

The Manitoba Bleeding Disorders Program

Blood Day

November 4th, 2009

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Nurse Coordinator

History



Background Information

- Manitoba Bleeding Disorders Program
- A provincially funded (November 2005) program providing comprehensive care services for children and adults with bleeding disorders in Manitoba, Eastern Saskatchewan and Northwestern Ontario

Comprehensive Care

- Core Team: clinic directors, nurses, physiotherapist and social worker
- Other vital team members include: CBS, ward and ER nurses and MD's, Blood Bank staff, Hemostasis lab technologists, Hepatology, Infectious Diseases, Orthopedics, Dentistry to name a few

Patients registered with the MBDP

- Over 300 patients, adults and children are registered with the national data base CHARMS
- Variety of Bleeding Disorders, including deficiencies of factor I (fibrinogen), VII, VIII, IX, XI, and XIII, and severe forms of von Willebrand disease
 - incidence ranges from 1:7,500 to 1:10 million
- Majority of patients with von Willebrand disease (incidence 1 per 100) are not registered and are seen on an as needed basis for trauma and or surgery or dental extractions

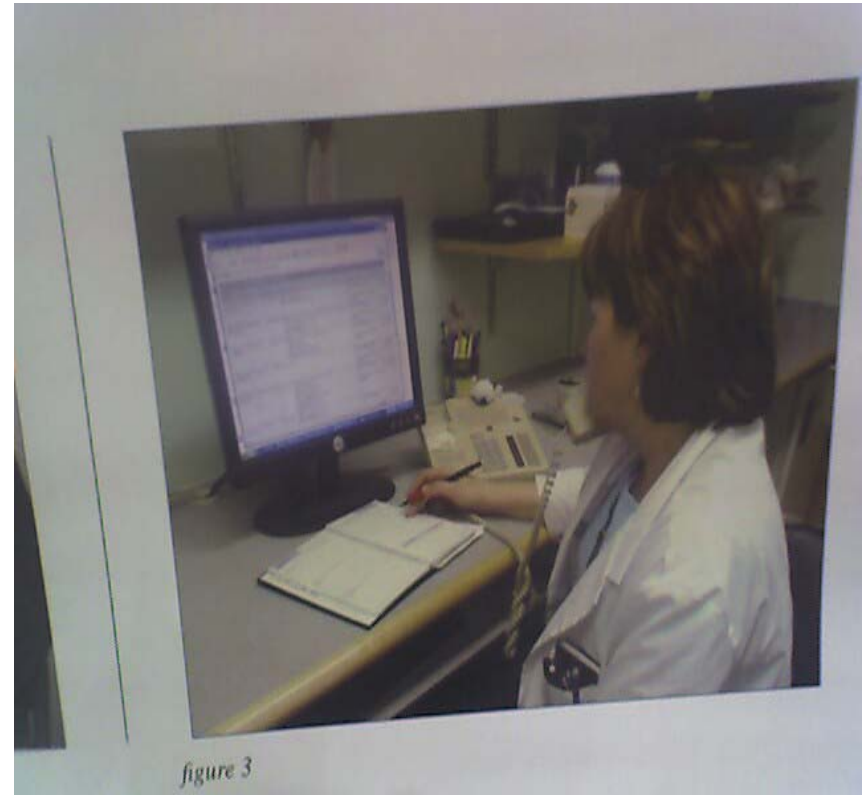
Home Treatment

- Most patients with moderate to severe bleeding disorders are on home treatment
- This requires patient education, supervision, monitoring of home-treatment records, and tracking of product
- Home treatment is the gold standard of care for Hemophilia



Working in Partnership

- Patients logs indication for treatment, dose, and effect and communicates this information to the nurse
- Nurse contacts clinic directors when necessary
- Logs routinely reviewed at clinic



A MODEL OF COMPREHENSIVE CARE

- Nurses; Nora Schwetz, Rose Jacobson, Janice Karasevich
- Provide education and support to patients, their families and health care providers
- On call 7 days a week from 0800-2400



Clinic Directors

- Adult Program: Dr. Don Houston
- Pediatric Program: Dr. Sara Israels, Dr. Patricia McCusker, and Dr. Jayson Stoffman
- Provide guidance for the use of derivatives
- Note, there is a hematologist on call 24/7



Physiotherapy

- Pediatrics: Kathy Mulder and Matthew Thiessen
- Adults: Greig Blamey
- *Joint and muscle bleeds are a common feature of hemophilia*
- Physiotherapists work to **prevent** and **treat** these complications in consultation with the team by
 - Patient education
 - Directly supervised physiotherapy treatments
 - Prescribed home exercises with telephone supervision
 - Follow up
 - Discussion re: Lifestyle choices



Social Work

- Patty Phrakonham-Ali
- Provides support for individuals with bleeding disorders and their families
 - Crisis intervention
 - Ongoing assessment
 - Resource management
 - Advocacy



Manitoba Bleeding Disorder Program Objectives

To ensure appropriate use of expensive coagulation factors (derivatives).

To provide ongoing support and education working in partnership with patients, their families and other health care providers

To ensure that the gold standard of care is provided.