

GLOBAL NEWS SERIES FOR HEMOPHILIA NURSES



Second Issue

Message from the Editor

From the feedback we have received, the first edition of the Global News Series for Hemophilia Nurses was a success. Thank you for your responses. I hope you enjoy the second edition which focuses on Joint Health. For those who may be receiving the Global News Series for the first time, its purpose is to share knowledge, experience and current events among hemophilia nurses around the world. It is sponsored by an educational grant from Baxter Bio-Science. Each edition will be developed in conjunction with nurses specializing in the care of persons with hemophilia.

The June edition of the Global News Series for Hemophilia Nurses was sent to over 300 nurses in 34 different countries. Regarding your messages, most comments were positive, some gave suggestions for improvements and other comments were on the opposite end of the spectrum. We

expected that because everyone needs different information. We will continue to try to provide hemophilia nurses with quality information that can be used by as many as possible. Due to the variation in approved therapies and practices, we will not provide specific prescriptive recommendations or treatment guidelines.

The best way for us to make this useful to you is through feedback on the current edition and sharing ideas and topics for upcoming editions. We also welcome your participation as a subject matter expert in the development of this newsletter. To provide feedback or express your interest as a subject matter expert, please e-mail us at contactus@solutionsight.com or write us at SolutionSight, Inc., 2191 Avalon Drive, Buffalo Grove, Illinois 60089. ❖

Cindy Ping, RN, BSN, MBA, CPP

Advisory Board September 2006

We are pleased to introduce the subject matter experts for the second edition of the Global News Series for Hemophilia Nurses. We graciously thank and acknowledge Sue Geraghty, RN, MBA and Kate Khair, RN for their support in the development of this edition of the newsletter. Their knowledge and honest feedback, coupled with their expertise in orthopedic and pediatric hemophilia conditions, have added to the newsletter. Sue Geraghty is the Nurse Coordinator at Mountain States Regional Hemophilia and Thrombosis Center located in Aurora, Colorado. Kate Khair is a Nurse Consultant at the Haemophilia Centre, Great Ormond Street Hospital for Children in London, England. ❖

This Issue's Focus

Joint Health

Physical activity allows us to do all kinds of things we enjoy. For that reason, joint health is very important to the hemophilia patient and his family. Joint bleeds are one of the most frequently occurring complications with hemophilia and are a major concern in hemophilia care. Prevention and treatment of joint bleeds are keys to an active lifestyle. In this edition, an overview of the anatomy and physiology of joints will explore the components and function

of a healthy joint before we discuss the physiology of joint damage. Several aspects of keeping joints healthy are presented: nutrition and weight control, exercise, physical therapy/physiotherapy and adherence to a treatment plan. Specific guidelines for weight training, aerobic exercise and preparing for sports activities are included. Simple methods of treating damaged joints as well as surgical interventions are addressed. ❖

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Joint Health

More than "Just Joints"

Anatomy of a Joint

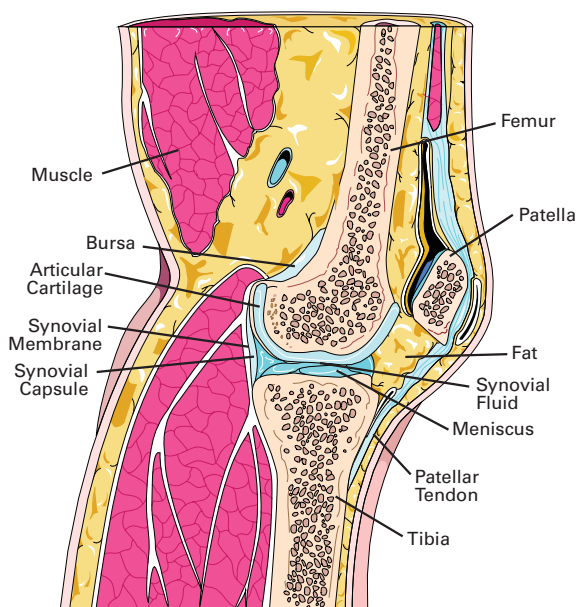
Joints are amazing! Their anatomical complexity and the things they allow us to accomplish are quite spectacular when you think about it. A joint is formed where a bone meets another bone. The structure of the joint depends upon its function. The union might be rigid or there may be quite a bit of motion in the joint. Motion may occur in one, two or three planes of movement. The security of a joint depends upon the closely fitting parts of the joint, including bones, ligaments, muscles and tendons. A joint has numerous parts and functions.

