



Australia Alopecia Areata Foundation Inc.

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Cover photo: Joshie Rooks with his book  
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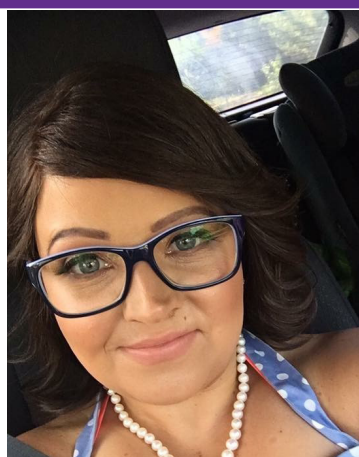
## PRESIDENT'S WELCOME

My journey with Alopecia Areata started almost 20 years ago. I recently wrote about my experience with having my son diagnosed at age 20 months, which focused on the treatments available at that time and the delivery in which the treatments were advised to me by the Dermatologist. You can read about my experience [here](#).

I'm sure many of you will report back similar thoughts. So why am I hashing up old news, old treatments, and what same might say is the same old, same old in treatments? Last month I sat with Professor Rod Sinclair, who had just returned from the National Hair Conference in the USA and he said these words " Dermatologists in three years will be able to give a positive treatment strategy to patients and actually say this treatment will grow back your hair". Bring on 2020 I say! Please see our research section for more details.

AAAF welcomes a new Support Ambassador to our team. Bianca Young is especially passionate about mentoring and coaching young people in the areas of self-love and self-expression. She has 18 years' experience working with young people, teaching, coaching and mentoring. She is currently working on a program called Urban Heart, which delivers support and empowerment for young people who may be struggling with confidence and self-acceptance Bianca also writes for Love, Alopecia. Read Bianca's story [here](#).

Congratulations to all of you who have been getting behind our theme for 2017 of Embrace Alopecia. The feedback is encouraging and shows that AAAF is running programs to improve the quality of life for people living with this condition so we thank you for your support.



# MEET OUR COMMITTEE

Introducing our Support Ambassador,  
Shea

I am a founding member of AAAF and by being a Support Ambassador I have been able to offer my support through my story, experiences and Alopecia knowledge.

My alopecia story started when I was just 7 years old. And my life changed forever. Mum and dad had bought a block of land and we were moving from my safety spot. My house. My home. I knew things were about to change I just didn't realise how much. To be honest I have blocked out a lot of stuff from that period of time. I guess for me I didn't want to accept what was happening (both the moving and the alopecia). I changed schools and have a very clear memory of my first day. Standing waiting for assembly with my mum wearing overalls and a hat and a little boy coming up to me and saying "hey are you new?" I nodded yes in response to which he followed with "are you a boy or a girl?" and they all ran off laughing. Right at the moment I decided I would never let words hurt me!

My alopecia at first was quite easy to hide. It began at my part and fell out like a receding hairline from my part. I remember wearing lots of side ponytails until it became too hard to hide and I started to wear hats. I was never big on hiding it because let's be honest I love to be the centre of attention. I came to a crossroads with my hair. I had a tiny plait left on the back of my head and thought I can either keep this plait or let the alopecia control me or I can cut it off and take control! So I did just that. I took control and I have never looked back!!! It wasn't hard with the amazing support I had surrounding me from my family. My rocks. My mum used to tell me that I was just more evolved than everyone else! And I liked to think that made me extra special.

I have always used humour to deal with the nastiness and cruelty of people's stares and name calling. It's been my coping mechanism and the best way I knew how to deal with the stuff coming my way.

I also use dance as an outlet for me to express myself and my emotions and still to this day, as a dance teacher myself, I do that very same thing! I have decided this year it is time, time to embrace the world and dance bare naked. Well not naked but without a wig. Something I have never done before. I have always wanted to do this but I have never ever felt like I could do it.

My wigs have been a security blanket ever since I got them 15 years ago! It is so much easier to blend in, that address the unwanted questions and stares. Wigs are a massive part of my confidence and helped me as a teenager to get through day to day life.

In saying that, I have also highly enjoyed the fun that comes along with wearing wigs! I remember when I was younger being dared by my sister to "flash" my bald head at the cars driving past our house. So I did and the poor driver of the car had such a fright. My sister and I on the other hand went laughing up the hill.

