

## National Metabolic Biochemistry Network

### Minutes of Stakeholder meeting held on 1<sup>st</sup> February 2006 at Birmingham Children's Hospital

<b>Present:</b>	Ann Bowron	(AB)	Mick Henderson	(MH)
	Guy Besley	(GB)	Steve Krywawych	(SW)
	Jim Bonham	(JB)	Tim Lang	(TL)
	Amy Brown	(ABr)	Stuart Moat	(SM)
	Jacqui Calvin	(JC)	Paul Newland	(PN)
	Tony Fensom	(AF)	Mary Anne Preece	(MAP)
	John Fyffe	(JF)	Colin Samuel	(CS)
	Anne Green	(AG Chair)	Valerie Walker	(VW)

#### 1. Apologies

Mike Badminton, Ying Foo, David Isherwood, Helena Kemp, Mori Pourfazam, Fiona Carragher, Lesley Tetlow, Professor E. Trimble, Janet Stone

#### 2. Minutes of meeting held on 04.11.05

These were approved as an accurate record of the meeting without any amendments.

#### 3. Matters arising

##### 3.1 Workshops Update

Amino acids - November 22<sup>nd</sup> 2005

Anne Bowron gave an overview of the Bristol Workshop on amino acid disorders. The meeting had been a huge success and the Bristol team were congratulated and thanked by the Stakeholders for organising this.

Two specific issues came up for discussion. Firstly, to take forward the issues relating to harmonisation of reference ranges and guidelines for standardising practice in monitoring amino acids. The Bristol group agreed to take this work forwards as a taskforce.

The issues relating to standardising practice for monitoring would be best undertaken as a joint initiative with the BIMDG, possibly as a 'Do once and share' project - see later in the minutes (3.5).

#### ACTION

AB/ABr/HK

## ACTION

Another issue was the possibility that the Stakeholder labs could offer support to other less specialist labs providing amino acid investigations. Mick Henderson outlined the Yorkshire model which has this function.

Anne Bowron to send report of workshop to AG to put on web site.

AB

February 23<sup>rd</sup> 2006

The Associate Laboratories workshop 'Oxalate and inborn errors of dopamine and serotonin metabolism', organised by Gill Rumsby will be taking place in London.

**It was agreed** that this would be a useful initiative for the Network, jointly with UK NEQAS, and Jim Bonham and Anne Bowron agreed to take this forward by firstly sending a letter to the ACB News offering support.

JB/AB

Future workshops planned are:-

November/December 2006

Vitamins

Mary Anne Preece

MAP

Early 2007

Intermediary metabolism Jim Bonham

JB

### 3.2 Consent form for authors

Appropriate arrangements will be made via the Training and Education Section on the web site.

MH

### 3.3 Guidelines

Paul Newland updated Stakeholders on the current guidelines and circulated an Excel spreadsheet. The system for reviewing guidelines has been established.

**It was agreed** that there was no need to commission any further guidelines at this stage, but to concentrate on completing existing commissions.

PN

#### The Unconscious Child Guideline

This is still undergoing appraisal but is available in draft form. Stakeholders have already been circulated with details.

### Guideline Clearing House Proposal

The proposal to have a national clearing house for completed guidelines and guidelines in progress has been supported by the Joint Committee for Medical Genetics, and will be taken forward in collaboration with the Royal College of Pathologists.

### 3.4 National IMD Review

The review has now been circulated and is available electronically via the Network web site link. A national stakeholder group is to be established and the lead will be a commissioner, Jacqui Meakin. We await further plans with regard to the details.

AG and JB reported on some preliminary meetings that have taken place between the Midlands, West and East, Yorkshire, South West and Wales, regarding clustering of centres. These were very preliminary discussions. The way forward would be very much dependent on how the future commissioning arrangements were going to operate.

### 3.5 Do Once and Share Projects (DOAS)

Jim Bonham explained what 'Do Once and Share' stands for, and the possibility that MetBioNet may have an involvement with one or two projects. The DOAS philosophy is very much related to Connecting for Health. AG and JB had had a preliminary meeting with Jane Slater on behalf of Sir Muir Gray and three ideas had been submitted:-

Reference ranges for amino acids  
Care Pathways following Newborn Screening  
A guideline such as Developmental Delay

An outline proposal has been submitted and we are awaiting further discussion.

