

**Summary**  
**Paget Foundation For Paget's Disease of Bone**  
**and Related Disorders**  
**Activity**  
**2009**

**Service to Patients and Consumers**

The Foundation continued its 31<sup>st</sup> year of service to patients with Paget's disease of bone, primary hyperparathyroidism, fibrous dysplasia, and the rare bone disease osteopetrosis and, through its two year old program The Bone and Cancer Foundation, to cancer patients with bone-related complications.

Information was disseminated to patients through two websites, the Paget Foundation website, [www.paget.org](http://www.paget.org) and the Bone and Cancer Foundation website, [www.boneandcancerfoundation.org](http://www.boneandcancerfoundation.org) and through distribution of print copies of booklets. Booklet distribution is accomplished in two ways: 1.) in response to requests from patients and health professionals and 2.) by pro-active distribution to health professionals and medical institutions for distribution to patients.

The Foundation newsletter Update which includes Paget Foundation and Bone and Cancer Foundation information was published online and in print one time in 2009.

Select physician referral lists for patients with Paget's disease of bone, primary hyperparathyroidism, fibrous dysplasia and osteopetrosis were distributed upon request by patients or family members.

A patient education meeting for Paget's disease patients was held at the Massachusetts General Hospital in October.

**Educating Health Professionals**

Educational publications were distributed to physicians, nurses and other health professionals in response to requests and by pro-active distribution to individuals and health institutions.

The Foundation organized the symposium, IX International Conference on Cancer-Induced Bone Diseases (October 28-31, 2009). The 240 symposium attendees included physicians, basic scientists, NIH staff, representatives of pharmaceutical companies and other interested individuals. Of particular interest was the large number of young investigators and attendees from outside the U.S. Enduring materials from this symposium will be published in March 2010 as a supplement of the journal Bone.

### **Coalitions, Research and Advocacy**

The Foundation presented a research award of \$20,000 to Dr. Luigi Gennari of Siena, Italy for his research on genetics and Paget's disease.

A Request for Proposals for the Noa Schwartz Siris Research Award on bone metastasis or osteosarcoma was distributed. The research grant of \$20,000 will be awarded in the near future.

The Foundation continued its membership in the National Coalition for Osteoporosis and Related bone Diseases. The Coalition's mission is to increase research funding and awareness related to all bone diseases. One highlight of the National Coalition was a Congressional Briefing in May.

The Foundation continued its participation in several NIH institute coalitions, particularly those related to the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) and the National Institute of Dental and Craniofacial Research (NIDCR). Foundation Executive Director Charlene Waldman was an invited speaker at the NIAMS Coalition in December.

Advocacy was also expanded by the election of Mrs. Waldman to the Board of Directors of the National Organization for Rare Disorders (NORD).

### **Other Memberships and Affiliations**

In addition to affiliations mentioned above, the Foundation continued its participation in the U.S. Bone and Joint Decade, The Rare Bone Disease Patient Network, The Combined Federal Campaign and Independent Charities of America.