

Newsletter

Spring 2009



Dear Colleagues,

There are a number of changes taking place in our EQA schemes and the website which we want to tell you about. We also want to bring you up to date with our progress towards accreditation for ERNDIM. This is going to be an increasingly important issue since organisations responsible for laboratory accreditation encourage, and may eventually insist, that EQA is only provided by accredited organisations.

Website Reporting of Results

1 Existing Website

The website operated by SKML (www.erndimqa.nl) for the submission and reporting of results for the quantitative schemes has been redesigned. Major changes are in the presentation of your results in your own annual report. For each analyte each of the various parameters are scored and those falling outside the 95th centile for all laboratories are indicated with red shading. Two or more parameters with red shading, or insufficient submissions are equated to unsatisfactory performance for that particular analyte. Satisfactory performance for an analyte is depicted by green shading. In this way laboratories are able to evaluate their own performance for individual analytes and overall.

In addition Scientific Advisors are able to evaluate performance of all laboratories based on this scoring system. This allows identification of laboratories which fail to meet a level of performance set in the Scientific Advisory Board and which will be contacted with an offer to help to identify and solve possible analytical problems (i.e. warning letter).

It will be appreciated that this is a complex system and although we have tested this exhaustively within the Scientific Advisory Board fine tuning may still be needed and we encourage your feedback and any suggestions for improvement.

2 New website for DPT results entry

Together with the CSCQ (Swiss Centre for Quality Control) we have developed a web-site for online submission of results for the Diagnostic Proficiency Testing. As well as reliable and systematic input of data the system will allow generation of summaries of data and conclusions to aid in the evaluation of results and report production by the Scheme Advisors. A pilot version of the system was available in November for testing by more than half of our participants and Scientific Advisors. A final version of the web submission system will be available by the end of February. It is planned to use the system, adjacent to old system for all participants in round one of 2009 samples.

New Certificates of Participation

The ERNDIM board and Scientific Advisory Board have been working for some time on the development of a new participant certificate to provide more detailed information on both participation and performance achieved within our schemes. We are pleased to be able to introduce this certificate for the 2007 and subsequent schemes, albeit with delay for which we apologise. The new certificate lists more detailed information on the numbers of analytes within the quantitative schemes as

well as which of the special assays have been measured in your laboratory. For these schemes performance criteria are obtained from the existing website as described above. For the proficiency tests performance is judged as described within the annual reports for those schemes.

It must be emphasised that the certificate has to be evaluated together with the laboratory's own annual report and these together should serve to provide full transparency in evaluation by internal or external quality assessors.

Update on resources available from our ERNDIM website

The laboratory directory: Participants that are already registered are requested to update their information. Other participants are strongly encouraged to apply to join the directory (go to <http://www.erndim.org/> → directory of laboratories → participants etc.).

Educational Documents

Theoretical aspect of QC in IEM and Method validation

Control of Accuracy and Precision

Amino Acid Analysis Recommendations

Biomed 2 Recommendations

Polymorphonuclear Leucocyte Preparation

Mixed Leucocyte Preparation

White cell cystine determination and the role of EQA

Role of EQA in special assays for IEM

Training Documents

European Training Schemes for Scientists

Pdf 1 EC4 European Syllabus for Post-Graduate Training in Clinical Chemistry.

Version 2-1999

Pdf 2 The practice of Clinical Chemistry in the European Union

Pdf 3 Higher Specialist Trainee LogBook

Pdf 4 Diplome Inter-Universitaire: Les Maladies Héritaires du Métabolisme 2006-2007

Pdf 5 Metabolic Map

Meetings & Reports (presentations etc.)

ERNDIM workshop / SSIEM, Lisbon, 02.09.08 ERNDIM / EUGT National

Representatives Meeting, Basel, 09.05.08

ERNDIM/EUGT workshop on peroxisomal disorders Hamburg 4.9.2007

EUGT/ERNDIM at ICIEM Tokyo 12-16.9.2006

EUGT/EU25 ERNDIM Best Practice Prague 5-6.10.2006

ERNDIM/EUGT workshop on purines and pyrimidines Paris 6.9.2005

EUGT/EU25 Best Practice meeting Basel 2.12.2005

Participants feedback questionnaire 2007

Miscellaneous Meeting Reports

ERNDIM DPT Reports

Best Practice EUGT UPDATED report 3.09.2007

Best Practice EUGT report 31.12.2008

Pilot Schemes

ERNDIM is constantly reviewing the profile of schemes offered to participants and intends to fill gaps in provision where this is feasible.

There are two pilot schemes in progress, both showing promising results.

