



Australia Alopecia Areata Foundation Inc.

ISSUE 11 NOVEMBER 2020

Alopecia
Areata
Totalis
Universalis

research R A I S E
awareness A I S S E
information I S S E
support S S E
embrace E

research awareness information support embrace



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Front Cover: Alopecia Awareness
Ribbon art by Rino at [instagram](#)



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PRESIDENT'S WELCOME

- Chel Campbell

As you know AAAF is run 100% by volunteers and this year Greg our W.A. Branch Manager celebrates 10 years. When I founded AAAF in 2010, I was compelled to help others in the same position that I found myself in 23 years ago in supporting a person with hair loss. Like most of you, I knew nothing about Alopecia Areata when first diagnosed, I just knew deep inside I wanted the journey of others to be easier than mine, I just wasn't sure what that would look like or where it would take me. So far it has taken me on a path of meeting so many passionate, caring, devoted individuals all wanting to make a difference to the lives of those with hair loss.

Each year AAAF committee come together to plan out the next year and the activities, competitions and where the next kids camp will be held. Unfortunately this year with restrictions we have not been able to do this and therefore any announcements on next year's camp and major activities will be postponed until February 2021.

As we are heading now into our next five years of operation, it's a time to reflect back on the goals we set for the first five years. Our first five years in operation were all about connecting and creating. We grew a dedicated volunteer team and created state-based support groups all around Australia. We established life-changing programs like our Hair Donation Program, Wigs for Kids grants, research grant program and support ambassadors.

The last five years have been focused on launching the AAAF branding. We launched this newsletter, established the annual AAAdventure Camp for Kids, created targeted support groups for Men and Teens. We've delivered resources and support tools like our Wig Video Series, our blog Love, Alopecia, and funded a range of medical and psychological research projects.

Established at our AGM in 2019, our next five year goal is securing a corporate partner and funding. Securing ongoing funding is the key to AAAF achieving our goals in awareness, support and research for Alopecia Areata.

We must be doing something right! In 2010 when AAAF was founded, the most common question sent to us, was "Am I the only person with Alopecia Areata?" I don't think I have been asked this in many years. The most common question we field now is "What causes Alopecia Areata?" and trying to navigate the many myths circulating. As we get closer to a successful treatment, we are also edging closer to getting this answer. Stay tuned as more medical trial opportunities are announced in 2021.

On a lighter note, I thought I would share with you a quote that sticks with me the most is: "If you look in the mirror and see your insecurities, so will everyone else. The moment you step back and realise you are beautiful as you, whatever your difference, then others will see this too".

Just a reminder, to check out our website, youtube channel and social media hubs as you will find many resources to assist with life style changes, transitioning into school, how to tell friends, family and peers, along with just some great tips and techniques. If there is a topic you would like answered, just drop a line as we are always looking for new ways to help and development of new resources.

MEET OUR COMMITTEE

GENERAL COMMITTEE MEMBER Vivien



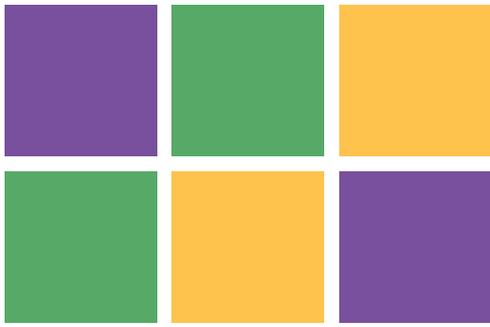
Hi, my name is Vivien and I am a relatively new committee member, having joined AAAF as a General Committee Member at the start of 2020.

Whilst I do not personally have my own alopecia journey to share with you all, I became very much invested in alopecia areata from a scientific, research perspective from 2018.

Having completed my medical degree in 2017, I was curious to explore the world of research and decided to pursue an immersive research program that involved developing my own project, contributing to a body of knowledge and testing hypotheses and limits of our current clinical practice. It was then, that I was introduced to my research supervisor, Professor Rodney Sinclair, an expert in the field of hair disorders and who was already involved in a body of work surrounding alopecia areata. I quickly realised that there was much unknown about alopecia areata, ranging from its exact pathogenesis, triggers, prognosis and more importantly, treatment and their effectiveness.

Throughout the year, I developed a number of research projects designed to evaluate the psychological impact of alopecia areata and the effectiveness of various treatments. I was very lucky to receive a research grant from AAAF to support this research. Some of my very first projects involved detailed interviews with patients describing both the shock and relief from getting a diagnosis; the psychological impact it had on appearance, confidence and mental health; the burden of having to adapt lifestyle choices to fit the logistics of wearing a wig; and the winding journey of trying various treatments and hoping that a good response could be had.

