AHCDO update

Andrea Johannessen

GENE THERAPY ROADMAP

The Australian Haemophilia Centre Directors' Organisation (AHCDO) has 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.

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

EDUCATION DAY

AHCDO held a full-day Education Day for Director and Associate Members in October 2022.

We were very enthusiastic about having the event in person after two years with virtual events, which was reflected by the very high attendance in person this year. The clinicians who were not able to attend on the day have access to the presentations using their member portal.

A challenging opening session focussed on **ethical considerations in the care of haemophilia patients** facilitated by clinical ethics expert Prof Lynn Gillam. Attendees discussed how values and judgement influence decision-making processes in different cases and while we were not able to solve the dilemmas with a single outcome, the session gave our members the opportunity to reflect on the elements of the process.

The morning sessions were focussed on **Bleeding Disorders of Unknown Cause (BDUC)** and we were very fortunate to have Prof James O'Donnell from Irish Centre for Vascular Biology to present his research program and facilitate an engaging discussion on recent insights and clinical issues related to **low von Willebrand factor**.

In the afternoon, the 2021 and current AHCDO Research Fellows presented an update on their projects utilising **Australia Bleeding Disorders Registry (ABDR) data**. Carly George gave an update on firstly, the use of **Extended Half Life (EHLs) treatment products** and secondly on the **Haemophilia Joint Health Score assessment tool**. Both of these projects will be submitted for publication over the next couple of months. Radha Ramanan presented single site interim results on two projects which are currently being prepared for multi-site authorisation. AHCDO's ABDR Senior Research Fellow, Sumit Parikh, gave an update on the ABDR research projects and discussed future projects and development of additional tools to facilitate AHCDO research.

Sally Campbell presented an engaging discussion on **haemophilia and participation in sport**. Dr Campbell's initial research carried out in one state demonstrates that there are many benefits for participation in sport and supported further research to determine the safety profile of sport for patients with haemophilia.

We finished the day with a presentation from Stephanie P'ng, chair of AHCDO Research Committee, and the development of a research plan to investigate longitudinal (long-term) outcomes of emicizumab treatment.

AHCDO EXECUTIVE OFFICER

Dr Megan Sarson

Dr Megan Sarson has been the Executive Officer with AHCDO since 2002 and has made significant contributions to the development of the organisation over the years. Megan has decided to finish her role at AHCDO, although she will continue her role with the Thrombosis and Haemostasis Society of Australia New Zealand (THANZ).

Dr Andrea Johannessen is AHCDO Executive Officer

Dr Andrea Johannessen

Dr Andrea Johannessen (BSc (Hons), PhD) was recruited to cover Megan's recent 6-month long service leave and following Megan's resignation has been offered and accepted the role on an ongoing basis. Andrea has a background in medical research followed by 20 years in senior management in health care, academic and not-for-profit organisations, with a particular focus on research governance. Andrea is very pleased to be able to continue in the role and work with AHCDO members to facilitate clinical care and research and continue the collaborative work with HFA that Megan started.

Starting school with a bleeding disorder

Janine Furmedge and Jaime Chase

Starting childcare, kindergarten or school – or high school - can be both an exciting and daunting transition for children and their families.

When a child has a rare bleeding disorder such as haemophilia, there is additional anxiety for both parents/guardians and educators. Parents may worry about entrusting the care of their child to others. Most educators will not have experience with bleeding disorders and are often worried about what this might mean for the inevitable falls and scrapes in the playground and be unsure about including children in activities and sports.

HOW TO EDUCATE SCHOOLS?

Providing information for schools and childcare is a key role of the Haemophilia Treatment Centre (HTC) with the goal to support parents, allay the fears of educators and for children to have a safe, active and full school life.

Depending on the size of the school, key contacts may include teachers, first aid officers and a school nurse.

Some of the key messages provided to schools include:

- Most students with haemophilia can lead healthy and active lives and participate fully in the school community
- Appropriate activities and sports are encouraged to promote physical and mental health
- A student with haemophilia will NOT bleed profusely from a simple fall in the playground or a minor cut or injury
- Standard first aid is the same as for any other student
- A knock to the head or major injury requires prompt medical attention which may require factor replacement
- In the instance of an injury, contact the parent or guardian immediately.

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