This submission was formulated to provide feedback on the draft National Guidelines for the management of patients with haemophilia.
6 August 2015

Australian Haemophilia Centre Director’s Organisation
1622 High Street
Glen Iris VIC 3146

Via Email:

Dear [Name],

**National Guidelines for the management of patients with haemophilia**

Thank you for seeking The Royal Australasian College of Physicians (RACP) feedback on the draft National Guidelines for the Management of Haemophilia, developed jointly by the Australian Haemophilia Centre Director’s Organisation (AHCDO) and the National Blood Authority.

The introduction of new health services and treatments over the last several years has brought about substantial improvements in health and quality of life of people living with haemophilia. The improvements made by these new health service modalities include the provision of effective treatments and the delivery of comprehensive care by multidisciplinary teams. As a result, life expectancy for people with haemophilia is now almost comparable to that of the general populace. To continue these improvements, it is essential the medical community embrace effective health services and treatments.

The RACP supports the adoption of the existing World Federation of Haemophilia’s (WFH) Guidelines on the Management of Haemophilia (2nd Edition) and the inclusion of an additional chapter detailing the component of care relevant to the Australian healthcare setting. Overall, the RACP agrees with the recommendations made in the WFH’s Guidelines and makes the following comments concerning the additional chapter:

- **1.3.7** - We welcome the inclusion of rheumatologists as musculoskeletal experts to address prevention and treatment within a comprehensive care team.
- **1.3.11** - We recommend ‘chronic pain specialist’ be changed to ‘pain specialist with expertise in both acute and chronic pain’.
- **1.1.9** and **1.1.10** - the ‘Bleeding manifestations’ section, should recognise that bleeding score is an important indicator to assist with diagnostic evaluation of...
mild forms of haemophilia A, B and von Willebrand disease (vWD) and appropriately highlighted.

- **1.2** - It is important to note that a normal activated partial thromboplastin time (APTT) or coagulation profile does not exclude mild haemophilia; factor assay needs to be repeated to ensure the test result.

- **1.9.11** - The sale of nimesulide is banned in many countries worldwide due to its adverse cardiovascular effects. In light of this, the removal of nimesulide, as an example of COX-2 inhibitor, from the table 1.6 is suggested.

- **1.9.11** – Considering the use of narcotics have the potential to produce a wide range of problems, the table 1.6 warrants further explanatory comments on the use of opioids in pain management – including its adverse effects, potential for abuse and steps that can be taken to minimize these problems (e.g. adoption of holistic approach for long-term management of pain and close supervision of prescribing narcotics with the assistance from the primary health care provider).

- **1.10** - Surgery and invasive procedures need to be accessible to patients with hemophilia and vWD, regardless of their severity.

- **1.10.3** - Emergency surgical procedures, if required, can be conducted in other non-haemophilia treatment centres that provide general haematology services, in consultation with haemophilia treatment centres under the cover of clotting factor administration.

- **1.11.11** - To reduce the need for replacement therapy, tranexamic acid should be prescribed in conjunction with factor administration.

On another note, narcotics are effective analgesics, but their use is often associated with a broad range of problems, including the development of opioid tolerance, dependence and opioid-induced hyperalgesia. As such, the long-term use of narcotics for the pain of chronic haemophilic arthropathy is currently controversial; the use of potent narcotics, such as morphine and oxycodone should be reserved for acute pain caused by bleeds and perioperative pain.

Instead of prescribing potent narcotics for long-term management of pain due to haemophilic arthropathy, the RACP recommends that a holistic approach be employed encompassing physical, psychological and musculoskeletal care, with the use of non-opioid agents. Care from pain medicine specialists should be arranged where chronic pain is poorly controlled.

Should you require any further information regarding this response, please contact [Policy Officer at [Redacted]].

Yours sincerely

[Laureate Professor Nicholas J Talley](mailto:Your@email.com)

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2. [Thrombosis Research](#) 134(2014)S68-71: Legal requirements for optimal haemophilia treatment in Germany