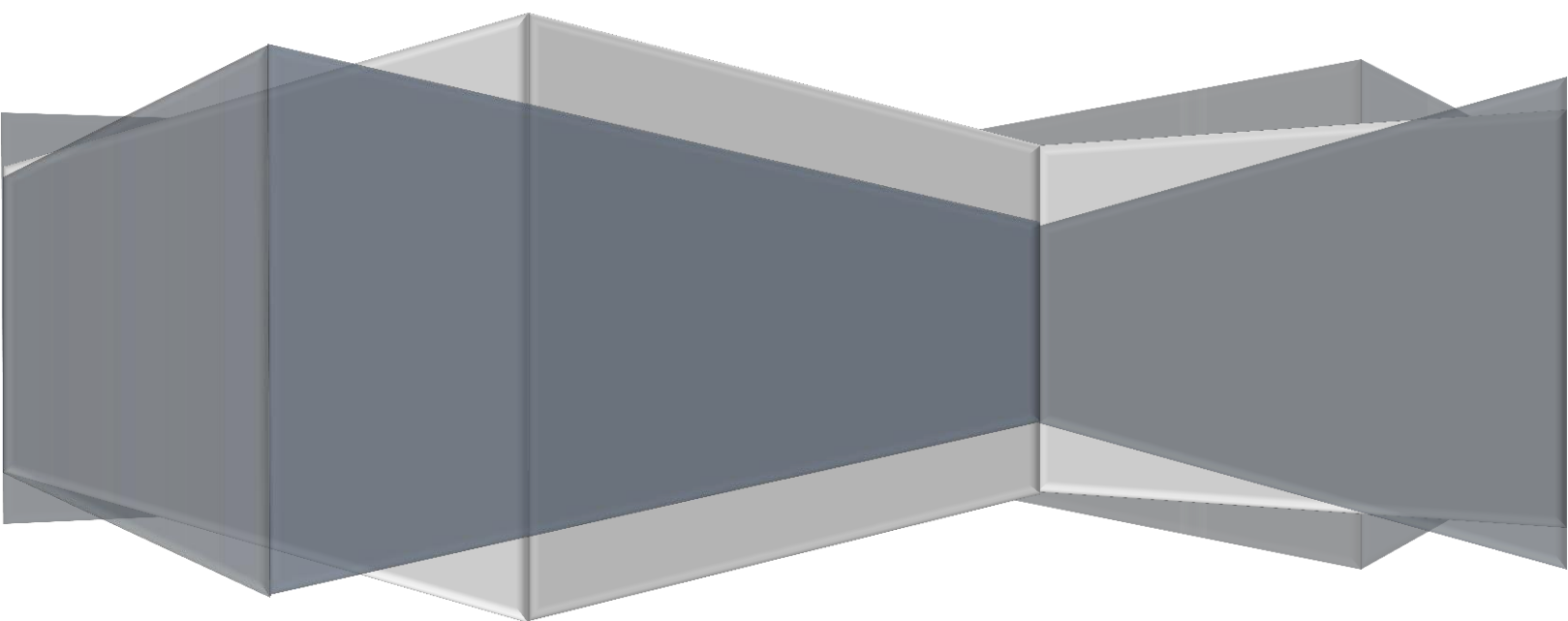


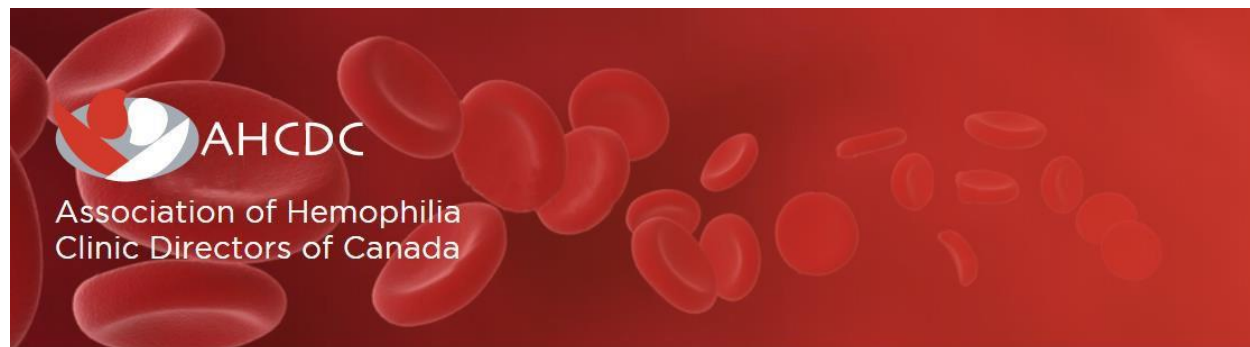
Association of Hemophilia Clinic Directors of Canada

CBDR Committee Report.

2018-19

Alfonso Iorio





The Committee

Chairman: Dr. Alfonso Iorio

Members:

Dr. Jayson Stoffman
Dr. Margaret Warner
Dr. Irwin Walker
Dr. MacGregor Steele
Dr. Jean St Louis
Dr. Anthony Chan
Dr. Jerry Teitel
Dr. Alan Tinmouth
Dr. Margaret Rand

Ex-officio member: Dr. Arun Keepanasseril (Project Manager)

Report

This report summarizes the key activities of CBDR committee of AHCDC since the last AHCDC AGM at Quebec city. This report has been created by summarizing content directly from the minutes of the Committee meetings. The minutes in their entirety are available in original via the AHCDC secretariat.

Activities in the past year have been very intense and productive for the committee. Most notably, CBDR implementation was completed in all non-BC HTC's. Data reconciliation between CHR, RIBDR and CBDR registries have been successfully completed. Secure pathway has been provided to BC centers to obtain registry numbers as well as report adverse events anonymously. As far as the system itself is concerned, a major release (CBDR 3.11) and a smaller release (CBDR 3.12) are ready to be implemented as a twin release encompassing notably a revamp of inhibitor recording as well as improvements to the dashboards. Lot number feed from CBS has been operationalized; a similar feed from Hema Quebec is undergoing testing. A pilot project to test the feasibility of using product order forms directly generated from CBDR is underway at select centers. The system is also ready to allow centralized genetic test result reporting from Kingston – SOP and training to this objective has been completed.

With implementation declared complete, great deal of emphasis is currently expended on data cleaning initiatives and producing summary reports for centers and third parties. For the first time, national reporting to WFH Annual Global Survey was accomplished from CBDR data. Data from BC was sourced through a preliminary process for obtaining categorized aggregate data and amalgamated with rest of the national data from CBDR. A formal Data Transfer Agreement with BC is under process.

CBDR-C continued to work closely with the Stakeholder Advisory Group (SAG) led by CANHC nominee Kay Decker in providing user level feedback. The group meets monthly and also serve as the first point of deliberations for feature requests from users.

We believe we have been able to create an impactful dedicated information system for the Canadian hemophilia community. However, our work is far from over. We plan to dedicate our greatest efforts on improving data quality, creating effective reporting as well as leverage the data accumulated in the system both for clinical and research purposes along with continuing to improve the system interface for usability.

Alfonso Iorio

Hamilton, May 13 , 2019