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Autoimmune Resource and Research Centre 2016 Activity Report

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.

Each year ARRCs support service requests increase and we need to find innovative ways of still delivering a quality service that meets the needs of the growing autoimmune community. Service requests know no geographical reach as requests have been received from all States of Australia and from other countries, in particular our Asian neighbours. This year we have started to develop autoimmune disease specific seminar DVD resources which have enabled greater geographical delivery of education program content. 2017 ARRC would like to expand this delivery mode and also include more online resources.

2016 has been a year where ARRC staff could consolidate delivery processes; however, efficiencies to reduce high impacts on ARRCs human resources are needed. As per 2015, ARRC would benefit from greater fundraising and financial resources that could enable us to increase our staff numbers to help reduce the workload of existing ARRC staff. In particular there is a need for a patient education officer and also research support officer.

In the previous year ARRC engaged a contractor to help with grant applications and submission on a per grant basis. This system did increase the number of grants that could be submitted and reduced the workload stress impact on ARRC staff that took on the role of final review of applications rather than having to complete the whole process. Grant funding still remains one of the primary sources of potential funds for ARRC and as such an important aspect of our work. Research and marketing responsibilities have remained with the employed part time staff of ARRC.

Whilst we adhere to maintaining the vision and mission of ARRC the lack of funding and increasing demand for our services does make this a increasingly difficult task. Since we still do not draw any funding support from Government organisations being either Commonwealth or State based, the resourcing of ARRC remains to be drawn from donations, sponsorships, grants and fundraising. The hard work of our dedicated part-time staff of 4 continues to provide a solid platform to support patients and they are to be congratulated on their efforts. We will continue to apply for grants and subsidies whenever possible with the hope that these applications will be rewarded with financial support. We will also continue to lobby Government and local Health organisations for greater recognition and support of ARRC and its autoimmune community.

Legislative requirements

All financial reports, audits and supporting documentation were submitted on time as per legislative requirements for:

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

Financial audit reports are published on the ACNC website and as of this year so will the annual activity reports. These reports will also be uploaded to the ARRC website so as to complete transparency requirements of NFP rating systems developed to guide fund givers. To date we have not published Activity reports publicly however our members receive regular activity updates and annual activity reports within the quarterly ARRChives newsletter. It is not a legislative requirement for a NFP of our size to produce and publically display a hard bound separate document annual report however the new rating systems and the increased transparency scrutiny of NFP governance analysts and Government regulators recommend publication.

The activity reports of ARRC 2013 – to 2016 will be uploaded to the website ASAP.

Members

ARRC currently has 827 active members, 59 General Practitioners and Specialist Physicians, and network registrations for 55 separate autoimmune organisations. Members are drawn from all over Australia and also internationally. Membership is steadily growing.

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 2016 for another year with AON Risk Services Australia Limited.

Financial Audit

ARRC financials and audited accounts were undertaken by Antony Vidray of AV Chartered accountants. No anomalies were identified. ARRC for 2015-2016 financial year has a Net current year surplus of \$36,783. This is reduced from the previous 2015 year.

Education

This year ARRC education events concentrated on developing education resources that could be posted to individuals based on requests. The back to basic series of DVD has concentrated on the more prevalent diseases of Lupus, Scleroderma, Sjögren's, Raynaud's and the condition Fibromyalgia. The diseases and conditions are the most requested support and information request. The Back to Basic seminars are presented by the Medical Director of ARRC, Assoc. Prof Glenn Reeves, and are recorded with the help of volunteers. The DVDs are then available for purchase and

can be posted to any Australian address. The series is proving to be highly successful and new disease presentation will be recorded in 2017 including Thyroid illness, Rheumatoid Arthritis, Pulmonary Arterial Hypertension and Vasculitis. The seminar events had the following patronage: Scleroderma (30), Sjögren's (40), lupus (40), Raynaud's (30) and Fibromyalgia (40).

Self-management workshops were not held in 2016, however Question and Answer events were held in 7 different areas of NSW and ACT; Newcastle, Central Coast, Merriwa, Mudgee, Wollongong, Canberra, Port Macquarie. The Q&A events of Dubbo and Tamworth were postponed till 2017 due to staff workload and also due to the successful Newcastle Permanent Charitable foundation Community autoimmune project which supports 13 separate self-management workshops across NSW in 2017.

Individual patient education sessions in the wards with inpatients continued with limited request approx.10. However individual telephone support requests have increased with phone consultations numbering on average 5 patients per work week. In addition the contact us section of our www.autoimmune.org.au website has also seen increased requests for individual support or information questions.

