BACKGROUND TO HAEMOPHILIA NURSES COURSE

1. SUMMARY OF THE COURSE

Title: Haemophilia Nurse Training course

Providers of the course: World Federation of Haemophilia nurses
Jill Smith Haemophilia nurse Royal Perth Hospital
South African Haemophilia nurses

Hours: Theory - 32 Hours
Clinical - 8 Hours

Mode of Delivery: Lectures
Practical
Case presentations

Maximum No. of Students: 30

2. BACKGROUND AND RATIONALE FOR THE COURSE

Incidence
Haemophilia affects 1 in 10 000 males born in the world. It affects males of all races and social classes equally. Haemophilia is a very rare condition and thus very under diagnosed in South Africa.

Haemophilia information
Very little information about this disorder is available in most medical textbooks used in the basic training for nurses and doctors. Thus many physicians and nurses have very little experience in the treatment of this uncommon disorder. 80% of people with Haemophilia receive no treatment; many die in childhood and the rest are crippled.

Recognition of Haemophilia treatment in SA
In July 2000 the Minister of Health approved the treatment of all people affected with Haemophilia and that:

i. The hospitals offering comprehensive haemophilia care be recognised as Haemophilia treatment centres.
ii. All Provinces be encouraged to retain the posts of haemophilia nurse co-ordinators.

In line with this, it necessitated the training and empowering of nurses with Knowledge and skills to enable them to manage the haemophilia centres.

3. THE PURPOSE OF THE COURSE

- To equip the professional nurses with relevant skills to enable them to manage and administer Haemophilia Centres effectively.
- To enhance their professional practice by effective analysis, problem solving and development of an innovative and efficient approach to care.
- To enable the professional nurses to develop a critical and analytical approach to their own performances as practitioners.
- To enable the practitioners to transfer knowledge gained in a critical manner into novel and challenging situations within a range of settings.
- To enable practitioners to develop conceptual understanding which can be applied in an appropriate manner to practice.
BACKGROUND TO HAEMOPHILIA NURSES COURSE

- To enable the practitioners to explore and analyse a range of theoretical perspectives relevant to their area of practice

4. PARTNERS

- South African Haemophilia Nurses Committee
- World Federation of Haemophilia Nurses’ Committee
- South African Foundation Medical Advisory Committee
- South African Haemophilia Foundation
- Department of Health - Directorate - Maternal Child and Women’s Health and Nutrition and in Western Cape Chronic care Mrs Unita van Vuuren

Aims of partners

a) To promote staff and student education and training in Haemophilia (both clinical and theoretical) so that they are strong enough to support service, research and development aims.
b) To provide nurses with specialist education and knowledge on Haemophilia and other related inherited bleeding disorders.

5. THE COURSE:

Target Student group

The course is targeted for –

- Registered professional nurses working with patients with Inherited Disorders and or bleeding disorders and circumcision coordinators. Staff Nurse and Enrolled Nurses Applications may be considered if actively involved in Haemophilia Care with some hands on experience.
- The professional nurses working within the republic of South Africa, though nurses from the SADC countries will be welcomed as part of the mission of the WFH to improve haemophilia care in SA and the SADC region
- The medium of instruction is English

6. ANTICIPATED LEARNING OUTCOMES:

At the end of the course the student will be able to –

1) Discuss the physiological causes of and consequences of haemophilia and related bleeding disorders.
2) Examine the psychological, economic, ethical and social implications of having a lifelong bleeding disorder.
3) Explore the range of therapeutic skills and nursing intervention required for holistic care of the affected individual and family and friends.
4) Discuss the range of treatment modalities available to treat bleeding disorders.
5) Analyse the research base which supports best practice in haemophilia care.
6) Discuss the role of the nurse as an educator in caring for individuals living with haemophilia or related bleeding disorders and their families.
7) Explore the role of the nurse within the multi-disciplinary team and its impact on client intervention outcomes.

7. THE LEARNING CONTENT:
BACKGROUND TO HAEMOPHILIA NURSES COURSE

The content includes the following:

- Understanding the genetic base of haemophilia and related disorders: history of haemophilia and related bleeding disorders; aetiology of haemophilia and related disorders; model of coagulation cascade; types of bleeding disorders; DNA and chromosome structure, genetics of haemophilia and related disorders; ante-natal diagnostic testing techniques; carrier testing.

- Manifestations and management of haemophilia and related disorders: symptoms of haemophilia and related disorders, applied anatomy and physiology, process of acute bleeds (cerebral, gastro-intestinal, muscle joints etc imaging and diagnosis of bleeds); treatment of haemophilia and related bleeding disorders; pharmacology, pain control, plasma sourced products and product safety, recombinant products, inhibitor management, gene therapy, physiotherapy, orthopaedic interventions for joint arthropathy; treatment regimes, nurse prescribings.

- Complications of treatment of haemophilia and related bleeding disorders; immunology and blood borne infections; immune system and pathogenesis, transmission; clinical manifestations and treatment of identified blood borne pathogens, infection control; psycho-social aspects of blood borne infections, stigma and HIV/HCV, physiology and treatment of inhibitors, presentation of inhibitors, treatment of bleeding episodes in patients with inhibitors, treatment products available, immune tolerance regimens, financial considerations.

- Specialist role of the nurse in haemophilia and related bleeding disorders: the nurse as a practitioner – ethical, legal and professional issues, clinical supervision, clinical governance, the nurse as educator/advocate, the nurse as a specialist information resource within the National Health system, the nurse as a advisory link between people with haemophilia and social net work e.g. schools, workplace and social services, the nurse as a researcher, research ethics, organisation of formal research, clinical trials, nursing trials, and nursing research in haemophilia.

8. ASSESSMENT AND EVALUATION STRATEGY

- Test written
- Pass mark is 80%
- Case presentation

9. INDICATIVE READING FOR COURSE OBTAINED FROM:

- WFH (World Federation of Haemophilia) Journals
- WFH Textbooks
- WFH Haemophilia Treatment Monographs

Expectations from participants by Course providers

We enjoy doing this course with the participants and to make it run smoothly we request the following please from all attendees

To attend all 5 days
To arrive promptly at 08h00 every day
Do set work on days requested and revise in evenings
Cell phones on Silent. May take calls if urgent outside venue
Parking is unavailable at the venue participants need to park level 3 GSH
Thank You! You will all enjoy the course and feel more confident to manage these patients

3 SA Nurses Committee revised June 2014 Cape Town 13/06/2014 A-L C