

1978–2003



ANNIVERSARY

OF

THE

PAGET

FOUNDATION

THE PAGET FOUNDATION
For Paget's Disease of Bone and Related Disorders

120 Wall Street, Suite 1602
New York, NY 10005
Tel 212 509-5335 Fax 212 509-8492
Website www.paget.org
Email pagetfdn@aol.com



THE WHITE HOUSE

WASHINGTON

December 2, 2003

Congratulations to the Paget Foundation as you celebrate your 25th anniversary.

Since your founding, members of the Paget Foundation have helped those who suffer from bone diseases. Your important work to support research and raise awareness of these conditions reflects the compassionate spirit of our Nation.

I applaud those who lend their time, energy, and talents to the Paget Foundation. Your efforts bring hope and healing to citizens across our Nation.

Laura joins me in sending our best wishes.

A handwritten signature in black ink, appearing to read "George W. Bush".

**MESSAGE FROM
FREDERICK R. SINGER, M.D.
CHAIRMAN
BOARD OF DIRECTORS**

My role in the Paget Foundation during the past 25 years has been one of the most rewarding aspects of my career.

In those years the Foundation confronted a succession of challenges. Initially it was to reach and assist individuals afflicted with Paget's disease of bone, and to educate the medical community in diagnosis and treatment. Research efforts were supported and advocacy undertaken to fund research.

International conferences, sponsored by the Foundation, explored from a diversity of viewpoints the etiology of Paget's disease, and brought together clinical assessments of current therapies which were then communicated to physicians and patients.

In years to come, these activities, which now include other disabling bone diseases, will continue a fundamental part of the Paget Foundation's mission, a mission now advancing with great strides thanks to our electronic outreach worldwide.

Today, as for the past six years, the Paget Foundation is in the forefront of advocacy for research into skeletal complications of malignancy, co-sponsoring international conferences which bring together in collaboration an all-star cast of top-flight researchers and clinicians. I'm proud to be associated with such a compassionate enterprise and pleased to see that research funding has increased.

Finally, I have greatly enjoyed working with an excellent Board of Directors and Advisory Medical Panel and am grateful for the privilege of working with three outstanding Executive Directors.



**MESSAGE FROM
CHARLENE WALDMAN
EXECUTIVE DIRECTOR**



For twenty-five years, the Paget foundation has provided information for patients and health professionals worldwide and has supported and encouraged research on all bone disorders.

Since 1986, it has been my responsibility and my privilege to oversee the foundation's programs.

The programs that are included in this publication would not have been possible without the support and assistance of the members of the Foundation Board of Directors and Advisory Medical Panel.

I am also very grateful to our colleagues from the pharmaceutical industry who have supported and encouraged our work.

Our collaborations with the staff of several National Institutes of Health (NIH) institutes have made it possible to expand research and educational opportunities for the scientific community.

The financial support of our thousands of members and friends has sustained our work and enabled us to continually reach out to broader audiences.

The commitment and hard work of the Paget Foundation staff has made it possible for an organization that is small in numbers to be huge in scope.

All of us at the foundation look forward to continuing our work for the next twenty-five years. We hope that the support of our many friends will make that possible.



**LETTER OF CONGRATULATIONS TO
THE PAGET FOUNDATION FOR PAGET'S DISEASE OF BONE
AND RELATED DISORDERS
IN CELEBRATION OF YOUR 25th ANNIVERSARY**

On behalf of all of the staff of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS), at the National Institutes of Health, I am delighted to extend my warmest congratulations to The Paget Foundation for your remarkable achievements during 25 years of service. The NIAMS has been privileged to partner with The Paget Foundation in several areas of mutual interest. Your ever-present commitment to patient advocacy for enhanced research and to disseminating information to patients and their families, health care providers, and the public has been truly remarkable. Your Foundation is very appropriately recognized internationally as a respected source of information on Paget's disease as well as on other related bone disorders.

Much of the success of The Paget Foundation can be attributed to the tireless dedication and advocacy of Charlene Waldman, the Executive Director of the Foundation. She has unfailingly been on the front line in leading The Paget Foundation efforts. Examples of her successful efforts include the meetings, initiatives, and now-funded research projects in skeletal complications of malignancy. This is an area of shared interest for The Paget Foundation and the NIAMS, and we are grateful for the leadership role that Ms. Waldman has provided.

The Paget Foundation is also to be commended for the vital support and advocacy that you have provided for many "orphan" diseases of bone, including bone malignancies, osteopetrosis, and fibrous dysplasia. You have made significant contributions in identifying research opportunities in these areas and for providing both health information and networking support.

The landscape of medical research in bone has undergone a revolution over the last 25 years. At every step of progress, The Paget Foundation has been in the forefront of advocacy and support for patients and their families. You have truly made a difference in the lives of countless affected individuals, and can be justifiably proud of the contributions that you have made. The NIAMS looks forward to continuing to partner with you in areas of mutual interest.

With great admiration and warmest regards,

Stephen A. Katz, M.D., Ph.D.
Director, NIAMS



National Institutes of Health
National Institute of Dental
and Craniofacial Research
Bethesda, Maryland 20892

October 31, 2003

Charlene Waldman
Executive Director
The Paget Foundation
120 Wall Street, Suite 1602
New York, New York 10005

Dear Ms. Waldman:

On behalf of the National Institute of Dental and Craniofacial Research, I would like to congratulate the Paget Foundation for Paget's Disease of Bone and Related Disorders, on the occasion of its 25th Anniversary, and to wish you all of the best in the coming years.

During these past 25 years, the Foundation has served as a beacon of light for all of the patients and their families. The website, along with the newsletter, fact sheets, pamphlets, and booklets, so carefully prepared by the Foundation, have proven to be an invaluable source of reliable information about the nature of Paget's disease of bone and related disorders to all. The Foundation has not only provided a central source for educational materials; it has served as a hub for networking of patients and physicians, and offers a tremendous amount of peer support. Equally as noteworthy are the efforts of the Foundation in organizing meetings not only for patients, but also conferences for basic and clinical scientists working in the area. These conferences have been of the highest quality, and instrumental in moving the field forward in understanding the nature of bone diseases characterized by derangements in bone resorption, how to best treatment them with current therapies, and what can be explored for even better treatments in the future. As a voluntary health organization, it is remarkable how much support the Foundation has provided to researchers in the field, not only by providing funding for specific projects, but also through its advocacy of increased research in skeletal diseases. The partnerships that the Foundation has made with related societies has been instrumental in making Congress aware of the need for increased support of bone related biomedical research, and for this, we are very grateful.

Last, but certainly not in the least, we thank the current and past chairmen of the Foundation, and you in particular, Charlene. We hope that you know how much your tireless efforts are appreciated by all. We look forward to working with you more in the coming years as together we continue to unravel the causes and potential cures for these skeletal disorders.

Sincerely,

Lawrence A. Tabak, D.D.S., Ph.D.
Director



DEPARTMENT OF HEALTH & HUMAN SERVICES

**Public Health Service
National Institutes of Health**

**National Institute of Diabetes and
Digestive and Kidney Diseases
Bethesda, Maryland 20892**

October 17, 2003

Ms. Charlene Waldman
The Paget Foundation
120 Wall Street, Suite 1602
New York, NY 10005-4001

Dear Charlene:

I would like to congratulate you and all members of the Paget's Foundation on your 25th anniversary. You have provided valuable information to a large number of patients and families affected by this and other bone disorders, as well as to health professionals. I appreciate the tremendous service the Foundation performs in disseminating information on research, symptoms and treatment to those who need it most. As Director of NIDDK, one of several NIH Institutes that support a significant portfolio of research grants on bone, I appreciate the advocacy of the Paget's Foundation and the private funding it secures in support of bone diseases.

Also, speaking personally as a bone researcher, I value the Paget's Foundation's efforts to promote novel research and treatment strategies for diseases of the skeleton. Keep up the good work. We look forward to the Foundation's next 25 years serving the public and health professionals and facilitating research to understand how best to treat, cure and prevent various bone disorders.

Sincerely,

A handwritten signature in black ink, appearing to read "Allen M. Spiegel".

Allen M. Spiegel, M.D.
Director



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
National Cancer Institute
Bethesda, Maryland 20892

NOV 7 2003

The Paget Foundation
120 Wall Street, Suite 1602
New York, New York 10003

Dear Friends:

It gives me great pleasure to congratulate the Paget Foundation on twenty-five years of service to patients, health professionals, and the scientific community.

The National Cancer Institute (NCI) has had a long partnership with the Foundation, especially in co-sponsoring several scientific conferences on bone metastasis. I particularly commend the Foundation for its leadership in advancing research on this subject through its organization of symposia and publications. The NCI looks forward to continued cooperation with the foundation, to expand research to control and prevent bone metastasis.

