

## INSIDE THIS ISSUE:

Progress towards...	1
Critical Error - a lab...	2
EQA Schemes update	2
Pilot schemes	3
CSCQ results website	3
Accreditation status of...	3
Participant Survey 2017	4
Appeal for donated...	4
Chromatogram Library	4
Laboratory Directory	4
Training Support Grants	5
In Memorium...	5
Participants' Meetings	6
ERNDIM at International...	6
ESHG EuroGentest...	7
SSIEM Academy	7
National Representatives	7
MetabERN	7
ERNDIM Management...	8
Website	8

## Message from the Chair

Dear Colleagues,

ERNDIM continues to be a growing organisation seeing increases both in our numbers of participants and our activities. Last year we had 1752 scheme registrations from 397 participants (an increase of 16% compared to 2012) from 60 countries. Part of this growth is explained by the introduction of new schemes, such as Pterins in urine and Quantitative acylcarnitines in serum, in 2017. However, the number of participating labs has also increased. We are happy to see that an increasing number of labs active in diagnostics of inborn errors of metabolism (IEM) acknowledge the importance of external quality assurance and start to participate in ERNDIM schemes. The importance of high quality in diagnostics is also clear from the fact that the number of IEM labs becoming accredited steadily increases (page 3).

## Progress towards Accreditation

We are still making slow but steady progress towards applying for accreditation. In the past year we have:

- Made further changes to the EQA Scheme Calendar to allow the annual reports, performance support letters and certificates of participation to be produced earlier than previously.
- Implemented a procedure for persistent poor performers, global poor performers (poor performers in more than one

In 2018 we will continue to organise the two current pilot schemes, Special assays in DBS and Cognitive amino acids (see page 3 for a short report on the two 2017 pilot results).

Our educational activities include co-organisation, with SSIEM, the SSIEM Academy, which has held in London in April 2018 (page 7), and providing grants for both scheme participation and visits of individual scientists to centres of expertise (page 5).

In addition, we provide educational materials, such as the oligosaccharide kit (in conjunction with our partner SKML/MCA laboratory). This kit contains positive urine samples of oligosaccharidosis patients and may help labs to set up or optimise methods to screen for these very rare disorders. (<http://cms.erndimqa.nl/Educational-Panels.aspx>)

scheme in one year) and persistent global poor performers.

- Continued to formalise many of the administration procedures for the Administration Office.
- Continued progress on formalising our relationships with our subcontractors.
- Introduced centralised dispatch and online results submission for the Acylcarnitines in DBS scheme.
- Introduced online results



**Dr George Ruijter, Chair, Executive Committee**

Unfortunately we had very sad news in 2017 as Dr Jane Dalley passed away in November 2017. Jane was the Scientific Advisor of the Qualitative Organic Acids scheme organised from Sheffield and is greatly missed. A short memorial has been prepared by Dr Camilla Scott and Prof Jim Bonham (page 5).

Best wishes

*George Ruijter*

On behalf of the ERNDIM Executive Committee

submission for the Qualitative Organic Acids scheme.

- Introduced a third organising centre for the Qualitative Organic Acids scheme.
- Increased the resilience of the Administration Office by the recruitment of a deputy Scientific Administrator, with funding support from SSIEM. We were all extremely happy to welcome Jenny Barrett to the Admin Office in August 2017.

## Critical Error - a lab perspective

Critical Errors (CE) were introduced to the Qualitative EQA schemes in 2015 and are errors that would be unacceptable to the majority of labs and would have a serious adverse effect on patient management. CEs are proposed by the Scientific Advisor for a scheme and must be approved by the Scientific Advisory Board (SAB) before they are confirmed. A participant who missed the diagnosis of a sample confirmed as a CE will be considered as a poor performer even if they reached a satisfactory score.

In summer 2017 we asked the participants of our qualitative schemes to complete a short online survey on CEs. The data from this survey was used as part of a presentation by Christine Vianey-Saban at the ERNDIM Participants' meeting held in Manchester in November 2017. Christine's presentation on the survey results is available on the ERNDIM website under [Meetings and Reports/Meetings](#).

