



Australia Alopecia Areata Foundation Inc.

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Alopecia
Areata
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Universalis

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research awareness information support embrace

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Photographer: Sharalyn Robertson

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PRESIDENT'S WELCOME

This year has been both challenging and productive and has engaged the alopecia community in a range of new and diverse activities. Looking back, it has been a very busy year which involved a core of supportive and committed committee members working together, determined to maintain and grow our Alopecia community.

Communication was predominantly done via social media, where the engagement has been very strong, and the theme of Embrace Alopecia having some people quite vocal in their opinions on what "embrace" meant to them. What this produced however, was very healthy conversations, expressions, coping techniques and overwhelming support for those progressing their journey with Alopecia Areata.

For those who have missed how others #EmbraceAlopecia you can find the short videos here:

<https://www.youtube.com/watch?v=Y4xvsrbIfGw>
https://www.youtube.com/watch?v=au_qbadZbPg
<https://www.youtube.com/watch?v=8kDrwyegqj0>

A very warm welcome to returning and new committee members, without dedicated volunteers, AAAF would not be able to bring so many activities, programmes and events. Bianca has joined in the role of Support Ambassador, living in Queensland. Carlo in the role of general committee and residing in New South Wales and Vesna returning from a very short break lives in Victoria. It has been very noticeable this year and it is heartening to see so many of our members volunteering so much of their time and energy providing support and being leaders to champion the awareness into Alopecia Areata.

Support is also increasing externally with 63 individual fundraising activities championing awareness of Alopecia Areata within their family and friends.

For AAAF 2017, was to champion awareness and understanding of alopecia, promote acceptance of appearance diversity and provide support to help individuals find self-confidence and happiness on their journey with this condition. The increase in participation within AAAF indicates that we are on the right path. So as we say a goodbye to #EmbraceAlopecia for 2017, and being mindful not to lose any momentum on our objectives, the theme for 2018 will be #HealthyAlopecia. This campaign will focus on a broad range of health and wellbeing areas, including positive mindsets, mental health, physical exercise, appearance control, empowerment, diet, nutrition, healthy social connectedness and skills to support a healthier you. #HealthyAlopecia.



MEET OUR COMMITTEE

Introducing our General Committee Member Carlo Napolitano

Carlo Napolitano is the newest committee member to join the AAAF team. The former Head Coach of the Italian National Rugby team has had Alopecia Areata almost all of his life and attributes many of his personal successes to his experiences growing up with AA.

“Although it was tough growing up, I never used my Alopecia as an excuse to not achieve. I failed many times but I used the failures as a lesson on how not to do things. With or without hair we are all capable of success. Negative energy creates nothing, positive energy creates champions. Be a Champion!!”

My alopecia triggered when I was around 4/5 years of age. I don't really remember too much from the time. I do remember that my parents constantly fussing around me and I was whisked off to various doctors and countries to try and find more answers and a cure. I've always been a pretty laid-back character and not much really bothers me. I do remember that during this time my Grandfather passed away and I have always attributed my alopecia trigger to this moment. Either by the loss of my Grandfather or the pain the family was going through at the time. Alopecia took a hold quite quickly and within weeks I was completely bald.

It was quite tough growing up. I was born in Salford, UK (next to Manchester), and Salford is a working-class city with a high crime rate. So on the streets you had to think quick and be ready to defend yourself at all times. I wore a hat till I was 21 so I constantly got bullied by older kids who would take my hat off and throw it away. Or the chants of “baldy, you're not going to live long” would be frequent. I discovered that humour was the best way to overcome these types of people and always tried to light up a room by using my alopecia.

It was difficult going through the teenage years especially dealing with puberty, relationships and always wearing a hat! The best part was a supportive friends and family network. They gave me the confidence to do things I wanted to do and help me deal with the ups and downs of alopecia. There are a few challenges (as people with alopecia already know). The first one is the acceptance and understanding of alopecia. It affects us all differently, both physically and mentally. So the more we know about alopecia and the more we can learn to accept it. When my alopecia started to appear, there was no real knowledge of it, so it was hard to understand why this was happening to me. My parents were more worried that I; it didn't really bother me that much but I could see the pain in my parents face and that hurt the most.

