

HOT HEADS

WIG WEARERS OF THE WORLD UNITE!

92% Surveyed
R e p o r t e d

HEAT

As an issue
When wearing

WIGS

**AUGUST
2013**

- From the President's desk
- Interviews
- Three local research studies seek volunteers
- International news
- Annual General Meeting August 31st

Hot Heads image created by
Karena Moore-Millar © 2013

52 participants completed a UK survey conducted online using Qualitrics software, detailing their personal experiences with wigs.



**Alopecia Areata
Support Association**
support services since 1980

PO Box 89 Camberwell 3124
Melbourne Australia
Registration No. A 0017172Y

Helpline: (03) 9513 8580
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It's AGM time again!

Can you play a part in making AASA a more effective organisation in 2013-2014?



The August meeting brings us to the end of another financial year and to our AGM. I have enjoyed my time as President of AASA but due to family commitments, I will not be standing for re-election this year. It's especially important that we have at least 4 people to stand for committee. Please consider offering yourself for election and I urge all members to come along and vote for the new committee.

The coming year will be an important one as we want to ensure that we can continue our most successful programs, the Helpline and our newsletter. Both these services give support to people with AA from near and far, mostly in Victoria, but also some people from

other states.

I look forward to meeting you on August 31st.

Garry Lonsdale,
President

Editor's Note: Thankyou to Karena Moore-Millar, Rose Marie and Margaret Helman for their contributions to this issue

To quote Karena Moore-Millar in this edition

"wigs are not just something you wear and forget about, they can really alter a person's life in many ways not discussed openly".

This issue takes wigs seriously and we have spoken with 3 women who work in different ways to ensure that the quality of the wig wearing experience can contribute positively to the life of people with hair loss and prevent them contributing to the downside of having alopecia.

Karena Moore-Millar is a PhD student in Glasgow and explains her research on wig technology and how she came to be interested in this.

"Rose Marie" is the pen name of a New Zealand woman who has a child with alopecia. Rose Marie's comments on Alopecia World are much appreciated by people who are concerned about hairloss. She works with Freedom Wigs.

Margaret Helman is a hairdresser of 40 years experience who has specialised in helping mostly women with cancer and with alopecia. She has some commonsense advice about successful wig purchases.

Getting Wiggy With it!

University of Strathclyde Glasgow

ADDRESSING THE NEEDS OF WIG WEARERS THROUGH MATERIAL SCIENCE, PSYCHOLOGY AND PRODUCT DEVELOPMENT

What do you get when you cross a Chemist, Chemical Engineer and a Psychologist with Product Design?
A super wig of course!

Ahead of the Game!
BY MS KARENA MOORE-MILLAR

Email: Karena.moore@strath.ac.uk Tel: +44 (0)786805509

PHOTO BY FRANK GAZDAS



Our Cover: The cover graphic for this issue was created by Karena Moore-Millar © 2013 and is based on a self portrait



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Wig Research: Karena Moore-Millar



Editor's Introduction:

Karena Moore-Millar is associated with a number of alopecia support groups, including Alopecia UK, Alopecia Help & Advice Scotland (AHAS) and recently formed Scottish Alopecia Support Group (SASG). She is currently engaged in research for her PhD which is highly original and important to all of us who wear Wigs.

Karena: Thanks For giving me this opportunity to talk to your members and discuss my work on this global platform.

Karena Moore-Millar

A Bit about me:

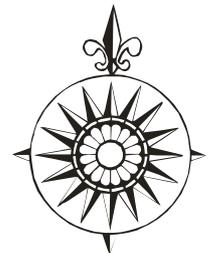
My name is Karena and I'm a product designer based at the University of Strathclyde in Glasgow Scotland, I'm working on research focusing on wig technology for medical users with alopecia.

What I'm doing: I'm working collaboratively with a Chemist, Chemical Engineer, psychologist and a Health Engineer looking at wig user's experiences to see how technology is affecting their quality of lives in positive or negative ways. I'm hoping to raise awareness of the inherent problems associated with wearing wigs for people with alopecia, as many depend on wigs in a variety of ways to maintain some social normality.

