



# Exercising Safely at All Ages

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# Say what we mean...Mean what we say

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- We recommend physical activity for ALL people with bleeding disorders
- Is a recommendation enough?
- Considering the potential power of exercise to mitigate the impact of haemophilia and other bleeding disorders in a factor-rich environment?
- Would we be comfortable with simply recommending that PWBD's use factor?

# Objectives

- Draw parallels between the impact of medical management, and physical management of bleeding disorders in terms of MSK & overall health
- Demonstrate why it is critical to design exercise programs for PWBD's just as individually as we do their factor replacement regimens in order to expect the best results
- Suggest practical solutions for HTC's in Australia



# The Factor Revolution

- The impact of clotting factor concentrates – plasma derived then recombinant is undeniable
- Severe haemophilia can be converted into mild haemophilia on a temporary basis
- The advent of prophylaxis is a pillar of maintaining excellent joint and muscle health from childhood into adolescence and adulthood



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# Is that all there is?

- The WFH promotes the concept that “treatment is more than just factor”
- What if prophylaxis was expanded beyond
  - Primary
  - Secondary
  - Tertiary
- What if we **prescribed** Physical Prophylaxis?



# New Concepts

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- Physical prophylaxis : The implementation of a life-long fitness program that is:
  - Individualised
  - Inclusive of all major joints and muscles
  - Inclusive of the major elements of fitness
  - Adaptable
  - Enjoyable
  - Monitored and when needed, modified



# Existing tools



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- We already use electronic bleed reporting to track factor usage for prophylaxis as well as injury related doses
- Could we adapt this technology more effectively to fine tune reporting of physical prophylaxis as well?
- Electronic reporting & tracking of exercise would allow PWBD's as well as HTC staff to track progress, know when to make adaptations, and ensure exercise programming was targeted appropriately

# A matter of need...not want

- Evidence shows that MRI can detect damage to joint surfaces without a history of clinically evident bleeding (Manco-Johnson et al, 2007)
  - All adults with haemophilia demonstrate clinically and radiographically evident signs of arthropathy
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- Increasing levels of arthropathy limit the opportunities for exercise, the extent of the benefits to be gained, and the drive for an individual to participate



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# Clinical translation...

## Lobet et al (Haemophilia 2019 Sep; 25(5): 859-866

- 20 week self and clinically applied exercise program
- 50 patients; battery of disease specific and non-disease specific outcomes at onset of the program; again 20 weeks later
- Improvement across all measures
- 94% of participants reporting regular performance and high satisfaction



**How Much  
Exercise is  
Required?**

Public health agencies in Canada suggest:

- Children require 60 minutes of daily activity
- Adults require 30 minutes of daily activity

**How are we doing as a global bleeding disorders community?**



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# Seuser et al, 2007

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- Assessed 233 people with haemophilia (131 with severe disease)
- 43% exhibited fitness levels lower than age matched norms
- 93% exhibited below average flexibility
- Average to low scores in endurance, coordination, torso & abdominal strength



# Gradual Transformation...

## Gonzalez, et al – 2011

- A cross-sectional study using accelerometry to determine activity levels in adolescents with haemophilia A, and age matched controls
- Haemophilia A patients showed higher levels of light/moderate and moderate/vigorous activity

## Groen, et al – 2011

- Physical activity levels in PWH aged 8-18 in Holland were similar across haemophilia severities and comparable to the general population



# Personalisation of Care

- Many publications have attempted to categorise sports and activities, assessing levels of safety, or relative risk for PWBD's
- Although the rules, scoring, equipment, playing surface, and mechanics of the sport will essentially be a constant...
- Every individual with a bleeding disorder is different



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# Playing It Safe

BLEEDING DISORDERS,  
SPORTS AND EXERCISE





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# You KNOW you've heard this...

“You should take up swimming because it is the best exercise for people with haemophilia.”

“It's non weight bearing so it is easy on your joints and muscles”

# One size fits all?

## 1 Golf

Golf is a low-impact, lifetime sport that provides a good workout for those who walk the course rather than use a cart. Expense and access to a course are limiting factors.



Specific bleeding histories and target joints may convert “safe” sports into hazardous activities



Personalised medical management, and advanced physical fitness may mitigate supposed risks

## Begin With Assessment

- Routine examinations in medicine and allied health inquire about drug history, allergies, and sensitivities
- Patients can frequently discuss from memory the drugs they are taking, as well as their doses
- We specifically ask about the therapeutic effects of drugs taken, as well as any unwanted side effects
  - How many...How often...How well...Any issues????

# Where do we go from here?



- The development of the “core” team concept of comprehensive care has had some unintended consequences:
- Haematologists functioning as primary care MD’s
- RN’s triage all kinds of non-bleeding disorder issues
- SW’s become tasked with absolutely anything psycho-social
- PT’s are expected to be experts in every domain of MSK function
- Inherently limits individualisation in care

## New Approach...Old Concept

- Every person with a chronic disease should have a specialised team of professionals to assist with and coordinate care
- The likelihood that members beyond the “Core 4” are going to be needed increases as a person with haemophilia ages
  - Hepatologist
  - Gerontologist...

# Enter...the personal trainer

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- HTC's operate on a formula of core interdisciplinary care with referral as needed to multiple medical and health professionals
- Courting and securing the services of accredited personal trainers with supportive education provided by the HTC staff is a potential option that could fill the exercise prescription void

# A cautionary note...

- Personal training is usually an unregulated occupation, with numerous certification programs available throughout the world
- The HTC Physiotherapist could be tasked with assessing the credentials of a personal trainer, and selecting individuals best suited to the needs of the BD's population



# Counting the costs...

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- The services of a personal trainer are not cheap, and not insured
- PWBD's may need to explore alternate funding models
- My clinic in Manitoba implemented a joint PT/PT/PT program
- The potential savings - factor usage, increased productivity, and overall health benefits is assumed to be significant, but not yet fully evaluated

# One Example:

- 28 year old patient with Severe FVIII deficiency
- Pre-exercise program proph schedule of 3 x 2000 IU per week
- Combined effort of the PT, the PT, and the PT ( and the rest of the team) determined daily exercise would be coupled with low dose proph
- 500 IU daily = 3500 IU/wk as opposed to 6000 IU/wk – with enhanced results

# In summary...



- The information presented here is not new, but in part constitutes a new approach to what we already know
- We may be able to maximise the impact of exercise for PWBD's if we formalise our advice, transforming recommendations into prescriptions
- Alternate models of funding and exercise delivery should be explored

# The All Important Truth...



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- All successful and sustained exercise programs hinge primarily on the commitment and dedication of the athlete
- The best exercise programs make effective use of the interests of the athlete, and adapt activities they enjoy as needed to produce the desired effects