My journey that year also gave me an insight into the challenges of scientific research. My main project had one question, only one hypothesis to essentially prove or disprove, however as I began to design each parameter of the project, I quickly realised that there were many variables to define – some of which could take on different definitions, depending on the context.



MEET OUR COMMITTEE -Continued

An example of this was in defining what 'effective' treatment was, that is, what amount of hair regrowth constituted valuable, effective regrowth? This particular question, if analysed in detail, could vary from person to person, but in the realms of quantitative research, we needed to decide on a cut-off.

After my year of being immersed in evaluating the disease from all angles, I grew a deep appreciation for the foundation on which medical knowledge grows; an appreciation for the amount of work previously done for alopecia areata, and for the vast unknowns that there are still to be discovered. Whilst no single project can provide the breakthrough that we all need, a collective amount of work with time and perseverance will help progress our knowledge in this field forward.

I decided to become a General Committee Member this year to support the work that AAAF has done in terms of providing awareness to the disease in the general public, creating important support networks and being a welcoming group for anyone with the disease. I look forward to continuing my research in the field and being part of such a great initiative!



COMMUNITY STORIES

This year has held some challenges and changes. AAAF had to pause in-person events in most of our states. But our volunteers and community weren't going to let that stop us connecting and providing support.

This year we ran a record number of online campaigns, projects, giveaways, and competition. Thank you so much to everyone who took part in some way or another!

As a special edition of our community story, we'd like to share some of the amazing stories, artworks and engagement we've seen this year. AAAF is so inspired by the resilience and spirit of our amazing community. In a time when we have had to be apart, coming together online means so much more.

From Mary - I was diagnosed with alopecia Totalis when I was 10 years. I got married ten years later, when I was 20. I had my third child when I was 30. At 40 I had my first overseas holiday to my country of birth, Scotland. I became a grandparent also at 40. I was 40 when we had our first house built. . When I turned 50, I wondered where the years had gone and my youngest child turned 6 year old. At 60 I became a great-grandparent. I became a widow at 70. I am now 80. I've lived with alopecia most of my life. I started wearing wigs when I was 18. Alopecia never stopped me living my life. I loved to dance, and met my husband at a big dancehall in Edinburgh. Although there was times that i envied woman who had beautiful hair, I've never said why me, I have at times got upset at people's intolerance. I live in a retirement village and I'm a very active 80 year old.

ACCEPTANCE Journey poem by Ryan



Continued Over

COMMUNITY STORIES

Continued

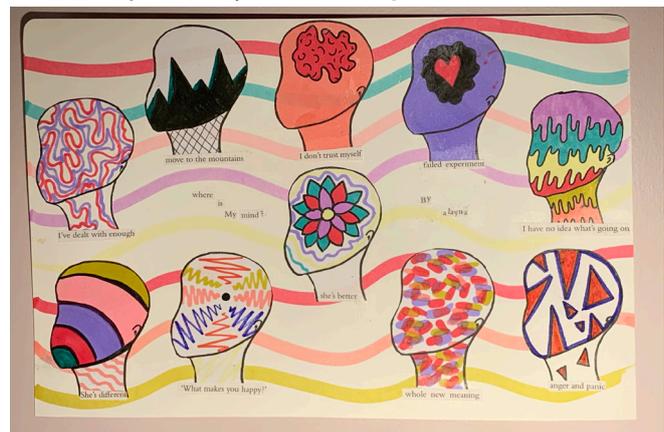
Ten Truths from My Alopecia Journey – Creative writing by Michelle, full version can be viewed [here](#).



Self Portrait by Rani



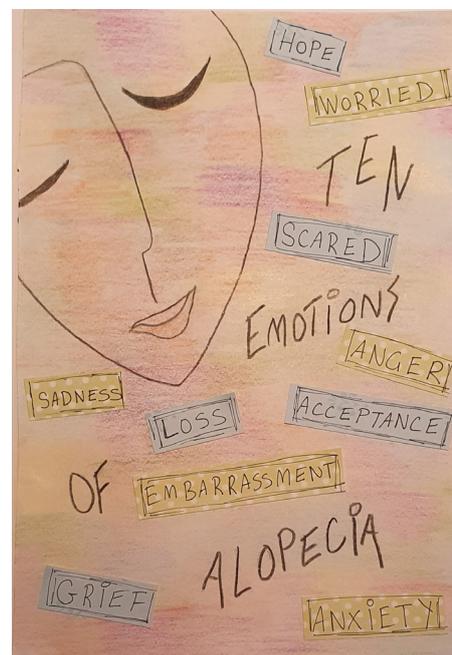
Why Is My Mind?" Artwork by Alayna about her journey with Alopecia Areata



Chel's Easter Hair Donation



Ten emotions of Alopecia by Angela





RESEARCH UPDATE

RMIT University Research 2020 - Pathways for better mental health for AA community

RMIT university in collaboration with AAAF had conducted a randomised control trial involving physical activity using the Fitbit wearable device together with Acceptance and Commitment Therapy (ACT), a self-help intervention to improve mental health among the individuals in the AA community.

