

# Canadian Hemophilia Registry

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# Utility of Hemophilia Registries

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- Canadian Hemophilia Registry (CHR) <sup>1</sup>
- Austrian Hemophilia Registry <sup>2</sup>

*Walker IR. Survey of the Canadian hemophilia population.*

*Can J Public Health (1991) 82:127-9*

*Reitter et al. Austrian Hemophilia Registry: design, development and set of variables*

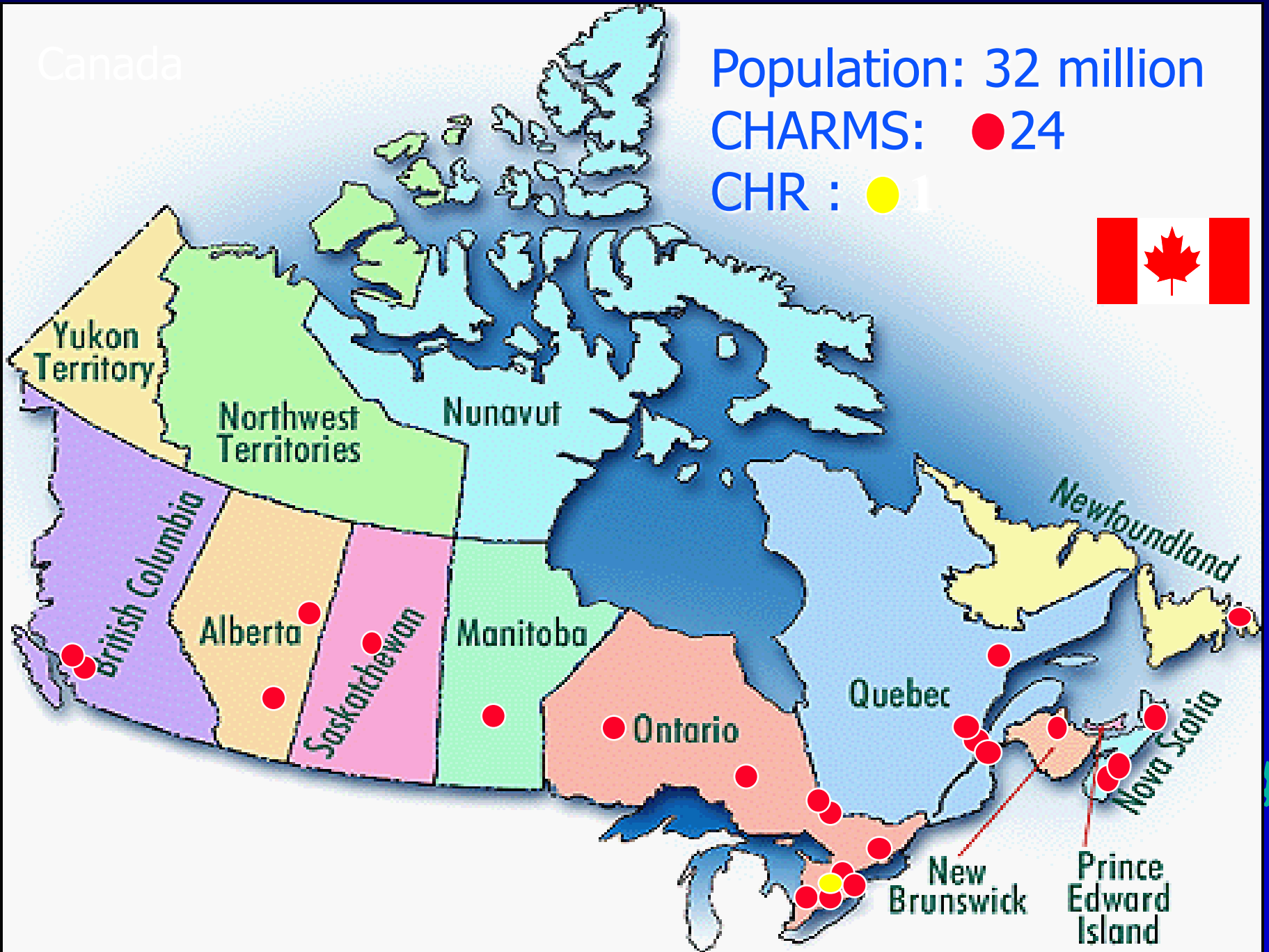
*Wien Klin Wochenschr (2009) 121: 196–201*

Canada

Population: 32 million

CHARMS: ● 24

CHR : ● 1



# What is CHR?

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- An anonymous registry of Canadians with inherited bleeding disorders
- Owned and operated by AHCDC
- Request of Proposal
- Decision made by a committee

# Funding

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- 1 time funding for creation of the registry
- Goodwill by many for many years to provide information
- Free for many years – Dr Irwin Walker
- \$8000. in 2009 for data entry

