

DRAGON CLAW

The New Year.....

Over November and December

Yep! This period has been busy for the team. We are pleased to announce a new governance structure has been put in to place; a completely new function on our website; and an indigenous project to commence.

2017 saw us obtaining charity status via government approval which means that all donations over \$2 are tax deductible in Australia. In addition, the year was complex as we had to change our legal structure to a company limited by guarantee. This means we are an association where all members have equal rights. All formal positions will be voted upon or endorsed at an AGM planned for later this year.

Membership growth has been slower this period than expected probably because we don't have enough feet on the ground and financial resources are very tight. We need every cent for our work. Planning for 2018 should see significant financial growth and a much higher level of visitor-to-member conversion on the web site. On a good month, we receive 900 visitors.

New Governance Structure

On the financial side, we have established an Operational Fund Account and a separate Gift Fund Account. All donations go to the Gift Fund. The primary governance point is the Board which is made up of the three directors, the patron and appointed members. Membership is subject to an annual AGM of all members. In addition, members can belong to the Patient Advisory Committee which is charged with ensuring member interests are upheld. Three other advisory groups are Products and Services, Marketing and Health Advisory. This latter committee is chaired by our founder and is populated by invited clinicians. The new structure emphasizes the fact that Dragon Claw is run by patients for patients. The Patient Advisory Committee (PAC) is chaired by Susan Hughes and is charged with representing the patient viewpoint in all major Dragon Claw projects. Such projects relate to branding, public relations and marketing including website content. As time goes on we will seek to establish a PAC group in all major Dragon Claw geographies. Currently we are planning for the USA, Canada and UK.



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Our Website

If you visit the website, along the main menu line at the top of the page, you will see a brand-new function – Search. The website has over 280 documents and articles, especially in Literature Central. Many members have asked for a way to search quickly and our CIO Leo rose to the occasion. The new function will let the visitor search the entire site. Those articles and services available only to members will be flagged to the visitor but full access will be denied. We want more visitors to register and become members. Log-in and have a try. In addition, the Prednisone sub-menu has been completely re-written, new videos added, links to useful lupus blogs and a number of new articles.

Indigenous Project

Indigenous Australians, especially in rural and remote Australia, have a significantly higher rate of rheumatoid arthritis than the general population. Health literacy, access to care and motivation are key elements in developing a greater awareness and self-care activities. Dragon Claw has targeted Indigenous Australians to produce a patient specific video in four languages suitable for remote communities in central Australia.

We are very pleased to announce that Janssen Australia have very kindly stepped up to the mark and provided significant funding for this project. Field work for the project will commence in May and June.

Social Media and Statistics

Have you noticed our social media activity? Please link up, ‘accept’ and be a member by visiting: LinkedIn and Facebook searching **DragonClaw** and **Dragonclaw** respectively. **Dragon1** on Twitter is now active.

Branding Workshop

A full working session was hosted by the NTF Group to improve our branding and its market position. The session was very well facilitated by Nettie Burke CEO of Cystic Fibrosis Australia. Thank you, Nettie. The work continues.

First Video Interview

Next month we will load our first webinar style video interview with a rheumatologist renowned for his meditative self-care position. Watch for it!

Interested in volunteering then call Susan Hughes 0421459 757



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Please circulate

January 2018, # 30

Forum

Did you know as a member you can go to the Forum and ask questions or exchange views. The Forum is part of the Dragon Claw community. Login then select Forum on the left-hand side.

Donations

Dragon Claw is run by volunteers. None get paid so we use all cash for projects and our overheads are very low.

I may be the face of the Dragon, but there's a small army of volunteers behind the scenes. They work tirelessly to bring you the site contents, to develop projects and to engage with our commercial supporters. That is right! To date we have not been reliant upon a single benefactor or government. This is why membership is free.

We'd love you to become a monthly donor, which helps ensure a predictable steady stream of support. Notify us of your proposed donation at infor@dragon-claw.org and we'll prepare a tax-deductible receipt. Alternatively visit the website and use the sub-menu "Donations".

- Send donations to Dragon Claw GIFT FUND, Commonwealth Bank of Australia, Account: 062000 - 16849830. If needed our SWIFT code: CTBAU2S.
- Alternatively, deposit via PayPal: select 'send money'; then 'friends and Family'; then amount. Use the "to" email account migill88@me.com

Thank you.

Michael

<https://www.dragon-claw.org>

AIM

Dragon Claw provides information, community and support.

Why the Name?

Rheumatoid Disease (RD) can be felt like an unpleasant animal moving around the body biting and scratching. Occasionally, the dragon rears up and breathes fire, which is felt as a flare, hence the name.

Our Patron

Dr. Mukesh Haikerwal AO former National President of the Australian Medical Association. He is currently a board member of Beyond Blue, Cancer Victoria and Brain Injury Australia. In addition, he is a professor at the School of Medicine, Flinders University, Adelaide.

Encouraging self-care and care co-ordination to reduce isolation and stress



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