



Support services since 1980

Alopecia Areata Support Association (Vic) Inc.

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Registration No. 0017172V

May 2012

This Month

From the President's Desk

Rob's Rant

Stories: Why we love them and why they matter

Stories from Children in the UK

Kylie's Wedding Story

New Businesses and Products

Our next Members' Meeting will be held at 2pm on 26th May, 2012 at Skin and Cancer Foundation, 80 Drummond St (cnr Queensberry St), Carlton, Victoria

All Welcome!

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.

From the President's Desk



Welcome All,

My granddaughter (who was born without eyebrows but doesn't have AA) told me that the kids at school pick on her for

that. I told her "Don't think about it because it's not about how you look, it's about who you are. Tell them that "Only the smartest people don't have eyebrows". Nobody picks on her now, she is a class ahead in some subjects.

A friend of mine knows a lady who doesn't have AA, but she does have health issues. She has just separated from a long-term relationship which was very demanding and it was a brave and stressful decision for her to make. But for her too, the support of her friends and family will be important in getting through troubled times.

For all of us, life deals out all sorts of challenges and it's how we deal with these challenges that makes us stronger.

Our committee faces new challenges this year as some of our committee members will not be up for re-election.

We want to ensure that AASA prospers as a source of support for future generations so I would

ask all members to consider if you can join us as a committee member.

Please drop us a line, phone AASA MessageBank or email us.

The AASA committee meets 4 times a year and the workload is not great.

I look forward to meeting you at our next members' meeting.

Garry Lonsdale

President

What's coming up?

Our next meeting on Saturday 26th of May is the last one before our AGM in August. At the AGM we will elect our new committee of management for 2012-2013.

Do you have some ideas about what could be done to support people with alopecia? What about joining the committee?

Email our secretary Pat Crotty on aasavic@gmail.com if you would like to discuss your ideas and the possibility of becoming a committee member, or leave a message for her on AASA MessageBank. (03) 9513-8580.



ROB'S RANT

Before you read this article, I want to make one thing clear. I have no ill will against any organisation that raises money to help those in need. In fact, I applaud it. However, this is just an account of how I, as someone who has Alopecia, felt when witnessing first hand the activities associated with this particular event.

As most of us know, the Leukaemia Foundation's highly successful campaign "World's Greatest Shave" has concluded for another year. This year, they raised over \$15 million, which is a phenomenal amount by any standards. For those unfamiliar with the campaign, you participate by either shaving, colouring or waxing your hair in order to gain sponsors. The shaving part, I assume, is to dramatise the effects of chemotherapy.

I always felt uncomfortable about this cause. Again, I stress that I'm not against raising money for the Leukaemia Foundation. But the actual activity of shaving off all your hair for no apparent reason made me feel queasy. Oh what I would give to even dream of having the luxury to be able to choose to shave off my hair. I guess at the end of the campaign, all the participants and myself would look all the same, with a nice bald head. Except one thing. They will grow their hair back. I will not.

I had never met anyone who had participated in the event. Until this year.

My fellow female workmate, this year decided to participate in shaving her head. This was in support of a friend who had just battled with cancer. So for a couple of months, I had been exposed to all the particulars of the campaign - the donations, the emails, the merchandise, etc. Everyday, other employees would come around and give a pat on the back and ask questions, and so forth. Through the years, whenever conversations tended towards anything to do with hair, I would somehow try to back away. This felt like one of those situations. I didn't want to be a part of it, but yet I had to show my support.

So the day came when the actual shave was to take place. It was quite the workplace event, for the whole workforce had gathered into the cafeteria to watch the shave take place. Of course I went along too, as I didn't want to seem unsupportive. And then it started. My workmate didn't have long hair. Probably a short bob is the way I would describe it. But with the electric shears in hand, the representative went about it and started shaving all her hair off.

Row by row, the hair fell to the ground. All the while the audience was watching in jest. And yet, I felt sick to the stomach. The longer it went, the more hair dropped to the floor. In the end, I think she ended up getting a "Number 2". By no means bald, but bald enough it seems.

My workmate ended raising over \$2000 for this exercise. That is a fantastic effort, and I applaud her for that. But it doesn't lessen the way I felt seeing all that hair wasted and swept away, when I would do anything to be able to have hair again.

