

# Update

## THE PAGET FOUNDATION BOARD OF DIRECTORS ELECTS NEW LEADERS

**A**t its annual meeting on December 10, 2010 the Paget Foundation Board of Directors elected Dr. Theresa Guise to serve as Chairman and Dr. Robert Gagel to service as Vice-Chairman. Drs. Guise and Gagel have served as members of the Board of Directors for several years.

The other officers elected were Dr. Stanley Wallach to serve as President and Dr. Kenneth W. Lyles to serve as Secretary-Treasurer. Drs. Henry Bone and Frederick R. Singer were elected as members of the Executive Committee. Dr. Bone will continue to serve as Chairman of the Foundation Advisory Medical Panel as he has done for the past several years.

Dr. Guise is the Jerry W. and Peg S. Throgmartin Professor of Oncology and Professor of Medicine at Indiana University School of Medicine.

Dr. Gagel is Professor of Medicine and Head, Division of Internal Medicine, University of Texas M.D. Anderson Cancer Center.

The Board of Directors and staff are deeply grateful to Dr. G. David Roodman who served as Chairman from 2007 to 2010. Dr. Roodman's commitment and leadership helped advance the Bone and Cancer

Foundation program as well as all Foundation programs and activities.

For a complete list of the Board of Directors, please see page 8. ●



Dr. Theresa Guise

*I am thrilled and honored to serve as Chair of the Foundation Board of Directors.*

*I am deeply committed to continue the outstanding work to educate physicians, patients and healthcare providers on the diagnosis, treatment and pathophysiology of Paget's disease, rare bone diseases and cancer and bone.*

*It is a distinct honor for me to serve an organization that has helped patients with Paget's disease and other rare bone diseases. The addition of cancer and bone to the Foundation's mission makes participation even more appealing to me because of my location in a major cancer hospital.*

*I look forward to the challenge of improving bone health for these disorders where there is an unmet need.*



Dr. Robert Gagel

## WORKING TOGETHER: ADVOCACY AND THE NATIONAL BONE COALITION

Since the 1990s the Paget Foundation has been a member of the National Coalition for Osteoporosis and Related Bone Diseases.

The Coalition's mission is to increase federally funded research on all bone diseases including osteoporosis, Paget's disease, osteogenesis imperfecta and several rare bone diseases including fibrous dysplasia, fibrodysplasia ossificans progressiva (FOP), melorheostosis, x-linked hypophosphatemia, multiple hereditary exostoses, lymphangiomatosis and Gorham's disease, osteopetrosis and others.

Although progress has been made in the understanding of bone health in general, there is still a great deal of research to be done in the area of rare bone diseases. Through our own efforts and as a member of the Bone Coalition, we hope to stimulate interest among members of Congress and at the National Institutes of Health in funding research on rare bone diseases.

We also hope to increase research on skeletal complications of cancer. Hundreds of thousands of cancer patients every year suffer from bone-related complications and studies focused on the connection between cancer and bone health is a step toward more effective treatments.



In 2009, through the Coalition's work, The Bone Health Promotion and Research Act of 2009 was introduced in the House of Representatives. The Coalition is hopeful

that this bill will be introduced in the Senate this year. The bill would expand educational programs for all bone diseases and increase bone research activities of the National Institutes of Health.

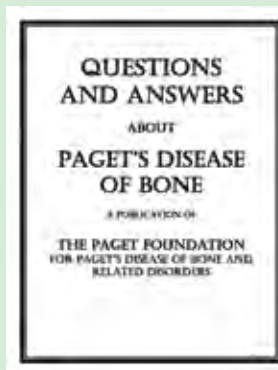
Coalition members, in addition to The Paget Foundation, include two other voluntary health agencies: The National Osteoporosis Foundation ([www.nof.org](http://www.nof.org)) and the Osteogenesis Imperfecta Foundation ([www.oif.org](http://www.oif.org)). The other Coalition members are two professional medical societies, The American Society for Bone and Mineral Research ([www.asbmr.org](http://www.asbmr.org)) and The American Academy of Orthopaedic Surgeons ([www.aaos.org](http://www.aaos.org)).

Working together with the other Coalition members enhances our message and helps Congressional Representatives understand the importance of funding bone research at the NIH and the impact this research may have on their constituents. ●

### PUBLICATION UPDATE

The popular Foundation publication Questions and Answers about Paget's Disease has been updated. The new edition of the publication is available on the website and in print.

Please use the enclosed Paget Foundation Order Form to order a copy of this booklet and other publications.