ARRC Psychology service provided support sessions to 20 patients with 49 separate appointments in 2017. Approximately 50% of the patients saw our Psychologist for a single session for support and guidance on how to cope with living with and autoimmune illness. Other patients have needed multiple sessions and appointments. The service is open to all ARRC members for help however, as our clinical psychologist is only contracted for a small amount of hours, therefore appointments are limited. People seeking psychological support are also informed of alternative avenues available through GP referrals to private psychologist and other psychology services in their area.

ARRC brochures are now used within hospitals and private practices in all States and Territories. In addition brochures are also requested for use in patient support groups via Arthritis association NT, SA, and VIC. No new brochures have been developed and published in 2016 however plans for brochures/factsheets for B12 deficiency, autoimmune gastritis, Addison's, Vasculitis, UCTD and MCTD are being developed in 2017. In addition ARRC has been approached to potentially jointly produce a myositis brochure with the Myositis Association of Australia.

In addition educational support has been given to the NSW University Rheumatology Society (\$500) to help provide specific Autoimmune seminars to educate Rheumatology and Immunology registrars and trainees of that University. To recognise our sponsorship the society displays our logo on all advertising materials and on their website which raises awareness of the centre with training specialists. In 2017 Assoc. Prof Glenn Reeves has been asked to present at one of their events to talk about the diagnosis and management of autoimmune patients.

Other events in 2017 were limited with only 1 specialty event. This event "Chair Yoga" was requested by the members as part of an exercise alternative education program. 25 people attended the introductory session and a number of them have asked ARRC to organise a regular program. This will commence in February 2017. Other exercise programs for 2017 include Tai Chi and Qigong.

Café Conversation

Café conversation groups have been continuing as a useful social support network. Some of the groups have joined forces and some have waned in their attendance. We have 14 different Café conversation groups active and discussions occurring for formation of new groups in the New Year. We anticipate that new groups will form following planned education workshops of 2017. In total 78 separate café social events were held in 2016.

A presence of an ARRC member was requested at 2 café groups over the past year to address member health questions and some operational issues. Many groups now run without major input from ARRC, others still require us to provide a linkage service sending out invitations. One of the groups are planning to have fundraising as a component of the meeting with a gold coin fine type fun activity as part of monthly event. This activity is by the groups voted choice and is adopted as means to help raise funds for ARRC.

Events are all published on the website, through the ARRC hive newsletter and will also be on Autoimmune Australia Facebook events page.

Research

4 clinical trials are currently being undertaken with ARRC. These trials are:

- PAH – GriphonOL (extension trial)
- RISE – a clinical trial looking at skin improvements in Scleroderma with the use of Riociguat.
- EXPERT - database monitoring program for Riociguat patients.
- CATALYST – clinical trial for Connective tissue Patients using Bardoxylone Methyl as a potential therapeutic agent.

In addition ARRC is seeking ethics approval for a clinical trial in Myositis associated Scleroderma and the use of Intravenous IVIG and the effect on skin thickening.

Lupus post doc studies following on from the Environmental Determinants of Lupus Flares (EDOLF) main study include the

1. investigating Midkine inflammatory markers;
2. cytokine polymorphism quantification (HMRI funded through support by Richard and Paula Anicich)

ARRC has also been provided with funds to purchase a new and updated capillaroscopy video recording system. Funding for this new technology has been provided by the Lions Club of Charlestown (\$15,000) and as a result ARRC now has an Optilia video capiscope to help in the differential diagnosis of Raynaud's/ scleroderma and for the use in research activities. The new Capiscope will allow the completion of the postponed Paediatric dermatomyositis long term assessment study and also the potential for new imaging studies in Vasculitis and myositis in 2017.

Other research projects for 2016 that commenced planning and preliminary protocol workup include

1. A study examining the adaptive behaviour of autoimmune patients. This is a study that will be conducted in collaboration with Rachel Rossiter of Charles Sturt University with the help of either honours or graduate researchers.
2. The health economic study looking at the financial and social costs of living with autoimmune illness. This study was to 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. Preliminary discussions and tool modifications have occurred however, due to increased workloads of each unit and the lack of available funds this study has been postponed until adequate resourcing can be found. Results of this study will provide data for future projects as well as data for awareness and advocacy programs.

3. Sjögren's and organ involvement a prevalence study has been commenced in a planning stage and it is hoped that this study will be able to move towards ethic application in the New Year.

As in previous years research projects will not proceed without full and adequate funding as ARRC has no surplus to invest in unfunded research.

