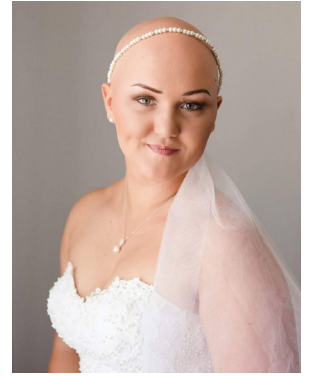
There are moments throughout the ten years that have been challenging, heartbreaking, exhausting, but also so powerfully rewarding. None better than a thank you card I received with these words...." her passion, energy and strength of never giving up and spreading awareness of alopecia in our community. She is a wonderful, kind and caring person, has a positive attitude and is not selfish person.... She is my role model". That one kind act from an 11-year-old, sits framed on my desk to remind me of the GREAT that the AAAF Team is doing.

Throughout next year we will be celebrating our 10 years with many new initiatives and I hope to see many of you at our pop-up events.



MEET OUR COMMITTEE

Introducing our New South Wales Branch Manager -Breanna



I am relatively new to the AAAP committee and am looking forward to celebrating my 10-year alopecia diagnosis anniversary alongside the AAAP 10-year anniversary.

My alopecia journey began in June 2010 when I was 15 years old. I was living in the small town of Grafton, and had just finished a game of netball when I discovered my first bald patch. I felt through the rest of my thick, blonde hair and found another patch, 2 in total, about the size of a 50cent piece. I wasn't too phased at the time as I thought maybe it had been somehow pulled out, or that it would just grow back, but time would tell that I was very wrong.

I went to the doctor within a couple of days and finally began to realise that my hair may not "just grow back". Within the next few weeks it became clear that alopecia was taking its grip as my hair fell out drastically. I tried to cover my patches using thick headbands and pins, but before long I had no hair to cover the patches and turned to wearing a wig. I had blood tests taken regularly, biopsies and scrapings, I saw several specialists and tried many treatments including Minoxidil, oral steroids. By Christmas I shaved the remainder of my hair and began wearing wigs.

It was at this time that I found out I was pregnant and had to stop treatments. I tried to cover and hide my head. I had my daughter in June of 2011 and my hair started to regrow. It grew to a length of 2 inches before it started falling out again and this cycle repeated 3 or 4 times, but then stopped growing back at all. I started the DPCP treatments and purchased a blonde wig which made me reasonably comfortable. However, I was still terrified of the prospect of people knowing I was bald. Eventually the specialists I was seeing told me they had no more options for me to try. I was devastated. My alopecia at this stage was universalis.

In 2013 my boyfriend and family encouraged me to go without my wig and with their support I made a facebook post revealing to all of my friends and family that I was bald. I felt like a weight had been lifted from my shoulders and I could resume being me. Having 4 sisters, I felt that my hair was a huge part of my identity, and my biggest challenge was coming to terms that I am me, with or without my hair.

At the end of Year 12 I was featured on the front page of my local newspaper for completing highschool being a teen mum with alopecia. The story spread far and wide and I received many messages of support and people telling me how brave I was. In 2014 I began University and was offered a position as an Outreach mentor with Southern Cross University to go to local schools and share my story. This greatly increased my confidence.

I have since completed a double degree in business and law and will be beginning my career as a solicitor in 2020. I have been a passive member of the AAAP for several years, and when I received the email advertising the NSW Branch Manager role, I felt it was a perfect way for me to become involved. In this role I hope to connect with others who have alopecia to share knowledge and increase connectedness within NSW.

There have been many setbacks and obstacles in my alopecia journey. I still have days where I feel self conscious and wish that I could blend in; but these are becoming few and far between. I am grateful to be a part of the supportive alopecia community.

COMMUNITY STORY

Oscar



Hi, my name is Oscar and I am 13 years old. I'm the eldest and I have a brother and sister. I have Alopecia Universalis.

