

Alopecia Areata Support Association (Vic) Inc.



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Registration No. 0017172V

November 2009

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Lisa from Atmashakti, will be our special guest at our next General Meeting on 28th November. She will be showing techniques to help reduce stress and improve general health in both physical and mental aspects of the body.

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 fellow members. It's so hard to believe that we are staring down the face of Christmas again! In the August Newsletter I sent a plea for some volunteers to help us keep the support group alive. Our aim is to have a number of people volunteering for projects for a short period of time, after which someone else will put up their hand. Our key project areas are around children, research, fund raising, targeted events and effective communication and response vehicles.

At our Open Day on 24 October, I discussed the "helping hands" concept at further length and I am very pleased to say that we had a number of people putting their names on the "Helping Hands Register"; a great start to the coming year and the projects we really want to focus on. Please keep an eye on our website and the newsletters, as there may be a whole new look and feel to the meetings/events that we have on offer over the coming 12 months, as well as the support for groups within our membership, such as the children.

In relation to Open Day, it was again a great success. On behalf of the committee, I would like to thank all of our sponsors/presenters: Angela and Sam from Angel Wigs
Natalie from Chiquel
Lidia from Lidia's Wigs
Rachel from Waks Wigs
Michelle from Wig Works on Wheels
Rhonda from Barnettts
Kerry and Tracy from KD Cosmedics
Sandy from Permanent Beauty

Pam from Head Wraps
Phil from Head Sox
Linda from Feel Good Look Good
Creative Wigs
Freedom Wigs
Beaux Chapeaux

Thanks to all of the above we had a great range of raffle prizes.

As always, we hope you have a lovely, and very safe, Christmas and New Year and we look forward to 2010 with you.

Take care

Julie Billings, President

From the editor

Once again its time to welcome you to another edition of the AASA newsletter. This year has really flown by us so quickly. It felt like just yesterday I was preparing my first newsletter for all of you, and now here I am one year later with this next issue.

So I hope you enjoy this bumper edition of the newsletter. We have a wrap up of the Open Day just passed, which was a great day as always. We also have some great articles featuring some personal stories I'm sure we can all relate to.

One of our newest committee members, Toulia Vlazakis, is very keen to setup events focused around children. If you have any interest at all, please fill in the form at the back of this page and return to us.

So enjoy this issue, and I hope you have a safe and Merry Christmas, and a great New Year.

I'll see you in 2010!

November 2009**Housekeeping Notes:**

Your newsletter editor:
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4 newsletters a year and all contributions by:

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

2010 Meeting Dates:

27th February 2010
29th May 2010
28th August 2010
27th November 2010

Next Meeting
28th November 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.

AASA Open Day 2009

The annual AASA Open Day was held on the 24th October, 2009 at the MS Nerve Centre in Blackburn, and once again, it was a huge success. We had a large turnout of 78 attendees and was extremely happy to welcome back our Consultant Dermatologist Prof. Rod Sinclair, and also our wig and make up suppliers, who kindly donated their time for the day.

The day started off with our President Julie Billings welcoming all our attendees, and a brief overview of what the day would entail. In the meantime, all the kids who attended had a great time in the Kids Room where activities this year included video games, face painting and a lucky dip just to name a few.

Unfortunately, due to a scheduling conflict, Prof. Sinclair's talk had to be started earlier than expected, which meant the panel could not go on as planned. Prof. Sinclair, who graciously offers his time each year to attend our Open Day, gave a very generous two hour talk on Alopecia, and what the future for treatments may hold.

By this time, another popular part of the day came around, which was lunchtime! This is always a good opportunity to meet new people, catch up with old faces, and just have a good old chat.

After lunch, we all reconvened in the meeting room to introduce our wig suppliers and make up artists. This is a very popular part of the Open Day, as it gives our attendees a chance to try new products, and get a good general idea of what's available to them out there. We then drew all the prizes in our annual Raffle, which is always lots of fun. A big thanks to those who donated their products this year, and congratulations to all our winners this year!

So once again, a big thank you for all those who attended the Open Day this year. We hope to see you all again next year!



