# Update

**The Newsletter of The Paget Foundation ◆ Summer 2004 ◆ Vol. 26, No. 2**

Elizabeth W. Lewis
Greenville, VA

## PAGET PEOPLE: ELIZABETH LEWIS

### Undergoing Surgery for Hyperparathyroidism A Patient's Perspective…

**Interviewer:**
When were you diagnosed with hyperparathyroidism?

**Elizabeth:**
Let me start at the very beginning. Thirty years ago I was diagnosed as being hyperthyroid and treated with radioactive iodine. My surgeon is collecting data on people who were treated with radioactive iodine for Graves Disease. He believes that there is a causal relationship – so maybe that was the initial cause. I was diagnosed with hyperparathyroidism in December of 2003 and I was operated on in March.

**Interviewer:**
Did you have any symptoms?

**Elizabeth:**
No, none, or I should say I had symptoms but none that alerted me. The symptom I had was extreme fatigue. I teach for the Jamestown Foundation and I was uncharacteristically tired. That was the only real symptom. The symptoms of hyperparathyroidism are vague and come on gradually. And I'm no spring chicken, so I thought that was it. I'm regaining my energy level now.

I went to the doctor because I periodically get my thyroid levels checked. I don't think they would have checked my parathyroid except that my general practitioner insisted on a bone density test.

I was cocky about the bone density and told him I'd done my own test – I fell while ice-skating and didn't break a bone. Because I exercise and I'm careful about my diet, I really was horribly cocky. Then the bone density test showed osteoporosis! Which led me to the thyroid and parathyroid check as well. According to my surgeon the hyperparathyroidism had gone on for years – and caused my osteoporosis.

I'm no longer so cocky.

***(Paget People Continued on pages 2, 4 & 5)***

## THE PAGET FOUNDATION

### Helping Patients, Educating Health Professionals, Supporting Research

When The Paget Foundation was founded in 1978 its' mission was to provide information on Paget's disease of bone to patients, family members and health professionals. Beginning in 1992, the Foundation expanded its mission to include other bone disorders including primary hyperparathyroidism, fibrous dysplasia, osteopetrosis, (not the more common disease osteoporosis) and the effects of certain cancers on the skeleton.

The Foundation provides publications on all of these disorders, physician referral lists for Paget's disease, primary hyperparathyroidism, fibrous dysplasia and osteopetrosis, research grants for scientists studying Paget's disease and hyperparathyroidism and educational programs for physicians and scientists in the bone-cancer field.

Information on all foundation publications and programs is available on the foundation website at www.paget.org. ■

# THREE NEW MEMBERS JOIN FOUNDATION BOARD OF DIRECTORS

The Paget Foundation welcomes three new members to the Board of Directors: Joseph L. Shaker, MD; Margaret Seton, MD; and Betsy Love McClung, MN, RN. Doctors Shaker and Seton have been members of the Foundation Advisory Medical Board for several years. Ms. McClung assisted the foundation in educational projects and was a lead author of the publication *A Nurses Guide to Paget's Disease of Bone.*

Besty Love McClung, RN

Ms. McClung is the Associate Director of the Oregon Osteoporosis Center in Portland, Oregon, a medical center that specializes in the treatment of patients with osteoporosis, Paget's disease and other bone diseases. Ms. McClung states, "I am honored to join the Paget Foundation Board. I look forward to working with the other members of the Board of Directors to create and implement a wide range of program activities. As a nurse I hope to contribute to this foundation's strong mission to provide patients, families and health providers with continuing education and resources for Paget's disease."

