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## **Autoimmune Resource and Research Centre 2014 Activity Report**

As an overview: The goal for ARRC in 2014 was set as “consolidation and communication” and it has been a busy year getting everything done and making new connections with other autoimmune groups. Team members have organised and participated in a number of seminars, expos, awareness booths and fundraising activities. There have provided patient education sessions bedside with inpatients, as well as via telephone and ARRC side with members of the public requesting to understanding more about their illness and ways that they can gain some relief from symptoms. This year has seen a rise in our profile across medical professional and the wider community. ARRC is making a positive impact in the world of autoimmunity with numerous thank you messages from patients at events or as part of general communication. Importantly ARRC is networking with many other organisations and where possible will collaborate and host joint events.

In the research world, 2014 has been an important year for completing, writing and publishing numerous journal articles. This work will continue with plans for new studies and additional post PhD studies. The **Vision** of ARRC is to provide a world-best-practice centre to support people who experience chronic autoimmune disease. Our **Mission** is to improve the health & quality-of-life of individuals with autoimmune disease, through education, support, empowerment, advocacy and access to the latest screening, therapeutic, psychological and research-based strategies. In 2014, the work that we did, the resources and services we provided went a long way towards meeting our vision and mission. We did this through hard work and without either State or Commonwealth Government funding

Please find following a summary of activities for 2014

### **Organisational changes**

- No new changes to constitution.
- MAC member vacancies still exist for General Practitioner, and a Legal/Accountant representative.
- 2014 vote for 3 executive positions – Chairperson (Marline Squance), Treasurer (Angela Giakoumatos), Secretary (Janine Furner).
- ARRC registered for PAYG withholding on 1<sup>st</sup> January 2014.
- Financial reports, audits and supporting documentation were submitted on time for:
  1. Australian Charities and Not-for-profits Commission
  2. NSW Fair trading
  3. NSW Trade & Investment, Office of liquor, Gaming & Racing

### **GST and BAS**

ARRC is a Tax exempt charity with GST registration since 2013. Quarterly BAS forms are submitted reflecting the expenses and income of ARRC for that quarter. BAS payments have all been made on time and without adjustment, a final 2014 BAS statement due in December.

### **Fundraising approvals**

ARRC's authority to fundraise with the NSW Office of Liquor, Gaming & Racing is current until February 2019. We were formally authorised on 28/02/2014. CFN/22223  
This authorisation allows us to fundraise for financial support of ARRC services.

### **Insurance**

Our insurance cover was renewed in May 2014 for another year with AON Risk Services Australia Limited.

### **Financial Audit**

ARRC changed auditors as agreed from Evolution Financial Services to AV Chartered accountants. Official Financial reports and audits were completed efficiently and have been circulated for review and approval. ARRC for 2013-2014 financial year has a surplus of \$24,415.

Corporate donations are expected to be reduced in the next financial year due to funding associated with PAH clinic moving across to Cardiology. However this should not cause any great cash flow concern as the staff members attached to that funding has ceased employment with ARRC as of January 2014.

The use of the new XERO software has streamlined book keeping and financial management allowing direct downloads and ease of reporting. XERO has a monthly subscription fee but is easier to use than other MYOB programs.

### **Website and online activities**

Our website [www.autoimmun.org.au](http://www.autoimmun.org.au) is regularly updated with events and new factsheets. Improvements have been a direct link to product ordering with PayPal direct interaction, addition of contact us link going directly to our email, addition of Facebook link and everyday hero link with plans for Utube link in the near future to house information podcasts when developed.

It is difficult to gauge the exact traffic we are getting now as the analytics process has recently changed and become quite complicated. Janine and Marline will work with Redback solutions to establish a google analytics account so we can capture this information in the near future. Anecdotal feedback is that our website is very user friendly and easy to navigate with up-to-date information. We do get a lot of requests for information via the site and inter organisational requests.

