



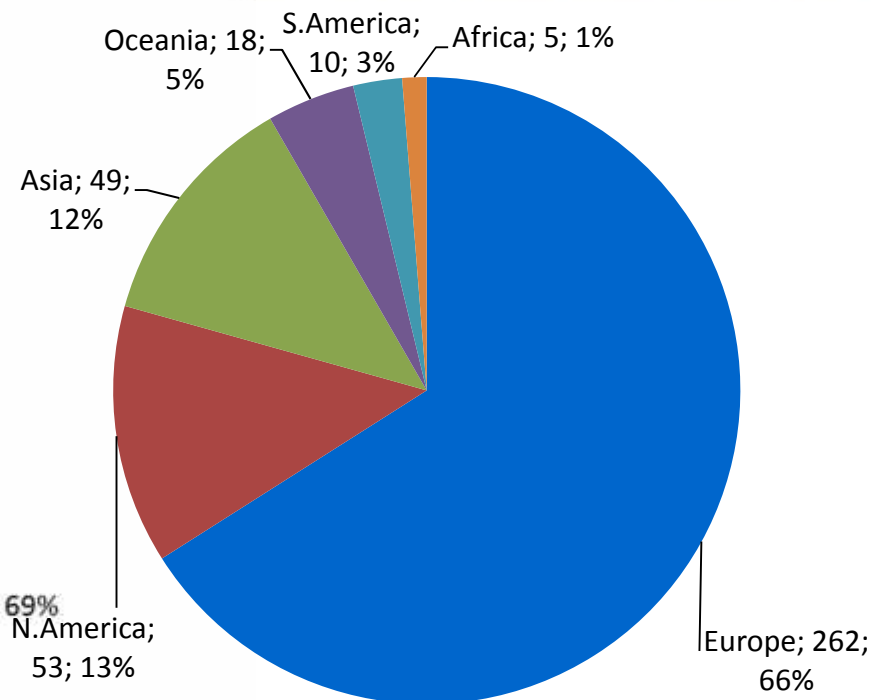
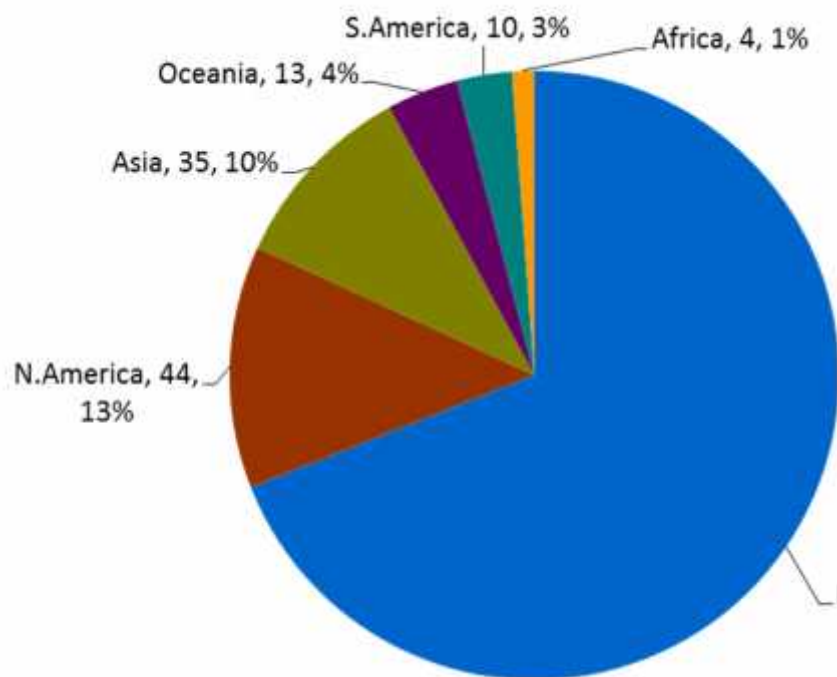
# **Exec Chair's Update**