Sincerely,

A handwritten signature in black ink, reading "Andy von Eschenbach".

Andrew C. von Eschenbach, M.D.
Director
National Cancer Institute

**National Institutes of Health
Osteoporosis and Related Bone Diseases ~ National Resource Center**

Charlene Waldman
Executive Director
The Paget Foundation
120 Wall Street, Suite 1602
New York, New York 10005

Dear Charlene,

On behalf of the National Institutes of Health Osteoporosis and Related Bone Diseases~National Resource Center, I would like to extend our congratulations to you, your staff and the Board of Trustees of The Paget Foundation on the occasion of your 25th anniversary. Sir James Paget certainly would be gratified if he could be here today to see the accomplishments of the Foundation over the past quarter of a century to educate patients and health care professionals about the disease he identified and to advocate for increased research on bone diseases.

Your partnership with the National Resource Center over the past nine years is just one example of the important work of The Paget Foundation. Through your efforts, the Center's resources and outreach have been enriched immeasurably. Your expertise in Paget's disease of bone and other bone diseases, as well as insights into the information needs of patients, their families and the medical community, have been invaluable. Thousands of physicians, nurses and other allied health professionals have had access to the most current thinking about the management of Paget's disease of bone. Thousands of patients have found information to help them understand their condition, whether it is Paget's disease of bone, primary hyperparathyroidism, fibrous dysplasia, osteopetrosis, or breast and prostate cancers metastatic to bone.

Looking back at the quality and diversity of materials and programs you developed as part of the National Resource Center, it is clear that our goal to increase knowledge and awareness about these bone diseases and our particular mandate to fill information gaps and address underserved populations have been well met. We look forward to working together in the future to continue to fulfill this shared mission.

May your next 25 years be as accomplished as your first quarter century has been.

Sincerely,



Susan J. Whittier, MHA
Project Director

2 AMS Circle, Bethesda, MD 20892-3676 • Tel (800) 624-BONE or (202) 223-0344 • Fax (202) 293-2356 • TTY (202) 466-4315

The National Resource Center is supported by the National Institute of Arthritis and Musculoskeletal and Skin Diseases with contributions from the National Institute of Child Health and Human Development, National Institute of Dental and Craniofacial Research, National Institute of Diabetes and Digestive and Kidney Diseases, NIH Office of Research on Women's Health, DHHS Office on Women's Health, and the National Institute on Aging.

The National Institutes of Health (NIH) is a component of the U.S. Department of Health and Human Services (DHHS).



NATIONAL
OSTEOPOROSIS
FOUNDATION

Fighting Osteoporosis & Promoting Bone Health

October 21, 2003

Ms. Charlene Waldman
Executive Director
The Paget Foundation
120 Wall Street
Suite 1602
New York, NY 10005

Dear Charlene:

On behalf of the National Osteoporosis foundation, I am writing to congratulate you, your Board of Trustees, staff and volunteers on The Paget Foundation's 25th anniversary. Your organization has provided strong leadership on many diverse fronts in addressing a disease that can have such a devastating impact. In addition to Paget's disease, your advocacy efforts on behalf of other rare bone diseases are to be commended.

NOF values its long-standing partnership with The Paget Foundation in addressing areas of mutual concern related to bone health. As you reach this landmark anniversary, we applaud you for all that you have accomplished and we thank you for your partnership on the Bone Coalition. NOF most certainly looks forward to continuing to work with you in the coming years.

In closing, I would again like to extend warmest congratulations from the NOF Board of Trustees and staff. This anniversary serves as a tribute to your past and all the lives that have been touched by The Paget Foundation's efforts. It also serves as a bridge to the future and all the lives that will be changed as a result of your efforts.

With best wishes and kind regards,

Bess Dawson-Hughes, MD
President

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The Paget Foundation
120 Wall Street, Suite 1602
New York, NY 10005

Dear Board Members:

Congratulations to the Paget Foundation on your 25th Anniversary of providing quality information for patients, the general public and health professionals, and supporting and advocating for increased research on all bone diseases. We look forward to following the Paget Foundation's growth during the next 25 years and beyond as you continue to meet new challenges.

The Osteogenesis Imperfecta Foundation relies on the Paget Foundation for model programs and resources, and collaboration in advocacy efforts. Many of our most successful programs are modeled on those developed by the Paget Foundation. As colleagues in the National Coalition for Osteoporosis and Related Bone Disorders, we have benefited from the impressive advocacy skills demonstrated by Executive Director Charlene Waldman. The Paget Foundation's collaborative efforts benefit all of those with bone disorders.

It is an honor to work with the Paget Foundation on behalf of people with bone diseases.

Sincerely,

Heller An
Heller An Shapiro
Executive Director



**THE AMERICAN
SOCIETY
FOR
BONE AND MINERAL
RESEARCH**

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October 27, 2003

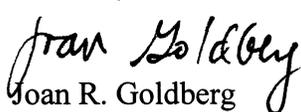
Charlene Waldman
Executive Director
The Paget Foundation for Paget's Disease of Bone and Related Disorders
120 Wall Street, Suite 1602
New York, New York 10005

Dear Charlene,

It is my great pleasure to extend the ASBMR's congratulations on the Foundation's 25th Anniversary. A Silver Anniversary is a tremendous accomplishment for a voluntary health agency, and Paget's record of achievement is laudable. The Foundation's work on behalf of patients with Paget's disease, as well as more recently with primary hyperparathyroidism, osteopetrosis, fibrous dysplasia, and breast and prostate cancer metastatic to bone, fills an important need.

We are proud to partner with The Paget Foundation in advocacy efforts and fully support the Foundation's work. Again, our congratulations on this important milestone.

Sincerely,


Joan R. Goldberg
Executive Director


Robert A. Nissenson
President

**TO YOUR GOOD HEALTH
PAUL G. DONOHUE, M.D.**

**NORTH AMERICA/KING FEATURES
P.O. BOX 3000
FARMINGTON HILLS, MI 48333**

Dear Charlene:

During the twenty years of syndicating a medical column I have dealt with a large number of medical foundations and support groups. The Paget Foundation is one by which I judge all others. Few organizations deliver so much to so many. Up-to-date information, support for those with illness and a willingness to go farther than the extra mile in helping members make the Foundation a model for all such organizations.

It is my sincerest wish that the Foundation continue its work for another 25 and more years unless the happy day arrives when a cure has been found.

Sincerely

Paul Donohue, M.D.



Novartis Pharmaceuticals Co
59 Route 10
East Hanover, NJ 07936-1080
Tel 973 781 8300

October 30, 2003

Charlene Waldman
Executive Director
The Paget Foundation
120 Wall Street, Suite #1602
New York, NY 10005

Dear Charlene:

Novartis Pharmaceuticals Corporation congratulates The Paget Foundation on 25 years of leadership in education and research, serving as the most reliable source of information on Paget's Disease of bone and other related disorders.

We salute the dedication and strength of commitment of each and every staff member and volunteer who distinguishes The Foundation as the only volunteer organization devoted solely to advancing the understanding of Paget's Disease and improving its diagnosis and treatment. We at Novartis are proud to share the Foundation's steadfast commitment to this important cause, and reaffirm that commitment on the occasion of the Foundation's 25th anniversary. We look forward to exciting and fruitful new developments in the treatment of Paget's Disease that will ultimately achieve our shared goal of improving the lives of patients.

Congratulations on your remarkable accomplishments.

Sincerely,

A handwritten signature in black ink that reads "Drake R. Parker".

Drake Parker
Marketing Director
Novartis Pharmaceuticals Corporation



P&G Pharmaceuticals, Inc.
Health Care Research Center
8700 Mason-Montgomery Road
Mason, OH 45040
www.pg.com

October 29, 2003

Charlene Waldman
The Paget Foundation
120 Wall St., Suite 1602
New York, NY 10005-4001

Dear Ms. Waldman

Procter & Gamble Pharmaceuticals congratulates the Paget's Foundation for 25 years of dedication to Paget's patients and their families. The Foundation's success in improving the lives of patients with this debilitating bone disease makes us proud of our pivotal role in founding the Foundation and our continued support over the past 25 years. The Foundation's commitment to educating patients and health professionals is to be celebrated.

Congratulations, again, to the Foundation on this milestone achievement!

A handwritten signature in black ink, appearing to read 'Rick June', with a long horizontal flourish extending to the right.

Rick June
Vice President
Procter & Gamble Pharmaceuticals,
North America

John Yates, M.D.
Vice President
Medical & Scientific Affairs
U.S. Human Health

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Tel 267 305 2193
Fax 267 305 2845



October 15, 2003

Ms. Charlene Waldman
Executive Director
The Paget Foundation
120 Wall St., Suite #1602
New York, NY 10005

Dear Ms. Waldman:

On behalf of Merck & Co., I would like to offer my congratulations and best wishes on the Paget Foundation's 25th Anniversary and to wish you continued success in meeting patients' needs in this important area.