ARRC Facebook page has links to many autoimmune organisations and allows a single point for all to advertise education and social events and community meetings relevant to patients. The site does not have interactive capability so as to reduce administration and moderating requirements. There are a large number of Facebook type blogs and discussion groups already existing, therefore we have elected not to establish yet another.

On the Facebook site we encourage people with questions to contact us directly through our email [arrc@hnehealth.nsw.gov.au](mailto:arrc@hnehealth.nsw.gov.au) so that appropriate responses can be researched and answered. The Facebook page will allow other organisations across the country to post events as well which hopefully will further cement strong networks with other organisations.

### **Links with other Organisations**

In this year ARRC concentrated on linking with other organisations and practitioners providing services for people with autoimmune illness. Discussions have occurred over the past months with the building of relationships with Arthritis NSW and Osteoporosis, Arthritis Vic, Arthritis WA, Lupus NSW, Lupus Foundation, Scleroderma Australia, Scleroderma NSW, Coeliac Association NSW, Immune Deficiency Australia, Invisible Illness, Lifestyle

Solutions, St Vincent De Paul, Not for Profit Connect (Hunter), Rare Diseases Australian Association and Sjögrens Australia.

We will continue to work with these organisations and plan to have joint education seminars next year. Working with other organisations will enable us to grow collectively and have greater capacity to raise awareness of autoimmunity.

## **Projects**

### **1. Autoimmune Awareness campaign**

Whilst the YAPEP project has now been completed we have continued to develop brochures using the same format. 11 brochures have now been developed with the addition of Raynaud's, Fibromyalgia and Sjögrens. Next brochures and factsheets will be for pernicious anaemia, autoimmune hepatitis, MCTD, UCTD and Antiphospholipid syndrome. Printing and distribution of brochures will continue in 2015 with the first dissemination points being pathology clinics and Specialist clinicians. Wider dissemination to General Practitioner medical clinics will occur at a later date. We are currently on our 4<sup>th</sup> print run of brochures and have approached corporates for 2015 sponsorship support for printing additional brochures and also our quarterly newsletter as an unrestricted educational grant.

The Australian Animal graphics have also been used in other advertising materials and flyers to draw instant attention and focus. We now have developed posters and banners that will be used as part of awareness advertising, conference booth and campaigns pdf files of these are attached. This year in September ARRC was given the opportunity to have an awareness exhibition booth at the Australasian Society of Clinical Immunology and Allergy (ASCIA) in Melbourne. This allowed us to showcase ARRC services and resources. The presence at the conference introduced us to a number of clinicians, nurses, scientists and patients with a large number taking ARRC information. Since this conference we have posted our brochures to 4 different states for Specialist rooms and have also resulted in a number of follow up enquiries. ARRC has been invited back in 2015.

Due to the success of the ASCIA conference booth I would like to contact the organisers of the Australian Rheumatology Association to request a booth at their National conference in Adelaide in May 2015.

### **2. Environmental Determinants of Lupus Flares (EDOLF)**

This study has seen a large amount of work completed in 2014. 5 papers have been written with 4 either published or in press at the moment. The 5<sup>th</sup> paper is under review. All these papers will be submitted for review and assessment as part of PhD by publication in December 2014. Findings to date are presented within a separate summary document attached.

The study was large in its scope and has many separate studies planned with targeted statistical evaluations and interpretations. These will occur over the next years when time allows.

### **3. Art Visual Narrative and Wellbeing Project (AVNAW)**

The original study has been completed with a single paper published to date. Analysis of clinical assessment data including salivary cortisol measurement will be undertaken in the 1<sup>st</sup> half of 2015 with the view of writing and publishing more papers. This study was a pilot study which hopefully will be built on for a targeted art narrative project at a later date and with secured funding. Findings to date are presented within a separate summary document attached.

### **4. Systemic Lupus impaired cognition evaluation (SLICE)**

SLICE study has been completed with findings reported within a prepared journal article. This article has undergone many reviews with some discussion regarding interpretations.