We received survey responses from 117/530 contacts and over 92% of the respondents (108/117) agreed with the concept of CE for all qualitative schemes. When asked which types of errors should be classed as CEs the majority of labs thought all the options should be CEs (see Figure 1).

We also asked which of a list of diagnoses, if missed, would be a

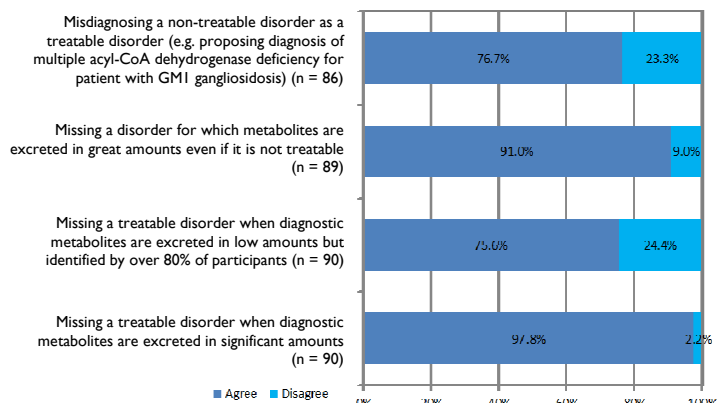


Figure 1: Responses to the question "Which definition(s) of critical error do you agree with?" (Online survey carried out in summer 2017)

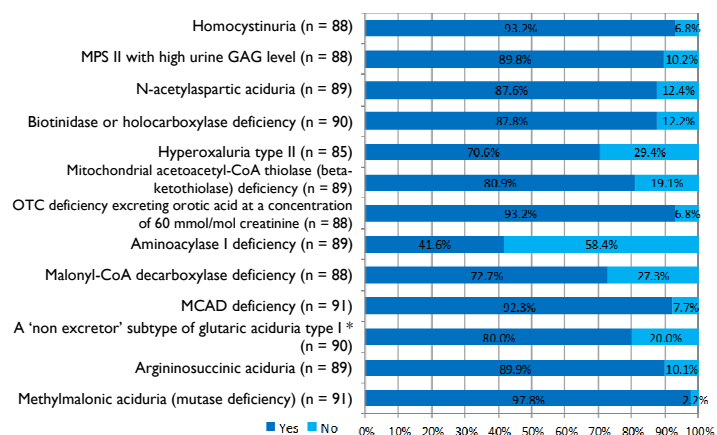


Figure 2: Responses to the question "Would you consider it a critical error if any of the following diagnoses were missed?" (Online survey carried out in summer 2017)  
\* = normal glutaric acid level but high increase of 3-hydroxyglutaric acid and glutaryl-carnitine

CE and the responses were also, in the main, overwhelmingly in favour of the mistakes being classed as a CEs (see Figure 2). However, for Aminocyclase I deficiency only 58.4% of respondents were in favour of a critical error if this diagnosis was missed.

Also included in Christine's

presentation to the 2017 ERNDIM Participants' meeting was an E-voting section which asked the audience whether potential mistakes in some of the 2017 EQA samples should be considered CEs. The results from the E-voting section are included in the presentation on the ERNDIM website.

*“over 92% of the survey respondents agreed with the concept of critical error for all qualitative schemes”*



## EQA Schemes update

### EQA Calendar

In 2017 we made changes to the submission deadlines for the Quantitative schemes which allowed the scheme results to be finalised at the November SAB meeting with the annual reports and performance support letters, in the main, being issued in the first quarter of 2018. This allowed the 2017 certificates

of participation to be published in May 2018, one month earlier than the 2016 certificates were issued.

For the 2019 & 2020 schemes we will continue to make further changes with the aim of publishing the certificates of participation even earlier.

