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8 THINGS THAT EVERYONE WITH

ALOPECIA AREATA WILL HEAR

IT'S JUST HAIR**YOU CAN JUST
WEAR A WIG****AT LEAST IT'S NOT...****EVERYTHING HAPPENS
FOR A REASON****HAVE YOU
TRIED...****YOU'RE SO BRAVE****AT LEAST YOU DON'T
HAVE TO ...****WHY ARE YOU STRESSED?**

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PRESIDENT'S WELCOME

#HealthyAlopecia is our 2018 theme and in this newsletter you will get a insight into how our community is embracing a range of health and wellbeing areas, including positive mindsets, mental health, physical excise, appearance control, empowerment, diet, healthy social connectedness all to support a healthier you.

For those interested in the JAK Inhibitors, I encourage you to read the Research section as I have attempted to answer the many questions received into AAAF on this topic.

Daily I receive between 5 – 10 inquiries asking me to explain why is there a different understanding of what Alopecia Areata is? Why do some people recover without treatment? Why do others progress to totalis or universalis? Why do Dermatologists offer different treatments? Does the presentation of the first patch play a part on progression of hair loss? Why do some people progress to Universalis? Can I recover without treatment?

These questions were discussed at the 10th World Congress for Hair and Wool Research Society in November 2017, resulting with acknowledgement that a consensus statement should be developed on the systemic treatment of Alopecia Areata. This is a huge step forward for Alopecia Areata, finally we can all be singing from the same page.

This consensus statement, when finalised, will be used nationally with Dermatologists to explain and treat based on learned historical and current data. The historical data dates back to 1965, where a study of 1989 patients were followed for 15 years, noting the % of patients that presented with a single patch and achieved complete remission within 6 months, noting those who developed additional patches, but still had complete remission within 12 months, to those that progressed to totalis or universalis. This historical data has then been compared with more recent data with surprisingly similar % observations. Markers such as age of the patient and positioning of the first patch also played a part in the progression of AA. Overall, this has provided valuable and consistent information that can be used to form the consensus statement.

So it would be wrong of me to keep you hanging on what those % are! The good new is that for those who present with a single patch 40% had spontaneous remission without any treatment within 6 months., and at the other end of the scale only 15% of patients progress to universalis without treatment. The report is due out later this year.

MEET OUR COMMITTEE

Introducing our Support Ambassador
Bianca



Alopecia was an unknown condition to me until it touched my life around 10 years ago now. I first noticed very small patches of hair falling out after suffering with viral meningitis. I was 32 years old. I was fortunate to be able to hide it, and my hair grew back within a year and my life went on as normal.

It wasn't until around 2 years ago that I noticed my hair falling out again. At first it was a small patch and it was easy to hide. But it started to recede along my hairline and was worsening by the day. I hadn't told anyone and was terrified to say the least. It brought up many different emotions and fears. In the space of a few months my whole world had started to turn around. I withdrew and became terribly sad and frightened. It was extremely challenging and even though I have been through a lot in my life, this was very different.

Having lived a very colourful life and experienced a great deal, this was something that rocked me to the core like nothing else. Although I was at my lowest, I knew I wasn't going to shrink and hide away and become controlled by how I looked. So I decided to shave my head and take some power back around it. I didn't want to mourn the hair as it slowly worsened nor did I want to be paralysed by it.

It was a spring evening in September 2016 and I was surrounded by a few of my family and closest friends and I decided to shave my head. Although it was the most terrifying decision, it was also the most liberating and empowering experience to date.

I spent the next year delving deeply into my self worth and confidence. I worked incredibly hard to change my mindset, to adapt to the changes that were now me. I learnt to accept and love who I was with no hair. It was one of the hardest, yet most rewarding, years of my life and I'm extremely proud to say I stand here in awe of the journey, in love with who I am and who I am not and happy to have experienced it all.

I did occasionally wear wigs throughout the journey and still do some days. I found they were fun and a safe place in times that I just didn't want to be stared at or when I wanted to blend in. I still have 2 wigs that I wear and it's really wonderful to have the choice. But mostly I bald it up because I am incredibly proud of my journey and of who I am.

