



Support services since 1980

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## February 2011

### What's in this issue?

Complementary and Alternative Medicine in AA

Multi vitamins and herbs for AA

Recently in print

\* Helping people cope with hair loss more important than medical treatment?

\* Quality of Life and Female Pattern Hairloss

Goodbye A&EP Hello SWEP

Celebrities in the Media. What's the message?

Health Action Group

Next members' meeting

Our next Members' Meeting will be  
2pm on  
26th February, 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 in this issue?*

This issue of the AASA newsletter has a few changes.

You will notice that our banner has been updated and we have added a slogan to our logo.

Because we tackle some serious subjects we also have (hopefully) some things to laugh about. The selection of visual jokes from the wonderful site [icanhascheezburger.com](http://icanhascheezburger.com) is a possibly poor reflection on the editor's sense of humour, but we hope you like them.

The topics in this issue are all timely, from the consideration of Complementary and Alternative medicines and what they offer as a form of therapy for people with alopecia, to the changes that have recently taken place in the administration of the Department of Human Services wig subsidy program. What was once A&EP is now SWEP.

One of our favourite themes in the past few years has been how AA affects quality of life. In this issue there is a summary of a new Australian study on quality of life for women with Female Pattern Hair Loss which suggests the need for psychological support services to be more available and 2 UK dermatologists make the groundbreaking suggestion that it may be time to consider that helping people cope with hair loss

could be more important than medical treatments and that more attention should be paid to research into the value of areas such as 'counselling services, prosthetic support, and self-help groups than has been the case to date'.

We may be seeing the start of a new way of 'treating' people with alopecia.



We hope you enjoy this edition and look forward to meeting many of you on the 26th of February at the Skin and Cancer Foundation in Carlton.

The editor

February 2011

### Complementary and Alternative Medicine in Alopecia Areata

The authors of this article provide an overview of 13 studies that have been published on complementary and alternative medicine (CAM) used in AA. One author is affiliated with the AA patient organisation in Maastricht in The Netherlands (van den Biggelaar)

In the introduction they say,

“Alopecia areata is an unpredictable hair-loss condition. As there is no cure for alopecia areata and no effective conventional therapy, a substantial number of alopecia areata patients resort to complementary and alternative medical remedies and therapies”.

The therapies that were studied included homeopathy, hypnotherapy, aromatherapy, onion juice, garlic gel, Vitamin A, massage and acupuncture. Whilst all these studies recorded positive results (some of the studied people had hair regrowth), the authors have reservations about this. Firstly the study methods were not strong enough to give confidence that the results were reliable and secondly they say because no study reported negative results (ie. that the method studied **wasn't** successful) they think that publication bias was at work. Publication bias occurs when only positive results are reported in the literature. Studies with negative results may not be written up and published, that is researchers in this area may only report the 'good news'.

Unfortunately, none of the 13 studies were good enough to provide robust evidence of the benefit of CAM. The nature of Alopecia Areata requires an especially solid trial design to properly assess the therapeutic effects of any treatment, for example distinguishing between spontaneous regrowth and regrowth caused by a treatment.

The review concludes with some recommendations for improving the quality of trials incorporating CAM in the treatment of alopecia areata. They emphasise that hair growth is not the only outcome of a treatment, the impact on a person's wellbeing is also important, as is a treatment's safety and any adverse effects from it.

Because the use of CAM by AA patients is so common the authors think that doctors should be familiar with this practice and understand their patients' use of CAM and why their patients have confidence in these methods, despite their unproven nature.

Some of the CAM methods studied may eventually find a place in the treatment of AA but it will require more and better research to establish this.

Frank J H M van den Biggelaar, Jost Smolders and Jacobus F A Jansen  
Complementary and Alternative Medicine in Alopecia Areata Am J Clinical Dermatology  
2010;11:(1), 11-20



Source:  
[icanhascheezburger.com](http://icanhascheezburger.com)

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## Multi Vitamins and Herbs for AA: Fusion Vitamin Tablets

Recently you may have seen an article on Today Tonight about Willow, a young girl who has alopecia, and how her parents had started her on Fusion Health Multi Vitamin and Fusion Health Women's Balance tablets. The Women's balance tablets contain Chinese herbs.

It is now 12 months since she started them, and the majority of her hair has grown back. One of our young members has also started on these vitamins. After just 2 weeks his mum could see a 'shadow' appearing on his scalp and after 11 weeks, there is a change happening on his scalp. Not all of his patches are re-growing but his hair is thickening up and getting longer. Some of you may have already tried these tablets, and I would love to hear if you had any re-growth from them.

