

Alopecia Areata Support Association (Vic) Inc.



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Registration No. 0017172V

May 2009

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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 to all.

Almost half way through the year already and Winter is just about upon us.

I have just been surfing the net and came across the Princess Charlotte Foundation website. The great news is that Stephanie Rice, the beautiful Olympic swimmer, has been announced as the new spokesperson for the Foundation and has nominated the Princess Charlotte Foundation as her charity of choice. It's a great little website and the Foundation is doing lots of good things. Have a look when you get a chance. It will certainly raise the awareness about alopecia and how, while it is not life threatening, it is certainly life changing.

We are still working through Open Day times, dates, alternatives etc and will let you know when any decisions have been made.

Enjoy your reading and take care out there.

Julie Billings, President

From the editor

Seems like it was just yesterday I was finishing up on the February newsletter, when May has come in and snuck up behind us!

In this issue, we highlight the efforts of Julia Crittendon, who has self published a book about the experiences women going through life without hair.

Our former editor Pat Crotty has written a great article about some of the recent papers published on Alopecia and quality of life issues.

As Julie has already mentioned, the announcement of Stephanie Rice as ambassador for the Princess Charlotte Alopecia Foundation is a great way to bring awareness to our cause.

We also have a poignant reader's response to a personal story that was printed in the February Newsletter.

And finally, we have a light-hearted article on the importance of childhood memories, where a certain day of the year can set someone's mind back to a maybe not so happy time.

Enjoy the issue, and if you like anything you read here, then please, please, please share your thoughts.

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Housekeeping Notes:

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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

2009 Meeting Dates:

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

Next Meeting
30th May 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.

Metamorphosis : "Inspirational Stories of Women Living with Alopecia"

Julia Crittendon has taken the old saying about making lemonade out of lemons to heart. Or rather she's taken it to her head, choosing to use the condition that caused her hair to fall out as an avenue to help others.

The former Mansfield (USA) resident recently self published "Metamorphosis: Inspirational Stories of Women Living with Alopecia." The book charts the experiences of 22 women as they dealt with hair loss and what it's like to be a bald woman.

"People are still hiding from it," Crittendon said, noting when she was diagnosed she found no literature or any support other than from her family.

"These women are standing up to what was meant to destroy and depress them and are turning it into positive productive energy so that the next woman who loses her 'crown and glory' won't fall victim to what society deems as 'normal.' "

Two of the women explained their own feelings about living with alopecia to the News Journal via e-mail.

"I feel honoured to have contributed to a book that may inspire and help all who are lucky enough to come across it," Jenn Pendergrast said. "I am totally bald and have finally accepted it."



A Fort Lauderdale, Fla., resident, she was diagnosed in March 2006.

She said the book provided a kind of therapy for her.

"It was actually the first time I put my story into words and I cried the entire time I was writing," Pendergrast, 31, said. "When I was done writing, I felt so good. It felt awesome to put all that had happened into words for others to read."

A resident of the Netherlands, Tamara Cramer Bornemann also contributed to the book .

"I am 31-years-old and was diagnosed with alopecia when I was 5-years-old," she said. "My parents always did their best to find a cure for me and took me to many hospitals and other specialist each in their own profession. I only wore a wig once

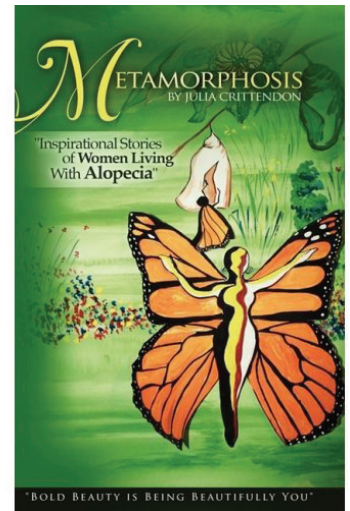
-- when I was about 7-years-old -- and I didn't feel too good about it. So from that moment, I went through life without a wig.