I have tried not to take my alopecia too seriously for fear of letting sadness and grief overcome me. Instead I have embraced it and used it to help others suffering with the condition.





## A Story from Raychel

Raychel's dad took her to Brisbane on 4th December to watch the Brisbane Roar W-League game so she could see her favourite player.

Everybody from Peninsula Power and Brisbane Roar were so friendly and kind to her.

Raychel got to run out with the girls, meet them in the dressing room and even have dinner with them.

A highlight was meeting her favourite player - Katrina Gorry.

Raychel in her own way spread the message of alopecia because as she was running out they announced it over the stadium so at least more people were educated about it.



Raychel has alopecia universalis and generally wears a headband most of the time.

Last year she played soccer representing her city Cairns, in the Un10/11 Girls at the Filippo Mele Carnival in Townsville and came away with the trophy for the player of the tournament for the girls.

Raychel hopes that by sharing this photo it might inspire other younger children with alopecia that might be struggling with confidence and self image to push past that as Raychel has and keep going for it.

Raychel dealt with the stares and questions as she always does at the carnival but she didn't let that stop her playing to the best of her ability.



## UPDATE ON JAK INHIBITORS

In 2015 AAAF gave a grant of \$88K to Sinclair dermatology to execute a topical JAK inhibitors data collection study. It is with great excitement that this trial has been extended into an American pharmaceutical firm to advance the hypothesis. A key learning from the AAAF study was that the JAK Inhibitors did not thin the epidermis as seen with the current treatments. 16 of the people on the trial showed hair growth. The lessons learned from the study were the trial period needed to be longer, the dosage of the topical ointment could be enhanced through antibiotics to penetrate the skin for faster absorption with no detriment to the epidermis quality.

In 2016 JAK studies combining Eczema and Alopecia Areata have shown improvement in the Eczema condition as well as hair growth.

In 2017 Pfizer announces funding for clinical trials in 17 countries for Alopecia Areata. Australia is selected.

## TRIALS COMMENCING IN 2017 IN VICTORIA, NEW SOUTH WALES AND QUEENSLAND

Join a clinical study for a treatment for alopecia areata.

The purpose of this clinical research study is to evaluate the safety and effectiveness of two investigational medications, in tablet form, or placebo, for the treatment alopecia areata.

You may be qualified to participate if you:

- \* Are between 18 and 75 years old,
- \* Have moderate to severe alopecia areata,
- \* Have been experiencing hair loss for 7 years or less, and
- \* Are willing to follow a treatment plan of scheduled study visits, lab tests and other study procedures for the duration of the study, up to 37 weeks.

For participants, all investigational medication (or inactive placebo), study-related tests and study doctor's visits will be provided at no cost for the duration of the study, up to 37 weeks. Participation is voluntary and you may withdraw at any time.

There are several Australian sites participating in this trial. For more information please contact the lead site on 0455 915 411 or email [clinicaltrials@sinclairdermatology.com.au](mailto:clinicaltrials@sinclairdermatology.com.au).



## RESEARCH UPDATE

### **Associations between physical activity, quality of life and mental health in patients with Alopecia Areata: The Physical Activity, quality of Life and Mental health (PALM) pilot study.**



This study conducted by Ms Yamuna Rajoo, Dr Jason Wong, and Dr Isaac Selva Raja at RMIT University School of Health and Biomedical Science sought to examine the relationship between physical activity and mental health in people living with Alopecia Areata. Though the sample sizes were small, the study found that rates of anxiety, depression, and stress were high among people with Alopecia Areata.

Approximately 80% did not meet suggested levels of physical activity, much higher than the national average. Given the known association between physical activity and improved mental health outcomes in the general population, this study recommends increasing physical activity levels among people living with Alopecia Areata, in addition to other psychological intervention tools like counselling and support groups, to improve mental health outcomes.

### **Pfizer upgrade JAK3 & TYK2/JAK1 Inhibitors**

Pfizer have officially upgraded the drug JAK3 & TYK2/JAK1 Inhibitors to stage 2. To help explain the advancement and investment being made read [here](#).

