



Support services since 1980

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Did you know?

Member's Meeting
All Welcome
Skin and Cancer
Foundation
80 Drummond St
Carlton
(cnr Queensbury St)

2 - 4 pm
Saturday
February 25th

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.



Hello and Welcome to 2012!

I am proud to say that AASA Open Day 2011 was a great success and that in 2012, Open Day will be back to our traditional month of October.

Put October 27th in your diary and I look forward to seeing you there.

Telling personal stories, (which played an important role in AASA Open Day 2011), is one of the most powerful ways to communicate.

I once had the privilege to board with a single mum and her two children. Her daughter (Cassie, not her real name) had a one in two million skin disorder. We all have 7 layers of skin, little Cassie had one layer. She would come home from school in a bloody and blistered condition. After removing her shoes, it would be time to change the bandages on her feet. I would see the skin peel off with the bandages, then she would calmly stem the blood flow with fresh bandages, whilst talking about the show on TV as if she was just trimming her nails. Once she sat watching a November thunderstorm as she spoke with the life experience of an 80 year old. Lisa was 12 at the time and not expected to live past 16.

Never have I met a person so much in awe of all the beauties this world has to offer, with a zest for knowledge and a thirst for life and more concern for others than herself.

Whenever I think my life is hard and it's getting me down, I always think of little Cassie and I thank her so much for the lesson she gave me. Beauty is only skin deep, true beauty shines from within.

I hope to meet you all on February the 25th at the Skin and Cancer Foundation.

Garry Lonsdale,
President

In this edition of the newsletter we make extensive use of web links

If there is something you would like to read, but you are not on the web, send us a note in the mail with a SAE. We will endeavour to get you a copy. Or call AASA MessageBank and we'll see if we can help you get the information you want.

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ROB'S RANT

I often see people on the street, or out in public, and I notice that they have some form of Alopecia. They may have a small bald patch on their head. I may notice that they don't have any eyebrows. I may even notice that they're wearing a wig. Being a "professional" wig wearer for so many years, I can usually tell when someone is wearing a wig even when 95% of the population cannot. When I see these men or women, I often want to run up to them and say "Do you have alopecia? So do I!!!". Of course, I do not, as this will probably mortify them. That's probably the last thing they would want to encounter during their day

I admire those who choose to venture the world sans wig, putting themselves out there. It's a brave thing to do, they must encounter questions all the time, like "Why no eyebrows?". The witty ones out there will probably say "I'm doing a Beth Ditto". Google her if you don't know who she is. She is the lead singer of a band, who does not have any visible eyebrows. Whether by choice or not, I'm not sure. But it sure is one hell of a fashion statement.

On another note, it's been roughly 18 months since I was editor of the AASA newsletter. Pat, the formerly retired, and then recently reactivated editor of the newsletter asked me to contribute an article for the next newsletter, I happily agreed. But then I thought, what to write about? What has happened in the last 18 months?

About the time I left the AASA committee, I decided it was time to give up my 10 year old Ford Festiva, and treat myself to a nice new car. So I decided to splurge a little and went European, in the form of a Volkswagen. Despite a few little hiccups in the beginning, it has been a pleasure to drive since. Up until Christmas Day, when Melbourne was hit by a freak hail storm, and I got caught right in the middle of it. So my poor little Jetta sustained quite a bit of hail damage, in which I am now in the process of repairing through the insurance.

It had been a while since I had gone overseas, so I finally decided to cash in my frequent flyer points, and visit Hong Kong in late February last year for 10 days. Though I was born and raised in Melbourne, my parents are from Hong Kong, and I always felt it was a special place each time I visited. It had been roughly seven years since I had visited, and it was great to be back there again. It was great to catch up with my sister, who was also raised here in Melbourne but now resides in Hong Kong with her family. I had an absolute blast, and by the time I left, I was already planning my next trip back.

