

# **NEWSLETTER**

- 1. Indigenous video project
- 2. Patient & Carer Advisors (PAC)
- 3. Government Health Affairs
- 4. Online Newsletter
- 5. Content Update
- 6. News
- 7. Donations



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## www.dragonclaw.net

## 1. Indigenous video project

Dragon Claw has completed all filming of Indigenous Australians in Central Australia. This is an Australian first in terms of health promotion and rheumatoid. Four videos in local language and one in English will be produced in about July. In addition, we have produced a stakeholder interview about the need for a medications adherence message and are in the process of developing a documentary of the entire experience. Each of the videos will promote medication adherence as its key health message. The end user will be patients and the completed videos will be available to all health and outreach workers in Central Australia.

It has been great fun and a unique experience working with the professional crew and the indigenous actors in valleys, the desert, in community and in Alice Springs. Each day the temperature ranged from 28 to 43 degrees centigrade. We put much of our effort in to preparing the actors and community and this, we believe, has paid off. If you'd like to see what the key stakeholders thought about our project have a look here: <a href="https://vimeo.com/323393500/059ed944b5">https://vimeo.com/323393500/059ed944b5</a>

We are grateful for a wonderful donation from **Janssen Australia** and a grant from the **Federal Department of Health**.



Crew filming indigenous artists I-r Brandon, Camera, Michael Gill, Dragon Claw, Don Palmer, Film Director.



I-r: Susan Hughes, Dragon Claw Tangentyere artists at the drone-film shoot where their painted dots echo voice over 'take your pills every day', Shannon Anthoness, Producer



Uncle Emu attending Alice Springs clinic film shoot



http://www.guild.org.au

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Central Australian Aboriginal Health Congress Clinic with Dr. Jarred

Spot the drone!

Artists in action

### New Patient Advisor



Annette McCarthy, Governance Officer for Congress in Alice Springs is the first indigenous member to join our Patient and Advisory Committee. Annette has RA and after having her RA damaged feet operated on she celebrated her recovery by walking the xxxxx trail across Scotland. Her family members have Lupus disease giving her an excellent understanding of the importance of patient self-care. The daughter of a proud xxxxxxx mother, Annette was raised in xxxxxxxx community near Alice Springs by her mum and Irish Carpenter father and then gained her education at the University of Canberra. She returned to her family in the Red Centre where she has developed her career with Central Australian Aboriginal Congress. Dragon Claw's Mike Gill and Susan Hughes had the pleasure of meeting Annette in person several times in Alice when she kindly attended our Maxine App focus session to enthusiastically give Dragon Claw's self-care proto-type app 'the thumbs ups'. Our PAC committee is excited to be working with Annette via Group teleconferences to providing patient-centred guidance to the management of Dragon Claw Charity.

L-R: PAC Carer members Ned Strong and Amanda Collins meeting Terry Jones from The Marketing Clan, our pro-bono Marketing Chair sporting our new T's which will be for sale in our e-shop when our new site is launched. Enquiries for purchase of T's info@dragonclaw.net





**Patient Tip** - Japanese Recovery Tonic.... Look what I found at my local Harris Farm Market — Turmeric Shots, Australian made with vitamins A & B anti-inflammatory properties...quick tonic for busy RA patients.

Tastes ok – and no this isn't an advertisement! Cheers, Susan Hughes - Chair, Patient/ Carer Committee

## 3. Government Health Affairs

This pre-election quarter we have been busy meeting our Health leaders seeking financial support to develop our Patient App 'Maxine' for patients to self-monitor their disease. In addition, we have been seeking funds to roll out our Medication Adherence video productions to remote indigenous communities along the top end of Australia.



Ken Wyatt Minister of Indigenous Health with Dragon Claw's Susan Hughes at Min. Greg Hunt's Budget Breakfast.



L-R: Maeve Eikie, Janssen Corp/Government Affairs Manager with Keith Besgrove, Dragon Claw's Marketing Chair.



Catherine King, Shadow Minister of Health with Dragon Claw's Michael Gill at Janssen sponsored Lunch.

## 4. Online Newsletter

For 32 editions we have published the newsletter to all members and other interested parties via PDF. This edition, number 33, is our last paper to PDF version. In the future we will be employing an automated email method making production and administration simpler.

The new newsletter is an evolving feast as its format will develop as we master all the new online features.

## 5. Content Update

We have added new articles and a video. Log in then select Literature Central from "Our Big Ideas" then select Quick Reads.

- Boosting DNA Repair
- Some Drugs Induce Lupus
- Early Intervention and Mortality



In Literature Central then select Scientific Articles

- Better Testing for Lupus
- RA Patients Do Better Using a Biologic together with Methotrexate
- Having Surgery and Stopping Your Biologic

Under 'Here to Help' then select 'Nutrition'

- What to Feed Your Gut

New Video found in the Video Library, scroll to the last topic line and select

- Turmeric vs. Exercise



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### 7. 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 here and we'll prepare a tax-deductible receipt.

#### **Volunteer Needed**

Dragon Claw Charity Ltd is a fully registered Australian charity and operates in the health promotion space. We focus exclusively on rheumatoid arthritis and lupus. Due to rapid growth and increasing opportunity we are seeking two people to fill the positions of Executive, joining the founding three. The executive team manages the organisation with the support of a formal Board and a number of advisory groups. If you are interested to make a difference, can focus, deliver on agreed outcomes and have the ability to donate about 10 hours per week, then please consider Dragon Claw. These two positions are entirely volunteer as are all positions. Please visit the website (<a href="www.dragonclaw.net">www.dragonclaw.net</a>) and if we pique your interest then send a one page application to the founder Michael Gill (<a href="mailto:mgill@dragonclaw.net">mgill@dragonclaw.net</a>) by 10 March, 2019.

### https://www.dragonclaw.net

#### 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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