

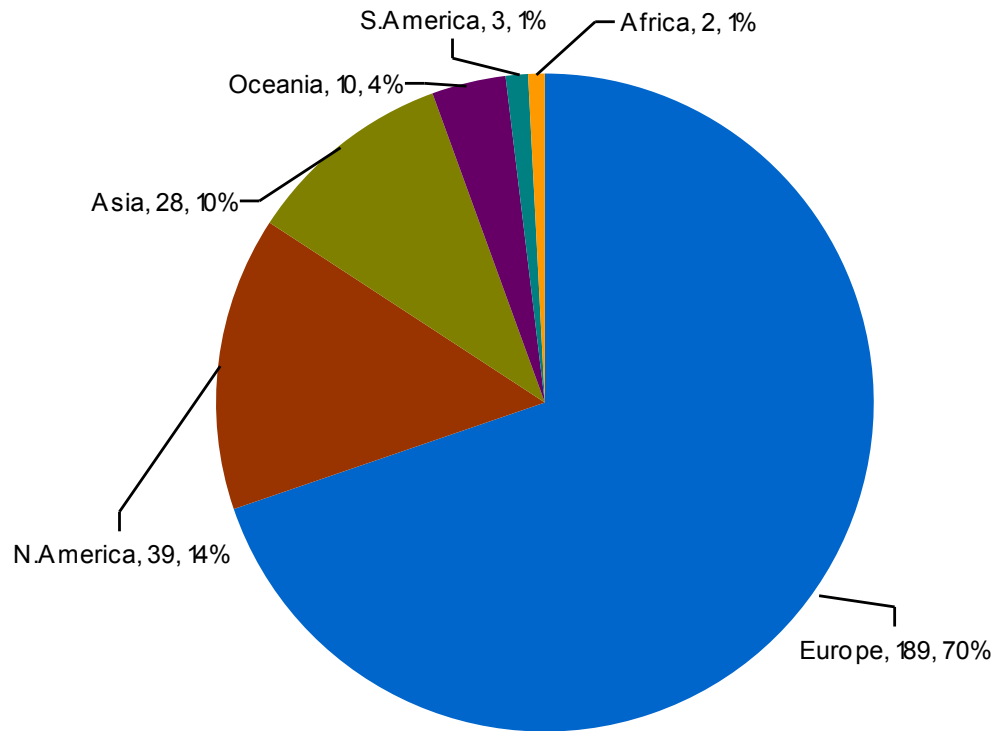


# **Chairman's Update**

## **2013**

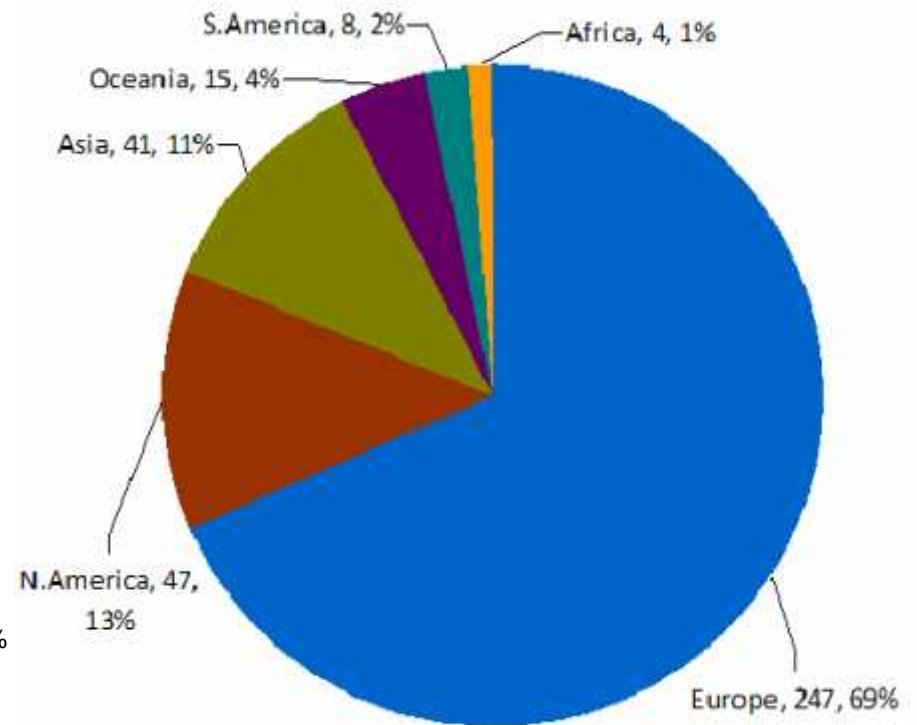
**Mick Henderson**

# ERNDIM: Participants



**2008: Number of participants = 271**

- Number of participating countries = 45



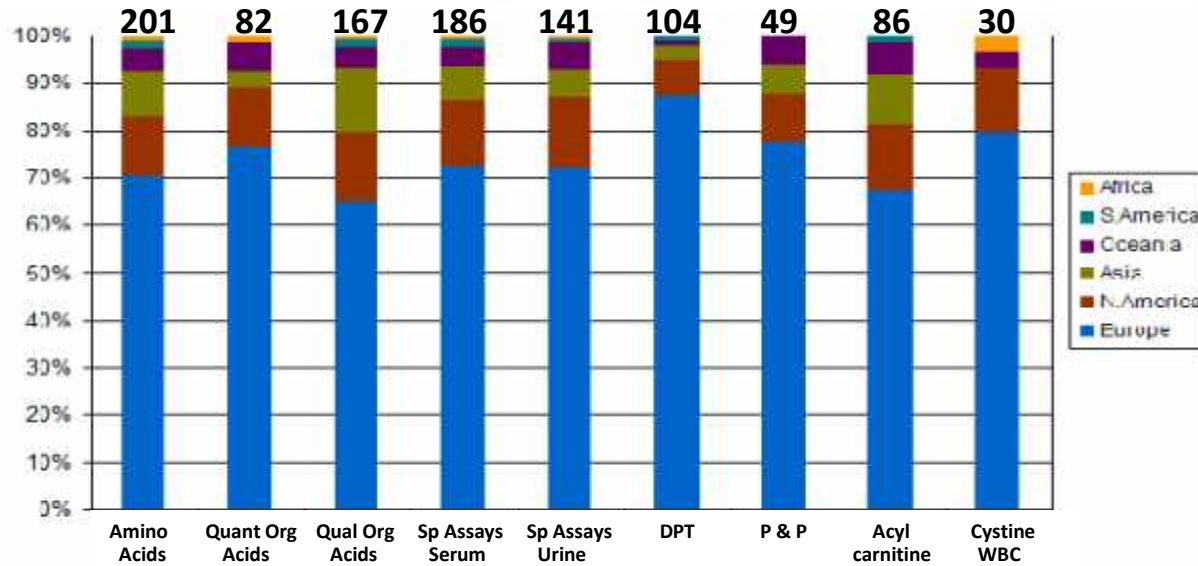
**2013: Number of participants = 362  
(34% ↑ on 2008)**

