



**STRATEGIES TO
PROMOTE HEALTHY
PARTICIPATION
OVERCOMING THE
BARRIERS**

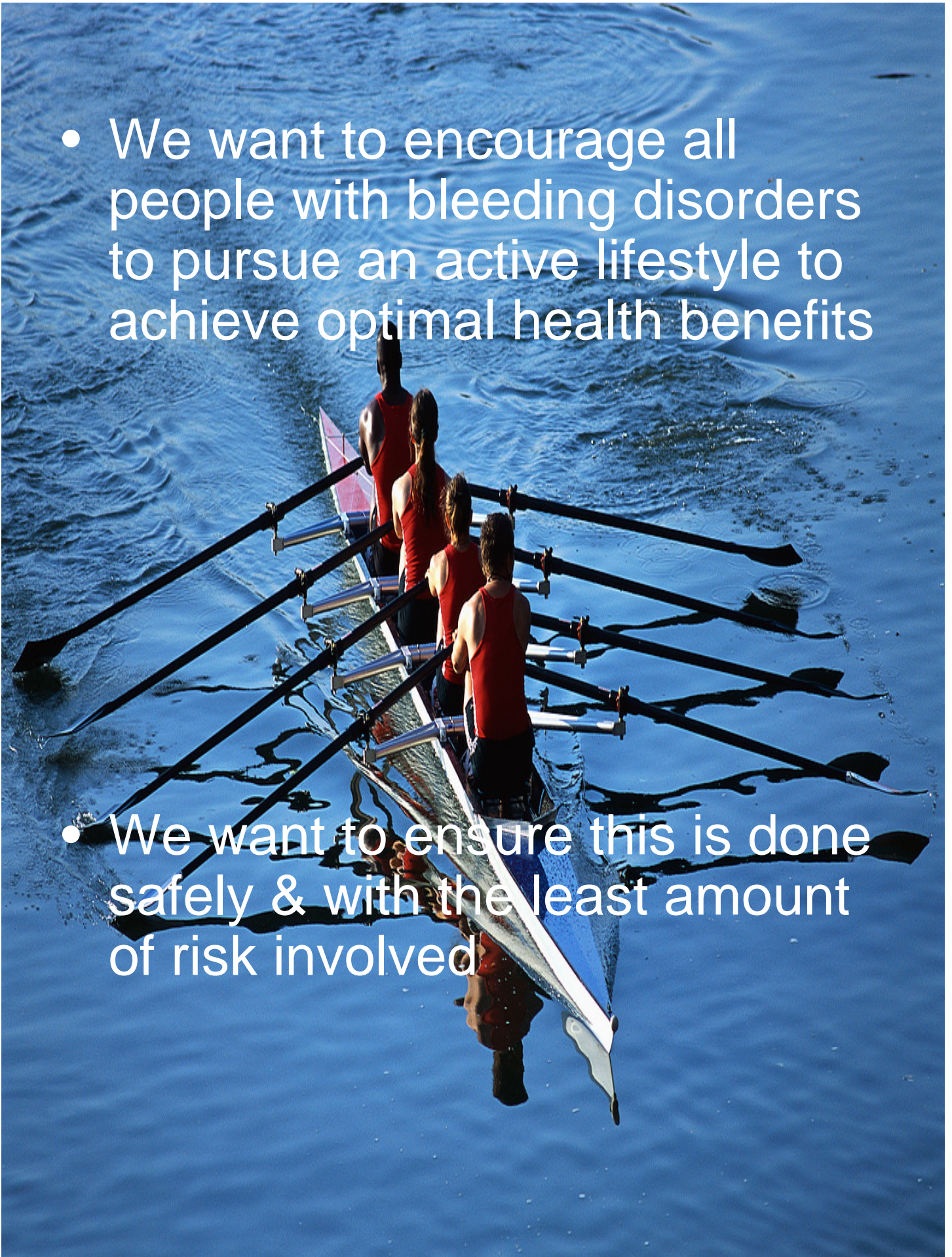
Salena Griffin – CNC

**Wendy Poulsen –
Physiotherapist**

**Qld. Haemophilia Centre
Royal Children's Hospital**

- We want to encourage all people with bleeding disorders to pursue an active lifestyle to achieve optimal health benefits

- We want to ensure this is done safely & with the least amount of risk involved



WHAT IS HEALTHY PARTICIPATION????