# What are its purposes?

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- To document the number and basic characteristics of individuals with hereditary bleeding disorders
- To provide CHR numbers, a method of maintaining the anonymity of individuals and the confidentiality of their health information
- To promote research

# History

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- 1987 - How many individuals are there with hemophilia
  - Principles: Must be anonymous, must be comprehensive
  - Data: Clinic, diagnosis, severity, dob, exid, sex.
- 1990 – Recognition of needs for updating and status designation
- 1992 – What is the extent of HIV and HCV infection
  - Data: HIV and HCV status
- 1993 – What are the causes of death
- 2001 – Addition of VWD registry
- 2002 – Incorporation of RIBDR (Rare Inherited Bleeding Disorders Registry)

# How does it work?

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## **CLINICS.....**

- Send anonymous data manually to CHR
- Maintain the accuracy of their data

## **CHR.....**

- Returns individual “CHR numbers”
- Tracks individuals, avoids duplication
- Returns individual clinic lists
- Posts collated data on the AHCDC website
- Responds to requests for information
- Reports findings at international forums and in journals

# 1988 - How many Canadians have hemophilia?

## Canadian Hemophilia Registry

### Clinics (24)

Various  
Data Methods  
- Manual or  
Computer

Paper-fax/email

Clinic Lists

National Data

CHR #'s

Clinic  
Province  
(Clinic code)  
Date of Birth  
Factor Deficiency  
Severity/Type  
Extra Identifier  
Sex  
Status (Alive/Lost etc.)

HIV (1990)  
HCV (1992)

# How do you define identity?

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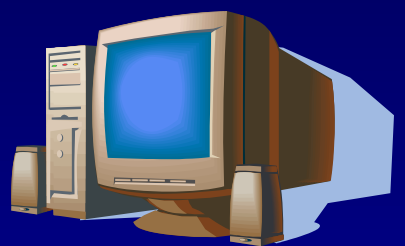
## DEFINITIVE

- DNA
- Fingerprints
- Iris patterns
- Biometrics
- Social Insurance Number
- Passport Number
- Health Insurance Number
- Name & date of birth (dob)

## ANONYMOUS PROXY ID

- Diagnosis
- Date of birth
- EXID (Anthony Chan = NYAN)
- (Sex)
- (Status)

Clinics → Data by email or fax



# McMaster University Medical Centre

University

Hospital

Data Summaries (.pdf)

anyone

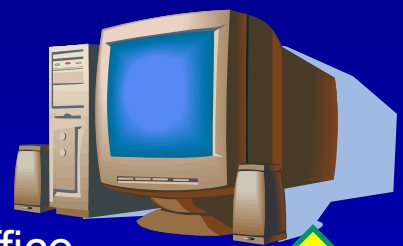
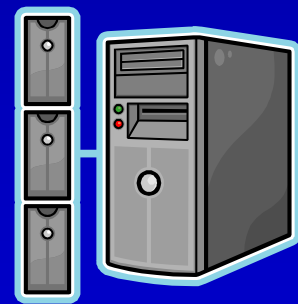
Irwin's office

Link

AHCDC  
www.ahcdc.ca

University Server for Website  
www.fhs.mcmaster.ca/chr

Hospital Server for data



# Governance

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- Committee within AHCDC
- Ethics approval at McMaster University
- Any member of AHCDC can make recommendation of changes/ enhancement
- Approval by members of AHCDC

# www.ahcdc.ca

Association of Hemophilia Clinic Directors of Canada (AHCDC)  
*L'Association Canadiennes des Directeurs des Cliniques d'Hémophilie*

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Welcome to the homepage of the Association of Hemophilia Clinic Directors of Canada(AHCDC).

The Association is an organization of Hemophilia Clinic Directors from across Canada, incorporated under the laws of the Province of Ontario in 1994. We share a common interest in improving the treatment of people with hemophilia. The association meets once a year, often in conjunction with the Canadian Hemophilia Society (CHS).

**Mission Statement**

# www.ahcdc.ca

Association of Hemophilia Clinic Directors of Canada (AHCDC)  
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# Canadian Hemophilia Registry & Rare Inherited Bleeding Disorders Registry



MEMBER OF THE ASSOCIATION OF HEMOPHILIA CLINIC DIRECTORS OF CANADA

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DATA SUMMARIES

OPERATING GUIDELINES

PUBLICATIONS

HISTORY

CONTACT US

LINKS

WELCOME

A registry of individuals with hereditary bleeding disorders, owned and operated by the Association of Hemophilia Clinic Directors of Canada (AHDCDC). The CHR exists to promote research, educational and administrative initiatives of the AHDCDC, which in turn welcomes the use of its data by all other organizations or individuals.