I am incredibly proud to work with the Alopecia Foundation as a Support Ambassador as it has allowed me to empower others living with Alopecia. It has also given me the ability to bring this to my work, mentoring young people and building strong foundations in self love and acceptance enabling them to have bright futures. I wouldn't change a second of it!!

Bianca.

HEALTHY ALOPECIA STORY

by Serina

The dancer in me she moves with no feet
Her heart it leaps in time with the beat
Of a drum that thumps
Or a cymbal that can tinkle
Her mind simply drifts
Like the golden suns tips

The dancer in me she moves with no fear
Her soul is free her thoughts are clear
Like a flute that whistles
Or a tune that can tickle
The dancer inside me is angle dust sprinkled

The dancer in me moves with the music
Her arms sway in rhythm she is one within it
Like a piano that whispers a beautiful song
In the notes are her life and she dances along

The dancer in me pairs with another
Together in unison sister and brother
Like a sweet guitar that strums so softly
Her limbs start to fly exactly as it should be

The dancer in me she is the dancer in you
Tis something so simple as
Step one and step two
Our bodies guide us where we must go
A current upon the ocean we float and flow
The dancer has wisdom in the spirit it lies
Allowing us the freedom to melt with the sky

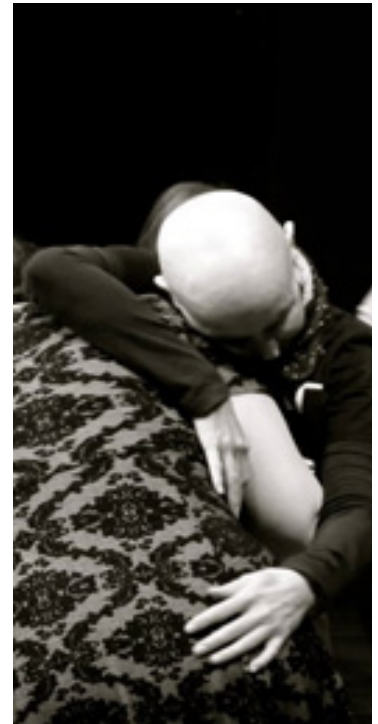
The Dancer in me forever will dance
Nothing will stop her
There simply isn't a chance.

My poem is written about my love of dance and how dance frees my body mind and spirit. When I dance I do not care that I have permanent hair loss. My spirit is free. Dancing and music enrich my life and give me confidence to face anyone and anything.

I write, sing, dance and swim and these activities help me cope with the woman I see each morning who has been bald now for over fifteen years.

This poem was submitted as part of our #HealthyAlopecia Blog Competition which is running throughout 2018. One winner every month will be drawn to receive \$2000 towards improving your journey with alopecia or creating a healthier you. You can find out more about this competition at

Love Alopecia - [click here.](#)





RESEARCH UPDATE



Physical Activity Study

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

Physical activity, like sport and exercise, is related to better outcomes in quality of life and mental health. Previous studies have found that patients with Alopecia Areata have much lower participation in physical activity than experts recommend.

This study aims to understand how physical activity impacts on your quality of life and mental health. Ultimately, we intend to create strategies to improve the lives and mental health of people living with Alopecia Areata.

This survey should take around 25 minutes. It covers questions your socio-demographic data, physical activity participation, your state of mental health and about how much Alopecia Areata has affected your quality of life.

By participating in this survey, you are not only helping AAAF to improve our strategies, you also help future researchers looking to support people living with Alopecia Areata.

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

Treatment of Alopecia Areata with topical JAK inhibitors findings from 2015 study available.

AAAF provided funding for a 28 week study in patients with Alopecia Areata comparing 2 different topical JAK Inhibitors, placebo, and a topical corticosteroid. 16 patients took part in the trial. Six patients demonstrated partial hair regrowth in areas treated with 2% tofacitinib ointment applied twice daily. Five patients demonstrated partial hair regrowth in the areas treated with 1% Ruxolitinib ointment while ten patients demonstrated partial hair regrowth in the areas treated with clobetasol dipropionate 0.05% ointment (the corticosteroid). No regrowth was observed in the placebo treated area.