Why I'm doing it: I started to wear wigs not long after joining the Royal Air Force (RAF) aged 23 when I experienced chronic AA. The radical change in my appearance, work and social surroundings caused me great distress; all of which were compounded by the choice to wear a wig. I thought wearing a wig would help conceal my hair loss, but in fact it did something different. I started to compromise my lifestyle and ultimately my job in order to accommodate for my wigs. I chose not to exercise as much and had to change my job because of the complications of a wig on a flight-line; I was told my wig could be considered "FOD" (Foreign object debris) and ultimately potential damage for aircraft. It was the start of this wig journey that wigs profoundly changed my life, both physically and emotionally; but not in the way I or others in my life anticipated.

Snap shot of my research: My work has taken a holistic approach and focuses on the wig users requirements and experiences. I have conducted focus groups, interviews and on-line survey to gain insight into a number of issues related to wig use and maintenance; all of which help to identify underlying design, technologies and manufacturing techniques which could be altered to enhance wigs for specific users. I've taken these detailed qualitative insights to inform detailed examination of a number of commercial wigs identified in the study; testing their fibres, foundation (cap) and fitment.

Inter-
view



News Local
and
International

In Melbourne

On September 19th
"Stress management" 5.30
to 7.30 pm. at the Skin and
Cancer Foundation in Carlton
More information to come on
[our website](#)

In Canada

The Canadian Alopecia Areata
Foundation has eg. local
support groups and camps
for children. It evolved from a
support group to a non profit
organisation in 2008.
<http://canaaf.org/about-canaaf/>

In the UK

Photography exhibitions
and participation in AA
research agenda setting -
Alopecia UK has been
busy! Read their report on
the World Hair Congress
held in Edinburgh
http://www alopeciaonline.org/g.uk/viewNews.asp?news_id=162

In the US

In St Louis in June, the 28th
National Alopecia Areata
Foundation's annual
conference drew over 700
attendees including people
from from a number of
countries. You can read a
summary of the conference
on their website.
<http://www.naaf.org/site/PageServer?pagename=2013ConferenceReview>



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To date:

I am in my final year of my PhD and am concluding some scientific testing of wig materials in order to establish the primary differences in common wigs and see where potential technologies are impacting on users' experiences. Alongside this vital analysis I have been very fortunate to have been supported by my University to hold an exhibition "Crowning Glory" in collaboration with Daniel Regan, a London based photographer, raising awareness of alopecia and some results from my own research. It is from this exhibition I have been able to promote a greater awareness of problems associated with wig technology and help reach a wider audience beyond the university and support group networks.

Future:

I aim to complete my PhD and look at ways to implement my findings at different levels, from promoting awareness and helping inform users, suppliers and manufacturers of ways to improve designs, use and disposal of wigs universally; as wigs are not just something you wear and forget about, they can really alter a person's life in many ways not discussed openly.

Thank you for giving me this opportunity and for taking an interest in my research. I hope my research will help inform you and others in the future to choose, maintain or dispose of wigs differently. Wigs are not for everyone, but those that do wear them have the right to a better quality of life. Wigs are more than a cover up story, they are something which can and do have an impact on our daily lives when living with Alopecia. ♥

Researchers at the University of Strathclyde are ahead of the game in developing ground-breaking research into wigs. A unique team from material science, design and psychology are examining wig fibres, function and fit with people who wear wigs for medical reasons, such as alopecia.

Meet the "hair" team

The team consist of Ms Karena Moore-Millar, Dr Avril Thomson (Department of Design, Manufacture and Engineering Management), Dr Sally Wiggins (School of Psychological Sciences and Health), Dr John Liggat (Pure & Applied Chemistry) and Dr Simon Shilton (Chemical & Process Engineering). The team are combining their expertise and knowledge of fibre technology, design engineering and embodiment in order to take wig research to new heights.

Let's talk about wigs

Wigs prescribed for long term medical users is a multimillion pound industry, however, current wigs are fraught with issues resulting in a poor experience for the wig user. The research has used focus groups, interviews, video diaries and a questionnaire to identify the priorities of each stakeholder in the provision, use and disposal of wigs. Current findings indicate that

there are a number of problems which effect the user's experience including poor fitment of the cap and fibres melting near heat. Encouragingly, these initial findings suggest the collaborative team could improve the long term wig user experience and enhance wig quality.

Off the top of your head!