?

- “Traditionally ,most exercise recommendations have indicated that activity needs to be performed continuously for at least 20 minutes to be beneficial.
- However, recent evidence suggests that activity accumulated in periods of 10 minutes or more can have significant health and fitness benefits.”

BENEFITS OF EXERCISE

A photograph of three people playing beach volleyball on a sandy beach. A net is stretched across the frame, and a yellow and white ball is in the air. The background shows the ocean and a clear blue sky. The text is overlaid on the image.

- Increased muscle strength
- Improved joint nutrition
- Maintenance of optimal R.O.M
- Decreased pain
- Improved overall fitness
- Improved mood and sleep
- Enhanced quality of life
- Prevention of obesity & other co-morbidities.

PSYCHOLOGICAL BENEFITS OF EXERCISE

A woman with dark hair tied back is sitting in a meditative lotus position on a wooden floor. She is wearing a dark grey tank top and dark pants. Her hands are pressed together in a prayer position (Anjali Mudra) at her chest level. In front of her, on a dark wooden surface, is a large, shallow, dark-colored bowl containing several lit candles of various sizes and colors (yellow, orange, and white). The background is a bright, out-of-focus window with horizontal blinds, suggesting a bright, airy indoor space.

- **Self confidence**
- **Being different**
- **Peer acceptance**
- **Increased relaxation**
- **Quality of sleep**
- **Coping with the stresses of daily life**



PSYCHOLOGICAL FACTORS – ADHERENCE

It has been suggested that one approach for programming long-term maintenance, may involve a greater emphasis upon parental participation and social reinforcement during mutual exercise with their child in more convenient settings.

The hospital may be a reasonable setting to teach an exercise regime, but long term involvement may be more successful in facilities more convenient to the family eg local pool ; sports clubs/centres, gyms.

Activities involving peers or family will be seen to be more desirable & therefore increase motivation to participate regularly.

FOR THOSE WITH BLEEDING DISORDERS

- **There are additional concerns when thinking about healthy participation:**

- * **bleeding episodes**
- * **pre-existing joint damage /restrictions decreased flexibility; joint surgery**
- * **altered biomechanics**
- * **decreased muscle strength & overall fitness**
- * **presence of inhibitors**