Fusion Health are donating some supplies of these Vitamin and herbal tablets for our members to try. If you would like to know more about the company and the tablets, their website is [www.fusionhealth.com.au](http://www.fusionhealth.com.au) or you can contact the Fusion Health advice line on 1800 550 103.

If you would like to try these vitamins, you can contact me directly on 9776 0488 (after 7pm) or email [tridley@optusnet.com.au](mailto:tridley@optusnet.com.au)

Terrie Ridley

### **Please Note:**

**The Alopecia Areata Support Association of Victoria does not endorse this product in any way.**

Alopecia Areata is an unpredictable, chronic disease and spontaneous regrowth and relapse is common, especially if the person is initially affected as a child. In the absence of well-designed studies, it is difficult to attribute hair growth to any particular treatment. There are no such studies available for these products.

Always tell your doctor if you are taking herbal and vitamin supplements, they may interact with medications you are already taking.

### **More information:**

Booklet from the US National Institutes of Health

[http://nccam.nih.gov/health/NIH\\_Herbs\\_at\\_a\\_Glance.pdf](http://nccam.nih.gov/health/NIH_Herbs_at_a_Glance.pdf) (15Mb)

<http://www.nlm.nih.gov/medlineplus/herbalmedicine.html>

Also see our article in this newsletter about Complementary and Alternative medicine in AA (page 2) and the state of current knowledge on medical treatments for AA.

## Know your medicines - Read the label on your medications

What is Dong Quai?

Some Chinese medicines contain this Chinese herb. An information pamphlet from the US National Institutes of Health informs people that this herb slows blood clotting. It is wise to ask your pharmacist for advice if you intend taking a product containing this herb, especially if you take blood thinning medication.

<http://www.nlm.nih.gov/medlineplus/druginfo/natural/936.html>

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## Helping people cope with hair loss may be more important than medical treatment.

The authors of this paper published in 2009, are from the Department of Dermatology at the Royal Hallamshire Hospital in the UK. The paper is basically a review of evidence for the effectiveness of commonly used medical treatments of AA. This has been the subject of a number of publications in the medical literature since the [Cochrane Collaboration's Review](#) was published in 2008 which was discussed in this newsletter in the May edition in 2008.

In the Cochrane Review the authors found 17 high quality studies and concluded "Only one study which compared two topical corticosteroids showed significant short-term benefits. No studies showed long-term beneficial hair growth. None of the included studies asked participants to report their opinion of hair growth or whether their quality of life had improved with the treatment" (1).

This latest paper by Garg and Messenger, concurs with the 2008 Cochrane Review in this respect and reiterates that the natural history of the disease is not altered by any treatments. AA runs its course despite treatments, rather than because of them.

There are some interesting statistics included  
10% of people with AA have nail involvement  
34-50% of people with patches recover within a year (spontaneous recovery), but the relapsing nature of AA needs to be discussed with patients (2).

Basically, whilst people with AA may experience spontaneous recoveries, there may also be recurrent relapses and for some the outcome may be permanent hair loss. Patients who first come to medical care with alopecia totalis/universalis still have severe disease in the long term and of those first coming with patchy disease only about half have been found to be disease free in the long term.

The final paragraph of this paper breaks new ground in suggesting that doctors may be beginning to think about the care of their AA patients in a different way.

*"..... management aimed at helping patients cope with their lack of hair is probably of greater importance than medical treatment.....until more effective therapies become available, clinical research in AA should perhaps place greater emphasis on the value of areas such as counselling services, prosthetic support, and self-help groups than has been the case to date".*

At this stage it might be better to think in terms of improving the availability of services of this type first and researching their impact after they are established.

(1) See the report of Biondo and Sinclair's Australian study.

(2) See this issue on the role of celebrities with AA



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### Quality of Life in Australian Women with Female Pattern Hair Loss

Psychosocial aspects of AA are being given more importance and a new Australian study discusses related issues in Female Pattern Hair Loss (FPHL), sometimes called androgenetic alopecia. This form of hair loss is more common than AA, it is estimated that 800,000 women in Australia have moderate to severe FPHL.

The figure for all forms of AA for Australia would be very roughly around 35,500 and for Victoria 8,500, based on a figure of 158 people in 100, 000 having AA.(1)

The authors of this paper will be familiar to many in the AA community. Professor Rod Sinclair, dermatologist and Seba Biondo a psychologist are both associated with the Skin and Cancer Foundation in Victoria.