Initial evidence gathered from the first stages of data collection suggests that there are a number of keys areas to be investigated, including:

- Introduction of a British Standard (BS) or a International Organization for Standardization (ISO) for wigs supplied within the UK
- Development of a wig design specification (PDS) for long term medical users
- Mechanical properties of synthetic vs. real fibres and the optimum method for attachment to the wig foundation (cap)
- Durability of synthetic fibres as degradation occurs through exposure to heat (ovens & heated styling products)
- Colour absorption, fastening and fading of real and synthetic wig fibres.
- Moisture retention & wicking problems
- Security and comfort of the wig cap when seated on the user's head
- Manufacturing techniques and delivery of

a quality product - bespoke vs. mass production

- Reproducing aesthetic qualities of human hair in a fine (70-90 µm) polymer monofilament whilst maintaining stability of the fibre, chemistry and manufacturability

The cover up story

The research so far also suggests that a number of components work together to make up the wig user experience. By combining knowledge from material science, psychology, and design it is becoming clear that a wig is complex and multifaceted, requiring cross pollination of disciplines and skills. There's more to wearing a wig and this study wants to look at the difficulties of acquiring, using, maintaining and disposing of wigs and highlight potential areas for practical scientific development through a product specification.

If you'd like to learn more about this study contact:

Email: Karena.moore@strath.ac.uk
Tel: +44 (0)7866805509

FRONT PHOTO L-R
DR S. SHILTON, DR S. WIGGINS,
MS K MOORE-MILLAR,
DR A. THOMSON & DR J. LIGGAT





Alopecia World: “Rose Marie”

Inter-
view

Editor's introduction:

“Rose Marie” is the pen name of a correspondent on “Alopecia World” (an international alopecia discussion site). Rosie is known for her kind and helpful comments on a range of topics of interest to us. She helps people with Freedom Wigs in New Zealand.

You have a quite a following on Alopecia World (AW) for your wise and empathic comments, what do you like to contribute on AW and other websites?

When my daughter was diagnosed with alopecia areata 10 years ago I felt frightened and uneducated around the things that could help her. I didn't know whether we were going to be ok. So, my biggest want on alopecia world and other sites I contribute to, is to make sure to the best of my ability that the information I give is constructive, educational and above all supportive of those who are working through the many choices and emotions that alopecia brings.

Have you any particular views on the place of support groups and discussion forums in helping people with concerns about alopecia, whether it's for a person with alopecia or a parent of an affected child?

I think support groups and forums can be a very positive resource for those that need guidance and support, whether that be a child, adult or parent. It is always great to get first hand knowledge from those that have been where you are. As with everything in life you must use your common sense on any forum site, not all information is going to be accurate and what suits one person may not suit another.



As a parent of a child with alopecia, what has been the most helpful thing which has supported you in your alopecia journey?

Through my personal journey I was supported and helped by many people on sites and in person (not the least of which was my family). I live in New Zealand and one of the first people that helped guide and educate me around what alopecia was and could mean for my daughter was a very supportive lady named Beverly Wright. Sometimes it just takes one persons commitment to support others that moves you in a direction that is positive and empowering. From the moment I realised I could also make a difference I have done my best to give back to the alopecia community. I think for me being able to find solutions that help my daughter drives me to always listen and assimilate the information passed on by family, friends and members of support groups. I receive so much more than I give.

There has been another vital component to my daughter's journey that I would like to pass on to those who need help. Her Freedom Wigs. The company and the product they produce is second to none. The ability to be able to take control of who knows about her alopecia in her own time has been something that has been a game changer for her and I. My daughter has worn Freedom Wigs for the last 10 years and has been able to present herself how she feels comfortable. A good wig empowers the wearer an inadequate wig can cause distress. I'm so thankful that we were introduced to Freedom Wigs early in the process giving my daughter the ability to grow her personality with alopecia being a small component, never something to be ashamed of, but never to be denied either. Here is a picture of my daughter in her latest Freedom Wig. She is now 22 years old and a Chemistry Teacher at an all boys school (over 2,000) boys. She is open and confident in all parts of her life with regards to her alopecia. All her students understand what alopecia is and support her and her different hair styles



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Local Expertise: Margaret Helman



Margaret Helman has owned her own very successful salon in the past and now practises part time from a small and intimate location in Geelong. She has been a hairdresser for 40 years and has specialised in wigs for 35 of them. She 'has always loved hairdressing" and her interest in wigs was sparked by her own experience with cancer as a young woman and her hair loss as a consequence of that. She estimates her current clientele is about 80% cancer patients and 20% women with alopecia.

Her goal for her clients is simple - "to provide them with a wig that doesn't look like one" - a goal that is a real challenge to achieve. It requires on her part, experience, a comprehensive and current knowledge of the industry and the latest wig styles and their features and the ability to empathise with

clients' desires and difficulties and ultimately, to give the best advice and service possible.

