

More Fun: More Opportunities

Announcements

We are pleased to announce that Roche Products Pty Ltd is going to list the Dragon Claw website on their Actemra patient support site. Roche are the makers of Actemra (Tocilizumab) a biologic therapy used to treat moderate to severe rheumatoid disease. This means that this patient group will be made aware of Dragon Claw.

Medivizor is an online operation providing research support for people with major chronic diseases. We have agreed to work together and provide cross-linked services and information between our two websites (www.medivizor.com). This is most exciting and members will soon be able to access some of the latest research findings presented in a short and easy to read format – no research degree needed!

The Dragon Claw executive has decided to seek charity status (DGR) and will be going through the process of registration over the next few months. This is not a simple exercise and will introduce compliance costs to our very stretched budget. Registration will, however, allow donations

made in Australia to be tax deductible.

Publicity

One of our directors, Susan Hughes, has published a short interview about disability parking services for those with our disease. Typically, members with Lupus and Rheumatoid Disease often have good skin health and appear outwardly well. Legally parking in a disability parking space sometimes causes raised eyebrows or open objection. Few members of the general public know what we go through so Susan wants to change this. While she has published via a number of online blogs, her latest interview can be read on the Dragon Claw landing page. Just scroll down.

In Australia Dragon Claw achieved national press coverage via the two main news services (The Age and the Sydney Morning Herald). In particular, the online publications presented a video segment detailing the website and our aims. This was our first national exposure to the general public.

The Profit Dilemma

Dragon Claw is slowly but surely coming to the attention of a wider audience. An angel investor broker recently phoned and wanted to introduce at least two commercial investors. Sounded great from our perspective but once I explained that we were not-for-profit, interest seemed to cool somewhat. Still, we note a surge in for-profit interest in our operation. Not sure where this may take us but Dragon Claw will remain not-for-profit and member driven.

New Website

In our last newsletter we lamented the derailment of building a new website. A kind donor has stepped forward along with our commercial partners (Princeton Digital; the NTF Group and LoneAlarm) and we have started to build a bigger and better version of our current website. We are so grateful to our supporters and to that very special donor. We have appointed a project manager and hope operations will commence in May. The new site will be easier to navigate, offer a number of new services and will present a new much more dynamic landing page.

Over

www.dragon-claw.org

Rheumatoid Disease Self Care

AIM

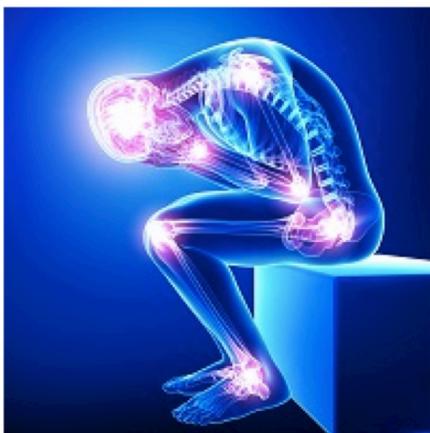
Dragon Claw aims to provide information, community and support for registered users. Eventually we will offer telehealth, self-care management and care co-ordination. We do not provide medical advice.

Why The Name?

For many people 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 has made a huge contribution to the medical field, through his leadership roles as Chairman of Council for the World Medical Association (2011-2015), and National President of the Australian Medical Association (2005-2007). He is currently a board member of Beyond Blue, Chair of the Australian Institute of Health and Welfare and Patron of Dragon Claw.



BITS

Our New Videos

Three new videos! One details the role and function of the *Executive Team*; another tells a story about one of our leading members (*My Story My Dragon*); and the final one details the scientific evidence for the use of turmeric in reducing the impact of Lupus. All videos are normally only available via the website but for the first time we are trialing the impact of making the first two videos publically available.

Access here: <https://vimeo.com/163791208/fce83b7abc>
and <https://vimeo.com/163791206/e9475d3547>

Social Media

We intend to develop a social media strategy and promote a greater understanding of the need for patient and carer support and engagement. **Do you have any suggestions?** Possibilities include patient centricity, pain management and invisible disabilities.

LoneAlarm – One of our supporters

LoneAlarm offers a falls monitor that works with your smart phone. The service has been taken up in over 13 countries. They are developing SafetyBand, a wearable extension to LoneAlarm, targeting those who don't carry their phone on their person all the time. As a DC member you can get a discount for the service via the code displayed on our home page. Visit their site: www.LoneAlarm.com

Supporters and Partners

The NTF Group is a leading *information based marketing consulting firm* - www.ntf.com.au : **The Pharmacy Guild of Australia** - <http://www.guild.org.au>: **Global Access Partners** (GAP) is an independent non-profit public policy think tank - www.globalaccesspartners.org : **Princeton Health** is a health sector publisher and marketer - <http://www.princeton.com.au>: **LoneAlarm** enables your phone to call for help when you can't -