



Support services since 1980

Alopecia Areata Support Association (Vic) Inc.

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<http://home.vicnet.net.au/~aasa>

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by Sue Blandford

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Our next Members' Meeting will be
2pm on
28th May, 2011
Skin and Cancer Foundation,
80 Drummond St
Carlton
(cnr Queensberry St)

See you there!
Read more on page 2

Disclaimer:

AASA provides information as a resource only and does not endorse the products or services being offered. Our aim is to help each other and advice given is of general nature and should not be regarded as professional advice.

What's inside?

Hello All,

Welcome to the May 2011 edition of your newsletter.

In this edition we have some slices of real life from people living with alopecia.

We have been able to republish an article from 'VOICE' the magazine of [Down Syndrome Victoria and NSW](#). For this we would like to thank Sue Blandford, mother of Ashleigh and an AASA member, who shares her daughter's story. Thank you too, to Jill O'Connor, Managing Editor of **VOICE**, who gave us permission to reprint the article, and thanks especially to Ashleigh.

I've found it easy to forget sometimes, that there are a whole range of medical problems that put the people affected at increased risk of losing their hair. People with Down Syndrome are one such group and people with Lupus another. In both cases there is an increased risk for them of also having alopecia areata.

AASA have begun a new service. We now have a patient advisor attending the Monday Hair Clinic at the Skin and Cancer Foundation. The clinic takes place every 6 weeks on a Monday afternoon and is conducted by two dermatologists, Dr Jill Cargnello and Dr Annette Callan.

People are referred to the clinic through their dermatologist and may have a wide variety of problems which affect their hair. This service has just begun and I am the current advisor. I'm busy brushing up my communications and counselling skills to ensure that the information and support AASA are able to provide is helpful to the clinic's clients.

Many thanks to Jane English the Nurse Unit Manager at the Skin and Cancer Foundation for facilitating this relationship between the Foundation and AASA.

I am hopeful that in future there will be opportunities for AASA to provide skill development courses or workshops for interested members who would like to take on the role of peer supporter or advisor in a variety of situations.

If you could be interested, contact AASA on aasavic@gmail.com or call our Message Bank on (03) 9513 8580.

For a bit of light entertainment, the Geelong group have put together a collection of "*....things people keep on the back of the toilet door*"!

We hope you enjoy this edition of your newsletter and we are always glad to receive your feedback and ideas.

Pat Crotty
editor

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Dealing with alopecia areata – Ashleigh's story

Sue Blandford

My daughter Ashleigh (Ash) is now 13 years old and has Down syndrome. Ash has always had quite thin hair but when she was about 7 years old she started to have small roundish patches of hair loss, usually around the front of her hair line.

I assumed it was the torment of hair styling for callisthenics competitions! I also noticed it seemed to be a seasonal thing... it would thin more in summer then grow back in winter.

Towards the end of 2008, at age 11, Ash's hair loss accelerated. That year our family had been through a lot of stressful issues, so I put it down to anxiety and possibly hormone changes.

At 12 years old things were not looking good, but I hoped the hair would start to grow back during winter. By age 13 years Ashleigh had almost no hair on top of her head and I was struggling to cover the bald area with a high pony tail. Her eyebrows were falling out and she'd lost half her top eyelashes on one eye.

A GP confirmed what I already knew: it was alopecia. The GP prescribed a topical cortisone cream (which had no effect), I tried silica and multi-vitamins and different shampoos but nothing seemed to improve the condition.

When the pony tail was barely covering the bald patches we started talking to Ash about the possibility of losing all her hair, and what we would do if that happened. We talked a lot about how 'fashion' (a favourite expression of Ash's) wigs, hats, bandanas etc were. We discussed the fact that having tufts of hair was not very pretty and that it would be much better to 'be brave and shave' (another favourite Ash expression, picked up from the CanTeen awareness and fund raising campaign in support of young people living with cancer).

In the mirror Ash could only really see the front of her hair which didn't look too bad, so of course she didn't love the idea of losing the lot. I used two mirrors, and took photos, to show her what it looked like from other angles... she was quite shocked.

We started searching for wigs online, I joined the Alopecia Areata Support Association and Ash entertained the idea of having long brown hair just like her big sister Jess. Jess and I took her to a wig shop and we treated her like a princess while she tried on all the different colours and styles.

We finally decided on a style and colour just like Jess' hair and then eagerly awaited the approval of a funding application (1) so we could pick it up. The approval took three weeks, then off we went to have the wig fitted and a little fringe trimmed into it – Ash was nervous but excited.

