

Alopecia Areata Support Association (Vic) Inc.



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February 2010

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Stop Press!!!

Our next General Meeting will be held at 2pm on 27th February 2010 at Albert Park Lake, entry at Aughtie Drive outside the Kiosk. Melway Ref 2K F9

**Please note the change of location!
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 and welcome to 2010. On behalf of the management committee, I hope you had a wonderful Christmas and New Year.

I don't know about you but 2010 is already shaping up to be a big one and it has started already.

You know that AASA has always been very passionate about supporting alopecia sufferers and their support network, as well as looking at ways we can create awareness in the general community and drive research to find answers...and who knows maybe one day a cure!

We are really excited to announce that a national alopecia group has been established. It is the Australia Alopecia Areata Foundation (AAAF) and it was established in January this year. Its mandate is to:

- educate the general public about alopecia,
- generate significant funding for research into alopecia and
- provide a tax deductible environment for any donations to the above.

The website is due to go live on 1st March this year. Please Google Australia Alopecia Areata Foundation at that time and have a look. Support in any way you can....**get involved.**

This is the best thing you can do to help provide the much needed answers. If you are employed by a company that could potentially help, see if they are interested in Workplace Giving and let us know.

Awareness and research funding are the key strategic directions for 2010.

We are going to have a change for meetings going forward and the

February meeting is the start.

Please note that the February meeting will not take place at Skin and Cancer in Carlton. We are going to have a Fun Run and/or Afternoon Tea at Albert Park. Around the whole park is 5km but you can choose to run a little or the lot.

Bring the kids, their bikes, scooters or whatever. What about aunts, uncles and cousins and all those people who have given you support over the years.

Saturday 27th February is the date to get connected. Refer to the General Meeting area for details.

Just be there if you can and have some fun. There will be more of the same in 2010 so watch this space.

Take care
Julie Billings, President



From the editor

Welcome to February edition of the AASA newsletter. As editor of the newsletter for the past year, I am asking for your help!!! Any ideas, news stories, articles or personal stories you find or would like to share would be greatly appreciated. I know there are many readers out there, but it's becoming increasingly difficult to piece together each newsletter, as I don't know if what I'm putting out there is what you, the readers, are looking for. So if there are any changes you would like to see, or if you'd like to contribute something to the newsletter, then please do not hesitate to send me an email at asavic@iprimus.com.au

February 2010**Housekeeping Notes:**

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

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

2010 Meeting Dates:

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

Next Meeting
27th February 2010
Albert Park Lake, entry at Aughtie Drive outside the Kiosk.
Melway Ref 2K F9
Please note the change of location

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

Valentine's Gift Brings Love to Children in Need

For seven years, salon owner Natallie Phillips of Artistry in Hair has collect ponytails ranging in length from 10 inches and up. With the help of her clients and the community, she has donated hundreds of ponytails along with monetary gifts and hair accessories to a nonprofit children's organization called Locks of Love.

This Valentine's Day weekend will be no exception as Phillips anticipates collecting even more for the national organization.

"Locks of Love is an unbelievable organization that makes prosthetic wigs for children," said Phillips.

The wigs are custom made for children who have cancer or alopecia areata (a medical condition that creates bald patches on the scalp for which there is no known cure).

Almost a decade ago, one of Phillips' clients had a child with alopecia. The client shared how her daughter needed a wig — but not just any wig, one that would stay whether she slid down a slide or performed a cartwheel.

That's when Phillip discovered Locks of Love, and that's when she began her crusade to collect as many ponytails as she could during the Valentine's Day season.

"We've probably donated hundreds of ponytails to Locks of Love over the years," said Phillips, recognizing her staff and other salon professionals who volunteer their time year after year for the one day event.

Phillips explained that the wigs cost anywhere between \$3,500 and \$6,000, but Locks of Love gives the hair prostheses to qualifying children at no charge.

It takes between six and ten ponytails to create one hair prosthesis, and after a plaster mold of the child's head is made, the donated ponytails are hand-sewn onto a skullcap that allows the child to have confidence in his or her wig.

In recognition of her "Outstanding Community Service," Assemblyman Joel Anderson acknowledged Phillips in 2008 for her commitment to give to Locks of Love.

