

## Proposed HAEI Agenda

- 9:00 am – 11:00 am Discussion with Professor Cicardi on HAEI's potential role in EU HAE Project.
- Issues to be discussed include facilitating communication among researchers, and sponsoring/coordinating Congresses and other meetings.
- Outreach to assist patients/ physicians outside of the EU/North America to
- Learn about HAE diagnosis/treatment
  - Establish new HAE Associations
  - HAEI's role in providing technical assistance
    - A prototype web page new HAE Associations can use to get started.
- Putting the HAE Attack Diary on-line (HAEI web page)
- Usefulness of an HAEI presence at the 12<sup>th</sup> Meeting of the European Society for Immunodeficiencies (jointly conducted with International Patient Organization for Primary Immune Deficiencies)
- 11:00 am – 12:00 Communications: HAEI web page as a clearinghouse for the latest HAE information
- Meeting dates for National Member Organizations
  - Meeting dates for key scientific/medical meetings
  - Posting links to key HAE research
  - Links to each company running clinical trials
  - List of where each trial is being run
  - Links to National Member Organization web sites
  - Suggestions for other items to be included
- 12:00 – 2:00 Presentation by Jerini AG on the Icatibant Clinical Development Program
- 2:00 – 2:30 Regulator Meeting: An HAEI-sponsored international meeting that brings together HAE physician/researchers and key regulators from the EU, North America, and Latin America where new therapies are candidates for licensure
- 2:30 – 3:30 Initiatives suggested by Vincenzo and Nilla in an email dated 11/2005 (document with this information will be handed out at meeting)
- 3:30 – 5:00 Discuss and gain consensus on specific HAEI goals for 2006 and make assignments to HAEI Board Members
- Evening Dinner with Genzyme to discuss international trials for subcutaneous DX-88