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## **Autoimmune Resource and Research Centre 2015 Activity Report**

### **Education**

The goal for ARRC in 2015 was set as “education and teaching people about living well with autoimmune illness. The year has involved a large amount of travelling reaching more rural and regional centres. This was possible due the successful grant submission to the Newcastle Permanent Charitable Foundation. Nine separate workshops days were held throughout the year. We are hoping that this program will be successful in gaining more funds in the April 2016 grants. This along with other education and awareness programs have taken up a lot of staff resource time however has resulted in a wide geographical spread of services and support to people that often do not have access to programs or support services. As a result of education seminars a number of flow on café conversation social groups have formed and are continuing, providing ongoing support in these regional centres.

In addition to full day educational workshops, ARRC held a successful seminar which focussed on elements of nutrition and the involvement of gut issues in autoimmune illness. This seminar was first held in August in Newcastle and was repeated in Gosford in November. Both seminars were popular with the Newcastle event having 50 participants and the Gosford event 30.

This year awareness booths were not held within the hospital precinct due to the space allocated by HNELHD. ARRC did was once again offered a gratis exhibitor booth at the Annual Immunology Conference ASCIA (Adelaide) were we displayed a number of our research posters and also the resources we have available to support patients. We were not successful in obtaining the same at the Rheumatology Conference however we have applied for representation at the 2016 conference in Darwin and are still awaiting approval. This mode of awareness targets clinicians and has great potential to reach a wide autoimmune audience through distribution of brochures and factsheets as well as notification of ARRC services. Our brochures are already used within a number of hospitals and outreach clinics across Australia, as well as through other linked organisations.

In addition to the ASCIA conference booth ARRC also attended the local NSW health Carers expo at Wests Panthers. Overall attendance at this event was very poor compared to the previous year; however the cost of attending was negligible.

Patient education sessions in the wards with inpatients has continued, however have been in reduced numbers however, telephone and ARRC education at the centre has increased with members of the public requesting to understand more about their illness and ways that they can gain some relief from symptoms.

## **Café Conversation**

We now have 19 different Café conversation groups with a further 7 starting in the New Year. Many of these have formed after education workshops. New groups will also be formed in Melbourne and in Brisbane. Many groups now run without major input from ARRC, others still require us to provide a linkage service sending out invitations. Whenever necessary and at the request of the individual group ARRC input can be changed. The groups are meant to be social groups with members having particular questions asked to contact ARRC directly to ensure appropriate answers will be provided. Janine is the overall convener of the groups as part of her role. Events are all published on the website and will also be on new Facebook events page.

## **Research**

2015 has been an important year for completing, writing and publishing numerous journal articles related to research projects. In particular, the Environmental Determinants of Lupus Flares (EDOLF) main study has been completed with some post doc PhD studies planned for the New Year. These studies will involve some lab based parameters investigating midkine inflammatory markers; as well as the potential for cytokine polymorphism quantification if funding is found. Unfortunately our HMRI grant was not successful this year. In addition, post doc descriptive studies looking at various aspects of the collected data will also be undertaken if time permits.

Other research projects for 2016 will include the economic study looking at the financial and social costs of living with autoimmune illness. This will be undertaken with help from the Health economic unit of the University of Newcastle and with modified tools supplied by the MS research team of the University of Tasmania. Results of this study will provide data for future projects as well as data for awareness and advocacy programs.

Clinical trials related to PAH – GriphonOL (extension trial) will continue with addition of a new clinical trial looking at skin improvements in Scleroderma with the use of Riociguat. In addition ARRC has been accepted to participate in a database monitoring program for Riociguat patients.

Discussions have begun with a number of different pharmaceutical companies for investigator initiated trials in Scleroderma, Sjögrens and Lupus, however progress is slow. These planned studies will not proceed without full funding secured.

## **Fundraising**

Fundraising events this year collectively raised around \$17,653. Events for 2015 were:

1. Open garden Easter events EARLYN gardens Gloucester (\$2000)
2. Kay Filewood – Gold Coast marathon- Everyday hero campaign (\$1,700)
3. World Lupus Day Trivia night \$2,000
4. City to surf – Everyday hero campaign (\$1,000)
5. Entertainment Books (\$480)
6. Chocolate sales (\$500)
7. ARRC community collection tins (approx.\$500)
8. Sale of ARRC goods – silver thread socks, gloves, triple headed toothbrushes and other mouth products, cards, novelty items and breathe bracelets. (approx. \$3,224)
10. Donations from members and via community donations with and without membership (\$33,978)

## 11. Workplace giving (\$250)

### **Organisational changes**

No new changes to constitution.

MAC member vacancies still exist for General Practitioner, and a Legal/Accountant representative.

Financial reports, audits and supporting documentation were submitted on time for:

1. Australian Charities and Not-for-profits Commission and
2. NSW Fair trading

### **Members**

ARRC currently has 709 active members. Members are drawn from all over Australia and also internationally. Membership has grown considerably in 2015 as a result of website connections and referrals, advertising and word of mouth referrals.

