

Alopecia Areata Support Association (Vic) Inc.



PO Box 89 Camberwell 3124
03 9513 8580
<http://home.vicnet.net.au/~aasa>
Registration No. 0017172V

August 2009

In this issue:

Distressing truth about alopecia

Rob's Rant

GST on wigs - an ongoing saga!

Alopecia: I wish I could be bald and proud

Annual General Meeting on 29th August 2009

Open Day 2009

New AASA website

Natalie from Chiquel Salon and Fine Wigs, will be our special guest at our Annual General Meeting on 29th August. She will be showcasing some of her products available to people with Alopecia.

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 Report

Hi everyone, I hope you are all weathering the winter OK.

We are coming to the time of year again when we have our Annual General Meeting (AGM), Saturday 29th August to be precise. At the AGM we will be spilling all committee roles and asking for volunteers and I would now like to say that we need your help. As you are no doubt aware, AASA is a support group and the management committee is made up of a few volunteers. The things that need to be done to keep the group functional and meaningful are not big things but they do need to be done. I am asking you to consider putting your name forward if you have any interests, hobbies or skill sets that you would like to pursue or utilise, while at the same time making a contribution to the group and the broader community. Some of the things you might like to consider doing are:

a. Doing some research on the net for any bits of information we could use for the newsletters. I know that there will many of you who spend time surfing around and I am sure it wouldn't take much more time to do a bit of fishing for us!

b. Updating our website;

c. A little bit of book keeping;

d. Seeking out some potential speakers we could have for our quarterly meetings or workshops ;

e. Being on the support line group, which simply means responding to a few incoming calls from people to our voicemail once every month or so;

f. Managing or little support line group, which is making a reminder call once a week to the next person on the roster and taking some stats;

g. Communication and marketing ideas;

h. Being a part of the committee to think about how we can better support our members and others who are touched by alopecia in some way;

Any contribution you could make will be a worthwhile one.

Remember that many hands make light work. Please send us an email if you can help in some way. You can also give me a call on 0411 268 042 or at home on 03 9583 5658, if you would like to have a chat about any of the little jobs that you might like to do.

Take care and we look forward to seeing you at the August Meeting and the AGM!

Julie Billings, President

August 2009**Housekeeping Notes:**

Your newsletter editor:
Robert Chan

E-mail address:
aasavic@iprimus.com.au

Postal address:
PO Box 89
Camberwell 3124

4 newsletters a year
and all contributions
by:

Mid October for
November edition
Mid January for
February edition
Mid April for May
edition
Mid July for August
edition

2009 Meeting Dates:

28th February 2009
30th May 2009
29th August 2009
28th November 2009

Next Meeting
29th August 2009
Skin and Cancer
Foundation
80 Drummond St,
Carlton
(cnr Queensberry
and Drummond St)

All meetings are on
the last Saturday of
the month in
February, May,
August and
November,
commencing at
2.00pm.

Distressing truth about alopecia

Like the elephant in the room, alopecia is a subject people tend not to talk about.

Doctors have little knowledge of the reason for the loss of hair and no cure has been found, as Sunshine Coast sufferers Ivonna Mroz and Pat Law know full well. Underneath the wigs and cosmetically tattooed eyeliner and eyebrows, both women are bald.

No, they are not dying.

They are as healthy as the next person, though quite often they are mistaken as having cancer - an honest mistake, but one which negatively affects anyone with alopecia (pronounced al-oh-peeshia).

"If we go out in a scarf, you feel like such a fraud because we're not sick," Pat said.

Ivonna said that without eyelashes or eyebrows, she had no colour on her face, which made her look sick and pale.

"We don't want people to feel sorry for us," she said. "We just want to go out and be able to enjoy the day without worrying about our hair falling off, or just be able to go for a swim without losing our hair."

Ivonna, 29, suddenly developed alopecia at age four, after her family moved to Australia from Poland.

"It wasn't until I was in Grade 4 or 5 that it got really horrible," she said. "Kids would single you out because you were different - I really feel for any kids that are different at school."

As a result, Ivonna was subjected to bullying as a child.

"Kids would hide your wig when you go swimming or just pull it off," she said.

"They would just give me a hard time about it and I never really did much sticking up for myself."

Around the house, Ivonna wears a scarf but she is still trying to be comfortable with wearing it in public.

"I've just started wearing my scarf to the beach, too, now," she said. "Before, I was like, 'No, I don't want to do that' because I didn't want to attract any unwanted attention, so I was always wearing my wig."