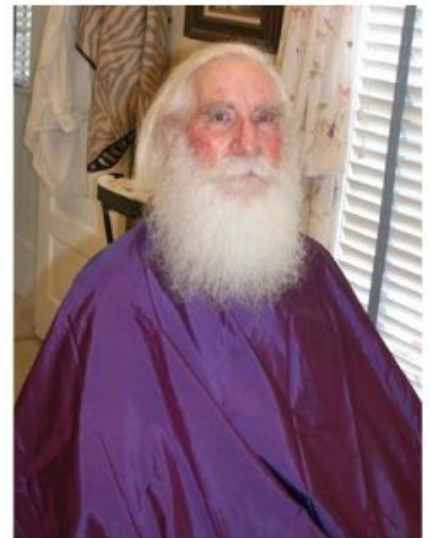
Phillips said, "It was an honor to meet Mr. Anderson. He was very sincere and told me he appreciates businesses in the community who go above and beyond, and who keep their efforts ongoing."

This year's event will be no exception as Phillips has already booked several appointments and lined up numerous volunteers, including her niece Jessica Sosbee, 12, whose responsibilities will include sweeping, cleaning and offering drinks to waiting patrons.

Phillips' mom, Sandi Phillips, will man the phones and oversee the reception area while patrons, including 8-year-old Isabella Gangitano of Ramona, wait to donate their hair.

Isabella's mother, Kim Gangitano, read about the salon's Locks of Love event last year in Ramona Journal. She shared the article with her compassionate daughter who was inspired to grow her hair and has already made her appointment for the one-day event.

"Isabella is a very heartfelt little girl. She loves to give and is particularly excited about



Above, Paul Holbrook before his haircut last year. Below, Paul Holbrook after his haircut.



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donating her hair this year," said Kim, explaining that one of Isabella's schoolmates has alopecia.

Isabella will donate 12 inches, and said, "It's good to give to those who are less fortunate and I'm giving what I can, my hair."

Phillips said that while the prosthetic wigs go to children under the age of 18, people of all ages can donate, including those with chemically treated hair.

Last year, one local man, Paul Holbrook, donated his hair and the hair from his beard. He didn't tell his wife, Sarah, that he had made an appointment.

Later that day when he went home, she didn't recognize him.

Sarah said, "He came to the door and I said to him, 'I'll be with you in a minute, Sir.'"

Phillips is certain this year's event will bring even more heartwarming stories.

Phillips vows to make this an ongoing event and says, "I'll never stop donating to Locks of Love."

Written by Tracy Rolling, originally published in The Ramona/Julian Journal

(<http://www.ramonajournal.com/link.asp?sdetail=2484>)

Locks of Love is a public non-profit organization that provides hairpieces to financially disadvantaged children in the United States and Canada under age 21 suffering from long-term medical hair loss from any diagnosis.

If you are thinking of donating hair, the Australian based Princess Charlotte Alopecia Foundation has a Tresses for Princesses program to facilitate this.

For more information, visit:

<http://www.princesscharlottealopecia.com/AboutAlopecia/TressesforPrincesses.aspx>

General Meeting on 27th February 2010

Our next general meeting details are as follows:

Date : Saturday 27th February 2010

Time : 2pm

Location : Albert Park Lake

Entry at Aughtie Drive outside the Kiosk

Albert Park, Victoria

Melway Ref 2K F9

Please note our change of location for the next meeting! See map below for Meeting Area. Bring the whole family for a day out in the sun.



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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Alopecia sufferer Gail Porter has hair sprouting on her head again

UK TV's Gail Porter has started to sprout hair on her head again- just as she is finally coming to terms with being bald.

Instead of greeting the tufts on her scalp as the end of a nightmare, she said she likes "being different".

Gail, who lost her blonde locks five years ago due to alopecia, said on Twitter: "Don't know what to do with my dodgy hair! I'm too used to being bald. I love being bald."

And she said her six year-old daughter likes the look. She said: "Honey thinks I'm really cool. Her friends at school love me because of my bald head.



"I bend down and everyone rubs it and makes a wish, which is so cute. Honey says, 'That's my mum and she's different to everyone else's mum.'"

The presenter, who caused a stir in 1999 when her naked rear was projected on to the Houses of Parliament for FHM magazine, added: "I'd love my hair to grow back one day but it's important to me that Honey thinks I'm different and cool."