The second challenge was to get rid of the cap. I wore a hat every day to hide my alopecia. This ended when I was 21 and in Ibiza, Spain. I was coming through the ranks playing professional Rugby League when we had an end of season trip away. One of the lads was my idol growing up and he took me to one side and said that I couldn't wear the hat forever and that tonight in a place where no-body knows you, to take the hat off. I did and never wore the hat ever again!! This was the most liberating day of my life as it was a weight off my shoulders.

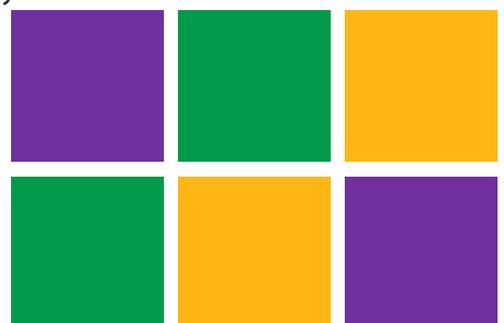
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Alopecia has taught me to accept everyone for who they are and to never let anyone say you can't do it. I love having alopecia and telling people about my journey of dealing with my life with alopecia. I now know that if people treat me differently because of alopecia, then they're not worth knowing anyway. I don't think I would have done the things I've done if it wasn't for alopecia. It has taught me to be resilient, respectful and driven to achieve success. It has also taught me not to judge anyone, on the way they look, until I speak to them and make my own judgement. Alopecia has had a positive impact on my life and work on this craft every day. I don't see alopecia as a negative, as I'm in control of what I do or say and I make sure I'm not seen as a victim of a condition that I have no control of. I have alopecia and I'm proud of who I am.

I think most of my memories of having alopecia are really good. I had alopecia so young that I never was really used to having hair. I think in all the successful things I have done and when I have completed some media interviews that I am promoting that having alopecia is OK, you can still achieve your dreams with or without hair. These days I love to promote and educate people on alopecia – especially young children on importance of having a focus and good family / friends network. My door is always open and I'm always available for a chat. Really honoured to have been a part of the Alopecia UK Charity and now to be a committee member of the AAAF. Some good things in the pipeline!!!

Watch this space!



Davina's Story



NO HAIR...DON'T CARE!

So the other day I had a professional photo shoot done. The first I have had done since having alopecia. I have a very dear friend who came & had coffee with me about 5-6mths ago and we had a conversation about hiding. He pointed out how I was still hiding in areas of my life and asked me to consider what it would look like if I made a decision not to hide anymore. Little did I know how powerful that question would turn out to be.

It made me reflect on my journey with Alopecia over the past 10yrs. When I was younger I always had long blonde beautiful hair then after the birth of my daughter I started to notice I was losing it. A little at first, then a lot. Until one day on a Saturday morning in 2010 I was washing my hair and it was coming out in clumps and I was crying in the shower. I decided then and there to shave it for the first time. I thought if I'm going to go bald I'm going to do it on my terms. I remember crying more before I shaved my head (because of the thought of it and the fear around it) than I did after shaving it.

It's funny that it is totally normal & acceptable for a man to be bald in our society and yet there seems to be this mindset around women being bald. And I suppose for me and maybe other women in a similar situation, so much of our Identity seems to be wrapped up in our hair. In the following weeks and months and years it was interesting to see the responses I got from people.

I felt so many people felt the need to pigeonhole me. People who didn't know me from a bar of soap & people I knew as well. "I'm so sorry you're sick", "how long have you been having treatment for?", "what's wrong with you?", "how long have you got?" "Are you gay?" And the stares and finger pointing from children. Also some people actually in my life who whilst I know they care, didn't actually help with comments of your so beautiful, just get yourself a nice wig and wear makeup all the time and no one will be able to tell and you will feel so much better about yourself. Whilst I know that this came from a place of love and them wanting to ease my suffering, it still didn't help. "I am not my hair!"