Fundraising

Fundraising events this year collectively raised around \$13,514. Donations from individuals and other community groups totalled \$67,208.

Events for 2016 were:

1. World Lupus Day Lavender Lunch \$1,000
2. World Lupus Day Tamworth Lunch
3. World Scleroderma Day Lunch \$300
4. Grill'd Local Matters donation \$300
5. Charlestown Golf Day \$1050
6. Wangi Point Lakeside Holiday Park - \$1463
7. Wangi Point Lakeside Holiday Park - \$1500,
8. Holy Trinity Primary School ACT \$430
9. Rotary Kariong presentation Raffle night \$500
10. Barefoot Bowls Paddling4PAH event \$1500
11. City to surf – Everyday hero campaign \$1,000
12. Entertainment Books \$480
13. Chocolate sales \$500
14. ARRC community collection tins \$1200 (Gourmet & Glutton Morpeth, Alice in Paperland Port Macquarie, Café de Beaumont, Solid Scaff)
15. Sale of ARRC goods – silver thread socks, gloves, triple headed toothbrushes and other mouth products, cards, novelty items and breathe bracelets. \$2,800
16. Workplace giving \$950
17. Donations from members and via community donations with and without membership \$67,208

Awareness

Hospital based awareness booths on significant days of recognition (ie. World Lupus Day) no longer occur due to availability of hospital space with public traffic.

Health profession speciality awareness booths have occurred as part of the Australian Rheumatology Association (ARA) annual conference in Darwin and also the Annual Immunology Conference (ASCIA) in the Gold Coast. Both exhibitor booths were provided gratis to ARRC although the ARA conference was a shared booth with Scleroderma Australia. ARRC is thankful for the opportunity to be present at these conferences as it promotes ARRC and its support services to clinicians and has great potential to reach a wide autoimmune audience/patients through distribution of brochures and factsheets as well as notification of ARRC services.

ARRC's EO was asked to present at the Immune Deficiencies Foundation Australia (IDFA) conference in July. The topic focussed on Autoimmunity and self-management approaches. Evaluations indicate that the presentation was well received and has connected ARRC to a wider patient group.

Other presentations have been by request at special meetings and dinners of the Rotary club Kariong, and the Lions clubs of Charlestown and Toronto.

This year ARRC has been invited to be a regular contributor to Hunter and Coastal Living Magazine. This was arranged by a Management Committee member, Don Langford, with the support of the editors Marilyn and Phil Collins. To date we have had four 2-3 page articles on various topics that raise awareness of autoimmune illness and also ARRC.

1. July issue: The pioneering legacy of Lee Langford, her story of Scleroderma and the start of the Centre
2. September issue: A good doctor. A story of Assoc. Prof. Glenn Reeves and the balance of managing patient health and also home life.
3. November issue: Misplaced maladies. A story of the diagnosis pathway and autoimmune family connections of Pam Tobin.
4. January issue: The quilt donation "Cold hands warm hearts" and the support links with Pathology North.

We hope to write and present a story for publication every 2 months as it gives us a great opportunity to showcase ARRC, its members and importantly the autoimmune illnesses they live with daily.

An ARRC awareness booth was arranged to be present at the Gathering of the Clans event in Norah head. This event normally draws approximately 7000 people however due to the windy weather and the storms in the preceding day the crowds were not as large. Despite this a great day was had and ARRC staff spoke to a large number of interested individuals and offered brochures and support to a people with autoimmune illness. As a result of their presence ARRC has a number of new members. ARRC has been invited to attend again next year and have also been invited to attend the larger Clan gathering in Aberdeen in July. These community events present an opportunity to raise awareness of autoimmune illness and also the profile of ARRC.

ARRC was contacted by The Westpac Rescue Helicopter to be a part of their Club 139 group. Club 139 provides the opportunity for 139 like-minded organisations to collaborate for the benefit of our community. Each membership helps the Service raise some funds but also give ARRC the opportunity to raise awareness of our service through their network connections.

Advertising

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. In the coming year we will have a more prominent position in the distribution magazine and have opted for a larger and new graphic for an increased presence. The guide to giving has widened its scope this year and is now has a stronger focus on workplace giving with regular donations as well as taxation giving and will and bequests. It is difficult to judge effectiveness of will and bequest nominations.

ARRC also purchased some advertising space in a Retirement living magazine. Advert was designed to indicate the different autoimmune illness groups that we support and also invite donations and bequests. ARRC purchased a ½ page graphic space however as there was room in the magazine the designer upgraded our colourful advertisement to a full double page feature spread. A repeat advertisement is being published in their December edition; this advertisement will be the original ½ page.