1. Sialotransferins being organised by Dr Dirk Lefeber, Nijmegen
2. Lysosomal enzymes being organised by Dr Otto van Diggelen, Rotterdam

The practicality of establishing a scheme for urinary mucopolysaccharides is being investigated. There has been a successful scheme in the UK for many years run by the Willink Laboratory, Manchester but notice has been given that this will finish in 2009. Expressions of interest have been sought by Drs Huijmans and Ruijter, Rotterdam, metab.CL15@erasmusmc.nl

Urine Samples for DPT distributions

We have appointed Camilla Reed, Sheffield to organise an archive of urine samples held for distribution in the DPT schemes. Camilla will liaise with the scheme organisers and the Scientific Advisors Board to ensure an equitable distribution of cases and to facilitate distribution of common samples when required. In the UK an agreement has been made with the parent organisation Children Living with Inherited Metabolic Diseases, CLIMB, to encourage donations of urine samples. The agreement enables parents to make donations anonymously to ERNDIM but records will be kept in the office of CLIMB. Full details of this agreement can be downloaded from our website. We would also very much like to encourage urine donations from participating laboratories. We will pay transport costs. If are able to donate a sample(s) please contact Camilla:

Camilla.Reed@sch.nhs.uk

Training Day and Participants Meeting

Following the success of last year's training day in Lisbon we are organising a two day training event later this year. It will be in collaboration with the ETAC committee of SSIEM who will organise training for paediatricians. There will be some joint sessions. This will be held in Basel during the week beginning October 19th and will be followed by a one and a half day scientific/clinical meeting together with the ERNDIM DPT participants meetings.

Further information and a programme will be circulated later in Spring.

CPD Approval for ERNDIM

We have recently applied for, and been granted, automatic CPD (continuing professional development) approval for scientific meetings that we organise. The application was made to the Royal College of Pathologists in the UK, but all British Royal Colleges work recognise each others schemes and approval processes. There are certain conditions attached. This approval will last for three years. We must keep records of programmes and attendance for five years and should produce and retain feedback questionnaires. This is a recognition of the increasing role of ERNDIM in training and education and will contribute to the status of our meetings.

Accreditation of ERNDIM

A critical step to allow accreditation of ERNDIM (see above) is to establish a single location for our administrative activities

Therefore Executive members are in discussion with a sister organisation, the European Molecular Genetics Quality Network (EMQN). EMQN has an office based

at St. Mary's Hospital in Manchester. They are well organised and are close to being accredited by UKAS. We are exploring the possibility of having ERNDIM office functions run jointly with those of EMQN. It will become necessary to organise an administrative office anyway because Malcolm Heron, who has been our administrator for many years, will retire in 2011

The EuroGenTest Project

We are now in the fifth year of this project.

Benefits resulting from our participation in this project include: development of the ERNDIM website (www.Erndim.org) including the laboratory directory and linking this to the Eurogenetest directory for Cyto- and molecular-genetics with Orphanet ; moves towards expansion of biochemical genetic testing in Europe through establishment of National Representatives network and best practice meetings to establish guidelines for organisation of services at the national level; development of the fifth DPT scheme in Basel; development of standard methodologies and standard reporting procedures, development of guidelines for accreditation of EQA schemes together with our Cytogenetic and Molecular Genetic partners. Further we have developed important links with our partners in other genetic disciplines culminating in the establishment of a sub-committee of the European Human Genetics Society devoted to quality issues which includes two representatives from our organisation.

The Executive Committee

This year sees the retirement of Prof Brian Fowler as Chair of the Executive Committee. Brian will continue as a co-opted member to maintain our liaison with the EuroGenTest project. Dr Mick Henderson has succeeded Brian as Chair
Dr Jim Bonham has joined the executive having taken over from Dr Marius Duran as Chair of the Scientific Advisors Board.

The Executive and Board members wish to extend their gratitude to both Brian and Marius for many years of conscientious and dedicated work that have lead ERNDIM to be the successful organisation that it is today.

In addition Dr Viktor Kozich has been co-opted onto the executive. Viktor represents ERNDIM at SSIEM Council and the newly created quality sub committee of The European Society for Human Genetics.

We hope that 2009 will be a good one for you all.

Best wishes,
The ERNDIM Executive Committee

Publications

Fowler B, Burlina A, Kozich V, Vianey-Saban C. (2008) Quality of analytical performance in inherited metabolic disorders: the role of ERNDIM. *J Inherit Metab Dis* 31: 680-689.

Peters V, Garbade SF, Langhans GF, Pollitt RJ, Downing M, Bonham J (2008) Qualitative urinary organic acid analysis: methodological approaches and performance. *J Inherit Metab Dis* 31: 690-696.