

## National Metabolic Biochemistry Network

### Minutes of Stakeholder meeting held on 22<sup>nd</sup> June, 2004 at Birmingham Children's Hospital

<b>Present:</b>	Mike Badminton (MB)	Helena Kemp (HK)
	Jim Bonham (JB)	Mori Pourfavzam (MP)
	Anne Bowron (AB)	Mary Anne Preece (MAP)
	Jacqui Calvin (JC)	David Stansbie (DS)
	Ying Foo (YF)	Lesley Tetlow (LT)
	John Fyffe (JF)	Professor R. Swaminathan (PRS)
	Anne Green (AG)	Valerie Walker (VW)
	Mick Henderson (MH)	<b>By Invitation:</b>
	David Isherwood (DI)	Anne Sheldrake (AS)

#### ACTION

The Chairman welcomed Anne Bowron from Bristol and Anne Sheldrake, Laboratory Manager, from Great Ormond Street

#### 1. Apologies

Guy Besley, Jean Kirk, Philip Mayne, Geraldine Roberts, Janet Stone, Hilary Wastell. Apologies were received from Kim Bartlett and Neil Hamilton.

#### 2. Minutes of meeting held on 25.02.04

These had been previously circulated. Please note that Andy Brown should read Anne Brown.

#### 3. Matters arising

##### Guidelines

Progress had been made with the following guidelines:-

Fits & Seizures - now on the web site

Second draft for rhabomyolysis, hypoglycaemia and hyperammonaemia - these should be on the web site within the few months

Sudden unexpected death in infancy - **it was agreed** that this was a high priority and should be pursued as a priority item.

MH reported that it had been agreed that the Network guidelines would be published in the BIMDG Bulletin with acknowledgement and reference to the Network.

MAP

MH

## ACTION

### Molecular

The Genetic Testing Network (GTN) is holding a workshop on 23<sup>rd</sup> July for individuals wishing to share and discuss about how to complete the gene dossiers for new molecular tests. Further information is available via Maureen Boxer.

### Workshops

Workshops planned for 2004 include:-

Organic acids (Jim Bonham) - date to be confirmed but planned for early October

JB

Carbohydrate disorders (JC) - to include glycogen storage disorders, disorders of glycosylation and hereditary fructose intolerance. This is being planned for March 2005.

JC

Non-lysosomal enzymes (George Gray) - ? November/December 2004

GG

Guy's Hospital are still planning to organise a workshop on acyl carnitines, probably in November.

PRS

Guy Besley is to convene a small group to provide advice to the GTN on molecular tests for inherited metabolic disorders. The group will be multidisciplinary. Anyone interested should contact Guy directly.

GB

### CPA

The Chairman fed back from the communication with CPA confirming that there are no specific inspectors for paediatric metabolic biochemistry, although this is a recognised sub speciality which applicants are asked to declare.

Members are encouraged to consider being nominated as a CPA inspector

All

### Electronic Learning

MH and JB gave an update on the electronic learning proposals which Kim Bartlett has proposed. MH explained the SQL data base approach to the electronic learning pilot proposals. After further discussion, **it was agreed** that we should proceed with a focussed pilot whereby Kim is commissioned to do a piece of work on MCADD. This has been agreed with Kim for delivery by the end of 2004/5.

AG/KB

There are concerns about the cost of electronic learning packages for the future and it is important that the Network does not work in isolation and will, therefore, be collaborating with the ACB via the

Education Committee.

The role of trainees in production of appropriate material was clearly important and could be very useful for the future.

MH

#### RCPATH links with the Genetics SAC

John Crolla, Chairman of the Genetics Standing Advisory Committee of the RCPATH has agreed that we should have a Network member on this SAC as a link with Genetics. **It was agreed that** MH should be proposed as the formal link.

AG

#### Genetics IT

MAP gave feedback on a meeting that she had attended on behalf of the Network, looking at the IT proposal for laboratory genetics. The next stage is to develop an output based specification for a genetics laboratory system. There are issues as to whether this will be a stand alone system or part of a pathology system.

It was felt important that the Network be aware of this initiative and establish whether there is appropriate input into this activity, ? via Rick Jones. MH was asked to explore the situation.

MH

#### 4. Metabolic Assay Directory Update

Unfortunately, neither Kim Bartlett nor Neil Hamilton could attend the meeting today and Janet Stone has sent her apologies.