Gail suspects the spurts of regrowth on her head could be down to romance. Her new boyfriend is indie rocker Jonny Davies, who is 14 years her junior.

They have been secretly dating for four months and guitarist Jonny has been telling friends he is "really happy".

Speaking at her home in Primrose Hill, North London, Gail, 38, said: "I'm getting very hairy so that must mean I'm happy.

"I've got a bit of hair and a bit of a boyfriend and I'm very happy. He's a musician in a band called New Vinyl."

Gail, who has hosted shows including Dead Famous and The Big Breakfast, lost her hair during a hellish four weeks in 2005 while she was in the grip of post-natal depression.

There was more stress with her divorce from former Toploader guitarist Dan Hipgrave, father of Honey.

She found love with cameraman James Lloyd but the relationship ended last May when she kicked him out of her home.

Since she was diagnosed, Gail has refused to wear a wig and has used her public profile to raise awareness.

She is an ambassador for the Little Princess Trust - a charity which provides wigs to bald children.

But at first she struggled and said the condition left her feeling "ugly". Now she is so used to being bald she said she would continue to shave her head because regrowth is patchy.

This week Gail was all smiles when spotted with Jonny at central London's Groucho club.

New Vinyl, formed in Wakefield in 2003, have a website on which they introduce "our new manager: Gail Porter".

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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What Is Alopecia? Alopecia is a hair-loss disease which can affect men, women and children of any age. It often occurs suddenly and without warning, and is notoriously unpredictable, making it difficult to treat.

Types include alopecia areata, where isolated patches of hair on the body are lost; alopecia totalis, where all hair on the head is lost; and alopecia universalis, where all hair on the entire body is lost. This is the rarest form of the condition.

Alopecia does not affect health in any other way. The challenge lies in coping with hair loss and the change in appearance which can affect confidence and mental wellbeing.

What Causes It? The exact cause of alopecia is not known but it's generally agreed that it is an autoimmune condition, whereby the body's immune system mistakenly attacks hair follicles.

These follicles remain active, so the potential exists for hair growth to restart but the unpredictable nature of the condition means it's difficult to control.

The more severe the hair loss, the less likely it is that growth will restart.

Some studies show a link between alopecia and stress or trauma, while other conditions eczema, asthma or a thyroid disease can also mean you are more susceptible.

How Common Is It? Alopecia can affect people of any age and it affects men and women equally. Research suggests 1.7 per cent of us will have alopecia to some degree, and while it can strike without warning, there does appear to be an hereditary aspect to it.

Around a quarter of people with the condition have a family history of the disorder but this doesn't mean there is an "alopecia gene" which you can pass on to your children.

It's more likely to be a combination of genes which leave you more predisposed to the condition.

How Is It Treated? There is no cure for alopecia just as there is no cure for male pattern baldness but there are treatments which can help in some cases.

The most common for people with less than 50 per cent hair loss are steroid creams or injections applied to the affected areas. Dithranol ointment, which is used to treat psoriasis, is another option.

For people with more than 50 per cent hair loss, immunosuppressant drugs can be used to lower the immune system and give the hair a chance to grow.

The problem is that lowering the immune system increases your chances of infection.

Irritants can also be applied to affected which draw the T lymphocytes away from the follicle to deal with the irritation, allowing the hair to start growing.

There's never a guarantee of success because the condition is so unpredictable.

For this reason, some people with alopecia decide on no treatment.

What Are The Chances Of Hair Growing Back? Most people with alopecia experience some degree of regrowth and as the hair follicles remain active, the potential for regrowth always exists, even if the likelihood of it diminishes over time.

The problem is that the condition is so unpredictable that sufferers may experience hair loss or hair growth at any time and it's perfectly possible to have both at the same time in different areas of the head or body.

Regrowth can be of any texture or colour. Sometimes, new hair can be identical to the original hair, while other times it can be much thinner or white, only regaining its original appearance over a period of months.

