

Osteogenesis Imperfecta Foundation Advocacy Article

On July 1, 2009 the Osteogenesis Imperfecta Foundation (OIF) began working with Washington Strategic Consulting (WSC), a professional government relations firm located in Washington D.C., to significantly bolster the OIF's federal advocacy efforts. WSC has a long history working to increase awareness of osteogenesis imperfecta among federal law makers, and has in the past assisted in developing our federal priorities and coordinated OIF federal outreach opportunities such as the 2008 OIF "Hill Days." We are pleased to have WSC 'officially' join the OIF team.

As a largely grassroots organization with personalized knowledge of OI, OIF has the ability to educate and influence legislators and government officials who create the laws and regulations that guide policy and programs relevant to OI. Thus, federal advocacy has become an increasingly important mission of the OIF.

During the month of July, WSC worked with the staff at OIF to formulate the ***OIF 2009 Federal Advocacy Agenda***. The Federal Agenda outlines legislation and federal programs significant to OI and describes suggested courses of action for the development and funding of these programs. It also sets out new initiatives consistent with the OIF's mission for which OIF will likely seek federal funding.

The Agenda outlines five over-arching goals for OIF advocacy efforts in 2009:

1. To secure additional federal funding and other forms of support for OIF-sponsored projects and programs; including the Linked Clinical Research Centers and the OI Registry, through the Congressional appropriations, legislative and competitive grants processes.
2. To promote legislation in Congress consistent with OIF's mission and vision. In the current Congress, OIF is working to support the ***Access to America's Orthopedic Services Act of 2009*** (H.R. 1021) and the ***Medicare Fracture Prevention and Osteoporosis Testing Act of 2009*** (H.R. 1894 and S. 769). Both of these bills promote access to care for those affected with osteopathic diseases.
3. To secure increased funding in fiscal year 2010 for the National Institutes of Health (NIH) overall and, in particular for research on bone diseases and disorders. In 2009, the NIH committed \$5 million to research into the causes, symptoms and potential treatments and/or cures for OI. The OIF is urging NIH to increase funding dedicated to OI to \$9 million per year starting in 2010.
4. To support Federal Government Bone Health Initiatives by working to engage with the Department of Health and Human Services and its subsidiary agencies on existing OI-related initiatives such as Healthy People, Healthier US and Verb TM.
5. To become a proactive voice in Health Care Reform. The OIF encourages Congress to pass Health Care Reform bill that promotes access to high quality health care for all Americans by expanding health insurance coverage, emphasizing chronic care management programs, eliminating any waiting period for Medicare benefits, ensuring high quality of care through expanded use of quality measures linked to payment incentive, encouraging better coordination

and integration of care across specialties, and protecting current access to durable medical goods including assistive equipment like wheelchairs and hearing aids.

OIF is looking for additional voices to add to the federal advocacy movement! To join the OIF Advocacy Team send your Name, Address, Email Address and Connection to OI to jstup@oif.org.

To access the entire **OIF 2009 Federal Agenda** please see the “Advocacy” section of the OIF website (oif.org) under “How to Help” on the navigation bar.

Link: http://www.oif.org/site/PageServer?pagename=HH_Advocacy