Obviously, the Leukaemia Foundation are onto a winning formula, for raising the amount of money that they end up with, is phenomenal. But Cancer and Alopecia are two very different things and psychologically speaking, the mind goes through an equally different journey. With Cancer, you are fighting for your LIFE. We alopecians are merely fighting to keep our hair. With Cancer, I would imagine you would have to go through hell to beat the disease to come out on top. With Alopecia, our hell is the emotional roller coaster we go through once we lose our hair. And then, we're stuck with it. For many of us, we are bald for LIFE.

In conclusion, I would again like to point out that I'm not against the Leukaemia Foundation, or its efforts in raising money. I am positive that what they do will benefit a large number in the community. But I cannot help the way I feel when put in a certain situation. It's almost an irrational or even selfish way to think. But in the end, this is just the humble ramblings of an observer, and though I applaud their efforts, I will still prefer to keep my distance, thank you very much.

Seeking information or support?

Phone the AASA MessageBank
(03) 9513-8580.

One of our phone volunteers will return your call within 24 hours



Stories: Why we love them and why they matter

"A support group brings you in touch with a variety of people who are all dealing with the same situation. The benefit comes from observing how different people manage their lives around whatever the disability or condition is. At a support group there's often a lot of information exchange - helpful hints and tips on how to manage, what remedies work, where there's a good supply of product/help/support or whatever may be useful. As well, with a good, chatty meeting when people are talking about things other than their particular ailment and just sharing a social experience, it can also be of benefit: it reminds members that they are people first, not solely defined by their disability or condition"

Rossllyn, peer volunteer leader quoted on the Chronic Illness Alliance website
<http://www.chronicillness.org.au/peersupport/index.html>

Stories are important to us. We read them, watch them, buy them and we tell them to children. We swap stories when we get together and we often look for stories which are like our own, to understand how other people have dealt with problems similar to our's. Take Rob's story about his reactions to a fundraising event which involved someone shaving their head. Many people might also feel, like Rob, a bit "queasy" about some things to do with hair, ads on TV, or jokes, but find it hard to "put their finger on" exactly what it is that makes them feel uncomfortable. It's easy to think that "it's just me" and maybe to believe that you shouldn't feel like that.

Support groups can be a real boon when it's not easy to talk about alopecia worries with those closest to you either because of the fear of burdening them, or perhaps the difficulty they may have in understanding your concerns. As Rossllyn says, in peer support groups, information is communicated, tips exchanged and a social experience is shared. People tell stories, about their alopecia journey and regardless of whether you are a "listener" or a "teller", or both, there are always opportunities to learn something and to give support to others who share a similar experience.

There are also forums other than face to face meetings where people share their concerns. Articles like Rob's and Kylie's can also be a way of learning more from others with alopecia. On line discussion groups such as Alopecia Online UK and Alopecia World have very active discussion groups.

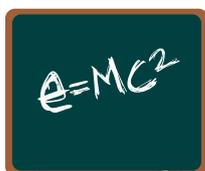
It may sound funny, but if you're not ready to share your story with others you might consider sharing it with yourself. Writing a journal or a diary can not only be enlightening, there is evidence that this can be a health benefit, a burden shared is often a burden reduced even when the sharing is with your journal. Putting feelings into written words it seems, can be helpful.

AASA Support Groups: Call AASA MessageBank for information on support groups in Melbourne (AASA quarterly meetings), Geelong (head2head) and Rosebud.

Online: AASA Discussion forum <http://home.vicnet.net.au/~aasa/discussionforum.html>
 Alopecia World - <http://www.alopeciaworld.com/forum>
 Alopecia Online UK - <http://www.alopeciaonline.org.uk/forum/>



Teachers and Students 1



TEACHER: Millie, give me a sentence starting with 'I.'

MILLIE: I is..

TEACHER: No, Millie..... Always say, 'I am.'

MILLIE: All right... 'I am the ninth letter of the alphabet.'

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Stories from children in the UK

Headzup (www.headzup.org.uk) is a website for children with alopecia, their parents and teachers. The book "Alopecia: My Story. Young people talk", was written by Mandy Ross who says. *"This booklet is a collection of true stories and photos of real people with alopecia, so you can read about how they coped with it...I've learned a lot from meeting these children and young people, and their families. I have been hugely impressed to see how they have dealt with the challenge of alopecia – with love, courage and humour"*.

The introduction was written by Consultant Dermatologist, Professor Celia Moss. We're grateful to Professor Moss for allowing us to include her introduction here.



Professor Moss

"During 30 years as a skin doctor I have seen lots of young people with alopecia (missing hair). Some have lost their hair and some never had any. Some will get better by themselves, some may be helped by treatment, but some will never have a full head of hair. People come to me because they are fed up with having no hair, and it makes me sad when there is nothing I can offer.

