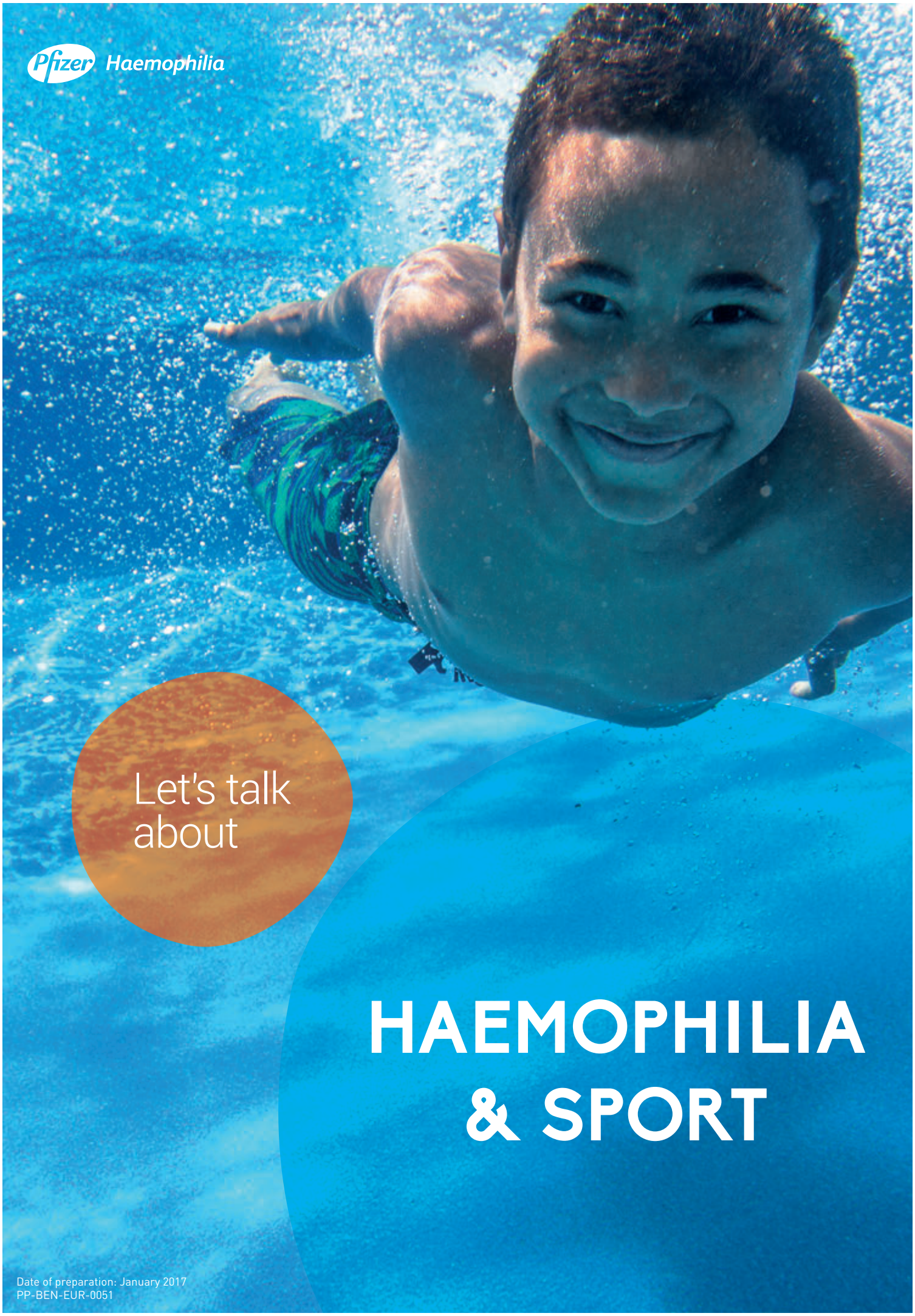
Pfizer Haemophilia
Let's talk about
HAEMOPHILIA
& SPORT
Date of preparation: January 2017
PP-BEN-EUR-0051

Let's talk about...

INTRODUCTION

In the past, people with haemophilia had to be very cautious and talking about sports was out of the question! Today, thanks to effective new treatments, **people with haemophilia CAN participate in sport and exercise**. In addition to its beneficial effects on the body in general, regular physical activity actually helps prevent bleeds and joint damage. Choosing the right exercise is important and will be different for every child, and should be based on discussions between the patient, their parents and the doctor who looks after their haemophilia. Many factors will influence the choice of exercise, including overall enjoyment, if their friends are interested and the overall risk to their joint health.

This booklet will equip people with haemophilia, and their families, with the knowledge that they need to exercise wisely, allowing young people with haemophilia to participate in sport and exercise. The booklet may also be useful to physical education teachers, class teachers and sports instructors who want to know more about the benefits and limitations of physical activity in children and adolescents with haemophilia.