To get the best match of all those features requires a trusting relationship between the client and Margaret. Some of the biggest challenges to that relationship come when clients buy a wig, especially an expensive one, either off the net or through a catalogue. These have been created, as all synthetic wigs have, in a particular style, and some clients ask to have them styled differently (see point 2 in Margaret's priority list).

The local Geelong alopecia support group, head2head, highly values Margaret's skills and willingness to impart her knowledge, her commitment to offering a quality service, as well as her sense of humour and positive attitude.

Pat Crotty (a member of head2head)

Margaret's Priority List for choosing a wig

- 1. Fit is the most important feature!**
Buying from a catalogue or off the web will not let you assess this
- 2. How the wig is sewn**
Look inside as this will determine the style and how the wig can be finished off for the individual person ie. cut and fitted. The style is set by the way it is made and cannot be altered although it can be trimmed and shaped to suit the individual.
- 3. Colour comes last**
Don't buy a wig solely because you like the colour

Wigs: Nearly Everything You wanted to know but were afraid to ask

Possibly the best place to start is the extensive information published by Alopecia UK on their website. <http://www alopeciaonline.org.uk/wigs.asp> Although some of the information is UK specific, it's a must visit to learn about wigs before you purchase one.

Informative article

The free article published last year in the Dermatology Online Journal , [A review of scalp camouflaging agents and prostheses for individuals with hair loss](#), has a thorough discussion of the many types of products available for hair loss, including wigs.

The illustration included here is part of a larger image clearly showing the construction of different types of wigs. The photos in the article were provided by Dr Jeff Donovan a Canadian dermatologist specialising in hair loss.

Wig Illustrations



Another free article

This is a brief but accesible article also by Dr Jeff Donovan about AA published in the magazine of the Canadian Skin Patient Alliance. It is only one page and might be useful if you want to give someone a straightforward explanation of alopecia.

This link courtesy of the Canadian Alopecia Areata Foundation
<http://canaaf.org/alopecia-areata-article-by-dr-jeff-donovan/>

We all deserve good customer service!

This includes privacy when you buy a wig and a back up service for adjustments. A good relationship with your wig expert or knowledgeable hairdresser is just as important as a good relationship with a doctor.

Most people buy a pair of shoes after making sure they fit and most would put clothes back on the rack if they don't fit or they really don't like them.



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Local Research Studies

Please consider being part of these studies. You will be contributing to a better understanding of the experience of having AA. Jessica's study is seeking women 18 or over with any kind of AA. Ryan's is seeking adults both men and women who have AA as is Jane (see next page).

Two studies into alopecia areata are being conducted through Victoria University in Melbourne

Jessica Martino is conducting her honours thesis, sponsored by the Australian Alopecia Areata Foundation (AAAF Inc.) "Investigating the impact that Alopecia Areata has on women's self esteem and mood states, as well as exploring adjustments made in coping with the condition. She is seeking women with any type of alopecia areata aged 18 years and above with an Australian residency. Participants would be required to complete 4 questionnaires (which would take approximately 10 minutes). At the participants preference, Jessica can post out the questionnaires (which will include a prepaid envelope for participants to send back cost free) or send them via email.

Jessica acknowledges that alopecia areata research is lacking worldwide, especially within Australia. She hope to contribute to the body of knowledge providing beneficial information to individuals diagnosed with the alopecia, and encourage future research opportunities. Jessica's research will further lead to increased community awareness about the relationship between alopecia and possible psychological concerns. It is anticipated that by participating in this study, the information collected will also promote positive adjustments made in coping with the condition.

Your participation would be much appreciated.

If interested please email Jessica at jessica.martino@live.vu.edu.au for further information.

Ryan Veal's study is to investigate the comparative psychological impact of AA diagnosis between people who have grown accustomed to having AA over several years (diagnosis of 5 years or more) compared to people with a more recent diagnosis. Differences in levels of depression, anxiety, stress and overall quality of life will be observed. An additional focus of the study will be on the different reactions to news of the diagnosis, including the bedside manner of the health professional and the current level of acceptance of the diagnosis. If you are interested please contact him before the end of August at ryan.veal@live.vu.edu.au or 0429931043

[AAAF is funding these studies](#)



The Good News

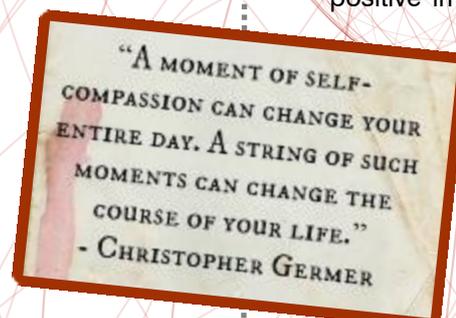
- There is growing interest internationally in the impact on quality of life from skin disorders of all types including alopecia.