Sincerely,

A handwritten signature in black ink that reads "John Yates". The signature is fluid and cursive, with a long horizontal stroke extending from the end.

John Yates, M.D.

One hundred years after Sir James Paget first identified the disorder that bears his name, the first effective drug had been approved by the U.S. Food and Drug Administration for the treatment of Paget's disease of bone. This advance in clinical medicine presented an impressive challenge: to advise physicians and other health care professionals that treatment was now available, and provide them with information on accurate diagnosis as well as proper management of the disease; also, to reach and help those who suffer from the disease to find the best possible treatment.

The challenge was initially one of communications. Accordingly, a group of the pioneering physicians, who had worked in developing the treatment, sought experts in medical communications, and together they established a foundation to address Paget's disease, and later to address other bone disorders as well.

AN EMERGING RESPONSIBILITY

OVERVIEW

Since its inception 25 years ago The Paget Foundation has been providing up-to-date information on Paget's disease to doctors and helping patients obtain the best possible treatment.

During those first 25 years, while serving the needs of health professionals and patients concerned with Paget's disease, the Foundation continuously fostered research into a number of other disorders involving abnormal bone absorption, disorders that include hyperparathyroidism, fibrous dysplasia, osteopetrosis, and, over the past seven years, the skeletal complications of malignancy.

In recent years The Paget Foundation has organized International Conferences, wherein clinicians and basic researchers in the United States and from other nations meet to report on and discuss the pathophysiology and management of cancer-related bone disorders, including the metastases to bone of breast cancer, prostate cancer, and myeloma. Thereby, research discoveries are translated into treatment strategies.

An Executive Director is the human keystone of any voluntary organization. During the first 25 years of its mission, The Paget Foundation has had three dedicated and able Executive Directors. Sophie Gerber, the founding Executive Director, served from 1978 to 1980. She was succeeded by Ann Kone, who initiated early information, education, and advocacy programs. In 1986 Charlene Waldman became Executive Director, and has overseen an ambitious variety of education, advocacy, and public awareness programs.

1876

• Sir James Paget, a physician who served in Queen Victoria's court and as the President of the Royal College of Surgeons, presented a paper *On a Form of*



Chronic Inflammation of Bones (Osteitis Deformans) to the Royal Medico-Chirurgical Society of London, which described the clinical history of a patient with

Paget's disease. This paper established the disorder as "Paget's disease of the bone."

1976

• Calcitonin, the first effective drug treatment for Paget's disease, was approved by the FDA. Approval for etidronate, the first bisphosphonate drug, followed.

DEVELOPING AWARENESS AND IMPARTING KNOWLEDGE

PATIENT EDUCATION BOOKLETS

The growth and changing nature of the Foundation is reflected in our methods of communication.

Twenty five years ago the Foundation began distribution of booklets on Paget's disease. Addressing a need for basic information, each new booklet was snapped up by patients and their doctors. As the Foundation's programs expanded to include other metabolic bone disorders, new publications were developed for each individual disorder — fibrous dysplasia, hyperparathyroidism, osteopetrosis, and cancer metastatic to bone.

THE NEWSLETTER ("UPDATE")

From the very beginning in 1978 the Foundation has produced a newsletter for patients and their families and for anyone interested in Paget's disease and related bone disorders. Published three times a year, the newsletter contains articles on treatment, research, and any number of subjects of interest to patients and health providers.

Since 2001 the newsletter has included the feature "Paget People," profiles based on interviews of individuals coping with Paget's or other bone diseases.

PATIENT EDUCATION MEETINGS

A significant form of patient education began in 1987 when the first regional Patient Education Meeting was held in Los Angeles. Over the next fourteen years the Foundation organized more than a hundred such meetings throughout the United States and Canada.

PUBLIC AWARENESS STRATEGIES

It could be said that the Foundation came into being through its first public awareness effort. A 1978 article placed in *Parade Magazine*, announcing our creation as a resource, was in all probability the first time the general public had ever encountered the subject of Paget's disease of bone. Accordingly, we have long recognized the importance of general media in delivering our messages to the public.

Public Service Announcements have further expanded the Foundation's outreach. Minnie Pearl, then a popular entertainment personality, did our first public service spot on radio in 1985. Dom DiMaggio, the famed baseball player, Paget's disease patient, and a member of the Foundation Board of Directors, starred in a television public service announcement in 1989.

1978

- John B Johnson, Dr. Stanley Wallach, and Sophie Gerber founded the Paget Foundation.
- John B. Johnson became the President and Chairman of the board of Directors. He held both posts until 1987.
- Dr. Stanley Wallach was named the first Chairman of the Advisory

Medical Panel. He continued to serve through 1983.

- Sophie Gerber became the first Executive Director; she served through 1980.

- The Paget Foundation opened its first office in Englewood, New Jersey, remaining in that location until 1980.

1980

- Ann Scott Kone became the second Executive Director, serving until 1986.
- The Paget Foundation moved from Englewood, New Jersey to Brooklyn, New York.

Jane Brody's important health news story in *The New York Times* in 1991 was one of many such columns by syndicated medical writers, including Dr. Paul Donahue and "Family Physician" Dr. Alan Bruckheim.

WEBSITE

The Paget Foundation's outreach and patient education program was revolutionized in the year 2000 when we launched our website — www.paget.org. The Internet's ability to reach vast numbers of people in far-flung places around the world cannot be compared to any other medium.

Since its inception, thousands and thousands of people in the United States alone have taken advantage of our website to obtain information. And with equal effectiveness we have been able to help people in distant places, far from our shores.

In 1998 Dmitry Bystrov began his e-mail correspondence with The Paget Foundation. He had been diagnosed with Paget's disease in St. Petersburg, Russia, but he wanted more information about his condition and the best treatment. He was happy to learn that better treatment was available outside Russia. The Foundation arranged for him to travel to Heidelberg, Germany, a trip that we managed to have underwritten by a pharmaceutical company, where he was examined and received treatment. Unfortunately, Mr. Bystrov died later due to osteosarcoma, a very rare complication of Paget's disease.

The life of Sijia Lee, a little girl born with osteopetrosis, was also changed by The Paget Foundation Website. Her uncle made his initial contact with the Foundation via the Web. She traveled with her mother from mainland China to visit Dr. L.Lyndon Key, a pediatric endocrinologist at the Medical University of South Carolina hospital. Eventually, the rest of her family joined her. Sijia received treatment unavailable in China. Both the quality and duration of her life were improved. And during her three years in the United States, this brave girl touched the lives of everyone who met her.

EDUCATING THE CAREGIVERS

THE INITIAL CHALLENGE

Twenty-five years ago Paget's disease was a relatively unrecognized disorder, in part because there had been no effective treatment. The introduction of salmon calcitonin, in 1978, as the first approved therapy for Paget's disease prompted the founding of The Paget Foundation.

The Foundation has worked diligently to increase the awareness of manifestations of Paget's disease by practicing physicians and to make them aware of the growing number of drugs available for treatment, many of them developed with the Foundation's support.

1980

- Twenty-two experts on Paget's disease met at the first ever conference devoted exclusively to Paget's in the United States, sponsored by the Kroc Foundation.
- The National Institutes of Health prepared a comprehensive brochure on Paget's disease for the Foundation.



1982

- John B. Johnson and Ann Kone represented the Paget Foundation in a coalition of thirty-six voluntary health agencies urging Congress to fund more bone disease and other research.
- Dr. Frederick R. Singer began his tenure as Chairman of the Advisory Medical Panel, serving until 1989.
- The Paget Foundation became a charter member of the National Organization for Rare Diseases (NORD) and attended the first annual meeting.

Very much as a result of the Foundation's work, Paget's disease has become recognized by many physicians as a distinct and treatable disorder; furthermore, many are aware of the importance of early diagnosis. And most know they can depend on the Foundation as a reliable source of information regarding the treatments now available. Importantly, we also serve as a resource whenever a patient may need to be referred to a specialist.

Obviously, nothing was, nor is, more important to us than making sure all health care providers receive the best and most up-to-date information on diagnosis and treatment. This determination applies to all the bone disorders we now address. Education is the key.

KEEPING INFORMATION UP-TO-DATE

Publications play a major role in our educational campaign. The Foundation publishes timely literature to keep the medical professions well informed and guided.

Information must have a source. New information about bone resorption disorders is derived from ongoing clinical research, the findings of which are brought together in conferences sponsored, or co-sponsored, by this Foundation.

Publications that issue from these conferences are made available to all health care professionals.

The Paget Foundation will continue to host important meetings, for they benefit a great number of health professionals and bone disease patients throughout the world.