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Let's talk about

WHAT HAEMOPHILIA IS

Haemophilia is a relatively rare condition that causes bleeding problems. People with haemophilia do not bleed any faster than normal, but they can bleed for a longer time if they are injured, as their blood does not have enough clotting factor.

HAEMOPHILIA A

They do not have enough clotting factor VIII (8)

Affects 1 in every 5,000 males – 5,467 registered patients in the UK

HAEMOPHILIA B

They do not have enough clotting factor IX (9)

Affects 1 in every 30,000 males – 1,156 registered patients in the UK

DID YOU KNOW?

Haemophilia is quite rare. About 1 in 10,000 people are born with it.

SEVERE, MODERATE OR MILD

The frequency and severity of bleeding depend on the level of clotting factor VIII activity in the blood. The lower the clotting factor, the more frequent the bleeding, in most cases.

SEVERE

Less than 1% of normal clotting factor activity

- Bleed often into the muscles or joints (mainly knees, elbows and ankles)
- Might bleed 1 or 2 times per week
- Might bleed for no clear reason

MODERATE

1–5% of normal clotting factor activity

- Might bleed for a long time after surgery, a bad injury, or dental work
- Might bleed about once a month
- Rarely bleed for no clear reason

MILD

5–30% of normal clotting factor activity

- Might bleed for a long time after surgery or a very bad injury
- Might never have a bleeding problem
- Do not bleed often
- Do not bleed unless injured

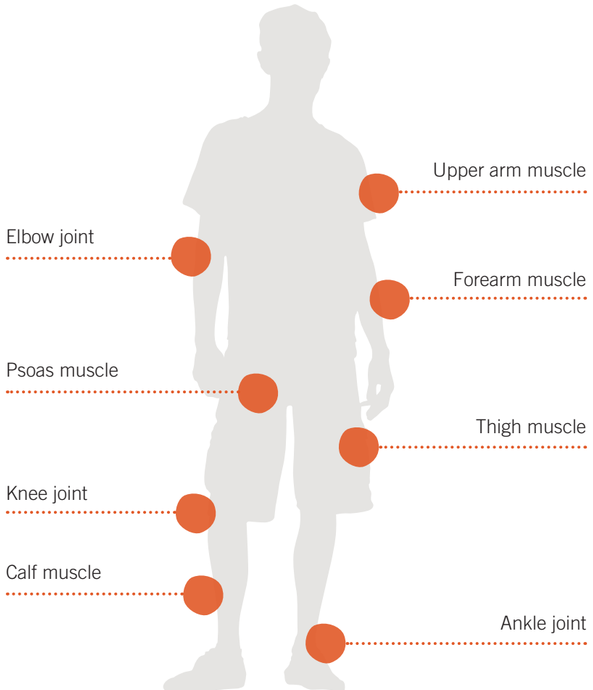
Let's talk about

WHAT TO LOOK OUT FOR IF YOU HAVE HAEMOPHILIA

HAEMORRHAGE INTO A JOINT

At first, the bleeding causes tightness in the joint with no real pain or any visible signs of bleeding. The joint then becomes swollen, hot to touch and painful to bend. Eventually, movement in the joint will be temporarily lost.

BLEEDING OCCURS MOST OFTEN IN THESE AREAS



Repeated bleeding in the same target joint can cause severe pain, stiffness and weakness, leading to **haemophilic arthropathy**. Sometimes bleeding can affect the muscles. If a bleed occurs in the deeper muscles, the swelling may press on nerves or arteries which will cause tingling and numbness.

An area of particular concern is the muscle that runs inside the pelvis along the inner side of the hip bone. These muscles (iliopsoas muscles) control movement of the upper thigh. Bleeds here are relatively common and recovery can be slow.

Joint bleeding is a primary concern for people with haemophilia, with bleeding in the knees, elbows and ankles being the most common areas to look out for. Bleeding is often caused by minor injury – a bump or a slight twist of a joint. However, bleeding can also occur without obvious injury, especially in joints that have bled often in the past. The more a joint has bled, the easier it bleeds again with no external cause.

If you are experiencing a bleed, please contact your doctor who looks after your haemophilia.

Let's talk about

HAEMOPHILIA & SPORT

Physical and/or sporting activities were not recommended for people with haemophilia until the 1970s. Today certain physical activities are recommended! With the advent of factor replacement and prophylaxis treatments, people with haemophilia have an even broader range of activities from which to choose.

This has raised plenty of questions about suitable exercise and sport for people with haemophilia. Every person with haemophilia is different...so activities that are OK for some people may be more dangerous for others.

WHY PARTICIPATE IN SPORT?

