

Alopecia Areata Support Association (Vic) Inc.



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August 2010

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Our next Annual General Meeting will be held at 2pm on 28th August 2010 at Skin and Cancer Foundation, 80 Drummond St (cnr Queensberry St), Carlton, Victoria
See you there!

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. Well the year is well and truly flying past and we are nearly into Spring.

It has been a challenging year for the group as we have struggled to find the right way forward. But I am really pleased to say that, while this will be my last President's Report, we have a few people who have put up their hands to lead the group into the next year and beyond. More importantly, they are very keen to do so.

I would urge you to try to get to the Annual General Meeting on Saturday 28th August to show your support for the to be elected management team. They will certainly have all of my support.

On the awareness front, don't forget to visit the Australia Alopecia Areata Foundation website www.aaaf.org.au. They have some great things happening too and also need your support.

As a final note I would like to thank my management team for all of their efforts and commitment to the continuation of AASA.

All the very best for the future.

Take care

Julie Billings, President

From the editor

Welcome to the August edition of the AASA newsletter, which will also be my last as editor.

It has been a pleasure bringing you the newsletter each quarter, and I hope you have all enjoyed the articles and my occasional rants throughout the last couple of years.

But as with all good things, it is time for me to step aside and let the next phase of the AASA newsletter continue.

Although it is a labour of love, it is a mighty effort in creating the AASA newsletter. If you would like to see the newsletter continue, it is vital that you, as members and supporters, become active in letting us know what you want to see in the newsletters. If you see a story, or have a suggestion, or you would like to share your experiences, then please do!

Just remember how you felt when you have read someone else's story, and imagine how your story can also help someone else.

So once again, I hope you enjoy this August issue of the newsletter, and here's to many more to come in the near future.

Signing off,

Robert Chan



August 2010**Housekeeping Notes:**

Your newsletter editor:
Robert Chan

E-mail address:
aasavic@gmail.com
*** Note new email address!**

Postal address:
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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

2010 Meeting Dates:

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

Next Meeting
28th August 2010
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.

Miss Delaware 2010 — Bald and Beautiful!

Kayla Martell, Miss Delaware 2010, is on a mission — and it's not to create world peace.

Rather, she's taking off her wig to tell the nation — especially young girls — about alopecia areata, an autoimmune disease that usually leads to baldness.



Martell began losing her hair at a young age, leaving her completely bald in her late teens. Yet she's gone on to compete and win beauty pageants both with and without a wig. She certainly deserves applause for her courage to walk the runway, face pageant judges and talk to the nation about this disease.

Martell has competed in the Miss Delaware pageant 4 times, with wigs and without. She took the title this year as a blond.

The graceful 21-year old became an instant champion for young women stricken with the disease when she donned a blonde, shoulder-length wig and beat out 15 other contestants to be crowned Miss Delaware 2010.

Now the illness is her platform for the Miss America competition in January. She says wearing a wig presented her with a surprising opportunity to bring attention to alopecia and those diagnosed with it. Martell entered the Miss Delaware pageant four times - twice without a wig - before winning.

"I'm living proof that you can wear a beautiful wig and still be comfortable with who you are," says Martell, who volunteers at alopecia support groups and speaks at events sponsored by the National Alopecia Areata Foundation, which supports research to find a cure or treatment.

"It's my hope that the attention I receive will make a difference in the lives of any child or person who loses their hair to alopecia," she says.

Fox Entertainment blog says, "Martell plans to use her platform to raise awareness for Alopecia Areata, which afflicts more than four million Americans and two percent of the world's population."

"I hope to show people that beauty comes in all different kinds of packages," she said. "No beauty queen should fit into a box and look like a Barbie every time they wake up and none of us do, as you know. So I hope to show people that you are beautiful and whatever makes you different, you should embrace it."

Contains excerpts written by Parasshuramin, originally published in Filmyfair
<http://www.filmyfair.com/fashion-news/bald-miss-delaware-kayla-martell-raises-awareness-on-alopecia-photo-gallery>;
WebMD - <http://blogs.webmd.com/breaking-news/2010/07/miss-delaware-2010-bald-and-beautiful.html>;
Troy McMullen in ABC News - <http://abcnews.go.com/Health/MindMoodNews/alopecia-sudden-hair-loss-caused-autoimmune-disease/story?id=11087033&page=1>



August 2010**Annual General Meeting on 28th August 2010**

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 2010-11, the Treasurer will present the financial report for 2009-10 and the new committee for 2010-11 will be elected.

Location details are:

Date : 28th 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!



ROB'S RANT

You want me to do what???

I have lived with alopecia for most of my life.

Some may say that's so unfortunate, but I tend to look at it with the glass half full and say, "Hey, I can't even remember what its like to have hair!".