# THE PAGET FOUNDATION AND THE INTERNATIONAL OSTEOPOROSIS FOUNDATION: A NEW COLLABORATION

The International Osteoporosis Foundation (IOF) [www.iofbonehealth.org](http://www.iofbonehealth.org) is made up of 196 patient organizations and medical societies, making it the largest global non-profit organization dedicated to osteoporosis and related skeletal diseases. With a mandate that encompasses patient advocacy, medical research and professional education, the IOF is an important voice in field of bone health. The Paget Foundation is joining IOF to work on expanded programs on rare bone diseases.

“The Paget Foundation is recognized as the leading organization to advance patient and health

professional knowledge as well as research efforts in Paget’s disease and other related bone disorders. IOF looks forward to strengthening its ties with the Foundation on different levels. In particular we are pleased to announce the creation of an important new scientific working group devoted to rare bone diseases in cooperation with the Paget Foundation. Research into skeletal diseases — whether common or rare — can only benefit from mutual dialogue and shared research efforts across disciplinary boundaries. As we improve our understanding of the mechanisms of bone disease we will advance our shared goal



Professor John Kanis

of achieving new diagnostic and therapeutic advances for patients around the world,” IOF CEO Professor John Kanis said. ●

## A NEW LOOK FOR THE PAGET FOUNDATION WEBSITE

The Paget Foundation website [www.paget.org](http://www.paget.org) has a new look! Please visit the website and let us know what you think.



# BONE AND CANCER FOUNDATION NEWS

## INFORMATION FOR PATIENTS

### PUBLICATIONS

In its continuing effort to put accurate, up-to-date information into the hands of cancer patients, BCF has updated six of its publications on breast cancer, prostate cancer, lung cancer, pain, osteonecrosis of the jaw and vitamin D deficiency.

All publications are available on the BCF website at [www.boneandcancerfoundation.org](http://www.boneandcancerfoundation.org) and in print. Please use the enclosed Bone and Cancer Foundation Order Form to order print copies.

### WEBSITE INFORMATION FOR PATIENTS:

- A glossary and frequently asked questions section
- Ten patient publications
- Information about regional patient meetings
- Information on Clinical Trials
- A Public Service Announcement featuring Dr. Theresa Guise

## FACE-TO-FACE MEETINGS OFFER A UNIQUE OPPORTUNITY

**B**CF received overwhelmingly positive feedback after holding a patient meeting entitled 'Caring for Your Bones When You Have Cancer' in New York City last August. In 2011, BCF is expanding this educational program, organizing similar events in other cities.

These meetings offer patients the unique opportunity of listening to top experts, connecting with fellow patients and participating in a Q&A session. This face-to-face access to knowledgeable specialists provides a unique opportunity for patients.

Meeting topics will include an overview of bone health in cancer patients, the diagnosis and management of bone-related complications,

physical therapy for cancer patients with bone complications with special emphasis on breast cancer, prostate cancer and myeloma. BCF reaches out to hospitals, cancer centers, regional cancer organizations and healthcare professionals in the cities where the meetings take place to inform patients about the events.

The Los Angeles Patient Meeting was held on March 26 at the Doubletree Suites, Santa Monica and was chaired by Frederick R. Singer, MD. Director of the Endocrine/Bone Disease Program at the John Wayne Cancer Institute at Saint John's Health Center, Santa Monica, California, and Clinical Professor of Medicine at UCLA School of Medicine. Dr. Singer is

a past Chairman of the Board of Directors of the Paget Foundation and a current member of the Foundation's Board of Directors. He was instrumental in beginning the Foundation's work in the bone metastasis field.

The other speakers included:

- Mark Scholz, MD, Medical Director of Prostate Oncology Specialists, Inc and Co-Founder and Executive Director of the Prostate Cancer Research Institute;
- Catherine Van Poznak, MD, Assistant Professor, Department of Internal Medicine at the University of Michigan Health System. Dr. Van Poznak specializes in Breast



Cancer and the effects that cancer and its treatment can have on the bone. She is a member of the Paget Foundation Board of Directors and the Bone and Cancer Foundation Advisory Medical Panel.

- Robert Vescio, MD, Director of the Multiple Myeloma and Amyloidosis Program at Cedars-Sinai Medical Center in Los Angeles, CA
- Laryssa Ruppert, a physical therapist from Memorial Sloan-Kettering Cancer Center.

- The John Wayne Cancer Institute, USC Norris Comprehensive Cancer Center, Prostate Cancer Foundation, American Cancer Society, Cancer Support Community-Benjamin Center (formerly the Wellness Community), Susan G. Komen for the Cure, and CancerCare assisted with outreach for the meeting.

