National Haemophilia 225, March 2024

AHCDO update



Andrea Johannessen

AHCDO ANNUAL GENERAL MEETING

The Australian Haemophilia Centre Directors' Organisation (AHCDO) held its Annual General Meeting in November 2023.

A new Executive Committee was elected:

- Chairperson Dr Stephanie P'ng (Fiona Stanley Hospital, WA)
- Deputy Chairperson Dr Jane Mason (Royal Brisbane and Women's Hospital, QLD)
- Treasurer Dr Chee Wee Tan (Royal Adelaide Hospital, SA)
- Research Committee Chairperson -Dr Sam Hitchins (Royal Hobart Hospital, TAS)
- General Member Dr Chris Barnes (Royal Children's Hospital, VIC)
- General Member Dr Liane Khoo (Royal Prince Alfred Hospital, NSW)

EDUCATION DAY

AHCDO held a half-day Education Day for Director and Associate Members in November 2023 at the Melbourne Convention Centre. We had great attendance from our Haemophilia Treatment Centres.

The opening sessions were focussed on the treatment of women with known and unknown bleeding disorders in pregnancy, labour, and the postpartum period, using a case series of two patients. Thank you to Dr Briony Cutts for sharing the cases of two patients to provide AHCDO members with a great insight into these complicated cases. Professor Sonia Grover, a paediatric and adolescent gynaecologist, spoke about the options available to women with bleeding disorders to manage menstruation. Suzanne O'Callghan presented an update on the 2020 PROBE Australian data.

Our AHCDO members are Heads of Haemophilia Treatment Centres so we had a session focused on Mental Health at Work with a presentation by Dr Sarah Dawkins and the opportunity for much discussion. Sarah focussed on identifying strategies for wellbeing at work for yourself and for others, identifying and managing mental health hazards and managing risks.

We finished the day with presentations from our AHCDO Research Fellows and will provide those research outcomes in future editions.

VON WILLEBRAND DISEASE

AHCDO has recently published 'Recommendations for management of type 3 von Willebrand disease in Australia on behalf of the Australian Haemophilia Treatment Centre Directors Organization (AHCDO)' and it is available on our website www.ahcdo.org.au. If you have any questions or feedback, please contact AHCDO at info@ahcdo.org.au.

GENE THERAPY ROADMAP

AHCDO developed the Gene Therapy Roadmap to provide a Clinical Implementation Plan that sets out AHCDO's position on the preferred approach to implementation of gene therapy for haemophilia in Australia, with a focus on patient needs that is informed by clinical experience.

AHCDO has progressed implementing the Gene Therapy Roadmap with a Gene Therapy Workshop in August 2023 attended by all members of the HTC team. The Workshop was on the day prior to the HFA National Conference so we were able to maximise attendance. We were grateful to have Dr Glenn Pierce present on the global perspective of gene therapy for bleeding disorders, which was a great introduction for the session. Many of our HTCs and Australian patients have been involved in developing this technology and it was a very valuable discussion.

The Roadmap can be viewed from the AHCDO website - www.ahcdo.org.au.

Dr Andrea Johannessen is AHCDO Executive Officer