

# Development of the Association of Hemophilia Clinic Directors of Canada (AHCDC): 20 years - an Oral History

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## BACKGROUND/RATIONALE

- A historical record of hemophilia care is meaningful for future generations of physicians, nurses and patients
- We have undertaken such an oral history related to care in Canada
- Our oral history has included interviews of personalities involved in hemophilia care from the 1950s to the present
- As part of this we have documented how advisory bodies evolved and specifically how and why the AHCDC came into being. We wished to look at the role the AHCDC has had in collaboration with the Canadian Hemophilia Society (CHS) in promoting optimum care for Canadians with bleeding disorders

## METHODS AND RESULTS I (Time Lines pre AHCDC)

So far we have interviewed over 70 personalities (patients, family members, MDs, RNs, other health care professionals) at 16 Comprehensive Care Programs. Review of archives and literature is underway to supplement the interviews. A number of our interviewees were hemophiliacs or physicians involved in hemophilia care prior to 1960. This poster represents one portion of our project, specifically documenting the evolution of the advisory bodies over the years, especially development and potential successes of the AHCDC, and the complementary relationship with advisory bodies such as the CHS

### Time Line (1950s to early 60s)

- 1952.** First formal concentration of care: **Dr. Cecil Harris** – St. Mary's Hospital, Montreal, had room 7, with 6 beds, often fully occupied by hemophiliacs 24/7
- 1964.** First production and use of cryoprecipitate in Canada may have been by **Dr. Alvin Zipursky**, Winnipeg, who recalled doing as soon as he saw the original Pool paper – he was Red Cross Director, Lab Director and managed the patients (had Clinic since **1958**). Able to set up very quickly donor to patient
- 1965.** Several quotes from MDs who were present when cryo introduced: *"Treating hemophilia became a piece of cake"* (Dr. Peter Galbraith); *"The world of hemophilia has changed forever"* (Dr. Alvin Zipursky)

### Time Line (Advisory Bodies – 70s/early 80s)

Early to late 1960s – Meetings of hematologists to look at optimum care, the minutes and records of these meetings have not surfaced to date. We continue to look for help in locating these.

#### **Advisory Committees under aegis of CHS:**

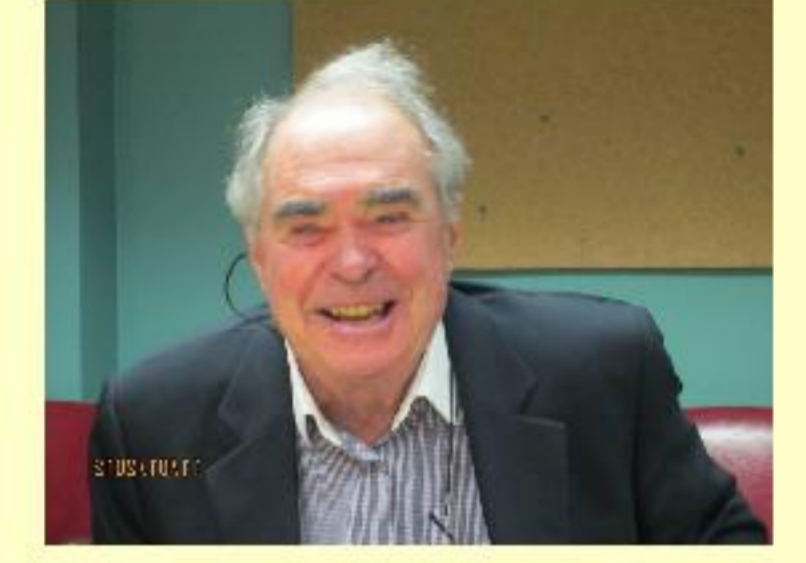
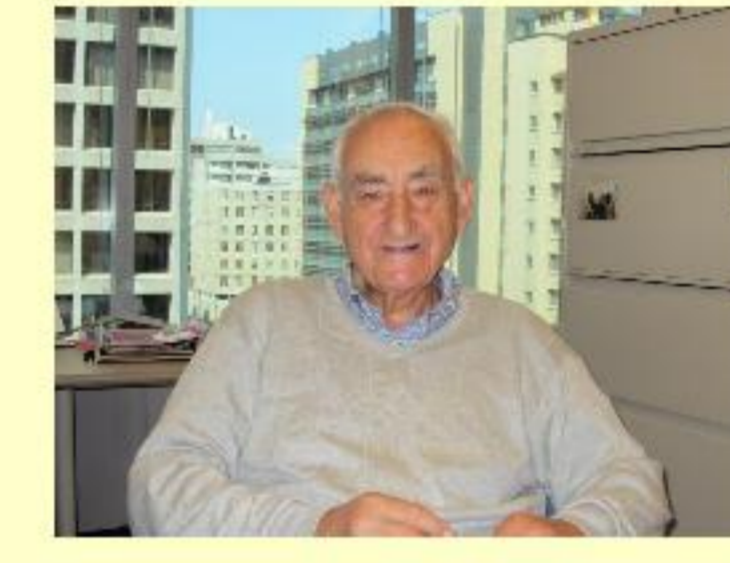
- Professional Advisory Committee (**PAC**), 1972 (*reported to CHS*), became:
- Medical and Scientific Advisory Committee - **MSAC (Dr. Martin Inwood)**, 1977 or 1978 modeled after NHF MASAC. One MD from each province to reflect pattern of health care funding in Canada. One representative from various other bodies – e.g. RN, PT, CHS, etc. (*reported to CHS*).

