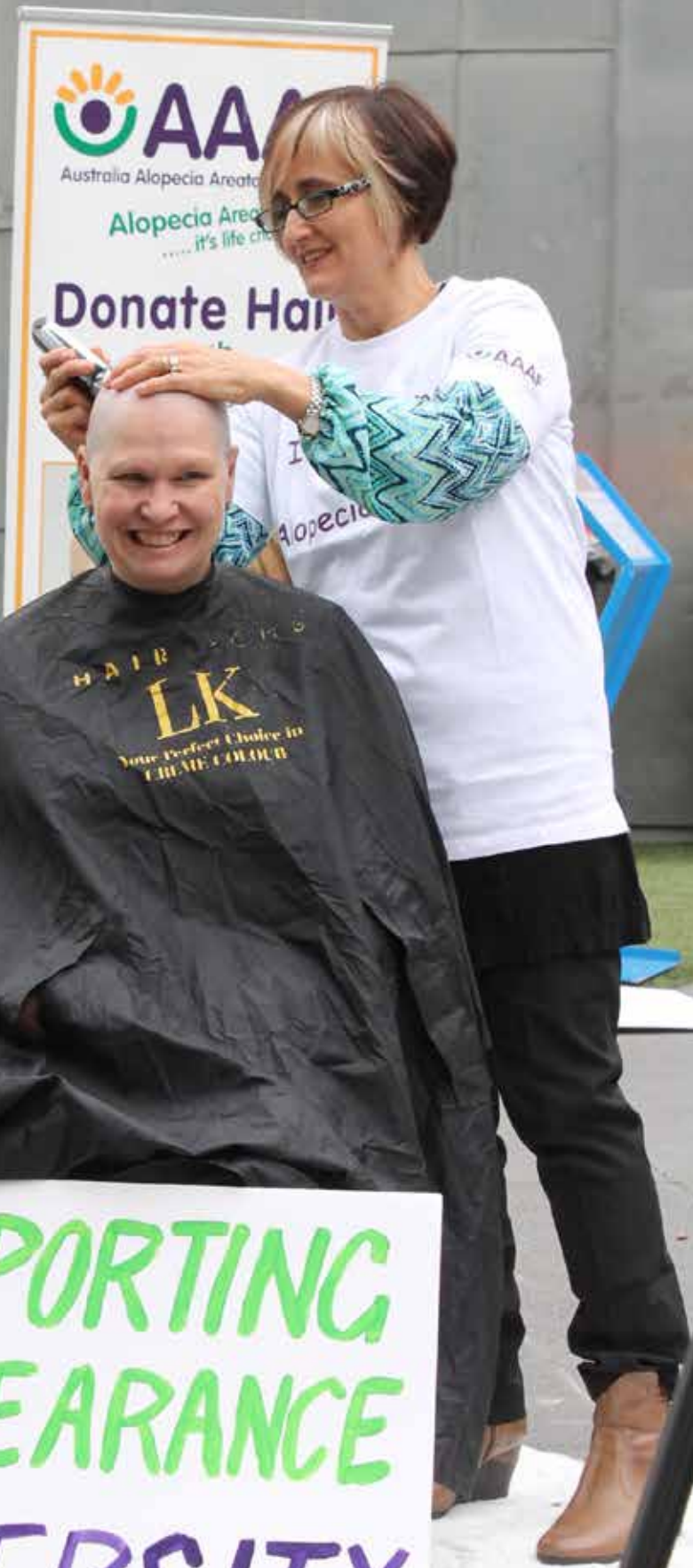


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RESEARCH
AWARENESS
INFORMATION
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 **AAAF**
Australia Alopecia Arecta Foundation Inc.