A big thanks to our providers this year:
Natalie from **Chiquel Salon and Fine Wigs**
Lidia from **Lidia's Wigs**
Rhonda from **Barnett's**
Michelle from **Wig Works on Wheels**
Angela from **Angel Wigs**
Rachel from **Waks Wigs**
Pam from **Head Wraps**
Tracy and Kerry from **KD Cosmedics**
Phil from **Head Sox**
Linda from **Feel Good Look Good**

Congratulations to all our raffle winners this year:

Permanent Beauty voucher - Glenda
Barnett Wig Voucher - Pinar
Creative Wig Voucher - Elsie
Wig Works on Wheels pack - Terrie
Child Chair - Ryan
Travel Wig - Sabine and Heather
Foam Wig Stand - Sue
Hair Rescue Kits - Vesna and Violeta
Lidia's Hair Pack and Voucher - Chel
Head Wraps - Dianna, Garry, Rob and Betty
Hats by Beaux Chapeaux - Elsi and Vesna
Insulation Hat - Oliver
Chiquel Vouchers - Andrew, Violeta, Garry, Sue, Phil, Oliver, Louise, Ann, Dani and Helen

November 2009**General Meeting on 28th November 2009**

Our next general meeting details are as follows:

Date : 28th November 2009

Time : 2pm

Location : Skin and Cancer Foundation
**80 Drummond St (cnr Queensberry St),
Carlton, Victoria**

Our special guest for the day will be Lisa, a health counsellor who specialises in meditation classes, Reiki and Bach Flower essences.

Lisa runs Atmashakti, which offers a range of treatments that help alleviate stresses in the Mind Body and Soul.

Reiki and Meditation are both known to reduce stress and improve general health in both the physical and mental aspects of the body.

Reiki is an ancient form of Hands on Healing that helps improve the natural flow of your body's energy, which in turn aids your body to work more efficiently, both physically and mentally

Meditation is an easy way to relax both body and mind, it is said that even five minutes a day can improve your overall wellbeing. This can be done through visual guidance where your mind is told a story to help you find a peaceful and relaxing state.

At the meeting Lisa will explain how Reiki is a complimentary therapy that assists in balancing your energy throughout your body, so the healing process can work more efficiently.

This will be followed by a Body Rotation Meditation session, using visual guides, after a short explanation on the psychological, physical and spiritual benefits of meditation.

It is often said that Alopecia is caused by stress. Although stress has never been proven to be associated with hair loss, doctors are still diagnosing patients with hair loss as being from stress. More research is still needed to prove or disprove this statement. If it can ever be proven that stress is a contributing factor to hair loss, stress reduction can then be lowered in order to control hair loss.

Whether stress causes hair loss or not, one thing is crystal clear, we can all do with a bit of stress relief in our life! So come along to our next meeting, and maybe you can learn a few techniques to help you lower those stress levels.



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.

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After years of prejudice, it's time to shine

For years Shea Giordimaina, Jenene Rodrigo and Tamara Curran have been the subject of taunts and stares, but now it is their time to shine.

The trio have won a major beauty competition and are set to strut their stuff on the catwalk in a glamorous fashion show as part of a Fox FM competition.

Ms Giordimaina, 22, has alopecia, Ms Rodrigo, 19, is missing a hand and Ms Curran, 26, has Friedrich's ataxia, a degenerative neuromuscular disease. She will go down the catwalk in a wheelchair.

They will feature alongside stars including Jessica Mauboy and Cassie Davis in Fox Fashion 2009, which is part of Melbourne Spring Fashion Week.

Winning the Matt & Jo's Real Beauty Search competition has been a life-changing experience for the trio, and they hope it will alter everyone's perceptions of people with physical disabilities.

"I would love people to see and understand that people in wheelchairs can also be attractive. When I was younger I did some modelling and I want to show that even now, wheelchair and all, I've still got it," Ms Curran said.

Ms Giordimaina lost her hair at seven.

"People at school would say, 'you should cover it up and try to be normal'. There were a lot of harsh words said on the streets. I had to make fun of it or I would have gone crazy," she said.

Ms Rodrigo, who was born without a right hand, said: "Society really is trying to accept beauty in a different light."

