



## Submission: Management and communication of medicines shortages

144 Young Street  
Annandale  
NSW 2038  
20 April, 2018

Dear Sir

This short submission relates to our member concerns. Dragon Claw specialises in people with rheumatoid arthritis, lupus, their care givers and supporters. A significant number of our members receive medical infusions to manage their condition, take strong pain control medication and use glucocorticoids. Any shortage of these medications can have *major disabling* impacts on sufferers.

Two years ago, a biologic medication manufactured by Roche was in short supply in the USA. There was a flow-on concern in Australia amongst our members, some of whom became very concerned. There was a feeling at the time that supply would be 'managed' by the multinational by shifting stock based on profitability irrespective of national need. Pharmacists appeared to have little idea and this lack of knowledge compounded anxiety. There needs to be a means to determine if a shortage is *evident or likely* in Australia by a simple lookup web portal designed for both clinicians and patients. The current site known as MS11 is adequate, is not user friendly and is unknown amongst our members. Pharmacists in particular need to be informed as they are the front line dealing with patients, more so than GP's.

From our perspective the proposed Medications Watch List is irrelevant as it does not address key medications associated with major chronic conditions. The incidence of "death adder antivenom" use would be minute when compared to the top three biologics currently used by our members. An example is Tocilizumab.

- A. We agree with the proposed definition of medicine shortage. We think that the scope of listed medications needs to focus on people with chronic conditions in addition to those with life threatening acute conditions.
- B. We suggest that all medication shortages be based on a reporting period of 12 months.
- C. The business case dynamics of the supply industry requires monitoring by well informed TGA staff to avoid a *managed shortage scenario*. The notification content seems simplistic to us.

- D. It would seem to us that the TGA should send out quarterly emails to all charities listed by the Australian Charities and Not for Profit Commission under the general label of 'health' and 'health promotion'. In this way members can be alerted to the issue and be provided with a link to MS11.

I look forward to further communication.

Yours sincerely,



### **About Dragon Claw**

Dragon Claw is an organisation about wellness and self-care and is focused on the creation and development of a community of common interest around sufferers of rheumatoid arthritis, lupus and Juvenile Idiopathic Arthritis, their carers and supportive clinicians. Dragon Claw ([www.dragon-claw.org](http://www.dragon-claw.org)) is owned and operated by, Dragon Claw Charity Ltd (ABN 7361371775 and ACN 621371775), a national tax-deductible charity. Our patron is  who was the 19th Federal President of the Australian Medical Association, its Federal Vice President and, prior to that AMA Victorian State President.

The driving force behind Dragon Claw is closing the gap that exist in our healthcare system and failure to provide ongoing support and advice that surrounds the management and lifestyle impacts that these awful conditions require. We care because most of us in Dragon Claw have these conditions and we wish to make a positive difference to the way health jurisdictions treat people with chronic disease.

Ten commercial partners including the British Medical Journal and the Pharmacy Guild of Australia support Dragon Claw. To date, no government support has been obtained and base membership is without charge.

The organisation is run by 28 volunteers. No salaries are paid.

### **Rheumatoid Disease**

Rheumatoid Disease (RD) or Rheumatoid Arthritis (RA) is a systemic immune-mediated disease that can affect any part of the body. Typically, RD attacks the musculoskeletal system, causing joints or tendons to become painful, swollen, or weak, and leading to disability or permanent damage. The disease can also lead to problems with various organs or systems, including the circulatory or nervous systems, eyes, skin, bones, heart, or lungs. The disease affects about 2% of the population and is 1.6 times more common in women than in men. People of Aboriginal background in Australia have a 40% greater incidence of the condition than the general population.

Rheumatoid arthritis can be a significant cause of disability and has considerable impact on quality of life with sufferers reporting 3.3 times as likely as those without the condition to have poor health.

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease that affects multiple systems of the body. Worldwide estimates of the prevalence of SLE vary from 4.3 to 150 per 100 000 population, with higher prevalence in women, particularly those of childbearing age. In Australia, SLE is more common and more severe in Indigenous Australians and descendants from South-East Asia. Australia has about 4000 cases of Lupus.

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