- Number of participating countries = 58

# ERNDIM: QA Schemes

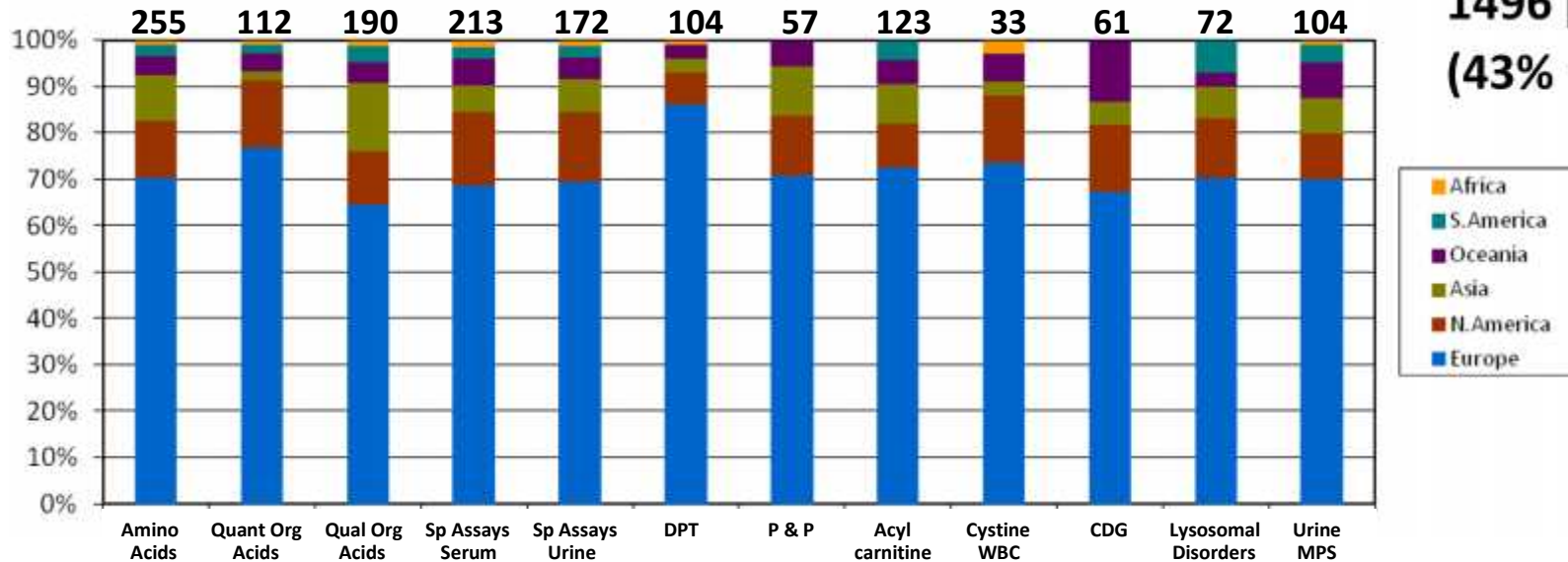


2008: Participations



2008: 9 QA schemes  
1046 participations

2013: Participations



2013: 12 QA schemes  
1496 participations  
(43% ↑ on 2008)

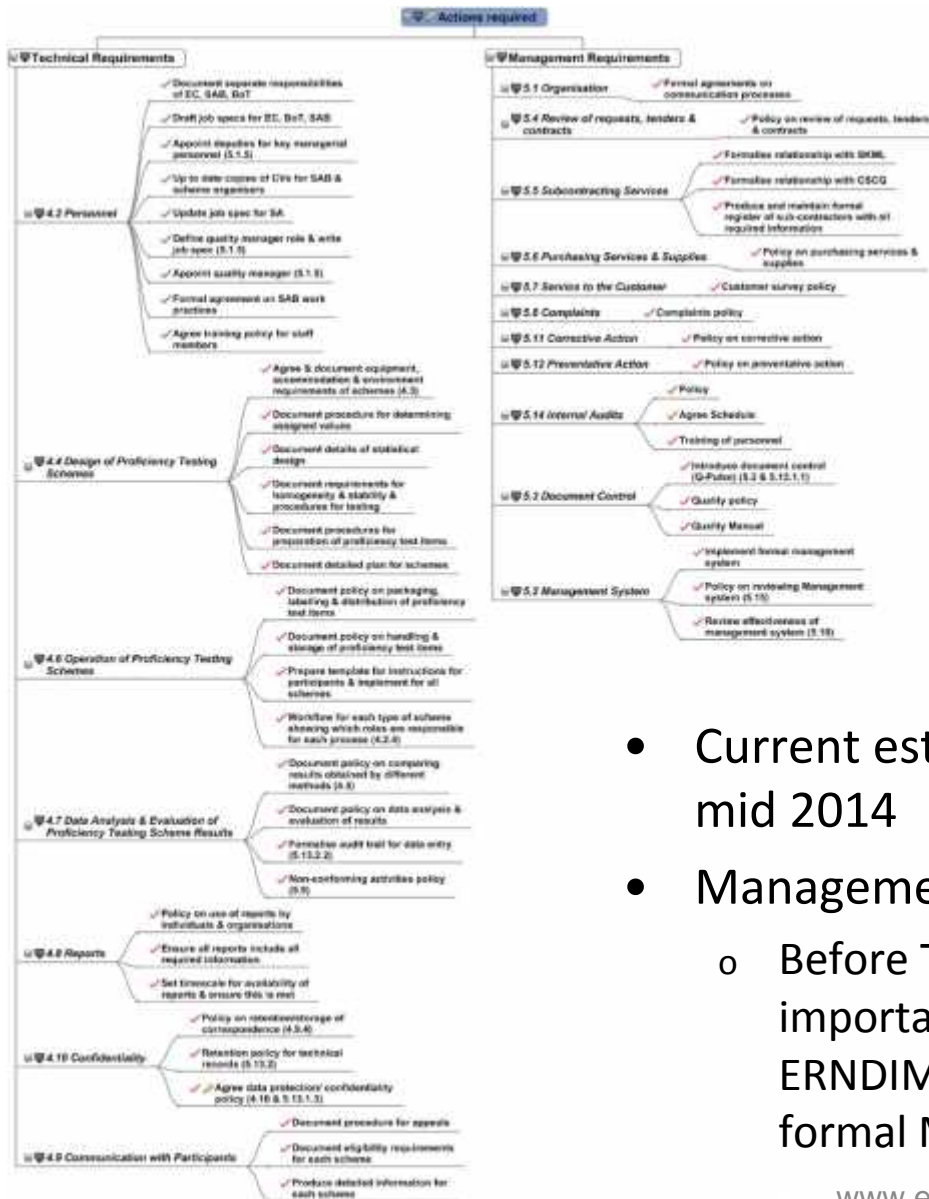
# ERNDIM: QA Schemes



## Plans for 2 pilot schemes

1. Pterins in urine and dried blood spots organised by Nenad Blau (University Children's Hospital, Zurich, Switzerland)
  2. Neurotransmitters in CSF organised by Simon Heales (UCL Institute of Child Health, London, UK London)
- It is planned that both pilots will start in January 2014 with registrations in September 2013