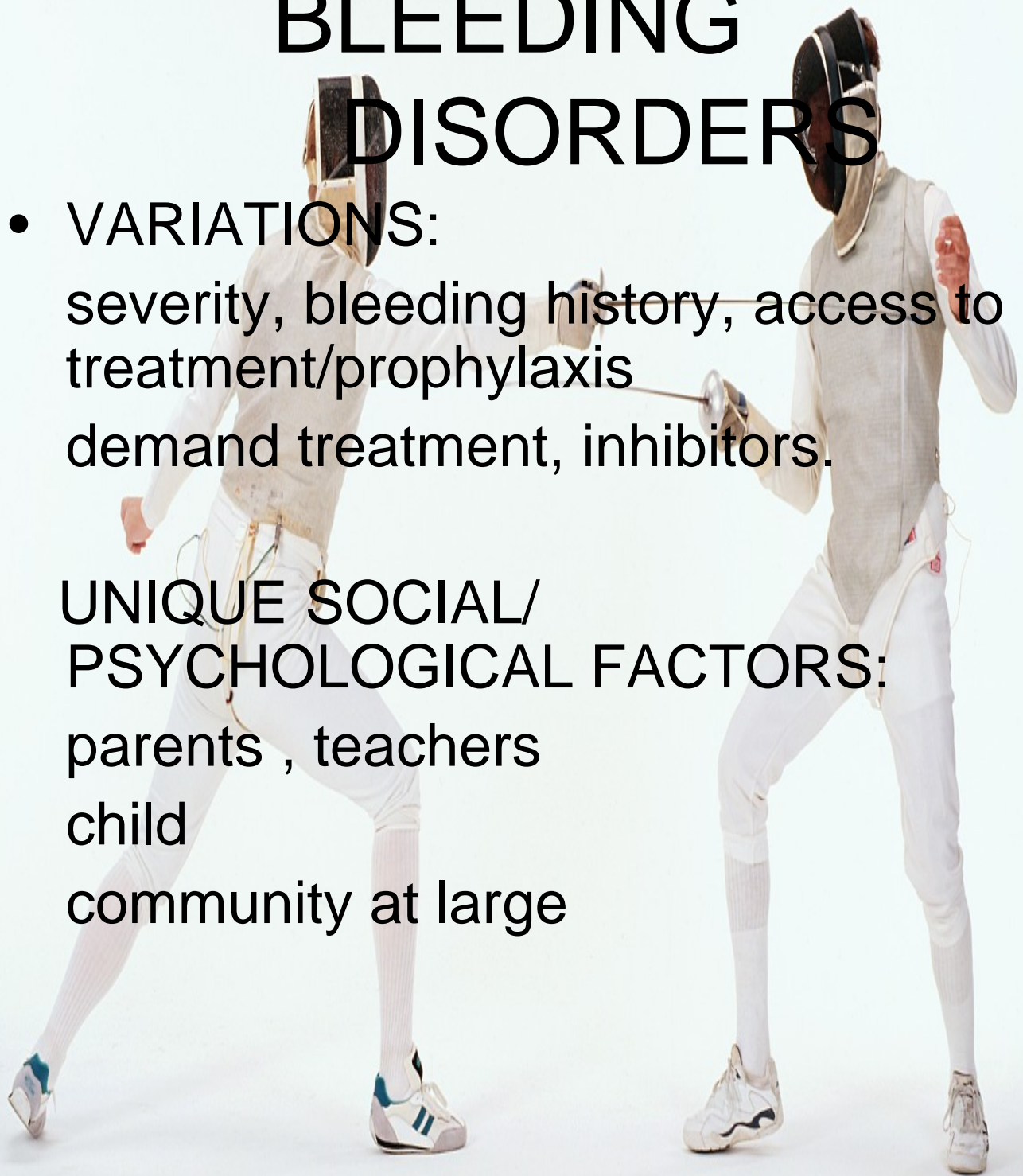


FOR THOSE WITH BLEEDING DISORDERS

- VARIATIONS:
severity, bleeding history, access to
treatment/prophylaxis
demand treatment, inhibitors.

UNIQUE SOCIAL/ PSYCHOLOGICAL FACTORS:

parents , teachers
child
community at large



Parent/child behaviours

- Role modelling
- Guidance
- Parents behaviour
- Lack of insight (child's)



Categories of sports-

(www.HemophiliaGalaxy)

- Category 1-recommended sports in which individuals with bleeding disorders can safely participate.

swimming
sailing

archery

stationary bike

fishing

walking

fris-bee

hiking

tai chi

golf

Categories of sport (cont.)

- Category 2- sports in which most people with a bleeding disorder can participate safely or with moderate risk.

bicycling

soccer

gymnastics

cricket

field

rowing

skateboarding

softball/baseball

canoeing

certain

running/track &

windsurfing



Categories of sport (cont)

- Category 3- The nature of the sports makes them dangerous. They involve high speed or heavy contact/collision. They are **NOT recommended.**

Boxing

Rugby league

AFL

Rugby union

wrestling

hockey

karate

motorcycling/motorcross

competitive diving

racquetball





CHOICE OF SPORT

The choice of a particular sport is a very individual matter. However, there are common factors that influence choice & must be always considered:

- * enjoyment
- * capability
- * previous experience
- * the attitude of others

A group of young boys in a baseball team celebrating with their arms raised and holding a trophy. The boys are wearing white pinstriped jerseys with blue collars and blue caps. One boy in the center is holding a large trophy. The background is a blurred outdoor setting, likely a baseball field.

**WHAT ARE
THE
BARRIERS???**

**-to healthy
participation**

Many people, whether they have a bleeding disorder or not, find reasons to avoid physical activity.

Do any of these statements sound familiar ?

