



Saskatchewan Bleeding Disorders Program

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NRBDO COMPREHENSIVE CARE CONFERENCE

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Objectives

- ▶ To describe the Saskatchewan Bleeding Disorders Program
- ▶ To describe how the program was formed
- ▶ To discuss the program's successes and challenges

Saskatchewan

- ▶ Province - 1.1 million people
 - ▶ Saskatoon – 295 000
 - ▶ Regina – 236 000
 - ▶ Prince Albert – 36 000



Saskatoon, Saskatchewan



Our Patients

Diagnosis	% of Patients (318)
Von Willebrand	41%
Hemophilia A	29%
Platelet Disorders	10%
Hemophilia B	9%
Other	11%

Gender	% of Patients
Male	45%
Female	55%

29 have severe hemophilia (9%)

Who We Are

Clinical Staff:

- ▶ Medical
 - ▶ 2 adult hematologists
 - ▶ 2 pediatric hematologists
- ▶ Nursing
 - ▶ 3 RNs, total of 2.4 FTE
- ▶ Physiotherapy
 - ▶ 1 PT, 0.5 FTE
- ▶ Social work
 - ▶ 1 SW, 0.6 FTE

Closely Associated:

- ▶ Genetics counsellor
- ▶ Obstetrician/gynecologist
- ▶ Dentist
- ▶ Pain consultant

Administrative :

- ▶ Facilitator
- ▶ Manager
- ▶ Office administrative staff
 - ▶ 2 admins, 1.8 FTE
- ▶ Data entry
 - ▶ 1 clerk, 0.1 FTE

Other Resources

- ▶ Ambulatory Care Space (Saskatoon, Regina, Prince Albert)
- ▶ Treatment Room
- ▶ Conference Room
- ▶ Point-of-Care Ultrasound Machine
- ▶ Access to outpatient physiotherapy space
- ▶ Specialized Coagulation Testing
- ▶ Reimbursed Parking
- ▶ Access to emergency funding (gasoline cards, one-time tranexamic acid coverage)
- ▶ After hours/weekend nurse on-call service

How did we get here?

- ▶ 1999
 - ▶ Proposal was submitted to the Ministry of Health
 - ▶ Strong advocacy by Hemophilia Saskatchewan
- ▶ 2000
 - ▶ Proposal accepted and direct provincial funding was officially legislated
 - ▶ Communication plan to announce the new program, begin accepting referrals
- ▶ 2001
 - ▶ First clinic

Initial Feedback

- ▶ Mostly excellent, but some room for improvement
 - ▶ Identified hemophilia patients as the targeted audience, but left out other bleeding disorders
 - ▶ Nursing was not always available
 - ▶ Completing and submitting treatment logs was a burden

What happened next?

- ▶ Annual Planning Day
 - ▶ Key stakeholders meet off-site
 - ▶ Review of program activities, outcomes, and long term goals
 - ▶ Problem-solving and planning

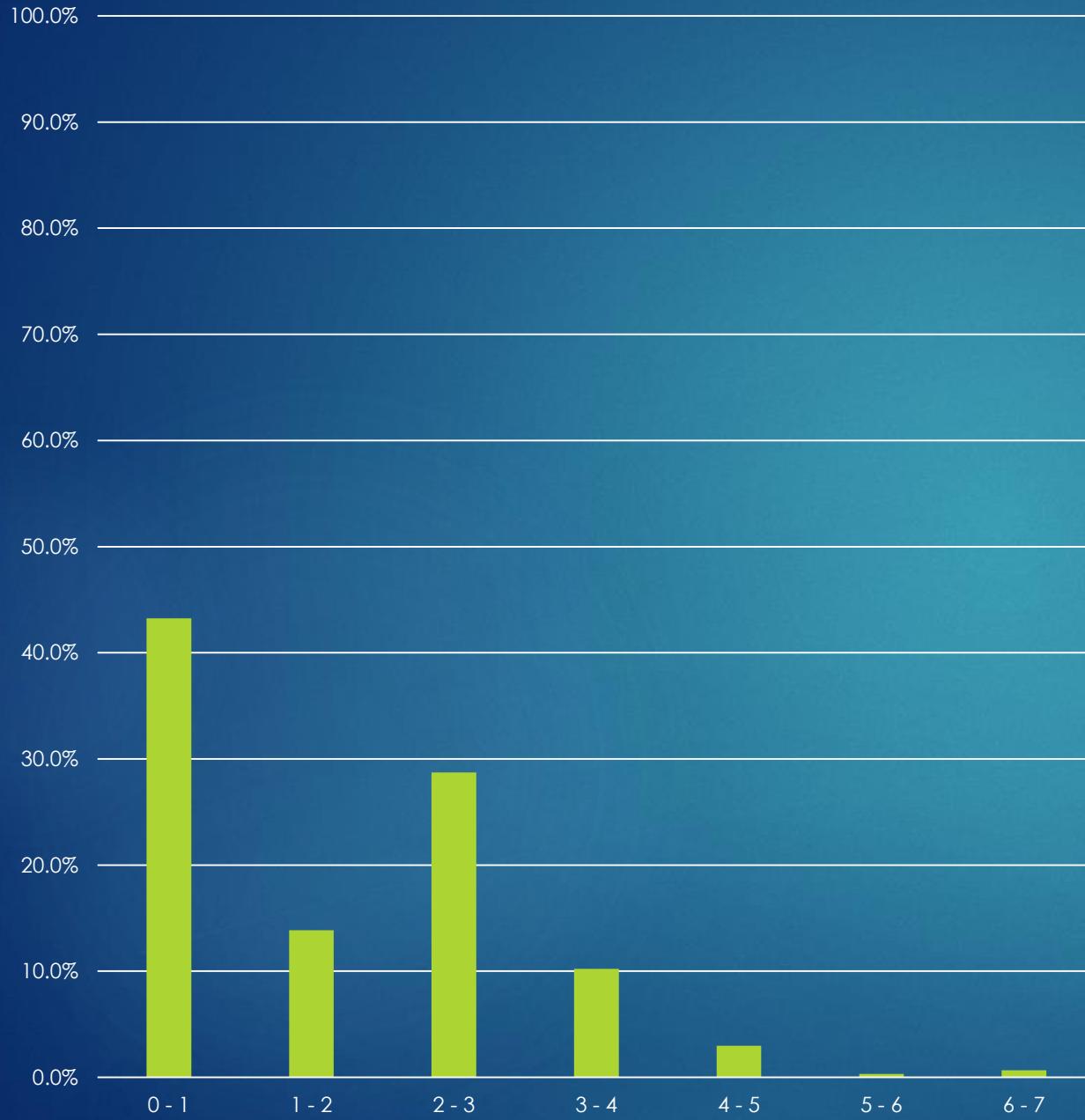
What Keeps Us Excited?