Hopefully these will be shortly resolved so that the article can be submitted to an appropriate journal for publication. Findings are presented within a separate summary document attached. The results of this study, as well as feedback from ARRC seminars, have identified a need for a developed education program to provide strategies for patients to improve cognition. ARRC will follow this up with help from Sally Gulliver our clinical Psychologist and Heidi Saxarra the research officer from the SLICE study.

#### 5. GRIPHON (PAH clinical Trial)

GRIPHON trial has now been completed with finding being feedback to investigators as part of an International meeting in Hong Kong, 21<sup>st</sup> January 2015. The extension open label trial GRIPHON OL, is continuing with a single participant. A number of participants have sadly passed away or have needed to go onto alternative available treatment. The trial is an International Clinical Trial which is fully funded by Actelion pharmaceuticals.

#### 6. SAPHIRE (Investigator initiated clinical trial)

SAPHIRE has been completed with the final recruited numbers to be 90 RA patients. The trial was fully funded by GlaxoSmithKline as an investigator initiated trial. This study explored the prevalence of PAH in RA, using exercise echocardiography (EchoCG). The study found a high prevalence of EchoCG-derived elevation of PAP (EDEPP) (14%) suggesting that, like other autoimmune conditions, RA may be a risk factor for PAH.

The project is financially managed through Newcastle Innovation/ Newcastle University.

#### 7. Paediatric Investigation of Nail fold Capillaroscopy Appearances review (PINCA2)

Recruitment commenced for this follow up study however unfortunately the Capiscope did not function. The machine is very unstable and despite attempting many different solutions it is still not functioning. Therefore this study is on hold awaiting a functioning machine.

#### 8. Café Conversation

43 separate meetings throughout the year with 12 different groups functioning with new groups Scone/ Muswellbrook, Raymond Terrace, Dubbo. Groups stretch from Port Macquarie, Port Stephens, Sydney, Tamworth, Gosford, many suburbs of Newcastle

2014 has seen the café conversation groups (ARRC social support program) grow from 5 last year to 12 this year. Groups are now running in numerous suburbs across Newcastle and Central Coast as well as Port Macquarie, Port Stephens, Sydney and Tamworth. Next year groups will be started in Scone/Muswellbrook, Raymond Terrace and Dubbo. Many groups now run without our input, others still require us to send invitations with also ARRC staff representation. Janine is now the convener of the café conversation program and groups.

The breakfast meeting for young people planned for Blackbutt in November last year was cancelled due to lack of interest. It seems that despite many attempts at planning different events for young people, lack of attendance still proves to be an issue. ARRC is planning to interact with Kaleidoscope to see how we may work together on a joint event. It appears that the need is more for the parents of children and young adults at this stage. We keep getting feedback that they want to meet however finding the right venue and format is difficult.

Events are all published on website and will be on new Facebook events page which may boost interest.

### **2015 projects in development**

#### 1. Presentation Podcast project

This project is an overflow from last year. The project involves the production of a series of Presentation Podcasts to be uploaded onto the ARRC website via the U tube portal. 10 podcasts about autoimmune illness and self-management are planned with a PowerPoint format and explanatory voiceover. Project funding grants would provide funds for human

resources and production costs needed for the project. The project needs dedicated time for staff to write grant applications to secure funds to produce podcasts and upload to site.

## 2. Economic study

A prospective study to explore the economic burden of autoimmune illness. The study will ask patients to log costs associated with illness including medicines, medical review costs, travel, therapies, loss of work time etc. I am following up similar studies such as the longitudinal MS economic study underway with the Menzies Institute. I will also discuss the project with experts in HMRI to find the best way to approach this type of study. Results of this study will allow ARRC to be better informed of illness costs and we will be able to use this as a basis for future advocacy and grant applications. Costs will be met via funds that have been reserved with the addition of any new funds as a result of successful grant applications.

## 3. Preliminary discussion regarding Clinical trial for AntiPhospholipid Syndrome APS – funded Alexion Pharmaceuticals Australasia

## 4. Discussion regarding database registry for PAH patients on Rituximab – funded Bayer

5. Planning and development of Sjögrens and Mestinon Clinical Trial. This would be an Investigator initiated trial funded via either a Pharmaceutical company or through grants from various Dental Associations. Currently investigating some different options for funding.