I still manage to play tennis at least twice a week. I had been playing tennis on and off over the years, but in 2009 I decided to take it a little more seriously and start playing regularly. So I started playing every Saturday, and then even decided to start playing in a competition on Wednesday nights, which really tested my skills. It's not only helped keep me a little more fit, but I've met lots of great people along the way. Of course, it's all for fun, but I still somehow managed to win last season for my grade (A2, in case you were wondering!) in doubles. Not sure how I managed to make it into the finals, but I have the trophy at home should anyone contest it!

Work wise, 2011 was a pretty dramatic year. The company I had been working for, which would have been four years this February, suddenly decided to change my shift in September last year from day shift, to afternoon shift, in which my hours would have been 3pm to 11pm. This was not a choice, it was a case of take it or leave it. I had no choice but to accept it. So I was doing that for a couple of months, taking advantage of the fact that not working during the day allowed me to go on job interviews during the morning. Luckily for me, though that process I had been offered a position in a much larger company, in which I accepted, and started in December. So far, it has been good, and I'm still learning the ropes, so to speak. I'm working within the same industry, but in a different role, so I've still got a huge learning curve to go through.

Welcome
back
Rob!

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As angry and upset as I was when they forced me to change my shift, I can't help but look at the positive of the situation, for had this not occurred, I would have been stuck in my old job, and my career would have still been travelling at a neutral trajectory.

So what does all this have to do with alopecia? Nothing really. Its just an update of my life in the last 18 months, and I also just happen to have alopecia. My point is, life goes on. There is no point putting everything on hold because you have alopecia. Sure, it's not the best thing to have, but if you have it, then there literally isn't much you can do about it. It's just grabbing the short end of the stick. But what you choose to do with that stick, is entirely up to you.

AASA Message Bank - A Community Service

By Terrie Ridley

Messagebank was formed to take the load off Juliet, who was President and who received all the calls regarding Alopecia . Her home number was listed whenever a phone number for AASA was needed. It was not unusual for Juliet to take 20 -25 calls in a week, each call lasting a minimum of 20 minutes. This was prior to us having access to the internet, so the only way to gain information was phone calls and books, etc.

Then along came Telstra's messagebank! This gave us the opportunity to have a central number and access to it remotely, to retrieve messages.

What a wonderful concept, and it was also a bonus for country people who wanted to be involved! We started with 4 people, each doing a week's roster every month.

As time went by, we found this is the one area that people like to get involved in, and the messagebank roster now runs on an 8 week cycle. (One person enjoys it so much, they do two rosters per cycle!)

Heather is the service co-ordinator and has been for several years, providing support for the volunteers who staff it. *(Terrie, immediate past-president of AASA, has overseen MessageBank since it started).*



Being involved in the roster is not difficult, it's all about listening to another person and joining into a conversation with them. The wonderful thing is that when you pick up the phone to speak to the person who wants your help, you know you will have something in common with them, that they, like you, are touched by Alopecia.

No matter where the conversation leads, something will strike a chord with you, be it wanting to know a good dermatologist, where to find a wig, having a down day that no-one understands, or when to tell a friend you have alopecia.

MessageBank volunteers have information, such as a list of wig suppliers and contact details for interstate support groups, which assists in passing on the information callers are looking for.

"Somebody has to do something, it is just incredibly pathetic it has to be us".

Jerry Garcia, The Grateful Dead

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Centre for Appearance Research Seminar
Pat Crotty

On 7th February in Melbourne I attended a seminar organised by the Health Psychology College of the Australian Psychological Society. The College sponsored a program presented by staff from the Centre for Appearance Research (CAR) in the UK. CAR is located in Bristol at the University of Western England. Over the past 12 years the co-directors of the Centre Professor Nichola Rumsey and Dr Diana Harcourt, and their staff have been researching the appearance concerns of people with a visible difference. The category 'visible difference' includes a wide variety of conditions from cleft lip and palate, skin conditions to burns scars. In some of their research studies a few people with alopecia have been included.

