

# DRAGON CLAW

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# www.dragon-claw.org

## 1. Indigenous video project

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



Central Australian Language Groups



L-R: Susan Hughes, Dragon Claw, Dr. Stephen Brady, Rheumatologist (Alice Hospital & Consultant), Dr. Tasha Robertson (Congress) and Denis Tebbutt, Chair of Dragon Claw Charity

After a successful field visit last month and wide support from stakeholders we plan on commencing filming in March during the cooler weather. The project has launched thanks to a wonderful donation from **Janssen Australia** and a grant from the Federal Department of Health. Our plans call for at least three visits to Central Australia, the engagement of an experienced production crew and an Indigenous elder.

Each of the videos will promote medication adherence as their key health message. The end user will be patients and the completed videos will be available to all health and outreach workers. The final videos will be produced around August next year and will be mounted on the Dragon Claw website.



The Pharmacy  
Guild of Australia

<http://www.guild.org.au>



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public policy think tank -  
[www.globalaccesspartners.org](http://www.globalaccesspartners.org)

janssen  Immunology

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<http://www.janssen.com/australia/>

## 2. Version 3 of our website

Through the kind offices of **Pfizer**, we have been provided with enough financial support to rebuild our website and three things are going to happen before Christmas:

- We are moving from “.org” to “.net”. We have concluded that many potential members have trouble with the hyphen in “dragon-claw” so we have bought “dragonclaw” on the dot net platform. What this means is that if you use the old dragon-claw.org address you will be automatically switched to the new *dragonclaw.net* website. The new site will become active in mid-October;
- We will be releasing an exciting new look and feel to our home page and will progressively modify how the website works in terms of links and navigation; and
- The mental health subsection has been completely rebuilt with new content and some fun self-test exercises.

You are able to search the entire site by using the ‘search’ button located along on the top with the main menu items. Dragon Claw offers members very specific and in-depth material related to rheumatoid arthritis and lupus. Nowhere else on the planet will you find this content in one place. We plan to continue loading up to date material about the diseases and to provide simple to read summaries.

Our approach is to make the content available on the website via video whenever possible. To this end we have over 70 videos covering everything from diet to remission. Many more are planned. If you are a keen video photographer your involvement would be very welcome. Below is a screen view of the members Forum and a list of recent articles held in Literature Central, Quick Reads.

**DragonClaw Forum** 26 topics

Category

-  **Welcome Mat** 2 topics
-  **Quality of Life** 8 topics  
This forum deals with all areas address a range of topics to im
-  **Medications** 6 topics  
This part of the forum will addr unusual solutions to common p
-  **Carer Issues** 3 topics  
In this forum we discuss all thi their issues and how to improv
-  **Nutrition** 2 topics  
There are many tips and tricks : when you are taking medication examples.
-  **Co-morbidities** 5 topics  
Anyone who has a medium to s called co-morbidities. This sect little irritations.

Title
Patient-reported outcomes from a trial of two biologics in patients with rheumatoid arthritis
What is Your Patient is Talking About: Remission?
Emerging IL-6 Inhibitors - Biologics for your RA
10-year outcomes of patients with early inflammatory arthritis improved compared with the last decade
Risk of preterm delivery in women with autoimmune disease using biologics
Effect of pregnancy on disease flares in patients with systemic lupus erythematosus
Plaque burden stabilized or reduced in patients on psoriasis biologics
Education and Pain Together with Learning Does What?
Comparison of Humira with its Biosimilar Replacement

### 3. MAXINE for smartphones

We have been privileged to have the on-going support of the **NTF Group** from the first day Dragon Claw was established. The NTF Group built our first website and now have come on to build our first smartphone application, called MAXINE. The prototype is now active, and we are seeking further funds to complete the build and market the product. All very exciting!

MAXINE has four unique features:



- It is purely patient centered and is not designed for the clinician;
- Physical strength forms the basis how the application works;
- Maxine monitors joints via international standard measures known as DAS28; and
- it teaches the user about how to monitor themselves.

The key to success for people with chronic disease is to observe themselves. No one understands their body and their feelings better than the sufferer. MAXINE will teach the user how to observe and how to monitor the disease from a wellness perspective. By answering a set of questions every day for a month the user will be able to manage their own condition better, improve the co-ordination of support resources and have a more informed dialogue with their clinician. Our unique feature is that the user's strength forms the base to which the measured variables are assessed. In short MAXINE will make you feel better and will assist in keeping you out of hospital.

## 4. New content on Dragon Claw

There are about 30 new articles on Literature Central. You will find information about new medications, the impact of some of the newer biologics, an opinion about remission and studies on pregnancy and RA treatments.

The Video Library contains recently loaded video dealing with inflammation and meat; why ginger and turmeric are important; leaky gut; improving patient experience and a video by one of our members Susan Hughes.

We have upgraded our Terms and Conditions and our Privacy Policy, both of which can be viewed under menu items "Becoming a Member" and "Important Stuff".

## 5. News bits

Pfizer has developed a website of its own Get Healthy Stay Healthy and is dedicated to a number of conditions including rheumatoid disease. We are pleased that visitors to their site can directly link with Dragon Claw. We are one of five organisations listed (see <https://www.gethealthystayhealthy.com/en-au/articles/it-rheumatoid-arthritis-ask-rheumatologist0>).



- Members will be soon notified about our first AGM date. It will be online so come along and have your say;
- We have updated our terms and conditions. You can see these online;
- This newsletter will soon move to a fully online version within the near future;
- Our Chairman and our chief patient advocate attended a Janssen sponsored Ministerial Breakfast followed by a meeting with Department of Health head Glenys Beauchamp in Canberra.
- If you wish to "unsubscribe" from Dragon emails, please send an email to [info@dragon-claw.org](mailto:info@dragon-claw.org) with "unsubscribe" in to topic line.



Pathways based on scientific knowledge and the accumulated wisdom of many cultures -  
[www.pathways2wellbeing.com.au](http://www.pathways2wellbeing.com.au)



Health information, personalized –  
[www.medivizor.com](http://www.medivizor.com)



British Medical Journal  
[www.BMJ.com](http://www.BMJ.com)

## 6. Donations

Dragon Claw is run by volunteers. None get paid so we use all funds for projects and our overheads are very low. 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 [info@dragon-claw.org](mailto:info@dragon-claw.org) and we'll prepare a tax-deductible receipt.

### For Thought

*As a friend what can you do if someone close has rheumatoid disease or lupus?*

Talk to them often. Take them out to coffee, to the movies or just for a walk. Help them to address their pain by planning an event or outing with them. Even talking about it can help especially during the early days of multiple drugs, brain fog and always feeling unwell. Assure them that things will get better. Select a few videos and articles, show them and discuss them. There is a wealth of support on Dragon Claw. Many of the medications have side effects. Read up about these or seek responses from others via the Forum. There is a wealth of information archived there as well. Remember their primary care giver (partner or significant other) may also need a chance to talk if not some time off. Perhaps you as a friend can step in for a little while?

### Indigenous Dream Time Images



<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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