The basic parts of the knee joint are shown in this graphic. Each part has its own function:

- **Bones** – primary support component of the body
- **Cartilage** – translucent, elastic tissue that covers the end of bones at the location where they meet one another; allows the surfaces of the bones to move smoothly on one another; also acts as a shock absorber
- **Meniscus** – fibrous cartilage within the joint
- **Bursa** – small fluid-filled sac between a bone and a tendon assisting in proper functioning of the joint
- **Synovial or Joint Capsule** – tough, elastic casing that surrounds and protects the joint

- **Synovial Membrane** – lining on the inside of a synovial (joint) capsule; contains many small blood vessels and produces synovial fluid
- **Synovial Fluid** – a clear fluid that fills the joint capsule; protects the bones from wear and tear and makes the bones in the joint slide over each other smoothly
- **Muscle** – tissue that functions to produce motion and is capable of contraction when stimulated
- **Ligaments** – tough band of tissue connecting bone to bone, or bone to cartilage
- **Tendons** – tough band of dense, fibrous tissue connecting muscle to bone

Knee Joint



How a Joint Functions

Joints allow us to move, bend and straighten body parts. Muscles, ligaments and tendons are all involved in supporting the bones of the joint and making the joint more stable. Muscles move body parts through contraction (shortening) and relaxation (lengthening) of the muscle fibers. The power behind movement comes from the muscles. Ligaments keep bones in the joint from moving the wrong way and dislocating, while tendons provide additional support between the muscle and bone. Joints bend when all these parts work together effectively.

Keeping Joints Healthy

Staying strong is one of the best ways to keep joints healthy and prevent joint bleeds. If joints are strong and healthy, the person with hemophilia is less prone to joint damage.



Once a bleed occurs, rehabilitation of damaged joints is aided if the patient is strong. Using good judgment in daily activities helps keep joints from being injured by avoiding high-risk behavior. Good nutrition and appropriate exercise are vital in strengthening bones, muscles, ligaments and tendons. Physical therapy/physiotherapy is important for recovery once injury or damage has occurred in a joint. Adherence,

Key Term

Target Joint: A joint in which recurrent bleeding has occurred on four or more occasions during the previous six months.

Frequency of a target joint is:

- Most likely – elbow, knee or ankle
- Rare – shoulder or hip
- Least likely – wrist, fingers or toes

Consequences of a target joint:

- Once identified, the joint may always have a problem
- Once damage is done, arthritic changes are likely to develop

sticking to a treatment and activity plan, is also a large part of keeping joints healthy.

Maintaining a healthy weight is not always easy, but it is very beneficial for many reasons. A healthy weight means less stress on a joint. A balanced diet can help a person lose weight and maintain their goal weight.



Exercise strengthens muscles, ligaments and tendons leading to fewer bleeding episodes and lessens the risk of joint disease. Strong muscles reduce the chance of injury while flexible tendons allow a greater range of motion. Aerobic exercise increases the need for oxygen through sustained activity using the large muscle groups. This type of exercise places increased demands on the cardiovascular system. Other benefits of exercise include increased energy and an overall feeling of wellbeing.

Physical therapy/physiotherapy involves physical treatments, exercises and activities that help restore function, improve conditioning of the joints as well as reduce the chance

of permanent joint damage. It is usually employed following significant bleeding episodes or a surgical procedure. A therapist evaluates a patient's condition and creates a program of treatment with exercises that fit the patient's specific needs.