Fox FM's Matt & Jo Show co-host Matt Tilley agreed.

"We were very passionate about this, presenting an opportunity for people with 'body differences' (physical disabilities or impairments) to have the spotlight and live their dream of being a model for a night," Tilley said. "Why should a disability or impairment stop someone from being considered beautiful?"



AASA recently spoke to Shea, and asked her why she entered the competition, and what she hoped to achieve.

AASA : How long have you had Alopecia for?

Shea : I have had Alopecia since I was 7yrs old.

AASA : What was it like to grow up with Alopecia.

Shea : It had its good points and bad points good points were that I could laugh at myself and have fun with it with different wigs and painting my head for dress up parties but as I headed into my teens, realism hit me that I wasn't like the other girls and boys seemed to stay far away from me. I have struggled with depression since probably about grade 6 and has been extremely severe at times.

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Seeking information or support?

Phone our MessageBank on (03) 9513-8580.

A group member will return your call within 24 hours.

AASA : Why did you decide to enter the Fox FM competition?

Shea : I decided to enter the competition to try and improve my self esteem and show people that we "sufferers" are not freaks of nature or weirdos or anything like that, that we are all beautiful no matter what's on the outside! Because of this I have become more comfortable with myself.

AASA : Were you afraid of all the attention you were going to receive through the general public?

Shea : I was a little afraid of the attention at first but I think because I have done dancing since I was two and I tend to be a bit of a show off (especially without my hair on) it wasn't as scary as I thought.

AASA : How did you feel during the photo shoot?

Shea : During the photo shoot I felt very confronted as I don't spend a lot of time around other people without my hair on only because I have become so used to just fitting in with the masses. After being around the other winners who were also different and sharing stories I started to become more relaxed in my own skin than I had felt in a very long time.

AASA : What do you hope this photo shoot will achieve?

Shea : I hoped that the shoot would possibly get me some more confidence in myself and give other girls with alopecia the confidence to be comfortable to be themselves and not cover up.

AASA : What did your family and friends think of you entering the competition?

Shea : My family and friends were so excited for me and so happy. My boyfriend was telling everyone he knew and always telling me to be proud of who I am because he is. And my mum, dad, and sister supported me every step of the way. They were at the photo shoot and then at the catwalk and made sure I knew how much they all loved me and were so proud.

AASA : Are you happy with how the shots came out?

Shea : The shots came out beautifully. I have never ever looked at myself without my hair and thought "Yeah I look amazing" but after there photos I thought wow that's not me!

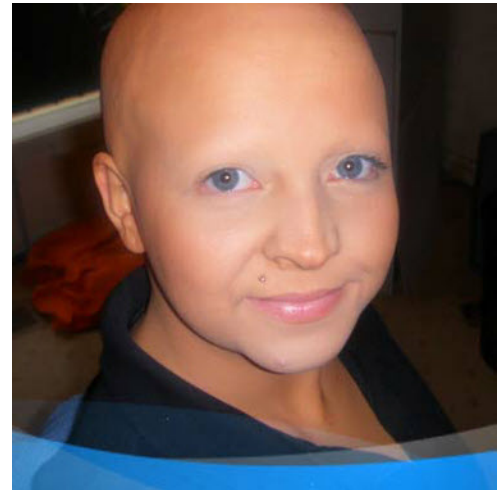


AASA : What advice do you have for young people dealing with Alopecia?

Shea : When trying to think of advice to give young people I think back to everything that everyone told me and I always felt so alone, so I guess I would say you are never alone we sufferers can stick together and lean on one another because as much as your friends and family are support they will never know exactly how it feels to go through this condition and feel alone and lost.

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 Congratulations to Shea, Jenene and Tamara, as no doubt this is not something that anyone would be able to do. We only hope their actions will encourage more people to feel confident, no matter where they are at in life.

Article contains excerpts written by Colin Vickery, originally published in the Herald Sun (<http://www.heraldsun.com.au/news/after-years-of-prejudice-its-time-to-shine/story-e6frf7jo-1225767224811>)



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YABBA - "On the other hand" short story

YABBA, which stands for Young Australians' Best Book Award, are a not-for-profit organization run by a volunteer committee. Their aims are to encourage and promote children's reading and to promote an awareness of Australian children's fiction.