Currently a total of 30 CAR psychologists are conducting a whole range of studies and the Centre is also involved in policy work, education of the public and health professionals and the development of programs which aim to identify what programs will provide "best care for best adjustment to a visible difference".

Professor Rumsey provided a case for why psychologists should 'do looks'. She explained how originally CAR's focus was on 'disfigurement' but that their focus was now broader because 'appearance concerns' were widespread in the community and that this had recently intensified. As a result, in the community today there is a stronger emphasis on 'looks', there is less diversity in desirable looks (more people desire a similar look) and the 'desired looks' are harder to attain. We now make comparisons with celebrities rather than our peer groups, for example aging women are likely to compare themselves to older famous women who are 'doing well', such as Helen Mirren or Jane Fonda.

Our beauty ideals come from many sources, for children, sources include fairy tales, toys, parents and teachers. For adolescents, sources include friends, video games, the media and social networking. Professor Rumsey noted the practice of adolescents turning the camera on themselves (rather than others), photoshopping the image and then posting it on line.

For adults the sources include magazines, TV, films, advertisements and celebrity culture. She noted that the popular 'make-over' types of programs, strongly equated appearance with happiness and a better life. There is a widespread 'beauty myth' which associates ideal beauty with many positive benefits such as health, success and happiness.

Appearance concerns are important because they can have negative psychological effects on wellbeing and mental health, especially on self perception and self esteem. Some other consequences can be on school

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performance (some young people stay home from school if they're having a bad day), on social relationships and physical health (eg through dieting). About one in five people in the UK have a 'visible difference' and CAR's aim is to promote acceptance of diversity in appearance to the point that a person's 'looks' don't matter.

Some of CAR's most recent research has been studying people who have successfully adjusted to a 'visible difference', in the hope that what CAR finds out, can be incorporated into programs so that more people can learn how to do this. Adjusting to a visible difference means having the skills and mind-set enabling you to get on with your life without the difference being a barrier to living as you would like. (See Rob's Rant on page 2 for his take on this).

The research has found that adjustment is closely related to what people think, for example, Are they optimistic? Are they satisfied with their social support? Are they fearful of negative evaluation? Do they think they are socially accepted, and How do they interpret how other people respond to them?

The good news is that people can learn how to change their thoughts in ways which will help rather than hinder their wellbeing (See our Open Day story pages 6 and 7). Not only that, self help and peer support can be an important part of this learning process which is the stock-in-trade of support groups such as AASA.

A recent outcome of the research program is the development of the "CAR Framework of Intervention Delivery" which provides an integrated model for how people with a visible difference can get access to **"best care for best adjustment to a visible difference"**.

"This was the largest study to date in the field of psychosocial adjustment to disfigurement. One of our key findings was that distress about appearance can impact on a wide range of daily activities – how a person feels about themselves, and how confident they feel about social situations and intimate relationships.

In an ideal world, specialist psychological support would be offered to anyone experiencing such difficulties but this just isn't currently widely available. As a result of this study we have developed a new intervention for psychologists to use with their patients to help them adjust to visible disfigurement and build their self-esteem." Professor Nichola Rumsey.

What can AASA do to ensure that programs based on this model are accessible to people with alopecia? Such a framework would recognise the good work that we already do in our support activities. The support AASA and similar groups offer (1), could become part of a well structured framework that is understood and implemented by professionals from GPs to dermatologists, nurses, psychologist and counsellors.

(1) Printed materials, face-to-face groups, peer support, telephone support lines such as AASA MessageBank etc.

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Open Day Report - 2011

Our day's program was ably chaired by Jenny, who introduced our speakers and exhibitors. We had four main presenters, Ruth Boydell, Rod Sinclair, AAAF, Kylie and her mother Joanne plus the exhibitors who were available for us to speak with, wig suppliers, makeup experts and retailers of interesting headware products.

