

Research Collaboration & Research Training in Europe

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Topics to be covered

- Introduce some of the Societies involved
- What do they provide?
- Information resources
- Potential for partnership

Organisations involved in Europe

- **ERNDIM** – www.erndim.unibas.ch
Largely works in EQA, 250 participating labs mainly in the field of IEM's with some relevance for screening eg phenylalanine.
Organises schemes, education and standard setting.
- **Eurogentest** – www.eurogentest.org
Standard setting and education. EU funded to agree standards of practice and quality across the EU 25.
Broad definition of genetics, molecular genetics, cytogenetics and biochemical genetics, hence the screening implications

Organisations involved in Europe

- **International Society for Neonatal Screening – Europe** – www.isns-neoscreening.org
The society has the objective of promoting the carrying out of appropriate screening for foetal, neonatal and infant sicknesses and disorders, world-wide.
 - a. developing, coordinating and maintaining practice and quality standards;
 - b. carrying out or commissioning scientific research and the enlargement of scientific knowledge concerning neonatal screening by means of meetings, symposia, discussions, reports and publications;
 - c. contributing to development and teaching;
 - d. harmonizing screening programs, methods and protocols.

National Societies

- DGNG, Germany – www.screening-dgns.de
- AFDPH, France – www.afdphe.assoc.fr
- SEQC, Spain – www.seqc.es/semc
- UKNSLN, UK – www.newbornscreening.org
- Portugal – www.diagnosticoprecoce.org

Related Societies

- SSIEM - www.ssiem.org
– IMD's but a lot of screening emphasis
- MetBioNet - www.metbio.net
– A National IMD/Screening alliance
- Other National IMD Societies eg BIMDG

Regulatory bodies and agencies

- UK newborn Screening Program centre - www.newbornscreening-bloodspot.org.uk
- UK NEQAS - www.ukneqas.org.uk
- Clinical Pathology Accreditation - www.cpa-uk.co.uk

How does it work in practice?

- Most societies promote and organise meetings to discuss scientific issues and present research findings and discuss audit findings
- Overarching regulation is provided by country law guided by International standards eg Eurogentest and accreditation eg CPA informed by EQA (NEQAS, CDC, ERNDIM, audit data etc)

Where can we go from here?

- Access to information – free
- Membership of EQA schemes – reduced fees on a case by case basis
- Exchange visits
- Partnership support
- Joint applications for research