"The teenage years were pretty difficult because I wanted to be normal. In my 20s I felt in bloom and enjoyed my life. I got married after years of living together with my boyfriend. Now I am divorced and single. I am a teacher at a school for teenagers who are dealing with learning difficulties.

"I had a look on Julia's Web site, but I met her on [www. alopeciaworld.com](http://www.alopeciaworld.com). When she gave me the opportunity of writing my story about alopecia, I started to write my story down on paper, with the key points she gave me. I saw this opportunity as a chance to inspire other people who are dealing with alopecia and to support them with my side of the story alopecia. I didn't want to inspire only the people who have alopecia, but also parents, family and friends of people who are dealing with alopecia."

Crittendon hopes "Metamorphosis," which she hopes to support with a tour, will help her fulfill a desire to become a self esteem coach and motivational speaker.

"It's amazing how everything comes full circle," she said.



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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.

She is employed with an e-commerce company in Louisville. The Mansfield Senior High School graduate has her own experiences with the condition. According to the National Alopecia Areata Foundation, more than 5 million people in the United States have the affliction.

"The affected hair follicles are mistakenly attacked by a person's own immune system (white blood cells), resulting in the arrest of the hair growth stage," according to the foundation. "Alopecia areata usually starts with one or more small, round, smooth bald patches on the scalp and can progress to total scalp hair loss (alopecia totalis) or complete body hair loss (alopecia universalis)."

Crittendon started losing her hair in 2002, six months after giving birth to her daughter, Scotlyn. That started the then-28-year-old on a round of tests, a diagnosis, depression and treatment including painful cortisone shots to her scalp every four weeks.

The impact of alopecia can't be written off as mere vanity.

Dr. Patricia Tucker of the University of Western Ontario, Canada, earlier this month released a study, "Bald is beautiful?: The psychosocial impact of alopecia areata." It reviewed 19 previous studies representing 1,271 participants from nine countries.

Tucker's study found that the condition causes dramatic and devastating emotions in patients, which can negatively affect their self-esteem, body image, and self-confidence. That impact can be heightened in women and girls because of social pressures on them to be attractive. The study's conclusion suggested treatment for alopecia patients should offer psychological support to foster increased self-esteem and adaptation to their disorder.

Crittendon credits her mother, Linda Johnson, and husband, Dwayne Crittendon, with helping her get through her depression.

Still, she said it took five years before she went bald in public.

At one point she tried wearing a \$3,000 wig.

"It was awesome," Crittendon said, but these days she shaves her head every other day. She recalled telling herself before that first outing sans wig or head wrap, "This is me, take me as I am."

From there, Crittendon started the Web site bbibby.org, which stands for Bold Beauty is Being Beautifully You.

Also a mom to Kya and Alex, Crittendon has tried to instill her mantra in her daughter, Scotlyn, who also has the condition. Since she was a baby, Scotlyn has had small spots on her head, then the hair grows back. Last spring, the largest spot was the size of a half-dollar, which also grew back. So far she hasn't lost a lot of hair.

"She sees how I handle it," Crittendon said of her 7-year-old, who also has a part in the book. "She will still keep her head up."

Crittendon, 35, originally planned on creating a documentary on alopecia. When funding from the Kentucky Foundation for Women didn't work out, she decided she stilled "needed to do something with this."

The book, her back-up plan, is available online.

"The number one comment that I get is 'My hair is not coming out' or 'I don't know anyone to give this to.' This book is about hair loss, yes, but most importantly is about accepting change. The only thing constant in all of our lives will always be 'change.' This book is showing others how to embrace change no matter how bad it may seem. Life's too short. Where there is awareness and education, there is understanding."

Buy the book : <http://www.amazon.com/Metamorphosis-Inspirational-Stories-Living-Alopecia/dp/0578004461>

Julia's website : <http://www.bbibby.org>

Written by Lisa Miller, originally published in the Mansfield News Journal (<http://www.mansfieldnewsjournal.com>)

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ROB'S RANT

As Good As It Gets?