AG reported that a DOAS initiative had also been suggested for the metabolic service, and that a meeting with Muir Gray and representatives of BIMDG, MetBioNet and Hilary Burton will be taking place on 1<sup>st</sup> March 2006.

### 3.6 Membership Review

AG reported that she had written to Jeff Barron regarding Carshalton and there had been no further correspondence.

**It was agreed** that all requests for membership should come via the Stakeholder Group for the future.

### 3.7 Specialist Substrate Availability

The issue about obtaining specialist substrates has been taken up with the ACB Scientific Committee.

**It was agreed** that Rodney Pollitt would be ideal if he would be prepared to take this forward, and Jim Bonham agreed to suggest this.

JB

It was decided that anyone who has a problem with a specific substrate should contact Jim Bonham so that a 'hit list' of specific problems could be communicated to Rodney.

ALL

## 4. Reports/Liaison with Other Groups

### 4.1 UKGTN

The UKGTN has been restructured and there has been no meeting since September 2005. The next meeting is scheduled for 16<sup>th</sup> February, 2006.

#### **New advisers have been appointed**

The clinical adviser is Dr. Peter Lunt from the United Bristol Healthcare and NHS Trust, and the scientific adviser is Dr. Joanne Whittaker, Director of Cambridge Genetics Laboratory.

Five new working groups have been established. These are:-

- Gene dossier and NHS directory of molecular genetic testing
- Laboratory membership and criteria, performance and monitoring
- Systems and communication
- Clinical appropriateness, future service development and links with other specialties
- Commissioning initiatives including the national tariff

MetBioNet has representatives on the systems and communication (Paul Griffiths from the Birmingham Laboratory). Laboratory membership and criteria (shared arrangement - Mike Badminton, Cardiff and Sarah Ball, Birmingham) Group.

## ACTION

Unfortunately representatives on the other groups were declined. However, AG has reassurance in writing from Jacqui Westwood that there is a possibility for ad hoc attendance at meetings on specific issues where biochemical genetics issues may be particularly relevant.

JB for future

### 4.2 UKNSLN

Jacqui Calvin reported on current newborn screening issues. There has been no definitive outcome on the issue of the Programme Manager role/regional structures. It has been extremely busy and there is clearly a huge amount of screening activity which is extremely difficult for the UKNSLN executive to handle, and Jacqui is seeking suggestions as to how the UKNSLN may restructure itself to provide a more effective vehicle for laboratory input.

All

CF screening is being rolled out across England. Other big issues include IT, newborn screening and molecular tests, the need for screening tariffs and how to deal with unidentified variants from the sickle programme. MetBioNet wish to continue to work closely with UKNSLN and, where possible, strengthen the laboratory input into national initiatives, particularly at Programme Centre level.

AG

AG/JB

### 4.3 Blood Spot Advisory Group

A new Blood Advisory Committee has been established and had its first meeting on December 2005. Clearly this is a high level committee to meet twice a year, and will not be an appropriate vehicle for more detailed discussions.

The Lead Scientist attended this group as representative of MetBioNet.

### 4.4 JCMG

Two meetings have taken place - 08.11.05 and 19.01.06. The new chair from January 2006 is John Crolla.

The November meeting included a major presentation on IMD services by Hilary Burton and a Network presentation by AG. These were both very well received and have clearly raised the profile of metabolic services within the UK and, specifically, within the genetic community.

The new RCPATH SAC Genetics Chair is John Old.

There is a national review of specialist services taking place; the Lead Scientist has sent input from the Network which has been already been circulated to Stakeholders.

Issues under active discussion include:-

Enzyme replacement therapy  
Human tissue authority  
Consent and confidentiality policy

There is great concern amongst all the laboratory disciplines within genetics about the future for training post. John Crolla, as new Chair of the JCMG, is planning to make this a major initiative during his term of office.

#### 4.5 RCPATH SAC for Pre, Perinatal and Paediatric Pathology

No report.

### 5. Training and Education

Mick Henderson gave an update on Training and Education - see appendix.