Planning Day

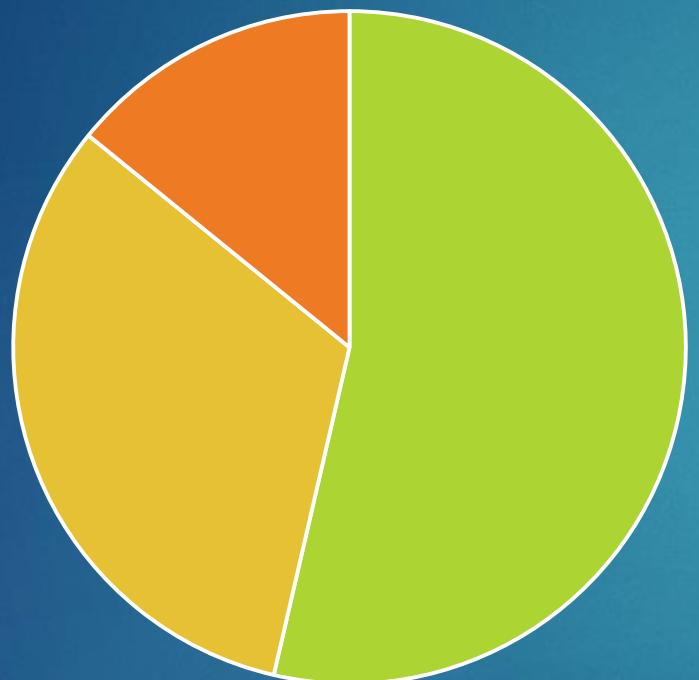
Planning Day Example

- ▶ Clinic Location

Driving Time to Saskatoon (Hours)