ISSUE 3 NOVEMBER 2016



SUPPORTING
APPEARANCE
DIVERSITY

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Cover photo: Alopecia Awareness Day,
Federation Square, Melbourne
Photographer: Eli Cox

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PRESIDENT'S WELCOME

Can you believe that AAAF has been operating for 7 years! Did you know that we are run by volunteers? Being on a committee is hard work, but also extremely rewarding. We are delighted to welcome Sarah, our new NSW Branch Manager. Sarah studied commerce at university and was recently head of marketing for a pharmaceutical company, before venturing into her own business that combines her passion and career and founded The Beautiful Hair Boutique. Her personal goal is to remove the stigma around wearing wigs, so everyone with any form of medical hair loss will feel confident and beautiful with any hair they have on. Sadly, we say goodbye to Vesna, who has been on our journey from the start. We thank her for all her input and look forward to seeing her at our social events. We are currently looking for Tasmania and Victoria Branch Managers, but any help is always welcome, so please contact me.

Once a year, our committee comes together to explore ways we can continue to promote awareness, raise funds for research and support our community. To encourage open communication about Alopecia Areata, our theme for this year is Embrace Alopecia. We hope to improve the quality of life for people living with this condition across the country and look forward to your involvement. Liz, our SA Branch Manager and Georgia, our Secretary will also be attending the 2017 NAAF Conference in the USA to strengthen our networks and get some new ideas.

Embrace Alopecia will be at the core of all programs, events, competitions and campaigns that AAAF runs over the next year.

How will you embrace Alopecia?

Georgia, AAAF Secretary and James, Support Ambassador at the AAAF annual General Meeting



Marshmallow Challenge



MEET OUR COMMITTEE

Introducing our WA Branch Manager,
Greg O'Rourke

I was born in Narrogin in rural WA in 1962. My parents were both country folk. I was the second of four children. I had an older sister, a younger brother and a younger sister.

In 1966 my sister Jenny was born and was later diagnosed as profoundly deaf, a victim of rubella before the time when a vaccination was available.

Once diagnosed, our family moved to Perth in 1969, as there were no educational opportunities for deaf children in rural areas and they needed to start their education very early. My parents put everything into ensuring Jenny got the best opportunities and that the impacts of her handicap would be lessened.

Looking back, I believe having a sister who is deaf, gave us all an appreciation not only of deafness, but an insight into differences amongst people. Jenny turned 50 in August and we are all very proud of what she has achieved in spite of some difficult obstacles.

By training I am an engineer and have worked in Australia, England and Scotland. In 1993 I married Marie and we have three children aged 18, 16 and 13. Two of our children have Alopecia Areata and it was during a period where I was trying to obtain information that I encountered AAAF. And it was shortly after that that I was asked if I would be interested in becoming the WA Branch Manager for AAAF. I'm not sure if there were any other applicants but I ended up with the gig and have been in this role now for nearly 5 years! All of the committee roles in AAAF are voluntary, and although it does take a fair amount of effort, it is immensely rewarding when you can make a difference.

I don't have Alopecia Areata myself so my own experience is as a parent. I don't believe that having Alopecia should stop anyone from achieving in life, but unfortunately it sometimes does. We have to keep working hard as an organisation to address this, but parents also have an incredibly important role to play. Both of my kids that have Alopecia have worked with me and helped a couple of younger kids in their journey and I believe that helping others that can turn someone from a victim ("Why me?") into someone who can use their experience to change someone else's life. Empowerment.

With parents of children with Alopecia, it is very important to stay positive, despite the very real grieving process that parents go through ("This isn't fair, this is so difficult for my child, why can't it just go away?") I have found that children are often less concerned about it than their parents, but if they get too much of an inkling that their parents are hugely worried, it will rub off on them. Instead, put your energy into trying to make a positive difference in the life of your child. Build supportive networks, help educate family, friends and the school environment. These networks are very important as they counteract issues such as bullying which can make life harder for people who are visually different. Seek out others who are going through or have gone through similar experiences. Let your child know that they are loved and not alone. Help build their self-esteem. Alopecia is about so much more than how you look. It is about how you feel and your sense of self-worth.

Being part of the AAAF has been a great experience for me. I am passionate about making life better for people with Alopecia through our threefold mission of Support, Awareness and Research. The quest is never-ending and there is still much to do.

Siarrah's Story



At the age of two my journey started. We were at the Gold Coast and just had a wonderful day at Sea World.

Exhausted, mum was tucking me into bed, gently pushing my hair away from my face to give me a kiss good night. There it was "the bald spot." Within two months I was Bald and Beautiful.