They recently had a short story competition for all students in Victoria in Year 2/3 levels which had to begin with the words "On the other hand".

Jasmin Vlazakis, is a 9 year old girl who is the daughter of one of AASA's newest members, Toula Vlazakis. Jasmin also has Alopecia Areata. Toula was over the moon to learn that Jasmin had won the short story competition for her level.

The following is Jasmin's winning entry. Her positive outlook is something that we can all aspire to.

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On the other hand I am grateful I don't have alopecia Universalise.

When all of us were babies we got injections which are called immunisations to stop us from getting diseases. When I was 14 months old I got my MMR & Hep B injections – 4 of them!!!! Unfortunately soon afterward I started to loose my hair on my head. Well it turned out I was allergic to them and I got Alopecia Areota.

If you are wondering what Alopecia Areota is, listen to me.

Alopecia Areota is when you loose your hair in various spots of your body. Most people don't know what brings it on and some even outgrow it as they get older. Others have it all their lives. I think am one of the lucky ones because I only loose my hair on my head but there are more serious cases of Alopecia and one is called Alopecia Universalise. Like some kids or adults they loose all their body hair. I mean, no eye brows, no eyelashes, no private spot hair or hair on their head at all. They have to wear wigs, paint on their eye brows and some wear stick-on eye lashes. It's harder for suffers of Alopecia Universalise.

I know how it feels to have Alopecia. People at school or on the street stare at you and even call you names like, "baldy" or look at you strangely and ask "what is that?" I can hear kids in the playground playing on the monkey bars above me and they say to their friend who they are sitting next too, "What's that girl got on her head? That's ugly"! That makes me feel angry and I don't want to go to school. I tell mum & dad, I want to wear a wig so that other people won't know I have Alopecia. When I get angry or cry my hair falls out even more and I have to learn to control my emotions.

They say, Alopecia is an auto immune virus. I don't get sick very often but we have discovered that, for an example, when I am loosing my baby teeth, or growing new teeth, my auto immune attacks my hair which then falls off. It starts with small patches the size of a 5 cent coin and slowly as I loose more hair, the patches join and get bigger. Some patches are as big as my fists. Sometimes people think I have cut my own hair because some hair is falling and some hair is growing which it looks strange to them. Other people mistake Alopecia for Cancer which is a very serious sickness not like alopecia. You can die from cancer but not from Alopecia. Another good thing about Alopecia is you cannot catch it and there is nothing to be afraid of if you get it or if you see someone with it.

Mum, dad and I have found some things that can help my hair grow back quicker, but not stop it from going. These things are, Dr Wheatgrass cream that we put on my bald spots and a tablet called Silicaptex. I hate the table, it tastes disgusting. Mum has to find new ways to mix it with other stuff to make it taste better because I can not swallow tablets. If you saw the size of them, you wouldn't be able to swallow them either.

Today we found a mixture I like. You open the tablet in a glass with a little bit of hot water to help it dissolve, mix well, then add Rybena & water and mix that. Then it's ready to drink! Its good, but I could taste it a bit which I didn't mind. The worst mixture was



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.

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when mum put the tablet powder in a chewy lolly and I had the flavour in my mouth for a very long time until I could swallow the lolly. Yuck!!! Another time she mixed it in Yoghurt, it made the yoghurt look a yucky poo colour and I hated the flavour! I told mum never to do that again and I have to find something I like. I will use the Rybena mixture from now on.

I am an 8 year old (almost 9) and I am sick of having kids teasing or people looking at me, but on the other hand I have a great life. I am now also grateful my school principle lets me wear a non school colour cap to school that mum and dad found for me at Pumpkin Patch which hides my Alopecia. Its purple and grey, I don't really like grey but the purple makes it look nice. It really doesn't go with my green/red school uniform.

Also mum always reminds me, whether I have hair or not, that is not who I am, but the person inside is more important. Oh well, we can't have everything we like or want in life, but I look forward to the Alopecia going away one day, hopefully.