Data Summaries are available for viewing, or for downloading in "portable document file" format (PDF). Last Updated April 27, 2007.

Additional summaries can be made available on request to the director of the registry\* provided that requests are consistent with the Operating Guidelines.

DOWNLOAD FORMS



VISITORS SINCE  
JUNE 2003:

sitemeter   
3,214

\*Dr. Irwin Walker: [walkeri@mcmaster.ca](mailto:walkeri@mcmaster.ca)

Site Design by: [Biro Creative](#)

## INDIVIDUALS WITH FACTOR VIII DEFICIENCY

1. [CHRVIII080417](#) (PDF April 27, 2008)

'Hemophilia A' grouped by:

- A. Severity (Severe  $\leq 1\%$ , Moderate = 1-5%, Mild  $\geq 5\%$ ); and
- B. Age, according to Statistics Canada age groups; and
- C. Gender (females can be registered if factor levels are  $\leq 40\%$ ).

2. [CHRVIII080417b](#) (PDF April 17, 2008)

Same as 1, but age grouped according to pediatric (<18 years) & adult ( $\geq 18$  years).



## INDIVIDUALS WITH FACTOR IX DEFICIENCY

3. [CHRIX080417](#) (PDF April 17, 2008)

'Hemophilia B' grouped as for those with factor VIII deficiency.

4. [CHRIX080417b](#) (PDF April 17, 2008)

Same as 3, but age grouped according to pediatric (<18 years) & adult ( $\geq 18$  years).

## INDIVIDUALS WITH VON WILLEBRAND FACTOR DEFICIENCY

**CANADIAN HEMOPHILIA REGISTRY**  
**Factor VIII Deficiency (Hemophilia A), May 8, 2005**  
**STATS CANADA - AGE GROUPS**

Report Date: Saturday, May 07, 2005

Selection	Prov: *	Inhib.: *	HIV: *	HCV: *	Gender: *	PtStatus: <b>Active or Pending</b>	Level: *
	Centre: <b>All Centers</b>						

Category	Gender	Count	(0-4)	(5-9)	(10-14)	(15-24)	(25-34)	(35-44)	(45-54)	(55-64)	(65-74)	(75-84)	(85+)	
<b>Factor VIII</b>														
FVIII severe	F	1	1	0	0	0	0	0	0	0	0	0	0	
	M	585	69	62	71	139	99	77	46	18	3	1	0	
		<i>subtotal :</i>	<b>586</b>	<b>70</b>	<b>62</b>	<b>71</b>	<b>139</b>	<b>99</b>	<b>77</b>	<b>46</b>	<b>18</b>	<b>3</b>	<b>1</b>	<b>0</b>
FVIII severe Inhib	M	69	9	16	9	6	4	10	6	8	1	0	0	
			<i>subtotal :</i>	<b>69</b>	<b>9</b>	<b>16</b>	<b>9</b>	<b>6</b>	<b>4</b>	<b>10</b>	<b>6</b>	<b>8</b>	<b>1</b>	<b>0</b>
FVIII mod	F	2	0	1	0	0	1	0	0	0	0	0	0	
	M	251	16	25	30	57	29	36	32	13	9	1	3	
		<i>subtotal :</i>	<b>253</b>	<b>16</b>	<b>26</b>	<b>30</b>	<b>57</b>	<b>30</b>	<b>36</b>	<b>32</b>	<b>13</b>	<b>9</b>	<b>1</b>	<b>3</b>
FVIII mod Inhib	M	6	1	1	0	1	0	1	1	1	0	0	0	
			<i>subtotal :</i>	<b>6</b>	<b>1</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>1</b>	<b>1</b>	<b>1</b>	<b>0</b>	<b>0</b>
FVIII mild	F	120	2	11	6	21	20	30	20	8	0	1	1	
	M	1249	36	74	114	228	194	181	176	123	68	41	14	
		<i>subtotal :</i>	<b>1369</b>	<b>38</b>	<b>85</b>	<b>120</b>	<b>249</b>	<b>214</b>	<b>211</b>	<b>196</b>	<b>131</b>	<b>68</b>	<b>42</b>	<b>15</b>
FVIII mild Inhib	M	5	0	0	0	2	1	2	0	0	0	0	0	
			<i>subtotal :</i>	<b>5</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>
FVIII unknown	M	3	2	0	0	0	0	1	0	0	0	0	0	
			<i>subtotal :</i>	<b>3</b>	<b>2</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>
		<i>total :</i>	<b>2291</b>	<b>136</b>	<b>190</b>	<b>230</b>	<b>454</b>	<b>348</b>	<b>338</b>	<b>281</b>	<b>171</b>	<b>81</b>	<b>44</b>	<b>18</b>
<b>Report Total</b>			<b>2291</b>	<b>136</b>	<b>190</b>	<b>230</b>	<b>454</b>	<b>348</b>	<b>338</b>	<b>281</b>	<b>171</b>	<b>81</b>	<b>44</b>	<b>18</b>

\*\* Statistical archives are also available for:  
2003, 2004, 2005, 2006 and 2007.