### Scoring Policies

The possibility of including an interpretative element in the

scoring policies for the Lysosomal Enzymes in fibroblasts, Pterins in Urine, Neurotransmitters in CSF and Cystine in WBC schemes will be reviewed in 2018.

We will let all participants know in advance of any changes to the scoring policies or the calendar but if you have any questions please email [admin@erndim.org](mailto:admin@erndim.org).

# Pilot Schemes

## Special Assays in DBS

ERNDIM began a pilot EQA scheme in 2017 to report on dried blood spot samples containing: phenylalanine, tyrosine, leucine, isoleucine, valine, allo-isoleucine & homocysteine. Samples were distributed by SKML on 11<sup>th</sup> September 2017 to 109 laboratories with a deadline for results of 3<sup>rd</sup> November 2017. Responses were obtained from between 88 laboratories for phenylalanine to 30 laboratories for homocysteine.

The results indicated that recovery ranged between 78% - 124% and was considered acceptable. Linearity was also acceptable with a range of  $r=0.869 - 0.997$ . Within laboratory precision, measured as CV%, was better than anticipated for a method of this type & ranged from 5.9% - 11.6%. The clear analytical challenge was the dispersion revealed when

assessing inter-laboratory precision which ranged from a CV% for phenylalanine of 21% to an inter-lab CV = 65% for homocysteine. These findings are characteristic of variably standardised assays.

To help address this issue the pilot scheme for 2018 circulated samples alongside the usual EQA samples that will be used as virtual standards by participants. These reported results will be used as means of re-calculating the EQA responses based on a common standard.

This scheme is a good example of one of the key founding principles of ERNDIM to help evaluate and support the application of international clinical guidelines in the area of inherited metabolic disorders and improve the performance of analytical methods used to investigate and monitor these patients.

The **Cognitive amino acid** pilot scheme started in 2017 with offline submission, reporting & evaluation.

Three cases were sent to 31 participants & 26 sets of results were returned & scored with a 2+2 points scoring for abnormalities and diagnosis + interpretation. The final report was sent out on 19<sup>th</sup> December 2017 & overall performance was high for the cases of homocystinuria, lysinuric protein intolerance & non-ketotic hyperglycinemia.

For 2018 we have increased the number of participants to 54 & set up a portal for online viewing of cases & entry of results. We thank our scientific advisors, Brian Fowler, Rachel Carling, Mary Anne Preece & Sabine Scholl for all their efforts.

Reports for both pilots are on the ERNDIM website under [Meetings & Reports/EQA Scheme Annual Reports](#)



*“.....a good example of one of the key founding principles of ERNDIM to help evaluate and support the application of international clinical guidelines in the area of inherited metabolic disorders ...”*

## CSCQ Results Website

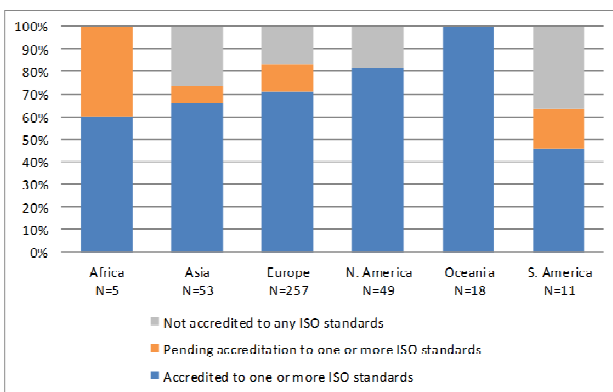
CSCQ are continuing to work on expanding the Results website for the qualitative schemes and we are very pleased that the submission of results for the first round of the 2018 Qualitative Organic Acids and Acylcarnitines

in DBS schemes were online. Testing and development work is ongoing for the CDG submission website with the aim being to use this for the second round of the 2018 CDG scheme .

We are very grateful for support

from SSIEM in funding the development of these CSCQ website extensions which will allow a more rapid transition to online results submission for these schemes than would otherwise have been possible. .

