



ADVOCACY E-MAIL

INFORMATION FOR OI ADVOCATES

JANUARY 4, 2010

Advocacy Update: OIF Leadership Lobbies on Capitol Hill for Federal Agenda

On Monday, December 14, Roger Bache, President of the Board of Directors, and Tracy Smith Hart, OIF Chief Executive Officer, visited Capitol Hill to continue advocacy efforts in support of the OIF Federal Government Advocacy Agenda. Roger and Tracy met with key staff members for Representative C.A. "Dutch" Ruppberger (D-MD), Senator Benjamin L. Cardin (D-MD), and Senator Barbara A. Mikulski (D-MD).

The meetings focused on critical components of the OIF Federal Agenda, including: federal funding for the Linked Clinical Research Centers and OI Registry; support for the recently introduced Bone Health Promotion and Research Act; increased federal funding for OI research at the National Institutes of Health; and support for Congressional efforts to increase access to and improve quality of health care.

OIF's priorities were well received and all of us at the Foundation are proud that our advocacy efforts are starting to gain recognition on Capitol Hill as lawmakers become more informed about OI through the efforts of OIF leadership and staff and, most importantly, the members of the OIF Government Advocacy Team. We look forward to working together throughout 2010 to make our advocacy priorities a reality.

January 2009 Advocacy Issues: Federal Agenda Issues, How You Can Help

Bone Health Research and Promotion Act

As a reminder, we addressed the Bone Health Research and Promotion Act in the November advocacy e-mail. The bill is currently in the House Committee on Energy and Commerce, so it is not too late to contact your Representative and ask them to support the bill!

Congresswoman Shelley Berkley introduced the Bone Health Promotion and Research Act of 2009 (HR 3856) to the U.S. House of Representatives on October 20, 2009. The measure currently has 62 co-sponsors in the House. The Bone Health Promotion and Research Act authorizes more than \$20 million for competitive grants to support bone research, establish an Osteoporosis and Related Bone Disease Advisory Committee, and creates the Bone Health Initiative, which aims to strengthen current bone health programs at the NIH. The National Coalition for Osteoporosis and Related Bone Diseases, of which OIF is a member, has endorsed this legislation.

Linked Clinical Research Centers

There are six nation-wide Linked Clinical Research Centers (LCRCs) for OI, two of which are in Maryland, at the Eunice Kennedy Shriver National Institute of Child Health and Hu-

man Development (NICHD) in Bethesda and the Johns Hopkins School of Medicine, Kennedy Krieger Institute in Baltimore. These LCRCs not only define the standard of medical and surgical care for patients with OI and improve treatment through clinical research, they also ensure that people with OI through the U.S. have access to this care. If you have not already taken advantage of what these LCRCs have to offer, you can learn more about the LCRCs and find your closest program at <http://www.oif.org/site/PageServer?pagename=RegistryLCRCs>.

The OI Registry

OIF and the OI Clinic at Kennedy Krieger have also created a confidential database of people with OI. The registry collects information about the OI symptoms experienced by each enrolled adult and child and opens up the opportunity for patients to participate in research and/or clinical trials. This registry is currently far from exhaustive and, to make it as useful as possible, we ask that you add your name and contact information to this database. To find out more information, please go to http://www.oif.org/site/PageServer?pagename=RS_Registry.

To Contact the OIF Advocacy Team, or to remove yourself from this email list please email oifadvocacy@wscdc.com or call Washington Strategic Consulting at (202) 333-5750