Parents are one of the main people who can encourage sport participation in their children.* This is more than friends, brothers and sisters, and physical education teachers.* In the case of young people with haemophilia, parents and therapists should therefore be on the same wavelength so that the child understands, accepts and dares to participate in sports.*

Desire plays a crucial role in maintaining exercise. It is important to consider the child's likes, because if a child feels that they have to do it, they may drop out. Plus, any exercise or sport needs to be factored into a busy schedule of schoolwork. As with any child, finding a balance between work and play is important for their development.

Children with haemophilia, and their parents, need to understand the benefits of exercise in keeping the joints in good condition. Exercise should continue into adulthood and become part of a healthy lifestyle.

THE BENEFITS OF EXERCISE

- Strengthens bones and increases muscle strength and tone.
- Keeps the structures of the joints in good shape.
- Improves endurance and physical condition.
- Develops interpersonal skills through playing sport with others.
- Reduces stress and anxiety, facilitates sleep and can be LOADS OF FUN!

Sport thus contributes to the child's physical, mental and intellectual development. They teach self-control to the most unruly, confidence to the most timid, autonomy to the most withdrawn, the spirit of decision-making to the most fearful, and above all teamwork.

* Please note that many recommendations and advice stated in this booklet are based on the opinion of Dr. S. Lobet (a physical therapist at the Saint-Luc University Clinics of Brussels). We always advise you to consult your haemophilia treatment centre before taking part in physical activities.

IS SPORT GOOD FOR YOUNG PEOPLE WITH HAEMOPHILIA?

The positive effects of sport and exercise on children are well known. But are the positive effects enough to risk a bleeding episode in children with haemophilia? Choosing the right activity and being cautious from the outset are crucial. There are still many misconceptions, but we now know that sport and exercise are beneficial to children with haemophilia.

Some possible benefits of physical activity for people with haemophilia:

- Strong and coordinated musculature **protects joints** from pressure and trauma, and may reduce joint bleeding
- Sport **keeps joints mobile** through movements with a large range of motion, which may promote lubrication of the cartilage and fights stiffness
- Sport **improves balance, coordination and reflexes**, which may reduce the incidence of sprains, for example, which cause bleeding
- Sport enables **better knowledge and positioning of the body,** which may prevent joint injuries and possibly give children a better grasp of their limits
- Exercise also **reduces the risk of being overweight**

ARE YOUNG PEOPLE WITH HAEMOPHILIA LESS CAPABLE OF PARTICIPATING IN SPORT?

In a Dutch study, young people with haemophilia on prophylaxis who have no joint problems were comparable to other children for:

- Joint range of motion
- Muscle strength
- Motor performance and skills
- Physical condition and endurance

However, children with haemophilia may feel bad as they may not be allowed to participate in all sports.

AT WHAT AGE SHOULD PHYSICAL ACTIVITIES BE STARTED?

Before the age of **5 or 6 years**, children may not have the motor skills, coordination abilities and synchronisation abilities to truly participate in a sport.* However, they can potentially **become familiar** with a sport, become comfortable in the water, learn to control the body, or learn about contact with others.*

Starting at **6 or 7 years of age**, the child's physical capabilities may allow for real participation in a sport.* Learning capability may improve between **8 and 13 years of age**.* Flexibility, dexterity and the sense of balance may then continue to progress.*

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Let's talk about

WHAT PHYSICAL ATTRIBUTES MAY BE DEVELOPED

While learning any physical activity, young people with haemophilia will acquire certain physical attributes such as endurance, strength, flexibility, coordination and balance.

ENDURANCE

Endurance is important to help maintain or enhance physical fitness and health. Endurance exercise is suitable for children and adolescents from an early age. **Swimming, rowing and cycling** are all good to improve endurance. Endurance exercise should be varied, appealing, gradual and individualised, without becoming excessive.

STRENGTH

Although in the past, injuries went along with strength training, young people with haemophilia today are encouraged to build muscle to prevent injuries. Strength improves the work and resistance capacity of muscles, bones, tendons and ligaments, and thus reduces the risk of injury. A strength workout that is too strenuous can be dangerous. The programme needs to be appropriate for the child, to prevent excessive use of muscles and joints.

Developing strength before 10 years of age is unnecessary.* From 10 to 14 years old, **overall muscle strengthening is recommended**.* The program should include a very gradual increase of the weights without overloading the spine and a variety of short muscle-building routines.* After 15 years old, strength workouts can gradually become more strenuous.*

Strength training, fitness or power strength training are not the only sports that effectively lead to strength. Think also about **climbing or rowing**, for example.

CAUTION!

Strength training programmes or general physical training may be beneficial if it includes exercises for strengthening the back and abdominal muscles.

These two muscle groups are the relay between the top and the bottom of the body. Core-strengthening exercises are a very good example.

Please note that decisions regarding the choice and intensity of exercise should be made in conjunction with the child's haemophilia centre.

FLEXIBILITY

Flexibility is a physical attribute that most athletes and health specialists consider important for injury prevention, but it is too often neglected.