## Accreditation Status of ERNDIM Participants



Since 2017, during registration for the EQA schemes, labs are asked to complete a short survey asking for details of the ISO standards they are accredited to. For the 2018 EQA schemes, 98% of the labs that registered (393/400) completed the survey which asked if they

were accredited to ISO 9001, ISO 15189, ISO 17025 or another ISO standard. 284/393 responding labs (72%) replied that they were accredited to one or more ISO standards, with 63 of these labs (16%) stating they were accredited to more than one ISO standard. A further 38/393 labs (10%) reported that their accreditation to one or more ISO standards is pending, while 71/393 labs (18%) stated that their lab was not accredited (or had any pending applications) for any of the specified ISO standards.

This was a 3% increase in response rate and a 4% increase of accreditation to any ISO standard by ERNDIM participants in 2018 when compared to 2017. A decrease in the number of registered labs for whom accreditation was pending can be seen from 13% in 2017 to 10% in 2018. The number of labs who are not currently registered to any ISO standards and have no accreditation pending has reduced from 20% (75 labs) to (18%) (71 labs) in 2018.

## Participant Survey [2017 scheme year]



We would like to thank everyone who responded to the Participant Survey in early 2018. We received responses from 195 participants from 190 centres in 51 countries; giving a response rate, by centres, of 48%.

The results from this survey help us to continue to improve the quality and efficiency of the ERNDIM schemes and also the service that we offer you so your input is very important to us.

[A full report on the Survey Results is on the website](#) but briefly 7 out of 12 of the schemes had the same overall scores as last year with 5 schemes (CDG, DPT, LEFB, SAS and UMPS\*) having slightly improved scores. The best score for an individual aspects was for 'Frequency of samples'.

The best scores of the whole survey were for 'Frequency of samples' (ACS, CWBC, DPT, LEFB, QTOU and SAU\*), 'Sample volume' (ACS\*), 'Adequacy of report' (DPT\*) and 'Usefulness of the annual report' (DPT, QLOU and UMPS\*)

The responses to the questions which assess the overall performance of ERNDIM were very positive with the overwhelming majority of respondents rating the quality of services provided by ERNDIM as 'excellent' or 'good', and having 'complete' or 'a lot' of confidence that ERNDIM can deliver the service required by participants.

We also asked if you would be interested in participating in a scheme to monitor drug responses in plasma.

Unfortunately the number of responses for each suggested analyte were too low for us to consider setting up a separate pilot scheme. However the inclusion of NBTC in the Special Assays in DBS pilot scheme is being investigated.

We will of course review this again in the future if a greater level of interest is noted and as always encourage you to make suggestions using future participant surveys or to contact us at [admin@erndim.org](mailto:admin@erndim.org).

[\*ACS = Acylcarnitines in serum, CDG = Congenital Disorders of Glycosylation, CWBC = Cystine in WBC, DPT = Diagnostic Proficiency Testing; LEFB = Lysosomal Enzymes in Fibroblasts; QLOU = Qualitative Organic Acids, QTOU = Quantitative Organic Acids. SAU = Special Assays in Urine, UMPS = Urine Mucopolysaccharides]

*"Details of the types of samples that are needed can be found on the EQA schemes tab of the ERNDIM website"*

## Appeal for donated samples

If you would be able to collect a clinical sample that could be used as an EQA sample for one of ERNDIM's qualitative schemes please contact the Administration Office who will send you the ERNDIM consent form and details of how and where to send the samples.

Details of the types of samples that are needed can

be found on the EQA schemes tab of the ERNDIM website but please contact [admin@erndim.org](mailto:admin@erndim.org) before sending any samples and please do not send any samples to the Administration Office.

If you have any questions please contact the Administration Office ([admin@erndim.org](mailto:admin@erndim.org)).