The encouraging results are that the topical JAK Inhibitors showed no side-effects or damage to the skin where the treatment was applied. Many corticosteroid treatments do have side-effects and can cause dermal atrophy.

In two cases, individuals also experienced generalised hair regrowth across the scalp and eyebrows outside of the patches being tested with the topical treatment. This may have positive indications for the systemic benefits of topical JAK Inhibitors.

The findings of this research suggest that topical JAK inhibitors could be developed as a new treatment for AA and alternative to corticosteroids. The findings of this trial were presented to pharmaceutical companies in 2016 with Aclaris Therapeutics Inc. investing in further investigational research.

For more details on participation in the Aclaris trial: [Click here.](#)

AAAF SPONSORS TWO YEAR INVESTIGATIONAL RESEARCH INTO THE EFFICACY OF CYCLOSPORIN A AND TOFACITINIB IN THE TREATMENT OF ALOPECIA AREATA.

Why?

There has never been a treatment for Alopecia Areata funded on the Pharmaceutical Benefits Scheme (PBS). AAAF are supporting researchers to gather more data and assist future applications for government support.

Cyclosporin is an immunosuppressant medication and natural product. It is approved by the FDA to treat and prevent a number of organ and skin diseases. It is currently funded on the Pharmaceutical Benefits Scheme (PBS).

Various studies have been done on Cyclosporin as a treatment of Alopecia Areata since 1990. It is known to inhibit the activation of the helper T cells. However, the side effects and high recurrence rates after discontinuation limit its use as a treatment of Alopecia Areata.

Current research into the effectiveness of Tofacitinib on Alopecia Areata is yielding positive results, with current findings seeing a reduction in side effects and low reoccurrence rates after discontinuation.

This study looks at comparing the effectiveness of Cyclosporin to Tofacitinib in the systemic treatment of Alopecia Areata. This data will qualify the difference between the treatment options. Having this data published enables the Government to reference this study in their assessment of application to the PBS.

A further requirement for PBS submission is the impact of Alopecia Areata on quality of life. AAAF will be gathering metrics through online surveys, discussion forums and personal interviews. This data will also provide a reference for any future assessment for government support.

Government support through the PBS can help make drug treatments affordable to a wider range of individuals. However, they need the research data to make this possible. AAAF is proud to support further research and enable future opportunities.

AAAF will be recruiting for this opportunity for those living in Victoria in June 2018.

Below is the first of our quality of life surveys that we encourage you to participate in answering.

The physical activity and mental health research survey. - [Click here to participate.](#)



DID YOU KNOW: JAK INHIBITORS



Janus Kinase Inhibitors,

also called JAK Inhibitors or Jakinhibs, were originally formulated for the treatment of blood cancers.

JAK Inhibitors were later modified for treatment of Rheumatoid Arthritis, an inflammatory autoimmune condition which effects the joints.



Researchers have found a genetic link between Rheumatoid Arthritis and Alopecia Areata. Both are inflammatory auto-immune conditions.

The JAK Inhibitor formula was then further modified to be tested as a possible treatment option for Alopecia Areata.



JAK Inhibitors are currently under trial.

Clinical trials work to gain data on the safety and efficacy of new treatment options. As the trials progress, the treatment options are refined as researchers gather more data.

Why do the costs and conditions for participation in different trials vary?

Sponsored trials are supported by pharmaceutical companies or other organisations, and generally have strict set conditions for trial participants.

Unsponsored trials are open to a wider range of participants, and gather data outside of the sponsored conditions. These are at the participants own cost.

The data collected in both trials is the same and is used by researchers to better understand the treatment option.



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Losing your hair can be an emotional and financial roller coaster. At LC Wigs we offer you a full service and quality European wigs to make this challenge as painless as possible. Being a hairdresser and a wig wearer herself, LC knows the ins and outs of wig wearing.

We provide top quality wigs, with comfortable caps, that feel like they are barely there. We provide you with wigs that are just as good (and sometimes even better) than our real hair.