The development of flexibility reaches its peak at 12 years of age and then declines.* So it is advisable to work on flexibility starting at 10 years of age while being cautious about the use of the spine and pelvis.* Some non-contact martial arts such **tai chi and stretching programmes** may be good ways to become more flexible.

COORDINATION AND BALANCE

Coordination and balance work on proprioception, the body's ability to recognise changes in the positions of joints and to react quickly as a result. These reflexes can avoid many injuries of everyday life, such as sprains.

This is an important attribute for young people with haemophilia that reduces their risk of trauma.

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Let's talk about

RETHINKING HAEMOPHILIA & SPORT

Classifying sports and exercises into low- and high-risk categories for people with haemophilia can often be too simplistic, leading to excessive restriction. For most activities, there needs to be a distinction between a leisure activity (playing football with friends on the playground), club activity (under supervision of an instructor) and competitive activity (training 2 to 3 times a week plus games on weekends).* The stresses on muscles and joints will be very different!*

There are many leisure activities suitable for people with haemophilia. They help with endurance, strength, flexibility, coordination and balance...and they are good fun too!

When supervised by a competent instructor some "high-risk" activities may often not be too dangerous. For example, some martial arts, when non-competitive and non-contact, improve flexibility and muscle strength.

Competitive activity can offer many positives including setting new personal targets. However, in some cases there may be cumulative stress to joints and an increased risk of bleeding.

Sports should be considered one by one and take into account the desired effect that, the way it is played, the pace and duration, the intensity of the training, the stresses on the joints, the child's age, and above all, the condition of the child's joints.

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CHOOSING THE RIGHT SPORT: DR SÉBASTIEN LOBET´S RECOMMENDATION

The content of the following table is based on the advice of Dr Sébastien Lobet (a physical therapist at the Saint-Luc University Clinics of Brussels) – it lists sports and physical activities for which the levels of risk of bleeding have been defined based on whether they are a leisure, club or competitive activity. A child's interest in a sport depends on many factors such as identification with a professional athlete, participation in a sport by their family and friends, and the child's own experiences.

These recommendations are based on Dr Sébastien Lobet's expertise, and are for information and guidance only to help support patients with haemophilia. Please note that the choice and intensity of exercise should be discussed between the child, their parents and the haemophilia treatment centre.

- **Activities that generally have only very few risks of bleeding.** Activity recommended for all people with haemophilia even if not on treatment.
- **Low risk of bleeding for a patient with mild or moderate haemophilia or for severe haemophilia on prophylactic treatment.**
- **Activity with a moderate to high risk of bleeding if not on treatment or if joint weakness is already present.** In discussion with the treatment team, this activity may be performed by a person with mild or moderate haemophilia, or a person with severe haemophilia on prophylaxis as long as joint condition is monitored.
- **Physical activities with a high risk of bleeding.** Strongly discouraged for all people with haemophilia even if on factor treatment.

SPORT	LEISURE	CLUB	COMPETITION	RECOMMENDED PROTECTION
Archery	🟡	🟡	🔵	Forearm guards
ATV / mountain biking	🔵	🟠	🟣	Helmet, elbow guards
Badminton	🔵	🟠	🟠	Indoor shoes
Baseball	🔵	🟠	🟣	Batting helmet
Basketball	🔵	🟠	🟠	Basketball shoes covering the ankles
Beach volleyball	🔵	🔵	🟠	
BMX	🟠	🟣	🟣	Helmet, elbow guards, wrist guards, knee guards
Bowling	🟡	🟡	🔵	
Contact martial arts and sports (karate, boxing, wrestling, etc.)	🟣	🟣	🟣	Mandatory protection depending on the sport
Cross-country skiing	🔵	🟠	🟠	Proper length skis and poles
Deep-sea diving	🟣	🔵	🟣	Never alone
Diving	🟠	🟣	🟣	
Downhill skiing	🟠	🟠	🟣	Helmet, proper length skis and poles
Fencing	🟠	🟠	🟠	Helmet, gloves
Field hockey	🟠	🟠	🟣	Shin guards
Fitness, strength training	🟡	🟡	🟣	Training by an experienced trainer
Football	🔵	🟠	🟣	Shin guards
Go-carting	🟠	🟣	🟣	Helmet, high-top shoes
Golf	🟡	🔵	🟠	Golf shoes
Handball	🟠	🟠	🟣	Indoor shoes
Horseback riding	🟡	🟠	🟠	Helmet
Indoor climbing	🔵	🔵	🟠	Climbing shoes
Judo	🟣	🟠	🟣	Club only
Motocross	🟣	🟣	🟣	Helmet, boots, protective clothing
Mountain climbing	🟠	🟠	🟣	Good hiking shoes, helmet
Non-contact martial arts (kata, capoeira, tai chi, etc.)	🔵	🔵	🟠	Mandatory protection depending on the sport
Orienteering	🟡	🔵	🟠	Regularly replaced jogging shoes
Parachuting, paragliding, microlighting	🟠	🟠	🟣	Helmet
Road cycling	🟡	🟠	🟣	Helmet, on an appropriate road or bicycle path
Roller skating, rollerblading, ice skating, skateboarding	🟠	🟣	🟣	Helmet, elbow guards, wrist guards, knee guards
Rowing, kayaking, canoeing	🟡	🔵	🟠	Life jacket
Rugby, American football	🟣	🟣	🟣	
Sailing	🔵	🟠	🟣	Life jacket, helmet, never alone
Snowboarding	🟠	🟠	🟣	Helmet, elbow guards, wrist guards, knee guards
Squash	🟠	🟠	🟠	Indoor shoes
Surfing, bodyboarding	🟠	🟣	🟣	Never alone
Swimming	🟡	🔵	🟠	
Table tennis	🟡	🔵	🟠	Indoor shoes
Tennis	🔵	🟠	🟠	Tennis shoes
Track: jumping and sprinting	🟠	🟠	🟠	Running shoes
Track: long-distance running, jogging	🟡	🔵	🟠	Regularly replaced jogging shoes, no flat soles
Track: shot put, javelin, hammer throwing, etc.	🟠	🟠	🟠	Outdoor shoes
Trampoline	🟣	🟠	🟣	Club only
Ultimate frisbee	🔵	🟠	🟣	
Volleyball	🔵	🟠	🟠	Kneepads, indoor shoes
Walking, hiking	🟡	🔵	🟠	Good hiking shoes
Waterskiing	🟠	🟣	🟣	Life jacket
Waterpolo	🟠	🟠	🟣	Cap with ear guards
Weightlifting	🟣	🟣	🟣	
Windsurfing	🔵	🟠	🟣	Life jacket, helmet