## Chromatogram Library

Following a delay in developing the ERNDIM chromatogram Library due to limited resources, it is now planned to open up the library online by late Summer 2018. Initially we will have 100 disorders and we will request ERNDIM participants to evaluate the content. We will add additional disorders later and encourage participants to send additional

material of their own to add to the library. Further details will be sent to all ERNDIM participants when they are available.

## Laboratory Directory

The [laboratory directory](#) remains available for all laboratories providing services for IEM, both as providers and users. Together with the Administrative Office we are checking the validity of existing laboratory entries and working with National Representatives to recruit further laboratories. As before we encourage present laboratories to validate and, if necessary update their details, and new laboratories to join. We remind participating labs that if a particular assay is not present in the drop down menu it can be added to the list just by contacting us. Finally we plan a questionnaire on the directory for all ERNDIM participants and are considering an update of the database software.



## Training Support Grants

As part of our aim to help improve standards in biochemical genetic testing ERNDIM offers a small number of Training Support Grants each year.

This grant is designed for trainees, in a permanent laboratory position, to gain experience and knowledge in a European ERNDIM approved laboratory in order to develop or introduce new methods to their own laboratory.

Funds can be applied for to cover the travel and accommodation costs incurred by such visits and a maximum of 6 grants will be awarded each year, subject to the approval of the Executive Committee. Full application criteria are given in the application

form which can be found on the ERNDIM website under [Training\Grants](#).

Since the last Newsletter, 3 training support grants have been awarded :

- Ms Bartlett from North West University, Potchefstroom, South Africa visited Dr Ruijter's laboratory at the Department of Clinical Genetics, Erasmus Medical Center, Rotterdam to receive training on the UPLC-MS/MS method for the quantification of glycosaminoglycans.
- Dr Georgiou from The Cyprus Institute of Neurology and Genetics visited Dr Henderson's laboratory at St James' University

Hospital, Leeds in the United Kingdom. The main aim of his visit was for him to be trained in the analysis and interpretation of amino acid profiles by ion-exchange chromatography with emphasis on short programmes for monitoring patients with PKU and MSUD.

- Mr Rodríguez Rivera visited Dr Ruiz Salas at the CEDEM laboratory at the Autonomous University of Madrid. While in Madrid Mr Rivera reviewed quantification techniques for organic acids in urine.

You can read reports on all these visits on the website under [Training\Travel Grant Reports](#).



**“ERNDIM offers a small number of Training Support Grants each year”**

## In Memoriam: Dr Jane Dalley, Scientific Advisor for the Sheffield Urine Qualitative Organic Acid Scheme 2014-2017

It is with extreme sadness that we have to pass on the very sad news that our dear friend Dr Jane Dalley, Clinical Biochemist, lost her courageous battle with leukaemia in November 2017.

Jane was an extremely talented Clinical Biochemist who worked in the Clinical Chemistry Department at Sheffield Children's Hospital, in the UK, since 2009 and previously at Stoke University Hospital. She was well known to many within the field of Metabolic Biochemistry and had been Scientific Advisor for the ERNDIM Qualitative Urine Organic Acid Scheme Sheffield since 2014.

Jane was the most enthusiastic, joyful person you could ever meet; she was always smiling and keen to improve diagnostics for children. Jane will be sadly missed by all her friends and colleagues.

Jane began working at Sheffield Children's Hospital in the summer of 2009 having already achieved distinguished Masters & PhD degrees followed by a sound grounding in

clinical science through her Grade A training in Clinical Biochemistry

Jane's role in Clinical Chemistry began in tissue culture working up the tricky assay of separating out the various collagen species in fibroblasts, as the important functional assay in detecting inherited disorders of collagen synthesis. This was an assay no other UK laboratory had managed to set up. Jane travelled to Ghent to see the assay at work. Jane then spent 9 months doggedly determined to succeed in establishing this assay & she did!!!

Jane was a very able speaker & presented at many national and international conferences, she had a thirst for knowledge and thrived on sharing ideas. Her talks & presentations were always well received and in addition Jane published some important manuscripts on aspects of her science.