Article contains excerpts written by Danielle Gusmaroli, originally published in the Mirror.co.uk (<http://www.mirror.co.uk/celebs/news/2010/01/27/alopecia-sufferer-gail-porter-has-hair-sprouting-on-her-head-again-115875-21998066/>) and Craig McQueen, originally published in the DailyRecord.co.uk (<http://www.dailyrecord.co.uk/life/women/health-and-fitness/2010/02/01/gail-porter-s-recovery-shows-there-is-hope-for-sufferers-of-alopecia-86908-22010815/>)

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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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.

Charlie the Bully Buster

Basketball has provided Detroit Pistons forward Charlie Villanueva with fame and fortune in the USA. But before either of those seemed possible, it gave him a much simpler gift: a way to silence the bullies who teased him. He wasn't always 6-foot-11, you know.

"The way I dealt with it was basketball," Villanueva said of his classmates' taunts. "When I was inside those [court] lines, I felt comfortable. I used basketball as a tool to overcome it."

Villanueva's pregame meet-and-greets with kids who have alopecia areata, the skin condition he has that causes hair loss on the scalp and elsewhere, have made him a role model for many youth. He remembers his struggle to fit in despite a conspicuous appearance – and the bullies at school who never let him forget it. That's why Villanueva spent a few hours last week at an anti-bullying event with children from The Children's Centre in Detroit.

"Bullies can hurt someone's self esteem pretty bad," he said, "that's why I'm here participating in this activity."

The Pistons and corporate sponsor MetroPCS hosted the event, which included Villanueva participating in a series of skits that illustrated the proper way for kids to deal with bullies, especially at school.

Some of Villanueva's roles many NBA players would not dare attempt in front of cameras. In one skit, Villanueva played the new girl at school, wearing a skirt over his Pistons sweatsuit and a blonde wig.

"To see him play a girl and put on a skirt and act like a kid, it brought it home to the kids," said Labelle Newby, who had four children take part in the assembly between the ages of six and 10. "It made them feel more comfortable with what's going on. It took something that's normally bad and made it fun for them."

Villanueva agreed that the lighthearted nature of the skits helped convey serious points to his young audience. In other skits, he dressed up as a bully leprechaun and a puppy, the peace offering between two friends and their tormentor.

"It was fun. I had a good time," Villanueva said. "I think all the acting and funny costumes helped get the message across."

Newby's eldest child, 10-year-old Bryce Tripp, played the role of the school principal in one skit that stressed the importance of reporting bullying to adults.

"I was very proud. Bryce loves acting and he loves being involved and I was really happy to see him to play his role and not be nervous and just go up and participate," Newby said. "It meant a lot to me."

"It's good for them to know that no matter what it's good to tell an adult and learn the proper way to do things."

Messages like that fit right in at The Children's Centre, which works with children who have serious emotional and behavioural issues and their families. MetroPCS, a partner of both the Pistons and The Children's Centre, helped arrange the event and supplied pizza, ribs and drinks for the children afterward.



Villanueva poses with members of "Brainstormers" and students as they prepare for a skit at The Children's Center in Detroit.

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"We wanted to make a difference, and that's why we partnered with The Children's Centre," said Tammy Capone, regional director of advertising and public relations for MetroPCS. "And we decided, because we have such a great sponsorship with the Pistons, let's put the two together."

The Children's Centre is one of the largest and most comprehensive child-serving agencies in Michigan. After the skits, the kids took an anti-bullying pledge, which they signed and then handed to Villanueva, who in return handed out autographed photos.

So how did Villanueva finally get the bullies off his back? He made sure they couldn't reach him.

"I wasn't always the tallest," he said. "I had a growth spurt my second year of high school. Then the bullies stopped."

For the children who can't outgrow their bullies, Capone is confident they'll be able to think of something else after watching the assembly.

"I hope they at least get some idea of how they can deal with bullies in their lives and the different tough situations that they get into," she said.

Schoolyard bullies may find they've lost a lot of their power in the last week. For the kids who remember their pledge, Charlie's in charge now.

*Written by Ryan Pretzer, originally published in NBA.COM
(http://www.nba.com/pistons/community/bully_buster_100203.html)*

Author's bare book signing bravery

An author who suffers from severe hair loss ditched her wig during a signing of her latest book on Saturday.

For 28 years Sue Hampton, of Lincoln Court in Berkhamsted, has suffered with alopecia- a hair loss disease.

During a signing of her newly released children's book- The Waterhouse Girl- which is based on the 53 year old's experience with the condition, Ms Hampton decided not to wear her wig.