Adherence, another important aspect of joint health, involves sticking to a

Related Resources:

US Department of Agriculture
www.nal.usda.gov/fnic

UK Department of Health
www.dh.gov.uk/

treatment plan and faithfully following the guidance of the treatment center and/or medical team. This includes recognizing symptoms of bleeding and starting treatment at the first sign of a bleed. It involves knowing when and where to go for treatment as well as who to contact on the healthcare team with a problem. Keeping good records related to bleeds, treatments and infusions is an important part of adherence. It provides the healthcare professionals with the information they need to adjust the treatment regime for the patient's needs.

Physiology of Joint Damage

In a healthy joint, synovial fluid protects and lubricates the cartilage. The majority of bleeding episodes associated with hemophilia occur within the joints with almost 80% of them seen in the knees, elbows and ankles.¹ When a bleed occurs, blood leaks into the synovial membrane and then into the joint capsule. A small amount of blood in the joint capsule may not cause serious damage, but if the bleeding is not stopped, the blood fills the joint capsule and is reabsorbed into the surrounding tissue, causing the tissues to stretch and become damaged. The reabsorption of blood causes the synovial membrane to grow and thicken with more blood vessels making joint bleeding easier in the future. When multiple bleeds occur, enzymes are produced by the synovial membrane causing more joint swelling and an increase in the amount of iron deposits in the joint. When bleeding persists and the synovium starts to hypertrophy, a vicious cycle of chronic synovitis develops, leading to joint destruction.

... continued on page 8

“Adherence, sticking to a treatment and activity plan, is also a large part of keeping joints healthy.”

Living with Hemophilia **Steps to Joint Health**

These action steps can help to meet the goals of managing hemophilia and joint health.

1. Comprehensive care

Delivery may vary from place to place, but usually includes an annual comprehensive checkup, which is an important part of the evaluation of joint health and treatment requirements.

2. Good nutrition and weight control

Keep joints from being stressed with excess weight.

3. Exercise

Stay strong and healthy; use good judgment with physical activity.

4. Recognize signs of bleeding

5. Treat bleeds early and adequately

Use prescribed treatment that is available at the time.

6. Get vaccinated

Hepatitis A and Hepatitis B are preventable.

7. Regularly get tested for blood-borne infections

8. Practice adherence

Stick to a specific treatment and activity plan.



For more resources and suggestions, log on to
www.SolutionSight.com/September2006

Adjunctive Therapy **R.I.C.E.**

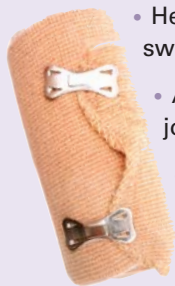
Rest.I.C.E.

- Helps stop bleeding; prevents further damage to the joint
- Supports the joint; reduces joint pain
- Reduces swelling
- If needed, use bedrest, splint, sling, crutches or wheelchair as suggested by medical team

R.Ice.C.E

- May be less available in some parts of the world
- Reduces swelling and pain
- Things that work:
 - A bag of crushed ice
 - A bag of frozen vegetables (peas or corn work well)
 - A commercial ice pack product
- Place a lightweight cloth between the ice and bare skin
- Leave on no longer than 20 minutes at a time
- Wait at least 40 minutes before applying again

R.I.Compression.E



- Helps reduce pain and swelling
- Apply pressure around the joint
- Use an elastic bandage or compression wrap/stocking
- Use pressure that is snug enough to support the injury but not uncomfortable

R.I.C.Elevation

- Keep joint elevated as much as possible, preferably above the level of the heart
- Helps blood flow away from the joint to reduce swelling

Joint Health Treating Bleeds

The most important thing to do when responding to a joint bleed is to treat with factor as soon as possible.¹ Use the amount of factor recommended by the treatment center or

medical team to raise the factor level high enough to stop the bleed. Other agents used in treating joint bleeds are briefly discussed below. An easy-to-use adjunctive therapy for bleeds is R.I.C.E. – rest, ice, compression and elevation of the affected area.