I developed this when I was nearly 8 years old. Before that I had thick, curly auburn hair. I had never lost any patches of hair before. I noticed a patch of skin on my scalp on the weekend and then it just all fell out! In one week I had no hair left on my head. I was in year 2 so I don't remember a lot about it. I do remember that I was dancing in a concert, so we went to the hairdresser and got the patches that were left shaved into a Mohawk, which was cool and everyone at school loved it. But that fell out pretty quickly too.

Then my eyebrows and eyelashes went too, after a few more weeks. It has not grown back, but occasionally it has tried to, sprouting some bits, sometimes I have eyelashes but mostly not.

I started drum lessons not long after the alopecia started. I was 8 years old and it was awesome fun. We got a drum kit at home too and I loved playing. Three years ago I started learning guitar and now I sing as well. I love listening to all kinds of music but mostly rock. My favourite bands would be Nirvana, Foo Fighters, Green Day, AC/DC, and Eminem. I think getting into music has helped me deal with my alopecia. When you are learning a song you have to really focus on that and not think of anything else, so it can be a good distraction. Apparently singing is one of the best things you can do to put yourself in a good mood, I definitely think that this is true! You can't feel upset or angry, after belting out some cool tunes.

I love playing guitar and singing for people. I practice my music all the time and love learning new songs and improving. I have singing lessons and guitar lessons, I just want to learn more and get better. While I've been learning guitar for a few years, I've only just started singing lessons, so I am grateful to the AAAF for providing this sponsorship as it means I can continue these lessons for two more terms. I've learnt lots of techniques that help with my singing, such as breathing and voice projection.

I go busking which is heaps of fun. I'm saving up to by a loop, so I can add layers to my music and start making my own songs. I have a band I play with at school too, it's fun to hang out with my mates and try and get songs going.

The AAAF have been an awesome support for me and my family, as we learned all about Alopecia. They gave us information and we have met and made great friends through meet ups with them. I've been on two camps with them, which are great because you get to meet other kids of all different ages who have alopecia too. It's nice to not feel like the only one! I also like helping kids that might have only recently got alopecia, I tell them and show them it will be ok after a while of adjusting to it.

I met a great mentor through AAAF, Carlo Napolitano who has the same alopecia as me and has had it his whole life. He was very reassuring especially as I moved from primary into high school. For a while I was worried about going to high school, I thought about getting a wig so I could blend in more.

But I realized I probably wouldn't like wearing something on my head all the time and it would be something to have to bother with. I am used to people staring and asking questions when they first meet me, but once people know why I have no hair, it is not a big deal to anyone. I decided the best thing to do was what I always do. Just go to the new school answer any questions and let people get used to it.

I'm pretty fine about having it, I can't really do anything about it anyway! If people ask I just tell them it's alopecia, my immune system attacks my hair follicles and makes it fall out. The worse thing is that my fingernails peel off and I get really cold or overheat because hair helps your body regulate temperature.

The best thing about having alopecia is that sometimes it is good to stand out and have something different about your-self. I like that I am unique. Everyone is different anyway but there is not many kids going around with no hair.

I hope by doing this sponsorship I can help other people who might be worried about their alopecia, I want people to know it is ok to look different and be different. There are more important things to concentrate on than your appearance, such as being kind, being creative and rock and roll.





RESEARCH UPDATE

Findings from the AAf funded research :

The Cost to Government and Disutility of Alopecia Areata and an Investigator-Initiated, Placebo-controlled, Clinical Trial Investigating the Efficacy of Two Treatments for Alopecia Areata.

<https://aaaf.org.au/research/>

Title:

Impact of Cyclosporin Treatment on Health-Related Quality of Life of Patients with Alopecia Areata

Authors' full names: Vivien Wai Yun Lai, Gang Chen, Rodney Sinclair

Introduction: Alopecia areata (AA) is a disfiguring disease with substantial psychological burden. No studies explore the efficacy of pharmacotherapy through health-related quality of life (HRQOL) using both disease-specific and generic quality of life instruments.

We present the first study to elicit health utility from patients with AA and to evaluate the efficacy of cyclosporin in relation to HRQOL using both measures.

