

for all bleeding and clotting disorders

MASAC Document #171

MASAC RESOLUTION ON NATIONAL HEMOPHILIA FOUNDATION SPONSORSHIP OF GENE THERAPY AND NOVEL TECHNOLOGIES WORKSHOPS

The following resolution was approved by the Medical and Scientific Advisory Council (MASAC) on October 14, 2006, and adopted by the NHF Board of Directors on October 15, 2006.

In 1996 the National Hemophilia Foundation initiated an annual Gene Therapy and Novel Technologies Workshop to bring together immunologists, clinicians and researchers in gene therapy. These workshops have been invaluable in providing an open and meaningful exchange of ideas among scientists in the field of hemophilia research, have enabled NHF to maintain a primary role in guiding and synthesizing such research, have been a primary means of keeping NHF research staff and members of various NHF committees abreast of developments in the field, and have identified NHF as a highly visible presence in supporting cutting edge research in areas that are likely to lead to improved care and/or a cure for hemophilia and related bleeding disorders. The workshops have historically been the single most effective tool for NHF to both promote and monitor developments in gene therapy and other related areas, and NHF sponsorship of these workshops is vital to maintaining NHF's leadership role in moving this type of research forward. The next Gene Therapy and Novel Technologies Workshop is scheduled at Children's Hospital of Philadelphia, September 28-29, 2007. NHF's commitment to sponsoring this ongoing program is unclear.

MASAC recommends that NHF resume its role as a primary sponsor of this event at a level that is as close as possible to what NHF has provided in the past. NHF should provide funding for members of the NHF New Research Initiatives and Cure Committee (NRICC) and appropriate NHF grant recipients to attend and present at this meeting. NHF should also support future workshops at a similar level to that which NHF has provided for past workshops.

This material is provided for your general information only. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

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