# ERNDIM: Path to accreditation



- ISO/IEC 17043 specifies the standards to be met for all aspects of a proficiency testing scheme and the management of the proficiency testing provider

- Initial GAP analysis allowed development of list of proposed actions required to meet ISO/IEC 17043

- Current estimate for meeting these requirements is mid 2014

- Management requirements have been prioritised
  - Before Technical Requirements can be formalised it is important that roles and responsibilities of the ERNDIM bodies are defined and agreed and that a formal Management System is implemented.

# ERNDIM: Path to accreditation



## Progress so far:

- Terms of Reference for each of the ERNDIM bodies
- Plans agreed to increase the role of the Board of Trustees so that it can carry out an increased governance role.
  - Aim: half of the Trustees will be people who are not members of the Executive Committee or Scientific Advisory Board, but are experienced in the field
  - New role of Chair of the Board of Trustees will be held by a Board member who is not a member of the Executive Committee or the Scientific Advisory Board
- Job descriptions for important ERNDIM roles have been completed
- Agreement on the appointment of deputies for EQA scheme Scientific Advisors
- Appointment of a Quality Manager
- Expansion of the Administration office to allow more time to be spent on preparing ERNDIM for Accreditation
  - Administration Assistant (0.5 x full time, for 1 year initially), post was filled in February 2013
- Documentation of existing ERNDIM policies and procedures is in progress
- Agreement on new policies.....

# ERNDIM: Path to accreditation



## Agreement on Important New Policies:

- **Poor Performance Policy**
  - EQA participants will be asked to give contact details for their Laboratory Quality Manager who will be contacted if the laboratory does not respond to a Performance Support Letter
  - The aim of the Performance Support Letters is to offer help and support to the laboratory and to start a dialogue between the Scientific Advisor and the laboratory so it is important that the Laboratory responds
- **Appeals Policy**
  - Appeals against scores or being classed as a poor performer should be sent to the Administration office within 3 weeks of the date of the Performance Support Letter
  - Scientific Advisor will consider appeal and respond within 3 weeks of receipt of the appeal
  - Full details will be sent to all EQA participants and will be on the ERNDIM website
- **Critical Error Policy**
  - Will be applied to Qualitative Scheme
  - Errors that would be unacceptable to the majority of labs and would have a serious adverse effect on patient management
  - Critical Error will override a satisfactory score and will be automatic poor performance; will be shown on Certificate of Participation
- **Full details will be sent to all EQA participants and will be on the ERNDIM website**

# ERNDIM: Path to accreditation



## Agreement on Important New Polices:

- **Educational Participations**
  - Aimed at laboratories who:
    - are developing a test
    - are not offering a clinical service
    - need ERNDIM samples and feedback to facilitate the test development
  - Will be available for Qualitative EQA schemes
  - For Educational Participants:
    - Results will be assessed but not scored
    - No Certificate of Participation will be issued
    - Poor Performance will not be recorded
  - Participation as an Educational Participant within a scheme will be limited to 2 years after which the laboratory will have to register as a full EQA participant
- **Full details will be sent to all EQA participants and will be on the ERNDIM website**