The End

By Jasmin Jade Vlzakis

P.S. I forgot to tell you – mum has e-mailed the alopecia society and I am very excited because I will get to meet other boys & girls who have alopecia and I look forward to hearing their life experiences and how they deal with Alopecia.

Jasmin has a great attitude on dealing with Alopecia. Perhaps you also have a young son or daughter, and you can also encourage them to express their feelings through a short story.



ROB'S RANT

An open letter to Alopecia

Dear Alopecia,

I've known you for almost 25 years now. You first came to me when I was around five years old. When I was a teenager, I thought, and certainly hoped, that you would wander away as suddenly as you came to me. But alas, now that I've just turned 30, you are still with me every single day.

We've had our ups and downs. More downs than I care to imagine. And the ups are really only the times where I've forgotten about you. But you are there, I can't deny that. And I have learned to accept you for what you are. I still hope one day that you might leave me. But I've also come to term with the possibility that you won't.

Summer is around the corner. The weather is getting warmer and warmer. And I have you to thank for suffering through the sweltering days with sweat dripping down from under my wig. At least in the winter time I don't feel it as much. But its just another thing that you've forced me to live with.

So why did you choose me? Why have you chosen any one of the men and women, boys and girls in the world. I guess you can't really answer that. Just like no one else can answer that. Should I have gone left instead of right? Should I have went up instead of down? Your selection criteria seems so random.

You may be non life threatening, but it doesn't make you any lesser of an evil to any other condition. In fact, you can almost say you are cruel. I mean, you take away a highly visible feature of us, and then say, "that's enough, now deal with it". Do you think its funny when we have to tell people, "No, I'm not sick, I've just got Alopecia".

I've lived with you for almost 25 years, and it probably looks like I'll live with you for 25 more. I'm not angry at you. The anger goes away after a certain time. I certainly have better ways to spend my spare time rather than thinking about you. But I cant deny that you are always there, in the back of my mind.

So Alopecia, although you are always by my side, don't be fooled by my good naturedness. If ever you decide to leave me, then I'll be the first one to show you the exit door.

Yours sincerely,

Robert

November 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 - update!

In the last newsletter, you would have read the email exchange between our former President and AASA Life Member, Juliet Aspden, and Trish from the Princess Charlotte Alopecia Foundation.

Also attached was a letter sent to Mr Petro Georgiou MP, Member for Kooyong, from the Treasurers Offices in Canberra, detailing the unlikelihood of the GST being removed from the purchase of wigs.

Since that time, Juliet has received a response from her local MP, Mr Mark Dreyfuss, Federal Member for Isaacs, who has also taken great interest in our plight. The following are letter exchanges between Mr Mark Dreyfuss, Mr Wayne Swan, and Mr Bill Shorten, who is the Parliamentary Secretary for Disabilities and Children's Services.

The first letter is the response received by Mr Mark Dreyfuss from Mr Wayne Swan:

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9 October 2009

Dear Mr Dreyfus,

Thank you for your letter of 10 August 2009 concerning the goods and services tax (GST) and medical wigs. I apologise for the delay in responding.

You ask about how you might seek to change the position adopted by the GST Administration Subcommittee (GSTAS) on the GST treatment of medical wigs.

As advised in my previous letter, GSTAS is a sub-committee of the Ministerial Council for Federal Financial Relations and is made up of senior officials from the Commonwealth and all of the States and Territories. For GSTAS to make a recommendation to change the GST treatment of a good or service, the recommendation must have the unanimous support of the representatives from all jurisdictions. At the current time, given the prevailing economic circumstances, it is unlikely that all of the States and Territories can be convinced to support an extension to a GST concession.

I note that in general, the Government prefers to assist those with disabilities by direct expenditures through the Budget process, such as the recent increases to the carer's allowance and disability support pension. Direct expenditures increase transparency, are more flexible for recipients and can be better targeted to those in need. In effect, by providing a benefit to a group directly rather than providing GST exemptions, greater advantages can be provided at a lower cost.

In the context of wigs, under the current National Disability Agreement the States and Territories are responsible for operating schemes to provide specific assistance in obtaining aids and equipment. However, the adequacy and accessibility of these state schemes is one of the issues that are being considered in the development of the Government's National Disability Strategy. More details on the National Disability strategy can be found at:

<http://www.fahcsia.gov.au/sa/disability/progserv/govtint/Pages/nds.aspx>.