Ruth Boydell is a family therapist and she spoke about how the ways we think, influence how we feel. However it is possible to learn ways of altering our thinking to improve well being and to lift low moods. There are lots of strategies which are practical, self-help techniques. Ruth brought some excellent handouts, one described unhelpful thinking styles such as using 'should' and 'must' in our 'self-talk', which can result in putting unnecessary pressure on ourselves, a Tip Sheet with 7 good ideas for coping strategies, a Quick Fix List for Bad Days and detailed information on "How Parents can help their child cope with a chronic illness" (Go to page 7 to see them or find a link that will let you download a copy from the web).

Ruth can be contacted at Neo Psychology in Hawthorn, phone 03 98103067. You can find Neo Psychology on the web at www.neopsychology.com.au

Professor Rod Sinclair is well known to many AASA members as a source of interesting and cutting edge thinking about alopecia areata. Some of the points he made were about current thinking on the causation, 'natural history' and treatment of AA. In terms of causation it seems this is an accumulation of possible 'triggers' which starts the hair loss, for example a combination of stress, viral infection, vaccination or pregnancy. It's a bit like playing the pokies, when a line of 4 cherries may come up once but never occur again.

In terms of treatment there is a question about whether treatment actually alters the 'natural history' of the disease. At present the statistics say that 40% of people who get AA will regrow their hair and keep it, 40% will regrow their hair but lose it again and about 20% do not regrow their hair. But does treatment have had an impact on that statistic? He currently believes that the first patch may make it more likely there will be other patches, as the first patch lowers some kind of threshold. This is a reason for trying the strategy of treating a first patch aggressively. It may be possible, that by doing this, the process will be stopped from spreading to other areas.

At the moment he believes that prednisolone offers the best option as a treatment.

Vesna and Sabine from the **Australia Alopecia Areata Foundation** established in 2010, reported on the Foundation's activities covering its mission and objectives and the activities it conducts. The Foundation has a website at www.aaaf.org.au.

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Do these ideas interest you?

Would you like to learn how to put them into practice in a supportive small group of others with AA?

Email us on aasavic@gmail.com

Or

leave us a message on AASA MessageBank with your contact details.

If enough people are interested, we may be able to organise a 'Positive Thinking' session.



Resources from Ruth Boydell's presentation

Unhelpful Thinking Styles.

This interesting information can be downloaded free from the Centre for Clinical Interventions in Western Australia

http://www.cci.health.wa.gov.au/resources/minipax.cfm?mini_ID=14

Tip Sheet

1. Examine your own self-talk and challenge any distorted thinking (reading 'Unhelpful Thinking Styles' will help you to do this)
2. Focus on what you do for your body each day not how others respond to it or view it. You can't control others' responses.
3. Be active in ways that you enjoy
4. Develop many sources of self-esteem
5. Reward yourself for each step you take
6. Get lots of sleep
7. Above all be kind to yourself

Quick Fix List for Bad Days

- Face that you are having a bad day as early as you can. Move into "Bad Day Mode" (ACCEPTANCE)
- Notice your thinking, your mood, your feelings. Don't try to do anything with your thoughts, just notice what they are. Are they helpful or unhelpful?
- Ask your self "What do I need?" Sometimes the best thing to do is to push through and sometimes it's best to have a rest. Only you know.
- Where possible get rid of unnecessary/unhelpful things to do/people to see.
- It helps some people to try to work out what led to the "bad day" e.g. Being overtired, worried about something/someone
- If you like writing, write down significant events (good or bad) that arouse strong emotions. (This can help get it out of your mind, down on paper. It's called externalizing).
- Choose something from your **Top 5 Good Things To Do** list. (On bad days we often cannot come up with new ideas)

Create your own list: "MY TOP 5 THINGS TO DO ON BAD DAYS"

How parents can help their child cope with a chronic illness

<http://www.parenting-ed.org/handouts/coping%20with%20a%20chronic%20illness.pdf>

This can be downloaded free from the Center for Effective Parenting in the US

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AASA Open Day 2012 at the Skin and Cancer Foundation in Carlton



You can view the complete photo gallery from the link on our web page www.vicnet.net.au/~aasa



Ruth Boydell
From Neo Psychology spoke on Positive Thoughts



Prof Rod Sinclair spoke on the latest research



Kylie and her family discussed their experience with alopecia areata



Sam from Angel Wigs served delicious coffee



And lunch was delightful!