Ashleigh's teacher spoke to the class about alopecia while Ash was at a speech therapy class, to prepare them and answer questions. It is important to stress, particularly in a classroom setting, that the child is not sick, that alopecia is not contagious, and that alopecia will not limit a child from doing all of the activities that other children do.

The first day Ash wore her wig to school happened to be the same day that the boxes of bandanna's for CanTeens National Bandanna Day arrived, so Ash went from class to class selling them, showing off her wig and answering questions about alopecia. She was very proud of herself.

Unfortunately, after two days she started to complain that it was itchy, and by about a week later she had decided she didn't want to wear it anymore because it was so uncomfortable. Ash's experience has taught us that wigs are hard to attach and very 'itchy' – if I had known I would have chosen one of the more expensive silicone cap moulded ones.

I decided it was time to bite the bullet and shave all the hair off. I hated the idea but the thought of Ash walking around looking like a monk was worse. I told the family

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that I was going to shave Ash's head and that I needed their support and encouragement. I then sat Ash down and suggested it was time we did it. Her siblings, Jess and Andrew, enthusiastically agreed and told Ash how cool it would be and how brave she was... she agreed.

I emailed all my family and friends, and Ashleigh's school, before the big shave day asking for their support and giving them information about alopecia. I got lots of very caring responses including one of my closest friends offering to shave her head too, so that Ash didn't feel alone... of course I wouldn't let her, but it was a lovely gesture.

We lopped off the thin pony tail and saved it, then proceeded to trim and shave. I cried quietly behind her back as Jess held her hand and told her how gorgeous she looked. Upon inspection in the mirror, she didn't agree with us but we managed to convince her she was very very beautiful. I was so proud of her!

Over the course of the next few months we learned a few things:

- If you shave your child's head, remember the sunscreen!
- Shaving a whole head every second day is time consuming and quite hazardous with the wrong razor.
- No head lice worries!
 - If you think your child gets stared at by strangers for Down syndrome, this in no way compares to the staring at a girl who is bald... especially from children. Ash often asked me why people were looking at her – to which I would reply, smiling sweetly (and as loudly as possible): "It's because you're so pretty and they're jealous".
- Wearing dresses, skirts, jewellery and a tiny bit of make-up has helped Ash maintain her femininity.

In February this year, after five months of shaving, Ash's hair regrowth seemed to be much thicker on the top of her head with about 80% coverage so I decided it was worth trying to grow it back.

The process of growing it back seems to take forever and has not been without stress, but Ash has coped really well with being called a boy, and is now enjoying her new hair. With seven months of growth it is now



Ashleigh's hair has grown in waves!

Alopecia areata is more common in people with Down syndrome, occurring in 5 to 9% of the population (compared to 1 to 2% of the general population). People with alopecia can have several episodes of hair loss and regrowth during their lifetime. The hair regrowth can be partial or complete, or there may be no regrowth at all. In most people, hair will eventually regrow to some extent within a year.

Dr Len Leshin, www.ds-health.com/derm.htm

long enough to clip back and style a little. And believe it or not it's gone from being very straight to very wavy!

As a parent, the drastic onset of Ashleigh's alopecia overwhelmed me with feelings of helplessness, but I chose to be positive, be brave like Ash, and be open and honest with people about it, just as I was when we discovered she had Down syndrome. It is not something you can change so you have to change your attitude towards it.

And like at her birth, Ashleigh once again challenged the world not to define her by how she looks or by what she has. But to see who she is and what she can achieve.

Useful contacts:

Australian Alopecia Areata Foundation: www.aaaf.org.au

Alopecia Areata Support Association (Vic)
ph: (03) 9513 8580 <http://home.vicnet.net.au/~aasa/>

Alopecia Support Group (Sydney/NSW)
ph: (02) 9874 4392 www alopecia-sydney.com/

For funding: Department of Human Services Aids and Equipment Program (Vic) ph: 1800 783 783 or www.dhs.vic.gov.au/disability/supports_for_people/living_in_my_home/aids_and_equipment_program; or Enable NSW Health Support (NSW) ph: 1800 362 253

Some wig suppliers use soft silicone caps (expensive, but I recommend them), eg Angel Wigs: www.angelwigs.com.au

Princess Charlotte Alopecia Foundation (raises funds for affected children): www.princesscharlottealopecia.com

¹Some funding is available for purchase of wigs (see contact details above). With a letter from a medical practitioner stating that the wig is required for medical reasons, you may be eligible for further reimbursement via a private health fund. We received a total of around \$500 which fully covered the cost of the wig and

Sue Blandford (formerly Modra) has been involved with Down Syndrome Victoria since her daughter Ashleigh was born in 1997, and has worked in both voluntary and paid positions with the organisation. She is now the Family Support and Training Coordinator.