I trust this information will be of assistance to you.

Yours sincerely,
Wayne Swan

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The next letter was sent to Juliet in response to the letter received from Mr Wayne Swan:

15 October 2009

Dear Juliet,

Goods and Services Tax on Medical Wigs

Further to my letter of 10 August 2009, I advise that I have received a reply from the Treasurer in relation to my ongoing representations on your behalf, regarding the Goods and Services Tax on medical wigs. A copy of the Treasurer's response is attached.

The Treasurer advises that "At the current time, given the prevailing economic

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circumstances, it is unlikely that all of the States and Territories can be convinced to support an extension to a GST concession". The Treasurer also advises that under the current National Disability Agreement the States and Territories are responsible for operating schemes to provide specific assistance in obtaining aids and equipment. He advises however, that the adequacy and accessibility of these state schemes is one of the issues that are being considered in the development of the Government's National Disability Strategy.

I continue to support your call for some form of financial relief for individuals who for medical reasons need to purchase wigs, and I have now written to the Hon. Bill Shorten MP, Parliamentary Secretary for Disabilities and Children's Services seeking his assistance. A copy of my letter is attached.

I will write to you again after I have received a reply from the Parliamentary Secretary.

Your sincerely,

Mark Dreyfuss QC MP
Federal Member for Isaacs

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Lastly, here is the letter Mr Mark Dreyfuss sent to Mr Bill Shorten:

Dear Parliamentary Secretary,

Alopecia Areata and Medical Wigs

I seek your assistance in obtaining financial assistance for people suffering with Alopecia Areata in regard to the purchase price of medical wigs. I have previously written to the Hon. Wayne Swan, Treasurer, seeking removal of the GST on the purchase price of medical wigs. The Treasurer has advised that the Goods and Services Tax Administration Sub-Committee (GSTAS) does not support a change to the GST treatment of medical wigs "a its preference is not to expand the list beyond substitutes for the types of goods presently covered".

The decision by GSTAS appears to me to be inconsistent with its support for the removal of GST on other appliances which serve exactly the same ameliorative function for people suffering Alopecia Areata, as do "nose prostheses or artificial ears" for people whose disabilities require these aids. The same point could be made for artificial eyes which have a primarily cosmetic purpose.

The Treasurer in his latest letter to me, says in clear terms that "the Government prefers to assist those with disabilities by direct expenditures through the Budget process, such as the recent increases to the carer's allowance and disability support pension". He also advises that "At the current time, given the prevailing economic circumstances, it is unlikely that all of the States and Territories can be convinced to support an extension to a GST concession" in relation to the purchase price of medical wigs. A copy of the Treasurer's letter is attached.

I am seeking to have you, as Parliamentary Secretary for Disabilities and Children's Services, pursue this issues on behalf of the small group of Australians who suffer this disability. I very much doubt that the number of medical wigs sold in Australia would produce a major reduction in revenue if they were exempted from the GST. However, if no adjustment to the GST is possible, I would ask you to investigate whether some other form of financial assistance is available for people requiring these medical appliances. I look forward to receiving your assistance on this matter.

Yours sincerely,

Mark Dreyfuss QC MP
Federal Member for Isaacs

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While it may seem that we are at exactly the same point as where we started, hopefully through the good work of Mr Mark Dreyfuss, we may be able to get somewhere, seeing as he is approaching this issue through different channels.

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/>

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I don't have cancer... I'm just bald

The Tower of London's first female Beefeater (otherwise known as a Yeoman Warder) Moira Cameron hit the headlines this week when it emerged she had gone bald from the stress of workplace bullying. The Former Army NCO has a hair loss condition alopecia and has resorted to wearing a wig. Here, fellow sufferer and TV presenter Gail Porter reveals what it's like to live with the condition.

Although the causes of alopecia are complex, stress can be a trigger. I was diagnosed five years ago while going through my divorce. I was working in America and noticed bald patches appearing on my head. Over the next two weeks my hair started to come out in clumps. I'd wake up with mouthfuls of it because so much would fall out overnight and the bathroom plughole would be blocked.