Dr. Seton is an Assistant Professor of Medicine at Harvard Medical School, Director of the New England Registry for Paget's Disease of Bone and a member of the Allergy, Immunology and Rheumatology Division, Massachusetts General Hospital, Boston, MA. Dr. Seton writes "It is a pleasure and a privilege to join the Board of the Paget Foundation, a Board passionate in advocating for better care and understanding of Paget's disease of bone and related disorders of bone"

Margaret Seton, MD

Joseph Shaker, MD

Dr. Shaker is Clinical Professor of Medicine at the University of Wisconsin School of Medicine and an endocrinologist at St. Luke's Medical Center in Milwaukee, Wisconsin. Dr. Shaker is " very pleased to be a part of the Paget Foundation which has done so much for patients with Paget's disease and other metabolic bone diseases." ■

## PAGET PEOPLE: ELIZABETH LEWIS

***(Continued from page 1)***

**Interviewer:**
The one treatment for hyperparathyroidism is surgery. How did you feel about that?

**Elizabeth:**
I don't like surgery and I've never had any – before this. My definition of major surgery is any surgery that happens to me – minor is what happens to someone else.

I was immediately concerned with my surgical options. There was one with a large incision done under general anesthesia. I got my nephew to help me do research on the Internet and he found another procedure – one done on an outpatient basis. I researched it very thoroughly. I wanted to be sure that it was doable – given my age.

It would leave a much smaller scar and 'vanity thy name is woman.' The down side is that I wouldn't need a necklace to conceal my scar (laughing). The surgery was done under local anesthesia and the scar is virtually invisible.

The surgeon did exactly what he promised to do.

***For information about osteoporosis contact:***
**The National Osteoporosis Foundation**
**Website: www. nof.org Tel: (202) 223-2226 or**
**The NIH Osteoporosis and Related Bone Diseases~National Resource Center**
**Website: www.osteo.org Tel: (800) 624-BONE** ■

# INFORMATION FOR PATIENTS

Q&A

**Q. After a Paget's disease patient has been treated with one of the approved bisphosphonate drugs, when should the patient follow up with his or her physician?**

A. For the oral drugs, Actonel®, Fosamax®, Didronel® and Skelid®, the foundation suggests that serum alkaline phosphatase (SAP), an enzyme that is over-produced in bone affected by Paget's disease, be checked at the end of the treatment period and again in three months. Then the SAP can be checked every six months to one year, depending on whether the SAP was in the normal range after the treatment.

For the intravenous drug Aredia®, the SAP should be checked three months after the last infusion and then every three to six months.

SAP readings vary depending on the laboratory that is used. The level 125 is often the reading that is the upper limit of normal.

The therapies of choice for treating Paget's disease are the three most potent bisphosphonates: Actonel®, Fosamax® and Aredia®.

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

## PHYSICIAN REFERRAL LISTS

The Foundation provides physician referral lists for patients who have Paget's disease, primary hyperparathyroidism, fibrous dysplasia and osteopetrosis. No physician referral lists are provided for breast and prostate cancer patients. These lists are distributed by regular mail upon request by a patient or family member. The lists are not available on the foundation website and are not sent by email. There are two lists for primary hyperparathyroidism patients: a list of endocrinologists and a list of surgeons who perform parathyroid surgery.

You may request physician referral lists by mail, telephone (1 800-23 PAGET) or email at pagetfdn2@aol.com. When requesting a list, please include your full name, mailing address, and the name of the list you are requesting (for example, Paget's disease list). ***(Continued on Page 6)***

# ADVOCACY

The Foundation has been very involved in legislative and advocacy activity during the last few months. On March 30th fourteen-year-old fibrous dysplasia patient Patrick Wenger and Joan Goldberg, Executive Director of the American Society for Bone and Mineral Research (ASBMR) testified on behalf of the National Coalition for Osteoporosis and Related Bone Diseases before the House of Representatives Appropriations Subcommittee on Labor, Health and Human Services, Education and Related Agencies about the need for expanded bone disease research funding. In addition to the Paget Foundation and ASBMR, the other coalition members are the National Osteoporosis Foundation and the Osteogenesis Imperfecta Foundation.

The Coalition published a new brochure that has been distributed to members of the Congress and submitted written testimony to the House, Senate and Department of Defense Appropriations Committees.

Charlene Waldman attended the annual meeting of the Coalition of Voluntary and Professional Associations Concerned with the Programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). NIAMS is the lead NIH institute that conducts research on bone diseases. Coalition attendees met with Congressional staff to advocate for increased funding for NIAMS.

Mrs. Waldman also participated in the annual National Institute of Dental and Craniofacial Research (NIDCR) Patient Advocacy Day.

