

## The New York City Council

City Hall New York, NY 10007

## **Legislation Text**

File #: Res 0593-2004, Version: \*

Res. No. 593

Resolution recognizing October 12-20, 2004 as National Bone and Joint Decade Awareness Week, and encouraging the promotion of education and greater awareness of Fibrodysplasia Ossificans Progressiva in the City of New York.

By Council Members Oddo, Baez, Barron, Clarke, Comrie, Fidler, Gennaro, Gentile, Gonzalez, Jackson, McMahon, Nelson, Quinn, Recchia, Reed, Sanders, Vann, Stewart, Liu, Seabrook, Boyland and Lanza

Whereas, President George W. Bush has recognized the importance of musculoskeletal research by proclaiming 2002-2011 to be National Bone and Joint Decade; and

Whereas, Every year, October 12-20 is recognized as the Bone and Joint Decade's National Awareness Week; and

Whereas, The Bone and Joint Decade initiative is a global campaign to improve quality of life for people with musculoskeletal conditions and to advance understanding and treatment of these conditions through research, prevention and education; and

Whereas, According to the Bone and Joint Decade organization, more than 35 million Americans, one in seven people, have restricted mobility caused by a musculoskeletal disorder; and

Whereas, One such musculoskeletal disorder is Fibrodysplasia Ossificans Progressiva (FOP), a rare genetic disorder which causes bone to form in muscles, tendons, ligaments and other connective tissues; and Whereas, FOP is a disease which appears early in a child's life and results in painful swelling and the binding of joints often beginning in the neck, spine and shoulder, and progressing along the back, trunk and limbs of the body; and

Whereas, According to the International Fibrodysplasia Ossificans Progressiva Association (IFOPA), it is estimated that FOP affects at least 2500 people worldwide; and

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Whereas, Current medical treatment of the disease is limited and any attempt to surgically remove the

extra bone often results in more bone formation; and

Whereas, According IFOPA, there is only one known research facility worldwide, the University of

Pennsylvania, investigating a cure for FOP at the present time; and

Whereas, Additional funding for research and public awareness of this devastating, rare genetic disorder

is necessary in order to eliminate misdiagnosis, develop a treatment and discover a cure for FOP; now,

therefore, be it

Resolved, That the Council of the City of New York recognizes October 12-20, 2004 as National Bone

and Joint Decade Awareness Week, and encourages the promotion of education and greater awareness of

Fibrodysplasia Ossificans Progressiva in the City of New York.

LS# 1706

9/22/04

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