In this research study the authors have looked at the impact of FPHL and its treatment on the quality of life of affected women. In addition the study looked at whether consultation with a dermatologist and commencing treatment had an impact on their quality of life (QoL).

One hundred and twenty seven women filled in a questionnaire on 2 occasions, 2 months apart. The study shows that prior to starting treatment women with FPHL had lower QoL than those in the study not affected. The QoL of the women who went on to treatment was not improved.

The most distressing aspects for the women was concern over whether their hair loss would continue and their appearance, for example their inability to style their hair, worry about their hair loss showing, feeling unattractive and feeling jealous of women with lots of hair.

In a recent study by Cartwright and others, in which 90% of the people studied had AA, illness perceptions which reduced QoL included the number of symptoms people associated with AA, how serious they perceived the consequences of their AA to be and if they had a strong emotional response to their AA.

Drawing on Cartwright and others study, the authors advocate that paying attention to individual's 'illness perceptions' is a consideration in helping women with FPHL too, and that research should be undertaken to see if there is a role for psychological interventions in the treatment of hair loss.

(1) Alopecia areata epidemiology and clinical disease patterns (<http://www.keratin.com/ad/ad038.shtml>).

Biondo S and R Sinclair Quality of life in Australian women with Female Pattern Hair Loss The Open Dermatology Journal 2010;4: 90-94

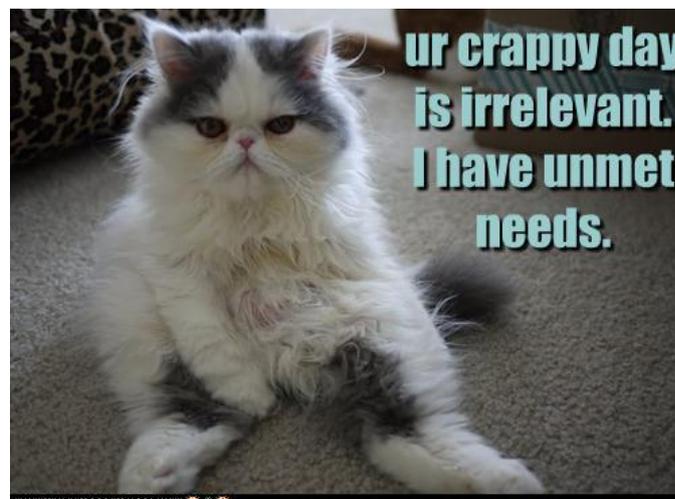
Cartwright T, N Edean, and A Porter Illness perceptions, coping and quality of life in patients with alopecia British Journal of Dermatology 2009;160:1034-1039

Seeking information or support?

Phone the AASA  
MessageBank  
(03) 9513-8580.

A group member will  
return your call within 24  
hours.

Source:  
icanhascheezburger.com



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## Goodbye A&EP, Hello SWEP

The Aids and Equipment Program (A&EP) which previously supplied a wig subsidy to people with alopecia has been replaced. The new program is called the State Wide Equipment Program (SWEP).

SWEP is a program of grants funded by the Department of Human Services and administered by Ballarat Health Services.

Ballarat Health Services was appointed as the state-wide administrator of the aids and equipment program in August 2010 following a competitive selection process. The State-wide equipment program provides people who have a permanent or long-term disability with subsidised aids, equipment and vehicle and home modifications.

The benefits available are

Two basic synthetic wigs (or equivalent contribution towards human hair wig, or more expensive synthetic wig up to the subsidy cost) \$240 per 2 years

One human hair wig (child 16 years and under) \$600 per wig

You will need to fill in an application form and have a letter from your GP to say that you have permanent loss of hair as a result of disease or disability.

If you have previously used the A&EP, your records will be transferred to SWEP automatically and the procedure to obtain the subsidy remains the same.

You can download an application form from the SWEP website  
<http://swep.bhs.org.au/>

### Contact Information for SWEP

Hours of Operation 8.30am to 5.00pm - Monday to Friday

Telephone 1300 747 937 or 03 5333 8100

Fax 03 5333 8111

Postal Address PO Box 577 Ballarat Vic 3353

### There are 6 municipal areas and groups of Issuing Centres

#### Group 1.

##### Council Areas:

Ararat, Ballarat, Colac Otways, Corangamite, Geelong, Glenelg, Golden Plains, Grampians, Grampians (Southern), Greater Queenscliff, Hepburn, Hindmarsh, Horsham, Moorabool, Moyne, Northern Surf Coast, Pyrenees, Warrambool, West Wimmera and Yarriambiack.