The mother of two, who spent Saturday at Waterstone's, Berkhamsted High Street, said: "As far as children's reactions are concerned, one admitted that it was strange seeing me like that- I could read it on her face."

"Some had already seen me without my wig. Otherwise they seem to take it in their stride. I was told by several customers, young and older, that I'm being brave and if they think that I'm pleased."

"I'd like to encourage others to be brave when they need to be, to be themselves regardless of what anyone else might think or say. I also think it's important for me to show it's okay to be different."

The former St Mary's School teacher added that speaking out about the condition in last week's The Gazette had inspired other women from Berkhamsted who suffer with the condition.

She explained: "Two women with alopecia came to meet me on Saturday because of the article and we chatted at length about feelings, experiences, treatments and other people's reactions. It was really good to meet them- two women who have become stronger because of alopecia, even though it's been hard."

The Waterhouse Girl is Ms Hampton's sixth book to be published by Pegasus.

For more information www.suehamptonauthor.co.uk

*Originally published in Hemel Today
(<http://www.hemeltoday.co.uk/berkhamsted-news/Author39s-bare-book-signing-bravery.6011621.jp>)*

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.

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HappyThankYouMorePlease

Josh Radnor (*How I Met Your Mother*) made his screenwriting and directorial debut at the Sundance Film Festival with his film *HappyThankYouMorePlease*.

This trio of intertwined stories involving six New Yorkers dealing with the complexities of love, friendship and identity. While this premise may sound familiar, its charm is refreshing and its character keeps the film from becoming just another romantic comedy.

The main story focuses on Sam Wexler, a struggling writer (Radnor), who, during a particularly bad day when he encounters a young boy (played by the adorable Michael Algieri) who's been separated from his family. When the boy reveals that he is unhappy in foster care, Sam decides to bring the boy back to his apartment, and a unique friendship begins to develop between the two. This friendship both initiates and complicates Sam's romance with a beautiful cabaret singer named Mississippi (Kate Mara).



The second story involves Sam's best friend, Annie (Malin Akerman). Annie has alopecia, which is a condition that prevents her body from growing hair. This could have easily been a cheesy addition, where a beautiful woman faces difficulty in courting deserved male affection. However, this is not the case. Instead, Radnor has portrayed Annie as a strong, intelligent woman who is coming to terms with her baldness in a very endearing way.

Basing the character on a real-life friend living with alopecia, Radnor has developed a character who is genuine and Akerman embraces that notion with an equally sincere performance. On the character of

Annie, Radnor says "I have a very good friend named Rachel who has alopecia universalis, which means she no hair anywhere on her body. She's just hilarious and wise and wonderful, so I wanted to base a character on her".

When asked what did it feel like to be shown on camera without hair, Akerman says "Shaving off the eyebrows and wearing a bald cap was kind of freeing. It was the first time I looked in the mirror and saw somebody else. I felt like Annie became more of an interesting person because of her alopecia. It was more about finding that character than even the lack of hair".

"It's a complex role. The story is this ensemble cast, all of them on their own quest for love, and me, being a woman with alopecia, that presents an extra obstacle in finding a love of your life, because some men can't accept that," Akerman says. "Sometimes, in anyone's career, sometimes you feel like you're hitting a wall and you need to get to the next level or the next phase. And Josh helped me out with that."

It's very clear that Radnor cares deeply for his characters and has shaped them affectionately. Each character displays moments of vulnerability and exposure that give a sense of history and moments that have defined them.

HappyThankYouMorePlease debuted in January at the Sundance Film Festival in the US. As of now, there is no general release dates for the film, although it would be one to keep your eyes open for.



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

Article contains excerpts written by Kristin Coates, originally published in *The FilmStage* (<http://thefilmstage.com/2010/02/03/sundance-review-josh-radnor-pleases-with-directorial-debut>), Kat Angus, originally published in *Dose.ca* (<http://www.dose.ca/movies/Interview+Couples+Retreat+star+Malin+Akerman/2513311/story.html>) and Stefanie Jackowitz, originally published in *AM New York* (<http://www.amny.com/urbanite-1.812039/sundance-film-festival-catching-up-with-malin-akerman-and-kate-mara-1.1730551>)