## **Education**

This year ARRC concentrated on seminars of special interest with 7 different events being held throughout the year. Most events were repeated with slight variation in Newcastle and Gosford. No full day self-management workshops were held in 2014 however these types of events will be the focus of 2015 with education and awareness being the focus of activities in 2015.

### **Seminars:**

1. Hand & Foot care Raynaud's, and Scleroderma Quiz (Newcastle and Gosford)
2. The other autoimmune illnesses – undifferentiated Connective Tissue Disease, Mixed - Connective Tissue Disease, Vasculitis (Newcastle and Gosford)
3. ARRC research- EDOLF, SLICE, Art and visual narrative project, and Sjögren's new products and discussion (Newcastle and Gosford)

### **2015 self-management workshops:**

ARRC was successful in obtaining a Newcastle Permanent Foundation community grant for \$45,000, The Autoimmune Community Education Project (ACEP). This funding will allow us to travel to more regional sites in NSW to deliver our developed one day self-management programs. The venues are not set however as per our grant we intend and are required to deliver programs in 6 different areas of the Hunter, Central Coast, New England, Central West, Mid North Coast and Northern Rivers of NSW. These areas were chosen as they fit with Newcastle Permanent Branch areas however some flexibility is allowed. As part of preliminary 2015 planning we have set some dates throughout the year for 11 different days across NSW with the first workshop on Friday 6<sup>th</sup> in Port Macquarie. These days will engage the help of allied health professionals of the health service areas in helping to better inform patients of available services as well as self-management strategies for everyday living. The workshops will be run with the help of Kerry Cooper (retired Rheumatology CNC). Kerry as part of her role in Rheumatology helped us to develop our various programs and also helped to deliver programs in the past years which were a great success.

### **Face to face:**

Education sessions still continue face to face at both the in-patient bedside and also as a booked 45 session. These are not done as often as the past however still continue. No general community presentations have been done this year unless part of a fundraising event.

### **Newsletter:**

ARRC has produced 4 editions of ARRC-hives Newsletter which includes information on requested topics and upcoming events. Numerous articles written and printed within ARRC-hives had been requested by other AI organisations to be reprinted for their members. Emailed copies are sent to 300 members and medical centres for their rooms and additional 175 are posted. ARRC currently has 350 signed memberships with nearly 200 ex SLSS members that need to sign membership form. As of next year these people will be sent a letter saying that membership to ARRC is required for receipt of future newsletters. We have managed to secure printing cost reduction support from Newcastle City Council printers and will continue with this arrangement in the following year.

### **Awareness**

In 2014 ARRC has attended a number of expos/conferences so as to raise our community profile. These expos have had mixed success regarding attendee numbers.

1. ARRC was given the opportunity to meet with The Honourable Jillian Skinner, Minister for Health, at the Regional Cabinet meeting, Maitland. At this meeting ARRC representatives were able to showcase what ARRC did and raise the need for greater awareness and services for people living with autoimmune illness. Present at that meeting was Mr Michael Drenzo CEO of the local health District, whom promised a round table discussion regarding Chronic Disease management programs and access to these programs. Despite many attempts at setting up this meeting to date it has not occurred. However, I will continue to try and raise the platform of ARRC and patient services for autoimmune patients.

2. Australasian Society of Clinical Immunology and Allergy (ASCIA). ARRC was invited to have a booth within the exhibition hall at no cost. This was a great opportunity to showcase ARRC its brochures and services. A number of health professionals signed memberships and requested brochures for their rooms and patients. The general feeling was that this was worthwhile as it allowed those that help manage patients to find resources that were useful and allowed the patient to search for links to other reputable sites. ARRC has been invited to attend again next year and also been asked to present about self-management programs and benefits for patients.

3. Carer's expo. Local event that was also free to attend as we went under the HNE Health banner. This had a large number of attendees that were interested to find out about ARRC. Our brochures were a great hit. The greatest benefit was networking with other organisations.