A WIDENING SPECTRUM OF COMMITMENT

While Paget's disease remains the principal focus of our overall mission, and while we eagerly accept the challenge posed by rarer metabolic diseases such as primary hyperparathyroidism, fibrous dysplasia, and osteopetrosis, our assault on the bone metastasis caused by breast cancer, prostate cancer, and osteolytic lesions due to myeloma widen enormously the spectrum of our commitment. One of our major research physicians observed recently: "The Paget Foundation has been helping us deal with some rare diseases as well as Paget's disease, and now you are doing great work with cancer, which is anything but a rare disease."

Unraveling the molecular basis for cancer metastasis to the skeleton will improve understanding not only of tumor biology and this common manifestation of the most common cancers, but also provide new insights into normal and abnormal bone remodeling.

PROMOTING RESEARCH

The Paget Foundation's research program was initiated in 1986. Since then twenty-one recipients have received the Foundation's research awards. In 1997 the award program was named

1985

- Country music star Minnie Pearl recorded the first Paget's disease Public Service Announcement for radio.

- The Paget Foundation co-sponsored a Research Conference at the NIH, with thirty specialists from around the world.



1986

- Charlene Waldman became the Executive Director, a post she currently holds.

- The Paget Foundation awarded its first research grant to Dr. Ethel S. Siris.



1987

- Walter Oberstebrink was named President and Chairman of the Board of Directors, serving until 1989.

the John G. Haddad Jr. Research Award in memory of Dr. John G. Haddad, Jr. who served as Chairman of our Advisory Medical Panel from 1991 to 1997.

Another Paget Foundation award recognizes physicians and scientists who have made significant contributions to Paget's disease clinical and basic research. This award, the John B. Johnson Award, named in honor of our founder and Board president, has been given annually since 1988. There have been sixteen recipients to date.

The Foundation has played a strategic role in supporting clinical research by recruiting patient volunteers for every drug study for Paget's disease in the U.S. since 1990. This effort has helped gain FDA approval for several effective new treatment therapies.

Seed grants nurture the work of promising researchers. Several of the Foundation grants have helped investigators make major discoveries in defining the genetic abnormalities which account for familial Paget's disease.

ADVOCACY

Since its beginning the Foundation has sought government funding for research, making its mission known in the halls of Congress by direct contact with members of appropriations committees and others, and by submitting oral and written testimony to make the case for expanded research on all bone diseases. Over the years, joined by many bone disease specialists and patients, we have traveled to Washington, DC to articulate the need for research funds.

From its earliest days The Paget Foundation has joined forces with The American Society for Bone and Mineral Research. In 1991 the Foundation became a member of the National Coalition for Osteoporosis and Related Bone Diseases. Over the years we have worked closely with the National Institutes of Health (NIH) for funding to expand research on all bone disorders.

LEADERSHIP

The Foundation's growth has been supported by the dedication of the Board of Directors. Over the years many prominent physicians and scientists in the bone and mineral field and distinguished lay community leaders have served as Board members. The three Board members who have served as Board Chairman are:

John B. Johnson 1978–1987
Walter Oberstebrink 1987–1989
Frederick R. Singer, MD 1989–present

1987

- The first Paget Foundation patient meeting took place in Los Angeles California.

1988

- The first John B. Johnson Award was presented to Dr. Olav Bijvoet.

1989

- Dr. Frederick R. Singer became the Chairman of the Board of Directors. He continues to hold that post.
- Dr. John G. Haddad Jr. was named as the Chairman of the Advisory Medical Panel. He served until his death in 1997.
- The Foundation sponsored *Symposium on the Treatment of Paget's Disease*, in New York City—the first major conference for medical professionals.

The Foundation is also served by an Advisory Medical Panel whose members represent the various medical disciplines included in the Foundation's program. The following physicians have served as Chairman of the Advisory Medical Panel:

Stanley Wallach, MD 1978–1985
 Frederick R. Singer, MD 1985–1989
 John G. Haddad, Jr., MD (deceased) 1989–1997
 Frederick S. Kaplan, MC 1997–2002
 Henry G. Bone, III, MD 2002–present

COLLABORATION

The Foundation advances its advocacy and educational mission by participating in several coalitions and organizations including:

The National Organization for Rare Disorders (NORD), the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Coalition, the Friends of the National Institute for Craniofacial and Dental Research, the Ad Hoc Group for Medical Research Funding and the US Bone and Joint Decade. Since 1994 the Foundation has been a participant in the NIH Osteoporosis and Related Bone Diseases–National Resource Center which is operated by the National Osteoporosis Foundation in collaboration with the Paget Foundation and the Osteogenesis Imperfecta Foundation.

The Foundation also partners with several pharmaceutical companies, particularly Novartis, Merck & Co., the Alliance for Better Bone Health (Aventis and Procter & Gamble) and Amgen to organize and disseminate educational programs for patients and health professionals.

OVER THE HORIZON

The Paget Foundation's vision of the future sees three objectives. First, we look to improve our financial resources, the funding to carry out our continuing mission. The other two aims constitute that mission: research leading to discoveries that translate into new and better therapies for metabolic bone disorders; expansion of education and care capabilities throughout the world. And further? We hope to see research and education and care reach the ultimate goal of prevention and cure.

1989

- Dominic DiMaggio appeared in a Paget Foundation television public service announcement.

⋮

- The Foundation published the proceedings from the 1989 conference, *Paget's Disease of the Bone: Clinical Assessment, Present and Future Therapy*.

1991

- The *Symposium on Disorders of the Bone Resorption* was held in Chicago.

⋮

1992

- The first *Paget Foundation Working Group Meeting* was held in New York, New York.

- The Foundation co-sponsored the *First International Symposium on Paget's Disease* in Manchester, United Kingdom.



Advisory Medical Panel Meeting (1982). (Front row left to right) Dr. Stephen M. Krane, Dr. Frederick R. Singer, Dr. C. Conrad Johnston. (Back row left to right) Dr. Steven L. Teitelbaum, Dr. Genaro M.A. Palmieri, Dr. John G. Haddad, Jr., Dr. Roy Altman, Ruth Altman, Board of Directors Chairman John Johnson, Executive Director Ann Kone, Advisory Medical Panel Chairman Dr. Stanley Wallach, Dr. Robert Canfield

ADVISORY MEDICAL PANEL MEETING (2003)



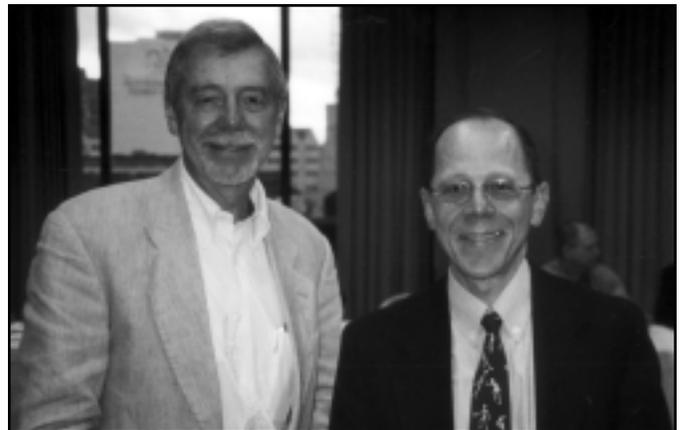
(left to right) Dr. Uri Liberman, Panel Chairman
Dr. Henry Bone



(left to right) Drs. Roy Altman, Carlos Mautalen, Joseph Shaker and Jean-Pierre DeVogether



(left to right) Drs. David Hosking, Peter Selby, Richard Bockman, Melvin Horwith and T. J. Martin



(left to right) Drs. Francis Glorieux and Fred Kaplan

1992

- The Foundation expanded its mandate from a single disease focus to include other bone resorption disorders. The first disorder addressed was primary

hyperparathyroidism.

- The Foundation moved from Brooklyn to 200 Varick Street in Manhattan.

1993

- The *Second Paget Foundation Working Group Meeting* was held in New York, New York.

1994

- The Foundation began participation in the NIH Osteoporosis and Related Bone Diseases ~ National Resource Center.

1995

- The Foundation added two disorders, fibrous dysplasia and osteopetrosis, to its program.

MEDIA



Radio personality Minnie Pearl recording a foundation radio public service announcement (1985)



Foundation Board member Dominic DiMaggio filming a foundation television public service announcement (1989)

ADVOCACY



John Johnson and Ann Kone on the steps of the Capitol beginning the Foundation advocacy program (1982)



Board members Dr. Henry Bone and Evelyn Nef testifying before a Congressional Appropriations committee for increased federal funding for bone disease research (1993)



Dominic DiMaggio meeting with Sen. Jesse Helms (R-NC, retired) to discuss bone disease legislative issues (1998)



Dominic DiMaggio and Charlene Waldman with Sen. Arlen Specter (R-PA) at a hearing on bone disease research convened by Sen. Specter (1998)

1995

- The Foundation participated in the *Second International Symposium on Paget's Disease*, in Sydney, Australia.