You see all that did was help to in bed "Shame". Like I wasn't good enough or that I had to be a certain way to be loved and excepted. It was if my 'nude nut' offended some people and I could of walked around naked and felt less vulnerable. And I remember being in Sydney with another dear friend when I bought a wig and people did treat me differently. It is only years later that I realise now that they couldn't fully accept me until I accepted myself!

So much 'LIFE' has happened over the past few past few years and whilst at the time some of it was extremely traumatic at the time and I have lost & found love and some friends and relationships came and went and came, & so much more. I can finally say I really do love myself and accept myself. And I am not saying that from a place of ego. I have just been to hell and back several times (and not just because of alopecia) & I have survived. And with that comes an inner confidence and knowing that if I have faced all of these obstacles, that I can face anything and survive.

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You are perfect in Your imperfection.

You are enough. You always have been.

I used to be the person that cared too much about what others thought about me. I used to be the person that believed others were so much better than me, or they knew better than I did and I would put faith in what they said or did or believed and I didn't back myself. I can now say with rock solid confidence that no one is perfect. Perfection is an illusion and a lie we have bought in to that keeps us playing small. We all have things we are going through, we have to in order to grow & as far as I can see that doesn't stop. And that's ok because that is life. You can choose to try and out run the wave and be dumped by it or you can choose to face it with courage and dive into it.

Here is what I know:

the more you face your perceived obstacles & dive into them, the quicker you will work through them & come out on the other side. Shame and fear cause us to hide, and it's your choice whether you choose to accept that and own it, or write yourself a different ending to your life's story.

Once you stop putting the attention on people and things outside yourself and do the inner work, those same things lose control and power over you.

You can Love yourself and Accept yourself fully and still strive for more. It's all a choice!

My imperfection is beautiful

My vulnerability is beautiful

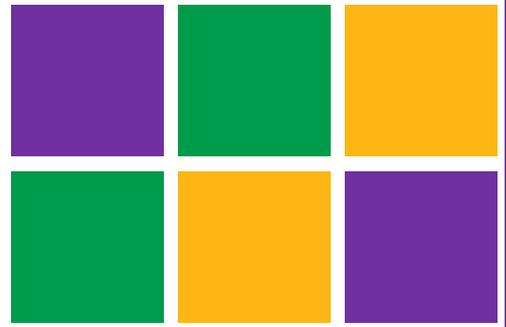
You are perfect in Your imperfection.

You are enough. You always have been.





RESEARCH UPDATE



Psychological Research

RMIT University Melbourne has jumped on board AAAF Healthy Alopecia theme for 2018 and is running a research study on the "Perceived barriers and enablers to physical activity for patients with Alopecia Areata". At AAAF many questions are received on Quality of Life, and a high percentage of these are about participating in physical activities.

Research has shown that physical activity (PA) participation has positive effects on mental health and Quality of Life (QoL) outcomes among the general population, where participants who are more active tend to report better mental health and QoL.

A qualitative study will be conducted from March 2018 – March 2019, comprising of two data collection methods (semi- structured individual interviews and focus groups) to understand perceived barriers and enablers to physical activity for patients with AA. Participation emails will be sent out by AAAF as qualitative studies are able to describe a phenomenon in some detail or with greater insights which can be subjective experiences of specific individuals (individual interviews) or a group (focus groups). The grounded theory is used as it allows researchers to have a deeper understanding of participants' perceptions and experiences on physical activities. With the identification of specific barriers and enablers to Physical Activities AAAF can then guide the development of interventions to facilitate Physical Activities to improve mental health status and QoL of AA patients.

Medical Research

In May this year, AAAF worked with 5 Australian Dermatologists around Australia, to provide the opportunity to join a clinical research study to evaluate the safety and effectiveness of two investigational medications, in tablet form, or placebo for the treatment of alopecia areata. This study received its maximum quota, with 13 Countries participating and 500 participants. The results will be known in early 2018.

DID YOU KNOW?

That there has never been a drug treatment for Alopecia Areata listed on the PBS?

AAAF are working hard towards changing that.



What's
new?

#HEALTHYALOPECIA

At our recent AGM, the AAAF team discussed the end of our #EmbraceAlopecia campaign and our theme for next year. We're very proud of the response we've had to the campaign to Embrace Alopecia, especially the individuals in our community who came forward to share their stories and personal journeys.