Attitude is everything, and with the right attitude, you can face whatever the world throws at you. You still have your down days, where you feel like everything is going against you. But then most days, you forget about it all and just get on with your life.

It's funny how "non-alopecians" can take little things for granted.

One of the things I enjoy the most is playing tennis, and I try to do that once or twice a week. Of course, after playing, no matter how cold the weather is, it's quite easy to work up a bit of a sweat. So usually after a session, the first thing I do is to wash all the sweat and grime off my wig, or in other words, "washing my hair".

So one Saturday after tennis I was going to have dinner with my sister and her family. I explained to her that I was playing tennis, then I had to drive home, wash my hair, then drive back out to the city again. She said, "Can't you just shower and wash your hair at the change rooms?". Simple statement, right?

What my sister doesn't realise, is that washing my hair is not some flippant thing you do whilst in the shower, but its a whole event. I have to get my combs ready to comb through the shampoo, then conditioner. I have to setup my wig head stand whilst the conditioner is soaking through. Then rinse it through and give it a quick gentle wipe, before casually styling it and placing on the wig stand while it dries. I dare not use a hairdryer lest it damage the hair. Once its finally dry, I have to style it again to how I want it to look.

So maybe I've dramatised it a little by making it a whole "event", but then again, I could never just have a shower, wash my hair, and be good to go within 10 minutes.

So that's my little alopecia quirk. I'm sure you have one too. Sure, it sucks sometimes. But hey, what can you do???

Please note that our email address has changed to aasavic@gmail.com Please use this address for any correspondence with AASA.

August 2010**Dodgy hairdressers causing hair loss**

Women wanting hair extensions have been warned to seek professional help after a recent spike in complaints about dodgy hair extensions causing scalp lesions, hair breakage and even hair loss.

The Hairdressers Registration Board's Registrar Les Marshall says there are 12 outstanding cases to be brought against unregistered hairdressers advertising their ability to attach hair extensions.

He said in the past six to eight months the number of complaints had gone up significantly, with consumer complaints ranging from tension headaches to traction alopecia, known as isolated hair loss.

Hamilton Hill woman Ella Stratton was recently fined almost \$2400 in damages after she pleaded guilty in the Perth Magistrate's Court to working as an unregistered hairdresser.

Three of her customers complained to the board after their hair extensions fell out in a matter of days.

Ms Stratton, who operated from home under the name of Glam Hair, said her business grew after she taught herself to put in hair extensions, and then started helping friends and friends of friends.

"I wasn't really aware of what I had to do (to become a licensed professional). It wasn't like I was cutting hair or dyeing hair, I was just putting hair extensions in for friends," she said.

"A lot of people don't know. I was unlucky that I got this girl who was difficult. She didn't speak to me about it she just went straight to the board."

Ms Stratton said she no longer applied hair extensions commercially, instead she had taken a job in real estate after being awarded her licence.

She said she now refers any customers to her step-mother who works as a hairdresser from home.

"I taught my mum to do hair extensions - putting the bead through the hair and clamping it on. A lot of friends doing hair-dressing courses don't know how to do them. I've been doing my own for a long time," Ms Stratton said.

Ms Stratton was fined \$150, and ordered to pay damages to her customers amounting to \$1,750 and court costs of \$467.

She said she had taken down her business website and emailed those with listing her business among other WA hairdressers to have her company removed. However Glam Hair and Glam Hair Extensions can still be found through yellowpages online.

Mr Marshall warned: "Before committing to having hair extensions, consumers should undertake a thorough consultation process with a number of experienced hairdressers who specialise in hair extensions."

Seeking information or support?

Phone our MessageBank on (03) 9513-8580.

A group member will return your call within 24 hours.

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Vet says alopecia in pet dogs should be checked out

Ethical insurance policyholders might be more concerned with bald patches on their pet dogs than they are about the state of their own barnet.

However, according to veterinary professional Dr Pete Wedderburn, writing for the Telegraph, animals are just as susceptible to alopecia - hair loss - as humans.

Although the condition can only occur without warning and without any real

cause, however, it should always be checked out with an expert, he continued.

"[It] can be an outward indication of a more serious internal problem. If the hair loss is ignored, the internal condition may progress and other symptoms may then develop," he added.

While hormonal disorders such as hypothyroidism can be the prime suspect behind hairless patches, a full health check-up should be performed, including bloodwork and biopsies.

Meanwhile, a blackbird has been spotted with a fine plumage but a bald head, leaving experts from the RSPB to speculate that the stress of mating season has taken its toll on the bird.