Our beautiful human hair wigs are sleeky, smooth, soft to touch and most importantly look like your natural hair. They can be styled, coloured and worn just like human hair. At LC Wigs, we pride ourselves with providing you quality products at a fraction of the cost. It's real. No joke. No hidden costs.

The consultation is free, and stock is always on hand. Love yourself and your look again. Contact LC Wigs and see how simple, fun and cost effective getting back your hair is.

LC Wigs

Contact Liron Murd: 0490 179 795

Facebook: [Click here](#)

Instagram: [Click here](#)

gmail: [Click here to send an email](#)

Location: East St Kilda



WHAT'S NEW?

AAAF is delighted to announce two new members to our Committee.

Cam has the role of support Ambassador - [Click here for more information.](#)

Jessica as the Tasmania Branch Manager. [Click here for more information.](#)

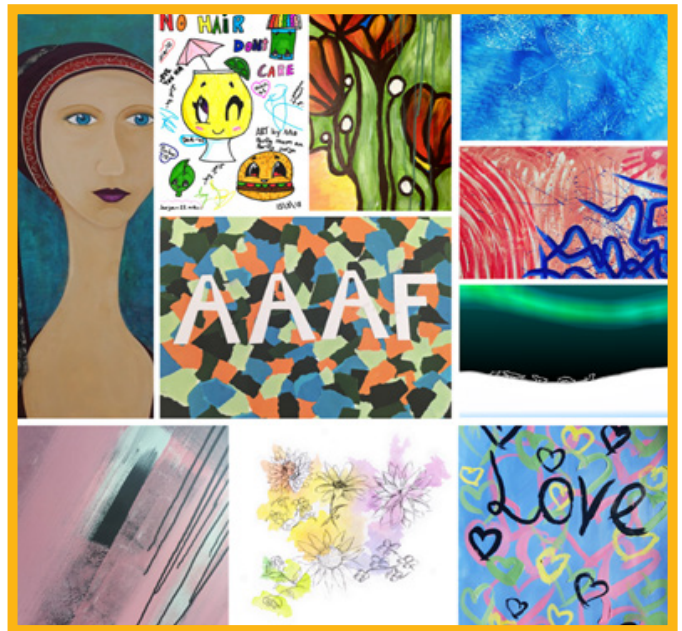
Scarf Art Project and Coming Up Rosies

Our Scarf Art Project for 2018 has been a huge success. We loved seeing so many beautiful designs sent in by members of our community to be made into gorgeous scarves. Thanks to all who submitted their artworks and designs.

AAAF are very proud to have worked with Coming Up Rosies to create beautiful scarves made by artwork by Australian kids, and now to have expanded this program to even more from our community.

Our current scarves are available on the AAAF eStore and the new designs are on the way! We will have them available shortly. Keep an eye on our Facebook for when the beautiful new designs arrive.

[Click here to order.](#)



DID YOU KNOW?



This stretch Stretches the **hips**, **hamstrings**, and **calves**, Strengthens the **thighs** and **knees**, Keeps your **spine** strong and flexible, Reduces **stress**, **anxiety**, **depression**, and **fatigue**, Calms the **mind** and soothes the **nerves**, Relieves **tension** in the **spine**, **neck**, and **back** and Activates the **abdominal muscles**.

WHAT'S ON?

May 20th – QLD Gold Coast Dinner

Join us for a casual dinner while our team are in town for the Australasian College of Dermatologists Annual Conference.

June 17th – SA Winery Tour

A relaxing afternoon exploring some of the amazing wine regions around Adelaide and chatting with other people living with alopecia near you.

August 3rd - WA AloPizza Night

Get the family together for a casual dinner with the team in Perth. These are always a highlight of our calendar, and a great chance to catch up with other kids and families in the support group.

International Alopecia Day – August 4th

VIC Annual Trivia Night

A fun night of games and trivia to share with family and friends, with amazing prizes and a silent auction. No need for a baby-sitter, as we have a separate games room with activities for kids (under 18 free to attend!)