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AASA received this much appreciated letter from Kathryn Swales

Dear Patricia

Saturday was a wonderful day due in great part to the organising team of AASA.

Jenny was magnificent in the role of MC - fluent, good humoured, excellent preparation with accurate information. The visiting suppliers were well introduced and treated with respect. She is a beautiful person in presence and character and perfect to look at as MC for the day.

The discussion session on individual choice, 'to cover or not to cover' was an exceptional concept. Kylie's family's presence with her in the forum said everything. The candour of this exchange was rivetting. Please continue such personal narratives in future sessions.

I would walk miles to hear Professor Rod Sinclair speak and we are utterly indebted to his patronage of our day. New information this year and a sense of hope...!! He is articulate, charming and working at the forefront of research. We are so lucky to remain a priority amongst his commitments.

The two women who spoke about their efforts in raising awareness of Alopecia in the media and in fund raising, showed what it is to be the backbone of our assembly, informing people out there as to the nature of alopecia and its personal and familial impact. Thank goodness for their energy and commitment.

Salute to Angela and Sam for their endless support of this day - real coffee has its ardent appreciators. The catering was magnificent and congratulations need to go in that direction.

I look forward to this Open Day each year. I honestly find that it's an essential pick-me-up in my attitude and experience of this peculiar condition that we share. Thankfully it didn't clash with the Spring races this year and the day out with friends that I really enjoy. Maybe a Sunday is worth considering if you time it for October next year.

Organizers are often faceless, though very precious workers. You ensure that whilst we may feel less than robust at times, we do count because we have mates like you who work on our behalf. Well done and thank you.

Kathryn Swales

Thankyou Kathryn for your generous comments, for letting us know you enjoyed the day and for allowing us to publish your letter. We will certainly consider your suggestions of including more personal narratives and a possible Sunday Open Day in future. Ed.

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Did You Know?



Did you know?

Octavia Spencer, who is favoured to win the Oscar for best supporting actress for her role in "The Help", has alopecia. In a recent interview she reported

"When I was 28 years old, I was on Broadway, and I just thought I could handle that success, and I lost my hair. I lost my hair because I was stressed out, because I think I read a bad review ... I had alopecia areata.

Now at 46, I just let so much of that go ... you just start to connect the dots and realize at the end of the day you really have to define joy and happiness for yourself, and I'm so glad all of the scrutiny and exposure is happening now,"

Good Luck Octavia!!

You can read more about Octavia on the web at this address

http://www.bhcourier.com/article/Local/Local/Oscar_Nominees_Lunch_at_Beverly_Hilton/85342

Did you know?

There are web sites for people with alopecia in Germany, Italy France and Spain (and elsewhere)?

Germany

Alopecia Areata Deutschland

<http://www.kreisrunderhaarausfall.de/15.html>

Italy

1. Associazione sostegno alopecia areata

<http://www.sosalopciaareata.org/>

2. Associazione Nazionale Alopecia Areata

<http://www.anaa.it/>

Spain

Asociación de Apoyo a los Afectados de Alopecia Areata

<http://www.areata.es/>

France

Mon Alopécie

<http://mon.alopécie.free.fr/>

We are curious about Alopecia support organisations around the world and we would love to give our newsletter an international flavour.

If you speak German, Italian, Spanish or French and are interested in writing a short update for our quarterly newsletter about the activities in these associations, send us an email at aasavic@gmail.com or better still, just write us something for our May newsletter!

Remember, February 25th, Saturday 2 pm is our regular quarterly meeting.

We look forward to sharing coffee and a chat with you