**George Ruijter**

**Manchester**

**November 22, 2017**

# ERNDIM: Participants



**2012: Number of participants = 342**

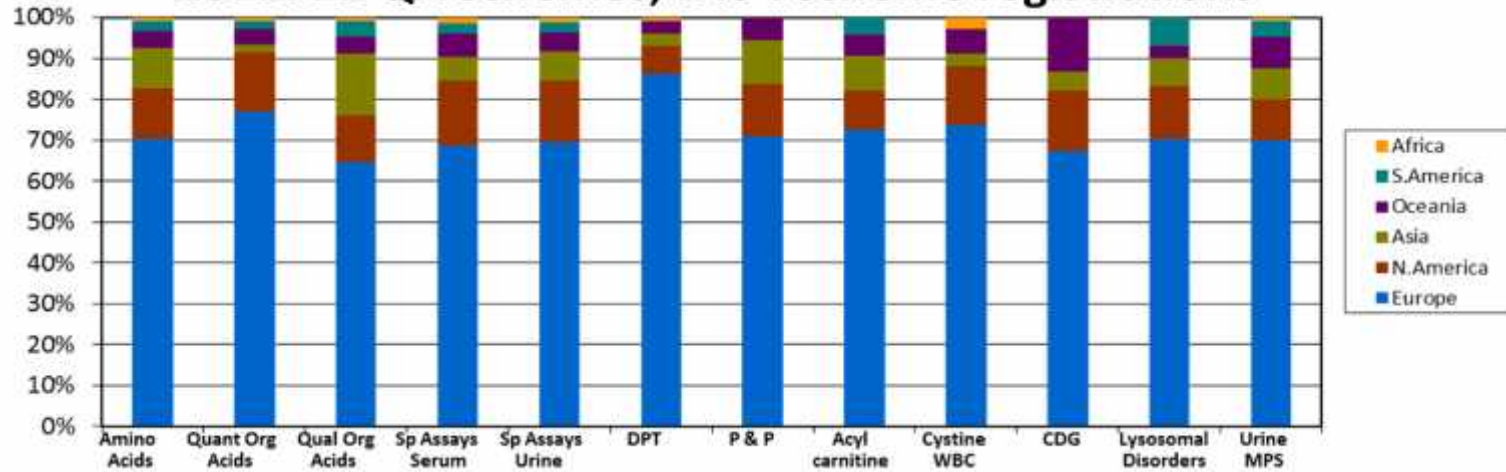
- Number of participating countries = 54

**2017: Number of participants = 397  
(16% ↑ on 2012)**

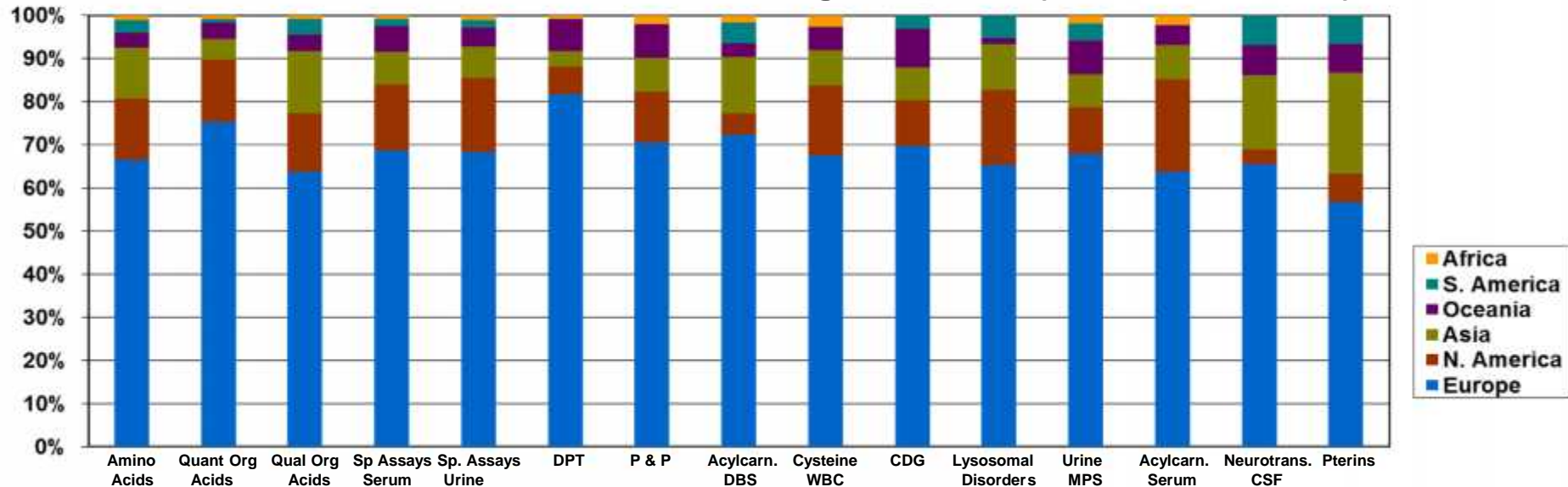
- Number of participating countries = 60