Young people with alopecia often feel very alone. It is good to know that someone else shares your problem and understands. So we have put together this collection of true stories and photos of real people with alopecia, so you can read about how they coped with it.

Most people with alopecia feel low about it sometimes. Some people feel upset about it all the time and think about it every day. Others manage to forget about it and get on with their lives. But the best thing is if you and your family can accept the alopecia as part of the way you are, just like the colour of your eyes or skin, or if you have freckles. Some of the people in this book have gone through bad times with their alopecia, and they have come through it. They inspired us and we hope they will inspire you.

Professor Celia Moss
Consultant Dermatologist,
Birmingham Children's Hospital"

The booklet can be downloaded from
[http://www.headzup.org.uk/resources/1/news/Alopecia My Story.pdf](http://www.headzup.org.uk/resources/1/news/Alopecia_My_Story.pdf)
The book was produced by Birmingham Children's Hospital..

A resource for parents of children with alopecia

The Australia Alopecia Areata Foundation has a brochure with helpful ideas for you if you are the parent of a child with alopecia.

You can download a copy from their website
[www.aaaf.org.au/uploads/AAAF Parents Talking DL Brochure 2012.pdf](http://www.aaaf.org.au/uploads/AAAF_Parents_Talking_DL_Brochure_2012.pdf)

Kylie and Mathew's Wedding

Some of our newsletter readers will know part of Kylie Clarke's story because of her family presentation at our Open Day last year - a presentation that touched all those present.

Last month Kylie and Mathew Baker were married and their story was published in 'That's Life' in April. The story covered Kylie's life so far with alopecia, from being first affected at age 6, through her school years and then becoming a primary school teacher. Kylie tells of how she has dealt with the good times and the bad, with courage and humour and with remarkable support from her parents, especially her mother Joanne.

Kylie tells how she has been helped by a sense of purpose in her life, which is to help others.

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volunteers will return
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Thanks to Kylie,
Mathew and Joanne
for sending us the
great photos!



You can read a more detailed story about Kylie and her family here
[http://www.aaaf.org.au/uploads/Kylie Clark v1.pdf](http://www.aaaf.org.au/uploads/Kylie%20Clark%20v1.pdf)

You can read the text of the AASA Open Day family presentation here
[www.aaaf.org.au/uploads/Joanne_Kylie Story.pdf](http://www.aaaf.org.au/uploads/Joanne_Kylie_Story.pdf)

A photogallery from our Open Day is here
http://home.vicnet.net.au/~aasa/AASAOPENDAY_2011/album/opendayindex.html

New Businesses May 2012

AASA makes information about products and services available to you, our readers, so that we are all better informed about the choices available to us. This does not imply a recommendation. We are interested in knowing when you have received good service from a supplier. Good service for people with alopecia contributes to our sense of wellbeing and word of mouth advertising is great for good businesses!

Let us know your experience.

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Hair 4 Me - Stawell

Eleisha Clementson has recently started a new business in Stawell Victoria, called Hair 4 Me. Eleisha is a qualified hairdresser with over 17 years experience. After much difficulty finding a wig for someone close to her who lost her hair through chemotherapy she found there was a real need for a business in the Stawell area to remedy the situation.

Contact No. 0400 631 685

Rinaldi Wigs - Moonee Ponds

Louise Rinaldi is a wigmaker from England who has relocated to Moonee Ponds and she supplies European hair, lace base, hand knotted wigs. They range from \$2500 upwards. Her contact no: 8781 5750

Website www.rinaldiwigs.com.au

Westend Hair - Windsor.

Westend Hair are hairdressers, and sell commercial wigs. Olga looks after the wig section, her email address is westendhair@gmail.com.

Website: www.westendhair.com.au

FOR SALE

FREE PUPPIES

1/2 Cocker Spaniel, 1/2 sneaky neighbour's dog.

FREE PUPPIES.

Mother is a Kennel Club registered German Shepherd.

Father is a Super Dog, able to leap tall fences in a single bound.

WASHER AND DRYER \$100.

Must sell - joining nudist colony



Teachers and Students 2



TEACHER: Why are you late?

STUDENT: Class started before I got here.

TEACHER: John, why are you doing your math multiplication on the floor?

JOHN: You told me to do it without using tables.



Don't forget
AASA Meeting
Saturday May 26th
2 pm