In the 1997 film *As Good As It Gets*, Jack Nicholson plays the character of an obsessive-compulsive, misanthropic, and bigoted romantic novelist named Melvin Udall. In one scene, he walks out of his psychiatrist's office, after just having had an argument with him. He walks straight into the waiting room, where there are six other patients waiting. Feeling the frustration from his psychiatrist from not being able to "fix" him, he utters the phrase to the awaiting patients, "What if this is as good as it gets?".

The six remaining patients stare at each other, almost in a look of hopelessness, forced to come to the realisation that, in spite of all their efforts, there may not be anything more than can be done for themselves.

The reason I quote that line from the film, is because that's what I thought of when someone had asked the question recently, "Have you given up on the hope of growing your hair back?". It was quite a confronting question. How was I to answer that? Had I given up on hope? Or have I just come to accept the fact? In my case, the latter is probably closer to the truth, and I think that there is definitely a great distinction between the two.

However, it's not easy to just accept the fact that you are losing or have lost all your hair. It's not easy to let go of the last few strands that are still clinging on to dear life atop your almost bald head. It's not easy to contemplate the thought that your hair is just not going to come back.

If you are just starting to go through Alopecia, by all means, never give up hope. Try everything possible under the sun to try and keep every last bit of hair that you have. What doesn't work for some people, could be the very thing that is just suited perfectly for you. You can come to accept the fact that you have Alopecia, but you can always have hope that it'll all grow back some day.

Have I completely given up all hope? Of course not. I still hold on to the hope that my eyebrows will come back. I've got little hairs growing along the edges of where my eyebrows should be, which gives me plenty of hope. As you may have read from my previous rants, I've started to wear silicon eyebrows. When I go to buy them online, I can save money by purchasing multiple sets of eyebrows, but I don't. Why? Because I hold on to the hope that by the time I need to purchase another set, my own eyebrows would have grown back. Granted, that hasn't happened yet, but there is always hope...

General Meeting on 30th May 2009

In keeping with the idea of having AASA meetings with targeted themes, the next meeting which is to be held at 2pm on 30th May 2009 will be focusing on information and support for people who have just started to lose their hair and/or need help coping with the loss.

Our special guest for the day will be Sebastiana (Seba) Biondo who is a Clinical Psychologist who has great experience with dealing with patients who have Alopecia. Our aim is for Seba to facilitate a discussion for parents with children suffering from alopecia, people who are new to it and are trying to come to terms with it, or anyone who is struggling in dealing with their hair loss.

We hope you can come along to the meeting no matter what stage of Alopecia you are in.

Date : 30th May 2009
Time : 2pm
Location : Skin and Cancer Foundation
 80 Drummond St (cnr Queensberry St), Carlton, Victoria

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.

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Cultural 'wound' or 'disease'

By Patricia Crotty

There have been some interesting articles appearing in medical and psychological journals.

In the past 12 months I have come to believe that alopecia areata is a sort of 'orphan problem', falling between the two stools of being a medical illness and the 'fallout' from our deviation from culturally acceptable appearance.

I don't need to repeat here that there are millions of words written about 'appearance', beauty, body image, fashion, overweight, cosmetic surgery, TV make-overs and more. We live in a society in which appearance is valued beyond its true worth. I believe we are some of the many 'casualties' of this pre-occupation.

Are the difficulties experienced by us caused by our bodies gone wrong, or by the culture in which we live? I think it's the latter. How many times have you read the statement people with alopecia areata are 'otherwise well' (Have nothing to worry about?) I've always believed that statement is made more from wishful thinking than lots of evidence. It can be a justification for those statements like 'It's only your hair', and the difficulty in getting needed support through the medical system. Often what we need is not provided by doctors, this is recognised by some patients with skin disorders (psoriasis, eczema and acne) studied by doctors in NSW ⁽¹⁾. The researchers say that,

"Some participants perceived their doctors as medical technicians and sought treatment for their physical skin disease, not for its emotional or social aspects".