"But then, I could never go swimming. So I thought, 'No, stuff it. I'll wear my scarf and if people look, they look'."

Even though her acceptance of the condition has taken nearly 20 years, Ivonna has bad days.

"I still have days where I get frustrated because it feels like such an effort to get up in the morning," she said. "It would be great to have it back, but I'm not struggling with it anymore, like I used to. It is a part of me now."

Pat, 59, started losing clumps of hair at 38. After about nine months, she had lost almost all her locks.

"You don't realise, until it happens, how much your idea of yourself is all wrapped up in your image," she said.

As a mother of two, she also watched her family go through her suffering.

"I always had to cover it up and pretend I was OK with it," she said. "I remember once, when I was in the bathroom and looking at myself in the mirror, I thought, 'What a freak? What is going on here?'"

In her mid-40s, in what she thought was a miracle, Pat's hair started growing back. But after a couple of years, she lost it again. "The second time around, I had the internet and that was such a life-saver for me," she said.



August 2009

Seeking information or support?

Phone our MessageBank on (03) 9513-8580.

A group member will return your call within 24 hours.

"When it started falling out again, I thought, 'I cannot go through this again'.

"People would give me funny looks and I didn't have it in me to tell them what was happening.

"I found that when I did, they would come up with all this crazy advice and it got a bit disheartening."

At times, she said she had felt unattractive and "weird looking", but talking about the condition and having the support of her family has helped Pat accept a life with alopecia.

"When I first lost my hair, I scared myself, so I can understand why people get a bit freaked out when they see a bald woman," she said. "I do miss my eyelashes. More than anything, that makes you feel bald, but it's a part of me now.

"Talking to others on the internet has been a big saviour for me to realise I'm not alone.

"People just need to break the silence, because it can be quite an isolating thing."

Ivonna said sufferers needed to work around the obstacles of alopecia, or regret it.

"I just grew up and realised there is more to life," she said. "People shouldn't stop their life because of it. I've missed out on a lot of things because of alopecia. Just look at the bright side of it and that's how you overcome it."

Ivonna and Pat are not the only ones who suffer this mystery condition and encourage any sufferers to talk about their condition, rather than hide it.

Written by Felicity Richardson, originally published in the Sunshine Coast Daily Online (<http://www.thedaily.com.au/news/2009/may/28/distressing-truth-about-alopecia/>)



ROB'S RANT

Welcome to the last ever issue of the AASA Newsletter. Do I have your attention now? How about if there is to be no more annual Open Days? The scary thing is though, that it may not be far from the truth.

Here at AASA, we need your help! As Julie mentioned in her President's Report, the few of us here at AASA are volunteers, and without some extra help, we are in dire straits of running out of resources. Besides myself, who has only been part of the committee since 2007, the stalwarts of the AASA committee have been involved with the group for many years, and it's about time they had a well deserved break!

If you are thinking, "What possibly could I do to help?", let me ask you this.

Do you ever buy groceries from the supermarket? Well, you can also provide tea and biscuits at our general meetings. Or, if like myself, you've been consumed by Master Chef for the last three months, feel inspired to whip up some crazy Afternoon Tea pressure test, then by all means, go for it!

Or do you ever spend your spare time surfing the internet? Well, you can become Executive Research Assistant (some fancy title I just made up), and provide help with content for the newsletter and website.

Or do you love nothing more than spending all your spare time talking away on your mobile phone? Then why not join the support line, and speak to people that really just need someone they can relate to.

You see, every little bit helps. It may even be a service you can provide. If you own, or work with a business, and you think there is some tiny little aspect that you can help with, then let us know! We're sure we can find some good use for it. The annual Open Day is our biggest event of the year. But as we are a non-profit group, the costs for hiring a venue, catering and logistics are getting more and more expensive. If you think you can offer anything in terms of event organisation, then we'd be more than happy to speak with you.

If the AASA has helped you in any way in the past, then just think of it as your opportunity to help out by giving a little back.

August 2009**AASA on Facebook!**

With all this talk about Facebook, there is now also an AASA Facebook group available, to allow members and supporters to interact with each other.

To join the group, type in "Alopecia Areata Support Association" in the search bar. You should see the AASA logo in the results.

You can also add AASA as your friend. Type in "aasavic@iprimus.com.au" and again you should see the AASA logo in the results.

Be aware that should you join the AASA group, or add AASA as your friend, your other friends will also see this, in case they don't know about your condition, and you are not ready to tell them.

GST on wigs - an ongoing saga!

In our never-ending effort to try and remove the GST on wigs, it seems that we keep ending up in the same position as we were in the beginning!