*Written by Elaine, originally published in Animal Friends
(<http://www.animalfriends.org.uk/afi-pet-community/pet-news/pet-care-news/vet-says-alopecia-in-pet-dogs-should-be-checked-out-19890473/>)*

Alopecia Areata and recent genetic research

The prestigious journal 'Nature' recently published a research letter from a scientific group partially funded by the National Alopecia Areata Foundation (NAAF) in the US. Although the news of the discovery of 'susceptibility' genes for AA didn't get much publicity here, the resulting media discussions in the US ranged through overhyped and the downright misleading to a more cautious 'that's interesting and new but we need to know more' response.

A research group at Columbia University identified gene variants associated with AA. A 'gene watch' website which reports on the Human Genome Project (SNP Gene Watch) says "These results not only shed light on (the) biology behind alopecia areata but may also guide the development of new treatments". (1)

The discoveries have identified genetic elements known as SNPs pronounced 'Sniaps' (Single Nucleotide Polymorphisms). SNPs do not cause disease but they can help determine the likelihood that someone will develop a particular disease. However, they are not absolute indicators of disease development.

Angela Christiano, the lead researcher in the group who made the discovery and who herself has alopecia, said that because drugs to target one of the problem immune cells were already under development, clinical trials using these drugs may be possible soon.

The scientists at SNP Gene Watch believe that more work will be needed to confirm the research findings.

*1. The Spittoon: More than you've come to expectorate
<http://spittoon.23andme.com/2010/06/30/snpwatch-genetic-variations-associated-with-autoimmune-form-of-hair-loss-alopecia-areata/>*

A comment from the NAAF website

"This research is very exciting as alopecia areata affects a huge number of people worldwide, and there are very few treatments for it-resulting in an enormous unmet medical need," said Vicki Kalabokes, president and CEO of the National Alopecia Areata Foundation, which has funded Dr. Christiano for the past 13 consecutive years. "Hair loss creates daily life issues, especially for children who experience social stigma. It affects their quality of life and can lead to long-term psychosocial impact."

http://www.naaf.org/site/PageServer?pagename=research_Columbia

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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A 'Forest Fire of Hair Loss,' and Its Scars

Matt Kelley was 38 when he first noticed a round, hairless spot in his beard. Within six weeks, every inch of his body that once had hair — including his eyebrows, eyelashes, arms and head — was completely bald.

"It was like a forest fire of hair loss," Mr. Kelley said.

Mr. Kelley, now 43, has alopecia areata, an autoimmune disease that causes the body to attack its own hair follicles. Alopecia, which does not include normal male-pattern baldness, affects nearly 2 percent of the global population and has no universally effective treatment. Its progression is unpredictable and can range from a few bald patches to a completely hairless scalp to the loss of every hair on a person's body — known as alopecia universalis. Sometimes the hair regrows, sometimes it does not, and sometimes it grows in only to fall out again years later.



Matt Kelley with his cat, Hairy, who plays Mr. Bigglesworth to his Dr. Evil on Halloween.

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@gmail.com" 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.

"There's no predictability to any of it," said Mr. Kelley, who lives in Menlo Park, Calif.

Only very recently have researchers begun to uncover the cause. In a study published last week in *Nature*, researchers from Columbia University found eight genes that appear to be involved in the mechanisms of the disease. One of them, ULBP3, acts like a beacon for the body's killer immune cells. In those with alopecia, it seems, this gene is greatly overexpressed in hair follicles, leading to rapid hair loss.

It was previously thought that alopecia was closely related to psoriasis, another autoimmune skin disease, but these findings indicate that alopecia operates more like the autoimmune diseases rheumatoid arthritis, celiac disease and Type 1 diabetes.

"We have a great advantage now that we know which genes are involved," said Dr. Angela M. Christiano, the lead researcher of the study and a hair geneticist at Columbia University Medical Center.

Dr. Christiano, who has alopecia herself, suggested that because alopecia only causes hair loss without pain or other symptoms, there was never an urgency to find an effective treatment. But with the genetic basis better understood, she said, she hopes that more researchers will find merit in treating this disease, which can cause severe emotional and mental distress.

"People think, 'Bald, no big deal,' " Mr. Kelley said. "But it is a big deal."

Mr. Kelley tried many treatments, including the pharmaceutical (steroid treatments and cortisone shots), the time-consuming (acupuncture and light therapy) and the alternative (hypnosis and vitamin therapy). "You name it, I tried it," he said. Nothing worked.

His appearance changed drastically. In addition to the hair loss, he also gained weight rapidly from the steroids. Mr. Kelley wore hats constantly and became isolated, depressed and frustrated. It took years for him to realize that it was not his head that needed treatment for his hair loss, it was his mind.