Mum noticed a lot of people assumed why I had no hair but no one ever really understood what Alopecia was.

Mum then contacted the local newspaper, they ran a beautiful story on Alopecia and this created awareness within our small town of Bargara Qld.

18 months later my hair grew back, not as full and a bit patchy but the Alopecia was mainly where my hair fell so it wasn't as noticeable.

At the age of 6 I lost all my curls once again, this time I was a bit conscious of my hair as I was in grade 1 school.

Mum wrote a caring letter to all my class mates explaining my condition and my mates were so kind and my Alopecia never became an issue. As the years went by I have been on the unpredictable rollercoaster,

At the age of 8 I was diagnosed with selected mutisium anxiety, I was unable to look at people trying to communicate with me and I defiantly was not going to talk to anyone.

At the age of 9 I was completely Bald and Beautiful again. No hair on legs arms eyes face nothing at all. I always had red eyes from dust, ear infections and scared terribly from mozzie bites.

Mum was aware stress and anxiety were the triggers to my hair loss, she then focused on me as a person and the healing process began.

Mum enrolled me in; Swimming for health and fitness, Netball for team sports, Dancing for personal development, piano for relaxation. I also see a Kinesiologist once a month to help me with my healing from the inside.

Now at the age of 11, I'm still bald and its Ok. I've tried a few different wigs but all seem very uncomfortable especially living in Yeppoon Qld, hot and humid. I now have a fantastic hat collection and I can wear a bandana to school, swim cap to swim in and a bandana on the netball court.

One day my goal is to remove my hats and my bandana's and find true acceptance with my condition. One day I will walk proud Bald and Beautiful in public and I will accept my condition.

I know I'm not ready, my whole family supports me and loves me just the way I am. They all understand I need to process this journey my own way in my own time.

I now talk in public, I enjoy my very busy life style that my mum has created for me, I have wonderful friends, my life is good.

It's OK not to have hair, it would be so much easier if I did but life sometime gives you challenges, it how you embrace those challenges that matter, my true beauty comes from the inside and the people that truly matter to me understand that.

Thankyou for taking the time to read my story.



The following is an excerpt from Rod Sinclair's presentation at the Australasian College of Dermatologists 49th Annual Scientific Meeting 2016. Alopecia symposium on May 17 about treatment of female pattern hair loss:

Treatment of female pattern hair loss with low dose minoxidil Presenter:
Professor R Sinclair

Summary and comment (AY): Treatment of female pattern alopecia has been challenging, with few effective options available. Combination low dose minoxidil (0.25mg daily) plus spironolactone (25mg daily) for 6–12 months has been shown to significantly improve hair growth, reduce shedding and improve hair density. Treatment was well tolerated with only a small proportion of patients having side effects severe enough to discontinue treatment. Average reduction in blood pressure was 5 mmHg for both systolic and diastolic blood pressure. Low dose minoxidil may be used in telogen effluvium and its use is being explored for other forms of non-scarring alopecia. Further research is examining its use in combination with other antiandrogens e.g. cyproterone acetate, flutamide, and bicalutamide.

Update on JAK Inhibitors

More and more studies are being carried out on the JAK Inhibitors. We are currently seeing news released each month. Optimistic results are being seen with both drugs ruxolitinib and tofacitinib. With current results (in small patient testing groups) it has been found to restore hair growth in 75% of patients with Alopecia Areata, the researchers are now targeting specific categories to the different JAK Inhibitors.

Dr. Angela Christiano, a co-author of the recently published study, has had success with Xeljanz (tofacitinib) when she made it into an ointment and rubbed it on the skin of mice with skin engineered to be like the skin of bald men. Bald mice regrew hair on their right sides but not on their left after being treated with an experimental cream for hair loss. The ointment was rubbed on the right side of the mice and not on the left, and the results are plain to see.

Although she thinks men might have the same success with an ointment, the trick is that it has to penetrate properly. Compared with the paper-thin skin of mice, human skin is "much thicker, and it's oily, and it's deep, and it's got a fat layer -- so there's a lot to think about when making a good topical formula," said Christiano, professor of dermatology and professor of genetics and development at Columbia University.

