

# Adding ORDR Rare Diseases Terms to MeSH Tree Structure

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# Scientific Disease Coding Within NIH

- NIH is developing the application of Knowledge Management (KM) tools for Research, Disease and Condition Coding
  - Building on expert science knowledge of NIH to develop standard definitions of topic areas
  - Automate the disease reporting across the NIH
  - Standardize the budget reporting by disease and condition areas
  - Provide technological infrastructure for additional forms of portfolio analyses
  - ~350 Categories Including Orphan Drugs, AT ,OI, CF,CMT
  - <http://report.nih.gov/rcdc/categories/>

# Expanding MeSH Tree with Rare Diseases Terms at the NLM/NIH

- >6500 Rare Diseases Related Terms
- ~ 2500 Disease Terms Present in MeSH Tree Structure as Main Headings or Entry Terms
- Supplemental Concept Records Class III Includes Terms Intended for Adoption into MeSH 2010
- Marked as In Progress>Provisional>Marked for Review>Authorized for Acceptance
- New Terms can be Main Headings or Entry Terms Based on Frequency in Literature

# Expanding MeSH Tree with Rare Diseases Terms at the NLM/NIH

- Value of Expansion
- Enhance Information Retrieval - Pub Med Articles And Others Will Have Terms Added During Indexing
- Linked to International Language Equivalents
- Part of UMLS linked to terms in
  - OMIM
  - SNOMED
  - HUGO
  - Other Databases

# An Approach to Coordinated Efforts for Successful Orphan Products Development/Rare Diseases Research – Limiting the Risk



# Moving Towards A Collaborative Global Approach