Let's talk about

THINKING INDIVIDUALLY

Everyone has limits! Just as people with haemophilia may be unable to participate in certain sports or exercise, people without haemophilia may also have limitations to consider. This may be for medical or other reasons, but nonetheless each of us has to accept our own limits.

This booklet offers guidance on which sport and exercise may be suitable for people with haemophilia. However, other factors can increase the risk of bleeding and trauma. A reckless child may injure themselves more easily doing low-risk activities, whereas a cautious child may be able to do higher risk activities safely.* So "high-risk" can vary from child to child and depends on individual circumstances.*

SPORTS WITH "HIDDEN" RISKS

Without a doubt, combat sports carry risks for young people with haemophilia. But other factors play a part as well. Don't overlook them!

Contact with partners. In many team sports, the risk of collision and contact between players increases the risk of an injury. Competitive rugby is strictly off-limits for people with haemophilia. In most cases, contact can be limited by raising the awareness of the young person to the potential risks. But not everything can be controlled, especially in a competition.

Contact with game equipment. The danger comes from potential contact with game equipment. Think of hockey...contact in this sport is limited, but the consequences of being hit by a hockey stick are serious for young people with haemophilia. Again, when this sport is properly supervised, the risk of injuries is minimised, but there is no such thing as zero risk.

Risk of falling. Many sports can involve falls caused by a mistaken assessment, or by outside factors such as partners, weather conditions or uneven ground. Protection must be encouraged (protective gear, limitation of risk-taking, the right equipment, etc.).

Fast movements. This deals with how fast the athlete makes a movement. Sudden extension of the elbow when pitching a ball, extension of the knee while taking a shot with a soccer ball, etc. are all dangerous for weakened joints. Cyclical controlled movements are preferable such as rowing or cycling, because pain can generally be anticipated and the activity can be stopped if joint problems occur.

SPORT, YES, BUT HOW OFTEN?

Most specialists agree that exercising 2 times a week is a good base, with the ideal being 3 times a week. It is also important to space out the sessions to allow for good recovery and not doing too much strenuous activity at once.

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Let's talk about

BEFORE & AFTER PHYSICAL EXERCISE

Ideally all bleeding should be avoided in young people with haemophilia. Most importantly, the most serious bleeding and repeated bleeding into the same joint should be avoided.

Sports activities are not without risk. People with haemophilia can participate in many sports and the benefits of the sport clearly outweigh the risks. By using some common sense recommendations you will be able to minimise the risks.

INJECTIONS BEFORE OR AFTER SPORT?

In some countries in Europe, such as the UK, most young people with severe haemophilia are on prophylactic treatment, which consists of a preventative injection of the missing coagulation factor. This treatment does not cure haemophilia but stops bleeding after a bleeding event or even prevents bleeding. The treatment is generally given intravenously at home by the child himself/herself or by the parents.

The blood concentration of the medication, and therefore the effectiveness of coverage of bleeding events, declines very quickly. **In order to be truly preventive, the injection of factors should ideally take place BEFORE physical activity**. In practice, if the child has a sports activity during the day or in late afternoon, the child can inject the factor that morning and have optimal coverage for the whole day. It is therefore better if the treatment days correspond with the days of the most strenuous physical activity (training or game). It is preferable not to give the injection before bedtime because the child will lose the benefit of the optimum coverage during the next 10 hours.