We are in double trouble soothing our distress! Distress itself, damages health. Not only might it be hard to get emotional support when AA is treated as a disease, but disease treatments for AA are now recognised as (possibly) rarely effective. And it doesn't help me to be told that 'Bald is Beautiful'. Although I may desperately want to believe that, the culture around me very obviously does not. I need help and support to find a positive self image and to live self confidently on a different basis, and that's not easy.

Patricia Tucker ⁽²⁾ has recently reviewed research on the psychosocial impact of AA. She concludes that ".....AA causes dramatic and devastating emotions in patients which can negatively impact their self-esteem, body image and/or self-confidence. The negative impact of AA may be heightened for female patients due to the societal pressure to be attractive. Treatments for alopecia patients should offer psychological support to foster increased self-esteem and adaptation to their disorder'

This notion is supported by a recent special supplement of the Medical Journal of Australia devoted to establishing that chronic disease often comes with a burden of mental distress and that this hampers recovery and can cause further health problems. The importance of the impact of depression on physical health is now recognised as very important and the need for 'integrated models of care' is seen as a priority ^(3, 4).

We need to find a way to make this relevant to the care of people affected by AA.

1. Patients with skin disease and their relationships with their doctors: a qualitative study of patients with acne, psoriasis and eczema, Parker J Magin, Jon Adams, Gaynor S Heading and C Dimity Pond, Medical Journal of Australia 2009; 190: 62-64

2. Bald is Beautiful? The psychosocial impact of alopecia areata, Patricia A Tucker, Journal of Health Psychology 2009; 14: 142-151

3. Depression, anxiety and their relationship with chronic diseases: a review of the epidemiology, risk and treatment evidence, David M Clarke and Kay C Currie Medical Journal of Australia 2009; 190: S54-S60

4. Depressions and physical illness: more complex than simple comorbidity David M Clarke Medical Journal of Australia 2009; 190:S52

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Stephanie Rice - Ambassador for Princess Charlotte Alopecia Foundation

On April 17th, Olympic swimmer Stephanie Rice was announced as ambassador for the Princess Charlotte Alopecia Foundation during a media launch in Sydney.



The main focus of the day was "Tresses for Princesses", which is an outlet for the donation of hair in Australia and New Zealand. Three very brave young ladies and one amazing teacher had their long hair cut short to support others who have no hair at all.

Stephanie spoke about her interest in our foundation, and was amazed at the resilience of our young children who cope with such a difficult problem as hair loss. Her support of the Princess Charlotte Alopecia Foundation will hopefully spread the word about alopecia and about the positive way people can help by donating their hair.

"If I can encourage just a few more people to donate their hair to help Alopecia sufferers feel like a prince or princess again, it will be something I will be so proud of." Stephanie said.

With Stephanie Rice being such a high profile personality, her involvement with the foundation can only bring much needed awareness to Alopecia and its sufferers.

For more information visit <http://www.princesscharlottealopecia.com>

A response to "Learning To Be More Than Just Hair!"

In the February issue of the AASA newsletter, we featured a personal story from Jo, who talked about her journey as a woman living with Alopecia. This has prompted one of our readers to share her own experiences with the condition.

"Hello, my name is Sarah. It is the first time today I browsed AASA website. I was moved to tears when I read Jo's story, and I related a lot to myself as well.*

I have been suffering from Alopecia for about 19 years. It was a traumatic experience for a teenage girl to go through such a physical change and subsequently a huge psychological impact. What made it worse is I was in a small city in China when all of these happened. Alopecia is still not well understood and sympathized by general population today in Australia, not to mention 19 years ago in China. I went through the toughest phase in my life, especially after numerous treatments I went through turned out to be unsuccessful. In China, having a condition like this is unspeakable and of disgrace, so as depression. I avoided to talk about this issue to anyone, including my parents. Even though, I managed to pull myself together with my parents' support and finished high-school and uni. It was very disappointing to know after I finished uni (7 years ago) that I was still discriminated because of my condition, even by people who are quite well-educated. I, was at that point, made my decision to come to Australia by myself and start my new life here.

