



Support services since 1980

# Alopecia Areata Support Association (Vic) Inc.

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Registration No. 0017172V

## November 2011

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Members' Meeting  
will be in

February  
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For the latest  
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#### 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.

### President's Column

Hi, I'm Garry, the new president of AASA,

Welcome to our November newsletter!

Today I met someone who noticed I have no eyebrows, and she told me that her daughter had been affected by alopecia areata as a child.

I often run into people who know of someone affected by AA.

I tried to find AASA in the phone book. After much searching I found it in the business section. As life these days, seems to becoming more stressful for people, there is now more need than ever for a support group.

I would like AASA to 'come out' more as a support group because there is a need out there and people don't know who to talk to, nor that there is a support group available.

I'm hoping to live up to the tradition that Terrie has established as president and continue working for the benefit of members and I'd like to take this opportunity to wish everybody the best for Christmas and the New Year.

I hope we'll see new changes in AASA in the New Year and I look forward to being part of that and the challenges ahead in 2012.

I'm looking forward to meeting everybody at Open Day.

Take Care and Best Wishes,

Garry

### AASA President 2011-2012

At our AGM in August, Garry Lonsdale was elected president for the year August 2011 to August 2012.

Garry has been on the committee for 2 years and is a volunteer in our Message Bank service.

Welcome Garry to your new role and we hope you will enjoy the experience.

Thankyou to our immediate Past President Terrie Ridley for her work and especially for organising our upcoming Open Day on November 26th at the Skin and Cancer Foundation.

You will find more information on the day from Terrie on page 2.

AASA will conduct an informative day in a small, private venue and we hope everyone who comes will take the opportunity to try some thing new! It might be make-up, a different wig or a conversation about your hair loss that you don't usually share but would like to.

You will be amongst friends with similar experiences to yours and who understand what you're talking about!

The President and committee look forward to welcoming you to AASA Open Day 2011.



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Seeking information  
or support?

Phone the AASA  
MessageBank  
(03) 9513-8580.  
A group member  
will return your call  
within 24 hours.

You can also email  
us  
aasavic@gmail.com

### Open Day 2011 - What's it about?

This day is for people of all ages who have alopecia areata or care about someone who has. It will provide you with the latest information on medical and research updates to better understand and manage alopecia areata. It will also provide you with a wealth of support.

- o Learn from stimulating discussions about medical and research updates.
- o Experience a variety of wigs types, head coverings and accessories
- o Share personal connections with others who care.
- o Meet others to exchange ideas, support and advice.
- o Gain knowledge of products helpful to those with alopecia areata.
- o Learn you are not alone.
- o Unwind in an attractive setting with a warm, relaxing atmosphere.
- o Become empowered to go home and make a difference.

### Open Day Programme and Activities

#### Our Guest Speakers

Professor Rod Sinclair -The Director of the Department of Dermatology at St Vincent Hospital in Melbourne, has a passion for hair loss research and will share his team's findings at our Open Day.

We all have 'good and bad days', but living with Alopecia can make bad days worse. Ruth Boydell Social Worker and Family Therapist will talk on maintaining positive thoughts and give strategies on how to lift your mood.

#### For parents

Does your child not want to cover-up? Have you thought about throwing your wig away? Join in a group discussion about what to expect, how to handle it and enjoy the outcome.

#### For children

There is a bundle of activities organised for the children, so they can have a fun day while mum and dad learn more about Alopecia and chat to other parents – you are not alone.

#### For everyone

Hats, Caps, scarves, makeup, eyebrows, eyelashes, info on cosmetic tattooing.

Want to know what the private health funds will contribute towards your wig? Let us put you in the picture with all the major funds, and government funding.

#### Did I mention the food???

No need to run all over town - experience a range of wigs, all in the one place! Synthetic wigs, human hair, filament base, off the peg, custom made, gripper wigs, hair pieces, suction wigs. Private rooms to check out these goodies.

Lucky door prizes – many great gifts and vouchers to be won!

Terrie Ridley  
Open Day organiser.

Alopecia Areata Support Association



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## Alopecia Areata Support Assn (Vic) Inc Annual Open Day

Saturday 26<sup>TH</sup> November 2011

Limited numbers - Registration is essential

**VENUE: Skin and Cancer Foundation 80 Drummond Street Carlton**  
(cnr Queensberry and Drummond Street) – wheelchair access available

**Please note:** This is a preliminary program and is subject to change without notice.

### PROGRAM:

**Morning, afternoon tea and lunch provided**

9.30 am	Registration with a "cuppa" and friendly faces
10.00 am	Welcome and introduction to the day
	Childrens program, so many things planned, too many to mention
10.10	Ruth Boydell – Family therapist / Social Worker – will talk on maintaining positive thoughts and give strategies on how to lift your mood when you're having a down day.
11.00	Cuppa break
11.15 am	Professor Rod Sinclair – Leading Dermatologist on Alopecia, will update us all on current research and treatments for Alopecia Areata, along with question time
12.30	LUNCH
1.30	Introduction of Presenters & loads of Lucky Door prizes
2.00	Children's program, continued
2.00 - 4.00	Joanne & Kylie Clark – a mum and daughter's perspective on choosing not to wear a wig – with Ruth Boydell
	Workshops – wigs, hats, cosmetic tattooing, makeup artist (bring along your own makeup for an instant makeover)
	What you can expect to get from Private Health Funds when purchasing a wig, and also what government assistance is available through the State Wide Equipment Program (SWEPE)
4.00	Close of the Day