The Foundation is a member of the U.S. Bone and Joint Decade. Through the Decade, U.S. patient and physician healthcare organizations, government agencies and the pharmaceutical industry have come together to improve the prevention of bone and joint disorders, and to improve the quality of life of those affected.

More information is available at www.boneandjointdecade.org/usa. ■

# PAGET PEOPLE: MARY AND PATRICK
# A MOTHER AND SON DISCUSS FIBROUS DISPLAYSIA

**Fourteen-year-old Patrick Wenger and his mother, Mary Clements, discuss the impact of fibrous displasia on Patrick's life.**

**Mary:**
Patrick was diagnosed when he was four. The doctor knew nothing about this disease. He said, "Go home, there's nothing we can do." That was on a Friday, so of course, I couldn't even get in touch with anyone else. I didn't have the Internet then, either, so on Monday I got on the phone. One of the first people I managed to contact was Charlene Waldman and the Paget Foundation. If it wasn't for the Foundation, I don't know what I would have done. I am very much in debt to her and to the Foundation. I was very determined to get the information we needed and since then I've met or talked on the phone with doctors from all over the world.

Pat has done extremely well. He's had some setbacks, but he hasn't broken a bone in four years and, other than the pain related to surgery, he's been pain free too. During his last surgery he had pins and rods put into his legs. I attribute much of this to the research program at the National Institute of Dental and Craniofacial Research at the National Institutes of Health (NIH) and to good doctors. We feel very fortunate.

Pat's an A student with a perfect 4.0 average, even with missing school for treatments every four months. In addition to studying, he's also a big reader who enjoyed all the Harry Potter books and the *Chronicles of Narnia.*

**Patrick:**
I wrote a letter to President Bush after 9/11 asking if I would be safe flying to the NIH. I guess they really liked it because a couple of weeks later we got a phone call from the Nancy Theis, one of the President's secretaries. She said that when I came up to Washington, she would show me around the Old Executive Building – where she had her office then. It's a really cool place, and we had fun. We've been back there every year since. We even got a special tour of the White House. I was able to go into the West Wing. I saw the Rose Garden and stood right in front of the Oval Office!

I'm doing pretty well. The symptoms haven't affected me too much. Other people are worse off. To someone who was diagnosed, I'd just say – stick with it! Keep on going, try to do whatever is possible for you to get out of pain and try to have as much fun as possible too – which is sometimes hard when you have to go to doctors.

To parents I'd just say, try to help your son or daughter as much as possible – which is probably what you are trying to do. If they've just been diagnosed and going through a tough time figuring it out, I'd say – be patient, eventually the doctors will tell you what to do.

**Mary:**
The White House has been incredibly wonderful to Patrick. We've been to dinners with Nancy, the head of Student Correspondence for the President, and she's taken a real liking to Patrick. In addition to the personal tour of the White House, we've done tours of the Supreme Court and the Senate. Patrick has badges and patches from the Secret Service and at Easter Nancy even sent him one of the White House Easter eggs!

Patrick starts high school next year. I'm worried about him being knocked down the steps or about him falling. He missed two months of school after a fall last year. Emotionally I think he can hold his own. He looks normal so people don't know anything is wrong, but high school won't be like the school he goes to now where there are only 300 kids and everybody knows Patrick. The school has been wonderful, especially the girls, who look out for him.

It's been difficult for Patrick's brother. We took him to the NIH to see what Patrick goes through. He's afraid for his brother too. They'll be in the same school next year and I think John Paul will defend Patrick if someone dares to look at him cross-eyed.

Patrick is really dong very well right now. He hasn't broken a bone in four years – Knock on wood!

## PATRICK TESTIFIES BEFORE A CONGRESSIONAL COMMITTEE AND RAISES FUNDS FOR THE PAGET FOUNDATION

Patrick outside House of Representatives Appropriations Subcommittee Hearing Room

On March 30th Patrick testified before the House of Representatives Appropriations Subcommittee on Labor, Health and Human Services and Education. In his testimony Pat said,

" With the help of the Paget Foundation we were put in touch with Dr. Michael Collins at the National Institutes of Dental and Craniofacial Research (NIDCR). Dr. Collins is my friend now. I entered a research protocol at NIDCR in November, 1999. ….I started on a treatment program and am now almost pain free."