The following is an email exchange between our former President and AASA Life Member, Juliet Aspden, and Trish from the Princess Charlotte Alopecia Foundation.

.....
 From: Juliet Aspden
 To: Trish
 Subject: re GST on wigs an on going saga!!
 Date: Wed, 1 Jul 2009

Hi Trish,

My name is Juliet Aspden and have been involved with AASA Victoria since 1982. I have had Alopecia in various stages for over 50 years and now universalis for the past 15 years

Perhaps a little history on the GST saga!!

We always were sales taxed except prior to GST .

When I researched the transition paper after GST came in the wording of the old sales tax document was nearly word for word to the new GST documentation - except wigs were missing.

We wrote letters but we got different reasons one was something to do with the number people who wore them but for other reasons that were not medical. However this should never been an issue because we always had to supply a medical certificate in order to get the sales tax exemption. Our argument was it wouldn't cost the budget that much in \$ terms!

One of our members' has now received a letter sent to her Federal member declining the request.

I am in contact with my labour MP and as such have not had a formal rejection so am not holding my breath.

We did a direct submission right to the top in Canberra 2000 from AASA Victoria as well as our members writing individual letters

I am wondering whether you have any thoughts on another tact we could go on? Other then sitting in parliament and removing our wigs!!! God help us for that.

*Regards,
 Juliet Aspden
 (Miss)
 AASA Vic. Life Member*

.....
 Here is Trish's reply:

From: Trish
 To: Juliet Aspden
 Sent: Thursday, July 02, 2009
 Subject: RE: re GST on wigs an on going saga!!

Hi Juliet

Thank you for your email on this very important subject. Unfortunately I know the sad saga of the addition of GST on wigs, and can remember just needing to supply a medical certificate to avoid sales tax.

I have been corresponding with Canberra for 18 months, and have even spoken to one

August 2009

of the public servants who is on the GST Sub Committee that makes the final decision. He told me that they are not prepared to make any more exemptions to Schedule 3 of the GST Act.

What to do? the reason why I put my letter on the PCAF website was to see if we could get as many letters as possible sent to the PM and Treasury. They will not meet with any of us as I have frequently requested personal meetings with the Minister for Health.

Maybe it will take a bunch of bald headed people sitting on the steps of Parliament House to achieve something, but even then I am not sure.

This is an extremely frustrating situation and quite unfair. I have only received 3 replies to my letter request. Perhaps some are happy that others do all the work, and then they can reap the benefits.

We must keep in touch Juliet, and hopefully we can achieve some positive results

With kind regards
Trish

.....

The "member" that Juliet had mentioned in her email was Lois Grenfall, who is an AASA member and Past President of the group. She wrote a letter to Mr Petro Georgiou MP, Member for Kooyong. Mr Georgiou had taken great interest in our plight, but unfortunately in their attempt to lobby the Treasurers office in Canberra, was again met with another disheartening response.

The following is the letter received by Mr Georgiou, from the Treasurers office:

Dear Mr Georgiou

Thank you for your personal representations of 4 March 2009 to the Treasurer on behalf of Miss Lois Grenfall, concerning the goods and services tax (GST) and prosthetic wigs. The Treasurer has asked me to respond to you.

Miss Grenfall has requested that prosthetic wigs be made GST free.

Any proposal to alter the GST base requires the support of the Commonwealth, together with the unanimous agreement of the States and Territories. Proposals for change to the GST base are typically considered by the GST Administration Sub Committee (GSTAS), which is comprised of senior Commonwealth, state and territory officials.

GSTAS considered the GST treatment of medical wigs at the meetings of November 2008 and February 2009. GSTAS did not support a change in the GST treatment of these goods as its preference is not to expand the list beyond substitutes of goods presently covered. Therefore, a recommendation to agree to change the GST status of medical wigs will not be made to state and territory Treasurers.

The position taken by GSTAS means there is unlikely to be a change to the GST treatment of prosthetic wigs. Miss Grenfall may therefore wish to pursue other means of assisting alopecia sufferers.

I trust this information will be of assistance to Miss Grenfall.

Yours faithfully,

Chris Barrett
Chief of Staff

.....

Although its hard to stay positive in light of the governments refusal to budge, we must not give up hope. The government will only take notice if the numbers are there, so if you want to help, feel free to write a letter to your local member of parliament.

If you don't know what to write, you can download a template from our website at <http://home.vicnet.net.au/~aasa/>

August 2009**Alopecia: I wish I could be bald and proud**

Last year, Lulu O'Hagan, 45, was told she had the autoimmune disease Alopecia Areata. Here in a diary she recalls how she struggled to come to terms with her bald self.