See <http://www.aaaf.org.au/research/aus-medical-research/> for more information



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Custom Hair Pieces and Wig Repairs

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DID YOU KNOW?

Alopecia Areata is most commonly diagnosed by a dermatologist. The Australasian College of Dermatologists (ACD) has launched the 'A to Z of Skin', the country's first online, comprehensive directory of skin conditions, created and peer-reviewed by more than 100 Australian dermatologists. You can read about Alopecia Areata here.

AAAF is the proud sponsor of the two best posters at the 2017 Australasian College of Dermatologists 50th Annual Scientific Meeting (ASM) held from Saturday 6 May to Tuesday 9 May 2017 at the International Convention Centre Sydney. An AAAF representative will present cash prizes to the two winners. AAAF will be acknowledged by the President of the College and have signage throughout the conference.

We believe this is a way to promote awareness about Alopecia Areata and AAAF amongst dermatologists so they can better support our community.



Each year AAAF acknowledges individuals providing services and support in alignment with our service philosophy.



AAAF Supporter Award Nominations for 2016:

Chloe Elbe – (WA) Chloe raised \$3150 by doing a BBQ fundraiser . She just turned 13 and said she wanted to fundraise to try and help people with alopecia and let those with the condition know they aren't alone. Chloe knows two children with Alopecia and is hoping that we can find a cure. She knows kids get bullied for having alopecia and has been bullied herself.

Emma Butler - (VIC) Runs the AAAF Instagram account - has considerably grown our followers on that platform, kept our account active over the past year, as well as assisting us in running the Meme Competition earlier this year.

Nathan Ash - (VIC) provides ongoing technical assistance behind the scenes, running and updating the AAAF website.

Patricia Lamb - (SA) from Natricia Health. Patricia has run a couple of Health & Wellbeing sessions & donated prizes through her studio.

Annie Woolnough - (SA) from Utopia of London Hair who ran a fundraiser for a young girl to buy a wig. She also arranged for it to be made and promoted the AAAF in the community while fundraising.

Aimee Thomas - (WA) organized several events throughout this year (and last) to raise funds and provide supportive social gathering for our AAAF community in Perth.

Debbie Labe- (QLD) from The Beauty Spot in Burleigh Waters is offering free eyebrow tattoos to anyone with alopecia.

Congratulations to this year's winner:

Erin Tutty - (VIC) who provides regular weekly assistance responding to our hair donations with hand written and email certificates. We receive approximately 100 hair donations a month.

*Thank
you*

Update On GST Removal From Wigs

AAAF is leading a campaign for medical exemptions to GST on wigs. Below is the latest update. If you believe in fair taxation, please sign our petition here:

<https://www.change.org/p/the-hon-sussan-ley-remove-gst-from-medical-wigs>



TREASURER



Ref: MC16-015321

The Hon Julie Bishop MP
Minister for Foreign Affairs
Member for Curtin
PO Box 2010
SUBIACO WA 6904

Dear Minister

A handwritten signature in black ink, appearing to read 'Julie'.

Thank you for your personal representations of 27 July 2016 on behalf of Mr Greg O'Rourke concerning the goods and services tax (GST) treatment of wigs for alopecia patients. I sincerely apologise for the delay in responding to you.

Further to my letter of 7 March 2016 (dated 7 March 2015), following your previous personal representations of 18 November 2015, the GST has applied broadly to goods and services since its introduction, levied at a single uniform rate of 10 per cent. There are a very limited number of exemptions in areas such as basic food, education and certain medical goods and services. As Mr O'Rourke is aware, people suffering from alopecia areata are not able to access GST-free wigs. Only a limited number of medical aids and appliances that fit specific criteria are GST-free and there have been no additions to the list in recent times.

In deciding whether a type of product should be added to the list in Schedule 3 and the Regulations, consideration is given to the question of whether it fits within those categories and whether the public benefit the product provides is sufficient to merit special treatment. Consideration also needs to be given to whether a GST concession is the best and most efficient way of providing assistance.