SA Adelaide Alopizza Dinner

Our Support Group in Adelaide are excited to continue their tradition of hosting a fun and friendly dinner to celebrate International Alopecia Day. Bring family and friends - all are welcome to join!

QLD Family Picnic

Our lucky Support Group in Brisbane is still able to enjoy the sunshine in the park in August. Come along and join them for a family picnic and celebrate International Alopecia Day.



WHAT'S ON? - Continued

November 10th-18th – Alopecia Areata Awareness Week

Alopecia Areata Adventure Camp – November 10th and 11th

See Kids Korner for more

Boldest Bald Brunch

Usually held on the Wednesday of Awareness Week, the Boldest Brunch is a chance for workplaces to get involved in raising awareness of alopecia and supporting AAAF. Invite your co-workers to share a brunch and raise funds for a great cause or see if there is an official Brunch being run by AAAF near you.

Crazy Hair Day

Usually held on the Friday of Awareness Week, Crazy Hair Day is a chance to get your school or community group involved in raising awareness of alopecia and funds for AAAF. Find out how you can be involved [here](#).

November 17th - QLD Open Day

Open Days are some of the biggest events in our calendar. We'll be bringing displays and exhibitors from wig providers, cosmetic tattoo artists, health industry professionals and much more. There will be fun for the kids and a tonne of information for anyone wanting to know more about alopecia.

New events are will be organised and announced throughout the year. Stay informed via our online support groups or events page on our website.

Find out more about our support groups [here](#).

Find out more about our events [here](#).



SOCIAL MEDIA

8 THINGS THAT EVERYONE WITH ALOPECIA AREATA WILL HEAR (AND WHAT YOU CAN SAY INSTEAD)

IT'S JUST HAIR

While it's true that people with Alopecia Areata are physically healthy, the emotional impact is significant.

Try Instead



ARE YOU OKAY?

Check in with you loved ones who are living with Alopecia. Show that you are there for them, and support them with what they're going through.

AT LEAST IT'S NOT...

Alopecia Areata may look similar to hair loss caused by cancer treatment, but they are very different. To have them compared can be distressing, and can feel like being told to be grateful for the condition you do have.

Try Instead



HOW HAVE YOU BEEN?

If you have been worried about a friend's health, it can be a relief to hear that Alopecia Areata is not life threatening. However, remember that it is life changing, and your friend may need support.

WHY ARE YOU STRESSED?

It is a common misconception that Alopecia Areata is caused by stress. This is not true, and can feel like being blamed for causing your own condition.

Try Instead



THAT MUST BE STRESSFUL.

Showing empathy and, where possible, offering emotional support is the best way to help someone managing Alopecia Areata.

AT LEAST YOU DON'T HAVE TO ...

It's normal to try to cheer someone up by looking for a bright side, but many people with alopecia still have to do things like shave and visit a hairdresser.

Try Instead



HOW HAS YOUR LIFE CHANGED?

Let them share what they find positive about their experiences. If they feel like there is no bright side, encourage them to get in touch with an Alopecia Support Group.

HAVE YOU TRIED...

You may have heard of someone who was able to treat their alopecia with a new treatment, diet, or lifestyle change and want to share this to help. We recommend that you don't suggest treatments unless you are asked.

Try Instead



HAVE YOU FOUND THE RESOURCES YOU NEED?

People with alopecia are usually very well informed of their treatment options. If you are concerned, ask if they have been able to find the information they need. If not, let them know about the AAAP.

EVERYTHING HAPPENS FOR A REASON

While some people believe in this idea, and find it very comforting, others may not. Alopecia Areata can often feel very random and out of control, and this statement can feel distressing, even when meant out of love.

Try Instead



I BELIEVE IN YOU

Make sure they know that you are there for them and support them in whatever they do. The AAAP is also available if they need extra assistance.

YOU CAN JUST WEAR A WIG

Many people with alopecia wear very beautiful wigs. But for others, this isn't what works for them.

Try Instead



YOU LOOK AMAZING

Whether someone chooses to wear a wig or not is a very personal decision. Make sure they know that you love the way they look regardless.