##### Issuing Centres:

Ballarat Health Services, · Barwon Health, South West Health Care, · Western District Health Service, · Wimmera Health Care Group

#### Group 2.

##### Council Areas:

Alpine, Baw Baw, Bass Coast, Buloke, Campaspe (North), Campaspe (South), Central Goldfields, East Gippsland, French Island, Gannawarra, Greater Bendigo, Greater Shepparton, Indigo, Latrobe, Loddon, Macedon Ranges, Delatite, Mildura, Mitchell, Moira, Mt Alexander, Murrindindi, Rural City of Wangaratta, South Gippsland, Strathbogie, Swan Hill, Towonga, Wellington and Wodonga

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**Issuing Centres:**

· Bairnsdale Regional Health Service · Bass Coast Regional Health · Bendigo Health Care Group · Gippsland Southern Health Service · Goulburn Valley Health · Northeast Health Wangarrata · Sunraysia Community Health Services · Swan Hill District Health · (Albury) Wodonga Health

**Group 3****Council Areas:**

Knox, Manningham, Maroondah, Monash. Whitehorse and Yarra Ranges.

**Issuing Centres:**

Eastern Health – Box Hill Hospital · Eastern Health – Maroondah Hospital · Southern Health – Monash Medical Centre

**Group 4.****Council Areas:**

Bayside, Cardina, Casey (East), Casey (West), Frankston, Glen Eira, Greater Dandenong, Kingston, Kingston (Chelsea), Mornington Peninsula, Port Phillip and Stonnington.

**Issuing Centres:**

· Alfred Health - Caulfield Hospital · Peninsula Health - Mount Eliza Centre · Southern Health - Dandenong Hospital

**Group 5.****Council Areas:**

Banyule, Boroondara, Darebin (North), Darebin (South), Hume, Melbourne, Moreland, Nillumbik, Whittlesea and Yarra.

**Issuing Centres:**

· Austin Health - Heidelberg Repatriation Hospital · St Vincent's Hospital · Melbourne Health - Royal Park Campus · Northern Hospital

**Group 6.****Council Areas:**

(Brimbank, Hobsons Bay, Maribyrnong, Melton, Moonee Valley and Wyndham.)

**Issuing Centres:**

· Western Health - Sunshine Hospital · Royal Children's Hospital (Statewide)

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### **Celebrities in the Media. What's the message?**

Recently 3 major stories in the media about women with alopecia had at least one thing in common....they were all giving the message that beautiful women can be bald and still beautiful.

However, if you're not conventionally beautiful in the first place, having alopecia won't make you that, but it won't make you less of a great human being either.

The 3 women are Gail Porter who is a well known TV personality in the UK. Gail is beautiful and has been featured in stories in the newsletter before. She lost her hair to AA, regained it and is now losing it again.

Kayla Martell entered the Miss America Pageant for the 5th time and was very successful having been placed in the top 10 entrants whilst being open about her hair loss. This time she competed wearing a wig.

Gergia van Cuylenberg is an Australian who is making a film about her experience with alopecia. She is a beautiful woman making a career as a comedian in Los Angeles. In a morning TV appearance in Australia she showed that her hair had regrown.

Is the message 'bald is beautiful'?

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**What are AASA's services?**

- Annual Open Day
- Newsletter, published quarterly
- Message Bank phone contact: (03) 9513-8580
- Email contact: [aasavic@gmail.com](mailto: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

**Are you interested in joining a working group  
'Health and Quality of Life in Alopecia Areata'?**

A group like this could raise some important issues and gather ideas. It could influence services for people with alopecia in a positive way. It might be a group which meets face to face or we could be a 'virtual' group using an IT application to identify and discuss issues that interest us, such as Skype or even Moodle.

Although this is not an AASA group, within AASA members and friends there must be people with an interest in and/or professional knowledge relevant to health and wellbeing.

I have a background in food and nutrition and this year I'm doing a course in counselling.

If you are interested in working in a group like this, please contact me on email, [head2head\(AT\)quotidian.net](mailto:head2head(AT)quotidian.net) and I can give you my phone number and Skype contact.

Pat Crotty