1996

- The conference *Recent Advances in the Treatment of Paget's Disease and Related Bone Disorders* was held in Bethesda, Maryland.

1997

- The Foundation began developing programs on the skeletal complications of malignancy.
- The Foundation moved to The Association Building, 120 Wall Street, New York, NY.
- Dr. Frederick S. Kaplan became chairman of the Advisory Medical Panel, serving until 2002.

RESEARCH AWARD RECIPIENTS



Dr. Fred Singer with the first recipient, Dr. Ethel S. Siris



Board Chairman Walter Oberstebrink (left) and Dr. Singer (right) with recipient Dr. G. David Roodman (1989)



Dr. John G. Haddad, Jr. (left) with recipient Dr. Paul Sharpe (1990)



Dr. Fred Kaplan (right) with Dr. Andrew Arnold, the first recipient of a foundation research award for the study of primary hyperparathyroidism (2001)

JOHN B. JOHNSON AWARD RECIPIENTS



Dr. Olav Bijvoet, the first recipient.



John Johnson (left) and Dr. Singer (right) with recipient Dr. Louis V. Avioli (1996)



Dr. Singer with recipient Dr. Barbara Mills (1998)



(left to right) Dr. Henry Bone, Charlene Waldman, recipient Dr. Jacques Brown, Dr. Siris and Dr. Singer (2003)

1998

- The Foundation sponsored the *Third International Symposium on Paget's Disease* in Napa, California.

1999

- The Paget Foundation sponsored the *Second North American Symposium on Skeletal Complication of Malignancy*, Montreal, Canada.

- The proceedings of the *Third International Symposium of Paget's Disease* was published as a supplement of the *Journal of Bone and Mineral Research*.

2000

- The Foundation launched its website www.paget.org.

- The proceedings of the *Second North American Symposium on Skeletal Complications of Malignancy* was published as a supplement of the journal *Cancer*.

CONFERENCES



Symposium on the Treatment of Paget's Disease of Bone, New York, NY (1989)



First International Symposium on Paget's Disease of Bone, Manchester, UK (1992)

Top Row (left to right): B. Rima, S. Papapoulos, G.D. Roodman, D. Anderson, R. Smith, C. Mautalen. Middle Row (left to right): S. Wallach, H. Bone, P. Selby, M. Davie, P. Meunier, P. Burckhardt, R. Altman, C. Waldman, G. Russell, F. Singer. Bottom Row (left to right) J. Kanis, S. Lee, T. Orton, H. Fleisch, E. Siris, P. Sharpe



Recent Advances in Paget's Disease of Bone and Related Bone Diseases, Bethesda, MD, 1996. (top to bottom) Speakers Drs. Fred Singer, Henry Bone, Pierre Meunier, Ethel Siris, Fred Kaplan, Allan Spiegel, Salutarior Martinez and Hugh Watts



Poster session at Third North American Symposium on Skeletal Complications of Malignancy, Bethesda, MD (2002)

IVTH INTERNATIONAL CONFERENCE ON CANCER INDUCED BONE DISEASES

San Antonio, TX (2003)



Video message from Sen. Kay Bailey Hutchison (R-TX), welcoming attendees



Symposium Chairman Dr. Greg Mundy



Keynote speaker Dr. Joan Massagué



Poster session



Attendees

2001

- The Foundation awarded its first grant for research on hyperparathyroidism.

2002

- Dr. Henry G. Bone, III became the Chairman of the Foundation Advisory Medical Panel.

- The *Third North American Symposium on Skeletal Complications of Malignancy* was held in Bethesda, Maryland.

2003

- The proceedings of the *Third North American Symposium on Skeletal Complications of*

Malignancy were published as supplements of the journals *Cancer* and *Oncology*.

PATIENT EDUCATION MEETINGS



Meetings in Houston, TX (1995) (left) and New York, NY (1996)

PAGET FOUNDATION STAFF AND VOLUNTEERS



Volunteers Jesse Hahn and Winifred Hampton



Paget Foundation staff (left to right) Christal Sumpter, Carolyn Gaffney, Charlene Waldman, Charles Langley (2003)

2003

- The Foundation co-sponsored the *IVth International Conference on Cancer-Induced Bone Diseases* in San Antonio, Texas.
- The Foundation co-sponsored the *First International Symposium on Osteopetrosis: Biology and Therapy* in Bethesda, Maryland.
- Paget's disease and the Paget Foundation were prominently mentioned in the best-selling book *The Teammates* by noted author David Halberstam.

PAGET'S DISEASE OF BONE THEN AND NOW

by

Henry G. Bone, III, M.D.

Chairman, Paget Foundation Advisory Medical Panel

The history of the Paget Foundation corresponds to an era of dramatic progress in our knowledge of Paget's disease, especially its treatment. From the time of Sir James Paget's description of the disease until the 1960's, there was no effective treatment. The initial experiments with calcitonin and bisphosphonates in the late 1960s and early 1970s led to the U.S. approval of salmon calcitonin for injection later followed by human calcitonin and oral etidronate. These medications introduced suppression of osteoclast activity and, remarkably, permitted formation of new bone in a normal lamellar pattern. The introduction of these medications created a role for the Paget's Disease Foundation (as it was then known). Recognition of Paget's disease and the fact that it could be treated is of course essential to successful medical management. The Foundation played an important part in communicating awareness about Paget's disease and its treatment to affected individuals and their physicians.

Over the last 25 years we have seen the introduction of newer, highly effective bisphosphonates, including pamidronate, alendronate and risedronate. These drugs, which have become the mainstay of current therapy, produce very high response rates and prolonged control of disease activity in most cases, dramatically transforming the typical course of the disease. Newer laboratory tests have also contributed to the ability to detect disease activity and treatment responses. The technical improvements in radiographic imaging over the last quarter-century, especially computed tomography and radionuclide imaging, have improved our ability to detect and diagnose Paget's disease, but plain radiography continues to be of central importance.

Thus, over a medical generation, Paget's disease of bone has been transformed from a progressive, painful disorder to one for which highly effective therapy is widely available.

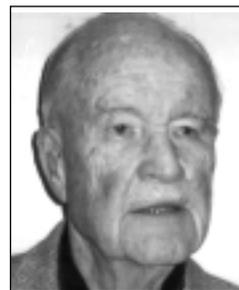
It is noteworthy that apart from being important for its own sake, Paget's disease has turned out to be an important "proving ground" for drugs for other bone disorders, especially osteoporosis.

The Foundation and its affiliated physicians, scientists, patients and advocates can look back with satisfaction on twenty-five years of remarkable progress. We then must look forward to the next cycle of laboratory and clinical investigation, using the tools of the new century to meet our ongoing challenges.

MESSAGES FROM THE BOARD OF DIRECTORS

John B. Johnson

*Westport, CT
President*



It was easy to start a foundation, I found; but it took the genius and energy of a unique team to set it in motion. The alliance of visionary volunteers who defined and carried forward the mission of The Paget Foundation over the past twenty-five years has achieved successes against disabling bone diseases worldwide that far exceed my fondest hopes, yet still do not fulfill theirs.

Ethel S. Siris, M.D.

*New York, NY
Vice-Chairman*



Science, education and advocacy form a triad. It is our responsibility at the Paget Foundation to encourage and support excellence in science, but the best science in the world will not be applied unless physicians and patients receive the needed education about the new knowledge that results from scientific research. Moreover, the continued funding of research programs requires diligent advocacy on behalf of both researchers and patients to be sure that the public and private agencies that support investigation into the diseases for which we advocate keep that support coming.

In my view, we have really come a long way in informing both patients and doctors about Paget's disease and the effective and safe treatments that now exist, making a huge difference in people's lives. Without the support and information generated by the Paget Foundation, many who need treatment would have gone untreated. Getting physicians to think about this disease and its management is the first step to getting patients treated appropriately.

The Paget Foundation has been and continues to be supportive of pharmaceutical research, publicizing clinical trials of new treatments, helping to enroll patients and making everyone a partner in the process. The Foundation also has played a major role in obtaining support for research by communicating with members of Congress who appropriate federal funds for science, and with the National Institutes of Health, who administer and grant this research money, to ensure that our patients are served well through the research support for the diseases that impact their lives.

The Paget Foundation has made things happen, and has made a difference. These efforts are a testament to past hard work and an inspiration to keep the process moving forward in the future.

Kenneth W. Lyles, M.D.

Durham, NC

Secretary - Treasurer



The Foundation's greatest achievement has been in educating patients and health professionals about Paget's disease of bone. The Foundation has been instrumental in helping recruit subjects for clinical trials. This partnering has led to new therapies for folks with Paget's disease and other diseases.