Patrick and Joan Goldberg, Executive Director, American Society for Bone and Mineral Research testify

Patrick and House Appropriations Subcommittee Chairman Congressman Ralph Regula (R-16th District, OH)

I am glad that the National Institutes of Health (NIH) is doing research on my disease. I hope that one day I will be cured. With the continued support of the Congress, I believe that the scientists at NIDCR will find a cure. I am studying very hard because one day I hope to join the team at NIDCR and become a research doctor."

Patrick is also helping raise funds for the Foundation. He sent letters to family and friends and has raised over $4,300 including a contribution of $1,000 from students and teachers at his school.

On April 23 during an honors ceremony at St. Joseph Elementary School, Congressman Dana Rohrabacher (R – 46th District, CA), Patrick's member of Congress, presented him with the American flag that flew over the U.S. Capitol on March 30th and with a Certificate of Congressional Recognition recognizing his extraordinary efforts on behalf of The Paget Foundation.

Congressman Rohrabacher presenting flag to Patrick

The Foundation is very grateful to Patrick and his mother for all of their work for the Foundation. ■

# INFORMATION FOR HEALTH PROFESSIONALS

## Paget Foundation 2004 Research Awards

Two $10,000 awards are being offered for research on Paget's disease and hyperparathyroidism. Guidelines and application forms are available on the Foundation website www.paget.org or by contacting the Foundation at 1 800 23 PAGET. The deadline for submission of applications is July 23. The awards will be announced at the annual meeting of the American Society for Bone and Mineral Research in October in Seattle, WA.

The Paget's disease award is supported by a grant from Mr. and Mrs. James Andreoli/The Jerome Foundation and the hyperparathyroidism award by a grant from Amgen Pharmaceuticals.

***The First European Conference on Paget's Disease*** took place in Siena, Italy June 17-18. Two Foundation representatives spoke at the symposium. Board Chairman Dr. Frederick R. Singer spoke on "Goals of Treatment for Paget's Disease of Bone" and Executive Director Charlene Waldman spoke on "The Experience of the Paget Foundation." Abstracts from this symposium will be published in the journal *Calcified Tissue.* The symposium launched a new Paget's disease patient organization for Paget's disease patients in Italy, the "National Patient Group on Paget's Disease of Bone," Associazone Italiana Malati Osteodistrofia di Paget (A.I.P.). Information about the group is available at Department of Internal Medicine, Endocrine Metabolic Sciences and Biochemistry, University of Siena, Policlinico Le Scotte, 53100, Siena, Italy, email osteogene@unisi,it, telephone +39 0577 585364, fax +39 0577 233446/ +39 0577 233480.

## Abstracts in *Journal of Bone and Mineral Research (JBMR)*

Abstracts from two conferences the IVth *International Conference on Cancer Induced Bone Diseases* (Dec. 7-9, 2003) and the *First International Symposium on Osteopetrosis: Biology and Therapy* (Oct. 23-24, 2003) will be published in future issues of JBMR.

## *Skeletal Complications of Malignancy IV*

This symposium, jointly sponsored by the National Cancer Institute (NCI), will take place April 28 – 30, 2005 at the Natcher Center on the campus of the National Institutes of Health in Bethesda, MD. The registration fee is $200 US. The deadline for submitting abstracts is January 21, 2005. Program information will be available on the Paget Foundation website at www.paget.org in the near future. ■

# INFORMATION FOR PATIENTS *(Continued from Page 3)*

## NEW EDITIONS OF FOUNDATION PUBLICATIONS

New editions of several publications for patients and health professionals will be available in the near future in print and on the website – www.paget.org.

Please use the enclosed Response Form to request copies of these publications. ■

Beginning with this issue, *UPDATE* will be available on the Foundation website at www.paget.org.