Jane gained her dream job of leading the metabolic section in 2016. Jane's true passion was in the diagnosis of

inherited disorders of metabolism. She was a member of the Society of Inborn Errors of Metabolism, and she sat on the committee for the British Inherited Metabolic Disease Group. She was also actively involved in the MetBioNet (a UK network of metabolic laboratories).

Jane was also a Scientific Advisor for ERNDIM. This was a role Jane was passionate about. She enjoyed the interaction with the participants and the Scientific Advisory Board.

Jane was a natural organiser and was keen to organise the national BIMDG conference in June 2018. The 2018 BIMDG meeting was held in Nottingham in June 2018 in her honour.

Jane leaves behind her devoted husband Jon and her two beautiful daughters, Isobel (5 years old) and Elsbeth (1 year old).

**Dr Jane Dalley  
6<sup>th</sup> September 1974 - 19<sup>th</sup>  
November 2017**

## ERNDIM Participants' Meetings

### 2017 Meeting, Manchester, UK

On November 21<sup>st</sup> and 22<sup>nd</sup>, 2017 the annual ERNDIM participant meeting was held in the Radisson Blue hotel in Manchester UK. A total of 112 delegates attended the meeting, which was very well organised by our PCO JM Associates.

The scientific programme started on November 21<sup>st</sup> with a session on novel approaches in the rapidly developing diagnostics of Lysosomal Storage Diseases, introduced by Dr Monique Piraud. This session also included lectures on determination of GAG, oligosaccharides and sphingolipids and closed with a comprehensive lecture on clinical aspects and treatment of LSD by Professor Simon Jones. This first plenary session was followed by the 5 DPT scheme workshops and in the evening a wonderful social dinner was organised.

On November 22<sup>nd</sup> we started with workshops on lysosomal enzyme testing, neurotransmitters in CSF, acylcarnitines in DBS and organic acids. The aim of these workshops was to discuss the

formats and results of these four EQA schemes and to address practical issues in diagnostic tests experienced by the participants. These workshops were well appreciated by the delegates and the Scientific Advisors received useful feedback.

The second day of the meeting ended with a session on current and future developments in Biochemical Genetics testing and external quality assurance. Dr Christine Vianey-Saban chaired a discussion with electronic voting on critical errors. Interestingly, the participants seemed to apply critical errors more strictly than the Scientific Advisory Board.

Finally, Dr Neil Dalton and Dr Karlien Coene presented their work on metabolic profiling and metabolomics. It is our belief that these approaches are complementary to whole genome sequencing and will be common methods for metabolic diagnostics in the future.

From the very positive feedback provided by the symposium participants we conclude that the meeting was a great success.

### 2018 Meeting, Athens, Greece

The 2018 annual ERNDIM workshop will be held on September 4<sup>th</sup>, on the Tuesday morning before the SSIEM symposium begins in Athens, Greece.

As usual the meeting will start with discussions on the Diagnostic Proficiency (DPT) schemes, which are open to DPT scheme participants only. The second part of the meeting is open to all conference delegates and, this year, will focus on purine and pyrimidine metabolism.

The results of the common DPT sample of 2018 will be discussed by Mr Petr Chrastina while Dr Saskia Wortmann and Dr Jürgen Bierau will be presenting updates on clinical aspects of purine and pyrimidine disorders, diagnostics, and pharmacogenetics.

The programme for the 2018 Participants' meeting can be found on the ERNDIM website under [News & Events](#).

We look forward to see you September 4<sup>th</sup>, 2018 in Athens!

*"We believe this was a small but very useful step in increasing the awareness of the SSIEM and ERNDIM in Africa"*



## ERNDIM at International Meetings

### ICIEM 2017, Rio de Janeiro, Brazil, 5<sup>th</sup> September 2017

ERNDIM were invited to present a short session at the 2017 International Congress on Inborn Errors of Metabolism (ICIEM) by the conference organisers.