Some of the tools we've developed studying Paget's disease can be applied successfully to other diseases, leveraging what we have learned. In the area of skeletal complications of malignancy there are now therapies that can improve quality of life. The investments that the federal government and the pharmaceutical industry have made in Paget's disease have paid off handsomely.

Henry G. Bone, III, M.D.

Detroit, MI

Chairman, Advisory Medical Panel



John Johnson and Anne Kone came to see me when I was working at Ciba-Geigy about getting funding. Back then the Paget Foundation had a miniscule budget. Anne was working out of a spare bedroom. At that time it was particularly crucial to link the people who were interested in Paget's Disease, to provide a structure linking the investigators and the clinicians, to connect the people who were needed to get the clinical trials going and to increase professional awareness. This was very important in the early days and the Paget Foundation fulfilled a unique role.

Then, as the foundation matured, working groups and conferences were held, moving the field along. The foundation brought together relatively small groups in a collaborative environment.

I think that the expansion into other disease areas grew organically out of the biology of the bone diseases, especially the central role of the cells we call osteoclasts. Controlling these cells is critical to the treatment of several diseases. The diseases are different, but the same or similar medications are used in their treatment.

Roy D. Altman, M.D.

Los Angeles, CA



The Paget Foundation was formed by a set of interested professionals and non-professionals to provide information to patients, relatives and physicians about an uncommon disease. At the time, there was research into new therapies and little knowledge about Paget's disease outside the few interested parties. It has been a source of pride to watch and be a part of the growth of the Foundation. The vision of the Foundation has expanded to other poorly understood bone diseases. On minimal budget and with outstanding staff, the Foundation has reached its goals. We look forward to continued growth, as the scientific community and the public continue to need the Paget Foundation.

Dominic P. DiMaggio

Marion, MA

My biggest satisfaction in working with the Paget Foundation is that it has done a beautiful job through the years, especially in getting the word out to the public about Paget's disease of bone.

I admire the dedicated people like Charlene Waldman, John Johnson, the doctors and all the fine women and men who have served on the Board so successfully. Although I am not a medical man and not familiar with all the scientific terms, I do continue to be involved with the Foundation and try to make myself available by supporting all the good work they continue to accomplish.



Edward Grieve

Bluffton, SC

It is an unpleasant experience to hear a doctor tell you that you have a disease of the bone for which the cause is unknown and there is no known treatment for your condition except an operation to remove the diseased bone and to also be told that the disease can spread to other parts of your body. In 1987, received that news from a doctor in San Francisco when he told me I had Paget's disease in the right leg. In 1995, through the Paget Foundation, I met a doctor who is affiliated with the Foundation who asked me if I wished to participate in a study for a new treatment for Paget's disease. I agreed and since I had that treatment and subsequent follow-up visits over five years, my disease has been in remission.

What the Paget Foundation has done for me it has done for tens of thousands of others suffering from this debilitating disease. Working with the pharmaceutical companies that develop new medicines, educating doctors and creating public awareness has proven to the medical community and the public the extraordinary value of the Foundation. I am honored to be a small part of that effort.



Theresa A. Guise, M.D.

Charlottesville, VA

The Paget Foundation has had a tremendous impact on the lives of patients with Paget's disease. All would agree with this, and most would have been satisfied with such success. Instead, the Foundation moved forward to attack other bone diseases—most recently the skeletal complications of malignancy. In only six years, the Foundation sponsored four major conferences on skeletal complications of malignancy.

As a participant in each conference, as well as a recent member to the Board of Directors of the Paget Foundation, I believe that this small Foundation has done more to encourage research into skeletal complications of malignancy than any major cancer organization to date. The result is amazing! The awareness of cancer metastases to bone is at an all-time high. More investigators have been drawn to the field and are making new and major breakthroughs. Should the current rate of advancement continue, the Foundation might need to find more bone diseases to conquer. Given their history with Paget's disease, I have no doubt of this prospect!



Frederick S. Kaplan, M.D.

Philadelphia, PA



A quarter-of-a-century ago, The Paget Foundation was born and has developed into one of the world's premier patient advocacy organizations to improve the plight of those who suffer from Paget's disease of bone. Born from the need to educate and advocate, The Paget Foundation has evolved into a vibrant, multi-faceted organization that serves the needs of those who have Paget's disease and more recently has expanded to help those with several related disorders. Education has improved awareness of Paget's disease among the relevant populations of patients and physicians, but education requires time, effort, and human resources. Advances in understanding Paget's disease are due largely to tremendous advances in research in molecular biology and genetics combined with the committed activities of patient and physician support groups such as The Paget Foundation and its sister organizations around the world.

The Paget Foundation is proud to have a dedicated advisory medical panel of distinguished physicians and scientists who work unselfishly to abolish ignorance about Paget's disease and related conditions through basic and clinical research and patient and physician education. It was an honor to have served as chairman of this panel for five years following the death of our colleague and dear friend, John Haddad, who served so admirably in that position and who we so dearly miss.

On the occasion of its 25th Anniversary, I want to express my tremendous gratitude to my colleagues and friends at the Paget Foundation, especially to our extraordinary Executive Director, Ms. Charlene Waldman, whose efforts embody the spirit of the organization she serves. I would like to extend my congratulations to my colleagues on the Board of Directors and the Medical Advisory Panel who join me in the hope for an even brighter future for sufferers of Paget's disease and related disorders.

Walter Keisch

Windsor, CT



A quarter century ago The Paget Foundation set out on a mission that has improved the health and quality of life of people throughout the world who suffer from certain disorders.

I find great gratification in being part of this mission.

Ann Scott Kone

Brooklyn, NY

From its very first days, the Paget Foundation has worked to help individuals manage their illness in order to live better lives. I believe we have achieved significant results by using the personal touch—communicating one-on-one—as much as possible. And the same approach is directed to the medical and research professionals who treat the patients and who explore better medical solutions. Having reached thousands over the last twenty-five years, this caring support continues today. As members of the Board of Directors, my colleagues and I are dedicated to making sure that the Foundation continues working to improve the lives of individuals in the coming years.



Stephen Krane, M.D.

Boston, MA

It has been a rewarding experience to work with such devoted and talented people and I wish the best for another 25 years.



Evelyn Stefansson Nef

Washington, DC

In the decade I have been associated with the Paget Foundation it has grown steadily and wisely from a fiercely devoted small group with a local influence to a world respected organization reaching and influencing a huge population. It has been in the forefront of disseminating helpful information to sufferers of Paget's, defining it and telling where help might be found and eventually educating the medical profession itself in the nature of the disease. It has been thrilling and rewarding to observe its role in the development of new drugs that are used for Paget's disease and other bone disorders.



I am a sufferer of Paget's disease and knew thirty years of chronic pain until I discovered the Foundation. Hail to the Paget Foundation for the splendid work it does to promote the dissemination of information about Paget's and all bone related diseases!

G. David Roodman, M.D., Ph.D.
Pittsburgh, PA



The biggest achievements have been in making doctors more aware of Paget's disease, more aware of both the diagnosis and the available treatments. But what has really put the Paget Foundation on the map is research. They've helped enhance funding for the entire field of bone research co-sponsoring international conferences, participating in the Bone Coalition and interesting new investigators with a grant program. Investigators are attracted when both patients and funds are available.

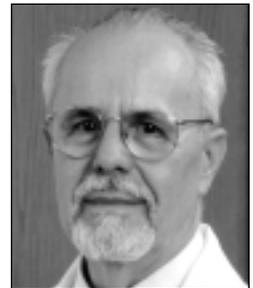
I think the future of research is going to take off with the identification of genes linked to Paget's disease and that Paget's disease will serve as a model for understanding other bone diseases.

Lawrence B. Thompson
New York, NY



The Foundation continues its successful work in expanding knowledge and making available information that helps those who must cope with Paget's disease and related disorders.

Stanley Wallach, M.D.
St. Petersburg, FL



My greatest satisfaction has come from the growth and respect that the Paget Foundation has gained in the clinical research community. Obviously, being a founder of the Foundation and also receiving the John Johnson Award were great honors for me; but, in addition, the opportunity to work with the Paget Foundation staff and the equally great scientists and clinicians associated with the Foundation has given me an added sense of satisfaction.

I think that Paget's has become a model for the study of other osteoclast diseases, a prototype for research into the many metabolic bone diseases. Extending the purview of the foundation was an important step.