A total of 58 individuals were recruited in this study which commenced on mid-May and ended late September. The self-help ACT a series of steps delivered in a week-by-week modular fashion and the interventions teach people how to re-establish daily routines, increasing activities that provide positive reinforcement while reducing negative reinforcement. The ACT programme comprises six sessions consisting of audio segments and printable and interactive worksheets. Along the six- week period, the participants were provided with Fitbit Inspire to perform physical activity to their ability.

A total of 44 participants has successfully completed the six weeks intervention. This intervention had benefited the participants and the testimonials are stated below:

1. I just wanted to say thank you for including me in the study. It really has been great. I have 2 toddlers at home and going out for a walk each day either with them or without them has forced me to realise I need to priorities me for myself even if it is just going for a walk or quick work out using the FitBit app. It has changed my mindset along with the ACT program which I really enjoyed. I'm feeling more positive and getting more out of life. It has made me think about my alopecia and how exercise, acceptance and positivity can be great in dealing with the condition.
(Participant from VIC, Female)
2. Thank you for allowing me to be a part of this intervention. It really has made some positive changes in my life. I hope your research is a success.
(Participant from VIC, Female).

RESEARCH UPDATE - Continued

VICTORIA -

Clinical trial in Melbourne, Victoria seeking participants aged 18-65 with a form of Alopecia Areata with hair loss over 50% or more of the scalp.

Participants must have experienced hair loss for at least 6 months but not longer than 8 years.

The study will involve 8 visits over 32 weeks. Participants will be provided care throughout the study period at no cost, and study related expenses like travel may eligible for reimbursement.

To read the Information Sheet and for contact details to register your interest [click here](#).

SOUTH AUSTRALIA -

Current study seeking adult participants for clinical trial in South Australia who have had hair loss to Alopecia Areata for more than 6 months.

Please [click here](#) for more details.

To register your interest in this study, or any other questions, please contact Christine Musolino at Christine@ctsa.com.au or Kimberly Hook Kimberly@ctsa.com.au.

ADVERTISE WITH US

Russell and Thyme make beautiful, fashionable, and comfortable headwear, created by a fellow person with alopecia to make the kinds of turbans that she needed but couldn't find elsewhere.

After tying headscarfs for years, Brigette struggled to find options that looked and felt great for people with alopecia with or without their wigs. After many prototypes, Brigette created a turban with a bamboo liner for comfort, an interchangeable rosette that can be worn as a headband on its own and darting and pleating for volume and style. This design gave the secure fit, comfort and style factor she was looking for.

Russell and Thyme now produce a gorgeous range of turbans, scrunchies and headbands. This amazing small business also supports AAAF's No Hair We Care package service.

If you're looking for fun, fashionable and comfortable headwear this summer, check out Russell and Thyme.

Click [here](#) to access the Website.

Click [here](#) to access Facebook.

Click [here](#) to access Instagram.



Russell
& Thyme



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The No Hair We Care Program (NHWC) is a care package service for people with a form of Alopecia Areata. Each care package is only \$16.50 and contains a big bundle of headwear, skincare, books, dvds, makeup, jewellery, games and more, as well as information and resources to support your alopecia journey.

These packs are made possible by the generous support of our amazing partner organisations, including Bravery Buddies, Ego Pharmaceuticals, Red Hill Road & Co., and Russel & Thyme. If you or someone you know owns a business who can help give a smile to people living with Alopecia Areata, please visit AAAF [here](#).

To check out the No Hair We Care packs, [click here](#).

If you or someone you know is connected to a business who would like to help change the lives of people impacted by Alopecia Areata, please visit our new corporate partnerships page.

AAAF President and Founder is available to chat with any businesses and organisations who would like to help us continue to make a difference. Find out more by visiting AAAF [here](#).





Alopecia
Areata
Awareness
Week
Nov 14 -
Nov 22

**SOCIAL
MEDIA**

AAAF has had ten amazing years providing life-changing support, funding research and championing awareness of Alopecia Areata! We are so excited to celebrate this amazing milestone with all our community.