#### **Formation of Clinic Directors Group Separate from MSAC**

The early 80s were full of turmoil, reported to us by all those who were there. It was felt that the MSAC format (one MD/province) and reporting through CHS had inherent difficulties. The priorities and needs of the Clinic Directors and the CHS, were not always the same – even though ultimate objectives (patient care outcomes) were identical.

**1987** – Discussion to form group separate from MSAC (Dr. Robert Card, MSAC chair at the time).

**1988** – Canadian Hemophilia Clinic Directors Group (CHCDC) formed – Irwin Walker first Chair, Victor Blanchette first *elected* Chair. Formal group *without funding or budget*. Canadian Hemophilia Registry (CHR) initiated (Irwin Walker).



## RESULTS II (Formation of AHCDC)

**1991-92** – Brainstorming meetings, concept of funded AHCDC developed. Canadian Blood Agency, Canadian Medical Protective (CMPA) advice, initially funded from Canadian Red Cross Blood Transfusion Service – later from Canadian Blood Services/HemaQuebec and industry. CHARMS database – developed.

**June 27, 1994** Formal incorporation, Victor Blanchette, first president, Jerry Teitel, first *elected* president (continues to serve as Executive Vice president).

**Major Program Achievements:** Cohesive, inclusive body of all Programs, CHR and CHARMS. Support for research protocols and educational programs. Working relationships with other health care professional groups. Significant synergy with CHS and joint advocacy programs for enhanced support of clinics. Works better than each group going alone. Support for trainees since 2000, with up to five trainees supported to annual meeting, has been very successful in introducing trainees to hemostasis and encouraging academic hematologic careers. The first group (shown) all went on to successful careers as have subsequent trainees. Note that the CHS MSAC itself in different format has remained to this date, modified to meet the priorities of the CHS.



## CONCLUSIONS

- Oral recording of history is a valuable way to learn about the lessons of the past and prepare for the future
- AHCDC has become a successful body, allowing for frequent dialogue and consultations across a country with widespread population
- 20th anniversary to come on June 27th, 2014 – has remained stable and continues to progress
- *"Research activities have been state of the art, recognized internationally"* (quote from Dr. Alfonso Iorio)
- Working with CHS major strides in advocacy for optimum programs and patient care
- CHR Registry and CHARMS (Canadian Hemophilia Assessment and Resource Management System) Database largely inclusive and give complete national picture of bleeding disorder care in Canada
- This model could work very well in other jurisdictions
- Indeed, many of AHCDC programs and members have been involved in various international twinning projects

## REFERENCES/THANKS:

Disclosure: Funding for the interview process has come from the AHCDC  
Thanks to all our interviewees for being so approachable  
*"Those who do not remember the past are condemned to repeat it"*  
-George Santaya