Methods:

Participants with moderate to severe AA from a placebo-controlled randomised trial investigating cyclosporin were administered the generic preference-based HRQOL instrument, Assessment of Quality of Life-8D (AQoL-8D) and the disease-specific HRQOL instrument, Alopecia Areata Symptom Impact Scale (AASIS). HRQOL was measured at each study visit and compared to baseline.

Results:

32 participants were analysed. The mean health utility was 0.748. At 3 months, the cyclosporin group had trends for greater improvement in HRQOL across 6 of 8 AQoL-8D dimensions and 5 of 7 AASIS symptom domains compared to placebo. HRQOL was lower than Australian population norms across 6 of 8 AQoL-8D dimensions.

Conclusion:

Patients with AA had a mean health utility of 0.748. Treatment with cyclosporin 4mg/kg/day for 3 months resulted in trends for improvement of HRQOL across multiple dimensions in both disease-specific and generic measures.



RESEARCH UPDATE

Continued



volunteers needed

Seeking Volunteers to enhance daily functioning through increased psychological flexibility

Project Title

Physical activity combined with Acceptance and Commitment Therapy for individuals with Alopecia Areata: A randomised controlled trial.

Summary of Project

Acceptance and Commitment Therapy (ACT) is a form of cognitive behavioural therapy, which may be beneficial for people with Alopecia Areata (AA). The approach aims to enhance daily functioning through increased psychological flexibility. Whilst the therapeutic model behind ACT appears well suited to individuals with AA, there is a need for further research to test its effectiveness through intervention, particularly with regards to combining ACT with physical activity to increase mental health status in individuals with AA. This intervention is a randomised control trial (RCT) to evaluate the effectiveness of PA and ACT for individuals with AA to improve mental health status among them.

Expected Duration

December 2019 to December 2020

Self- help ACT programme

It is an online self-help based on ACT. Participants will have to complete a total of six sessions, once per week, with each session lasting one hour. The sessions will follow the psychological approach Acceptance and Commitment Therapy (ACT) and are designed to promote psychological flexibility through methods that encourage openness, awareness and engagement and will be facilitated by the online platform Qualtrics.

For more information email info@aaaf.org.au

VOLUNTEERS

with a heart

Volunteers of the Year

Volunteer of the Year is an award AAAF provides to community members who have gone above and beyond to support people with Alopecia Areata and to assist AAAF. We couldn't be more grateful to all our supporters and volunteers, and to everyone who gives their time to assist others.

The Awards this year were presented to Shea Giordimaina (Support Ambassador) Elizabeth Bear (Adelaide Branch Manager) and Vesna Devcic (General Committee Member).

Liz was diagnosed with Alopecia Areata in 1985, and has offered support to women with hair loss ever since. So it was a natural stepping stone to her joining the AAAF in 2010 as the South Australian Branch Manager.

There is a family history of Alopecia Areata so Liz is passionate in offering support and raising awareness of the disease. She hopes that through research a cure will be found in the future. Liz works in the family Agricultural and Viticultural business and is a part-time Office Manager in her husband's legal firm.

Vesna joined AAAF in 2010 and previously held positions of Secretary, Treasurer and now General Committee Member. Having the condition for over 34 years she is passionate to make a difference to those affected with Alopecia Areata.

Vesna is currently a Stay at home Mum and enjoys spending time with her family & getting out into the great outdoors.

Shea has been living with Alopecia Areata from the age of 7. A busy dance teacher and proud mum of two beautiful girls, Shea knows that even through tough times, a strong support system and a vibrant sense of humor can get you through anything that alopecia may throw at you.



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ND Collection



The concept and burning desire for a better solution for women with thinning hair came from an organic need for sisters Ness and Dee both suffering from hair loss.

Ness a young mother and hairdresser of almost twenty years and Dee also a young mother and corporate consultant for twenty years, combined their personal struggles and professional experience. The result, ND Collection was born.

As a hairdresser, Ness was often embarrassed by her own hair. She tried everything available, from the inside out but nothing worked. She wore hair extensions for years but this only made the hair loss worse and was terribly expensive. She considered wigs but they were too heavy, itchy and terribly uncomfortable.