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## FREEDOM WIGS AUSTRALIA

**Martine of Freedom Wigs lost her own hair to alopecia at the age of 7.**

**She has spent the last 15 years dedicated to helping other people in the alopecia community regain confidence and self-esteem by providing incredible hair, a role that she absolutely loves. Freedom Wigs are completely customised, a medical scan taken of your head ensures the security and comfort of a vacuum fit. You can swim, play sports and resume the life you had before alopecia.**

**Freedom Wigs uses virgin European hair that can be coloured and styled anyway you wish, this also means an increased longevity for your new hair. The specialised implanting technique makes the hair move in a realistic way and looks like a natural scalp over the entire head. Martine travels throughout NSW, ACT and QLD offering the privacy of a home visit from someone who completely understands.**

**You can contact Martine at:** [www.freedomwigs.com.au](http://www.freedomwigs.com.au)  
**Ph: 0419 534 695**  
**[info@freedomwigs.com.au](mailto:info@freedomwigs.com.au)**

## SCALP MICROPIGMENTATION

Scalp Micro Pigmentation can:

- \* Give the look of a full, youthful head of cropped hair
- \* Simulate a full-front, side and/or rear hairline
- \* Restore hairlines on part-bald or fully bald heads
- \* Camouflage – permanently – the symptoms of all levels of alopecia
- \* Scalp Micro Pigmentation (medical tattoo) is a non-surgical treatment for both men and women
- \* Takes place over 3 sessions, each taking approx 3-6 hours
- \* Suitable for all types and stages of hair-loss, for all ages, colours and skin types

Contact	Phone	Website	Servicing
Anita - Olli Skin	07 3395 1088	<a href="http://www.olliskin.com.au">www.olliskin.com.au</a>	Brisbane
Ken - Vinvi Hair Clinic	1300 399 457	<a href="http://www.vinviscalppigmentation.com">www.vinviscalppigmentation.com</a>	Melbourne, Perth, Sydney





## DID YOU KNOW?

### Queensland Scientists Make Chronic Fatigue Syndrome Research Breakthrough

Many research studies continue in trying to link medical condition to a dysfunctional immune system. Griffith University have a centre for Neuro-immunology and they have made the connection of Chronic fatigue to dysfunctional immune system.

You can read more about this breakthrough [here](#).

## WHAT'S NEW?

**I.C.Emergency Fundraising Program** - a simple idea that will save lives and help raise funds for AAAF.

The I.C.Emergency USB is a keyring device that contains important contact and medical information in times of emergency. If you, or someone in your family is involved in an accident and they're unconscious or unable to remember who to notify, the emergency responders, or police or hospital emergency staff can simply use the device to find your emergency contact. Medical staff will be alerted potentially life-saving information about existing medical conditions or allergies.

This life-saving device also has an added benefit – if you purchase one online using the link below, I.C.Emergency will donate a portion of the funds to AAAF to help us fund life changing research into Alopecia Areata.

To order yours click [here](#).