### **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. All BAS payments were made on time.

### **Fundraising approvals**

ARRC's authority to fundraise with the NSW Office of Liquor, Gaming & Racing is current until February 2019. CFN/22223

This authorisation allows us to fundraise for financial support of ARRC services.

### **Insurance**

Our insurance cover was renewed in May 2015 for another year with AON Risk Services Australia Limited. AON ref: MFC A5445

### **Financial Audit**

ARRC financials and audited accounts were undertaken by Antony Vidray of AV Chartered accountants. ARRC documents were submitted to accountants for review in August 2015 and financials and audit received on 25 November 2015. Anomalies were identified in the salary sacrifice component of PAYG staff due to a misinterpretation of the ATO rules for salary sacrifice amounts for a Health Promotion charity. This error was picked up during the financial review process by AV accountant and has been rectified without penalty. The time taken to discuss and rectify the salary accounts and associated Tax obligation and superannuation added to delays in returning audited financials. This also resulted in an extra financial accounting cost of \$1,600.

Official Financial reports and audits were completed and are circulated for review and approval. ARRC for 2014-2015 financial year has a surplus of \$62,521.

The use of the new XERO software has streamlined book keeping and financial management allowing direct downloads and ease of reporting. However this takes a large amount of my time. Antony Vidray has offered to meet with our Treasurer Angela, Secretary Janine and myself to find a way to simplify processes to reduce costs and any potential errors in the future. This meeting will take place in the New Year and will not incur a cost to ARRC.

### **Website and online activities**

Our website [www.autoimmune.org.au](http://www.autoimmune.org.au) is growing in traffic. Janine actively updates events and activities. The website has had many positive comments and has attracted people looking to donate to an autoimmune cause. Comments reflect that the mix of both education and research is appreciated as it focuses on today as well as the future.

We have recently added some audio interviews with patients, autoimmune moments. These are part of the podcast project which will eventually have both audio moments as well as webinars. The first 5 audio interviews are now active.

Improvements that will be made in the near future will include direct links to social media such as Facebook, Instagram and twitter accounts of ARRC.

ARRC Facebook page linking educational events of autoimmune organisations from a single point has not really been utilised. However I am reluctant to reorganise and relaunch the page as a blog site as this requires a large administrator role.

### **Links with other Organisations**

No new links have occurred with autoimmune associations and organisations.

### **Newsletter:**

ARRC has produced 4 editions of ARRC-hives. These editions are disseminated at the beginning of each season and contain numerous articles based around a theme or events that have happened. The newsletter always receives great reviews with a number of other autoimmune organisations requesting use and reproduction of features. ARRC has engaged the services of the graphic designer that developed and produced our educational brochures to produce each newsletter with supplied content. Emailed copies of the newsletter are sent to 500 members and medical centres for their rooms and an additional 250 are posted.

To fund production and printing costs of the newsletter and also information brochures ARRC has approached Actelion Pharmaceuticals for educational funding for 2016. Printing cost reduction support has also been received from Newcastle City Council printers and we will continue with this arrangement in the following year.

### **2016 planned fundraising events and items (details to be provided when available)**

1. Trivia Games night Tuesday May 10<sup>th</sup> World Lupus Day
2. City to surf
3. Regal cinema film nights
4. Love Tree lupus lunch
5. Barefoot Bowls – Gwandalan – April 2016
6. Entertainment Books
7. Donation Tins
8. Sale of Chocolates
9. Sale of ARRC goods – gloves and socks
10. Community and corporate donations.
11. Seminar and workshop attendance payments
12. Workplace giving- \$1 a week campaign.

## **Bequests**

No bequests were received.

ARRC has renewed its advertisement to the Guide to Giving with advertising on both their website and also their reference book that is distributed to accountant and Solicitors across Australia. It is difficult to judge effectiveness of this advertisement as the target is for will bequests that may not occur for many years.

## **Media coverage**

Media coverage has occurred sporadically in 2015. Many stories were associated with Patient self-management workshops. Media coverage for these events was a mix of print, radio interviews and a single Television interview on Tamworth NBN.

In the last week a feature article that focussed on ARRC was printed in The Star newspaper as a result of a request by Grace Maclean of Not for Profit Connect program.

2015 was yet another busy year with greater geographical coverage and some great outcomes. The year was exhausting for staff and there is a need to build in more efficient ways of providing services. We would also benefit from greater fundraising and financial resources that could enable us to increase staff numbers. Particular roles of staffs could involve grant writing, research and media marketing. This would allow current staff to better complete necessary tasks and undertake new projects to ensure the growth and sustainability of ARRC whilst meeting our vision and mission.

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 2015, 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.

Thank you for your support over the past year and I look forward to working together again in the year ahead. I hope that everyone can find some time in 2016 to help with planning a better and more efficient ARRC. Please let me know of your availability in late January and early February so we can strategically plan together ARRCs future.

Kind regards

Marline