Brian Fowler presented "What is ERNDIM?", Viktor Kozich "The role of ERNDIM in the European Reference Network for Hereditary Metabolic Diseases (MetabERN)" and Jim Bonham "Practical relevance of measurement uncertainty in IEM" and "Targeted next generation sequencing (NGS)

for new-born screening of inborn errors of metabolism in UK: a pilot experience". The session was chaired by Christine Vianey-Saban.

The session was well attended with around 50 participants, mostly lab staff. The presentations are available on [www.erndim.org](http://www.erndim.org) under Meetings & Reports.

### ICPLM 2017, Durban, South Africa, 20<sup>th</sup> to 22<sup>nd</sup> October 2017

ERNDIM was represented at the 2017 International Conference on Pediatrics and

Laboratory Medicine (ICPLM) by Dr Anny Brown, Honorary Treasurer of SSIEM and member of the ERNDIM Board of Trustees. Anny gave a lecture on the ERNDIM schemes and educational activities and she had a booth to provide information to delegates with leaflets and pop-up posters.

The conference in Durban was quite small with just over 120 delegates who were very appreciative and interested in SSIEM and ERNDIM.

We believe this was a small but very useful step in increasing the awareness of the SSIEM and ERNDIM in Africa.

## ESHG EuroGentest Quality Subcommittee



The ESHG – EUGT Quality subcommittee (QSC) met twice in 2017 and alongside the annual reports from each of the main European genetic EQA providers, the committee focussed on overall performance of labs. Other activities include:

- Cooperation with non-EUGT EQA schemes organisers will continue in a forum meeting at the ESHG annual symposium in Milan, June 2018.
- A questionnaire on current practice on information and support given to parents has

been finalised, to be distributed by the ESHG to screening centres, as part of moves to evaluate quality issues in newborn screening.

The search for a successor to our current chair, Ros Hastings continues. Mick Henderson has replaced Brian Fowler and Katrin Ōunap will take over from Viktor Kožich at the end of the year as representatives of ERNDIM in the QSC.

## National Representatives

The ERNDIM National Representatives are key members of ERNDIM and assist the ERNDIM Management Committees in disseminating the activities of the network to laboratories in their country. National Representatives are selected by ERNDIM, where possible, following nominations by the National Society.

Over the last few months we have reviewed the current representatives with the result

that 22 remain unchanged and nine new representatives have been recruited. Please check the ERNDIM website for the current list of National Representatives ([About\ Organisation and Key Persons](#)).

We remind all ERNDIM participants that your representative is available for questions on all aspects of ERNDIM, especially local issues.

## SSIEM Academy

### SSIEM 2018 Academy

ERNDIM collaborated with ETAC to organise the two day training meeting that was held in Slough, UK on the 23<sup>rd</sup> and 24<sup>th</sup> April 2018.

The course was heavily oversubscribed: 123 applications were received and 42 scientists and 41 clinicians attended.

The topics of the Academy were Lysosomal storage disorders, Peroxisomal disorders and Purine & pyrimidine disorders.

The joint clinical and lab workshops proved very popular and the feedback was positive with over 96% of the returned evaluation forms agreeing or strongly agreeing that “The programme was relevant to current practice” and that “The academy was relevant to my educational needs”.

### SSIEM 2019 Academy

The 2019 Academy will take place in Zurich, Switzerland in late April 2019 and the topics will be mitochondrial diseases, glycogen storage diseases, congenital disorders of glycosylation and neurotransmitters.

Information on future Academies will be posted on the ERNDIM website under [News & Events](#).

**“96% of returned evaluation forms agreed that the academy was relevant to my educational needs”**

## MetabERN

MetabERN (<http://metab.ern-net.eu/>) is a European Commission funded project which aims to promote prevention, accelerate diagnosis and improve standards of care across Europe for patients living with Inherited Metabolic Disorders, which very much corresponds with the aims of ERNDIM.