I became tearful because I didn't know what was happening to me. I cried all the way back from America. The thing that frightened me the most was thinking about what my daughter Honey's reaction would be. She was only two at the time and I worried that my appearance would frighten her. However she thought my bald head was cool.

There are different types of alopecia. I have a very severe type called alopecia areata which causes hair loss all over the body. I lost my eyebrows, eyelashes and body hair.

Losing my eyebrows and eyelashes was pretty upsetting - I felt I looked strange, like someone had just rubbed me out. However, it doesn't affect everyone to the same extent.

In a documentary for BBC1 three years ago, I tried a number of treatments, including steroids and laser therapy, but nothing worked, and some even made me feel worse.

A major problem with alopecia is no one really understands what causes it and, as a result, there is no cure.

I chose not to wear a wig because I found them quite uncomfortable. Luckily I've got a nicely shaped head - although the first thing my mum said when she saw me bald was that I still had the forceps scar from when I was born.

I got a lot of kids pointing at me and people stared. Sometimes I held my head up high and other times I just didn't want to go out. But the support of my friends and family helped build my confidence. The letters and emails of support from other alopecia sufferers were also amazing. A lady in a wig once stopped and hugged me in the supermarket.

If Moira hasn't already logged on to an alopecia support group, I would recommend that she does, because it has helped me enormously.

Recently my eyebrows and lashes grew back and three months ago patches of hair started to grow on my head. I'm not sure why my hair has started to regrow, but it may have something to do with my changed lifestyle - I exercise more, am more chilled out and I appreciate everything in my life a lot more.

I still get the odd hurtful comment - a drunk guy once told me I looked ugly without hair. And some people assume I'm ill and ask me what type of cancer I have. But you're always going to get some comments - I just try to ignore them.

The best advice is to get on with your life and think positively.

November 2009

Confidence is key in Tracy's alopecia fight

Tracy Spencer was only in her twenties when she realised her long, light brown hair was starting to thin. "When I brushed it, it felt like it was coming out in handfuls. Then my hairdresser noticed a bald patch at the back of my head," she says.

Tracy, now 37, went to see her doctor and was devastated to learn that she had the hair loss condition alopecia. And so began years of fruitless treatment, during which time she became more and more withdrawn from normal life. It's 10 years since Tracy's life was turned upside down by the loss of something that most women take for granted.



The condition left her so psychologically traumatised that she says: "If it wasn't for the fact that I had children to care for and look after I don't think I would be here now."

In fact, a study by Hairline International, a support group for alopecia sufferers, found that more than 60% of women with hair loss have considered suicide and virtually all feel it is an assault on their femininity.

At the time Tracy was diagnosed with alopecia she was a young, single parent with her own home and a job – she worked as an assistant at Thornton's. "I was perfectly happy," she says, "but the doctors blamed stress for the alopecia. I felt as if the only stress I had was the alopecia.

"They said my immune system was too active and was treating my hair as a foreign body and rejecting it. I was given a treatment that lowered my immunity and my hair did start to grow back. But you could only take the treatment for a month at a time and as soon as I stopped it the hair all fell out again. I had constant colds because my immune system was so suppressed," she explained.

Eventually, Tracy's confidence became so undermined that she gave up her job. "The only time I'd go out of the house was with the kids or to a friend's house. I lived in bandanas and hats until I got an NHS wig, but it was awful and looked so artificial," she said.

Not long after her diagnosis Tracy met the man who was to be the key to her recovery and is now her husband, Steve. "I met him at a friend's house," she says. "But for a long time I made excuses not to go out with him because I didn't want to tell him about my alopecia. I'd sit at home on the sofa and cry." But Steve persisted. "I didn't know what alopecia was, I hadn't a clue," he explained. "But it never bothered me at all. It's the person who counts, not the way they look."

As they got to know each other better, Steve helped Tracy to find a better wig so that she could start going out in public once again.

Then four years ago Steve proposed. Tracy wore her wig for the wedding and says it was the best day of her life. Her children: Daniel, 14, Sarah Jane, 19, and Tammy, 20, were delighted to see their mum so happy. Today the entire family live near each other in three flats in the same Elland apartment building.