A written report has been received from Kim Bartlett - see appendix.

The current position is that the list of tests provided by each laboratory has now been completed and has been inputted into a data base by Janet Stone. The next stage would be to ask members to check their entries and provide information on specimen requirement. Janet Stone will be contacting members in the near future when this is ready.

JS

JS

The plan is then to pilot the directory during July with a start date for launch in August 2004 planned.

The Chairman thanked Janet (in absentia) for the enormous amount of work that has been undertaken in developing this assay directory on behalf of the Network members.

## ACTION

The Chairman informed members that Kim and Neil have now separated from the Institute of Child Health at Newcastle and have set themselves up as an independent business. There was some concern regarding the future for the Network web site, and the need to firm up arrangements by way of a formal contract.

AG

### 5. Workforce Strategy

LT gave a review of the workforce issues and presented an overview of the document that had been prepared on behalf of the Network for submitting to the Workforce Review Team. The Chairman thanked Lesley for her hard work in producing this, particularly over a very short time frame. A copy of the full document will be circulated to all Stakeholders.

AG

### 6. Training

MH was congratulated on his appointment as Lead Trainer for the Network. Mick gave an overview of his plans for the Network with the priorities being the appointment of cluster trainers and appointment of higher specialist trainees.

The current position is that the HST job description and personal specification is completed and will be going out to advert in July with a closing date of 13<sup>th</sup> August. The process for the HST appointments will be sorted out by Mick once it is clear on the level of interest and the Stakeholder Laboratories involved. **It was agreed that** Mick should proceed and involve individual Stakeholders as required.

MH

There was considerable discussion about the appointment of the cluster trainers and how this should proceed. Mick will prepare a job description and personal specification.

MH

It was reaffirmed that the three lead sites would be:-

Sheffield Children's Hospital (North)  
Birmingham Children's Hospital (Midlands)  
Great Ormond Street (South)

The trainers would be appointed to each of these sites.

Mick would circulate the heads of these three respective departments to ask that they identify individuals who might be interested in taking up this post, and write back to Mick with a proposal which would include the ability to organise appropriate backfill.

MH  
B'ham  
Sheffield  
London

## ACTION

MH would continue to represent the Network at the RCPATH examination discussions.

It was suggested that the HST trainees are provided with a training certificate at the end of their period of training. This to be considered in due course by MH and other trainers.

MH

## 7. Status of Network projects

AG reported that she had been asked to prepare a report and give a presentation to the Department of Health in September/October (date to be confirmed) 2004 on the status of the Network, in particular to document the 'highs and lows' of the Network.

A report will be prepared and circulated to all Stakeholders.

AG

### Quality/Audit Plans

YF reported that the next Network Quality Day will take place on 29<sup>th</sup> October 2004. Further details will be made available via the web site.

YF/AG

**It was agreed that** it would be good to invite Finlay MacKenzie to the Quality Day to interface with NEQAS.

YF

### Audit

After some discussion, **it was agreed that** we should take forward audit by initially finding out information on what audit projects individual laboratories had undertaken. To discuss at the next meeting on November 9<sup>th</sup>, 2004.

All/AG

**It was agreed that** some project to look at equity would be a good audit to undertake and this will be for discussion at the next meeting.

Jean Kirk has obtained some information about a quality assurance system for lysosomal enzymes. This will be circulated to Stakeholders and put on the web site.

AG

## 8. Objectives and Action Plan

A summary of our ongoing objectives were discussed - see attached. A full action plan for the Network for 2004/5 and 2005/6 will be produced and circulated.

## ACTION

### National Occupational Standards

No further progress appeared to have been made since our last meeting. Ying and Lesley will be attending the Chief Scientific Officer's meeting in July and will report back on any further developments.

YF/LT

### Links with the UKNSLN

JB and DI gave an update on recent events linking metabolic diagnostic services to neonatal screening services. Recent meetings had taken place with Muir Gray. We are awaiting the outcome of Muir's plans to establish a national operational strategy board.

### Agenda for Change

Concern was expressed from many laboratories about the Agenda for Change process and the lack of job profiles which related to our specialty. We agreed that we should work together to produce some generic job descriptions. LT agreed to take this forward.

LT

The Chairman agreed to contact the Federation of Clinical Scientists for advice on how we might input/prepare for the job matching process.