ERNDIM and MetabERN have agreed to collaborate in order to ensure the highest possible quality of laboratory services within participating health care providers. ERNDIM will not financially support MetabERN, but is

represented in the Advisory Board of MetabERN by Dr Victor Kožich.

MetabERN recently celebrated a year since it was first launched with a meeting in Frankfurt on the 9<sup>th</sup> & 10<sup>th</sup> April 2018. The meeting focused on the achievements of the first year and planning of the activities for the second year.

ERNDIM and MetabERN plan to collaborate on a number of issues including encouraging MetabERN members to participate in ERNDIM EQA schemes and MetabERN's proposal to create a central database



European Reference Networks

of available assays and laboratory tests for clinicians. Plans for this are at a very early stage but it is hoped this would build on existing databases such as the ERNDIM laboratory director and the Orphanet database.

If you would like more information on MetabERN please visit the website <http://metab.ern-net.eu/>.



# ERNDIM Management Committees

## Scientific Advisory Board (SAB)

There have been a number of changes to the membership of the SAB for the 2018 scheme year:

### Acylcarnitines DBS

Dr Cristiano Rizzo (Rome) has taken over from Dr Ralph Fingerhut, as the Scientific Advisor (SA) for the third centre of this scheme.

### DPT CZ

Prof Viktor Kožich stepped down as SA

and Mr Petr Chrastina has taken over.

### Qualitative Organic Acids (QLOU)

Ms Judit García Villoria has joined this scheme as the SA for a new organising centre in Barcelona.

Ms Sharon Colyer has taken over as deputy SA for the Sheffield QLOU centre after the sad loss of Dr Jane Dalley in 2017 (please see page 5 for a short 'in memoriam' article)

## Executive Committee & Board of Trustees

There were no changes to the Executive Committee or Board of Trustees in 2017-18.

Full details of the members of the Board of Trustees, the Executive Committee and the Scientific Advisory Board are on the website ([About\ Organisation and Key Persons](#)).

## Website update ([www.erndim.org](http://www.erndim.org))

### Documents added in the last year

#### Newsletters

- Newsletter 2018

#### EQA Schemes

- 2018 EQA scheme calendar
- Information on how to donate samples

#### Meetings

- Presentations, ERNDIM meeting at ICIEM 2017
- DPT Poster presented at ICIEM 2017
- Presentations, ERNDIM workshop, Nov. 2017

#### Reports

- Report on the 2017 Participant Survey
- 2017 EQA scheme annual reports
- Archived EQA scheme annual reports (2001-2010)
- Critical Errors in the 2016 & 2017 Qualitative EQA schemes

#### Travel Grant Reports

- Travel Grant Reports by Ms Bartlett, Dr Georgiou and Dr Rodrigues Rivera

### Educational Documents

- Please note that Educational documents are available on the website under the tab "Training": although some of them are somewhat old, they can be helpful. The goal of all ERNDIM Scientific Advisors is to update them. If you are willing to help us, please contact [admin@erndim.org](mailto:admin@erndim.org).

### Registration Website ([www.erndim.org/qa](http://www.erndim.org/qa))

Under the Participant Information tab which is only accessible if you log into the Registration Website:

- General Information
  - ERNDIM Participants' Guide 2018
  - ERNDIM Registration Website manual 2018
  - Educational Participation Application forms
  - Link to Repeat Sample Request form for 2018
- EQA Schemes
  - 2018 EQA scheme instructions
  - 2018 results submission forms for CDG scheme



*"Working towards a consensus between Biochemical Genetics Centres on reliable and standardised procedures for diagnosis, treatment and monitoring of inherited metabolic diseases"*

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### **ERNDIM Officers**

#### **Chair of the Executive Committee:**

George Ruijter, Rotterdam, The Netherlands

#### **Treasurer:**

Jörgen Bierau, Maastricht, The Netherlands

#### **Secretary:**

Viktor Kožich, Prague, The Czech Republic

#### **Chair of the Scientific Advisory Board:**

Christine Vianey-Saban, Lyon, France