Factor Replacement

Provision of some safe and affordable coagulation factor concentrates is essential for major bleeding and surgery. Low dose strategies for surgery in developing countries have been shown to be effective with acceptable rates of bleeding.² In western countries, common standards of care fall into one of two categories: on-demand or prophylaxis. On-demand treatment involves treating bleeding episodes once they arise. Prophylaxis involves the infusion of clotting factor on a regular schedule in order to keep clotting levels sufficiently high to prevent bleeding episodes.³

On-demand Treatment

Treating hemophilia on-demand is the treatment of choice for the majority of people with hemophilia. Treatment regimens will differ depending on regional practices, healthcare professional preferences, product and therapy availability and patient requirements. On-demand therapy is used only as needed, but should be started as soon as the bleed symptoms appear. Prompt and aggressive treatment is important in stopping the bleed and subsequent

For in-depth discussion of these therapies, request the June 2006 edition of the Global News Series for Hemophilia Nurses at contactus@solutionsight.com

damage to the joint. This may be the preferred treatment for patients with mild hemophilia, moderate or severe hemophilia when bleeds are infrequent, and difficult venous access.

Prophylaxis Treatment

Prophylaxis is preventative treatment, infusing factor on a regular schedule to prevent bleeds. This keeps factor level in a moderate range. The medical team determines the best dosage and frequency for the patient after reviewing the patient's health records and bleeding patterns. This type of treatment may be best suited for severe Factor VIII/Factor IX deficiency, when a target joint develops (secondary prophylaxis), or for a short term following surgery or severe bleeding.



Other Therapies

Desmopressin (DDAVP) is a synthetic analogue to a natural hormone that can be administered intranasally (IN), intravenously (IV) or subcutaneously (SQ). It is inexpensive and has no risk of blood-borne viral infections. This treatment will not work for patients with severe hemophilia, but it is one other option for controlling bleeding with those who demonstrate an adequate response to this medication.⁴ In the World Federation of Hemophilia publication "Treatment Options in the Management of Hemophilia in Developing Countries," the author discusses the use of cryoprecipitate and plasma for treating joint bleeds.³ ❖

1. Treating Bleeds. www.hemophiliagalaxy.com/patients/managing/joint/bleeds.html
 2. Srivastava A. *Haemophilia*. 1998;4(6):799-801.
 3. Hemophilia – Treatment. <http://en.wikipedia.org>
 4. Chandu M. *Treatment Options in the Management of Hemophilia in Developing Countries*. World Federation of Hemophilia. 2005;12, No.57.

Joint Health Treating Damage

Evaluation of Joint Disease

Treatment of joint disease starts with an examination of the musculoskeletal system. Initially, a medical team member (physician, nurse, physical therapist/physiotherapist, etc.) will evaluate the patient's range of motion, bony overgrowth, as well as signs and symptoms of target joint development. In addition to plain radiographs, computerized axial tomography (CAT scan) sonography and magnetic resonance imaging (MRI) are modalities used in the evaluation



Total Hip Arthroplasty

process.¹ An MRI can be used to detect early synovial and cartilaginous changes that may not be evident on conventional radiography and to differentiate between acute and chronic bleeding in soft tissues. A CAT scan is useful in evaluating subtle bony erosion and intra/extraosseous pseudotumors. Sonography is valuable in following the progression and regression of soft-tissue hematomas.

Surgical Options

A variety of surgical options exist for a patient with severe joint damage. Orthopedic surgery for the hemophilia patient is very specialized and usually performed by an orthopedic surgeon with knowledge and experience in treating an individual with hemophilia. Surgical care should always be planned with the treatment center's involvement. Orthopedic surgery is considered appropriate when:

- Conventional factor replacement no longer controls bleeding episodes
- A large, thick, baggy synovium exists

- Factor replacement and radionuclide synovectomies no longer help the symptoms
- Movement is very difficult and painful with decreased range of motion
- Arthritic changes have occurred as documented on radiograph

