

## Education Division Mission Statement

The Education Division at HSS is committed to being the source for outstanding initiatives in education, training, research and information for local, national and international communities to prevent and treat musculoskeletal conditions.

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## Arthroscopy of the Hip: What You Should Know

by Robert T. Buly, MD, Associate Attending Orthopedic Surgeon

The hip is a ball and socket joint. The head of the femur bone and the acetabulum (socket) are both covered with articular cartilage and enclosed by a tough, soft tissue capsule that holds the joint together and contains the synovial fluid that nourishes and lubricates the cartilage. In addition, the socket rim is deepened by the labrum (*lip* in Latin) that is made of rubbery fibrocartilage. The labrum is very analogous to the meniscus in the knee, with which most people are more familiar. When these structures are damaged or degenerate, the painful consequences will cause patients to seek medical attention.

The hip should provide a lifetime of painless function. However, certain conditions or events may cause structural damage very early in life. Trauma, of course, may occur at any time. Fractures may damage the bone or articular cartilage and are especially dangerous when the joint surfaces are displaced. Dislocations or repetitive stresses, especially in athletes, may damage the soft tissues and labrum in the absence of bone trauma. There are certain pathologic conditions in which the bony anatomy may be abnormal from birth or become abnormal during growth and adolescence. The two most common are hip dysplasia and femoral-acetabular impingement. Hip dysplasia refers to a shallow socket leading to insufficient weight-bearing contact between the head of the femur and the socket. Femoral-acetabular impingement occurs when there is an excessive bony ridge on the femoral head, leading to restricted range of motion and repeated damage to the rim of the socket. Because of the abnormal anatomy, the articular cartilage and labrum are subjected to abnormal stresses and may degenerate at a very young age, even in the teenage years. If left untreated, these conditions may lead to extensive loss of the articular cartilage (osteoarthritis) and ultimately total hip replacement. It is our goal to diagnose these conditions at an early stage and then provide surgical treatment, when necessary, to help prolong the service life of the hip.

Patients with these hip disorders will often present with an ache in the groin that is especially noticeable while walking or participating in athletic activities. Sometimes prolonged sitting is more painful than upright activities. The location of the pain is hard to pinpoint, and often patients are misdiagnosed as having a hernia, gynecological or abdominal problem. In addition, there may be a mechanical component, such as locking, clicking or catching that is especially noticeable with certain movements.

If the situation does not improve after a reasonable course of conservative measures, further investigation is required. The patient should see a physician who is familiar with disorders of the hip. X-rays with special positional views are extremely important and will often reveal the underlying cause.



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# Measuring Bone Quality

by Adele L. Boskey, PhD, Starr Chair in Mineralized Tissue Research  
Director, Musculoskeletal Integrity Program

**O**steoporosis is the most prevalent bone disease affecting aging adults in the U.S. and abroad. In the U.S. it is estimated that more than 1.3 million osteoporotic fractures occur each year. The National Osteoporosis Foundation estimates that one in two women and one in eight men are at risk for suffering such a fracture. The routine, clinical way to detect patients at risk of osteoporotic fractures is a bone density test. Scanning the spine, hip or wrist and comparing the amount or density of bone per unit area (BMD) to that of young adult women can provide a suggestion that the patient has too little bone mass and is at risk of fracture. However, many individuals with equivalent BMD scores do not sustain fractures, presumably because their bone is of better quality.

**What is Bone Quality?** The definition of bone quality is very elusive. In fact, the National Institutes of Health and the American Society for Bone and Mineral Research co-sponsored a workshop entitled “Bone Quality: What Is It and How Can We Measure It?” Bioengineers defined quality in terms of the measured strength of bone; radiologists in terms of density or the presence of detectable abnormalities; endocrinologists in terms of evidence of bone breakdown — the presence of breakdown products of bone components in the blood or urine (bone markers); and clinicians in terms of the number of fractures the individual in question sustained. Bone is a complex substance consisting of both mineral crystals (the hard, inorganic part) and pliable organic substance. In addition to mineral density (the amount of bone per unit area as assessed from the bone density test) and the structure of the bones, the characteristics of both the mineral and the matrix

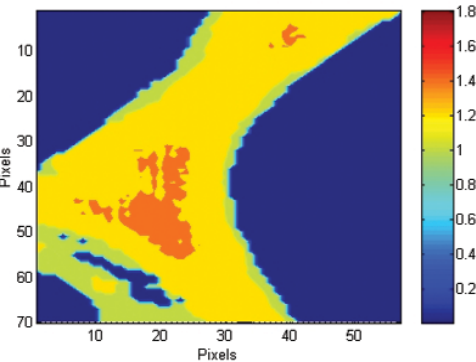
### Bone Quality-What Is It?

The characteristics of bone that alter its response to load and lead to fractures are:

|                                                                                                               |                                                                                                                                     |
|---------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"><li>• Mineral Content</li><li>• Bone Size, Geometry, Connectivity</li></ul> | <ul style="list-style-type: none"><li>• Presence of Micro-cracks</li><li>• Mineral Properties</li><li>• Matrix Properties</li></ul> |
|---------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------|

(the non-mineral part of the tissue in which the bone cells are embedded) can have a significant effect on the ability of the bone to resist fracture.

**How Do We Measure Bone Quality?** Here at Hospital for Special Surgery (HSS), we are developing methodologies based on the novel application of infrared spectroscopy. This technique, commonly used to identify the composition of materials based on the vibrations they produce when excited by light from the invisible (red) end of the spectrum coupled with a microscope, shows the infrared spectrum of bone at discrete locations.



▲ Image of the spatial distribution of mineral crystal sizes in a bony trabeculae (element connecting bones) in a healthy person. The largest crystals are in the center of the structure.

We obtain images (such as the one shown above) that indicate the amount of mineral present at each location in the tissue, the average sizes of the mineral crystals and the composition of both the

mineral and matrix. We combine this information with mechanical testing, chemical analyses and histology (the microscopic description of the tissue provided by a pathologist) to validate our data. Using a small piece of bone obtained during biopsy or fracture repair, we examine a thin section of unstained tissue and record infrared spectra with a resolution of 6-7 microns (about the diameter of a red blood cell). We have already demonstrated that bones from patients with osteoporosis have a decrease in the amount of mineral present, and an increase in the size of the mineral crystals, along with an increase in the apparent age of the major non-mineral

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### Get Moving!

The HSS Public and Patient Education Department offers a variety of exercise and wellness classes for all fitness levels, each designed to help you achieve a healthier lifestyle. Find a program that’s right for you. Classes fill quickly, so reserve your spot now. Register online at [www.hss.edu/shopping](http://www.hss.edu/shopping) or call 212.606.1057 for more information.

# Lupus Research Overview

by Michael D. Lockshin, MD, MACR  
Attending Rheumatologist  
Director, Barbara Volcker Center  
for Women and Rheumatic Disease

When we think about lupus, we like to believe that there is a very specific cause somewhere in the background. It could be a chemical, a bacteria, a virus or environmental triggers that are inducing the disease. These triggers cause the body to react violently in order to reject them. This cellular reaction is called the immune response. These cells activate chemicals in the liquid part of the body, called cytokines, thereby causing inflammation (swelling and redness). This inflammation produces symptoms that can show up in a variety of ways such as rashes, arthritis or a combination of other symptoms.

At Hospital for Special Surgery (HSS), we are very fortunate to be a part of the Lupus Clinical Trials Consortium (LCTC). This organization is supported by private funding from Rheumination, Inc., which also funds the Mary Kirkland Center for Lupus Research. HSS is one of the founding members of this organization that has over 25 centers in the United States and Canada. This is the first time in the U.S. that a group of institutions will combine the information that they have and use the same protocols to do trials together. This is extremely important because no one has an unlimited number of patients with which to conduct trials; this collaborative effort will help to maximize resources.

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## FROM THE EDITOR News&Views



### The Truth About Clinical Trials

Clinical trials are an essential component of the medical research process. Through clinical trials, scientific discoveries can lead to improvements in the prevention, detection and treatment of a wide array of diseases and medical conditions.

A study by the National Institutes of Health's National Institute of Neurological Disorders and Stroke found that new discoveries from the phase III clinical trials supported by one Federal agency were responsible for an estimated additional 470,000 healthy years of life.

If you have ever considered participating in medical research, the ins and outs of clinical trials may seem complicated and confusing. Answer these questions and test your knowledge of the world of clinical trials.

#### True or False

1. The Institutional Review Board is a group of physicians who decide what studies should receive funding from the government. ☐ T or ☐ F
2. In the U.S., mainly government agencies, private foundations and pharmaceutical companies sponsor clinical trials. ☐ T or ☐ F
3. Healthy and sick individuals can participate in clinical trials. ☐ T or ☐ F
4. If you sign an informed consent form, you are required to stay in the study until it ends. ☐ T or ☐ F

#### Answers

1. **False.** The Institutional Review Board is an independent committee of physicians, nurses, pharmacists, scientists, ethicists and community members who review clinical trials to ensure they are 1) run ethically and safely and 2) based on sound research design.

2. **True.** Government agencies, private foundations and pharmaceutical companies are the main sponsors of clinical trials of new drugs in the U.S.

3. **True.** Clinical trials include the sick and the healthy—a trial may test how a medicine affects the liver in healthy people or how it affects certain illnesses in sick people. Healthy or sick, if you meet the inclusion or exclusion criteria, you may be a candidate for a clinical trial.

4. **False.** The informed consent form outlines information about the study to ensure participants understand the aim of the study and what participation would require from the participant. The informed consent form includes a statement with respect to “voluntary participation” and “the right to withdraw from participation at any point in time.” It does not force participants to complete the study. Rather, participants can leave the study at any time and for any reason. Withdrawing from the study does not affect the care participants would otherwise receive from their physician.



# The HSS Institutional Review Board: Protecting People Who Volunteer to Participate in Research

by Edward C. Jones, MD, MA, Assistant Attending Orthopedic Surgeon, Chairman, Institutional Review Board

**T**he goal of clinical research is to translate new knowledge into safe and effective practices and procedures in medical and surgical care. As the leading academic center in musculoskeletal medicine, Hospital for Special Surgery (HSS) is dedicated to the highest standards of clinical care, education and research. Research is the engine that drives academic excellence.

The Institutional Review Board (IRB) watches over clinical research at HSS, with the primary responsibility of assuring that in the conduct of meaningful clinical research, the highest ethical standards and scientific integrity are maintained. Furthermore, that the rights, safety and privacy of our research subjects are protected at all times and without compromise.

## IRB Organization and Mission

Institutional Review Board oversight and regulatory review is provided by a panel of 12 full-time members and 10 alternates. The members are professionally diverse, consisting of doctors, nurses and professional staff representing expertise in all areas of scientific review. Membership also includes non-scientists who are unaffiliated with HSS outside of the IRB.

The mission of the IRB is to safeguard the rights, welfare and privacy of individuals participating in clinical research. In doing so, the board may approve, disapprove, modify and suspend research as it sees fit. The IRB has final authority within the institution with regard to human subjects research.

## Research Regulations and Guidelines

The guiding principles that became the core of human subject safeguards emerged in 1948, after World War II. Atrocities in the name of research and revelations that Nazi physicians had violated fundamental ethical standards of civilized society resulted in the Nuremberg Code, consisting of five basic human protections in clinical research:

### The Nuremberg Code, 1948

- ▷ Informed consent of the subject
- ▷ Benefit of research should outweigh its risk
- ▷ Research conducted by qualified scientists
- ▷ Scientists will do no harm, no death, no disabling injury
- ▷ Subjects are at liberty to withdraw

## The Informed Consent Process

One of the most important requirements imposed by the IRB in human subject research is the informed consent process. More than a written document for the research subject to sign, informed consent is a process, a course of action, which should clearly delineate

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**The Nuremberg Code, coupled with subsequent experience and more insightful ethical values, has resulted in eight fundamental standards or guidelines that are in place to guide clinical research:**

- 1** The risks of a study must be minimized through sound research design and methodology
- 2** Risks must be reasonable relative to the anticipated benefits of the study
- 3** The selection of research subjects must be equitable and without bias
- 4** Informed consent must be obtained from the individual participating in the study
- 5** The consent language agreed to and the process for obtaining consent must be carefully documented
- 6** Research subject privacy and confidentiality must be adequately protected
- 7** The ongoing safety of research subjects must be adequately monitored
- 8** Vulnerable subjects, such as children, must be adequately protected

**The mission of the IRB is to safeguard the rights, welfare and privacy of individuals participating in clinical research. In doing so, the board may approve, disapprove, modify and suspend research as it sees fit.**

proper setting, time, diligence and patience in obtaining consent. It is important that the research candidate have time to read and understand the consent form, and have all questions answered by an investigator or qualified hospital staff. The consent document must contain enough information about the research and its risks and benefits in order to reach an informed decision as to whether a subject will voluntarily participate.

Language and culture must be taken into consideration and when necessary, translated consent documents must be used or an impartial translator/interpreter provided.

#### HIPAA: “The Privacy Rule”

“The Privacy Rule” known as HIPAA, the “Health Insurance Portability and Accountability Act,” became effective in April, 2003. It was established to protect the privacy of individually identifiable health information. Generally, this is information provided for specific purposes that the individual can reasonably expect will not be made public, such as a patient’s medical record. The IRB must uphold HIPAA protection when considering how researchers may gain access to, use and safeguard Protected Health Information necessary to conduct research. Patient information gained in the course of standard medical care cannot be reviewed or disseminated to anyone other than the patient’s physician without specific authorization obtained at the time of written consent.

Everyone at HSS is dedicated to the highest standards of clinical research that improves the lives of our patients. The IRB serves as an ethics review board for this research. It is made up of knowledgeable and dedicated scientists and non-scientists who maintain a constant vigilance to protect the rights, safety and privacy of people

#### Consent documents should include the following eight basic elements:

- 1 Describe the study fully
- 2 Point out foreseeable risks or discomforts
- 3 Explain anticipated benefits
- 4 Explain alternatives
- 5 Describe how confidentiality will be maintained
- 6 Describe compensation, if any
- 7 Provide contacts—who will provide more information or discuss concerns
- 8 Explain that participation is voluntary and that the subject may withdraw at any time

who volunteer to serve as research subjects.

A more complete discussion of the evolution of research guidelines and safeguards, as well as more information on IRB process and procedures, can be found on the HSS website at [www.hss.edu](http://www.hss.edu).



## Lupus Research Overview

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If you enter a trial, be sure you know what it aims to do. You should know what phase of the trial you are participating in, what the researcher is looking for at that phase and what the benefits and downsides might be for you. Some disadvantages are:

- ▶ The trials are based on mouse models which are not the best to compare to some human symptoms that occur, such as rashes.
- ▶ Most of the trials are looking at very serious disease and not low-grade chronic illness that would allow use of little or no prednisone (a synthetic corticosteroid drug used for a variety of different conditions) and prevent long term complications. The focus is often on finding a “blockbuster” drug for more serious diseases.
- ▶ Clinical trials are sometimes very restrictive regarding eligible participants. They often look for people with specific disease parameters. For example, in some cases, participants who have received certain drugs or have been pregnant cannot participate. This limits the number of patients eligible for the trials.
- ▶ There may not be enough patients eligible for a certain trial, preventing the researchers from staging it successfully.

The good news in lupus clinical research is that there are many more opportunities than ever before. There are over 25 coordinated centers working together, good measurements of disease and real hope that even more effective treatment for people with lupus will emerge.

# The Kathryn and Alan C. Greenberg Center for Skeletal Dysplasias: State-of-the-Art Patient Care & Research

by Erin Carter, MS, Clinical Coordinator/Genetic Counselor

**S**keletal dysplasia is an umbrella term for a group of more than 200 genetic conditions. Characterized by differences in the size and shape of the limbs, trunk and/or skull that impact stature, skeletal dysplasias are frequently associated with a range of orthopedic problems such as joint dislocation and scoliosis. Although individually rare, collectively there are a significant number of individuals who have skeletal dysplasias.

The first of its kind in New York City, the Kathryn and Alan C. Greenberg Center for Skeletal Dysplasias (CSD) brings together an interdisciplinary team of health care professionals committed to improving the quality of life of people with skeletal dysplasias through clinical care, research, education and patient advocacy.

To round out their exceptional patient care curriculum, the Center has developed research, education and outreach programs. All patients are offered the option to enroll in a Skeletal Dysplasia Clinical Research Registry, with the goal of learning more about the various dysplasias to develop future therapies or treatments for children and adults who have skeletal dysplasias. This year, the Center will debut its mentoring program which offers internship opportunities to CSD patients between the ages of 15-18 years.

Children with a type of skeletal dysplasia called Osteogenesis Imperfecta (OI), also known as brittle bone disease, can break many bones that may not always mend properly. This can make it harder for them to move around by themselves. Children with

To round out their exceptional patient care curriculum, the Center has developed research, education and outreach programs.

brittle bone disease can also feel pain. The investigators at HSS are trying to learn more about how a type of medicine called bisphosphonates work to treat OI. There are currently two studies examining if a medicine helps children with brittle bone disease by making their bones thicker and stronger. One study is looking at how the bisphosphonate Alendronate works for children with more severe OI (type III), and the second study looks at how the bisphosphonate Risedronate works in children with mild OI (types I and IV).

“Care for patients with skeletal dysplasias begins at birth since it is a congenital condition,” says Center Co-Director, Cathleen Raggio, MD. “The Center insures patients continue to get the best care they can in the easiest manner possible when they can no longer qualify for pediatric care.”



## Arthroscopy of the Hip: What You Should Know

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MRI scans supply additional information regarding quality of the bone, presence of fluid and status of all the soft tissues in and surrounding the joint. MRI scans are not all the same and must be of high resolution in order to adequately assess the situation.

If surgery is required, the type of procedure indicated depends upon the age of the patient and the degree of degeneration. Total hip replacement is usually considered to be the operation of last resort, when all other joint saving procedures are futile. Osteotomy of the hip (cutting the bone to shape or change the anatomy) is used if there is a major structural abnormality that must be corrected to preserve the hip joint. Hip arthroscopy is an outpatient procedure where several small openings are made to insert a variety of instruments into the interior of the hip joint.



by Tim Roberts, MLS  
Medical Librarian  
Education Division

A great tip for healthy web surfing is to **consider the source** of the web page you are getting information from. Use recognized, trusted authorities on a topic whenever possible.

Any reliable health website will make it easy to know who is responsible for the content. Look for an "about us" page, and read the credentials behind the folks putting up the information. Websites should also have a way to contact them. If the site provides no contact information, or if you cannot easily find out who runs the site, the safest bet might be to look for another source. One-stop shopping for reliable consumer health information can be found on the MedlinePlus website ([www.medlineplus.gov](http://www.medlineplus.gov)).



MedlinePlus brings together authoritative information from the National Library of Medicine, the National Institutes of Health and other government agencies and health-related organizations. It covers everything from Alzheimer's Disease to tick bites—over 730 health topics in all (690+ in Spanish). With links to drug and supplement information and local resources, MedlinePlus can quickly become your most trusted source for any health question.

Also, Hospital for Special Surgery staff and other experts develop the medical content on the hospital's website. You can find a wealth of information on orthopedic and rheumatological conditions and treatments at [www.hss.edu](http://www.hss.edu).

## Measuring Bone Quality

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component of the bone, collagen. More importantly, the distribution (pattern of variation) of these properties, characteristic of age-matched bones of patients without osteoporosis, is lost. We are correlating these properties with the mechanical strength of bone and also using similar analyses to characterize the effects of pharmacologic agents on these parameters. Ideally, we hope to find drug therapies that restore the values of these parameters to normal, indicating patients will have a decreased risk of fracture.

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**Osteoporosis is the most prevalent bone disease affecting aging adults in the U.S. and abroad.**



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