Newsletter

Spring 2012



Dear Colleagues,

This year past year we have rebranded with a new logo and a new website <u>www.erndim.org</u>. The website will hopefully be the main portal through which our participants and visitors access the data entry sites organised by SKML and CSCQ.

This will enable participants to keep up to date with ERNDIM news or updates.

We have now started to prepare ERNDIM to become an accredited organisation. We plan to work towards applying for accreditation with UKAS under ISO-IEC 170473. A special meeting of the Executive Committee was held in Manchester in November to map out the key tasks that will have to be undertaken to achieve this. Dr Sara Gardner, the ERNDIM Administrator, has been appointed Quality Officer. We now need a Quality Policy and full documentation of our procedures and policies. We will be helped out by close association with EMQN who achieved full accreditation last year.

The New Website

The new site www.erndim.org is hosted by BlackCat websites, the same group that hosts SSIEM and other related organisations. This is not only a very reliable organisation, but with a critical mass of related sites it should be easier to share resources. The homepage is attractive and has a rotating molecule which we can change, when we get bored of homocysteine! We intend to introduce a sitemap for easy navigation. Please visit the site and give us feedback and suggestions for improvements, developments. sara.gardner@cmft.nhs.uk

CSCQ Website for DPT results entry

The system for entry of the DPT results by the web site went live last Autumn and is working well. It is much easier for scheme advisors to evaluate performance when participants' replies are structured in a uniform way. If you have any queries or concerns please contact CSCQ; xavier.albe@hcuge.ch

Update on resources available from our ERNDIM website

Newly added documents in 2011/12:

- Speakers' Presentations from the ERNDIM meeting held in Geneva, August 2011 (Meetings and Reports/ Meetings)
- Report on the participant survey carried out in August 2011 (Meetings and Reports/ Reports)
- Presentations from the Honorary Symposium which was held for Brian Fowler in Manchester in November 2011 (Meetings and Reports/ Meetings)
- Newsletter 2012

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.).

Eurogentest2 and ESHG quality committee

The first Eurogentest project ran for five and a half years and finished in June 2010. The follow up project which is on a much smaller scale and receives considerably less financial support began on January 2011 and will run for 3 years. We are participants in Unit 1 headed by Ros Hastings of CEQA. The aims of our work package are: improved organisation and coordination of EQA schemes when possible, working towards harmonization with our partners in Molecular Genetics and Cytogenetics; accreditation of both ERNDIM itself and our individual EQA schemes, developing generic criteria for assessing poor performance, especially when it is persistent and introducing measures to improve performance including the development of best practice guidelines.

Activities this year have included a meeting of Unit 1 of Eurogentest2 in London on September 15th and a meeting of ERNDIM National Representatives on 3 November 2011 in Manchester. The aim of the latter meeting was to finalise a report on recommendations for basic resources for Biochemical Genetic Testing in Europe.

ERNDIM is represented in the ESHG quality committee, to whom we report on all of our activities, by Viktor Kozich and Brian Fowler. We have met twice in 2011, on the 15th of January and on the 30th of May, both times in Amsterdam. As well as overseeing our activities in EQA this committee has promoted and supported our activities in developing poor performance criteria.

Our participation in these activities keeps ERNDIM at the forefront of efforts to improve the quality of genetic testing in Europe

SSIEM Academy

ERNDIM collaborated with ETAC, to organise the two day training meeting that was held in Amsterdam, November 23rd and 24th 2011. 40 participants were accepted for both the lab and clinical groups, making 80 participants in total.

The teaching materials are available to download through the members' area of the SSIEM website. It is hoped that these resources will be moved to the open access area of that site in the near future. That was the last Academy in a series of four and essentially the programme will start again now going back to revisit the topics covered in earlier Academies.

The next Academy event will be in October 2012 in Manchester, dates and programme to be announced. We will try to increase the number of joint, clinician and lab, sessions in the next round of events following feedback from participants.

ERNDIM participants meeting 2012

This will be a half day event held on the first day of the SSIEM conference as usual. This year that will be Tuesday 4th September in Birmingham. Further details will be circulated nearer the time.

National Representatives meeting 2011

There was a final meeting of the National Representatives from all 27 expanded EU countries. This took place in Manchester on Thursday 3rd November in the morning and was followed in the afternoon by a Farewell Symposium to mark the retirement of Prof Brian Fowler.

Participants Survey 2011

We would like to thank everyone who responded to the Participant Survey in August 2011. The results from the survey will help us to continue to improve the quality and efficiency of the ERNDIM Proficiency schemes and also the service that we offer you. A report on the results of the survey is available from the new website (www.erndim.org) under Meetings and Reports/ Reports. As we make progress towards applying for accreditation it's important that you are able to tell us your opinions on any changes that we introduce so we'll be carrying out the participant survey annually for the next few years with the next survey planned for May this year.

Samples for Acylcarnitine distributions

We would very much like to encourage sample donations for the Acylcarnitine scheme. To facilitate the smooth running of this scheme it is important that genuine clinically derived samples are available well in advance. To have sufficient material for one circulation we would need 3-4ml of lithium heparin anticoagulated whole blood or 60-70 30-50µl blood spots on Whatman (Schleicher & Schuell) 903 or Ahlstrom 226 paper. Samples for use in the scheme should be accompanied by a short clinical history and confirmation that informed consent/local ethical approval (as required in the referring centre) for the use of the sample has been obtained. If you are able to donate a sample(s) please contact one of the Acylcarnitine Scientific Advisors: Charles Turner (chas.turner@kcl.ac.uk) or Claus-Dieter Langhans claus-dieter.langhans@med.uni-heidelberg.de).

Performance Support

We have been developing Performance Criteria. It is important that persistent poor performance is highlighted and support offered. This will also be important for our accreditation application. The policies will be publicised on the website. In addition scheme scientific advisors have begun to write 'performance support letters' to participants whose scores in individual schemes fall below acceptable limits in the previous year.

Subsidised Scheme Participation

We received a number of applications from laboratories who requested financial assistance to remain in schemes or in some cases participate in new ones. We have been able to support most of these requests to date. We do indicate that this support is time limited and eventually the laboratories must seek local financial assistance. But we do feel that it is important for ERNDIM to be able to offer support of this nature.

Sponsored lab visits

In the past ERNDIM has enabled staff to visit Amsterdam, Sheffield and Paris to observe and gain experience in specific areas of metabolic investigation. This is invaluable for the visitor's laboratory but there are also benefits for the host. ERNDIM continues to offer some financial support to facilitate these visits. For more details please visit the website or contact sara.gardner@cmft.nhs.uk.

Very Best wishes for 2012,

Mick Henderson

On behalf of The ERNDIM Executive Committee