The most common orthopedic surgical procedures for a hemophilia patient are:

- **Radionuclide Synovectomy** – a procedure that injects radioactive material into the joint. This scars the lining of the joint and slows the growth of new synovial or joint cells.
- **Synovectomy** – a surgical procedure to remove excess synovial membrane. A thin layer of tissue grows back with fewer bleeds experienced. This procedure is performed arthroscopically or open.
- **Arthrodesis** – fusion of bones in a joint using staples, screws or bone grafting.
- **Arthroplasty** – a total joint replacement. The damaged portions of the joint are removed and replaced with metal, ceramic or plastic prosthesis.



Ankle Fusion With Screws



Total Knee Arthroplasty

With surgical procedures, follow-up care is critical for continued optimal use of the joint. Physical therapy/physiotherapy allows the patient to regain as much use of the joint as possible. Factor replacement helps to keep future bleeds under control. ❖

1. Hermann G. *American Journal of Roentgenology*. 1992;158:119-125.

Joint Disease FAQs

1. Is joint damage preventable?

Joint disease can be prevented. The right treatment plan, good nutrition and weight control, regular exercise and yearly check-ups can all be part of the prevention.

2. Why is a written record so important?

A written record allows the treatment center to tailor a treatment plan for the patient. The record should include:

- Location and severity of the bleed
- Time of bleed, infusion and dosage
- Symptoms and pain level
- Factor batch numbers

3. Why is it important for a patient to visit a medical team or treatment center at least once a year?

Comprehensive care allows healthcare professionals to evaluate the health status of the person with hemophilia and adjust treatment recommendations to address the current needs.



4. Why is it important to maintain a healthy weight?

Maintaining a healthy weight can be difficult, but helps prevent damage to the joints. Less weight means less stress on the joints.

5. Why is exercise important?



The benefits of being active can reduce the risk of future bleeds by improving strength, flexibility and balance. Strong muscles protect the joints.

Upcoming Events Conferences

12-14 October 2006
**58th Annual Meeting of the
National Hemophilia
Foundation**

Philadelphia, PA, U.S.
E-mail: meetings@hemophilia.org
www.hemophilia.org

9-12 December 2006
**46th Annual Meeting of the
American Society of
Hematology**

Orlando, Florida
E-mail: ash@hematology.org
www.hematology.org

19-20 April 2007
Canadian Hematology Meeting

Buenos Aires, Argentina
E-mail:
direccion@hematologia.anm.edu.ar

5-6 May 2007
**WFH 10th Musculoskeletal
Congress**

Milan, Italy
E-mail: msk2007@wfh.org
www.wfh.org
Call for Abstracts deadline:
7 February, 2007

6-12 July 2007
XXI ISTH Congress

Geneva, Switzerland
E-mail: isth2007@mci-group.com
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14-16 September 2007

**40th Biannual
Congress of
ESPFI
(European
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Pediatric
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Immunology)**

Athens, Greece
E-mail: info@esphi.org
www.esphi.org



For further detailed
information, go to:

www.SolutionSight.com/September2006

Maintaining Health Exercise & Sports

An active lifestyle is an important part of staying healthy. People with bleeding disorders should be strongly encouraged to exercise and/or participate in sports programs. Before beginning an activity, it is important to meet with the treatment center and/or medical team to make sure the activity is appropriate for the person with hemophilia and his family. Part of the preliminary plan is to discuss the possibilities of a bleeding episode and the resulting action to be taken.