# ERNDIM: EQA Schemes

2012: 12 QA schemes, 1454 scheme registrations



2017: 15 QA schemes, 1752 scheme registrations, (16% ↑ on 2012)



# ERNDIM: EQA Schemes



## Pilot schemes

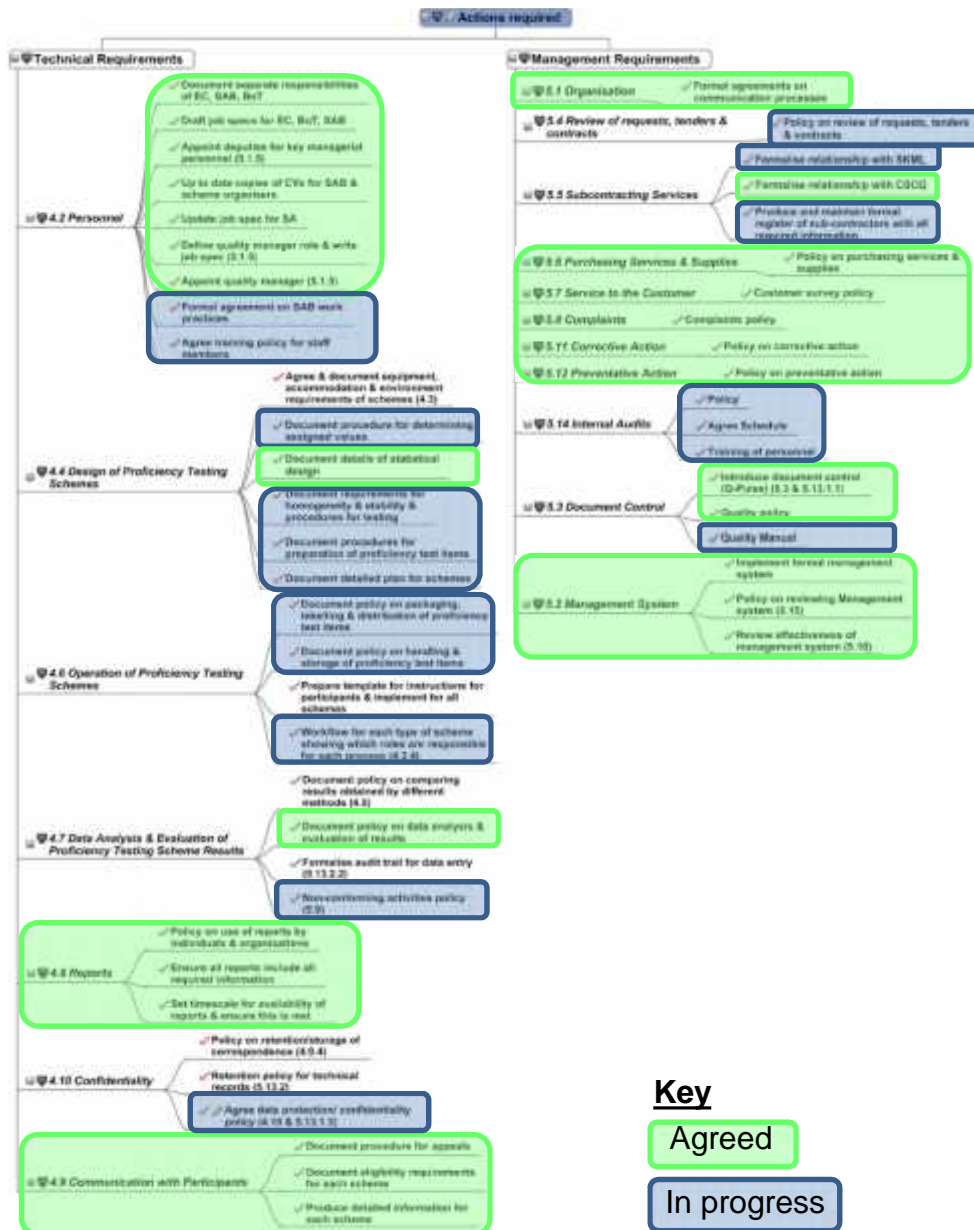
### Pilot schemes running in 2017

- 1. Cognitive Amino Acids**, lead organiser is Prof Brian Fowler (Basel/Zurich, Switzerland)
- 2. Special Assays in dried blood spots**, lead organiser is Prof Jim Bonham (Sheffield, UK)

