



Support services since 1980

# Alopecia Areata Support Association (Vic) Inc.

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Registration No. 0017172V



## August 2012

This Month

Peer Support - What is it?

A Participant's Perspective  
by  
Florence Kingsley-Mathews

The Skin and Cancer Foundation

Quality of life and AA  
Researchers are interested!

Terrible Histories!

Updates

AGM invitation for August 25th

AASA Membership

### The London Olympic Edition!

This Olympics has had many special features. One of them is the performance of "Team GB", which is having an unprecedented golden time.

Amongst their gold medallists is 23 year old cyclist Joanna Rowsell. She was a member of the trio who won the Women's Team Pursuit.

Joanna lost her hair at age 10, her athletic potential was discovered when she was 15, and she now credits cycling with transforming her.

Much has been written about Joanna but perhaps nothing better than the headline that appeared in the Melbourne Age

*"Rowsell defined by her win, not by her loss" The Age*



Photo:AFP

Our next Members' Meeting will our **AGM** 2pm 25th August 2012 at Skin and Cancer Foundation, 80 Drummond St (cnr Queensberry St), Carlton, Victoria

**All Welcome!**

**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.

## What is peer support?

*Peer support is one person with a problem helping another with a similar type of problem. Peer Support for people with similar life experiences (e.g., people who have lost children, people with diabetes or arthritis) has proven tremendously important in helping many move through difficult situations. In general, peer support has been defined by the fact that people who have like experiences can better relate and can consequently offer more authentic empathy and validation.*

(Adapted from [www.friendsaregoodmedicine.com/pdf/WhatisPeerSupport.pdf](http://www.friendsaregoodmedicine.com/pdf/WhatisPeerSupport.pdf))

A Victorian peer support program called LifeMoves is for people with an acquired neurological condition such as a stroke.

The LifeMoves programme was developed at The Royal Melbourne Hospital in 2002, and has been delivered regularly since then to people referred by the Hospital's team of specialist rehabilitation clinicians based at Royal Park. 'Peers Inspiring Peers' deliver the LifeMoves program. You can find out more about Peers Inspiring Peers on their website <http://www.peersinspiringpeers.org.au/about.htm>

As an introduction to LifeMoves here is a statement of their Vision, Mission and Values

Seeking information or support?

Phone the AASA MessageBank (03) 9513-8580.

One of our phone volunteers will return your call within 24 hours

### LifeMoves

#### Our Vision

Peers Inspiring Peers.

#### Our Mission

LifeMoves will provide structured peer support that empowers people with acquired neurological conditions

#### Our Values

You will see us -

##### Empowering

- Working with our peers as equals
- Modelling hope for the future
- Encouraging our peers to set and reach their own goals
- Celebrating successes and achievements

*Therefore, you will not see us 'dishing out' solutions, solving all problems or being 'The Expert'*

##### Supporting

- Actively listening to everyone's ideas, thoughts and opinions
- Sharing our experience where it may assist others
- Encouraging others to explore new possibilities
- Acknowledging that life is a journey
- Looking after ourselves and seeking help when we need it

*Therefore, you will not see us taking 'air time'*

##### Partnering

- Respecting each other and embracing diversity
- Being open and honest in all our dealings
- Working collaboratively to achieve common goals
- Recommending professional expertise where appropriate

*Therefore you will not see us being competitive or giving advice outside of our expertise*

Source: <http://www.peersinspiringpeers.org.au/about.htm>

## Peer Support: A Participant's Perspective

by  
**Florence Kingsley-Mathews**

Florence gave a moving presentation at a peer support conference in May. The conference was organised by the Chronic Illness Alliance in Melbourne. We thank Florence, who is LifeMoves Relationship Coordinator, for permission to publish her presentation here.



Eight years ago I had an unexpected curve in my Life journey when my heart was attacked by a virus. Luckily I collapsed in the emergency department of the Epworth hospital where I was in a coma for almost two weeks. When I woke up the doctors discovered that I had also suffered from a stroke which had affected the left side of my body. My neurologist advised me that I may never walk again.

After intense rehabilitation of just over two months I left the hospital all be it in a wheel chair. I continued my rehabilitation trek at the Royal Melbourne Hospital as an outpatient for another nine months where I slowly learned to walk again and look after myself getting more and more independent.

You may all find this truly remarkable or amusing, however when my physiotherapist told me that my rehabilitation journey at the hospital had come to an end and I was to be discharged, I broke down and cried as I did not know what I would do with my Mondays, Wednesdays and Fridays any more. My life had changed and how!

