

Alopecia Areata Support Association (Vic) Inc.



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Our next Members'
Meeting will be
2pm on
27th November, 2010
Skin and Cancer
Foundation,
80 Drummond St
Carlton
(cnr Queensberry St)

See you there!
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from the President's Desk

Hello all,

**Happy birthday to you,
Happy birthday to you,
Happy birthday AASA,
Happy birthday to you.**

Yes, our group is 30 years old this month. What an achievement! To every one of our members, I would like to say thank you. No matter how you have been involved in the group, whether you have helped out over the years, you have come along to only one meeting, or you just like to read our newsletter and nod your head when you read something you can relate to, you are all part of the reason why our AASA group exists.

Do you remember the first time you gingerly walked into an AASA meeting? I do. I felt a lot of relief that there were people who understood what I was dealing with. Later on, reality hit me. I was probably going to have Alopecia all my life! There was no magical cure that I'd hoped I'd find at the meeting. I know a lot of people have that rollercoaster of emotions initially, and they feel they would have been better off staying home.

Yes, I had received a slap in the face about my alopecia status, but I also met a group of people who have softened my life experiences with alopecia along the way,

simply by being able to talk about it openly, and also get practical advice.

So why not come along to our next meeting on 27th November, and help celebrate our 30 year milestone. There will be a yummy afternoon tea and of course, a birthday cake!

I hope to see you there.

Terrie Ridley

President
AASA



Where's Rob?

As the new, or more accurately, the returning old editor of the newsletter, I would like to say a big thankyou to Rob Chan. Rob took over the responsibility for the newsletter and our digital communications in 2008. He actually ended up with a lot of fans not only for the newsletter as a whole but for his personable column **Rob's Rant**.

Rob is having a well earned break from editorial duties and tells me he may send us some more rants in the future, meanwhile, best wishes Rob and thankyou!

Pat Crotty

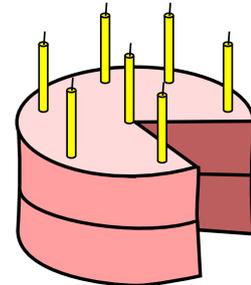
Next members' meeting

Join us in celebrating
the beginning of our 31st year!

Date: Saturday November 27th

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

Time: 2 - 4 pm



There will be a presentation on local support groups in Geelong and Rosebud, with an opportunity to meet members of the groups and chat about how the groups work.

Would you like to be part of a small friendly local group?
Come and find out!

Open Day is back in 2011!

AASA didn't hold an Open Day this year because of the transition work the new committee needed to do to ensure the continuation of AASA services. However in 2011, Open Day will be back! We have had lots of enquiries from members interested in our plans for the future of this valued event. We will have a format which will be familiar, but hopefully with some new twists.



Because there is a developing tradition of designated weeks for alopecia not only in Australia but elsewhere, we will run Open Day in October some time close to other events but Open Day will remain a separate AASA function for members which allows everyone to feel comfortable amongst friends and to get up to date information from medical experts, all in an atmosphere where we have the privacy to see and try wigs and learn about new products of interest without any pressure to buy.

We will keep you informed as plans evolve and of course we always need volunteers to help on the day. Watch this space!

Recently in print

This year the Journal of Investigative Dermatology declared 'It's all about patients' and published in their journal examples of patients' poems and art work which portrayed the patient's experience. They also included information on support groups.

Angela Christiano and her research team identified 8 genes which are linked to increased risk for getting alopecia areata

In 2009 Nina Welsh another researcher who has alopecia (as does Angela Christiano), published a paper on the experience of having alopecia. A rare example of research which documents the experience in peoples' own words.

Recently French medical researchers declared that 'severity' of alopecia areata should be judged by how distressed a person is by their hair loss, not by how much hair they lose. They also called alopecia areata 'this orphan disease' because so little is known about it. A point also noted by Christiano when explaining what motivated her to conduct her own research program into alopecia areata. She realised as a scientist how little was known about the condition she herself had.

Ria Willemsen a dermatologist and Johan Vanderlinden a psychologist published a version of Willemsen's PhD thesis on hypnosis and alopecia areata, showing that their hypnosis treatments could make a big impact on quality of life, but not influence hair growth. They remarked in conclusion that AA was a bit like the world financial crisis, it's a domino effect. One problem effects another until a major breakdown occurs. In the case of AA the hair follicle loses its protection from immune attack as a result of a whole cascade of consequences resulting in hair loss.