Participation in these schemes is limited but if you would like to be contacted if participation can be widened please email [admin@erndim.org](mailto:admin@erndim.org)



# ERNDIM: Path to accreditation



## Key

Agreed

In progress

- **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
- Current estimate for meeting these requirements is late **2018**
- Management requirements were prioritised but now working on the Technical Requirements

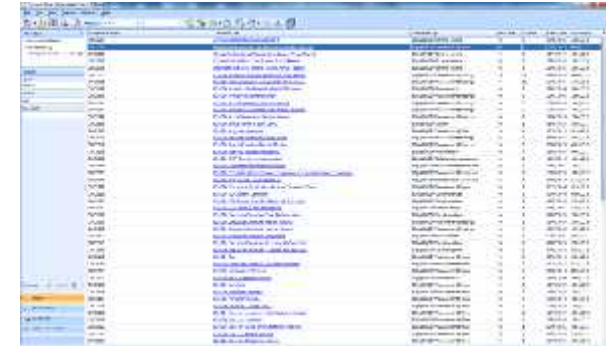


# ERNDIM: Path to accreditation



## Progress so far:

- Implementation of formal **document control** using Q-Pulse software
- Formal **management system** implemented and reviewed annually
- Documentation of existing and new ERNDIM **policies and procedures** is in progress
- **Audit calendar** and preliminary audits in progress
- Formalisation of relationships with **sub-contractors** (SKML, CSCQ, Black Cat Websites)
- Moving qualitative schemes to **centralised sample dispatch and online results submission** is in progress.....



	DPT	Urine MPS	CDG	Qualitative Organic Acids	Acylcarnitines
Centralised sample dispatch	✓	✓	✓	✓	To be agreed
Online results submission	✓	✓	2018	2018	2018-19



Stichting Klinische Genetica I

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Meeting of the "expert committee" of the ERNDIM,  
Diepenbeek, Belgium, May 7<sup>th</sup>, 1993

#### REPORT

Present: C. Bachmann, J.R. Bonham, J.L. Dhondt, A.H. van  
Gennip, P.P. Kamoun, J.L. Willems, L.J.M. Spaapen  
Excuses from: Mrs. P. Divry, B. François, J.M.F. Trijbels.

#### Historical milestones:

- December 1991 establishment of ERNDIM: EUROPEAN RESEARCH NETWORK FOR EVALUATION AND IMPROVEMENT OF SCREENING, DIAGNOSIS, AND TREATMENT OF INHERITED DISORDERS OF METABOLISM.
- January, 1992: initiative of Baudouin François for a concerted action to join the expertise in the various European

September 1992: first ERNDIM meeting at SSIEM in Leuven  
September 1994: formal registration of ERNDIM  
2011: office established – Sara Gardner

- participants.
- End of 1992: collaboration of the two Biochemistry Centres of twin universities of Belgian's and Limburg to work out a new proposal for BIOMED. The project was restricted to the development and execution of a European Quality Assurance Program (QAP) for genetics laboratories.
  - February, 1993 submission of the ERNDIM-II proposal



Courtesy: Alice Brooks



# ERNDIM: Administration Office



- Staff: Sara Gardner (Executive Administrator, full time)  
Jenny Barrett (Scientific Administrator, full time)  
Alice Brockway (Administration Assistant, 0.5 x full time)  
Katie Sheils (Administration Assistant, 0.5 x full time)
- Responsible for EQA scheme administration & administration for annual SSIEM Academy
- Increasingly central to the day to day running of ERNDIM
- In 2017, as recognition of the unique role ERNDIM has, SSIEM agreed to fund a full time Scientific Administrator (deputy to Sara) for 3.5 years.
  - Aims: to increase the resilience of the office, to allow more time to be spent on preparing to apply for accreditation and to allow ERNDIM time to develop a plan for sustainably funding this post for the future
  - Jenny Barrett was recruited to this post in August 2017
- SSIEM have also agreed to:
  - Support one-off software development costs to allow all schemes to move to on-line results submission within an agreed timetable.