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HOW TO PREPARE THE BODY FOR EXERCISE?

Exercise that is started suddenly without warming up is the source of many sports injuries as well as acute bleeding injuries specific to young people with haemophilia. Regardless of the sport, the body needs to be taken care of both before and after exercise to avoid going from resting muscles to working muscles too quickly. Warm up and cool down are essential; they vary in time and are proportional to the exercise.

THE WARM UP*

- Prepares the body with gradual exercise
- Raises the body temperature
- Facilitates circulation from the heart to the muscles
- Increases muscle, tendon and ligament elasticity that is needed for the exercise
- Avoids muscle pulls and sprains

There is a difference between cardiovascular or lung warm up and joint and tendon warm up.* A good warm up consists of three separate but complementary types of exercises:*

1) Running at a slow pace with a variety of movements to warm up the large muscle groups. If it is cold, windy or rainy, muscles should be covered up with warm clothing so they can adequately warm up. Hydration and warming up in the shade are the golden rules in hot weather.

2) Exercises for stretching and limbering up the main muscle groups. These exercises get muscles in condition before the activity. This stretching is indicated after muscle warm up and does not take the place of a proper warm up. The main stretches are described in more detail in the next section. During the warm up, these stretches should be done even more gently because the muscles have not warmed up yet. A stretch that is too sudden can cause injury.

3) Sport-specific warm up including exercises that are technically similar to the athletic exercise to come. For example, warm up the wrists and ankles before tennis or badminton.

CAUTION!

Even on prophylactic treatment, factor level remains below normal. If there is a serious incident, an additional injection of coagulation factors will often be necessary.

Let's talk about

WARMING UP*

01 NECK

Tilt the head to one side then the other, then forward and back. Do this slowly and gradually while increasing the range of motion.

02 NECK

Make big circles in one direction then the other.

03 SHOULDERS

Grab on to a bar or place your hands on a wall with palms down. Keep your arms straight and gradually bend down.

04 SHOULDERS

Gradually straighten your arms above and slightly behind your shoulders.

05 TRICEPS

With your arm above your shoulder, grab your elbow with the other arm and gently pull the elbow downward.

06 FOREARMS & BICEPS

Get down on all fours with straight elbows. Gradually point your thumbs outward and your fingers toward your knees. Keep your palms flat on the floor with your body bending back.

07 WRISTS

Interlock your fingers and make big circles with your wrists in one direction, then in the other.

08 BACK & LOWER BACK

Grab on to a bar or place your hands on a wall with palms down. Keep your arms straight and gradually bend down.

09 LOWER BACK

Lie on your back, bend your knees at a 90-degree angle keeping your feet on the floor. Place both arms at a 90-degree angle. Pivot your knees together to one side, then the other.

10 KNEES

Keeping your back straight, do small flexions and extensions of both knees simultaneously.

11 ANKLES

Make circles with your ankles keeping your toes on the ground. Do this in one direction and then the other.

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Let's talk about

COOLING DOWN*

01

PECTORALS

Place your forearm against a wall with your elbow at a 90-degree angle. Gradually move your body forward keeping your arm against the wall.

02

SHOULDERS

Pull your elbow toward the opposite shoulder by wrapping your arm like you're putting on a scarf.

03

FOREARMS & BICEPS

Get down on all fours with straight elbows. Place your thumbs gradually toward the outside and your fingers gradually toward your knees. Keep your palms flat on the floor with your body bending back.

04

LOWER BACK

Grab both knees and pull them to your chest. Always be sure to keep your lower back on the floor. It cannot lift off the floor.

05

HAMSTRINGS

Gradually lean forward trying to touch your foot. Don't curve your back too much.

06

HAMSTRINGS

Place your heel up with the toes pulled toward you. Bend forward keeping your back straight.

Be sure to keep the foot on the ground parallel with the leg that is up. Support yourself with one hand for better balance if needed.

07

QUADRICEPS

Lean on a support with one hand and use the other hand to gradually bend your knee.

08

GLUTEALS

Bend your knee at a 90-degree angle and place your foot outside the other knee.

Turn your body the opposite way using an arm as a counter support.

09

ADDUCTORS

With the soles of your feet together, gradually let your knees fall open, keeping your back straight. Press lightly on the insides of the knees to increase the stretch.

10

CALVES

Place the stretched leg behind you with the heel on the ground. Bend forward always keeping your heel on the ground.