Luckily for me, she suggested that it would be beneficial to attend a Peer Support Programme that was being run at the hospital. Not knowing quite what to expect, I attended the first session of the programme and for the first time, I realised that there were other people just like me. I.e. their lives had also changed radically due to an ABI; they could not just resume the lives they were living prior to their illness just as I was unable to.

For the first time since my illness, I listened as these other people described situations and challenges that I was facing in my own life and I felt really connected to this room full of strangers.

This especially came to light when we talked about things like

- fatigue,
- frequent changes in emotions (like crying all the time for no apparent reason),
- losing our identity
- having other people look at us strangely and sometimes even with pity
- unable to do simple tasks like pay the bills or do the shopping, cook dinner, etc
- scared of being a burden on the ones we love
- changed relationships with our partners and family

I could really relate to these strangers that I had never met before. They did not judge me and there were no expectations from anyone. I could tell them how I really felt and how lost and alone I was even with my loving family right there beside me. Most importantly, I did not feel guilty when I

AASA holds  
meetings  
quarterly  
on the

last Saturday of  
February, May,  
August and  
November

from 2 to 4 pm at

Skin and  
Cancer  
Foundation,

first floor

80 Drummond St  
Carlton  
(cnr Queensberry St)

All welcome!  
Join us for an informal  
social gathering

Check our website for  
the latest information  
[home.vicnet.net.au/~aasa](http://home.vicnet.net.au/~aasa)

shared these experiences.

As I listened to the other participants in the group, I realised that I felt more comfortable with them than I did with some of my closest friends. Over the next 7 weeks of the programme, we shared strategies and encouraged each other to overcome the many obstacles in our path and developed camaraderie.

As I moved on over the next few years still concentrating on my own recovery, I treasured those memories of the group and kept reminding myself that there was a whole world out there just waiting for the **new me**.

About 4 years ago my doctors told me that I had recovered as best I could. I was happy. After all, I could walk on my own, I could talk, and I could drive short distances however my short term memory, walking and fatigue issues remained. Unfortunately, I was not able to return to my previous employment and wondered, "What I was going to do with the rest of my life?"

They say that when one door shuts, another one opens and I remembered the LifeMoves peer support programme where I had felt so comfortable and I decided to volunteer with the organisation that was delivering the programme.

After I completed my training, I became involved first as a Peer Support Volunteer and then as a facilitator in the programme and continue to be amazed at how each group of clients bond. At every programme, I listen to other people whose lives have been changed by an ABI and the many challenges they face. I remember my own journey and while I would never guess or predict what their recovery would be like (after all I am not a medical professional), I could understand their frustrations and listen to them give voice in a relaxed and safe environment.

Every time they share their experiences, challenges and values, there is so much commonality; you can feel the atmosphere in the room become more and more comfortable. It is truly inspiring to see the strategies that clients come up with to help and encourage each other to take those first few steps towards regaining some control of their changed lives.

As a peer, it is truly energising to see the group interact with each other and help and support each other with their challenges. They assist each other to set small goals and celebrate as these goals are achieved. This gives the participants even more courage to take on new challenges as they arise and it truly gives them some semblance of control over a life that they come to realise they really have little or no control over (from an illness perspective).

While one can never truly know what it feels like to live someone else's life unless one actually walks in their shoes, true empathy and understanding and respecting that each person's journey is unique, helps people to really connect

As a control freak, I had quite an adjustment to make when I realised that I truly had very little control over my own illness and how it could affect me. Eventually, I did feel empowered that I could live my life in a totally different way and still use some of those skills that I had gained in my Pre-ABI days.

LifeMoves and so have I. Thank you. 



### The Skin and Cancer Foundation - Support Group Hub

The Foundation, located in Carlton, has been very supportive of AASA. For many years we have held general and committee meetings and a number of AASA Open Days, at the Foundation.

The Foundation provides assistance to other skin disorder support groups such as those for psoriasis, eczema and vitiligo. Recently a dedicated area within the Foundation's premises has been established resulting in a unique onsite support group hub.

This is an exciting development for dermatology support groups as it means that it will be possible to share resources and extend services beyond what individual groups can currently offer to their specific constituents. AASA has been involved in initial discussions through our secretary, who as a peer supporter, attends the Hair Clinics run at the Foundation.

AASA's work with the Foundation was recognised at the inaugural Healthy Skin awards in May. The Healthy Skin Awards aim to acknowledge and recognise employers and organisations throughout Australia who have supported and encouraged the promotion of skin health to their employees or members in their workplaces, as well as individuals and organisations raising awareness of skin health to the public.