As I noted in my previous letter, a change to the GST would only be considered if put forward by the states and territories. Changing the GST treatment of wigs for alopecia patients would amount to a change to the GST base. The GST is levied by the Australian Government on behalf of the states and territories. All of the money raised by the GST is provided to the states and territories, net of the costs incurred by the Australian Taxation Office in administering the GST. Under the *Intergovernmental Agreement on Federal Financial Relations*, any change to the rate or 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.

I trust this information will be of assistance to Mr O'Rourke.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Scott Morrison'.

The Hon Scott Morrison MP
12 110/2016

Parliament House Canberra ACT 2600 Australia
Telephone: 61 2 6277 7340 | Facsimile: 61 2 6273 3420



What's On

Alopecia Awareness Week 13/11/16 to 20/11/16

Sunday 13th November 2016

Melbourne Zoo Family Fun Day - Spread awareness about alopecia while having fun and using bald heads as canvases for beautiful animal inspired artwork.

Event Info: <http://www.aaaf.org.au/event/melbourne-zoo-family-fun-day/>

Australia-wide AAAF and Beautiful Hair Boutique Wigs for Kids Competition – is giving away one human hair wig worth \$2000! This competition is available for anyone under the age of 18, who has alopecia, and lives in Australia. The winner will be drawn at the Melbourne Zoo Family Fun Day.

Wednesday 16th November 2016

Australia-wide Boldest Bald Tea – Host your own event with friends, family or colleagues to raise funds to help people living with Alopecia Areata and their families.

Event info: <http://www.aaaf.org.au/event/boldest-bald-tea-hold-your-own-morning-tea/>

Friday 18th November 2016

Australia-wide Crazy Hair Day – Awareness, information and a day of fun activities held by primary and secondary schools across Australia, with the aim to support children living with Alopecia Areata and combat bullying.

Event info: <http://www.aaaf.org.au/event/australia-wide-crazy-hair-day/>

Sunday 20th November 2016

Brisbane Bald Canvas – a free, family-friendly gathering, featuring henna tattooing and face painting to create beautiful works of art on the heads of people with Alopecia Areata.

Event Info: <http://www.aaaf.org.au/event/qld-bald-canvas-event/>

Perth Boldest Bald Brunch – High tea style event to raise funds and awareness for AAAF

Event Info: <http://www.aaaf.org.au/event/perth-wa-boldest-bald-brunch/>

Sydney Morning Tea by the Sea – A casual and friendly gathering, a place to chat and meet AAAF's new NSW Branch Manager, Sarah.

Event Info: <http://www.aaaf.org.au/event/sydney-alopecia-awareness-week-open-day/>



13th and 21st of August 2017

Kokoda Trek to raise funds and awareness for Alopecia Areata!

We're looking for passionate and intrepid individuals to join our team as they rise to this challenge and raise awareness of Alopecia Areata. If this sounds like you, send an email to greg@aaaf.org.au for more information.



Love, Alopecia



During Alopecia Awareness Week, we'd like to introduce you to AAAF newest project, Love, Alopecia!

www.lovealopecia.wordpress.com

Love, Alopecia is our brand new blog, written by Alopecians, for Alopecians.

If you've ever wondered where you can find information, ideas, opinions and stories about the many ways Alopecia Areata affects our lives, this is the place for you. Our first article is up and waiting for you. Written by AAAF's wonderful Support Ambassador Stef, this article is the emotional journey of the day she told her entire year level at school she had alopecia.

If you've ever had a story, rant or opinion about alopecia you just couldn't keep to yourself – this is the place for you as well! We're looking for Guest Writers to feature on the blog. Get in touch with us by emailing lovealopecia@gmail.com if you're interested in sharing your stories with our community.

SOCIAL MEDIA LINKS

AAAF

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Go Fundraise

My Cause

Shopnate

Kids Korner

Would you like a scarf made from an original artwork that you designed yourself?

With our friends at Coming Up Rosies, AAAF are giving you the chance to submit a design and have a scarf made and named after you.

Be one of the first 10 to send your design to us and you could be wearing your scarf in no time.

Send your picture to AAAF
PO Box 5029
FRANKSTON SOUTH VIC 3199
AUSTRALIA



Pictures must be received by 31.12.16

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