- 
- I'm not in good enough shape
 - My joints hurt
 - I'm too busy
 - I have a target joint & I don't want to cause more damage
 - I have no-one to exercise with
 - I had a bad experience last time
 - I don't like exercise
 - I'm scared of injuring myself
 - I don't have enough time
 - I can't get motivated
 - It's too far to go
 - My Haemophilia team won't let me
 - It costs too much
 - The coaches aren't knowledgeable about the risks to me
 - My parents won't let me
 - I have an inhibitor
 - My family & friends don't support my efforts to exercise regularly

A photograph of a rowing team in a blue boat on a body of water. The rowers are wearing red tank tops and are captured in a synchronized rowing motion. The water is a deep blue, and the boat's reflection is visible on the surface. The text is overlaid on the upper half of the image.

OVERCOMING BARRIERS SPECIFIC TO BLEEDING DISORDERS

Whilst most people with bleeding disorders want to treat bleeds promptly, they may be challenged by a number of things, such as time constraints or fears.

A soccer ball is positioned in the center of a lush green grassy field. The background is a bright blue sky filled with scattered white, fluffy clouds. The overall scene is bright and clear, suggesting a sunny day.

Finding the time

The experts recommend parents involve children in their treatment plan from a young age so that they can be of assistance during busy times



Fearing the hurt

Talk to other parents who have been through the home infusion process. See if they had similar concerns & if so, how did they overcome these fears.

Accepting the diagnosis


A woman with dark hair tied back is sitting in a lotus position on a wooden floor. She is wearing a dark blue tank top and dark pants. Her hands are pressed together in a prayer position (Anjali Mudra) at her chest level. Her eyes are closed, and she has a calm expression. In front of her, on a dark wooden surface, is a large, shallow, dark-colored bowl containing several lit candles of various sizes and colors (yellow, orange, and white). The background is a bright window with horizontal blinds, creating a soft, diffused light. The overall atmosphere is peaceful and contemplative.

You don't have to do it on your own. Develop relationships with people & organizations that can help you & your child (HTC) – learning as much as you can is a second part of accepting the diagnosis



Recognizing & treating bleeds correctly

Learn the early signs of bleeds. Have your factor readily available at all times.



Will the treatment help
?

Read up on the consequences of not following your plan ; following your treatment plan can help prevent long term irreversible joint damage & other complications


Maintaining the balance between concern & control

***A balanced style will
encourage the child to be
active participants in all
aspects & decision making
regarding their treatment***



Testing the limits

Learning through networking with others with similar conditions who have experienced debilitation from their condition. Encourage them to think ahead – not 20 years, but 24 hours – when they might have significant pain from a poorly or inappropriately treated bleed.

A soccer ball with black and white panels is positioned on a lush green grassy field. The background is a bright blue sky filled with scattered white clouds. The text is overlaid on the upper portion of the image.