**Thank you SSIEM!**

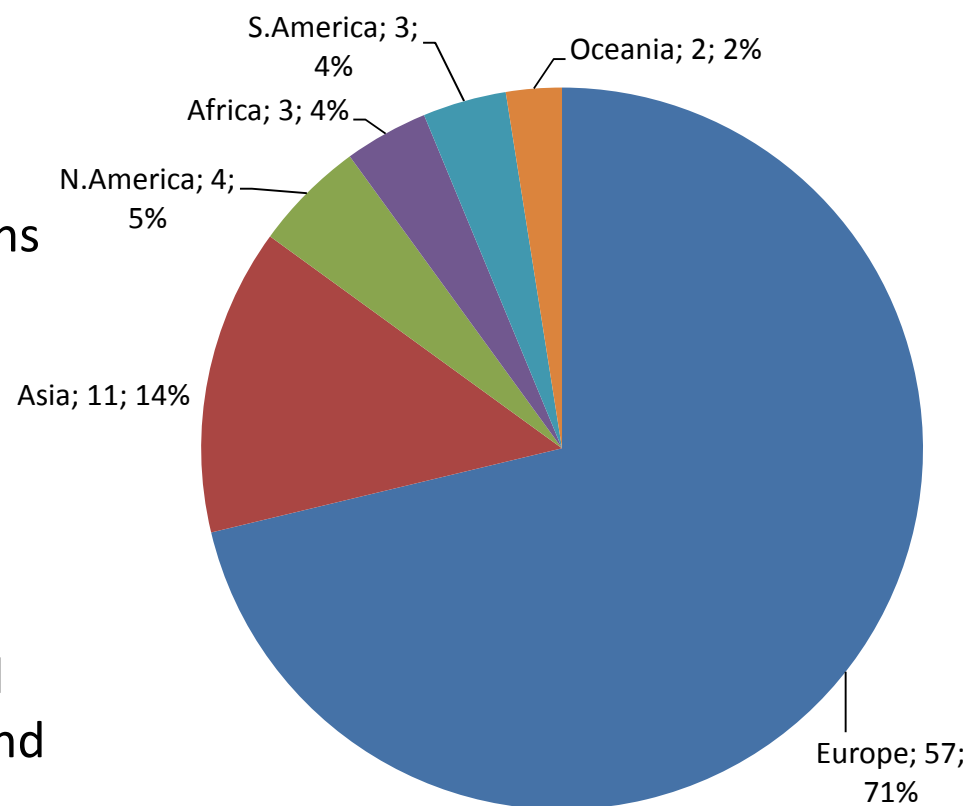
# ERNDIM: SSIEM Academy



**April 2017, Lyon, France**

- Course was heavily oversubscribed (62 lab & 55 clinical applications from a total of 42 countries for 80 places)
- Accepted applications from 40 clinicians and 40 laboratory scientists from 37 countries
- Topics: Organic acidemias, Fatty acid oxidation defects and Cardiomyopathy
- The programme was a mix of joint and separate clinical/laboratory lectures and workshops

**Origin of 2017 Academy trainees**



# ERNDIM: SSIEM Academy



## SSIEM Academy 2018

- 23<sup>rd</sup> & 24<sup>th</sup> April 2018, London, UK
- Topics:
  - Lysosomal storage disorders, peroxisomes and purines & pyrimidines
- The provisional programme and details of the venue can be found on the SSIEM Academy page of the SSIEM website ([www.ssiem.org/ssiemacademy](http://www.ssiem.org/ssiemacademy))
- Course applications opened in October 2017 on the SSIEM Academy page of the SSIEM website & will close on 23<sup>rd</sup> November 2017!

# ERNDIM - MetabERN



## Potential areas for collaboration

- Awareness of clinicians about laboratory performance and its assessment (including poor performance, PPP and global poor performance; in collaboration with QC ESHG, or e.g. uncertainty of measurement)
- Involvement of clinicians in designing new EQA schemes/review of existing schemes
- Mandating EQA participation for MetabERN Members
- Involvement of laboratory scientists in guidelines development/revision
- Provision of directory of tests for MetabERN members
- Involvement of laboratory scientists in research
- Patient organizations: sample donations

# Conclusions



- Continue to provide high quality EQA and QC materials
- Provide new schemes as requested by ERNDIM users, e.g scheme in Dry Blood Spots, scheme for metabolomics
- Complete Accreditation
- Professionalize EQA scheme provision
- Continue efforts to improve IEM diagnostics by providing education
- Enlist more labs, e.g through MetabERN





**Thank You!**