Mr. Kelley joined a support group with the help of the National Alopecia Areata Foundation, and he started to talk to others with alopecia. He slowly regained his sense

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of self.

"The emotional part is really all you can treat," he said.

It was October 2006 when Mr. Kelley first stepped out in public as a bald man — just not quite as himself.

He attended a Halloween party as Mr. Clean, complete with bushy white eyebrows, a white T-shirt and — of course — a shiny, clean scalp. Some friends assumed his bald head was a really good bald cap, but from that outing Mr. Kelley gained a bit of confidence. He slowly stopped wearing the baseball caps, fedoras and beanies that filled his closet.

He may now blend in with other bald men walking down the street, but Mr. Kelley knows that he is quite different from those who had time to accept a gradually thinning hairline.

"A bald man in today's society is pretty common, but the hard part is the adjustment to the change," he said.

What is the biggest difference, according to Mr. Kelley, between him and a bald man? Eyebrows. Without that arc of hair above his eyes, Mr. Kelley found his face to be expressionless and plain. So he had eyebrows tattooed on.

He would love to camouflage his scalp as well but says he feels that society looks down on men with hairpieces.

"As a male, I always thought I was at a disadvantage," he said. "There are all these toupee jokes."

Mr. Kelley is excited about the new understanding of how alopecia works, but he tries not to think about having his thick brown hair back one day. He does not want the hope for a cure to interfere with his newfound acceptance.

"I just try to stay calm and be O.K. with not having hair," he said.

Mr. Kelley prefers to focus on the one good thing alopecia has given him: perspective. Once a successful sports memorabilia store owner, Mr. Kelley is now attending school to become a family therapist and hopes to share the gift of acceptance with others facing alopecia.

Mr. Kelley does his best to find all the humor possible in his situation. The Halloween costume tradition has continued, with recent characters including Dr. Evil from the Austin Powers movies. Mr. Kelley purchased a hairless cat to portray Mr. Bigglesworth, Dr. Evil's pet.

That cat, now named Hairy, is possibly the first in a collection of hairless animals for Mr. Kelley. Next on the agenda is a hairless dog.

"I joke with my friends that I want to build a hairless Noah's ark," he said.

*Written by Karen Barrow, originally published in The New York Times
(<http://www.nytimes.com/2010/07/06/health/06voices.html?src=me>)*

Have you seen a movie or read a book which features Alopecia as one of its themes? We'd love for you to bring it to our attention. Let us know by sending us an email with the details.

Patient Voices: Alopecia

For those who have access to the internet, visit The New York Times website at:

http://www.nytimes.com/interactive/2010/07/05/health/healthguide/TE_alopecia.html?ref=health

They have seven very brave people speak about their experiences with having to live with Alopecia.

It's a very honest look into the struggles we all go through, and I'm sure we can relate to one or all of the people featured.

From the website above:

An estimated 4.7 million people in the United States have some form of alopecia areata, an autoimmune condition that causes round patches of hair loss, which can occur in just a few small spots or include the entire body. The cause is unknown, and effective treatments are elusive. What is it like to live with alopecia? Children, parents and adults facing the condition speak.

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Ashes the Hairless Chimp

KARNATAKA, INDIA – A mutated human? An alien hybrid? What is it?!

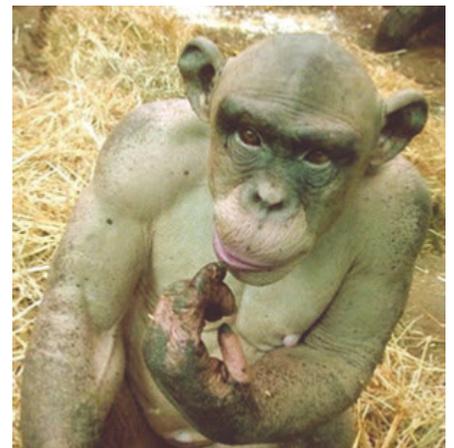


It's just Ashes, the hairless chimpanzee! Ashes is a 13 year old chimp that lives at the Mysore Zoo in India.



Ashes was born with fur like any other chimpanzee. But by just a year old, he had lost all of it! While he is somewhat frightening, it is a wonderful opportunity to be able to see a chimp's musculature.

Ashes is not the only one of his rare kind. Another hairless chimp called Cinder was born at the Saint Louis Zoo in Missouri. Also born with full hair, she soon lost it but was still readily accepted by the other chimps.



Both animals suffer from alopecia universalis, which is also found among humans! Sadly, Cinder passed away in February 2009, so curious visitors will have to travel to India to get a peek at Ashes.

*Written by Sarah Haddad, originally published in Weekly World News
(<http://weeklyworldnews.com/mutants/7727/ashes-the-hairless-chimp/>)*

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