

Comprehensive Care for Rare Blood Disorders

A Decade of Progress (!?)

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The cost of clotting factor concentrates for the care of people with bleeding disorders in Canada

Your guess for 2013-14?



The cost of clotting factor concentrates for
the care of people with bleeding disorders in
Canada

\$250,000,000*

* 2013-14 distribution data and prices from CBS and Héma-Québec





The annual cost of all other aspects of care
for people with bleeding disorders in Canada

Your guess for 2013-14?



The annual cost of all other aspects of care
for people with bleeding disorders in Canada

\$20,000,000*

*5-year data from St. Paul's Hospital, Vancouver: Master's Thesis of
Tomas Silva



Clotting factor concentrates:
\$250,000,000 or
93% of the total
cost of care

All other aspects of
care (salaries,
diagnostics,
admissions, capital
costs, clinical
support, etc.):
\$20,000,000 or
7% of the total cost
of care



The silo effect



Those who allocate the 7% for care delivery do not pay, and have no idea of, and do not care about, the cost of the therapeutic products, paid by provincial budgets

Those who manage the 93% have no role in allocating resources to care delivery



What about the cost of all plasma-derived products (and recombinant alternatives) for rare disorders?

	2015-16	2016-17	
CBS	\$623,198,000	\$678,368,000	+9%
Héma-Québec	\$239,118,000	\$264,735,000	+10%
Total	\$862,316,000	\$943,103,000	+9%

Data from 2016-17 CBS and Héma-Québec Annual Reports

What are the high-cost products supplied by CBS?

	2015-16	2016-17	+/-
Immune globulins	\$280,000,000	\$320,000,000	+14%
Factor concentrates	\$260,000,000	\$245,000,000	-6%
C1 esterase inhibitor	\$40,000,000	\$60,000,000	+50%
Albumin	\$20,000,000	\$20,000,000	0%
	\$600,000,000	\$645,000,000	+8%

Data estimated from 2016-17 CBS Annual Report



It is penny-wise to limit resources for care delivery when ...



... the system is being pound-foolish in not optimizing utilization of blood products

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1. Just keep doing what we're doing now
2. Decentralize provincial budgets for blood products to hospitals (so both budgets are in the same silo)
This would be disastrous for patients!
3. Invest in comprehensive care for bleeding disorders, HAE and PID so that products are used for optimal benefits without overuse
This makes sense! (cents? dollar-wise?)

More than 80% of clotting factor concentrates are infused in the home. This is the **standard of care** for most patients with hemophilia. Home therapy programs are increasing in PID and HAE.

How does one optimize product utilization when most of the products are being infused outside of direct medical supervision?

The only way to optimize utilization of blood products is through expert prescription, monitoring and long-term follow-up through well-resourced comprehensive care centres.

How is comprehensive care defined*?

1. Provincial designation
2. *National registry*
3. *Home administration*
4. Patient association involvement in care
5. Formal education program
6. *Standards of care*
7. Decentralization via outreach

* Principles adopted at the 2006 Conference on Comprehensive Care for Rare Blood Disorders

How is comprehensive care defined?

8. *Inter-disciplinary care*

9. *Defined core services*

10. Program accreditation

11. *National collaboration among HCPs*

12. Post-marketing surveillance

13. Collaborative national research

14. Flexibility in organization

	Bleeding disorders	Hereditary angioedema	Primary immune deficiency	Sickle cell disease	Thalassemia	Porphyria
Provincial designation	4 provinces	X	X	X	X	X
<i>National registry</i>	✓	X	Under construction	X	X	X
<i>Home administration</i>	✓	✓	8 provinces	NA	NA	X
Patient association involvement in care	✓	X✓	X	X	X	X
Formal education program	✓	X	X	X	X	X
<i>Standards of care</i>	✓ (outdated)	X	X	X	X	X
Decentralization via outreach	✓	X	X	X	X	X

	Bleeding disorders	Hereditary angioedema	Primary immune deficiency	Sickle cell disease	Thalassemia	Porphyria
<i>Inter-disciplinary care</i>	✓ (in most centres)	X	4 cities	2 cities	2 cities	Edmonton
<i>Defined core services</i>	✓ (under resourced)	X	4 cities	2 cities	2 cities	X
Program accreditation	X	X	X	X	X	X
<i>National collaboration among HCPs</i>	✓	X	Limited	Limited	Limited	X
Post-marketing surveillance	✓	X	X	X	X	X
Collaborative national research	✓	X	X	X	X	X
Flexibility in organization	✓	✓X	X	X	NA	X

The big question, however, is:

What evidence is there that comprehensive (integrated) care in the context of rare disorders actually leads to better outcomes?

Without evidence, progress will stall.

The purpose of this conference is to start to provide that evidence.