Click

# Annual Trends, Severe Cases

	SevereVIII	SevereIX	SevereVIII(0-4)
2003	615	137	54
2004	641	138	82
2005	655	140	79
2006	663	139	70
2007	697	145	65
2008	718	150	60

What can be done with a  
Registry

# HIV and HCV

- HIV infected 652 individuals, 31% of total, 82% of regularly treated individuals,
- HCV infected 1174 individuals, 63% of population tested, 90% of regularly treated individuals
- Blood products safe from HIV – 1985; HCV - 1988

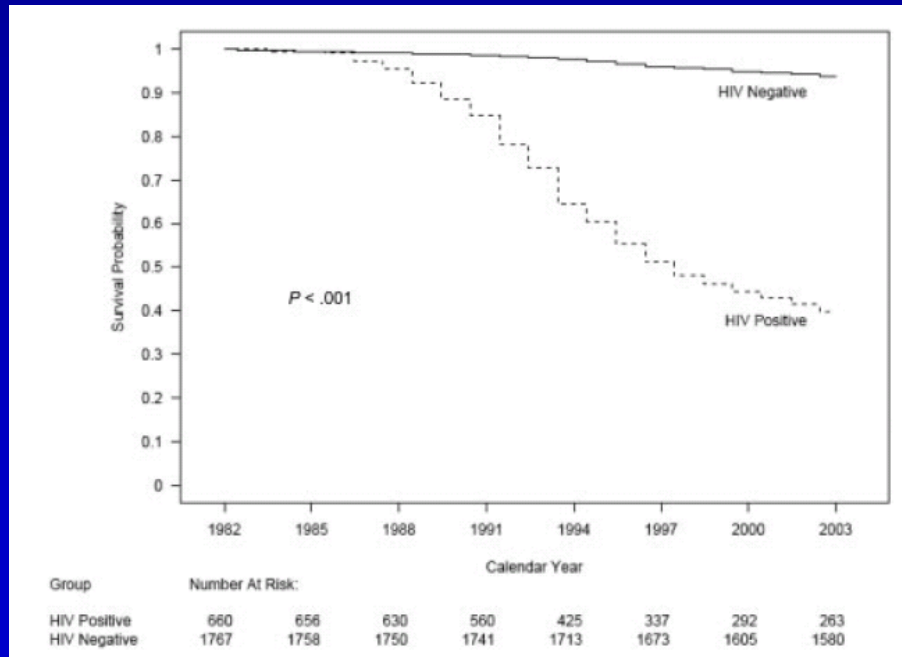
Decade birth	HIV			Unknown	Totals
	Neg	Pos	%Pos		
pre 26	65	10	13	35	110
26-35	89	17	16	24	130
36-45	148	56	27	30	234
46-55	241	126	34	64	431
56-65	314	213	40	85	612
66-75	322	173	35	61	556
76-85	472	67	12	62	601
86-95	497	1	0	100	598
96-05	271		0	146	417
Totals	2419	663	22	607	3689

Decade birth	HCV			Unknown	Totals
	Neg	Pos	% Pos		
pre 26	30	15	33	65	110
26-35	41	44	52	45	130
36-45	65	94	59	75	234
46-55	84	206	71	141	431
56-65	116	329	74	167	612
66-75	129	282	69	145	556
76-85	304	191	39	106	601
86-95	437	13	3	148	598
96-05	253		0	164	417
Totals	1459	1174	45	1056	3689

1. Walker I et. al. BMJ 1993;306:306
2. Blanchette et. al. Trans Med Rev 1994;8:210
3. Canadian Hemophilia Registry <[www.ahcdc.ca](http://www.ahcdc.ca)>

# HIV Infected

Alive	224	33.4%
Deceased	442	
Lost to Follow Up	5	



Arnold D, Julian J, Walker I et.al.  
Blood 2006;108:460

# Achievements

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- Research, direct and indirect
- Provision of CHR numbers
- Compensation, assistance programs
- WFH
- Credibility

# Why does it work?

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- Objectives (specific, useful, clear)
- Simplicity
- Feedback (research, access)
- Relationships
- Staff
- Pay
- Compatible culture (research, confidentiality)
- Validation
- Secure and confidential
- Performance

# What are the challenges?

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- Maintaining identities in an anonymous system.
  - Avoiding duplication.
- Maintaining accurate status of patients.
  - Those with mild disorders may seldom attend clinic.
  - Clinic may not be advised when patients move or die.
  - Requires pro-active program of review.

# Thank You