A new concept is being applied to chronic dermatological conditions -

"Cumulative Life Course Impairment".

This recognises that something like alopecia or psoriasis can have consequences for people's choices of education, employment, careers and relationships. These may add up to important influences on someone's life course.

However we should not forget that there may also be strengths and benefits as well as problems created by illness experiences. They may also have a positive impact on how people live.





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Alopecia Areata Research at the University of Melbourne/ Epworth Dermatology

Re-
search

Jane Li is a PhD student at the University of Melbourne, studying the subtypes of immune cells (known as T cells) in alopecia areata and the effects of corticosteroids on these cells. Corticosteroids are the most common treatment for alopecia areata, but often cause debilitating side effects, and there is a need for improved treatment strategies that reduce these side effects.

Jane is seeking any volunteers with alopecia areata aged 18 years and above who would be interested in donating scalp skin samples for laboratory analysis. Jane can email the study information sheet to anyone who is interested if they contact her. For more information please email her directly at jane.melb@gmail.com.

This project is supported by a grant from the Australia Alopecia Areata Foundation Inc. Jane's supervisors include Professor Rodney Sinclair, dermatology clinician-researcher and Director of Epworth Dermatology, the largest hair loss clinic in Australia, and Professor Frank Carbone, one of Australia's leading immunologists.

Your participation would be greatly appreciated!

The President and Committee
of the

The Alopecia Areata Support Association

cordially invite our members and friends
to the

2013 Annual General Meeting

2 - 4 pm Saturday August 31st

at the

Skin and Cancer Foundation

1st Floor, 80 Drummond St Carlton

(Corner of Queensberry St)

A business meeting of approximately 15 - 20 minutes will be conducted
to seek approval for the 2012-3 Financial Accounts and
to elect the Committee for the 2013/14 financial year.

Please join us for afternoon tea and an opportunity to catch up with
friends

Pat Crotty
Honorary Secretary AASA (Vic) Inc.,
PO Box 89,
Camberwell 3124
Registration No.A 0017172Y



Support services since 1980

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Agenda

Annual General Meeting
31st August 2013

Skin and Cancer Foundation
1st Floor, 80 Drummond St, Carlton

2 - 4 pm

Chair : Garry Lonsdale

Welcome

Apologies:

Confirmation Minutes 2012 AGM

President's Report

Treasurer's Report

- Introduction of 2012 -13 Financial Report
- Membership Subscription 2013 - 14
- Appointment of Auditor

Handover to interim chair for election of the incoming Committee 2013 - 14

Election of the New Committee

Declaration of membership of 2013 - 14 AASA Management Committee

Close of meeting.

Please join us for Afternoon Tea



ALOPECIA AREATA SUPPORT ASSOCIATION (VIC) Inc.

No. A 0017172Y

MEMBERSHIP 2013-2014

Membership for Adult/Child with the Association for the financial year **2013-2014**

Form of Alopecia : Areata Totalis Universalis Other

Child Details Only (Please fill in)

Child sufferer's name..... M F

Parent of sufferer Supporter

Surname: Mr/Mrs/Ms/Miss.....

First Name:.....

Address:.....

..... Post Code:.....

Tel. No:..... Mobile:.....

Email:.....

Date of Birth (of sufferer):...../...../.....

Year Alopecia appeared:.....(approx)

Occupation:.....or/Pensioner No:.....

MEMBERSHIP CATEGORY:

Full Member: \$25.00 per year (July/June)
Associate Member: \$25.00 per year (Supporter)
Student/Pensioners/Children: \$15.00 per year (Minimum donation suggested)

Money order/cheque enclosed made payable to Alopecia Areata Support Association (VIC) Inc.

\$..... (No cash through the mail please)

Signature:.....Date:.....

Please mail to: AASA (VIC) Inc.
Marked Attention of:
Membership Registration, Treasurer
PO BOX 89
Camberwell VIC 3124

Office Use Only
Date Received:...../...../.....

Treasurer:
Receipt No: