
Update

The Newsletter of The Paget Foundation ♦ Winter 2004-2005 ♦ Vol. 26, No. 3



Vice Admiral Richard H. Carmona, M.D.,
M.P.H., F.A.C.S., U.S. Surgeon General

SURGEON GENERAL'S REPORT INCLUDES INFORMATION ON PAGET'S DISEASE AND OTHER BONE DISORDERS

In October Dr. Richard H. Carmona, the Surgeon General of the United States, issued *Bone Health and Osteoporosis: A Report of the Surgeon General*.

This is the first Surgeon General's report on bone diseases and bone health. Although the primary focus of the four hundred-page report is on the most common bone disorder, osteoporosis, the report contains excellent information on Paget's disease of bone and the other disorders that the Paget Foundation addresses.

Historically, Surgeon General's reports have greatly improved the health of the U.S. population.

This Surgeon General's report emphasizes the importance of bone health in relation to the general health and well being of Americans. The report focuses on the fact that major improvements in the bone health of people with bone diseases and the general population can be made if physicians and other health professionals applied existing knowledge about the diagnosis and treatment of bone diseases.

Dr. Carmona pointed out that, "... *too little of what has been learned thus far about bone health has been applied to practice.*"

Following are excerpts from the report on Paget's disease of bone.

Early diagnosis and treatment:

Paget's disease of bone is a progressive; often crippling disorder of bone remodeling that commonly involves the spine, pelvis, legs, or skull (although any bone can be affected). If diagnosed early, its impact can be minimized.

Missed diagnoses or under-diagnosis:

Much less is known about the frequency of most other skeletal diseases. This is because many of them, such as Paget's disease of bone and primary hyperparathyroidism, appear to be under-diagnosed.

(Continued on page 2)

THE PAGET FOUNDATION NEEDS YOUR CONTRIBUTION

The Foundation Board and staff are very proud of the Foundation's many achievements during the past twenty-six years.

Despite these achievements we are struggling with our financial situation. This year has been particularly difficult. We have a long way to go to reach our fund-raising goal.

We have a generous and loyal group of contributors, including many of you reading this newsletter. But, we need the support of everyone who receives Foundation information. *(Continued on page 3)*

SURGEON GENERAL'S REPORT INCLUDES INFORMATION ON PAGET'S DISEASE AND OTHER BONE DISORDERS *(Continued from page 1)*

Diagnostic techniques, improved imaging technologies, and the importance of early diagnosis and treatment:

Diseases such as hyperparathyroidism, rickets, osteomalacia, and Paget's disease can often be identified by being aware of the warning signs and/or through simple biochemical measurements. Early identification of such diseases is critical, since treatment at an early state can often be highly effective.

Quality of life experienced by bone disease patients. The following information is taken from a 1996 study of Paget's disease patients:

Quality of life (QOL) is also reduced in patients with other bone diseases. For example, patients with Paget's disease report a high frequency of hearing loss and bony deformities, but many also report depression (53.4 percent), sleep problems (51.5 percent), and poor quality of life (42.1 percent report poor or fair QOL). In the only published study to explore factors related to QOL in Paget's disease (Gold et al. 1996), the authors found that the psychological factors (including depression and loss of self-esteem) were the most important contributors to reduced QOL in these patients; they explained more of the variance (19 percent) in QOL than did biomedical (3 percent), social (2 percent), or cost (1 percent) factors. They also found that QOL was significantly decreased in patients with more extensive or symptomatic Paget's disease.

On October 14th, Foundation Executive Director Charlene Waldman, and Paget's disease patient Linda Silfee from Baltimore, MD attended the press event that launched the report at the Department of Health and Human Services in Washington, DC.

Ms. Silfee commented,

"On October 14th, I heard statements that definitely made me feel like I was not alone as a Paget's disease patient. Bone diseases affect people socially and mentally – not just physically. I can only imagine how the medical professionals who have been in the trenches for many years striving for new developments of treatment for bone disorders, improvements in the educational process and the elevation of the public's understanding and awareness of the importance of overall good bone health must feel about this report, which will certainly help reach these goals."

Drs. Frederick R. Singer and Ethel S. Siris, Chairman and Vice-Chairman of the Foundation Board of Directors issued the following statements about the importance of the report to the Foundation.

Dr. Singer stated, *"The Surgeon General's report on Bone Health and Osteoporosis appropriately emphasizes the importance of osteoporosis as a public health problem. I am pleased to note that it also stresses the need to consider Paget's disease, malignancy affecting the skeleton, primary hyperparathyroidism, osteopetrosis and fibrous dysplasia as additional disorders to consider in promoting bone health in the United States. The Paget Foundation is pleased to participate in seeking better bone health for the people of our country."*

Dr. Siris commented that, *"The Surgeon General's report provides important information about the causes, clinical features and treatment of Paget's disease that support and amplify the messages the Paget Foundation has been sending for many years. This document gives the Foundation an even more powerful voice as we continue to advocate for greater levels of monetary support for research; as we work to teach physicians, nurses and other health care providers about the disease and its management; as we continue to inform patients and their families that this condition can not be ignored, because so much can now be done to help those who have it. Through the authority provided by country's chief doctor, the Surgeon General's report validates and enhances all that we do for those whom we serve."*



Allan S. Noonan, M.D., M.P.H., CAPT, U.S. Public Health Service, Scientific Editor, Surgeon General's Report and Linda Silfee.

The Paget Foundation will use the information in the Surgeon General's report to expand outreach to patients, health care professionals and the general public. The complete report is available at <http://www.surgeongeneral.gov/library> or by calling 1-866-718-BONE. ■



INFORMATION FOR PATIENTS

Q. How much calcium should a patient with Paget's disease receive daily from diet and/or supplements?

A. In general, patients with Paget's disease should get the same amount of calcium that is recommended for most people over 50 – 1000 to 1500 mg daily. This is usually achieved by a combination of dietary calcium (primarily from dairy products) and/or dietary supplements (calcium carbonate, calcium citrate or calcium phosphate).

It is particularly important for patients on bisphosphonate treatment (Actonel®, Fosamax®, Aredia®, Didronel®) to maintain a 1000 – 1500 mg calcium intake in order to maintain a normal concentration of calcium in the blood.

Patients with kidney stones containing calcium are an exception to this recommendation. These patients should consult with their doctor who may suggest that they reduce calcium intake to prevent the kidney stones from forming.

Since vitamin D is necessary for the absorption of calcium from the intestine into the blood, adequate vitamin D is needed. This can be achieved by adequate exposure to sunshine (extensive skin exposure to the sun for 10 minutes three times a week without using sun screen) or by at least 800 units of vitamin D supplement daily.

The information in this column is reviewed by members of the Paget Foundation Advisory Medical Panel. ■

THE PAGET FOUNDATION NEEDS YOUR CONTRIBUTION (Continued from page 1)

You can help now.

- If you have already contributed this year, please send another contribution before the end of the year. Remember that all contributions to the Paget Foundation are tax deductible.
- If you have not contributed this year, please send a contribution and be as generous as you possibly can.
- If you are willing to help the Foundation raise funds by soliciting contributions from your family, friends or associates, please contact Charlene Waldman for help planning your appeal.
- There are several ways to contribute. 1. You can use the form on page 11 of this newsletter. 2. You can contribute online with a credit card. 3. You can participate in the Readers Digest magazine subscription program that is part of our website. (We receive 40% of all subscriptions and renewals that are done through this program.)

Please contribute so that the Foundation can continue its important work.

Thank you so much!

A handwritten signature in cursive script that reads 'Charlene Waldman'.

Charlene Waldman
Executive Director

A handwritten signature in cursive script that reads 'Frederick R. Singer'.

Frederick R. Singer, M.D.
Chairman, Board of Directors

2004 PAGET FOUNDATION JOHN G. HADDAD, JR. RESEARCH AWARD RECIPIENTS

Dr. Julie Ann Sosa, Assistant Professor of Surgery and Clinical Epidemiology at Yale School of Medicine is the recipient of the Foundation hyperparathyroidism research award for her research project: Neurocognitive Changes in Primary Hyperparathyroidism.

The following article was written by Dr. Sosa.

Primary hyperparathyroidism is a condition in which the small glands in the neck, called the parathyroid glands, produce excess parathyroid hormone (PTH). It can lead to calcium leaving the bones and coming into the blood, which can slowly deplete the bones of calcium and weaken them. This condition is the third most common glandular disorder in the United States. It usually affects women in their sixties and seventies. The best treatment and cure for primary hyperparathyroidism is surgical removal (parathyroidectomy) of the gland responsible for the overproduction of hormone.



Julie Ann Sosa, M.D.

It has long been believed that primary hyperparathyroidism can cause depression, anxiety and memory problems - symptoms physicians have often ignored in their work-up of the disease. This has been due both to the lack of medical research and the fact that in the population most commonly affected by this condition, such symptoms are common. The aims of this study are: (1) to measure how common memory, concentration and depression problems are at the time of diagnosis of primary hyperparathyroidism; (2) to determine whether surgery improves these symptoms; and (3) if so, when.

This study will be conducted at the Yale School of Medicine. It brings together physicians from surgery, psychiatry, and internal medicine. Over the next two years, patients with primary hyperparathyroidism who undergo parathyroidectomy will be evaluated using several well-known and innovative psychological and memory tests before and after surgery at one week, three and six months. This will allow researchers to see if surgery for hyperparathyroidism improves mood, memory, and concentration. In addition, patients will have their blood tested for levels of calcium and PTH. Patients with thyroid problems who undergo thyroid surgery will be compared to patients with primary hyperparathyroidism, as thyroid surgery is similar to parathyroidectomy.

With better understanding of the psychological and memory aspects of primary hyperparathyroidism, we hope to increase physician awareness of these subtle symptoms. In so doing, we hope they will better recognize patients who may benefit from surgery.

This research award was supported by an unrestricted educational grant of \$10,000 from Amgen Pharmaceuticals.

Professor Dr. Wim Van Hul of the Department of Medical Genetics at the University of Antwerp in Belgium is the recipient of the Paget's disease research award for his study: Search for Susceptibility Genes in Non-familial Cases of Paget's Disease by Association Studies.

The following article was written by Dr. Van Hul.



Henry Bone, M.D., Chairman, Paget Foundation Advisory Medical Panel and Wim Van Hul, M.D.

At least 60% of the individuals suffering from Paget's disease of bone (PDB) are isolated cases, with no familial history of the disease. While a familial case of PDB is usually caused by a mutation in just one gene -- for example the *sequestosome 1 (SQSTM1)* gene -- things are more complicated for the isolated patients.

For this group of patients genetic predisposition also plays an important role, most likely in combination with environmental factors such as virus infections. It is assumed that natural variations in different genes might act together to increase the susceptibility for an individual to develop PDB.

The strategy to identify these susceptibility genes is by association studies whereby naturally occurring variations within these genes are analyzed in a large group of patients and control individuals. A significant difference in the frequency of these variants between the two groups indicates that the variant influences the chance to become a PDB patient.

We have collected a large number of DNA samples both from patients and controls and will perform such association studies on a number of selected candidate-susceptibility genes in order to identify genetic risk factors in these genes. The identification of these genetic risk factors can lead to a better understanding of the disease mechanism, and to the development of new therapeutic tools that can reduce or prevent the discomfort of patients.

This research award was supported by a \$10,000 grant from Mr. and Mrs. James Andreoli, Los Angeles, CA. ■

SOCRATES E. PAPAPOULOS RECEIVES 17TH ANNUAL JOHN B. JOHNSON AWARD

Socrates E. Papapoulos, MD, Ph.D. was awarded the Paget Foundation's John B. Johnson Recognition Award at the 26th Annual Meeting of the American Society for Bone and Mineral Research in Seattle, Washington. This award is given to individuals who have made major contributions to the understanding of Paget's disease of bone. It was established in 1988 in honor of John B. Johnson, one of the founders of the Foundation, who currently serves as the President of the Board of Directors.



Frederick R. Singer, M.D. and
Socrates Papapoulos, M.D.

Dr. Papapoulos is a Professor of Medicine, Consulting Physician and Director of Bone and Mineral Research at the Department of Endocrinology and Metabolic Diseases, Leiden University Medical Center, Leiden, in The Netherlands. He received the 2004 John B. Johnson Award for his research and his dedication to the treatment of Paget's patients.

For many years Dr. Papapoulos has treated patients at the largest Paget's disease clinic in The Netherlands, which also serves as the main referral center in the country. Dr. Papapoulos also sits on the Paget Foundation's International Medical Advisory Board and is the medical advisor to the Dutch Paget's disease patient's society.

A graduate of the medical school at the University of Athens, Dr. Papapoulos continued his training in internal medicine and endocrinology in Athens. He then moved to Middlesex Hospital in London to do research in endocrinology with Professor Jeffery O'Riordan. After five productive years in London he returned to Athens where he continued to do research and teaching in endocrinology. In 1989 Professor Olav Bijvoet, the first recipient of the John B. Johnson Award in 1988 recruited Dr. Papapoulos to work in Leiden.

Foundation Board Chairman Dr. Frederick R. Singer highlights Dr. Papapoulos's career with the following statement:

“Socrates Papapoulos has carried out very creative studies to determine the most effective means of using drugs to treat patients with Paget's disease. Most recently he has examined the prevalence of Paget's disease in Rotterdam and found that although Paget's disease was common (~3.6% of the population) only 14% of affected individuals had an elevation of alkaline phosphatase activity in blood, the most common biochemical test for disease activity. The past and continuing studies of Dr. Papapoulos in the field of Paget's disease have benefited and will continue to benefit patients with Paget's disease throughout the world. The Paget Foundation congratulates Dr. Papapoulos and wishes him continuing success in his work.”

The John B. Johnson Award recipient receives a grant of \$2,000. ■

MEDICAL SPECIALISTS FROM ITALY, SCOTLAND, THE U.S. AND CANADA JOIN THE FOUNDATION ADVISORY MEDICAL PANEL



Dr. Luigi Gennari

Dr. Luigi Gennari, Assistant Professor of Medicine at the University of Siena in Italy and his colleagues organized the *First European Conference on Paget's Disease of Bone* in June 2004. He is a founding member of the new Paget's disease patient organization, the Associazione Italiana Malati di Osteodistrofia di Paget. Dr. Gennari considers it an "honour and a privilege to join the Advisory Medical Panel of the Paget Foundation." He also said, "As a physician and researcher, I hope to contribute to the Paget Foundation's mission for better care and understanding of Paget's disease of bone and related bone disorders."

Dr. Stuart Ralston, Director of the Institute of Medical Sciences and Professor of Medicine and Bone Metabolism at the University of Aberdeen Medical School in Scotland states that "It is a great pleasure and honour to be asked to join the Paget Foundation Advisory Medical Panel. As a clinician and researcher who has had an interest in Paget's disease and other metabolic bone diseases over the past twenty years, I hope that my experience will prove of value to the Paget Foundation in its mission to provide high quality information about Paget's disease and other bone disorders to the public and to help promote research into the causes and treatment of these conditions."



Dr. Stuart Ralston



Dr. Paul J. Orchard

Dr. Paul J. Orchard, Assistant Professor in the Department of Pediatrics, Division of Blood and Marrow Transplantation at the University of Minnesota in Minneapolis is "honored to have the opportunity to serve on the Paget Foundation Advisory Medical Panel. He further states that "the Foundation is of fundamental importance in providing information and assistance to many individuals suffering with bone disorders and their families. As a pediatrician with a background in hematology and oncology, I have a particular interest in osteopetrosis and other bone diseases that may be amenable to cellular therapy. I look forward to serving on the Panel."

Dr. Orchard was one of the organizers of the conference *First International Symposium on Osteopetrosis: Biology and Therapy*, co-sponsored by the Paget Foundation in October 2003.

Dr. Jonathan Adachi, Professor in the Department of Medicine at McMaster University and the Director of the Hamilton Arthritis Centre in Ontario, Canada is “honoured to be a member of the Paget Foundation Advisory Medical Panel and looks forward to contributing meaningfully in the future.”



Dr. Jonathan Adachi

The Paget Foundation Advisory Medical Panel is composed of sixty-one members from sixteen countries. Panel members provide input and consultation for Foundation programs and publications. A list of the Panel is on the Paget Foundation website at www.paget.org. Dr. Henry G. Bone, Director of the Michigan Bone and Mineral Clinic in Detroit, MI is the Panel Chairman. ■



Left to right – Tony Barbera, Charlene Waldman, Joe Klecko, Cathleen Raggio, M.D., Adele Boskey, Ph.D., Gary Whyte.

Foundation Executive Director Charlene Waldman helped launch the U.S. Bone and Joint Decade (2002-2011) National Awareness Week at the American Stock Exchange on October 11th. Former New York Jets football player Joe Klecko rang the exchange opening bell. Other participants in the ceremony included Gary Whyte, Health Advocate for the rare bone disorder Fibrodysplasia Ossificans Progressiva (FOP), Tony Barbera another advocate for FOP and Drs. Adele Boskey and Cathleen Raggio of the Hospital for Special Surgery in New York, NY.

The United Nations, the World Health Organization and 37 countries proclaimed the years 2000 – 2010 as the Bone and Joint Decade. The purpose of the Decade is to improve the lives of people with musculoskeletal disorders, such as Paget’s disease of bone, and to advance the understanding and treatment of all musculoskeletal disorders through prevention, education and research.

On March 21, 2002 President George W. Bush proclaimed the years 2002-2011 as the National Bone and Joint Decade, recognizing the importance of promoting a healthy musculoskeletal structure for all people from childhood through adulthood. Also, all 50 U.S. state governments have officially endorsed the Decade.

The Paget Foundation is a Decade member. Information on the Decade is available at www.usbjd.org. ■

CONFERENCES FOR HEALTH PROFESSIONALS

SKELETAL COMPLICATIONS OF MALIGNANCY IV

Jointly sponsored by The Paget Foundation, the National Cancer Institute and the University of Virginia School of Medicine/Health System

April 28-30, 2005

Natcher Conference Center, NIH Campus, Bethesda MD

Registration: \$200 US

Abstract submission date: Jan. 21, 2005

Program online at www.paget.org or use the form on page 11 to request a print copy.

PAGET'S DISEASE OF BONE AND FIBROUS DYSPLASIA: ADVANCES AND CHALLENGES

January 13-14, 2006

Sheraton Yankee Trader Hotel

Fort Lauderdale, FL

Registration: \$250 US

Abstract submission date: September 1, 2005

Program announcement online at www.paget.org or use the form on page 11 to request a print copy.

For information about either conference, please contact The Paget Foundation at 212 509-5335 or by email at pagetsym@aol.com.

ADVANCES IN THE MOLECULAR PHARMACOLOGY AND THERAPEUTICS OF BONE DISEASE

July 6-7, 2005

&

INTERNATIONAL SYMPOSIUM ON PAGET'S DISEASE

July 8-9, 2005

Oxford, UK

Information about these two conferences is available on the National Association for the Relief of Paget's Disease website at www.paget.org.uk or by contacting the conference organizer Janet Crompton at The Old White Hart, North Nibley, Dursley, Glos GL 11 6DS, UK, Tel: + 44 (0) 1453 549929, Fax: + 44 (0) 1453 548919, Email: janetcrompton@compuserve.com. ■

NEW EDITION OF PATIENT PUBLICATION

A new edition of the patient publication "Questions and Answers About Osteopetrosis" is available on the foundation website or in print. Please use the form on page 11 to request print copies. Special thanks to Dr. Lyndon Key, Chief of Pediatrics, Medical University of South Carolina and Dr. Paul Orchard, Assistant Professor in the Department of Pediatrics, University of Minnesota for their editorial assistance. ■

WEBSITE USED BY PATIENTS AND HEALTH PROFESSIONALS WORLDWIDE

The Internet is rapidly becoming the first stop in the search for medical information. More and more people rely on websites for the basic information on medical conditions.

The Paget Foundation website is the authoritative site for accurate and reliable information on Paget's disease of bone, primary hyperparathyroidism, fibrous dysplasia, osteopetrosis (*not the common disease osteoporosis*) and the skeletal complications of cancer. (*Please note that this website does not include information on Paget's breast disease.*)

Nearly 400 people visit the site every day with an average of 11, 631 visitors each month. In the month of October alone, people from more than 100 countries in every corner of the world – from Brazil and Luxembourg to Malaysia and Namibia – logged on. For a relatively small organization servicing the needs of people affected by rare diseases and disorders, these numbers are truly impressive.

The website has a new look. If you have not visited the website lately, please do so and let us know what you think. ■

Paget Foundation Website Statistics

Website Traffic Jan. 12, 2002 – October 25, 2004

Total Visits	393,575
Total Pages Viewed	1, 485,104
Average Visits Per Month	11,631
Average Pages Viewed Per Visit	4
Average New Visitors Per Day	268

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PUBLICATIONS FOR PATIENTS**Q&A BROCHURES**

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| <input type="checkbox"/> Primary Hyperparathyroidism | <input type="checkbox"/> Breast Cancer Metastatic to Bone |
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FACT SHEETS**Paget's disease**

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| <input type="checkbox"/> Diagnosing Paget's Disease | <input type="checkbox"/> Surgery and Paget's Disease |
| <input type="checkbox"/> Medical Therapy for Paget's Disease | <input type="checkbox"/> Which Paget's Patient Should Be Treated? |
| <input type="checkbox"/> Paget's Disease and Osteoarthritis | |

Primary Hyperparathyroidism

- Surgery and Primary Hyperparathyroidism

PHYSICIAN REFERRAL LISTS FOR PATIENTS

- Statewide list of physicians who treat Paget's disease of bone in _____ (state/s)
- Statewide list of physicians who treat Primary Hyperparathyroidism in _____ (state/s)
- U.S. list of physicians who treat Osteopetrosis
- U.S. list of physicians who treat Fibrous Dysplasia/McCune Albright Syndrome
- U.S. list of surgeons who perform Primary Hyperparathyroidism surgery

INFORMATION FOR HEALTH PROFESSIONALS

- A Health Professional's Guide to the Management of Paget's Disease of Bone*
Information on pathology, clinical presentation, diagnostic evaluation & recommendations, indications for treatment & therapy options.
- A Nurse's Guide For Assessment and Management of Patients Diagnosed with Paget's Disease of Bone*
- Program: *Skeletal Complications of Malignancy IV*
April 28-30, 2005, Bethesda, MD
- Program Announcement: *Paget's Disease of Bone and Fibrous Dysplasia: Advances and Challenges*
January 13-14, 2006, Ft. Lauderdale, FL

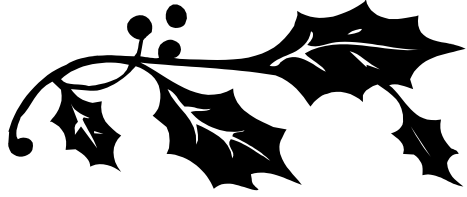
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for Paget's Disease of Bone and Related Disorders

120 Wall Street, Suite 1602, New York, NY 10005

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*Best wishes for the Holiday
Season and the New Year.*

Update

Winter 2004 - 2005

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