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Let's talk about

COOLING DOWN

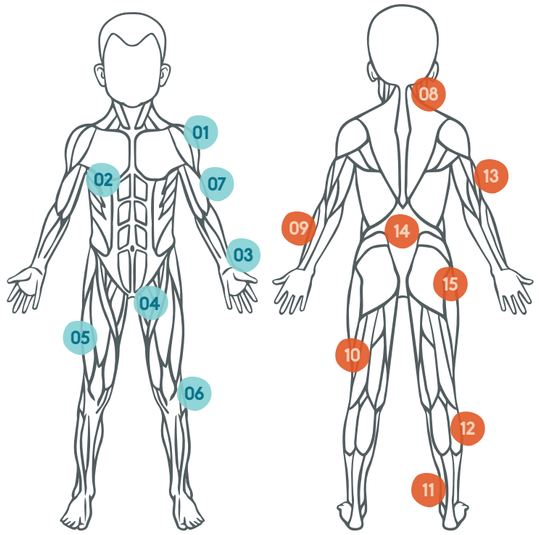
The cool down phase after exercise is very important for recovery and to avoid injury. It aims to lower body temperature and bring the body back to its resting state.

The cool-down stretches on pages 26 and 27 are designed to relax and lengthen the muscles.* As with warm up stretches, these stretches should be done smoothly and gently.

These stretches will become more effective the more they are done (at least twice per muscle group). Each stretch should be held for at least 30 seconds.*

The main muscles and joints to focus on during warm up and cool down:*

01 Shoulders
02 Pectorals
03 Wrists
04 Adductors
05 Quadriceps
06 Knees
07 Biceps
08 Neck
09 Forearms
10 Hamstrings
11 Ankles
12 Calves
13 Triceps
14 Lower back
15 Gluteals



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PROTECTING YOURSELF

The risks of some sports (e.g. skateboarding or roller skating) can be reduced by wearing protective equipment.

If appropriate to your sport:

- Wear a helmet
- Wear wrist guards, elbow guards and knee guards
- Carefully maintain equipment
- Stay "on track" (e.g. stick to cycle paths, don't ski off-piste, etc.)

Let's talk about

WHAT TO DO IN CASE OF BLEEDING

HOW TO RECOGNISE A BLEED

Despite its health benefits, participating in sport will always carry a certain degree of risk for people with haemophilia. Sometimes, joint bleeds are difficult to recognise.

Signs for parents to look out for:*

- Gradual joint swelling
- Limping
- Joint warmth
- Limb flexibility

Signs for the child to look out for:*

- Tingling
- Joint heaviness
- Gradual discomfort
- A feeling of rigidity in the muscle
- Acute pain in the muscle or joint

WHAT TO DO IN CASE OF A BLEED

If in any doubt, treat the child immediately with coagulation factors. This will stop the bleed and limit its complications.

The following actions can limit bleeding and relieve pain:*

- Stop exercising immediately, rest the joint and limit activity for a few days. The affected knees and ankles must not bear any weight
  - The rest period should be limited to 3 or 4 days, otherwise the joint may become stiff. Physical therapy sessions will remobilise the joint gradually and stimulate weakened muscles
- Apply cold to the joint or muscle for about 15 minutes every 3 hours for 2 to 3 days to relieve pain and swelling. Wrap the cold pack in a cloth to avoid agitating the skin
- Elevate the limb to prevent additional swelling
- Put gentle pressure on the joint with an elastic bandage. Be careful not to make it so tight that it interferes with the blood circulation
- For a scratch or small cut, put pressure on the wound for several minutes using a sterile dressing
- Give a pain medication recommended by the doctor
  - Avoid aspirin or intramuscular injections – these could make the bleeding worse

For more serious bleeds, go to the Emergency Room and contact your Haemophilia Treatment Centre, so that treatment can be coordinated.

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SPORT AFTER A BLEEDING EPISODE

After a bleed, physical therapy can help the full recovery of joint function. It is essential to monitor the joint throughout the recovery process. Once recovered, the child may gradually start a sport which is appropriate for their condition, in order to build up long-term joint health.

BIANNUAL PROFESSIONAL CHECK-UP*

Rather than waiting for a bleeding injury, the joints and muscles of a child with haemophilia should be evaluated every 6 months. This evaluation can be used to assess the effects of a particular sport, and to discuss what kind of activity is appropriate for the child.

SPORT AND INHIBITORS

For reasons unknown, some children with haemophilia produce antibodies against the coagulation factor concentrate, known as the inhibition formation process. This compromises treatment, as the child is no longer protected, which may mean that physical activity is not recommended. The haemophilia treatment team and the child should discuss the situation.

SPORT AT SCHOOL*

It is important to have a discussion with the physical education teacher, the child, the parents and the haemophilia treatment team, before participating in sport at school. This will allow the teacher to better understand the child's medical situation, and to identify activities that are potentially high risk.