When Ness discovered hair Toppers she was overjoyed at finally finding a solution. However, the quality and price tag of what was on offer just wasn't right. In came Dee, and the two of them spent almost two years collectively sourcing, buying and trying every kind of Topper available in the market in search for the best quality at an available price. After an exhaustive search of products both within Australia and overseas they decided they would make their own, high quality Remy Human Hair Toppers, that look amazing, natural, light and easy to wear. A product designed for those who appreciate quality.

Ness and Dee couldn't be prouder of ND Collection and elated at the opportunity to help women change their lives, the way they did. As real world suffers of hair loss, they know the struggles and what it means to women.

Please reach out to us for more information:

e info@ndhaircollection.com.au

w ndhaircollection.com.au

i [instagram.com/n.d.collection](https://www.instagram.com/n.d.collection)

fb [facebook.com/ndhaircollection](https://www.facebook.com/ndhaircollection)



Love, Alopecia

Have you visited the AAAF blog, Love, Alopecia?

It's full of personal stories, inspiring journeys and useful information.

Our "Alopecia Tips" series has been running over the last few months and has something for everyone!

Visit the blog at

<https://lovealopecia.wordpress.com/>

AAAF have also updated our website page to share more of our infographics.

You can find these at

<https://aaaf.org.au/support-material/>



Did you know that AAAF is about to celebrate our 10 year anniversary?

AAAF was established in 2010, with the purpose of providing funding into research, promoting awareness and providing support for people with Alopecia Areata and their families around Australia.

AAAF have provided more than \$300,000 in research funding, \$150,000 in grants for Alopecia Areata Community awards and over \$176,000 in Wigs for Kids grants.

We have now grown to have Alopecia Support Groups in every state in Australia and the ACT.



***President Chel Campbell
at the launch of the AAAF***



Donate Hair

2017 Kids Camp



***CBA Wigs for Kids
Donation***



Sydney Hair Expo



***Remove GST
from Wigs***



WHAT'S ON?

Melbourne Boldest Brunch

Sinclair Dermatology Boldest Brunch
10:00 am - 2:00 pm on Wednesday
November 13 2019
Level 1/2 WELLINGTON Pde East Melbourne



Ladies Night Out

ALOPECIA AWARENESS WEEK

6 PM
SAT 16TH NOVEMBER
INCHMEAL CAFE - 39 WESTERFIELD DRIVE, NOTTING HILL, VIC

Melbourne Ladies Night Out

Saturday November 16 6:00 pm
Inchmeal Cafe 39 Westerfield Drive
Notting Hill

Melbourne Christmas Catchup

Sunday December 8th – 10.00 am
Gumbaya World
2705 Princes Hwy, Tynong



SYDNEY ALOPECIA SUPPORT GROUP MEETUP

SAT 23RD NOV, 3PM-6PM
DURUWAN SHELTER,
PARRAMATTA PARK

Sydney Support Group Meetup

Saturday 23rd November 3.00pm - 6.00pm
Duruwan Shelter
Parramatta Park, Parramatta

Sydney Family Fun Day

Saturday December 14th – 10.00am
Raging Waters Sydney
\$42 per person RSVP 1st December
Inquiries to stephanie@aaaf.org.au



Hunter Region Alo-Pizza Night

Alopecia Areata
Awareness Week
5.30pm Sat the 16th Nov
Cardiff Seafood and Pizza
270 Main Rd, Cardiff NSW