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This warm and generous letter from a member was read out at the February AASA meeting in Melbourne.

The Editor

I am a 59 year old woman and I have androgenetic alopecia, which is a progressive thinning of the hair similar to male pattern baldness.

My condition was incorrectly diagnosed for many years and my hair became very thin making every day styling impossible. If diagnosed early enough some medications can help slow down this thinning process but it does not work for everyone.

I became very depressed and anxious and couldn't eat or sleep and my self esteem was gone. I refused invitations unless I could wear a hat, so I didn't go out very often.

For some time I agonised about purchasing a wig, and early last year I made an appointment with a local salon. This day turned my life around.

I was given a contact for the Geelong Alopecia Support Group. (1)

A get together was organised and three wonderful, caring women came to my home. I was able to talk to them and unload my feelings. They told me of their own journeys with Alopecia, some since early childhood, and how they had coped .

I cannot express enough how this get together lifted my flagging spirits and from that day I thought "I may be able to cope with this," and maybe there is a light at the end of my very dark tunnel.

The old saying "a problem shared is a problem halved" can be true.

Since this time the group meet every month for a cuppa when possible and these informal chats allow everyone to talk about their troubles or concerns, new wig styles or anything they like.

We laugh a lot and at the end of the morning we go home with very big smiles on our faces.

These get togethers have given me back my self respect and I can now deal with negative thoughts and situations at most times.

We also have a phone contact list and we can ring anyone from the group at any time if needed.

This support group has been a godsend to me so please organise a support group in your area to help other alopecia sufferers as I have been helped.

Thank You.

1. head2head <http://www.quotidian.net/head2head/index.html>

If you live in the Geelong area we'd love to hear from you. You would be most welcome at our meetings.

Email: head2head@quotidian.net

One of the topics of conversation which caused some merriment recently was.. *'the things people put on the back of their toilet door'*.. We have a selection from the group throughout this May newsletter

Found on the back of a toilet door No.1

"Laughter is the shock absorber that softens the blows of life"

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Peer Support for Families: It works!

Sue Blandford, Ashleigh's mother is also the Family Support and Training Co-ordinator for Down Syndrome Victoria. In the Summer 2009 issue of their Victorian members' magazine, Sue wrote about the role and value of the Family Support Service. This is a comprehensive range of services for all families with a child with Down Syndrome, but especially for families whose child has been recently diagnosed.

To quote Sue,

"Down Syndrome Victoria is committed to a model of peer support and empowerment to build resilience within families. We believe that while professional counselling can be helpful, there is nothing more powerful than talking to another family".

Here are the services that are available -

- An initial support visit from the co-ordinator
- New parent information evening held 3 times a year
- A link with family network groups in local areas
- An early intervention program with opportunities to meet with professionals and other parents
- Online chat groups
- Phone support
- Events, occasions which can provide a sense of belonging and lots of fun for the whole family
- Help for families to link to professional support services

People with alopecia in Victoria need you!

The extent to which a voluntary organisation can offer services and support to its members and the wider community, depends on successfully recruiting and maintaining a band of willing volunteers. We have a team of members who staff our Message Bank and a small voluntary Committee of Management.

If you are willing to meet once a month to play a part in maintaining and extending our services, please consider standing for the Committee at the August AGM,

AASA's services are listed on page 6.

Found on the back of a toilet door No.2

LIFE

- Enjoy life
- Yesterday is history
- Tomorrow is a mystery
 - Today is a gift
- Live for the present

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Haven't met your AASA friends in quite a while?

Come to our reunion meeting on the 28th.

Bring a plate to share and catch up with all the news!

Our next members' meeting

Date: Saturday May 28th

Place: Skin and Cancer Foundation
First Floor, 80 Drummond St, Carlton
(cnr Queensbury St)

Time: 2 - 4 pm

The Reunion Meeting

What are AASA's services?

- Annual Open Day
- Newsletter, published quarterly
- Message Bank phone contact: (03) 9513-8580
- We provide a patient advisor to the Monday Hair Clinic at the Skin and Cancer Foundation, Victoria **(NEW)**
- Email contact: aasavic@gmail.com
- Web page: <http://home.vicnet.net.au/~aasa>
- Facebook page: <http://www.facebook.com/home.php?#!/group.php?gid=35443026444>
- Discussion Forum: <http://aasavic.19.forumer.com/index.php>
- Information
- Members meetings
- Opportunities to volunteer
 - Message Bank roster
 - Help with members' meetings
 - Open Day activities
 - Writing for the newsletter
 - Membership of our committee of management
 - Start and/or support a local group
- Occasions to meet friendly supportive people who also have alopecia

Followup story about unproven treatments.