4. Big ideas disability expo. This was the 2<sup>nd</sup> time we have attended this expo. This is not a free expo with cost of \$990. Although this was much cheaper than the previous year, it did not meet with the same returns. Reasons for this were due to the extreme hot weather, the location, poor planning on the organiser's part, as well as the fact that the NDIS is now operational. The attendees were about 30% of the previous year with very few presentations. Attendees were a different mix to previous year and did not fit with ARRC and autoimmune illness. I would elect not to attend this expo in future.

5. Hospital foyer awareness booth has been hosted by ARRC on a minimum of 4 days per year. Usually these days coincide with major International awareness days or events. The booths were held in the foyer of the Royal Newcastle Centre however since the Hospital commercial café business has taken over that spot we have been holding booths in the main entrance foyer near emergency. This unfortunately does not get the same sort of traffic, as patients park at the other end of the hospital attend clinics in RNC, and the location prevents attracting staff during breaks. Despite this we did maintain the space on four different occasions and provided some information to interested persons. These booths do provide some opportunity to spread awareness about autoimmune illness and ARRC with the community and also health professionals within the Hunter New England Health District.

However I would suggest we reduce the number to 2 events and investigate other areas for display, maybe outside Pharmacy or within the North Block.

6. NAIDOC Week awareness was supported by ARRC with our Clinical Nurse Judy Knapp coordinating the event. ARRC members knitted many metres of red, yellow and black tubes that were then secured on to railing leading to and from the hospital to the Kookaburra units. This was done and helped bridge a relationship with Indigenous health workers and raise awareness of indigenous health needs. We hope to work closer with the Aboriginal Health Units across our country in the future.

7. Communities in Control – Our Community. This is a not for profit think tank and conference which either Janine or Marline attends every year in Melbourne. It gives us the opportunity to understand what the new direction and issues are for NFP organisations such as ours. It also provides a great opportunity for networking with other NFP and grant makers which could open avenues for discussion.

8. Specialised dentistry conference. This conference will be attended on the 27<sup>th</sup> and 28<sup>th</sup> of November. The conference topics included Special care for patients with oral health issues e.g. Sjögrens. It also has presentations regarding reflux issues and consequences and updates.

### **Fundraisers**

This year has been a busy fundraising event year that has collectively raised around \$16,000 Events for 2014 were

1. World Lupus Day Trivia night \$1500 May 10<sup>th</sup> was World Lupus Day. A great night that will be repeated in 2015 with easier questions and greater accuracy in scoring. This year it will be held on May 9<sup>th</sup> which is a Saturday night.

2. Scleroderma Day Sunday 29<sup>th</sup> June “Snuggle up for Scleroderma”. \$250 The concept for this event was to recognise the need for rest and to encourage people to spend a day in bed. ARRC held a “snuggle up event” here in the Hunter which was a ‘snuggle up afternoon tea pyjama party’. There was also a 2<sup>nd</sup> event hosted by the Budgewoi Café conversation group it was a community walk done in their PJs. It attracted some great attention including the local police. This event will probably be undertaken again next year with a joint event finishing in a picnic/BBQ.

3. City to surf – Sydney. Janine and small group of walkers participated in the City to surf and raised collectively \$2700. They wore ARRC t-shirts and raised our profile as well as having a great time. Next year we are hoping to encourage more walkers. Due to the high profile of the event we signed up with everyday hero which costs us \$490 annually and they do take a 4.9% of fundraising dollars earned, however the website attracts a large audience and as a result we received donations from people that did not know about us, that we wouldn't have otherwise attracted, and wanted to support our cause and centre. We are investigating cheaper option however at this stage this works well. We have also used everyday hero for 2 other events this year – ‘Head shave’ and ‘ Paddling4PAH’. We are hoping to have a group of 20 walkers next year.

4. Head shave for Scleroderma and PAH raised \$3,400. The shave was done in Canberra by Katrina Easey, daughter of Helen. Helen passed away earlier this year from Scleroderma and PAH.