In 2009 and 2010 the interest in the complex connections between the body's endocrine and immune systems was well represented and one article in particular discussed this in relation to the hair follicle and stress.

This year one dermatology journal published two detailed articles on AA one on clinical aspects and the other on treatments and a British Medical Journal article discussed the management of AA. In their summary the authors supported the importance of quality of life measures in assessing treatment outcomes. A theme which seems to be

gathering momentum.

Two articles published in 2009 speak directly to the experience of having alopecia and hopefully represent a trend in research. Both papers are from UK researchers.

Tina Cartwright and colleagues wrote about '*Illness perceptions, coping and quality of life in patients with alopecia*' and Nina Welsh and Alison Guy wrote on '*The lived experience of alopecia areata*'. In Welsh and Guy's study the researchers tried to take a holistic approach and to look at not just the negative outcomes of the alopecia experience. They asked people about the coping strategies they used and documented how these strategies evolved over time. The good news is that for their small group of 12 people, coping improved as time went on and the people in the study became more optimistic about living with the condition. It's worth noting that one of the authors, Nina Welsh has alopecia herself. (Can you see a pattern emerging here?).

Tina Cartwright and colleagues identified that some beliefs that people with alopecia hold about the condition may be linked with decreased quality of life score. They discuss the possibility that the uncertainty and unpredictability of alopecia, coupled with limited treatments may make it difficult for affected people to make sense of the condition and this in itself creates difficulties. This paper concludes with the authors stating that because there is a strong relationship between beliefs about alopecia and quality of life, health professionals should recognise the psychological impact of alopecia and address the negative beliefs and emotions as part of treatment programs.

Over the past couple of years there seems to have been more interest in alopecia, from both the medical and the psychological perspectives. Given the number of researchers involved who themselves have alopecia perhaps they should get a special pat on the back for increasing the knowledge available to us.

Media celebrities with hair loss aren't the only ones with alopecia 'out there' raising awareness!

T. Cartwright, N. Edean, A. Porter *Illness perceptions, coping and quality of life in patients with alopecia* British Journal of Dermatology Volume 160, Issue 5, pages 1034-1039, May 2009

Nina Welsh, Alison Guy *The lived experience of alopecia areata: A qualitative study* Body Image, Volume 6, Issue 3, June 2009, Pages 194-200

Other published researchers who have alopecia are Patricia Tucker and Nigel Hunt

Patricia Tucker Bald Is Beautiful?: The Psychosocial Impact of Alopecia Areata J Health Psychol January 2009 14: 142-151

Nigel Hunt, Sue McHale The psychological impact of alopecia. BMJ. 2005 Oct 22;331 (7522):951-3

I have become my own version of an optimist.
If I can't make it through one door, I'll go through
another door - or I'll make a door.
Something terrific will come no matter how
dark the present.

Rabindranath Tagore

Hope and Inspiration

The editor

I recently found an inspirational quote which I thought might interest readers. It was supposed to be from a speech by Nelson Mandela. It turned out to be from a book by Marianne Williamson, who it seems, is one of America's most popular New Age spirituality writers. Her book was one of the first books to be endorsed by Oprah Winfrey.(1)

I was really disappointed!

However I read the quote again and it does have a strongly hopeful sentiment. So here it is, see what you think.

"Our deepest fear is not that we are inadequate. Our deepest fear is that we are powerful beyond measure. It is our light, not our darkness, that most frightens us. We ask ourselves, who am I to be brilliant, gorgeous, talented, fabulous? Actually, who are you not to be? You are a child of God. Your playing small doesn't serve the world. There's nothing enlightened about shrinking so that other people won't feel insecure around you. We are all meant to shine, as children do. We were born to make manifest the glory of God that is within us. It's not just in some of us; it's in everyone. And as we let our own light shine, we unconsciously give other people permission to do the same. As we're liberated from our own fear, our presence automatically liberates others".

I think we probably all appreciate some inspiration on our journey with alopecia, inspiration fires up hope and it's hope that keeps us going. One of our recent newsletters carried an inspirational story making this very point ('Curly' giving hope to thousands', AASA Newsletter, May 2010)

Whatever it is that inspires you, gives you hope, this edition of the AASA newsletter explores the idea of hope, the lubricant that helps us get from where we are, to where we want to be in our lives.