A follow-up to our story in the February edition about the herbs and vitamins marketed as a cure for alopecia. The Princess Charlotte Alopecia Foundation website has an excellent story about a 3 year old who has alopecia and includes some wise words about the problems with unproven treatments.

You can find the story here [including a video](#)

Found on the back of a toilet door No.3

*"I wish I was a glow worm,
A glow worm's never glum,
'Cos how can you be grumpy
When the sun shines out your bum!"*

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What's Going On?

The March 2011 edition of the Skin and Cancer Foundation's newsletter 'Skin Deep' published information about AASA. 'Skin Deep' is distributed to all Victorian dermatologists.

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Alopecia Areata Support Association



Support services since 1980

The Alopecia Areata Support Association Vic. Inc

provides information and support for people with hairloss disorders, principally alopecia areata, but also alopecia androgenetica. AASA is an incorporated, not for profit entity which is run on a voluntary basis with a budget based on a membership fee. We maintain a membership base of about 120, but serve the wider community.

Dedicated volunteers have maintained the organisation for over 30 years.

We provide:

An Annual Open Day. This event includes medical information as well as, information and displays on various types of make-up, wigs and 'cover-ups' such as scarves and hats.

A free Newsletter, published quarterly and available to download from our web page. The newsletter emphasises psychosocial issues, particularly quality of life and well-being and includes summaries of research of interest to the members. The February 2011 issue included articles on, 'Multi vitamins and herbs for AA', and summaries of 3 recent papers, as well as information about the changed administrative arrangements for the state government program which subsidises wig purchases.

AASA also provides:

- Message Bank phone contact: (03) 9513-8580
- Email contact: aasavic@gmail.com
- Web page: <http://home.vicnet.net.au/~aasa>
- Facebook page: <http://www.facebook.com/home.php?#!/group.php?gid=35443026444>
- Discussion Forum: <http://aasavic.19.forumer.com/index.php>
- Information brochure
- Local support groups in Geelong and Rosebud

AASA values the support of the Skin and Cancer Foundation.

Seeking information or support?

Phone the AASA MessageBank (03) 9513-8580.

A group member will return your call within 24 hours.

We assist the work of AAAF by providing use of our Post Office box number and access to our Message Bank service which is staffed by AASA's valued volunteers.

From Chel Campbell President Australia Alopecia Areata Foundation

AAAF are holding a Trivia Night as a general get together and a fundraiser. Everyone 18+ is welcome. Please feel free to organize your own group or come in with another team.

Includes door prize, prizes for winning team, activities played between sessions. Individuals or groups

Where: South Melbourne Community Centre

Cnr Park Street & Ferrars Place

Date: Saturday June 18th 2011

Doors Open: 6:30pm Doors Close: 9:30PM

Entry Fee: \$15 per person BYO Food & Drink

All inquiries to info@aaaf.org.au and RSVP and payment by 5th June 2011. The AAAF committee looks forward to meeting you.

Angel Wigs Invitation:

ACTIVITY / INFORMATION DAY

Come join us and other clients to share and learn from each other on topics such as:

Wearing eye brows, eye lashes, or the best eye liners/makeup that stays on,

Have you had your eye brows tattooed, have you had your eye brows injected with cortisone,

Have you tried any vitamins such as the ones featured recently on 'A Current Affair' or any other treatment - what results have you experienced

Have you found a hair style/s that has worked well, or any styling techniques or hair accessories that work well.

When: Sunday 22 May 2011

Where: 12th Caulfield Scout Group Hall

1 Beavis Street, Elsternwick, 3185

If coming by public transport, go to Elsternwick station on the Sandringham line, or tram

Melway Reference: 67 H3

See map below for location of venue

Time: 1 pm – 5 pm

Cost: There is no charge Finger food, tea, coffee & light refreshments provided

RSVP: Wednesday 18 May 2011

angela@angelwigs.com.au or 0400377375 or 95231131

PS. If you feel you can contribute in any way that will be great, this day is for you!

We will have some retail products DISCOUNTED FOR THIS DAY
(There will not be credit card facilities on the day but many banks are located nearby)



Come a join share with others who deal with hair loss and understand how YOU feel, please come along and share with each other