

The Marta Marx Fund for the Eradication of Scleroderma

Most patient-oriented research in the U.S. is funded by the pharmaceutical industry. Scleroderma, as an "orphan disease," has not traditionally attracted much support or interest.

One man and one woman decided to do something about this.

In 2000, the late Rudolph Juhl, a New York stockbroker, honored his sister, Marta Marx with the largest gift ever made to the Scleroderma Foundation—a \$5 million bequest to establish the Marta Marx Fund for the Eradication of Scleroderma.

Mr. Juhl's bequest fulfilled a longstanding promise. Many years ago, Mr. Juhl wrote to Marie Coyle, then President of the Scleroderma Federation, expressing his frustration that drug companies were not doing more to promote research on the cause and cure for scleroderma. Thus began a correspondence, which culminated in a vow by Rudolph Juhl that when he died he would leave money to be used solely for scleroderma research.



In 2002, the Estate of Marta Marx added to the Marta Marx Fund for the Eradication of Scleroderma with an additional gift of \$5 million thus making the total gift for scleroderma research \$10 million.

In September 2000 the Foundation convened a blue-ribbon group of scleroderma experts in Pittsburgh to plan how to put these new funds to work. As a result, we have now increased our grant amounts and added an overhead expense component. In honor of Mr. Juhl's gift, the Foundation has designated the Marta Marx Fund for the Eradication of Scleroderma Award to be presented to a recipient of a research grant whose score ranks among the top two scored proposals.

We need more generous gifts like Rudolph Juhl's to accomplish the ultimate goal: a cure for scleroderma.

The Mark Flapan Award

The Mark Flapan Award is presented annually to a scleroderma researcher whose proposal for a research grant is ranked highly by the Peer Review Committee of the Scleroderma Foundation. Along with the Marta Marx Eradication of Scleroderma Award, the Flapan Award is one of the two highest ranking grant proposals as scored by the committee.

The award is named in honor of the late psychologist and scleroderma patient whose contributions to the Foundation's publications and literature of scleroderma paved the way for greater patient understanding.

The New England Chapter Research Grant Award

In 2009, the New England Chapter of the Scleroderma Foundation, generously established a research grant award. The chapter will endeavor to name a grant each year with the help of the many who take part in its fundraising and other activities.

2009 Award: The Norma Nadeau/Mary Van Neste New England Chapter Research Grant.

The grant honors the memory of two great women who were instrumental in the formation of the Scleroderma Association support group that went on to become the Scleroderma Federation. Both had severe disease involvement, which they fought courageously for many years before succumbing. Both are fondly remembered by SFNE members who were with SFNE in its early days and aware of their efforts for the cause.

2010 and 2011 Award: **The Walter A. Coyle Memorial Research Grant.**

Walter Coyle, together with his wife, Marie, was one of the founders of the Scleroderma Foundation, as well as one of its predecessor organizations, the Scleroderma Federation. For more than 30 years, he was a tireless volunteer and devoted champion for scleroderma-related causes, working almost full-time for the Foundation's New England Chapter and the national office of the organization. During his long tenure of service with the Foundation, Walter served on the national Board of Directors as treasurer. When he retired from the national Board, Walter devoted his time to serving on the New England Chapter Board of Directors, as well as taking an active role in the daily management and fundraising activities of the Chapter. In 2007, he was honored as the Scleroderma Foundation's "National Volunteer of the Year" in recognition for his long and dedicated service to the organization at all levels.