AG

## 9. Service Questionnaire

Following our discussion, the following are in hand:-

1. A full report to be prepared by AG for circulation to Stakeholders **AG**
2. Discussion on specialist enzymes, issues and plans for the future via a workshop **GG**
3. To circulate a mini questionnaire on plans for new tests **AG**

The real issue is how we should take forward any proposals with the Department of Health. ? what, how, when.

The major issues seems to be:-

- The Workforce Plan for all staff
  - this is being covered by the Workforce Review Submission.
- Links with neonatal screening
  - ongoing discussions via Muir Gray and the UKNSLN
- Accommodation and number of labs ?

- Links with the Clinical Strategy
  - the Joint Medical Genetics Committee has established a programme of work via the Cambridge Public Health Genetics Unit to look at scoping the issues related to inherited metabolic disorders with particular emphasis on services for adults but with links to laboratories.

The real issue would appear to be is how are our services linked with the commissioning links and whether there is equity of access across the country. We have agreed that this should be discussed at the next meeting in the context of any audit initiative, and any feedback from the DOH meeting (September/October)

#### 10. Any other business

There were no other items of business

#### 11. Next meeting date

November 9<sup>th</sup>, 2004 commencing at 11.30 a.m.

# ADDENDUM

## Objectives & Action Plan 2004-2006

- **Service Provision**
  - how to progress issues ?
- **Training & Education**
- **Best Practice Guidelines**
- **Web Site**
  - **MAD**
- **Workshops**
- **Molecular Testing Group**

# Objectives & Action Plan 2004-2006

- Quality
  - QA
  - Audit
  - CPA
  
- National Agenda
  - Workforce planning
  - NOS
  - Agenda for Change
  - Newborn Screening

# APPENDIX

## Report on the development of the National Metabolic Biochemistry (Biochemical Genetics) Network website and Metabolic Assay Directory

June 22<sup>nd</sup> 2004

Following a meeting on 29<sup>th</sup> March 2004 with Janet Stone and Anne Green a number of changes and additional features were agreed. The work has been carried out by Kim Bartlett and Neil Hamilton (Maria Healthcare Networks Ltd).

### Current Web Site

Textual changes to background and current activities have been made. The title of the Assay Finder will be changed to "Metabolic Assay directory" when it "goes live". The best practice guidelines now include an introduction. Links to ERNDIM, NEQAS and SAS have been provided. Modifications to disclaimer notices have been made. An introductory paragraph introduced. A page ascribing web site management has been provided.

### Outstanding tasks

"Quality Assurance" will be modified to "Quality".

A number of 'Associate' laboratories are to be added:

Oxford	[Gary Brown]
University College London	[Gill Rumsby]
Institute of Neurology	[John Land and Simon Heales]

The list of laboratories is to be modified so that a single entry per city appears linked to the full list of centres within a city (Oxford will require a separate entry).

Copyright is to be vested in the National Metabolic Biochemistry Network and will appear on the home page - similar to that used by the Royal College of Pathologists. However, in the case of presentations made by individual stakeholders, copyright will remain with the author(s).

### Metabolic Assay Directory

The name of the assay finder will be changed to "Metabolic Assay Directory". Each laboratory record will include mandatory fields for contacts and accreditation status (CPA & EQA). The list of analytes/tests has been updated. A software tool has been developed to allow JS to enter data for each laboratory.

## Outstanding tasks

A statement regarding accreditation status and disclaimers to be provided. Also, a general introductory text is to be displayed. A list of EQA schemes for metabolic biochemistry authored by Jim Bonham to be displayed. A separate login for laboratories with 'Associate laboratories' will be provided.

It is anticipated that the remaining outstanding tasks will be completed by June 30<sup>th</sup>, subject to receipt of the textual material, leaving a month for testing, with a target for 'going live' 1<sup>st</sup> August 2004

## Metabolic Biochemistry CAL facility

It has been agreed to develop a trial module for MCADD. This will be on a 'case oriented' basis with links to analytical methods, reference ranges, background biochemistry, related differential diagnoses etc. It will be designed and implemented in a way which allows future refinement and the development of additional modules, should the general approach be acceptable. An outline of the work and a costing has been provided.

Links would be sought to the *Genetic Testing Network* and other initiatives such as the London Ideas Park, University of Greenwich.

Kim Bartlett  
Neil Hamilton  
June 2004