Hunter Region Alo-Pizza Night

Saturday 16th November 5.30pm
Cardiff Seafood and Pizza
270 Main Road, Cardiff

WHAT'S ON? - Continued

Perth Family Picnic

Sunday 17th November 11.30am- 3.30pm
Sheoak Lawn, May Drive Parkland
Kings Park



Launceston Dinner Time

Tuesday 12th November 6.30pm
The Irish 211 Brisbane St, Launceston

Adelaide Alopecia Awareness Week Dinner

Sunday 17th November 6.00pm
Cafe Brunelli, Rundle St, Adelaide



SOCIAL MEDIA

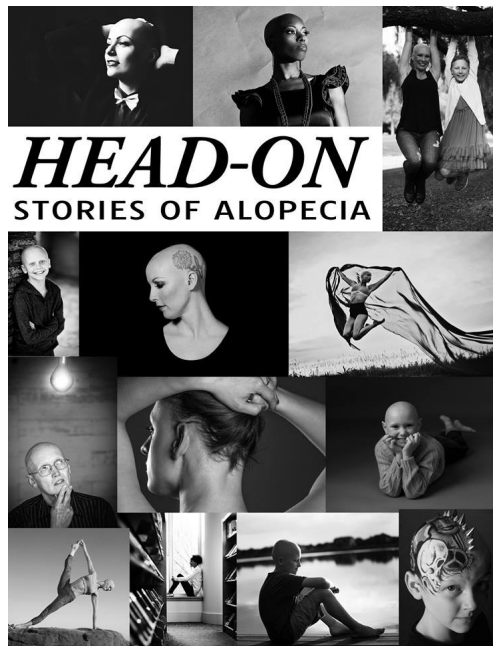
Are you looking for a new podcast to listen to on your morning commute or while walking the dog? Check out "Alopecia Life" by our friend from the USA, Deeann Graham!

"Alopecia Life is here to provide you with support, accurate information, inspiring stories and life hacks to help you navigate the world of hair loss. You'll hear interviews with specialists in their field and parents who are helping their child move through life while living with alopecia areata, along with conversations with alopecia rockstars who are making a difference. Whether you've just been diagnosed or have had it for ages, Alopecia Life has been created to share all the information you may want or need to do alopecia your way."

Deeann is also the author behind "Head-On, Stories of Alopecia" a fantastic book featuring 75 personal stories and beautiful photography of people living with Alopecia Areata.

Listen on Spotify [here](#)

Listen on the Apple podcast [here](#)



SOCIAL MEDIA LINKS

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Shopnate
Love Alopecia

How to run a Crazy Hair Day at your school/club

Crazy Hair Day is a fun way to spread awareness of this condition in your local community. You can also raise funds for research into a treatment for Alopecia Areata.

Step one: Talk to your school or club about your idea .

Reach out to your principle, teacher, or coach, and let them know you'd like to run a Crazy Hair Day to raise awareness of Alopecia Areata. You can tell them why Alopecia is important in your life, and that awareness of the condition can help reduce bullying.

Step two: Pick a date.

AAAF runs an official Crazy Hair Day on the Friday of Alopecia Areata Awareness Week. That's Friday the 15th of November in 2019. However, schools and clubs can pick any date which suits them. Crazy Hair Day can be a great way to celebrate the end of term, or a special sporting event.

Step three: Decide on fundraising.

Crazy Hair Day can be a fantastic way to raise funds for research into treatments for Alopecia Areata. There are lots of different options to raise funds. You could collect a gold coin donation from everyone with a crazy hair style. You could also set up an online fundraiser, and ask for donations in support of the event. You might even have someone interested in donating their hair as part of the day. Find out more about fundraising options at <https://aaaf.org.au/donate-funds/>

Step four: Prepare for the day

There are lots of different options for how to raise awareness of Alopecia Areata on the day. You might like to show a video designed to help kids understand the condition, or have some posters and brochures to display. You might host a talk and tell people about your experiences. You may be able to invite a support ambassador to take part in the day. Information for these options and more is available on our website

<https://aaaf.org.au>

It's Crazy

Step five: Choose your own crazy style

There are so many different ways to style your hair or head for a Crazy Hair Day, no matter what type of Alopecia Areata you have. You might be able to amazing braids or a crazy mohawk or spray colour your hair. You might be able to shave an awesome design around your patches. Maybe you could paint or bejewel your head, or wear the coolest, craziest hat. The options are endless!

Step six: Share your Crazy Hair Day

We love seeing and sharing your Crazy Hair Days! Feel welcome to share photos and stories from your event with us by emailing info@aaaf.org.au

Be sure to check for permission to share any images before you send!