A New York City Patient Meeting will be held at the Weill Greenberg Center on August 6, 2011. The chair and speakers will be announced soon.

Information about other meetings will be announced on the BCF website.

The BCF Patient Meeting Program was developed to promote patient education at its best. The attendees — both patients and medical experts — have found these face-to-face meetings extremely beneficial. ●

## INFORMATION FOR HEALTH PROFESSIONALS

**11th International Conference  
Cancer-Induced Bone Disease**

November 30 – December 3, 2011  
The Westin Michigan Avenue  
Chicago, Illinois

IBMS  
CANCER & BONE  
SOCIETY  
Bone & Cancer  
Foundation

BCF is working with the International Bone and Mineral Society/Cancer and Bone Society to jointly organize the 11th International Conference on Cancer-Induced Bone Disease which will be held at the Westin Hotel in Chicago, IL November 30–December 3, 2011. Information about abstract submission, registration and the conference program will be available in the near future on the Bone and Cancer Foundation website and by contacting the International Bone and Mineral Foundation 312-321-5113, email [info@ibmsonline.org](mailto:info@ibmsonline.org). ●

## EXHIBITS AT MEDICAL SOCIETY MEETINGS

### BCF EXHIBITS AT KEY MEDICAL MEETINGS.

In 2010, BCF exhibited at the annual meetings of American Society of Clinical Oncology, The Oncology Nursing Society, the Association of Community Cancer Centers and a satellite program at the annual meeting of the American Urology Association.

This year BCF will exhibit at the Oncology Nursing Society annual meeting and other meetings. ●

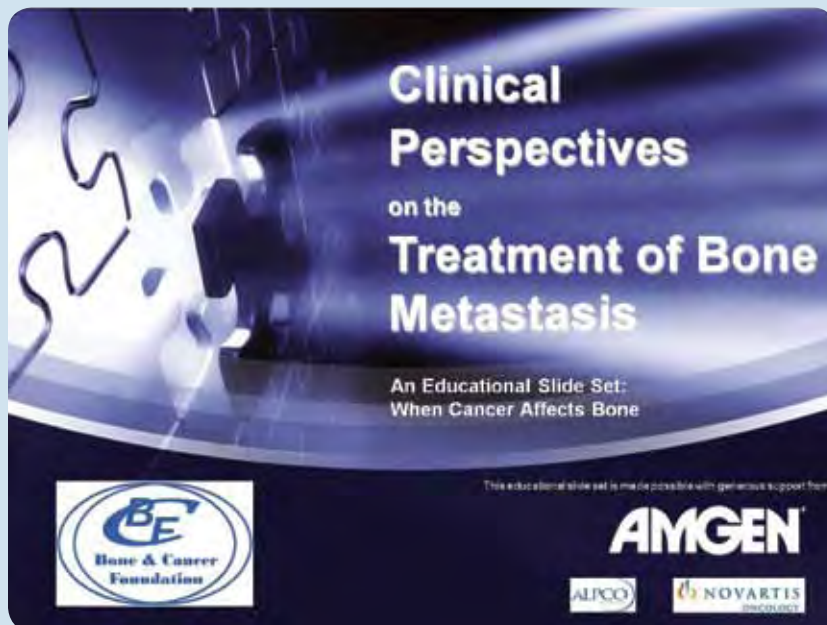


### VISIT THE BCF WEBSITE

Visit the site: [www.boneandcancerfoundation.org](http://www.boneandcancerfoundation.org) to find easy access to information critical to both cancer patients and their caregivers.

## SLIDE SET

BCF has produced a slide set based on the CME meeting Clinical Perspectives on the Treatment of Bone Metastasis which took place on October 9, 2010. The slides are available for download on the BCF website: [www.boneandcancerfoundation.org](http://www.boneandcancerfoundation.org). Topics addressed in the slide set include: pathophysiology of bone metastasis; breast cancer and bone metastasis; emerging therapies to prevent skeletal complications in men with prostate cancer; myeloma bone disease; and management of cancer therapy induced bone loss. ●



## THE PAGET FOUNDATION IS GRATEFUL FOR THE FOLLOWING CONTRIBUTIONS

### IN MEMORY OF

Wallace J. Beckman  
Paul Bennett  
John Crofton  
Clare DeMaio  
Dom DiMaggio  
Gwen Ellsworth

Charlotte Gidding Siris  
Arthur Golden  
Matthew J. Gregus  
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Michael Guerra  
Charles Guise  
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Gloria McAteer  
Father of Karen Johnson  
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Paul J. Vnohtadsky  
Dorothy Vitko  
Jack White  
Peggy Wilhelm  
Max R. Zamorano