AASA secretary Pat Crotty accepts one of the 2012 Healthy Skin Awards for AASA's work. Other 2012 award winners included King Wood & Malleons, the Victorian Trades Hall Council and Australian Men's Health.

Interested in volunteering to help establish AASA's role in the hub and work with other support groups?

Email Pat

[aasavic@gmail.com](mailto:aasavic@gmail.com)

See our other contact details on the last page

*"The Skin and Cancer Foundation 'Support Group Hub' is a great initiative. Peer support groups by definition, demonstrate commitment to improving the health and wellbeing of their peers. The hub offers opportunities for these groups collaborate towards creating even more positive outcomes for their group's members as well as the broader community. With the Foundation's support, groups could increase community awareness and strengthen their ability to advocate for their members and all people affected by a dermatological condition.*

*The success of the LifeMoves peer to peer program is inspirational and is an example of the type of activity that might work for the 'hub'". Pat.*

## **Quality of Life' (QoL) and research into the impact of AA**

It is common to measure the QoL of people with health problems to get some idea of the impact that the condition has on their lives, for example, does the problem prevent people from carrying out their normal daily activities? One of the most important aspects of measuring QoL is finding out to what extent people are distressed by their experience. Even within the same health problem with the same level of severity, for example arthritis, people can be more or less upset by it. The severity of a problem is not necessarily the most distressing part of the experience of having the condition. An example might be mild arthritis affecting the hands of someone, who although dealing with pain and stiffness, can still do the things they need and like to do. Compare this with a passionate musician whose livelihood depends on supple hands. The unwanted changes a condition places on a person may make it much more distressing.

Some questionnaires have been developed to measure QoL for particular conditions such as cancer, arthritis or psoriasis, but none have been developed especially for AA, until now. Recently two research groups have developed and tested QoL measures to assess the impact on the QoL of people with alopecia.

**An Italian QoL research group** said, "AA is a biologically benign disorder which, however, seriously impairs QoL by altering self perception and self-esteem and by interfering with social life. ....the standard measures, such as the percentage of affected skin, insufficiently describe the psychological distress of affected patients .....symptoms, such as worry or unhappiness or itching, as well as difficulty in relationships, should also be considered". Their questionnaire particularly picks up the impact of AA on relationships, they say. It is designed for use by doctors with their patients.

**A Japanese group** have been working in this area too, their questionnaire is a short self report measure which takes only a couple of minutes to complete. They are interested in AA's impact on restriction of activities, concealment and adaptation as important components of QoL in AA.

Hopefully these new measures will be tested widely in practice and help ensure that effective information and support programs will be an outcome for people with AA.

**In the United States** the National Alopecia Areata Foundation is recruiting participants for a project they funded called -The Alopecia Areata Symptom Impact Scale - Quality of Life questionnaire.

Let's hope that we can all soon read the results of studies that implement these AA specific QoL measures.

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Fabbrocini G and others (2012) Quality of life in alopecia areata: a disease-specific questionnaire J. Acad Derm Venerol. doi: 10.1111/j.1468-3083.2012.04629.x

Endo Y and others (2012) Development of a disease-specific instrument to measure quality of life in patients with alopecia areata. Eur J Dermatol doi:10.1684/ejd.2012.1752

National Alopecia Areata Foundation e-news [www.naaf.org/](http://www.naaf.org/)  
(You can sign up for their latest news updates)



## Terrible Histories!

Eventually, the Romans conquered the Greeks. History calls people Romans because they never stayed in one place for very long. At Roman banquets, the guests wore garlic in their hair. Julius Caesar extinguished himself on the battlefields of Gaul. The Ides of March murdered him because they thought he was going to be made king. Nero was a cruel tyranny who would torture his poor subjects by playing the fiddle to them.

The inhabitants of ancient Egypt were called mummies. They lived in the Sarah Dessert and traveled by Camelot. The climate of the Sarah is such that the inhabitants have to live elsewhere, so areas of the desert are cultivated by irrigation. The Egyptians built the Pyramids in the shape of a huge triangular cube. The Pyramids are a range of mountains between France and Spain.



The government of England was a limited mockery. Henry VIII found walking difficult because he had an abscess on his knee. Queen Elizabeth was the "Virgin Queen." As a queen she was a success. When Elizabeth exposed herself before her troops, they all shouted, "hurrah." Then her navy went out and defeated the Spanish Armadillo.