In 2018 we want to continue to build on the success of #EmbraceAlopecia and continue to champion for awareness and understanding of alopecia, promote acceptance of appearance diversity and provide support to help individuals find self-confidence and happiness on their journey with this condition. To help us on this path, our theme for 2018 will be Healthy Alopecia.

The Healthy Alopecia theme will structure much of the programs, events and communications executed by AAAF and is to be all inclusive audience program. This campaign will focus on a broad range of health and wellbeing areas, including positive mindsets and mental health, physical exercise and appearance control, empowerment, diet and nutrition, healthy social connectedness and skills to support these areas.

COMPETITION TIME! ENTER TO WIN

We're inviting you to take part in Healthy Alopecia too. #HealthyAlopecia

For the next 12 months, we will be running a competition over on our blog, Love, Alopecia. We'll be offering up to \$2,000 once a month towards a healthier you. All you have to do to be involved is write an article, at least 350 words in length with two images, on any topic that relates to wellness, health, or self improvement. Share your story, tell us how you are improving your body or mind, explore what wellness means to you – anything you like.

You will also need to provide a short description what Healthy Alopecia means to you and how you would use any winnings to support a healthier you. This can be up to 100 words in addition to your article

Funds won in this competition can go toward a wig to help support self-confidence, a gym membership to grow a stronger body, sessions with a mental health professional to build a resilient mind, and much more. Your entry will then go into the draw, with a chance every month to be a winner. We'll be launching this competition in December, so stay tuned for full terms and conditions and how to get involved in the campaign for #HealthyAlopecia.

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**CLIVE
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TRICHOLOGISTS
— EST NZ 1959 —

Clive Hair Clinics
Suite 414, 566 St Kilda Road
Melbourne, Victoria 3004

Phone: +61 3 9654 0022 or FREEPHONE 1800 80 42 47
Email: Melbourne@cliveclinics.com.au
Website: <http://www.cliveclinics.com.au/>
<http://www.cliveclinics.com.au/for-women/alopecia/>
<http://www.cliveclinics.com.au/for-men/alopecia/>



At Clive Hair Clinics we have noted an increase in male and female clients presenting hair loss due to Alopecia Areata. We recommend our non-drug treatments that take a holistic approach to treating each sufferer's condition individually.

Our scalp treatment therapy includes the replacement of missing Amino Acids along with scalp stimulation - over a 4-8 month period, depending on the severity of the condition.

For anyone suffering from Alopecia Areata the earlier the treatment is started the better the results. Phone Clive Hair Clinics on 1800 80 42 47 to book an Initial Consultation with our experienced Trichologist today.

Key words: Alopecia Areata, Trichology, Hair Loss Solutions, Hair Treatment Clinic, Alopecia Areata Treatment, Clive Hair Clinics, Alopecia Treatment Melbourne, Female Hair Loss, Male Hair Loss, Alopecia Hair Loss.

AAAF VOLUNTEER AWARD NOMINATIONS FOR 2017

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

AAAF relies on our volunteers to continue our mission to change the lives of people living with Alopecia Areata and their families.

- **Debbie Labes – (QLD) The Beauty Spot.** Cosmetic tattoo artist based in Brisbane, has been providing free and discounted brow tattooing for people with alopecia.
- **Erin Tutty – (VIC)** continues to donate time to handle the donate hair certificates, still roughly 100 a month.
- **Amy Thomas – (WA)** has organised several events in WA – Boldest Morning Tea last two years and this year, Alopecia Art monthly catch ups.
- **Marian McLucus – (SA)** representative from Zonta Club of Mt Barker, has organised funding and distribution of make up care packages to teen girls with Alopecia.
- **Melissa Edwards – (SA)** Has run a fundraiser and head shave with her family, announcing she is Embracing Alopecia. Has also arranged with her workplace some matching of donations and for AAAF to be added to a Charity of the Month listing.

CONGRATULATIONS TO THIS YEAR'S WINNER

- **Nathan Ash – (VIC)** for donating time and skills to redesign AAAF website, has provided invaluable technical support to AAAF for several years.