It has been said that hope is the perception that something desired may happen soon. However hope is a bit more complicated than that. There is good evidence that having hope is good for us, but on the condition that we know clearly what we desire and have ideas about how we can work towards reaching this whilst being confident that we can overcome or work around any difficulties. So hoping for realistic and challenging things that we can work towards ourselves might be the key to getting the benefits of 'being hopeful'.

The National Alopecia Areata Foundation in the US website says this.

".....Although not life-threatening, alopecia areata is most certainly life-altering, and its sudden onset, recurrent episodes, and unpredictable course have a profound psychological impact on the lives of those disrupted by this disease. But there is hope....." (2).

In this case NAAF are referring to hope for a cure, but a cure is not just around the corner, so that's not the hope that will get me fired up to deal with my day. So I've been wondering what else there is to hope for because a hopeful day, a hopeful life, is a much better and healthier prospect than the alternative, even if it requires some hard work!

C R Snyder who specialised in research on hope said that, high-hope is linked with people who set difficult goals for themselves, embrace challenges and expect excellent returns on their mental investments and they thereby gain an advantage in dealing with stressful situations.

That could all sound a bit gung-ho if you're feeling down!

I think that's where peer support can make a contribution.

Seeking information or support?

Phone the AASA
MessageBank
(03) 9513-8580.

A group member will
return your call within 24
hours.

My copy of the RACV magazine Royal Auto arrived whilst I was writing this. On page 74 there is an article called "Embracing hope". It's not about alopecia but about the families of people who have died in road crashes, families living with the tragic loss of a loved one.

Road Trauma Support Services Victoria (RTSSV), had its beginnings in Tasmania with Colleen Hall, a woman who had lost 7 relatives in road crashes. She set up a support service there for families bereaved by traumatic loss of a loved one and then came to Victoria to set up a similar support service for families here.

Road Trauma Support Services Victoria (3) is now 'an organisation which offers support, help and hope to the grief stricken', a great result, made possible because the people who started the group used their own experience and grief to reach out to others similarly affected.

Jeanette Suhr a founder of the Victorian group says "There is so much tremendous courage out there I never thought I would meet so many wonderful people, and be so involved with a service that gives them some hope again is a great privilege... I hope with the (memorial) service, we are able to bring the people attending some hope for the future."

What an inspiration and a fantastic, compassionate manifestation of hope!

AASA has been doing similar work on a smaller scale for 30 years now.

At the moment RTSSV is working on making their service, which includes free counselling, available in regional and country Victoria. AASA is looking at similar issues, and if you come to our meeting on November 27th, you can join in a conversation about how we might have a network of small groups to reach out to people both in Melbourne and in country and regional Victoria.

So, what do you hope for and what do you need to make progress towards this?
How can AASA support you in your endeavours?
How can you support AASA in our endeavours?

It is one of my hopes that AASA can continue and improve our services for people with alopecia. That hope **can** get me fired up to deal with the day!

1. Wikipedia http://en.wikipedia.org/wiki/A_Return_to_Love
2. http://www.naaf.org/site/PageServer?pagename=just_diagnosed_intro
3. <http://www.rtssv.org.au/>

RTSSV are looking at outer metro Melbourne and regional face to face counselling, and exploring innovative, telephone and internet based, personal and group support options.

Always Read the Signs!

IN A LAUNDROMAT:

Automatic washing machines: please remove all your clothes when the light goes out.

IN AN OFFICE:

After tea break staff should empty the teapot and stand upside down on the draining board

DURING A CONFERENCE:

For anyone who has children and doesn't know it, there's a day care centre on the first floor.

ON A FENCE:

The farmer allows walkers to cross the paddock for free, but the bull charges.

ON A REPAIR SHOP DOOR:

We can repair anything! (Please knock hard on the door - the bell doesn't work)

What are AASA's services?

- Annual Open Day
- Newsletter, published quarterly
- 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
- 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



*The President and Committee
Wish all our members and their supporters
A very happy Christmas and a
Safe holiday period*

*We look forward to meeting
more of you in 2011
Our 31st year!*