



National Marfan Foundation Comments for the NIH Transition Team January 5, 2009

Greater communication and collaboration between NIH institutes for multi-system disorders

Many disorders, not only rare diseases, involve multiple body systems. It is extremely important that the ability to collaborate, communicate and conduct research between institutes be simplified. Many opportunities to conduct comprehensive studies are lost because of the challenge working with multiple institutes.

Need for better synergistic dialogue between patient organizations and NIH research communities and institutes.

There is a need within NIH to work more closely patient organizations and include them in critical decision making meetings concerning the development of specific research projects and for NIH research agenda setting.

Development of incentives to increase research in rare diseases and to develop new or evaluate old drugs for rare disease populations

Rare diseases can be the key to understanding more common diseases but because the rare disease population is limited and therefore the profit potential is dim, research and drug development for rare diseases are difficult to implement. The development of incentives to NIH researchers and through other federal agencies will help broaden the research in this area which will have benefit to other with common diseases.