Conditioning Program

Once an activity is determined to be acceptable, a conditioning program is the next step. Conditioning will decrease the possibility of injury and focus on muscles used for the chosen activity. A total conditioning program includes:

- Stretching for improving flexibility
- Use of resistance equipment or weight training for increasing muscle strength which helps support joints and muscles
- Aerobic training for improving cardiovascular fitness and endurance
- Practicing skills specific to the sport or activity



Preparing for Sports

Preparing for an exercise or sports program will reduce the chance of injury and increase peace of mind. Here are some steps that you can suggest the person with hemophilia take before beginning a new activity:¹

- Discuss the sports activity with the medical team. Evaluating joint flexibility, ligament stability, muscular strength and overall health will provide a better sense of which sports are most appropriate.
- Schedule a meeting with the parties that will be involved in the actual sports activity (trainers, coaches, school nurses, etc.) to discuss the healthcare needs of the person with hemophilia.
- A conditioning program for the new activity is important.
- Know the early signs of a bleed and treat bleeding appropriately.
- Consider the timing of sports in relation to treatment administration.
- Prophylactic factor administration may be considered.
- Wear properly fitted equipment and a medical identification necklace or bracelet.
- Practice good nutrition and drink adequate amount of healthy liquids.
- Slowly build level of activity. Do conditioning exercises to improve flexibility and endurance.
- Refrain from activity when treating or recovering from a bleed. ❖

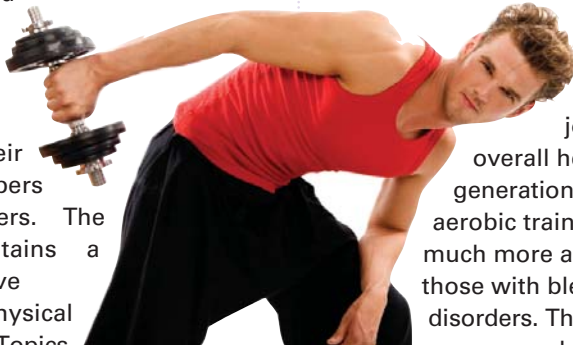
1. Living Well – Preparing for Sports.
www.hemophiliagalaxy.com/patients/living/sports/prepare.html

Interview with an Expert

Weight Training

The National Hemophilia Foundation (NHF) recently published a new educational booklet entitled *“Playing It Safe: Bleeding Disorders, Sports and Exercise”* by Alice Anderson, PT, MS, PCS and Angela Forsyth, MS, PT. This resource is a valuable tool for people with bleeding disorders, their family members and caregivers. The booklet contains a comprehensive catalog of physical activities. Topics include: conditioning, stretching and flexibility, weight training, cardiovascular exercise and sports. Also included is a safety chart rating many recreational activities and exercise regimens for people with bleeding disorders.¹

Alice M. Anderson, co-author of the NHF booklet, is the clinical team leader of Physical Therapy at Children’s Medical Center of Dallas. She is a board certified clinical specialist in pediatric physical therapy by the American Board of Physical Therapy Specialists. She serves as adjunct faculty at the University of Texas Southwestern School of Physical Therapy and guest lecturer at Texas Woman’s University School of Physical Therapy focusing on pediatric physical therapy. Ms. Anderson presents on the role of physical therapy for persons with bleeding disorders on local, national and international levels. She was awarded “Physical Therapist of the Year” by the National Hemophilia Federation (NHF) in 2005. Ms. Anderson would like to share the following information regarding resistance or weight training and aerobic exercise.



Alice Anderson, PT, MS, PCS:

More people today with bleeding disorders are likely to be involved with exercise and sports than ever before. Prophylaxis and improved treatment options allow the person with hemophilia a greater quality of life with better joint status and overall health than prior generations. Weight and aerobic training are now much more accessible for those with bleeding disorders. The recommendations below are from the American College of Sports Medicine, American Heart Association, and Centers for Disease Control and Prevention.

Resistance or Weight Training

- Before beginning a weight-training program, first check with your treatment center or medical team regarding possible prophylaxis before you begin the activity.
- Weight training helps to maintain muscle strength and prevent joint or muscle bleeding.
- Weight training builds strength by increasing the amount of weight used or repetitions, but it is very important not to put undue stress on joints.
- Young teens should not lift heavy weights until they are past puberty to avoid injuring the growth plates of their bones.
- Power lifting is a competitive sport that demonstrates maximum lifting ability through sudden, quick maneuvers and is NOT recommended for people with hemophilia.
- Begin by using resistance machines, under the supervision of

a therapist or trainer. Master the proper technique with the resistance equipment, then, free weights can be safely introduced. Form is the most important aspect of weight training.