5. To celebrate all things French and also the Tour de France we were offered the opportunity to be recipient of a fundraising Film afternoon. The host Deborah Moriceau was introduced to us through chatter on the Lupus NSW Facebook site and took the opportunity to review our website and also talk to us about ARRC and what we do. The afternoon involves silent raffles and High Tea and the viewing of the comedy movie ‘Tour de Force’. The event was held at Hazlehurst Gallery in Gymea Sydney and raised \$1500. Deborah is planning to help

us with other events and has a marketing fundraising background. Deborah has offered to discuss how we might advance our fundraising and profile.

6. Paddling4PAH event was held again this year with a 350 km paddle on the Hunter River. The event was undertaken by Allan Woods and his nephew Wayne Biggs with parts of the river having sand banks which required carrying Kayaks and other part with deep water or fast rapids with debris. This section was abandoned due to safety concerns. The paddle ended in a Pub lunch and raffles at the Washtub diner in Stockton. To date \$2500 has been raised with some funds still being raised through other fundraising activities.

Christmas cakes are for sale @ \$30 each with ARRC receiving \$10 per sale

Christmas raffle \$ 2 each. Drawn on December 22<sup>nd</sup>.

Paddling4PAH Cookbook \$12.00 each

Leading up to the event 2 x Bus trips were held to Mt Annan Botanical gardens with 3 course lunches and bus tour of grounds and seed bank. The events had small numbers but were lots of fun and very interesting.

Other ARRC fundraising activities:

7. ARRC community collection tins (approx.\$1,000)

8. Sale of chocolates (approx.\$1500)

9. Sale of ARRC goods – silver thread socks, gloves, triple headed toothbrushes and other mouth products, cards, novelty items and breathe bracelets. (approx. \$3,000)

10. Donations from members and via community donations with and without membership

11. Entertainment Book

#### **2015 planned fundraising events and items (details to be provided when available)**

1. Trivia night May 9th

2. City to surf

3. Regal cinema film nights

4. Gloucester Afternoon Tea. This event was hosted by Mary McLaughlin and brought together people that had participated in The Art Narrative project. Mary has said that she is planning an open garden festival event in 2015 to capture the best time for her garden and to raise awareness of Lupus and ARRC. She has hosted these events in the past with potential to raise a large amount of money.

#### **Bequests**

\$10,500 with 5 different bequests 2 were ARRC long-time friends and patients and the other 3 were in memory for people that were not previously known to ARRC. The families of two deceased persons found us through the Guide to Giving website and appreciated that we provide both education and research. In 2014 we had an online advertisement only. In 2015 are signing up to this site again, with advertising on both their website and also their reference book.

#### **Media coverage**

Many media releases being sent and minimal responses. This year both Judy and I were invited to participate in the ‘Story box’ of ABC. Both of us talked about our work, ARRC and in my case PhD. We have also had some print stories in the Maitland Mercury and Cessnock paper for Paddling4PAH. World Scleroderma Day was overtaken in 2014 by the Leukaemia Foundations ‘Sunflower dash’ event. I contacted the Herald and was told that they wouldn’t run 2 Sunflower stories and events as it would confuse the readers and they decided to go with the bigger organisation. This will change in 2015 as the Leukaemia Foundation has written to Scleroderma Australia and both apologised and said that if they run the event again they will do it on a different month.

We have had a note in the Herald in association with the Newcastle Permanent Foundation announcements. The official presentation is to take place on Wednesday 26<sup>th</sup> November with some media coverage.

Radio interviews were recorded and played on the local ABC and KOfm for Lupus awareness in May for World Lupus day. This is an area that would benefit from improvement and I still welcome advice on how to expand our success rate.

It has been an exceptionally busy year with some great outcomes. Next year we would like to focus on education and more awareness. Thank you for your support over the past year and I look forward to working together again in the year ahead.

**End of activity report  
Submitted and approved**

**Chairperson**

Marline Squance

24<sup>th</sup> November 2014