Special honorary mention and Junior Volunteer of the Year Award has also been given to Charlie for active participation at several AAAF events, including GST Rally and Pizza Night. Charlie has written 3 letters to local minister asking for GST removal. Charlie also asked his friends to donate money to AAAF rather than presents on his birthday, raising \$725.

Chel congratulating Charlie for his efforts in fundraising for AAAF.

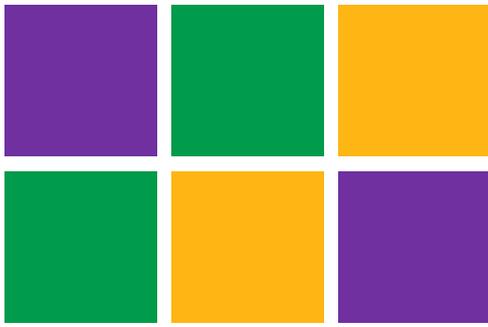
Chel presenting Nathan with his Award



Thank You!

Thank You!

Thank You!



What's On

ALOPECIA AWARENESS WEEK 12/11/17 TO 19/11/17

Sunday 12th November 2017

South Australia Open Day - Hear from industry experts, see displays of products and services and meet your local AAAF team members. Fantastic opportunity to see what's new and meet people with AA in your area.

Event Info: <https://aaaf.org.au/events/south-australia-open-day/>

Melbourne High Tea and Wig Sale – Join us in South Melbourne for some amazing deals on wigs and High Tea style refreshments provided by the AAAF team.

Event Info: <https://aaaf.org.au/events/melbourne-wig-sale/>

Wednesday 15th November 2017

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: <https://aaaf.org.au/alopecia-awareness-week/>

Friday 17th November 2017

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: <https://aaaf.org.au/alopecia-awareness-week/>

Saturday 18th November 2017

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

Event Info: <https://aaaf.org.au/events/perth-boldest-bald-brunch/>

Sunday 19th November 2017

QLD Charity Photo shoot and Picnic – AAAF are creating a charity calendar featuring beautiful photography of people living with Alopecia Areata. Join us to take part in the project and raise awareness of the condition, or just come along for a family friendly picnic in the South Bank Parklands.

Event Info: <https://aaaf.org.au/events/alopecia-calendar-photoshoot-and-awareness-week-picnic/>

What's On

Wednesday 22nd November 2017

Sydney Ladies Night In - Join us at the Beautiful Hair Boutique in Mosman for a social girls' night in. Ask all your alopecia questions, talk wigs and make up, and meet other ladies living with the condition in a relaxing and supportive environment.

Event Info: <https://aaaf.org.au/events/sydney-ladies-night-in/>

Saturday 25th November

QLD Christmas Soiree - Come on down to beautiful South Bank and join our team for a chance to celebrate the silly season and say thank you for a fantastic year.

Event Info:

Sydney Men's Alopecia Meetup – Catch the Sydney FC vs Brisbane Roar soccer game

Event Info: <https://aaaf.org.au/events/mens-alopecia-support-group-meet-up-nsw/>

Saturday 16th December

Wet'N'Wild Sydney Family Day – Invite friends and family for this celebration of summer with AAAF.

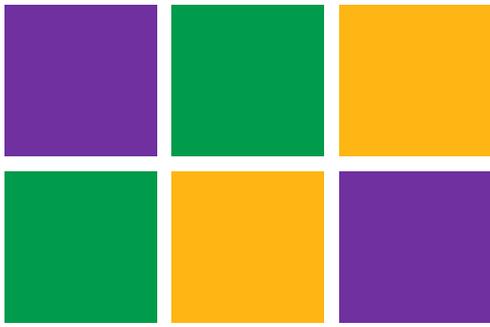
Event Info: <https://aaaf.org.au/events/wetnwild-sydney/>

The 2018 Calendar of events is in progress, with many exciting events being organised as we go to print, so be sure to keep checking the events calendar so you don't miss out on events such as:

Wine tours, breakout treasure hunts, women's, men's, and children support sessions, Pizza nights, regional events, and nationwide events.