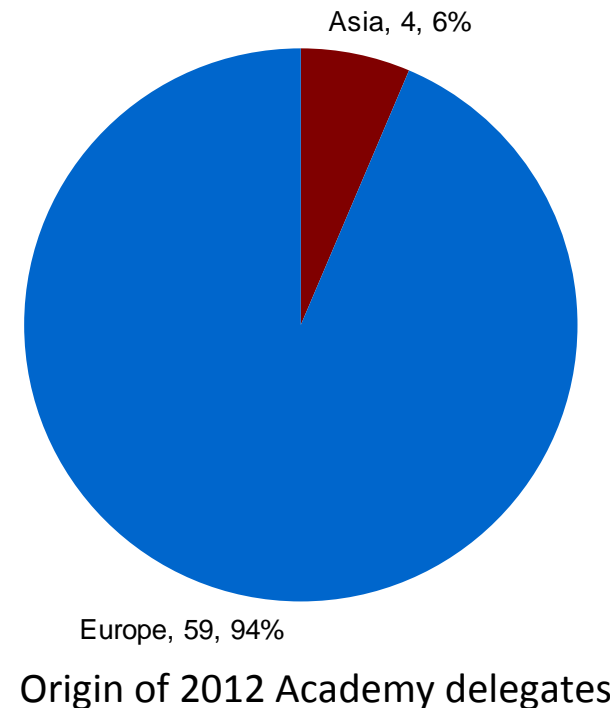


# ERNDIM: SSIEM Academy



## SSIEM Academy 2012

- October 2012, Greater Manchester, UK
- Attended by 25 clinical and 38 laboratory scientist delegates from 28 countries
- Topics:
  - **Joint Clinicians & Laboratory Scientists:** Hyperammonaemia & Metabolic Cholestatic Liver disease
  - **Clinicians:** Management of UCDs, Diagnosis & management of PKU (& Pterin defects), Diagnosis & management of Homocystinuria, Diagnosis & management of MSUD , Seizures due to inborn errors
  - **Laboratory Scientists:** Methionine & folic acid disorders: transsulphuration & remethylation pathways, Techniques, pitfalls & secondary changes in amino acid disorders, Rare Compounds



# ERNDIM: SSIEM Academy



## SSIEM Academy 2013

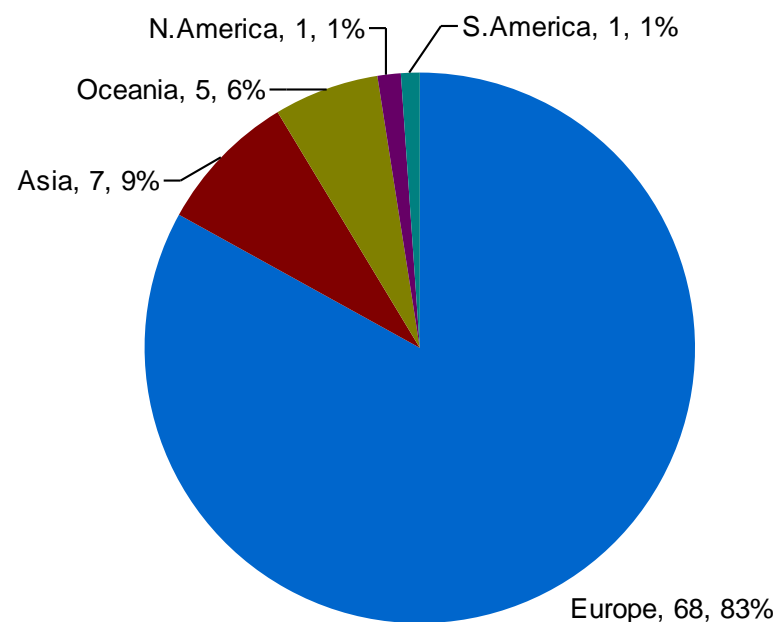
- April 2013, Lyon, France
- Accommodation (2 night's) paid by SSIEM & introduced 50 Euro non-refundable registration fee
- Course was heavily oversubscribed (46 applications for the clinical course and 65 for the laboratory course)
- Attended by 40 clinicians and 42 laboratory scientists from 33 countries
- Topics:

- **Joint Clinicians & Laboratory**

- **Scientists:** Organic Acidurias, Cardiomyopathy

- **Clinicians:** Management of Organic acidurias, Pathways & Diagnosis of fatty acid defects, Management of fatty acid defects

- **Laboratory Scientists:** Acyl carnitines, Organic acids – analytical, Organic Acids – interpretation



Origin of 2013 Academy delegates

# ERNDIM: SSIEM Academy



## SSIEM Academy 2014

- 1<sup>st</sup> & 2<sup>nd</sup> April 2014
- Proposed venue: Paris, France
- Topics:
  - **Joint Clinician & Laboratory Scientist:** Lysosomal Storage Disorders, Neurodegeneration
  - **Clinicians:** Management of LSDs, Peroxisomes, Purines and Pyrimidines
  - **Laboratory Scientists:** Peroxisomes, MPS, Purines and Pyrimidines
- The final programme and details of the venue will be announced at the end of September 2013
- Course applications will open in October 2013 on the SSIEM Academy page of the SSIEM website ([www.ssiem.org/ssiemacademy](http://www.ssiem.org/ssiemacademy))



**Thank You!**