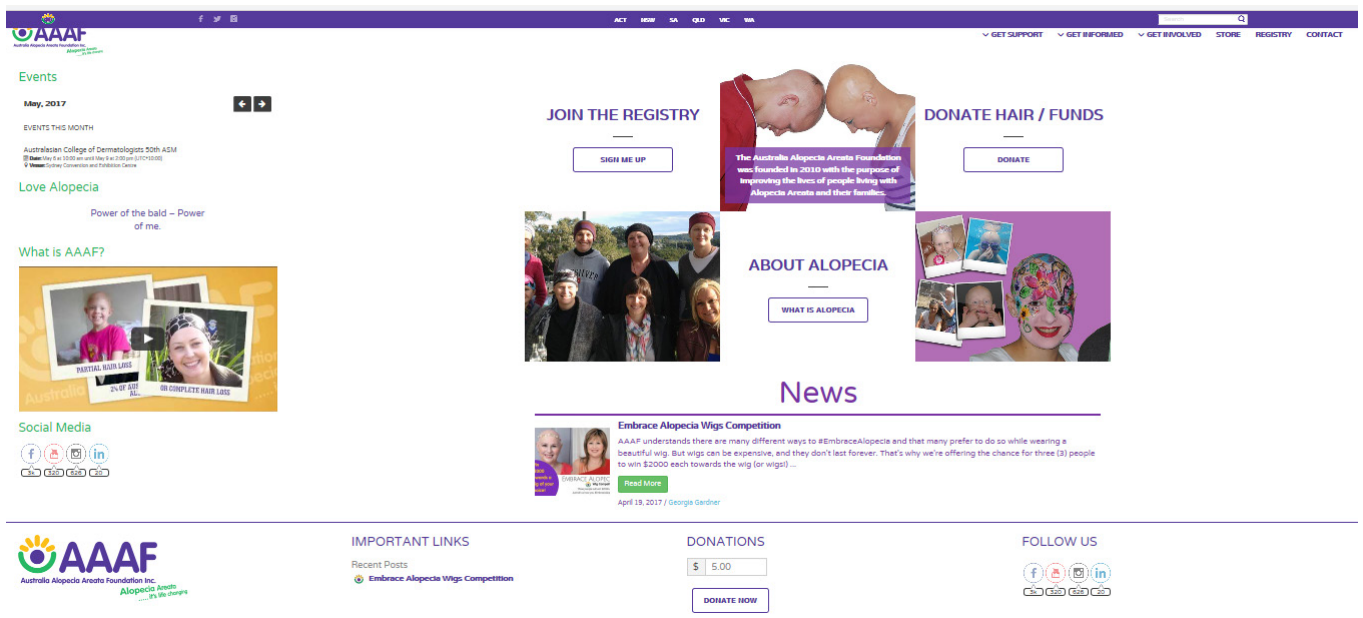


# WHAT ELSE IS NEW?



AAAF are excited to launch our new look and feel website, bringing the pages visited most by our varied audiences upfront for ease of use, navigation and targeted information sharing.

We love feedback here at [info@aaaf.org.au](mailto:info@aaaf.org.au) - so tell us what you think.



# Embrace Alopecia Wigs Competition

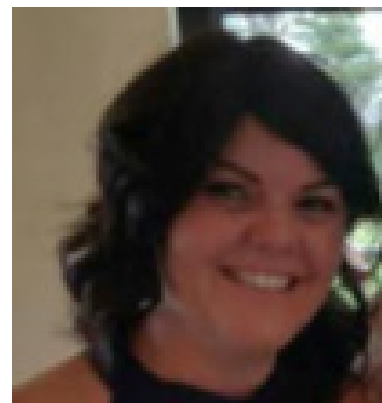
and the winners are:



## Kate:

I don't mind that people know I don't have hair, it's part of who I am. To say that it has been life changing is an understatement. I feel for the first time that I am in control of my hair loss. I am confident to talk about what alopecia is & what my choices have been.

Doing it for my children has become one of the very last reasons I did it, for once I did something for myself.



## Laura:

I love me for me! My hair does not define me , if anything it has really opened up my eyes to the world around me! 11 years on I have 3 beautiful daughters who don't mind telling their friends "why their mum has no hair?!" They simply just say "oh she just has alopecia , not sick"! I go to work with only a hat on and work with customers face to face and get to tell my story numerous times a week to my curious customers.



## Charlotte:

At the end of the year I won an award for the courage I showed!

I am now in Year 6 and still don't have any hair – although we are still trying! I now chose each day what I feel like wearing. Some days it is a wig, some days a head scarf and very occasionally I go completely bald. I need to keep showing courage and am learning to embrace my Alopecia!



## Update On GST Removal From Wigs

As many of you know over many years now the AAAF has been lobbying various Federal Government's, both Labour & Liberal, regarding the removal of the GST component on wigs purchased for Medical reasons. We have tried addressing the issue through a number of Parliamentarians in different states and the answers we received have been the same.

1. Anyone can purchase a wig. They are not specifically for people suffering from hair loss (Alopecia Areata).
2. "The State Governments have a scheme whereby a person can apply to receive a grant to purchase a wig". There is a big problem with this answer. Not all States have this scheme available and also in some States, as is the case in South Australia, people living outside of the Metropolitan Area are excluded from the funding.
3. We have been told that "under the Intergovernmental Agreement on Federal Financial Relations any change to the base of the GST will require the unanimous agreement of the states and territories, in addition to the passage of legislation by both Houses of the Commonwealth Parliament".
4. And "Consideration also needs to be given to whether a GST concession is the best and most efficient way of providing assistance".
5. Some Private Health Institutions give a rebate but you have to be on the highest table and the sum varies.

So where do we go from here?