Organisational changes

No new changes to constitution.

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

Website and online activities

Our website www.autoimmune.org.au is growing in traffic. It is updated regularly with news, events and activities. The website attracts many people looking due to the availability of educational resources and updated feed of information. This year patient audio interviews “autoimmune moments” has been added however more extensive podcast capability is not possible in the websites current format. We would also like to have a website that can easily transition between electronic device formats (ie. Phone, tablet, computer) and also have capacity for webinars and seminar programs.

Links to social media such as Facebook, Instagram and twitter accounts of ARRC have been made however; ARRC is not very active on these platforms due to time. This is an area for improvement.

The ARRC Facebook page Autoimmune Australia, which was originally designed to link educational events of autoimmune organisations is only utilised by ARRC. It will be maintained as it provides another avenue for linking to persons with Autoimmunity.

Links with other Organisations

ARRC now has links to 55 different organisations and in the past year has been invited to collaborate with joint educational materials and seminars with 4 of these organisations.

ARRCs Executive Officer presented at the Immune Deficiencies Congress in July 2016 and attended the Myositis Association of Australia conference in Oct 2016. At these conferences ARRCs presence was important as it provided resources and guides to patients with autoimmune illness allowing a stronger support network to be developed. Forming strong links with other organisations help us build a strong Autoimmune community.

Newsletter:

As in previous years ARRC has produced 4 editions of ARRC-hives. These editions have grown from a humble few pages of event information to a smart 28 page magazine which include educational articles on symptoms and issues that arise from living with Autoimmune illness. Each article printed is researched and the final printed information referenced adhering to reporting the most up-to-date information available. Past topics have been nutrition information about magnesium and calcium, the unspoken symptoms of incontinence and vaginal dryness and also articles on exercise suggestions. ARRC-hives receives many positive reviews and is appreciated for both its content and visual appeal. The Newsletters are disseminated at the

beginning of each season. As in previous years the articles are requested by other organisations for reproduction.

The graphic design and compilation of each Newsletter is undertaken by the graphic designer that developed and produced our educational brochures.

Emailed copies of the newsletter are sent to 600 members and an additional 250 are posted to individual members without email or via request. In addition posted copies are now being sent to Dr Surgeries and clinics across the country for their waiting rooms.

Bequests

ARRC received a bequest from the estate of Rhonda Nash. Through discussions with the family ARRC established a separate account which will hold in trust the bequeathed funds to be used for educational activities related to raising awareness within the medical professionals. Funds to date have been used to attend the Australian Rheumatology Conference in Darwin and Australasian Society of Clinical Immunology and Allergy in the Gold Coast. Funds have also been used for printing of brochures and posting to Doctors surgeries.

The year ahead: 2017

In 2017 ARRC has once again been awarded funds for the provision of self-management programs across regional NSW from The Newcastle Permanent Charitable Foundation. This will provide funding for 13 different self-management days in the Mid North and North Coast, New England, and Central West areas of NSW. In addition to this, ARRC will also plan a Brisbane self-management workshop with Scleroderma QLD and also a Canberra self-management day. These events will be a cost recovery event.

To fund production and printing costs of the newsletter and other printed resources ARRC has approached a corporation for educational funding for 2017. Printing support continues to be received from Newcastle City Council printers.

In March 2017, a major International conference Lupus 2017 in conjunction with the Asian Congress on Autoimmunity will be held in Melbourne. ARRC has been allowed to have a partially subsidised booth at the event along with having a satchel insert that will go to each delegate. Whilst the booth, even when subsidised, requires considerable funds it is felt that this would be a great opportunity to showcase ARRC and its services. Along with this event ARRC will also attend the ARA and ASCIA conferences of 2017. Funds will be drawn from Rhonda's Trust to cover these events.

2017 planned fundraising events and items (details to be provided when available)

1. Trivia Games night Wednesday May 10th World Lupus Day
2. Gathering of the Clans events July and also September
3. City to surf
4. Regal cinema film nights
5. Scleroderma lunch
6. Barefoot Bowls – Gwandalan – 2017
7. Entertainment Books
8. Donation Tins
9. Sale of Chocolates

10. Sale of ARRC goods – gloves and socks
11. Community and corporate donations.
12. Seminar and workshop attendance payments
13. Workplace giving- Gold coin to gold egg campaign.

The year of 2017 looks to be busier than the year before, but with the help of staff and volunteers we hope to make it a successful year. ARRC will continue to provide supporting activities and resources that enable autoimmune patients with skills and information that encourages them to learn about their illness and how to live well with illness.