**PAGET FOUNDATION
BOARD OF DIRECTORS
DECEMBER, 2003**

MESSAGES FROM RESEARCH AWARD RECIPIENTS

Stuart Ralston

*University of Aberdeen
Aberdeen, Scotland, UK*

I was a previous recipient of a Paget Foundation research award. This award was used to support my research into the genetic basis of Paget's disease and specifically helped me to identify individuals with familial Paget's disease and to collect samples and clinical data for genetic analysis. As the result of this, we contributed to the identification of mutations in the RANK gene as a cause of familial expansile osteolysis and early onset Paget's disease and recently showed that mutations in the SQSTM1/p62 gene were an important cause of Paget's in familial and sporadic Paget's patients. The family collection continues to be an important resource for identifying other genes that cause Paget's and we are continuing research in this area at present. Support from the Paget foundation was important in us getting our research "off the ground" when genetic studies of the disease were difficult to get funded. My thanks therefore go to all at the foundation for supporting us in the early stages of our research endeavors.

Jean Sibonga

*Mayo Clinic
Rochester, MA*

Since receiving my doctorate in Biochemistry fifteen years ago, I have been working with rat models for perturbations in skeletal metabolism. While under the mentorship of Dr. Russell Turner, I became the manager for the Mayo Clinic Bone Histomorphometry Laboratory. This lab is one of a very few clinical labs in the US that still prepares and performs histomorphometry on iliac crest biopsies for the diagnosis of metabolic bone disease. I feel that this transition from animal models to clinical specimens has clarified my role as a scientist in the treatment of human disease. Our observations made in the rat model for hyperparathyroidism translated to our investigations of the mast cell and the induction of osteitis fibrosa. I consider the research award from the Paget Foundation a validation of the critical role played by the pre-clinical researcher; and I appreciate the Foundation's support for my tissue analyses.

Sakamuri V. Reddy

*University of Pittsburgh
Pittsburgh, PA*

As a scientist, I have been extremely fortunate to study Paget's disease with my mentor Dr. G. David Roodman for thirteen years. The dedication and enthusiasm of Dr. Fred Singer, the Chairman of the Board of Directors of the Paget Foundation and that of Dr. Greg Mundy, the leader of the Bone Group at the University of Texas in San Antonio, inspired me to continue working in this field. Most of all the efforts of the Paget Foundation over 25 years and patients across the world who volunteered in studies are key to our understanding of Paget's disease of bone.

Edwin Monsell

*Wayne State University
Detroit, MI*

The Paget Foundation has become one of the best disease foundations in the US. It has been very effective in supporting patients, physicians, and researchers. The research grant program awarded me a grant for studying the mechanism of hearing loss in Paget's disease of bone. This work allowed me to produce work that resulted in my receiving the Harris P. Mosher Award from the American Triological Society, May 5, 2003. I look forward to many more years of fruitful association with the Paget Foundation.

Andrew Arnold

*University of Connecticut
Hartford, CT*

It is a pleasure to have this opportunity to contribute to the Paget Foundation 25th Anniversary Book. As a physician who has cared for many patients with Paget's disease, there is no question that the Foundation has been a tremendous support for our patients and has fostered their education and improved management. To me, the Foundation remains the preeminent model of how a patient/disease-oriented organization should approach its goals to achieve success, and Charlene Waldman deserves the highest accolades. Furthermore, as an investigator in the field of parathyroid disease, I laud the Foundation for the decision to expand its focus to include certain additional metabolic bone disorders, which have been sorely lacking in patient advocacy and support, and especially to offer a competitive research award in hyperparathyroidism. It was a great honor to have received this award in its first year of existence, and I look forward to helping the Foundation as it moves into the future.

Jill Cornish

*University of Auckland
Auckland, New Zealand*

"Seeds Successfully Sprout"

The John G. Haddad Jr. Research Award made it possible for us to initiate a detailed study investigating the pagetic osteoblast (bone forming cell) as playing a possible role in the pathogenesis of Paget's disease. Although Paget's disease has traditionally been thought of an osteoclast (bone resorbing cell) disorder, recent evidence indicates that osteoblasts are major regulators of osteoclast development and function. Thus, osteoblasts may be involved in the cause of Paget's disease. Identifying the cell responsible for Paget's disease may be important for improving its diagnosis and treatment.

The Paget Foundation funds acted as a seeding grant for the bigger study, which has since been funded by the Health Research Council of New Zealand. This seeding grant enabled us to set up the necessary methodologies for the study. Thus, we are most grateful for the Paget Foundation for making it possible for this research to be undertaken.

MESSAGES FROM PATIENTS

Twenty-five years ago, I went for a check-up. He drew blood, and the following week told me that I had Paget's disease. Never having heard of it before, I asked, "What do I do about it?" "There is nothing to do," he answered.

The following week I went to the dentist on Atlantic Avenue. While waiting for my appointment, I read *Good Housekeeping* magazine and noticed a six-line article saying that the Paget's disease organization was opening an office on Pacific Street. After the dental appointment, I walked to the brownstone on Pacific Street, was greeted by a receptionist, and told her that I would like to be on the mailing list. I have been receiving mailings for the past twenty-five years and find that every mailing has useful and interesting information.

I appreciate all that the Paget Foundation has done and hope that you are able to continue your good work.

P.L., Brooklyn, New York

The Paget Foundation website was extremely useful because it listed doctors who treat various bone diseases.

The Sperrings, Huntington, California

Best wishes for continued further success in your efforts to combat Paget's disease.

B.S., Los Angeles, California

In January 1993 I was stricken with a pain in my right hip. I could not bear to sit without several pillows and then I was not comfortable. I went to several doctors in the Roanoke, VA area and was diagnosed with Paget's disease. In searching for information on the disease, I learned about the Paget Foundation. That led me to a Patient Education day at Duke University in Durham, NC. Thanks to the Paget Foundation for getting me over this terrible pain.

N.R., Roanoke, Virginia

The Paget Foundation was not around some thirty years ago when I was first diagnosed as having Paget's disease. However, since then, I have been in several research programs at Columbia Presbyterian Hospital in New York City. I have also used the Foundation's services, especially their publications, to inform Paget's sufferers that help is available. Much credit is due to the organizers and supporters of the Foundation who are helping Paget's patients to finally receive the help they so desperately need.

R.M., Oakland, New Jersey

I have had Paget's disease for fifty years. Doctors stated that the cause was unknown and that there was no known relief for it. I wish your present findings had been known by doctors forty years ago.

J.H.M., Abilene, Texas

I have extensive Paget's disease of the bone with many skeletal deformities. Through a Paget Foundation program in Chicago, I was able to participate in many clinical trials. For this I am truly thankful.

M.R.H., Roscoe, Illinois

I would like to express my thanks to the Paget Foundation for all the information that I have received for the last twelve years. It sure has helped. Congratulations on your anniversary. You have served the Paget people well.

W.E.D., Canton, Massachusetts

Confidence: The invaluable gift is a treasure I receive through the Paget Foundation, both several years ago when my elderly father was diagnosed and every day since, knowing my sister and our children and I have a resource and outstanding continuing research and development. Thank you.

C.T., Tifton, Georgia

The Foundation gives me a sense of being one of group with similar problems. I rely greatly on the Paget Foundation newsletter for information.

J.E.W., Yakima, Washington

What would we do without the Paget Foundation's research, guidance and information? They are my lifeline with a treatment that stopped my excruciating pain for which I am very grateful. What a relief! What Joy!

A.H.N., Bannockburn, Illinois

When I was diagnosed with Paget's disease it left me feeling confused and frightened. How could a person 6'4", 270 pounds and very active in sports have this disease? But with the help of the Paget Foundation's information, I am on my way back.

C.F.A., Farmington Hill, Michigan

To me, the anniversary signifies that the Foundation was responsible for diagnosing my wife's Paget's disease. I was an early member of the Board. The Foundation's accomplishments are a tribute to the Board, Medical Panels and Executive Director.

J.T.G., Stamford, Connecticut

After two doctors told me that I had Paget's disease—but not to worry about it as it was slow growing and I would be certain to die of more serious problems.

They both insisted there was no known reason for it and no one in the United States was interested in the disease, as it was rare.

Five years later when I suddenly went deaf in my left ear, a lady ear doctor found that my ear had been affected by the Paget's disease. However, she also told me about the Paget Foundation. I am 83 now and I know I will die of something other than Paget's disease, which was diagnosed over twenty years ago.

J.P., San Mateo, California

Not enough space to write all that I want regarding the Paget Foundation. The staff at the Foundation has always answered my questions. They gave me hope and guided me through difficult times. The Foundation keeps me informed on new medications available. I appreciate the newsletters. Without your concern and help I would be lost today. Thank you most sincerely and please continue on with all your good work.

R.L., Northvale, New Jersey

I will be forever grateful to the Foundation. I can call and always receive courteous answers. I appreciate the Foundation newsletters.

C.F., West Milford, New Jersey

My mother became a member of the Paget Foundation early in its history. Since her death, I have been able to reach out to her through donations to and information from the Foundation. I now understand the emotional, physical and social impacts she suffered from having Paget's disease.