Cost: **Adults \$25.00,**  
**Children over 5, Students and card holders \$15.00;**  
**Family members ticket \$55**

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### The State-wide Equipment Program: Subsidy for wig purchases

This program enables people with medically certified hair loss, to receive a subsidy for wig purchases. For adults this is \$240 every two years. For children under 16, the subsidy is \$600 per human hair wig.

This program replaced the former Aids and Equipment Program (A&EP), but is essentially the same with the same level of subsidy. The subsidy is not paid retrospectively, that is you cannot purchase your wig and then apply for the subsidy. You must be notified by SWEP that funding is available for you before you can obtain your wig. The subsidy is paid to your supplier, not to you, **you pay the difference** between the subsidy and the actual cost of the wig, **to your supplier**.

You will not be eligible for the subsidy if you can claim against your private health insurance extras.

The SWEP web page explains all the requirements to get a subsidy, but we have also added here, some comments based on the experience of AASA members, and some of the questions they have raised.

#### Basic Steps

##### 1. For those who have not had a subsidy previously

If you have not applied for a subsidy in the past you will need to get on to the SWEP database. You only need to do this once. You will need to fill in an application form (Application/Eligibility Form) which is downloadable from the SWEP website or you can be mailed one by requesting one from SWEP

(SWEP form

[http://swep.bhs.org.au/sites/default/files/forms/Application%202011\\_0.pdf](http://swep.bhs.org.au/sites/default/files/forms/Application%202011_0.pdf))

Page 4 of the form is for your GP or dermatologist to certify that your hair loss results from a medical condition (SWEP says: ..(a wig) "*May be provided to persons suffering from permanent loss of hair as a result of disease or disability*"). Don't let the term 'permanent' stop you from applying if your hair comes and goes because this is the nature of AA and to our knowledge no one has been excluded on 'not permanent' grounds.

Post your completed form to  
SWEP  
A&EP Department  
PO Box 1993  
Bakery Hill 3354.

You can contact SWEP 8.30 am to 5 pm Monday to Friday  
phone: 1300 747 937 or 03 5333 8100  
fax: 03 5333 8111

SWEP will inform you they have received your application. SWEP will then notify you when funding is available for you to be able to go to the supplier you have nominated and purchase the wig that you want as detailed below.

##### 2. For those who have received a subsidy in the past

If you are already on SWEP's database, that is you have applied for the subsidy in the past under the Aids and Equipment Program, contact SWEP and let them know you need another wig and they will be able to tell you how long the waiting list is (currently we are being told 9 months). They will notify you when funds are available. You MAY be asked to send SWEP a quote from your chosen supplier (not everyone has been asked to do this). If this happens you need to go to your supplier, choose the wig you want, get your supplier to give you a quote and you then mail this to SWEP.

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SWEP will contact your supplier and you, to let you know when you can purchase your wig. SWEP sends the cheque to your supplier and you will then pay the supplier the difference between the subsidy amount (paid directly to your supplier) and the cost of the wig.

Firstly you need to do your wig 'shopping' before submitting your form. There are some variations in SWEP practices, for example some members have been able to divide the subsidy into \$120 a year instead of \$240 every 2 years. The SWEP web page notes,

*The replacement of a wig will be available after a minimum of 2 years, subject to reassessment by a general practitioner.*

There is a school of thought that as soon as you receive your wig, you should ask to go back on the waiting list immediately. This seems to be a practical way of coping with the fact that synthetic wigs only last around 12 months and if the waiting list is 9 months, this strategy would help ensure that a satisfactory and well maintained wig is available continuously for the person. But this would depend on whether the subsidy could be divided into \$120 a year. At present we do not know what the SWEP response to this might be. This may not concern someone who maintains 2 wigs and only wants to purchase new wigs every two years, but even in this case if the waiting list is 9 months, planning ahead about the best time to get back on the waiting list is still important, to avoid a lengthy delay in getting a new wig.

Also there are all sorts of specific circumstances in which the scheme may not meet a person's needs, for example if there are circumstances where a person needs a wig straight away such as in a case of accidental damage. Most people know that opening ovens wearing a synthetic fibre wig risks ruining the fibres, but it's very easy to overlook this.

If you are interested in raising issues of concern to you about wig subsidies and supplies, come to the Open Day when there will be an opportunity to get more information and get answers to your questions. We will also have information available on private health insurance companies' extras benefits.

Thankyou to those who shared their experiences with the subsidy program especially the head2head members in Geelong.

Walk proud!

