



Rare Inherited Bleeding Disorders (RIBD) Committee

Terms of Reference (February 16, 2024)

Inherited bleeding disorders other than factor VIII and factor IX deficiencies and von Willebrand disease can cause major health impairment and even death. Because most of these abnormalities, that encompass rare coagulation factor deficiencies and platelet function disorders, are rare, less is known about their natural history and optimal management.

Mandate

This Committee was established with the mandate to:

1. better understand these disease entities
2. enhance delivery of comprehensive care
3. establish management guidelines
4. provide education to patients and health care providers
5. promote safety of product supply
6. further basic and clinical research directed at these disorders

Membership

Chair – The Co-Chairs have been selected by the AHCDC Executive Committee and consensus recommendation of the members.

Members – Members should have substantial clinical experience in managing patients with the rare inherited bleeding disorders, and/or a basic or clinical research profile in the field, as evidenced by publications in scholarly journals.

The committee is made up of a maximum of 8 members, including a Nurse representative. Tenure has not been determined and should probably be at the pleasure of the AHCDC Executive Committee. However, there should be overlap between new and departing subcommittee members.

Meetings/ Communication

The members will generally meet by teleconference at the call of the Chair, with the Co-Chairs communicating with the members via e-mail. The Committee will report to the membership through the Executive Committee.

The Committee will also maintain liaison with the Research Committee when undertaking research projects.

Costs

Sufficient to hold 1 to 2 teleconferences per year.

Current membership

Chair	Dr. Walter Kahr (Co-Chair) Dr. Margaret Rand (Co-Chair)
Members	Dr. Stephanie Cloutier Dr. Sara Israels Dr. Man-Chiu Poon Dr. MacGregor Steele Dr. Irwin Walker Dr. Rochelle Winikoff Vanessa Bouskill (Nurse Representative)