J.V.D., Lansing, Michigan

Congratulations on twenty five years of providing information and encouragement for those who suffer from the still little known and little understood disease. I am gratified to have been a part of your history, and send best wishes for future accomplishments.

G.W., Tulsa, Oklahoma

The Paget Foundation has meant a great deal to me. It has kept me informed on the most current medications and procedures on Paget's disease. The patient meetings that were organized were especially helpful in allowing me to gain more insight.

R. P., Woburn, Massachusetts

RECIPIENTS OF ANNUAL RESEARCH AWARDS

1986–2003

- 1986 & 1987** ***“Paget’s Disease Patient Survey”***
Ethel S. Siris, M.D.
Columbia University College of Physicians & Surgeons
New York, NY
- 1988** ***“Genetic Susceptibility to Paget’s Disease”***
John Eisman, MBBS, Ph.D.
St. Vincent’s Hospital
Sydney, Australia
- 1989** ***“Osteoclasts Stimulatory Activities Produced by Paget’s Osteoclasts”***
G. David Roodman, M.D., Ph.D.
University of Pittsburgh
Pittsburgh, PA
- 1990** ***“Canine Distemper Virus and Paget’s Disease”***
Paul T. Sharpe, Ph.D.
Guy’s Hospital
London, UK
- 1991** ***“Dental Status of Patients with Paget’s Disease”***
Timothy T. Wheeler, D.M.D., Ph.D.
University of Florida College of Dentistry
Gainesville, FL
- 1992** ***“Expression of Calcitonin Receptors in Pagetic Bone and Associated Reparative Granulomas”***
Steven R. Goldring, M.D.
Harvard University
Boston, MA
- 1993** ***“Abnormalities in the Bone Marrow Microenvironment in the Pathogenesis of Paget’s Disease of Bone”***
G. David Roodman, M.D., Ph.D.
University of Pittsburgh
Pittsburgh, PA
- “A Transgenic Animal Approach to the Study of Paramyxoviruses as a Cause of Paget’s Disease”***
Paul T. Sharpe, Ph.D.
Guy’s Hospital
London, UK
- 1994** ***“Expression and Characterization of Calcitonin Receptors in Pagetic Bone and Associated Skeletal Disorders”***
Steven R. Goldring, M.D.
Harvard University
Boston, MA

- 1995** ***“Cochlear Capsule Density and Mechanisms of Hearing Loss in Paget’s Disease of Bone”***
Edwin M. Monsell, M.D., Ph.D.
Wayne State University
Detroit, MI
- 1995** ***“Detection of Measles Virus in Osteoclast Lineage”***
Sakamuri V. Reddy, Ph.D.
University of Pittsburgh
Pittsburgh, PA
- 1996** ***“Molecular Genetic Basis of Paget’s Disease”***
Stuart H. Ralston, M.D., F.R.C.P.
University of Aberdeen
Aberdeen, Scotland, UK
- 1997** ***“The Role of BCL-2 in Paget’s Disease”***
Andrew Mee, BVSc, Ph.D., MRCVS
Manchester Royal Infirmary
Manchester, UK
- “Identification of a Locus for Paget’s Disease Involved in Osteosarcomas”***
Robin J. Leach, Ph.D.
University of Texas
San Antonio, TX
- 1998** ***“Genetic Linkage Studies of Autosomal Dominant Paget’s Disease of the Bone”***
Vincent Raymond, M.D., Ph.D.
CHUL Research Center
Quebec City, Canada
- 1999** ***“Origins of Bone Tumors in Paget’s Disease”***
Marc F. Hansen, Ph.D.
University of Connecticut Health Center
Farmington, CT
- 2000** ***“The Role Osteoblasts Play in the Development of Paget’s Disease”***
Jillian Cornish, Ph.D.
University of Auckland
Auckland, New Zealand
- “The Genetic Analysis of Paget’s Disease in a Large Pedigree”***
Joanne T. Shaw, M.D., Ph.D.
Princess Alexandra Hospital
Brisbane, Australia
- 2001** ***“Molecular Mechanisms in Parathyroid Neoplasia”***
Andrew Arnold, M.D.
University of Connecticut
Hartford, CT

“Genetics and Paget’s Disease”

Joanne T. Shaw, M.D., Ph.D.
Princess Alexandra Hospital
Brisbane, Australia

2002

“The role of SHIP, a Phosphoinosityl lipid phosphatase, in Paget’s Disease of Bone”

Sunao Takeshita, Ph.D.
Washington University
St. Louis, MO

“Myopathy and Paget’s Disease”

Virginia Kimonis, M.D.
Children’s Hospital
Harvard Medical School
Boston, MA

“Hyperparathyroidism and Mast Cell Modulation”

Jean D. Sibonga, Ph.D.
Mayo Clinic
Rochester, MN

2003

“The Impact of Parathyroidectomy on Cognition in Primary Hyperparathyroid Patients Under the Age of 55”

Nancy D. Perrier, M.D.
Wake Forest University Health Sciences Medical Center
Winston-Salem, NC

“Clinical and Molecular Studies of the VCP Gene in Paget’s Disease of Bone”

Virginia Kimonis, M.D.
Children’s Hospital
Harvard Medical School
Boston, MA

RECIPIENTS OF THE JOHN B. JOHNSON AWARD

1988–2003

- | | |
|-------------|---|
| 1988 | Olav Bijvoet, M.D.
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| 1989 | Stanley Wallach, M.D.
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| 1990 | Frederick R. Singer, M.D.
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| 1991 | Pierre Meunier, M.D.
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| 1992 | Stephen M. Krane, M.D.
Boston, MA |
| 1993 | Charles Nagant de Deuxchaisnes, M.D.
Brussels, Belgium |
| 1994 | Roy D. Altman, M.D.
Los Angeles, CA |
| 1995 | Iain McIntyre, M.D.
London, UK |
| 1996 | Louis V. Avioli, M.D.
St. Louis, MO |
| 1997 | R. G. Graham Russell
Oxford, UK |
| 1998 | Barbara Mills, M.D.
Los Angeles, CA |
| 1999 | John Kanis, M.D.
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| 2000 | Ethel S. Siris, M.D.
New York, NY |
| 2001 | David Hosking, M.D.
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| 2002 | G. David Roodman, M.D.
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CONFERENCES ORGANIZED OR CO-SPONSORED
by
THE PAGET FOUNDATION

Symposium on the Treatment of Paget's Disease
New York, NY 1989

First Paget Foundation Working Group Meeting
New York, NY 1991

Symposium on Disorders of Bone Resorption
Chicago, IL 1991

Second Paget Foundation Working Group Meeting
New York, NY 1993

Recent Advances in the Treatment of Paget's Disease and Related Bone Disorders
Bethesda, MD 1996

Skeletal Complications of Malignancy
Bethesda, MD 1997

Third International Symposium on Paget's Disease
Napa, CA 1998

Second North American Symposium on Skeletal Complications of Malignancy
Montreal, Canada 1999

Third North American Symposium on Skeletal Complications of Malignancy
Bethesda, MD 2002

First International Symposium on Osteopetrosis: Biology and Therapy
Bethesda, MD 2003

IVth International Conference on Cancer-Induced Bone Diseases
San Antonio, TX 2003

PUBLICATIONS FOR HEALTH PROFESSIONALS

Paget's Disease of Bone: Clinical Assessment, Present and Future Therapy, Elsevier, 1991

Cancer Supplement 80/8, October 1997

Diagnosis and Management of Paget's Disease of Bone (educational slide program), 1998

Journal of Bone and Mineral Research Supplement 2, Vol. 14, 1999

The Management of Paget's Disease of Bone, 2000*

Cancer Supplement 88/12, June 2000

A Nurse's Guide to Paget's Disease of Bone, 2002*

Cancer Supplement 97/3, February 2003

Oncology Supplement Vol. 17-No.4 – Supplement No.3, April 2003

*Jointly published by the NIH Osteoporosis and Related Bone Diseases ~ National Resource Center

PUBLICATIONS FOR PATIENTS

BOOKLETS

Questions & Answers About Paget's Disease of Bone

Questions & Answers About Primary Hyperparathyroidism

Questions & Answers About Osteopetrosis

Questions & Answers About Fibrous Dysplasia/McCune-Albright Syndrome

Questions & Answers About Breast Cancer Metastatic to Bone

Questions & Answers About Prostate Cancer Metastatic to Bone

FACT SHEETS

Paget's Disease

Pain and Paget's Disease

Diagnosing Paget's Disease

Medical Therapy for Paget's Disease

Paget's Disease and Osteoarthritis

Which Paget's Patients Should Be Treated?

Surgery and Paget's Disease

Osteosarcoma and Other Tumors in Paget's Disease

Primary Hyperparathyroidism

Surgery and Primary Hyperparathyroidism