July 2008

My long blonde hair has started dropping out in two patches over each ear. My hairdresser notices it first and immediately says that she thinks it's alopecia. I make an appointment to see a dermatologist about my eczema and he diagnoses Alopecia Areata. He says that it is relatively rare and that little is known about how to cure it.



Apparently hair often grows back when it's treated with steroids to suppress the immune system but drops out again once the treatment has finished; the older you are the less likely it is to return. This is what I find most depressing. I know that my dermatologist is upset for me too - he has seen me battle eczema for years and now I have to deal with this.

I start a four-month course of steroids, which should help, but my hair just continues to fall, fall, fall. It's on my pillow, it blocks the sink, and worst of all it upsets my girls, aged 8 and 11. My husband is very kind about it, but it doesn't take away the horror I feel. It seems to be totally out of control. What is worse is that no one has any answers. I have every blood test under the sun to check my iron, B12 and hormone levels, but all come back negative. I take nail and hair-strengthening tablets and more B12. At the moment I am managing to put up a good front but behind closed doors it's another matter.

August

My husband, a film producer, has a premiere of his film in the West End. I am beside myself. How I can go when I have so many bald patches? He kindly says we will do whatever it takes to sort things out. I have hair pieces put in at great expense and we go to Harvey Nicks to buy a posh dress for the premiere. Afterwards I find the hair pieces so painfully tight that I have them removed. I have my remaining long hair cut to a chin-length bob to thicken it, but still the patches grow. I decide to place a £800 deposit on a top-of-the-range £1,600 wig made of real hair from India, which you stick on with tape and glue. It will take up to four months to be made, by hand, in Mexico.

September

My hair has decided to grow back of its own accord, so I stop the steroids and have my hair cut very short into an elfin-like dark-brown hairdo, which makes me feel much better. I don't mind the colour - it is close to my natural hair shade as a child. I am just happy to have a full head of hair, but I don't take it for granted.

December

At Christmas I fly to Thailand with the girls to be with my husband, who is working there on a film. I wake one morning to find short brown hair all over the pillow. This continues for the whole three weeks we're there - which means that I end up with two thirds of my hair gone and a skullcap of hair at the back. I have my head shaved on the beach to the sounds of Sinéad O'Connor. It upsets my 11-year-old, who can hardly look at me afterwards. My eight-year-old copes better. I am worried about how upset my daughters are. One of them tells me I look like an alien. I am beginning to feel really desperate.

January 2009

I am unprepared for how cold it is having no hair and I am totally unprepared for how I feel about going back to the school run and life generally after the holiday. Plus, I have very painful, unattractive boils on my scalp that require antibiotics. I don't do the school run for nearly two weeks; instead a friend takes the kids to school. I go into a bit of a decline. I am angry at spending years trying to find ways to cure my eczema, and now

Do you have a story to tell? Or you have some feedback to give? We'd love to hear from you! Please send any thoughts or comments, or if you'd like to share your story, email them through to us.

You can even remain anonymous if you like.

August 2009

having something else to work out. It feels too much. See my professor, who feels sure that my hair will grow back.

February

I go to try on my new wig and book in to have it cut in April - they all come in one style and you can choose the cut you want. I now have no hair under my arms, only two hairs on my left leg and none "down there". People joke that that's a good thing, but I'd much rather have a choice!

March

My hair still hasn't grown back. In fact, my professor thinks I have shaved it again - he says he can see it all waiting to grow. But now he knows that I haven't shaved it, he says he hasn't seen this before. I leave his offices in tears. Always the exception to the rule. He wants me to take steroids again for a month. I don't want to, so I don't. The next day my hair starts to grow back in two patches. It gives me some hope that all of it will return.

April

Still only two silly bits are growing on my head, nowhere else. My hairdresser trims them and I finally get to wear my new wig. It's long and blonde and looks just like my "old" hair. I have had it less than a week when I nearly lose the plot: having taken it off I can't get it back on again. My skin weeps where the tape has come off and the shampoo feels like it's burning. I get the glue I need to hold the wig in place everywhere and howl the house down. The glue is the only way to stop the wig moving around but it is very strong and my skin is delicate. I am not confident about any of this. My husband takes me back to where we bought it and gets them to show me again, calmly, how to put it on.