Language barriers – those medical terms which aren't understood

- *Talk to your
HTC and
ensure that
they use
terminology
that you
understand*

STRATEGIES TO PROMOTE HEALTHY PARTICIPATION



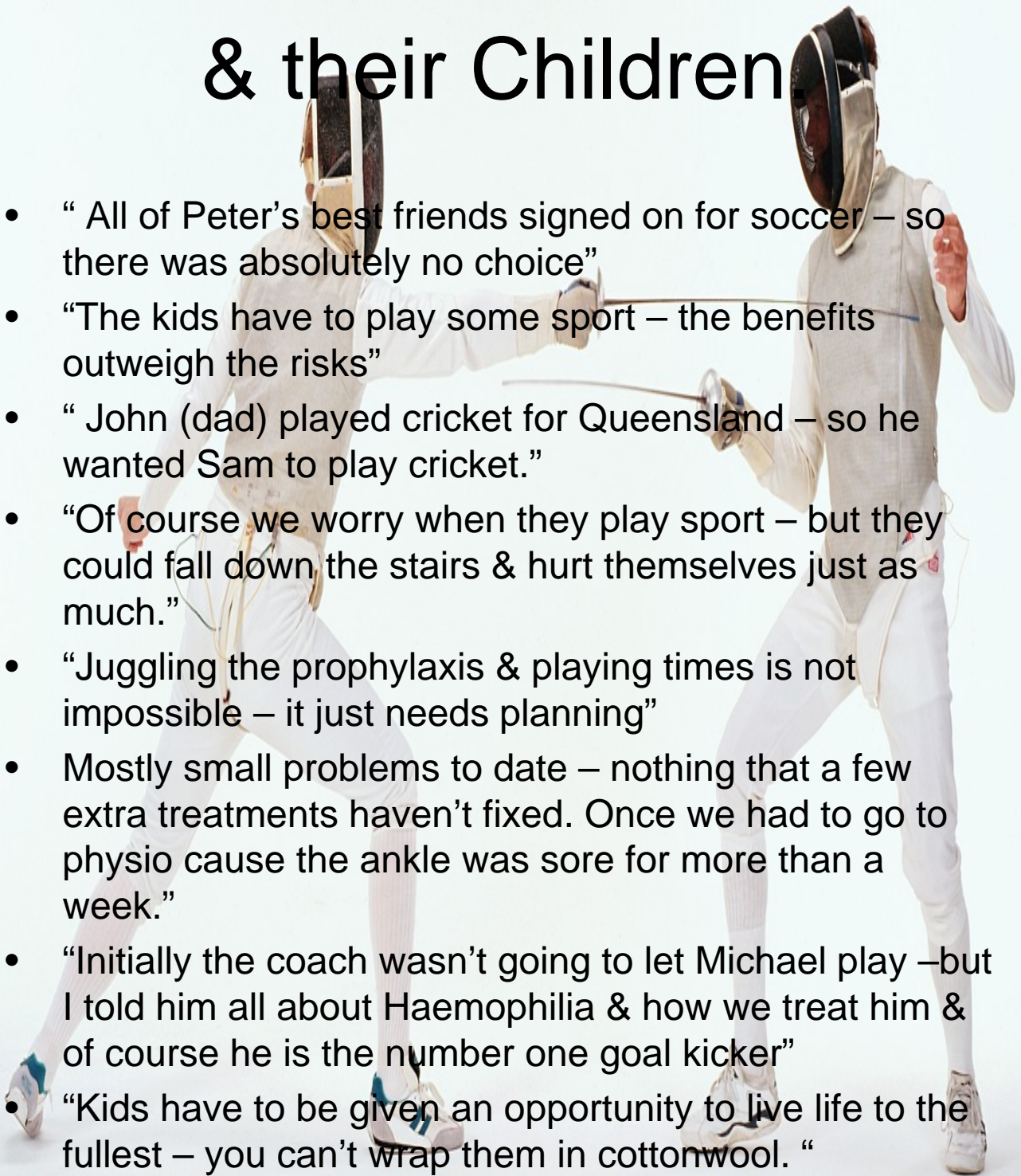
- **Overcoming these barriers will be a major endeavour of the staff within the HTC if the parent is to encourage healthy participation, particularly when participation comes with additional risks of injury.**

Interview results – Parents & their Children.

- “I don’t do exercise”
- “The rest of my family plays sports so I figure I should also”
- Soccer, cricket, swimming, golf, AFL, touch footie, skateboarding ,running.
- “You have to warm up properly & do the stretches & I wear an ankle brace at soccer. If we have time I get a treatment just before I play; but mostly the night before.”
- “I play everything – I always feel good playing sports with my mates.”
- “I’m not scared of playing any sports & I really would like to play footie, but I could get a head bleed & that could be dangerous”
- We have a first aid kit at the oval – so I can ice myself if I have been hurt.
- If you want to play a sport – just do it!!!

Interview results – Parents & their Children

- “ All of Peter’s best friends signed on for soccer – so there was absolutely no choice”
- “The kids have to play some sport – the benefits outweigh the risks”
- “ John (dad) played cricket for Queensland – so he wanted Sam to play cricket.”
- “Of course we worry when they play sport – but they could fall down the stairs & hurt themselves just as much.”
- “Juggling the prophylaxis & playing times is not impossible – it just needs planning”
- Mostly small problems to date – nothing that a few extra treatments haven’t fixed. Once we had to go to physio cause the ankle was sore for more than a week.”
- “Initially the coach wasn’t going to let Michael play –but I told him all about Haemophilia & how we treat him & of course he is the number one goal kicker”
- “Kids have to be given an opportunity to live life to the fullest – you can’t wrap them in cottonwool. “



