



AHCDC History Project – Update for AGM (May 24th, 2014)

Drs. Robert Card and Man-Chiu Poon

Drs. Card and Poon have continued to work on the history on the development of hemophilia (bleeding disorder) care in Canada, especially as related to the development of clinics and the eventual evolution of the Association of Hemophilia Clinic Directors of Canada (AHCDC). The project has been funded to date by the AHCDC, with the majority of the funds being used for various interviews

The plan is to present our interim status, with emphasis on the history of AHCDC, to the AGM so we will report in more detail with that presentation.

The major thrust in the first two years of the project has been to undertake interviews of key players, visiting, where possible, various Hemophilia Clinic centers. Thus this is becoming an oral history. In order to minimize travel costs we have attempted to combine these visits with other meetings. To do otherwise would be prohibitively expensive. The downside is that it will take time to finish this portion of the project. We have visited the majority of centers but there are several left that should be visited, and we may wish to return to several of the centers to meet with those who were unavailable on the initial visit. To date we have interviewed 43 Physicians, 14 Nurses, 4 Other Health Care Professionals, 5 Patients (including 3 who were cared for in the 1950s and earlier) and 4 Family Members.

We have developed a series of milestones from our interviewees. We also have attempted to relate these to the chronology of each center and the role of AHCDC (and its predecessors) in the evolution of care over the years. The overall picture will give us an important insight into how care developed and most importantly, provide material for future researchers and guidance for other jurisdictions who are trying to set up hemophilia care, as well as to ensure our younger colleagues are aware of the past. We have made three formal presentations, and by the time of the AGM will have had a poster presentation at WFH. The objective of this latter presentation is to show how AHCDC has evolved and enhanced care. This will assist other countries in looking at models that might work in their area. See List of Presentations at end of this document. The first two years of support from AHCDC has now ended and we need to look forward as to where this project goes from here and what support will be needed. There has been a great deal of information gathered already, and portions will be of interest to various audiences.

Some proposals for future direction follow (a related request is being submitted to AHCDC for budget consideration):

- There is a need to review archives, journals from the past, clippings, etc. to confirm issues that have been brought forward from interviewees' memories. A proper history publication needs verification of dates and names. This will take time, either by the authors, or by hiring researchers
- We need to transcribe the interviews themselves to make a written record available to researchers and those interested in the history of hemophilia care in the future. Much of this will allow them to build on the successes (and for that matter, failures) of the past

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- There are several sites that we still need to visit, which include Ottawa and St. John. In addition, there may be value in visiting sites that were done by phone only (St. John's and Quebec City) and to revisit several of the major sites as more questions have arisen as time progresses. As part of these and other visits we need to speak to a number of key RNs across the country
- We have found that patients' recollections are especially invaluable, so would like to add a number of patient interviews, with insight into the past and the evolution of clinics. Indeed, a number of patients have already approached us, asking to be interviewed
- Finally, we realize that it would be of great value in having a video record of some of the key players who we have interviewed. Again this would be of great value for future generations. This might be achieved by having one or two central sites and have the interviewees come for their video taping

In relation to presentations, publications:

- We are prepared to make presentations to any group that wants us to come – these would be tailored to local issues and history
- Portions of the data to date will be suitable for publication(s) in various journals
- We will continue to consider presentations to:
 - Hemophilia meetings
 - History of Medicine meetings
- In the long run, the authors propose that a formal book be developed. Such a book is not an easy task, and as before, requires that all dates, etc. be confirmed. This is a long range prospect for the project, but not in the immediate future – looking at experience of others who have developed such a book (Pemberton's interviews were over 10 years before publication – we won't take so long)

List of Presentations to May 24th, 2014

(Note: copies of these will be kept at AHCDC offices for future reference)

Hemophilia Care in Canada. An Oral History: A Work in Progress. *Presented to the Canadian Hemophilia Society Annual Meeting, Winnipeg, May 25th, 2013*

History of Comprehensive Hemophilia Care in Canada. A Tribute to the St. Michael's Hospital Program on its 30th Anniversary. *Presented at St. Michael's Hospital, Toronto, September 23rd, 2013*

History of Comprehensive Hemophilia Care in Canada. "Triumphs and Tragedies". *Presented to the Calgary History of Medicine Society, Calgary, February 24th, 2014*

Development of the Hemophilia Clinic Directors Group in Canada. An Oral History. *Poster Presentation at World Federation of Hemophilia, Melbourne, May 11th, 2014*