***Update* is published by**

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## In Memoriam

**The Foundation remembers our wonderful volunteer and friend Jesse Hahn. His generous and loving spirit helped us for many years.**

*Dom DiMaggio*
*Boston Red Sox, 1946*

Dear Friends,

In early 1967 approximately fourteen years after my playing days with the Boston Red Sox, I was diagnosed with Paget's disease of bone.

At that time there were few drugs available in the US to treat the disease, but I began treatment with what was available and was continually treated with improved drugs as they became approved.

Later I traveled to the Netherlands to be treated with a drug that was not yet approved in the US. (That drug was eventually approved for the treatment of Paget's disease in the US in 1994).

Through the physician who treated me in the Netherlands I was put in touch with The Paget Foundation and in 1988 I accepted their request to join the Board of Directors.

Over the years I have worked with the foundation in many ways including appearing in a television public service announcement, testifying before Congressional Appropriations Committees for increased bone disease research funding and helping to raise funds.

I am very proud of my relationship with this dedicated group and its' efforts to provide information to thousands of patients and health professionals.

The situation for Paget's patients today is much brighter than it was when I was diagnosed. Several effective drugs are now available. The foundation encouraged the pharmaceutical companies to develop these drugs and helped recruit patients for the drug studies that were needed.

Physician education is still a real challenge for the foundation, but after twenty-five years of concentrated effort, many more physicians are knowledgeable about the diagnosis and treatment of Paget's disease than they were when I was diagnosed.

Because Paget's and the other diseases that the foundation addresses are not well known, the foundation struggles to raise adequate funds to do its work.

I am trying to help as I have done in the past.

I am now volunteering to provide an autographed 8" x 10" picture taken during my Red Sox career to every contributor who donates $25 or more. I will provide an autographed American League baseball to everyone who contributes $50 or more.

I hope that you will help me raise funds for the Paget Foundation so that they can continue to assist every person who contacts them for information and assistance

Thank you so much.
Sincerely,

Dom DiMaggio

***Special thanks to Board member Dom DiMaggio for helping the Foundation raise needed funds. Please use the enclosed Response Form to support the DiMaggio Campaign***

# Response Form

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Name _____

Address _____

City _____ State _____ ZIP _____

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Enclosed is my tax-deductible contribution of:

☐$15 ☐$25 ☐$35 ☐$50 ☐$100 ☐$250 ☐Other _____

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

Card # _____ Exp. Date _____

Signature _____

## PUBLICATIONS FOR PATIENTS

### Q&A BROCHURES

☐ Paget's Disease of Bone - **NEW EDITION**
☐ Paget's Disease of Bone (Canadian – English Version)
☐ Paget's Disease of Bone (Canadian – French Version)
☐ Primary Hyperparathyroidism
☐ Osteopetrosis - **NEW EDITION**
☐ Fibrous Dysplasia/McCune-Albright Syndrome - **NEW EDITION**
☐ Breast Cancer Metastatic to Bone - **NEW EDITION**
☐ Prostate Cancer Metastatic to Bone - **NEW EDITION**

### 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 Patient Should Be Treated?
☐ Osteosarcoma and Other Tumors in Paget's Disease
☐ Surgery and Paget's Disease
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☐ Paget's Disease and Osteoarthritis (Canadian – ___English/ ___French)

#### Bisphosphonates

☐ Information for Patients on Bisphosphonates

#### Primary Hyperparathyroidism

☐ Surgery and Primary Hyperparathyroidism

### PHYSICIAN REFERRAL LISTS FOR PATIENTS

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

## INFORMATION FOR HEALTH PROFESSIONALS

☐ ***A Health Professional's Guide to the Management of Paget's Disease of Bone* – (This new publication replaces the previous publication The Management of Paget's Disease of Bone.)**
Information on pathology, clinical presentation, diagnostic evaluation & recommendations, indications for treatment & therapy options.

☐ Program Announcement**: *Skeletal Complications of Malignancy IV***
April 28-30, 2005, Bethesda, MD

## Dom DiMaggio Campaign

☐ **Please send the autographed photo (a contribution of $25)**

☐ **Please send the autographed official American League Baseball (a contribution of $50)**

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