I have been doing quite well since I came to Australia, and my career is going

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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smoothly. However, Alopecia is still the biggest secret at the bottom of my heart, and I have never been able to, or wish to talk about it with anyone. I really don't know whether I am still in denial or this is just the strategy I am using to cope with the condition.

I am so glad to see that so many people are so brave to talk about their experience, and share with us their suffer and joy. That's the main reason I decided to write you my story. Maybe it's time for me, after 19 years, to finally be able to speak about my experience."

Sometimes, reading someone else's story can make us realise that we are not going through this alone.

If any of the stories you have read in our newsletters have moved you, or you would like to share your own story, please contact us at aasavic@iprimus.com.au

No matter how long or short your story may be, any contribution or feedback is greatly appreciated.

** Name changed to maintain anonymity*

Valentine's Day brings back regrettable childhood memories

By Bill Brady

I've almost outgrown my antipathy toward Valentine's Day. I know, get over it; after all, it's been more than six decades.

That February so long ago, I was a kid of nine who needed glasses but then denied that and as a result, squinted. And I was bald -- ergo, a freak.

About the bald head, I was too young for that to be a fashion statement but old enough to be humiliated and constantly sad.

I was a victim of alopecia areata, a condition that causes bald spots. My parents were told the condition could spread to the entire scalp, so Dr. Mills urged that all my hair be removed. For a kid who shunned hats of any kind, the low point of my already unhappy existence was the need to wear that ugly wool tuque.

To avoid school, I tried all the excuses to no avail. Feigned cold/flu/upset stomach notwithstanding, I reluctantly walked through the snow and into the bustling schoolyard. All the kids were wearing hats, but they'd be taking theirs off once inside. I wondered if I would be allowed to leave mine on.

I dreaded the moment when I entered my room followed by Mr. Boyd, the principal. He called for attention, placed his hand on my shoulder and spoke.

"Boys and girls, I want you to listen carefully. Junior Brady (honest, that was my name back then -- I made the change to Bill in Grade 8) has a problem." Then he went into embarrassing detail meant to be of comfort,

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

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

but contributed even more to my humiliation.

He insisted that I not be teased, harassed or ridiculed and that no one was to mention my hairlessness. Then he told me to remove my tuque. I did and they all laughed, until he gave them the look.

His admonition worked indoors, but recess was hell. Bullying existed then as now but was called "teasing" and I was the subject of it all. I look now at the brave children who lose their hair while being treated for cancer and realize what a sissy I was and feel shame now for my self-pity.

The timing could not have been worse, the week of Valentine's Day. At the front of the classroom there was a large box decorated with hearts and doilies. Pamela was named postmaster and, as I recall, we all thought she was the teacher's pet. She was smarmy and too cute and always had her hand up to answer questions, most of which I couldn't answer.

She reached into the box filled with valentines that had been deposited during my brief hiatus while being shorn and called out the names. There was a steady parade of smiling kids walking up to get cards and notes. I did not hear my name.

At last after an endless day, I walked home. With my three older brothers looking on, I sniffled my way through the fact that everyone in my class had received valentines but me. I trust that now in a more enlightened time teachers have done away with this quaint tradition.

Later, I was called down from my bedroom and there on the table were many envelopes. "Look what was in the mailbox," brother Dennis fibbed. There were valentines -- big, small, funny -- some signed "from a secret admirer," others with names I did not recognize and one with the signature of the strange man next door who one day was taken away by the police.

All forgeries, of course. My three brothers showed compassion I had not seen before. I was thrilled by the outpouring of affection even if I had no idea who my admirers were. Were these the same sibs who tormented and teased the one they constantly referred to as "that pest, our little brother"?

In spite of those negative memories, today is a special day when love abounds and it's a huge day for the greeting card business. More than one billion valentines are sent each year. It's the second largest card-sending day of the year after Christmas.

Then there are the flowers and the ubiquitous heart-shaped boxes of chocolates.

A statistic that may not surprise you and tells a lot about men: women purchase about 85 per cent of all valentines.

Have a lovely day.

Originally published in The London Free Press (<http://www.lfpress.ca/home.html>)