#### MCADD CD

Jim Bonham reported that this is progressing well.

#### Electronic Learning Package

Mick has not had any further information from Kim, although he has sent additional material. He will chase up.

MH

#### Video Conferencing

Jean Kirk had raised the issues of difficulties in attending meetings and whether video conferencing would be a way forward. Whilst there was empathy with the issues and, in theory this was a good idea, there was little information about the practicalities and cost of this. Everyone agreed, however, that individual meeting organisers could consider this and the possibility of making a video/CD or a specific meeting as something for the future.

### Medical Scientist Group

The Stakeholders welcomed Linda Jenkinson from the Birmingham Laboratory who attended for this item to update everyone on the recent meeting which had taken place, to take forward training initiatives on behalf of the biomedical scientist staff working in specialist metabolic biochemistry laboratories.

The questionnaire has been circulated to request data and this is shortly to be compiled for circulation. A further meeting will be taking place in Birmingham in April to take forward specific suggestions.

## 6. Web Review

### 6.1 Assay Directory Links

The previous discussions with Assay Finder has ground to a halt as this now seems to be a private concern. AG has had some discussions with Jonathan Kay, but there is no real way forward at present.

#### EurogenTest

AG reported on a very useful meeting which had taken place in Basle in early December 2005, and the commitment between EurogenTest and MetBioNet to work together on the assay directory.

A financial contribution (see finance below) has been made by Brian Fowler in order to support this.

AG had been approached by a parent organisation to have a link to our web site. The issue of whether we should vet proposed links from parent/client organisations and how these should be agreed was discussed.

**It was agreed** as a matter of principle that the main parent groups CLIMB and GIG, with whom we had formal relationships, would be the main links, and that we would not plan to list other sites.

### 6.2 Disorder links

Unfortunately Janet Stone has sent her apologies. She is, however, starting to work on this and hopes to have a progress report for the Lead Scientist within the next few weeks.

The Lead Scientist reminded everyone that the update in process for test lists and specimen details is now required by everyone.

**PLEASE CONSULT THE WEB SITE FOR YOUR TEST LIST.**

JS

ALL

The Lead Scientist reported that the email messaging system was now live, and members were encouraged to try this out.

## 7. Audit

### 7.1 SUDI Project

There is potential interest in undertaking a joint project with the RCPATH.

### 7.2 Metabolic Screen Questionnaire

No further progress. TL to report back at a future meeting.

## 8. Workforce Planning

### Questionnaire Results

Colin Samuell presented the data for the 2005 survey. Stakeholders congratulated Colin producing such comprehensive information in such a timely manner.

**It was agreed** that we would continue to record against the old, pre-agenda-for-change grades, but asked for new AfC grades along side. We would continue to collect as per the 2005 categories and plan to do this in early 2006/7

### DH Workforce Group Update

There has been no further progress.

P.S. Recent news - a meeting is planned for March 2006.

## 9. Quality

### 9.1 QA Schemes for the Web

Jacqui Calvin reported that the data regarding the urinary steroid scheme can now be updated.

### 9.2 Quality Day

It was now confirmed that this will take place in Belfast on 4<sup>th</sup> October. Tim Lang reported that there would be a programme for April for circulation and to be put on the web.

## 10. Recommendations to changes to service provision for non-lysosomal assays update

This item was deferred to the next meeting at the request of Dr. Ying Foo.

CS

JC

TL/ET

YF

## 11. Network Future

### Finance update

AG confirmed that the DH would be supporting the Network for 2006/7 with an additional £15,000, plus £6,000 for training and education.

European Assay Link Directory Eurogen Test has promised €3,000. The possibility for further project income via Do Once and Share is being pursued.

AG/JB

### National Meeting Plans

A national meeting has now been agreed for 13<sup>th</sup> June in Manchester - organisers Guy Besley and Lesley Tetlow. This to feature some of our completed guidelines. A draft programme to be produced.

GB/LT/JB

### Lead Scientist/administrative support

It was noted that the Lead Scientist role will be handed over to Jim Bonham from 1<sup>st</sup> April 2006 with administrative support being provided by the Sheffield Team. Arrangements are being made with the Birmingham Team to hand over during March/early April.

