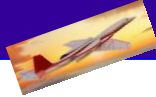




## Issue 1



# NEWS Update

THAOS has taken off!!!

Currently, 10 sites have been approved in 5 countries with 13 patients enrolled. Additionally, 24 sites in 10 countries are in various stages of the regulatory approval process. We have contacted 341 potential candidates and are in negotiations with 30 additional sites. Congratulations to our 10 enrolling sites:



- |                       |                                   |
|-----------------------|-----------------------------------|
| 1. M. Maurer          | Columbia-Presbyterian,            |
| 2. M. Waddington-Cruz | Clementino Fraga Filho            |
| 3. S. Shah            | Northwestern University           |
| 4. J. Campistol       | Hospital Clinic Villarroel        |
| 5. D. Quan            | University of Colorado            |
| 6. I. Conceicao       | Hospital Santa Maria,             |
| 7. O. Suhr            | Umeå University Hospital,         |
| 8. D. Cornblath       | Johns Hopkins                     |
| 9. T. Coelho          | Hospital Geral de Santo Antonio,  |
| 10. E. Cupler         | Oregon Health Sciences University |



**THAOS Database Update:** THAOS Version 1.01 has been rolled out as of November 1.

Updates include:

- a link to FAPWTR by accessing downloadable forms that can be faxed
- the ability to enter partial dates for some assessments when actual date is unknown
- the addition of conventional and international laboratory units and formatting of data fields to accommodate new units and values
- clarifications and revisions to the cardiovascular and neurological assessment pages in response to Board members input
- addition of multiple language versions of QoL questionnaires
- automatic submission of data to central database upon quitting or timing out of application
- a quicker installation process with automatic upgrades

**REMEMBER: Review and sign THAOS data. ONLY SIGNED DATA CAN BE ANALYZED!!!**

### PUBLICATION STRATEGY UPDATE

Country-specific THAOS data can be published if all sites within the country are in agreement.

Final Publication Strategy Document to be distributed soon

### THAOS Poster Presentations

- European Conference on Rare Diseases — Nov 2007
- European Neurology Society — June 2008
- Heart Failure Society of America — Sept 2008
- International Symposium on Amyloidosis — Sept 2008
- American Society for Human Genetics — Nov 2008
- \* THAOS Exhibit at American Heart Association — November 2008