### IN HONOR OF

Henry Bone, III, MD  
  
Holly Pollock  
Anita Rattner  
Frederick R. Singer, MD

### CONTRIBUTED BY

Theresa A. Guise, MD  
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 Website: [www.boneandcancerfoundation.org](http://www.boneandcancerfoundation.org)

## THE PAGET FOUNDATION BOARD OF DIRECTORS

### EXECUTIVE COMMITTEE:

**Chair** Theresa A. Guise, M.D., Indianapolis, IN   **Vice Chair** Robert F. Gagel, M.D., Houston, TX  
**President** Stanley Wallach, M.D., St. Petersburg, FL   **Secretary-Treasurer** Kenneth W. Lyles, M.D., Durham, NC  
**Chairman, Advisory Medical Panel** Henry G. Bone, III, M.D., Detroit, MI   ● Frederick R. Singer, M.D., Santa Monica, CA

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This edition of the newsletter was written and edited by:

Candida B. Korman, Maureen Mandel, Christal Sumpter and Charlene Waldman.

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## ESTATE PLANNING/BEQUESTS ANOTHER WAY TO SUPPORT THE PAGET FOUNDATION

Many people miss an opportunity to support a non-profit organization that made a difference in their lives while minimizing tax advantages in their wills. A bequest is part of a will that allows people to make a donation to a non-profit agency after they pass away. The gift may be a specific dollar amount, a percentage of an estate, or an asset such as stocks or real estate. A bequest of any amount can make a big difference to the future of The Paget Foundation. Suggested wording to use when you make a charitable bequest: "I give to The Paget Foundation, a New York non-profit corporation located in New York, NY the sum of \$ \_\_\_\_\_ (or otherwise describe the asset) to be used for its unrestricted charitable purposes.



**PLEASE USE THIS SIDE TO CONTRIBUTE TO THE BONE AND CANCER FOUNDATION  
AND REQUEST BONE AND CANCER FOUNDATION INFORMATION.  
THE BONE AND CANCER FOUNDATION (BCF) IS A NEW PROGRAM.  
YOUR CONTRIBUTION WILL HELP BCF EXPAND ITS IMPORTANT WORK.**

Mr.  Mrs.  Miss  Ms.  \_\_\_\_\_

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_ Fax \_\_\_\_\_ E-mail \_\_\_\_\_

Enclosed is my tax-deductible contribution of:

\$15  \$25  \$35  \$50  \$100  \$250  Other \_\_\_\_\_

**PLEASE MAKE YOUR CHECK PAYABLE TO BONE AND CANCER FOUNDATION.**

For contributions over \$25, you may use  MasterCard  Visa or  American Express

Card # \_\_\_\_\_ Exp. Date \_\_\_\_\_

Signature \_\_\_\_\_

Name on Card \_\_\_\_\_

**PUBLICATIONS FOR PATIENTS**

- Managing Pain Related to Cancer and Bone - ***NEW EDITION***
- Myeloma Bone Disease, Current and Future Treatment
- Osteonecrosis of the Jaw (ONJ): Information for Cancer Patients - ***NEW EDITION***
- Osteosarcoma
- Physical Therapy and Other Rehabilitation Therapies for Patients with Cancer and Bone Involvement
- Questions & Answers about Breast Cancer, Bone Metastases & Treatment-Related Bone Loss - ***NEW EDITION***
- Questions & Answers about Prostate Cancer, Bone Metastases, And Treatment-Related Osteoporosis - ***NEW EDITION***
- Surgical Management of Cancer That Spreads to the Bone
- Vitamin D Deficiency: Information for Cancer Patients - ***NEW EDITION***
- What Lung Cancer Patients Need to Know About Bone Health - ***NEW EDITION***

*(THESE PUBLICATIONS ARE ALSO AVAILABLE ON THE BONE AND CANCER FOUNDATION WEBSITE [WWW.BONEANDCANCERFOUNDATION.ORG](http://WWW.BONEANDCANCERFOUNDATION.ORG))*

**EDUCATIONAL INFORMATION FOR HEALTH PROFESSIONALS**

- Powerpoint Slide Set - ***Clinical Perspectives on the Treatment of Bone Metastasis: When Cancer Affects Bone*** - CD Rom. The slide set includes information on the pathophysiology of bone metastasis, breast cancer, prostate cancer, myeloma and cancer treatment induced bone disease.
- Please send information on the meeting, ***11th International Conference on Cancer-Induced Bone Disease, November 30 - December 3, 2011, Chicago, Illinois.***

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