Although Steve encouraged Tracy to start living life to the full once more – they ran a sandwich shop together – she still spent hours on internet support groups and looking for a wig that would fully restore her confidence.

"Then I found a company that made a cast of your head and designed wigs with human hair. They were called vacuum wigs because they stay on your head no matter what. You can even swim in them and they won't come off," said Tracy.

She bought a blonde wig and immediately felt the difference. "It looked so natural. Bizarrely, it gave me the confidence to be seen without a wig," said Tracy, who now owns three wigs and was happy to pose for a photograph to show her hair loss.

"It took me a long time to get where I am now, and I have that wig to thank," she added.

Tracy says her years of suffering made her realise that there is little concrete help for people with alopecia and so she set up her own support group, which meets monthly at her home. "Many of the members have similar stories to mine, but we have people who have not just lost the hair on their heads, but their eyebrows and eyelashes as well. Some are younger and some have been bald since they were children," said Tracy.

Her experience has also led to a new career, as an advisor for the vacuum wig company that she discovered while searching the internet. She's so enthusiastic about the wigs that she and Steve paid their own air fares to travel to New Zealand to train. Tracy is one of only four advisors in the UK.

Real human hair wigs, while costly (over £1,000), can be treated like a head of natural hair. "I wash mine, straighten it and have it highlighted. I go to the hairdressers to have it cut," she said. "It's quite handy really because someone else can actually wash my hair while I have a bath."

Tracy keeps her wig business separate from the support group but sees herself as a walking advertisement for vacuum wigs. "I feel totally confident in it. We even go jiving together and it stays firmly in place," she said.



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

Written by Hilarie Stelfox, originally published in *The Huddersfield Daily Examiner* (<http://www.examiner.co.uk/leisure-and-entertainment/2009/10/21/confidence-is-key-in-tracy-s-alopecia-fight-86081-24985856/>)

REGISTER FOR AASA CHILDRENS EVENTS FOR 2010

As the newest member of the Alopecia Areata Support Association (Vic) Inc and as a mother of a child suffering of Alopecia Areata it is my desire along with the Association to create a website for children with their stories, emotions feelings etc. So please e-mail to info@webink.com.au or mail your stories to PO Box 2112 Hampton East Vic 3188.



Also in association with AASA we are planning social events for children in 2010 who suffer from alopecia to socialise with other children.

Firstly I would like to gauge the age group of children, register your interest in participating in various activities and also call upon any of you with contacts that can help facilitate at a discount our fun days or know of people that are willing to donate venues, time etc.

Please fill in form below or preferable interactive detailed form online <http://home.vicnet.net.au/~aasa/>.

Look forward to hearing from you all.

Kind Regards,

Toula Vlazakis
Children's Event Co-Ordinator

Your Name:	<input type="text"/>	1 st Child's Name:	<input type="text"/>
Address:	<input type="text"/>	Date of Birth:	<input type="text"/>
Best Contact No.	<input type="text"/>	Child is: <input type="checkbox"/> Male <input type="checkbox"/> Female	
E-Mail:	<input type="text"/>	2 nd Child's Name:	<input type="text"/>
Activities interested in participating in:		Date of Birth:	<input type="text"/>
<input type="checkbox"/> Picnics	<input type="checkbox"/> Movies	Child is: <input type="checkbox"/> Male <input type="checkbox"/> Female	
<input type="checkbox"/> Bowling	<input type="checkbox"/> Luna Park		
<input type="checkbox"/> Bike Riding	<input type="checkbox"/> Indoor Play Center	Member of AASA: <input type="checkbox"/> Yes <input type="checkbox"/> No	
<input type="checkbox"/> Roller Blading	<input type="checkbox"/> Hiking		
<input type="checkbox"/> Coastal Drives	Others... <input type="text"/>		

Do you have industry contacts that can donate or discount facilities/venues eg. Village, indoor play centre etc.

Contacts Name:	<input type="text"/>	Phone Number:	<input type="text"/>
E-Mail Address:	<input type="text"/>		
Other Comments/ Suggestions:	<input type="text"/>		

Thank You For Your Feedback.