YOU'RE SO BRAVE

While meant with love, this can be hurtful if said during a normal, everyday activity. It isn't brave to go to the shops with alopecia -- it's just living!

Try Instead



I REALLY ADMIRE YOU

Focus on why you care for an individual outside of alopecia, and on the amazing things about them that have nothing to do with their hair.

SOCIAL MEDIA LINKS

AAAF
Linkedin
Facebook

Instagram
You Tube
Go Fundraise

My Cause
Shopnate
Love Alopecia

W.A. SUPPORT GROUP BOYS CAMP RECAP

In March 2018, AAAF ran our first event for boys with Alopecia Areata – a weekend camp in W.A. Hosted by Greg O'Rourke, the WA AAAF Branch Manager, at his holiday home in Eagle Bay, three hours south of Perth, the camp was attended by six boys aged nine to fourteen.

Some of their parents also attended, along with other members of the AAAF team – Support Ambassadors James Miller and Cam O'Rourke, and Carlo Napolitano. Carlo and James flew in from Sydney on the Friday evening especially for this camp.

The emphasis was on having fun – be it at the high rope course, playing touch rugby and swimming at the beach, making pizza or playing pool or board games, and just hanging with other boys who were going through the same thing.

This was also the first event featuring our newest Support Ambassador, Cam.

Cam officially joined the AAAF team in 2018, but he has been involved with us for some time, as his father Greg is our WA Branch Manager. Cam developed alopecia at the age of ten, and strongly believes that the amount of hair on someone's head shouldn't define them as a person. He was a great hit at this camp, and is happy to be contacted by anyone looking for support.



Kids Korner



AAAdventure camp

AAAF is now accepting expressions of interest for the Alopecia Areata Adventure Camp 2018.

This weekend of adventure will be hosted at The Summit Outdoor Adventure Park, Trafalgar East, Victoria, and is free for kids with Alopecia Areata. This includes flights, meals, accommodation and activities.

Attendance at the camp is on Saturday the 10th and Sunday the 11th of November, during Alopecia Areata Awareness Week.

Attendees can be from anywhere in Australia and aged under 18. A deposit must be made to secure a place at the camp, but this is fully refundable. Parents are able to join their child at the camp, but must pay their own way.

The Alopecia Areata Adventure Camp will be a fantastic opportunity for kids living with Alopecia to make friends, learn about the condition and – most importantly – have a very fun time.

To register your interest to receive an information pack, email info@aaaf.org.au. You **MUST** include the following details:

Child's full name, age, gender, state, parent/guardians name, contact number and email address. Be sure to note if a parent/guardian wishes to accompany the child.

Expressions of Interest will close on June 30th.

Information packs will be sent out by July 15th.

Kids Korner

"MY MUM" - NEW BOOK RESOURCE FOR FAMILIES LIVING WITH ALOPECIA AREATA

A brand new book has hit the shelves in the AAAF e-Store. "My Mum" is a super cute kids book about a little boy whose mum has Alopecia Areata.

This wonderful resource was produced by our friends at Alopecia UK. We thank AUK for their generous support in us get this book available for families here in Australia!

A great pick for any families living with alopecia! Find it at:
Our Webstore - [Click here to order.](#)



QUEENSLAND SUPPORT GROUP EMPOWERMENT WORKSHOPS FOR TEENS

AAAF is partnering with Urban Heart to provide 10 girls with alopecia, age 13-17, to take part in a series of empowerment workshops in Brisbane. Participants will develop resilience skills and self confidence, and meet other girls living with Alopecia – including the workshop facilitator Support Ambassador Bianca.

We ask for a deposit of \$60 to secure your place at these workshops. AAAF will be covering the remainder of the costs to participate (normal costs are \$160).

- Sessions are hosted on Saturday afternoons from 1pm-4pm, from the 11th August till the 15th September 2018.
- Workshops will be run at the Santosha Yoga Space 180a Latrobe Terrace, Paddington, Brisbane, QLD, 4064.

Find out more about the workshop provider [here.](#)

To express your interest in this program, email bianca@aaaf.org.au