AG/JB

It was agreed that meetings continue in Birmingham as this is most convenient for everyone., Jim confirmed that he was planning to proceed with various work streams via small working groups for the future.

AG thanked everyone for their help and support over the 3½ years she has been Lead Scientist. The huge amount of work and achievements of the Network would not have been possible without commitment and enthusiasm from the Stakeholders. AG also thanked Mary Anne Preece for her support in the department and Mary Dowling for the administrative support to the Network.

## 12. Communications/Presentations

AG reported that a flyer had been circulated to all RCPCH representatives.

An announcement for the ACB News Sheet, specifically referring to the guidelines, has been prepared by Paul Newland for publication in the February ACB News Sheet.

**ACTION**

An item for the RCPATH Newsletter is being prepared.

**AG**

Submission to the RCPCH York has been accepted as a plenary guest lecture as part of the BIMDG Mini-Symposium on April 6<sup>th</sup>, 2006.

**13. Miscellaneous**

AG reported that a submission to the Pathology Modernisation Carter Review has been sent on behalf of the Network and will be circulated to all Stakeholders.

**AG**

**The meeting closed at 1545h**

## Appendix

### National Metabolic Biochemistry Network (Biochemical Genetics)

#### Summary of progress in the Training Initiative

##### 1. HST training

###### a) Annual Assessment

Annual assessments for all the HSTs have taken place.

Guidance notes were posted on the website and will be discussed at the next joint meeting in February.

###### b) Future Trainees

The funding to secure future trainees needs to be planned. Heads of Stakeholder laboratories need to begin planning a strategy to secure this funding from Trusts and WDCs.

##### 2. Website group

###### c) The MCAD case and related developments.

We still await a pilot version.

###### d) Chromatogram library

Prof Rodney Pollitt is making progress.

###### e) Case reports

HSTs have been encouraged to submit one each per year.

###### f) Lectures

The lecture set is steadily growing.

##### 3. A grade training

A document recommending minimum standards of training for A grade clinical scientists in general training has been prepared and posted on the website. The ACB Regional Tutors are being encouraged to collaborate with MetBioNet local trainers to ensure that these minimum standards are achieved.

##### 4. Biomedical Scientist Training Group

A meeting was organised to initiate a BMS training group linked to the existing MetBioNet training structures. This initial meeting was chaired by Ann Sheldrake and comprised an ad hoc selection of BMS staff from around the country. Mick Henderson and Colin Samuell were also present.

A questionnaire had been circulated to lead BMS staff in the stakeholder labs and there was a good rate of return at short notice, 14 out of 18.

Key issues raised were:

- All labs welcomed the proposed training group initiative
- BMS2s and 3s highlighted a desire for more training
- All staff would like to improve interpretative skills
- Would like practical skills workshops, manufacturers courses noted to be very expensive

Intended actions following the meeting:

- hold an inaugural meeting, programme likely to be strategic planning in the morning and scientific in the afternoon
- create BMS discussion forum on IBMS website 'Metabolic Biochemistry'
- discuss workshops with commercial companies
- create BMS interest page on MetBioNet website
- organise exchange visits between centres for BMS staff
- discuss creation of Diplomas in expert practice in Metabolic Biochemistry with IBMS. This is being encouraged by the Institute and may be helpful in encouraging staff into the specialty and recognising their skills once there.

#### 5. Annual Review Meeting

An annual review meeting for all trainers, supervisors and trainees is planned to take place on Friday 17<sup>th</sup> Feb in London.

#### 6. BIMDG training day

I am helping to organise the pre AGM training day and am collaborating with Dr Chris Hendricks. We propose to have a theme of Clinical Audit. We will organise someone senior to describe the components of a good audit and call for presentations from trainees about audits they have been involved with.

#### 7. Metabolic map

The training group is collaborating with Donald Nicholson in reviewing the design of his Inborn Errors Metabolic Pathway chart. We have not been asked to offer radical solutions but to give advice on highlighting those disorders of most clinical relevance and helping them to be clearly marked.

Mick Henderson

National Lead Trainer

Tuesday, 31 January 2006

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