The AAAF will continue to lobby the Parliamentarians on the GST issue but now the ball has been moved to the State Governments. Our petition to remove GST on Wigs has received over 5,000 signatures so far. This ground work is not lost and can be used in our lobbying to State Government. I know that many of those signatories do not suffer from Alopecia Areata but I believe that many are family & friends of us who do. Members of Parliament are always asking if there is anything you want to discuss with them and any way they may help, this usually happens around election time. Maybe now is the time to make an appointment with your local State Government Member Of Parliament and ask them to help you, their constituent, change the ruling and add the removal of GST on Wigs used for Medical reasons or find an alternative. I know of one little boy who has started this snowball rolling by writing to his local MP. Let's keep this snowball rolling and create an avalanche.

AAAF is investigating with the Government the options around if the GST is not the best and most efficient concession.

Liz Bear  
SA Branch Manager



# What's On

## **Sunday May 21st – Brisbane Crazy “Hair” Day and Picnic**

Inspired by a wonderful story from the USA, our Brisbane based support group is getting together to host a picnic in the park and Crazy “Hair” Day. Meet us at the Roma St Parkland at 12.30 for a Sunday afternoon catching up.

## **Saturday June 17 – Wig Competition**

Wig Competition for University students commences.

## **Thursday June 22nd – Sunday 25th – 32nd Annual NAAF Conference**

For the first time, AAAF is attending the NAAF Annual Conference in Miami, Florida! We are very excited to represent our Australian alopecia community at this very special event.

## **Saturday July 1st – Victorian Charity Trivia Night**

Our annual Victorian Trivia & Silent Auction night is back again! Invite your family & friends, work colleagues & team mates, book a table – maximum team of 8 people per table. \$15 per head.

Included on the evening will be a Silent Auction & Raffle with some great items up for grabs – Keep an eye on this page or our Facebook event for updates on what will be available!

## **Saturday August 5th – International Alopecia Day (IAD)**

Look at your state for the activities posted.

## **Sunday August 13th – 21st – Kokoda17**

Our team heads off to PNG to tackle the Kokoda Trail and raise funds for research and champion awareness of Alopecia Areata.







## Embrace Alopecia – The Year So Far

Our campaign to #EmbraceAlopecia is a major part of our plan for 2017. Already this year we've seen some amazing things from our community. From official projects, to competitions, from fundraisers to personal successes.

Please click on the image below to enjoy a snapshot of just some of the ways AAAF and our beautiful community have been embracing alopecia so far this year.

# EMBRACE ALOPECIA  
The year so far



### SOCIAL MEDIA LINKS

**AAAF**

**Linkedin**

**Facebook**

**Instagram**

**You Tube**

**Go Fundraise**

**My Cause**

**Shopnate**

**Love Alopecia**

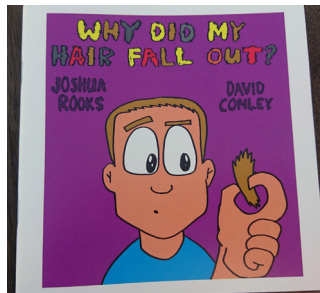
# Kids Korner

New children's books about Alopecia Areata have arrived at AAAP!

When young Joshie from Canberra was diagnosed with Alopecia Areata, he struggled to understand what was going on. After getting in touch with AAAP and finding resources like our kids DVD "Alopecia Areata: Why does my hair fall out?" he felt more confident and was able to explain what was going on to his classmates.

To help other kids who might struggle to understand Alopecia Areata, he wrote a book! A talented teacher at his school helped illustrate Joshie's work and another friend helped get it printed.

Find out more or to buy the book [click here](#).



Ben's First Day is a children's book about what a child might be thinking when they are going to school for the first time. Developed and donated by Alopecia UK, this is hoped to be the first in a series of books aimed to help young people with Alopecia Areata feel more comfortable at school. Item cost includes postage within Australia.

To find out more or to buy the book [click here](#).





# Kids Korner

## Custom scarves designed by kids with Alopecia.

Made with love by our friends at Coming Up Rosies, these scarves have been designed by kids with Alopecia Areata and named after them.

Bright and colourful, and full of love, these customised scarves are made from 100% microfiber polyester. This breathable fabric is UPF 35 rated, odour resistant, seamless, moisture wicking, quick drying, and machine washable in cold water.

Our one size fits all head scarf is 24widex51cm long. It's tubular in shape, which is easy enough for a young child (or adult) to put on and off independently. This versatile scarf can be worn on the head as a head cover or hair band, or worn gently around the neck.

To buy one of these scarves you can order [here](#).