AAAF knows that not all the events we organise meet the needs of everyone, but we are here to help in any way we can and we are always looking for suggestions.





AAADVENTURE CAMP



ALOPECIA AREATA ADVENTURE CAMP

NOV 18-19 | TARONGA ZOO | DUBBO

NEWCASTLE PERMANENT
**CHARITABLE
FOUNDATION**



On November the 18th we kick off the first ever Alopecia Areata Adventure Camp!

This new program brings kids with Alopecia Areata from across Australia together for a fantastic weekend, full of fun activities, informative workshops, and, hopefully, a whole lot of new friends.

Hosted this year at Taronga Western Plains Zoo in Dubbo, NSW, we have over 30 kids attending, from as far away as Tasmania and Cairns.

AAAF aims to host another AAAdventure Camp next year in a different location, and we plan to have even more kids attending. Be sure to stay tuned for updates and announcements about this exciting endeavour!

THE KOKODA CHALLENGE



In August 2017, two amazing members of our community, Greg and Tracey, headed to Papua New Guinea to tackle the famous Kokoda Track. This gruelling seven day journey took them through 98km of beautiful and harsh tropical landscape and profound history, as they followed in the footsteps of the ANZACs.

Kokoda17 aimed to champion awareness of Alopecia Areata and to raise much needed funds towards research into this condition. The team raised over \$12,000 to support individuals and families whose lives have been changed by Alopecia Areata.

In March 2018, a second team is taking up this challenge, and you're invited too!

Kokoda18 is now recruiting!

Andy, whose wife Amanda has Alopecia Areata, is tackling the Kokoda Trail in March 2018 and we're looking to recruit fearless adventurers to join him on this journey of a lifetime.

If pushing your boundaries to help support people in need sounds like a challenge you'd be winning to champion, get in touch with us at greg@aaaf.org.au to find out more about being part of the Kokoda18 team.





MEN'S ALOPECIA SUPPORT GROUP

AAAF is very excited to announce our Men's Alopecia Support Group, an online space for men of all ages to connect and share experiences and advice about living with Alopecia Areata. Like all our Support Groups, this is run as a closed Facebook group and is open to Aussie men of any age living with Alopecia Areata, and male family members supporting a loved one with the condition.

To request to join the group, please visit:

<https://www.facebook.com/groups/158070451460216/>

Note that only individuals living with alopecia or family members supporting a loved one with the condition will be accepted into the group. We also prefer to keep the Support Groups based locally, so only individuals from or based in Australia will be accepted into the group.



SOCIAL MEDIA LINKS

AAAF

Linkedin

Facebook

Instagram

You Tube

Go Fundraise

My Cause

Shopnate

Love, Alopecia

Kids Korner

Katie Cromie has a son, Oscar, who has AA. Katie decided to write a book to help children understand what appearance diversity is about. Oscar is 2 years old.

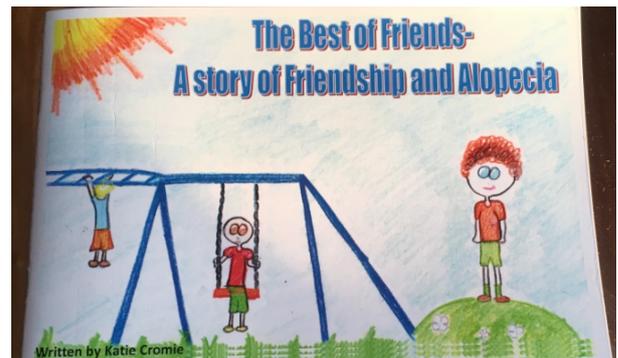
You can download the book as a PDF by using the following link:

<https://aaaf.org.au/wp-content/uploads/2017/03/The-Best-of-Friends.pdf>

Or you can buy a hard copy of the book for \$7.70 from our e-store.

<https://www.freewebstore.org/aaaf-buy-online>

While you're there check out the rest of our range of children's books, wigs to play with and our Jamie DVD.



What a great idea!

One of the teachers at a local kindergarten has created a corner using a table, wigs, bandanas and dolls heads. The purpose of the corner is to explore our physical identity and talk openly about Alopecia.