However, we need your help to provide life-changing support for kids and families with Alopecia Areata. And what better way to get involved than hosting a birthday party fundraiser?!

Your fundraising can help us support running the 2021 AAAdventure Camp for kids.

Set up your fundraiser [here](#).

This has been a challenging year. These uncertain times have meant the cancellation of many of our fundraising events. Our annual kids camp was cancelled for 2020, to the disappointment of many. We have not yet secured funding to support the 2021 kids camp.

The Alopecia Areata Adventure Camp for Kids is an annual weekend of fun, friendship and self-confidence for kids with any form of Alopecia Areata. The camp has been a huge success for the last three years and has had a profound positive impact on the kids and families involved.

This Alopecia Areata Awareness Week (Nov 14-22), set up a birthday fundraising page and gather your friends, family and workmates to celebrate! Just set a date, invite your friends to bring a plate and make a donation. Digital events are also a great way to celebrate. You'll have a great catch up together and can feel proud of the difference you'll be making in the lives of others.

This Alopecia Areata Awareness week, how about doing something different to make a difference?

SOCIAL MEDIA LINKS

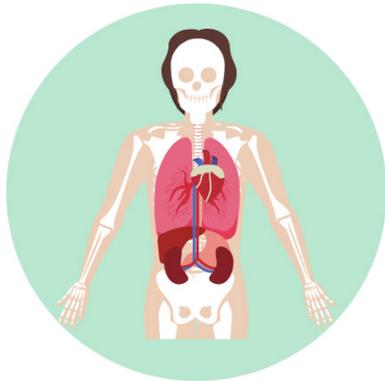
**AAAF
Linkedin
Facebook**

**Instagram
You Tube
Go Fundraise**

**My Cause
Shopnate
Love Alopecia**

Did you know?

Why do people with Alopecia get so hot and cold?

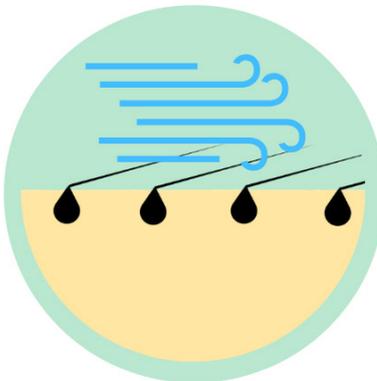


BODY HEAT, SKIN AND HAIR

Body heat is generated inside our bodies, mostly in organs like the brain, heart and liver. Our skin is the organ used to regulate our temperature. It does this through sweat and body hair.

HOW DO WE REGULATE TEMPERATURE?

When the air is a comfortable temperature, our body hairs lie flat and relaxed against our skin. Air can flow next to our skin and keep us cool.



WHEN IT IS HOT

When we are too warm, we secrete sweat from tiny glands under the skin. The moisture cools off our skin even more when air flow passes over.

The blood vessels in our skin also expand, increasing the blood flow to our skin surface. The blood near the surface can cool before being circulated back through the body. This helps to cool the body.

WHEN IT IS COLD

When the air is cold, tiny muscles at the base of body hairs tense and the body hair stands on end. We can see this as goosebumps.

The standing hair creates a barrier which traps a layer of air next to the skin. This layer of air becomes warmer, and prevents colder air touching our skin and cooling us down further.



For people with Alopecia Areata, these heat regulation systems may not function normally. People with Alopecia Areata may sweat much more than normal when they are hot, and may get cold very quickly. It's important to care for your needs, like using warm beanies and gloves in winter, and drinking extra water in summer.



WHAT'S ON?

SA Adventure Park 15th November



MEGA ADVENTURE PARK

Sunday, Nov 15th, 2pm
4 Hamra Ave, West Beach SA 5024, Australia
RSVP and Bookings Essential by Nov 10th
AAAF to cover the costs for people with a form of Alopecia Areata

SA Adventure Park 21st November



MEGA ADVENTURE PARK

Sat, Nov 21st, 2pm
4 Hamra Ave, West Beach SA 5024, Australia
RSVP and Bookings Essential by Nov 17th
AAAF to cover the costs for people with a form of Alopecia Areata

SA Awareness Week Dinner
22nd November



Alopecia Areata Awareness Week
Dinner Catch Up

Sunday, Nov 22nd
6pm
Cafe Brunelli
187 Rundle St, Adelaide

QLD Beach Picnic 15th November



Alopecia Areata Awareness Week
BRISBANE BEACH PICNIC

Sun, Nov 15th
11.30am
Suttons Beach Pavilion, Redcliffe

QLD Afternoon Tea 22nd November



ALOPECIA AREATA AWARENESS WEEK
BRISBANE AFTERNOON TEA

SUNDAY, 22ND NOVEMBER
2PM
SAN CHURRO, WESTFIELD CHERMSIDE

VIC Zoom Hangout 20th November



ALOPECIA AREATA AWARENESS WEEK
ZOOM HANGOUT

FRIDAY, NOV 20TH
7.30PM

NSW Fun Run 15th
November



A FUN RUN FOR AWARENESS

CELEBRATE Alopecia Areata AWARENESS WEEK
Come walk, run or cycle. Bring your family, friends and dogs!