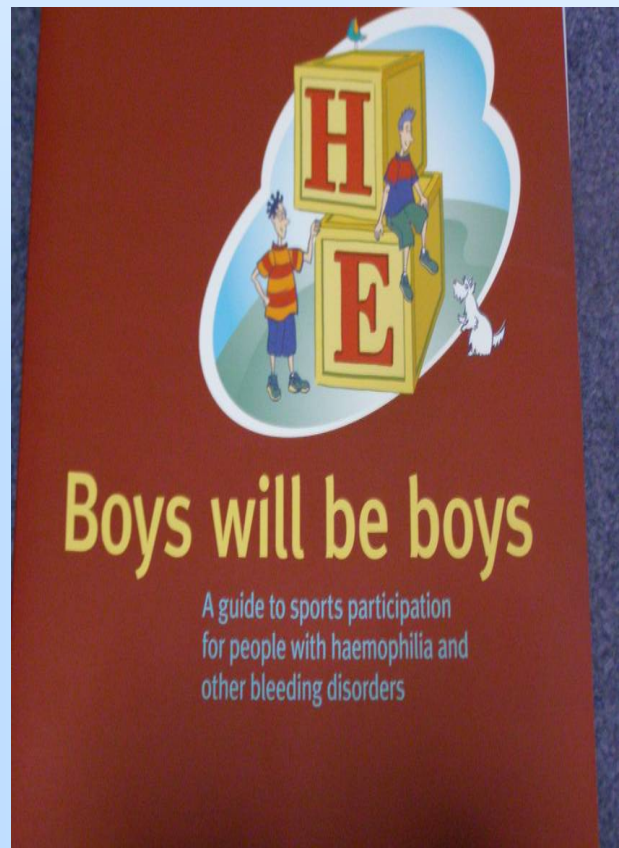
Summary – Strategies to Promote Healthy Participation

- Good education provided by the HTC staff, regarding types of sports and related risks.
- Acknowledging the individuals limitations
- Full assessment of the individual as opposed to “categorising sports” suitable to them.
- Parental support and appropriate role modelling.
- Education on appropriate prophylaxis timing to sports participation
- Appropriate liaising with teachers, coaches to enable full participation
- Advice on safety issues :
 - protective wear,
 - safe landing skills
 - Warm up / cool down
- Providing a plan of what to do:
 - - if injured
 - - if there is a recurrence of injury

BE ABLE TO OFFER OPTIONS OR ALTERNATIVES

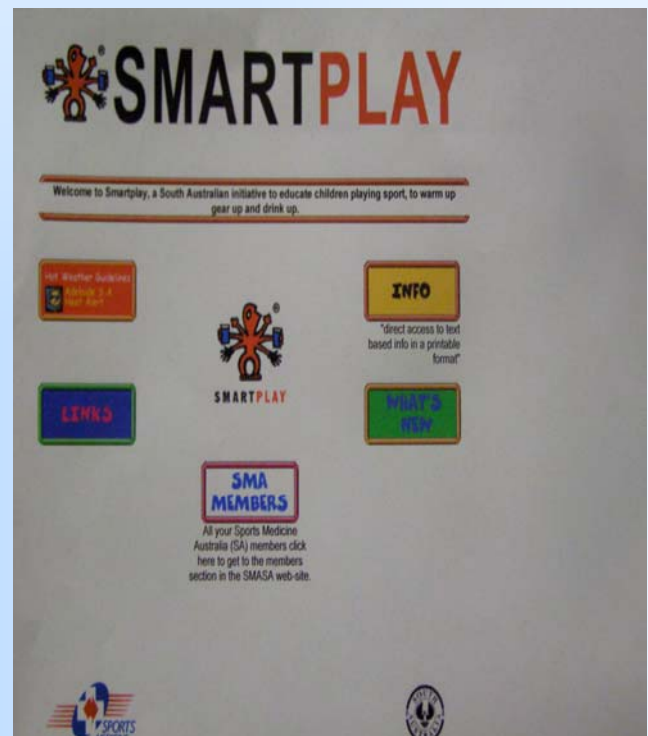
USEFUL RESOURCES

- Boys will be boys – a guide to sports participation for people with haemophilia and other bleeding disorders



Resources (cont)

www.smartplay



www.hemophiliagalaxy.com