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Let's talk about

SPORT CAMPS FOR YOUNG PEOPLE WITH HAEMOPHILIA

HAEMOPHILIA SUMMER CAMP

Every year, the Belgian Haemophilia Association **(www.ahvh.be)** organises a week of learning and sports during the summer. It is for children with haemophilia aged 8 to 14 years, and is supervised by a team of sports professionals, camp counsellors and a medical team trained in haemophilia. The camp promotes independence and gives children the chance to interact with other children with haemophilia. Over the week, the children participate in various sports and learn about risk management. They are also taught about daily management of their haemophilia, and are introduced to self-infusion. This gives them the ability to explain their condition to fellow students, teachers, family and friends.

SKI VACATIONS*

Before going skiing, please note that decisions regarding the choice and intensity of exercise should be made in conjunction with the child's haemophilia centre. For children with haemophilia, the following protective measures can manage the risks of skiing and snowboarding:

- Snowboarding and skiing are demanding sports. Several weeks of physical training are required in advance
- Equipment appropriate for the child's height and age is mandatory (appropriate length of skis and poles)
- Protective gear is essential to avoid injuries. A helmet, wrist guards, etc. are strongly advised
- Courses help the children to improve their technique
- Because falls are promoted by fatigue, the child should start gradually and take it easy during recovery time
- Following safety instructions is crucial. Be doubly cautious when the snow is hard, and control trajectory and speed in all circumstances
- Children with severe haemophilia should take prophylactic treatment the morning before the first run

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TRAVEL

In case of travel to another country, the child must take the necessary precautions and a supply of treatment. It is also important to carry the addresses and contact information for haemophilia treatment centres abroad. It is recommended to take along a certificate issued by the child's treatment centre.

The Haemophilia Association has the addresses of foreign centres and certificate templates. You can find the list of treatment centres on the internet at http://www.wfh.org under “Resources” then “Treatment Centre Directory (PASSPORT).”

IN CONCLUSION...

One thing is for sure: the benefits of a physical activity for young people with haemophilia outweigh the risks. As well as its overall beneficial effects on the body, appropriate physical activity keeps the muscles and joints of a person with haemophilia healthy.

The choice of sport is important and will be different for every child, depending on their personal preferences and physical capabilities. It should be discussed by the child with haemophilia, their parents and their referral team.

Although high-risk sports should be avoided, with a few precautions children with haemophilia can participate and find fulfilment in a great many physical activities.

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GLOSSARY

ARTHROPATHY:	A joint injury
COAGULATION:	The body's mechanism for stopping bleeding
FLEXION-EXTENSION:	Bending and straightening the legs, for example
HAEMORRHAGE:	Bleeding or a flow of blood after rupture of a blood vessel
INHIBITOR:	A type of antibody that cancels out the action of coagulation factors
INTRAVENOUS:	Given into a vein
JOINT CONDITION:	The general condition of all joints
JOINT DAMAGE:	Damage in joints
LIGAMENT:	Connective tissue that joins one bone to another bone; similar to tendon in that it is made of collagen
LUBRICATION:	The action of making something slippery
PROPHYLACTIC TREATMENT:	A treatment consisting of preventive injections of a coagulation factor (generally 2 to 3 times a week)
PROPRIOCEPTION:	The body's ability to recognise position changes of joints and to react quickly as a consequence
RIGIDITY:	Stiffness
TENDON:	Connective tissue that joins muscle to bone; similar to ligament in that it is made of collagen
TRAUMA:	All of the local or generalised manifestations caused by an injury or a blow to the body

NOTES

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WRITING AND ADVICE

This brochure was written by Sébastien Lobet, a graduate in sports physical therapy and specialised in paediatric orthopaedics. Sébastien is a physical therapist at the Saint-Luc University Clinics of Brussels (Catholic University of Louvain [UCL]) in the Hematology Department of Professors Cedric Hermans and Christiane Vermylen. In charge of the evaluation and treatment of children and adults with haemophilia since 2000, he has additional training at haemophilia referral centres in London and Brisbane.

Sébastien is also a part-time researcher in the UCL Physical Medicine and Rehabilitation Unit. In 2012, he completed a doctoral thesis (PhD) on the dynamic evaluation of haemophilic arthropathy using 3-dimensional modelling of walking.

Sébastien is also a sports enthusiast. He plays competitive tennis and volleyball and regularly runs marathons. As a physical therapist, Sébastien's main role is the daily treatment of patients with joint after-effects of haemophilia. As a teacher, his role with children who do not have joint after-effects is to prevent bleeding incidents including through regular physical activity.

This expertise is made possible only through regular evaluation of joints and muscles at a specialised consultation at the haemophilia referral centre.

DISCLAIMER

This brochure was produced by S. Lobet (a physical therapist at the Saint-Luc University Clinics of Brussels) with the support of Pfizer. The advice and information given in this brochure were written objectively for the sole purpose of providing young people with haemophilia and their families the most complete and pertinent information possible. It is for information only. We always advise you to consult your haemophilia treatment centre before taking part in physical activities. Neither the author, the publishers nor the sponsor are liable for the information given in this brochure, and they disclaim all liability in case of injury.

CHANGING THE WORLD
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