I now have to get help from my Primary Care Trust to help me to pay for the wigs as you need two - one for back-up if the other gets damaged. I also know I must talk to a counsellor and plan to go to my GP. Apart from getting help for the alopecia, I have to learn some kind of strategy for coping with my feelings of despair. So many people say to me, "At least it's not cancer"; "You have a lovely shaped head"; "Being bald shows off your pretty face more"; "At least you still have your eyebrows"; "It's only hair." The truth is I can't tell you how wobbly it has made me feel.

It is early days but the wig is definitely helping. I often wish I could be bald and proud, but after wearing a hat for the past four months, I've come to realise that I don't really like the bald me. Because it's expensive and looks incredibly real, the reaction I've had to the wig has been nothing but positive. But I can't ease myself back into public slowly; this is full-on. Even dealing with positive things takes all my energy; hiding would be easier. Sometimes I am so overwhelmed by the thought that I may never get my hair back that I can't breathe. But I keep going out the door every day. I am grateful for everyone's support, and I know I am OK really. It's just that my brain and my heart really hurt.

May

The wig is not working - it is constantly tangled and not even my hairdresser can get a comb through it. I have been back to the wig man but no joy. It is so bad they have had to cut two sections out over my ears. This is nearly as traumatic as losing my own hair.

June

My dermatologist is trying his best to keep my morale up but there are no answers. My hair is not growing back and no one knows why. Worst of all a teacher at my daughters' school says that she could see the hair falling out across my jacket this morning. I have spent so much money and I still have no answers. The glue for the wig hurts my scalp. All I want to do is lie next to my husband in bed with hair instead of a silk scarf. But I am beginning to cope a bit better. I have fewer down days. At least I am still me.

*Written by Lulu O'Hagan with Linda Duberley, originally published in The Times Online
(http://www.timesonline.co.uk/tol/life_and_style/health/article6632321.ece)*

Feel free to request bulk copies of our brochures. By handing them out, you not only create awareness of our group, but you create awareness of Alopecia in general.

.....
Editors Note : I think we can all relate to Lulu's diary, and the rollercoaster of emotions that one goes through. Whether you are a man or a woman, a father or a mother, a son or a daughter, the feelings experienced with having Alopecia, or knowing somebody who does, is far reaching and at times all consuming.

August 2009

Your Committee for
2008-9 is
Juliet Aspden
Julie Billings (**President**)
Robert Chan
Pauline Dargan
(**Public Officer**)
Jenny Juni (**Treasurer**)
Terrie Ridley
(**Vice President**)

A special thanks from
the editor to everyone
who contributed items
for the newsletter.

Annual General Meeting on 29th August 2009

You are cordially invited to the Annual General Meeting of the Alopecia Areata Support Association.

The President will report on our past year's activities and our plans for 2009-10, the Treasurer will present the financial report for 2008-9 and the new committee for 2009-10 will be elected.

Our special guest for the day will be Natalie, who has established Chiquel Salon and Fine Wigs. Natalie herself also suffers from Alopecia Areata, so she understands that people suffering from hair loss can experience significant emotional distress, which can also lead to feelings of low self esteem.

Feeling that there was limited resources in the hair replacement industry regarding wigs, false eyelashes, eyebrows and various other products, she decided to setup a one stop store suited to her condition. Natalie will introduce herself, and showcase some of her products that she sells.

Location details are:

Date : 29th August 2009

Time : 2pm

Location : Skin and Cancer Foundation

80 Drummond St (cnr Queensberry St),

Carlton, Victoria

We do hope you can come along. As well as formal AGM duties, there is of course the chance to catch up with friends old and new!

Open Day 2009

The annual AASA Open Day will be held on 24th October 2009, MS Nerve Centre in Blackburn, which is the same location it was held in 2008.

All the final details are still being ironed out, however keep checking the website for any changes.

An AASA Open Day Notice and Registration Form will be sent out to all members prior to the Open Day. If you are thinking of attending, please register so we will know how many people to expect for catering purposes.

The AASA Open Day is a great success every year, and we hope 2009 will be the same, if not better!

New AASA website

If you remember back in the newsletter for November 2008, I indicated that a new look website would be coming. I'm happy to say that this is now complete, and the updated website should be online by the time you are reading this newsletter.

A new addition to the website is the AASA Discussion Forum. To those not familiar with the concept, it is like an online message board, where you can post messages, and have other people read and reply to them. Be it a question, comment, or just something you'd like to share, the Discussion Forum is available to all Members, Friends and Supporters of AASA.

This will only work with user participation, so it is up to YOU to ensure that the discussion forum is a success.

Please take a visit to the new website, and let us know what you think.

<http://home.vicnet.net.au/~aasa>