In the Olympic games, Greeks ran races, jumped, hurled the biscuits, then threw the javas. The reward to the victor was a coral wreath. The government of Athens was democratic because people took the law into their own hands. There were no wars in Greece, as the mountains were so high that they couldn't climb over to see what their neighbors were doing. When they fought with the Persians, the Greeks were outnumbered because the Persians had more men.

Then came the Middle Ages. King Alfred conquered the Domes. King Arthur lived in the Age of Shivery, King Harold mustered his troops before the Battle of Hastings, Joan of Arc was canonized by Bernard Shaw, and victims of the Black Death grew boils on their necks. Finally, Magna Carta provided that no free man should be hanged twice for the same offense.

The sun never set on the British Empire because the British Empire is in the East and the sun sets in the West. Queen Victoria was the longest queen. She sat on a thorn for 63 years. Her reclining years and finally the end of her life were exemplary of a great personality. Her death was the final event which ended her reign.

### A couple of updates

There are two organisations in Victoria working with alopecia areata.

#### **The Alopecia Areata Support Association - AASA.**

We are a voluntary organisation incorporated in Victoria, established in 1980. AASA publishes this newsletter and our volunteers conduct the community enquiry MessageBank phone service. We have quarterly meetings, an Annual Open Day and also web and social media pages. A volunteer attends the hair clinics at the Skin and Cancer Foundation in Carlton. Our priority and principal activity is to support people in Victoria with alopecia, their family and friends. Our funds come from membership fees.

AASA  
PO Box 89  
Camberwell  
Vic. 3124  
AASA MessageBank  
Phone: 03951 38580 - for any enquiry about alopecia areata.

#### **The Australia Alopecia Areata Foundation - AAAF**

AAAF was established in 2010 *"to be the national Australian body supporting research to find a cure or acceptable treatment for all forms of Alopecia Areata, support those with the disease and their families, and inform the public about all forms of Alopecia Areata....."*  
(<http://www.aaaf.org.au/index.php?page=about-us>).

AAAF's funds come from a variety of fundraising activities.

#### **AAAF has recently changed its contact details to:**

**AAAF**  
**PO Box 5029**  
**FRANKSTON SOUTH**  
**VIC 3199**  
**Phone: 0412921013**

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#### **Rinaldi Wigs -Moonee Ponds**

Our May newsletter had some information about Rinaldi Wigs, a new service in Moonee Ponds

Louise has updated the information about the service and you can get more information via these contact details.

Phone: 03 9372 7822  
Mobile: 0428 133 889  
Email: [info@rinaldiwigs.com.au](mailto:info@rinaldiwigs.com.au)  
Web: [renaldiwigs.com.au](http://renaldiwigs.com.au)





**The President  
And  
Committee of Management  
of the  
The Alopecia Areata Support Association**

**cordially invite our members and friends**

**to the**

**2012 Annual General Meeting.**

**2 - 4 pm**

**Saturday August 25<sup>th</sup>**

**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 in order to seek approval for the 2012 Financial Accounts and to elect the Committee for the 2012/13 financial year.

There will be plenty of time to catch up with friends and to join us for afternoon tea.

Pat Crotty

Honorary Secretary

AASA (Vic) Inc.,

PO Box 89,

Camberwell 3124

Registration No. 0017172V

Alopecia Areata Support Association



Support services since 1980

Alopecia Areata Support Association



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**Alopecia Areata Support Association  
PO Box 89  
Camberwell 3124  
No. A0017172Y**

**Annual General Meeting  
25th August 2012  
Skin and Cancer Foundation  
1<sup>st</sup> Floor, 80 Drummond St  
Carlton  
2 - 4 pm**

### **Agenda**

#### **Welcome**

Chair : Garry Lonsdale

#### **Apologies:**

#### **Confirmation Minutes 2011 AGM**

#### **President's Report**

#### **Treasurer's Report**

- Introduction of 2011 -12 Financial Report
- Membership Subscription 2012 - 13
- Appointment of Auditor

#### **Handover to interim chair for election of the incoming Committee 2012 - 13**

#### **Election of the New Committee**

#### **Declaration of membership of 2012 - 13 AASA Management Committee**

#### **Close of meeting.**

**Please join us for Afternoon Tea**





AASA is funded by membership subscriptions  
Support the volunteers who work for us  
Help to continue and improve services for people with alopecia

Become an AASA member!

Become a volunteer!

Snail mail us - PO Box 89, Camberwell 3124

Leave us a message - 03 9513 8580

Email us - [aasavic@gmail.com](mailto:aasavic@gmail.com)

Find us on facebook - "Alopecia Areata"

And turn over this page - Thankyou!



