


Dr Robert Sidonio is a leading US haematologist specialising in women and girls with bleeding disorders and discussed the importance of collecting data about women and girls into bleeding disorders registries. This is new work that involves defining what data about female bleeding needs to be collected and how to restructure the databases to measure relevant treatments and outcomes.

Dr Sidonio described some US-based projects that had attempted this and outlined some of the issues they raised – for example, the diversity of bleeding disorders and treatments in women and girls and inconsistent documentation of heavy menstrual bleeding, joint damage and post-partum haemorrhage. He thought the new VWD (von Willebrand disease) guidelines may improve this, as they take into account the different patterns of bleeding symptoms in females. Quality of life impacts are also more common in females with mild bleeding disorders than males due to heavy menstrual bleeding and complications such as iron deficiency. He highlighted the benefits of having an obstetrician/gynaecologist as part of the comprehensive care team.

Following Dr Sidonio's presentation, Declan Noone from the European Haemophilia Consortium looked at data and why it matters. He explained some of the issues with registries – that they have not been designed to collect information on 'minor' bleeds, eg, nose, gum, menstrual, sub-clinical, reported bleeding. Moreover, for advocacy, good statistical data is very important but aligning it with the personal story to explain the human experience of the statistics is very important, otherwise the data will be misunderstood. Another complicating factor is that there have not been consistent and objective ways to collect information on health outcomes for females – for example, a woman might not judge her bleeding as a problem if all the women in her family have very heavy periods, but in surveys will comment on being weary of the 'monthly bloodbath'. Finding effective ways to measure symptoms like heavy menstrual bleeding and its impact on quality of life will make a big difference to meaningful data collection.

This is very relevant to our work in the HFA The Female Factors project to understand and explain bleeding disorders in women and girls. We are looking forward to the conference session on women and girls in our 2021 national conference, where we will be exploring this further!



Australia's COVID-19 Vaccine Roadmap

COVID-19 VACCINE

COVID-19 VACCINATION

With lockdowns around Australia due to COVID-19, getting vaccinated has become a high priority in all states and territories.

Do you have questions about the COVID-19 vaccine for people with bleeding disorders?

The Australian Haemophilia Centre Directors' Organisation (AHCDO) has advised HFA on answers to some common questions relating to the vaccine and bleeding disorders.

The HFA **COVID-19 vaccine FAQs** also includes links to the Australian Government information about the vaccine.

Read the COVID-19 vaccine FAQs on the HFA website - www.haemophilia.org.au

There is also a PDF version online for you to print or download and take to your appointment.

The FAQs may be updated as more information becomes known. Please check the HFA website for updates.

If you have any questions about your bleeding disorder in relation to the COVID-19 vaccine, contact your Haemophilia Treatment Centre or your treating haematologist.