Where: PARRAMATTA PARK
When: Sunday the 15th of November @2pm
RSVP: Stephanie@aaaf.org.au

WA Beach Bash 22nd November



ALOPECIA AREATA AWARENESS WEEK
BEACH BASH

SUNDAY 22ND NOVEMBER
9-11 AM
CITY BEACH, PERTH
RSVP IS ESSENTIAL

TAS Launceston Dinner 8th
November



ALOPECIA AREATA AWARENESS WEEK
LAUNCESTON DINNER

Wednesday, Nov 18th
6pm
The Commercial Hotel
27 George St Launceston Tas

TAS Hobart Dinner 14th
November



ALOPECIA AREATA AWARENESS WEEK
HOBART DINNER

Sat, Nov 14th
6pm
Dr Syntax Hotel
139 Sandy Bay Road, Sandy Bay Tas

TAS Hobart Bowling 14th
November



ALOPECIA AREATA AWARENESS WEEK
HOBART BOWLING

Sat Nov 14, 1.30PM
Zone Bowling
162 Main Rd, Moonah, TAS

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

Volunteer 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 **Barbara Tomasic** and **Greg O'Rourke** (Western Australia Branch Manager).

Barbara has been volunteering since 2014 in providing the self-tie scarfs that AAAF sell on our webstore. Barbara has supplied AAAF with an endless array of stock, no request has gone unanswered, even creating scarfs to match children's school uniforms.

Barbara jumped at the opportunity to be a proud supporter of our NHWC packs.

A special call out to Greg O'Rourke. Greg introduced himself to AAAF in 2011. Being a parent of 2 children with Alopecia Areata he wanted to know more about how he could assist them. What better way than becoming the Branch Manger of W.A. Greg has grown the W.A. community by 26.3% on average, and in the mix made some wonderful long time friends.

We would like to acknowledge the following nominees:

- **Nathan Ash** - ongoing tech support for AAAF website and emails (has received VOTY in 2017)
- **Emma Butler** - regular donations of a portion of all sales from jewellery business to AAAF, hosted events for AAAF free of charge, support of the NHWC packs
- **Mel Edwards** - has run several fundraisers and awareness events over the years through her work



Check out these amazing Kids supporting Kids with Alopecia

Every hair donation we receive is special. It represents years of patience and care from the donor to grow the locks. The donations go on to provide confidence and comfort for a young person with alopecia who needs a wig. However, there is something extra wonderful about hair donations made by kids whose lives have been impacted by alopecia directly

Siarrah –

St Ursula College, Yeppoon hosted an amazing fund- and awareness-raising event earlier this year. A very special thank you to teenager Siarrah, who spoke to the school about living with alopecia.

A group of senior students took part in organising this amazing hair donation event. The ponytails cut were sent to AAAF to become wigs for kids. These amazing young people also raised funds for a cancer charity. We are always so blown away when acts of kindness are able to support two important causes. You can read more of Siarrah's story and this amazing event [here](#).



Matilda -

Matilda, who has experienced alopecia herself, has donated her gorgeous locks and raised over \$2600 to support other kids going through alopecia.

“When I was 2 and a half years old my hair started to fall out. It was a few patches to start with, then more and more and by the time I was 4 and a half, I had been completely bald for quite a while. I even started losing one of my eyebrows! I was lucky enough to find something that worked for me and my hair started to grow back but not before I was teased and bullied at school. It’s now been 7 years and my hair has grown so much that I want to cut some of it off to donate so that it might help another child not be bullied and teased.”



Kids Korner - Continued

Erin –

This year, amazing young Erin donated her gorgeous thick curls to become a wig for someone in need. Erin's brother Oscar has featured in the AAAF Newsletter before, as one of AAAF's Sponsorship Program Recipients. Thanks so much to Erin, Oscar, and all the amazing siblings out there supporting brothers and sisters with alopecia.



Jamieson –

Jamieson started a 'Personal Best' project at school, aiming to raise \$350 for AAAF by making and selling lip balms. Her fundraiser had an absolutely amazing response and has currently raised over \$2700 to help kids and families with Alopecia Areata!