- Using less weight with more repetitions helps keep injuries minimized.
- Warm-up, stretching and cool-down periods should always be part of the program.
- Frequency, duration and intensity will vary and the therapist or trainer will give you specific direction.
- Spotting, having another person there to watch and help you, and maintenance of good breathing are essential with this activity.
- Stop exercise in the presence of pain. Do not lift weights with any muscle or joint that is currently bleeding. Do not exercise if ill or overly fatigued.



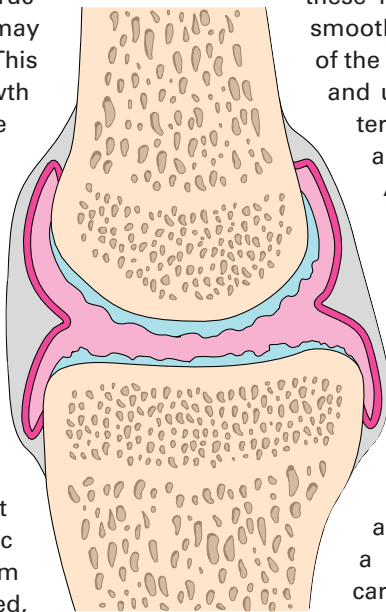
Aerobic Training

- Involves low to moderate exertion over extended time periods. Thirty minutes of moderate-intensity activities are recommended daily.
- By increasing the length of time and frequency of exercise, participants gradually become more fit. These time periods can be divided into shorter segments of time throughout the day.
- At least 50-60 minutes of aerobic activity 5 times per week is usually required for weight loss in adults.
- Lower impact training is better, leading to less potential for a bleed. ❖

1. Anderson A and Forsyth A. *Playing It Safe: Bleeding Disorders, Sports and Exercise*. National Hemophilia Foundation. 2005.

For more resources and suggestions, log on to www.SolutionSight.com/September2006

Rodriguez-Merchan¹ explains that in immature joints, this synovitis causes hypertrophy of the epiphyseal growth plates and significant structural deficiencies may rapidly develop. This stimulus to the growth plates results in bone hypertrophy, leg length discrepancy and angular deformities. In mature joints, hemophilia has a major detrimental effect on the joint cartilage. As it progresses, joint function deteriorates with loss of joint space becoming the most important radiographic finding. As the synovium becomes more scarred, there is conversion from weakened tissue congested with blood to fibrotic scar tissue. In time, the synovial membrane is destroyed by the recurring bleeds,



Cartilage Erosion

and scar tissue replaces the previously healthy synovial membrane. Erosion of cartilage also occurs with these repeated bleeds. The smooth cartilage at the ends of the bones becomes rough and uneven due to the interaction of the enzymes and iron deposits. Arthritis and eventual destruction of the joint are seen.

Roosendaal and Lafeber² describe the pathogenesis of hemophilic arthropathy as multifactorial. Their work shows intra-articular blood first has a direct effect on cartilage and then affects the synovium. Both processes occur at the same time, probably not depending on, but influencing each other. They go on to say that because of recurrent hemarthroses, specific changes occur

in the synovium and cartilage. Current concepts believe the synovium becomes catabolically active due to its exposure to blood components, and as a result induce cartilage destruction. Reports concerning blood-induced joint damage suggest that synovial changes have a leading role in the development of joint damage and therefore precede the changes in cartilage. There are also observations that question whether it is the only and the initiating mechanism of joint damage in hemophilia. Some believe that intra-articular blood has a direct harmful effect on cartilage before synovial changes. This suggests that joint damage may occur before synovial inflammation is evident.² ❖

1. Rodriguez-Merchan EC. *Clinical Orthopaedics and Related Research*. July 1996;328:7-13.
2. Roosendaal G. *Haemophilic Joints New Perspectives*. 2003:12-16.

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