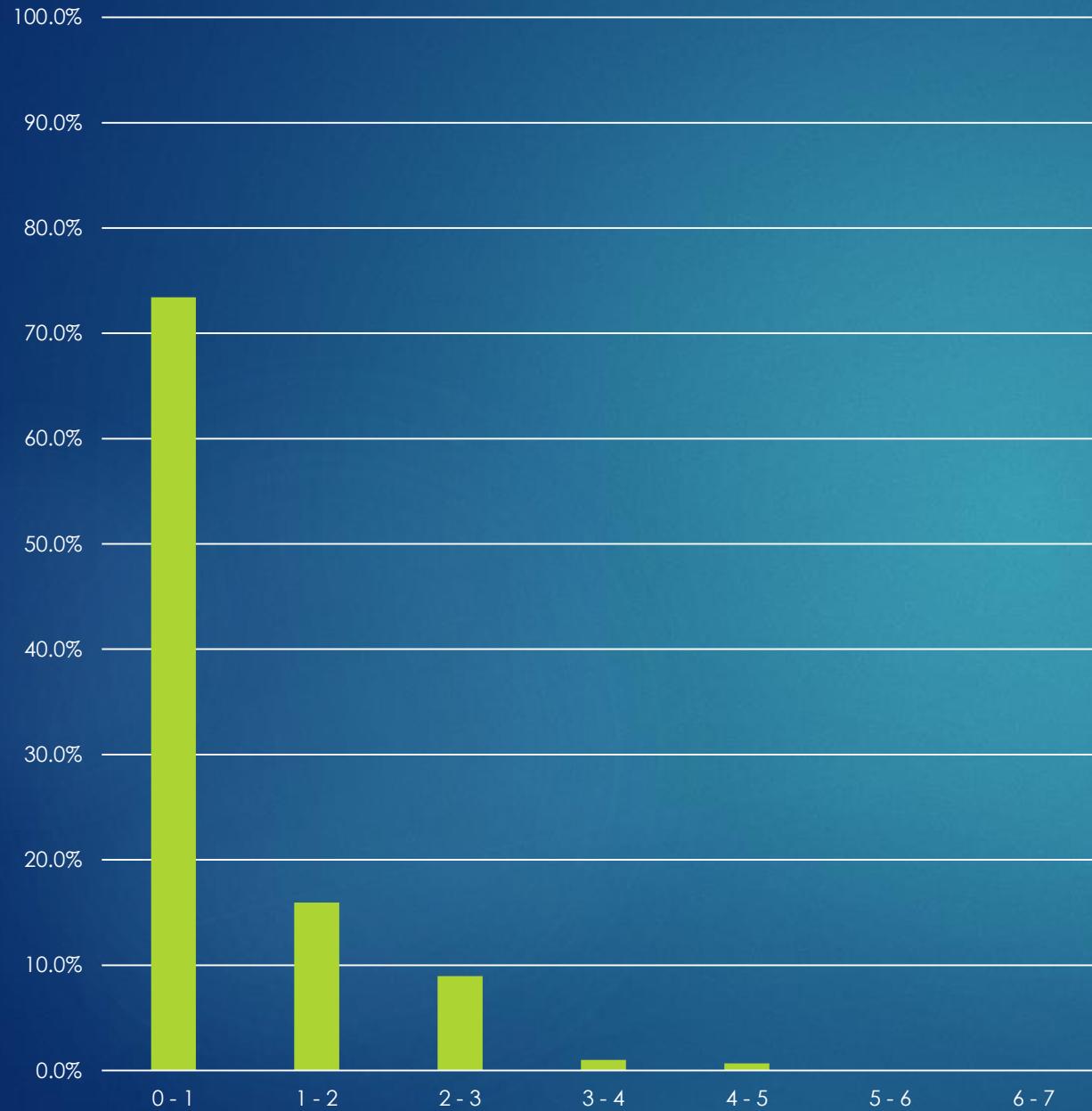
Closest Clinic Location (Percentage of Patients)



■ Saskatoon ■ Regina ■ Prince Albert



Driving Time to Closest Clinic (Hours)



Planning Day Examples

- ▶ Additional Clinic Location
- ▶ Women with Bleeding Disorders Clinics
- ▶ Nurse on-call
- ▶ Hiring of second pediatric hematologist
- ▶ Emergency room alerts
- ▶ Pain focus/support groups
- ▶ Pain questionnaire
- ▶ Improving needle phobia
- ▶ Pharmacokinetic testing

How do we avoid isolation?

- ▶ Participation in the national bleeding disorder networks
- ▶ Regular consultation in person and online
- ▶ Participation in national research studies

Why an Integrated Care Model?

- ▶ Better outcomes? Hard to obtain solid data, but we DO make a difference:
 - ▶ **We educate** - “My ENT surgeon told me it’s impossible to for a bleeding disorders patient to have surgery”
 - ▶ **We advocate** - A hemophilia patient in his 70s just had bypass surgery, a Saskatchewan first. This would not have happened without a team approach.
 - ▶ **We support** - “It used to take an hour every day for my child to get over his needle fear and take his treatment. Now we don’t even think about it and it just happens, thanks to the social worker”
 - ▶ **We personalize therapy** – using pharmacokinetic data and patient records, we help patients find a treatment program that meets their needs
 - ▶ **We re-design the system** - “The emergency department staff told me women can’t have hemophilia and made me wait 12 hours for treatment”

Our Challenges

- ▶ A truly provincial program is challenging
 - ▶ Local practitioners still need to authorize our suggestions and sometimes disregard them
 - ▶ As our program grows, it's harder to keep up with clinic demand outside of Saskatoon
- ▶ We are being asked to do more with less
 - ▶ More patients
 - ▶ Changing treatment availability and product switching
 - ▶ Transition to national electronic medical record
 - ▶ Dentistry and genetics used to attend clinics regularly, but are no longer able to do so

Managing Scarce Resources

- ▶ Coagulation product re-location
- ▶ Coordination with healthcare workers outside our program
- ▶ Consistent approach in prescribing treatment
- ▶ Home infusion training to avoid emergency room visits

Keys to Success

- ▶ Close working relationship with the patient advocacy organization
- ▶ Close working relationship with the provincial ministry
- ▶ Regular strategic planning

Thank you

- ▶ A special thanks to everyone involved with the Saskatchewan Bleeding Disorders Program, both past and present