

# National Metabolic Biochemistry Network

‘What is it and Progress to date’

**Anne Green**

Lead Scientist

On behalf of stakeholder laboratories

**October 20<sup>th</sup> 2004**

- **What is Metabolic Biochemistry**
- **What is the project?**
- **Outcomes**
- **Experiences**

# Diagnosis & Management of Inherited Metabolic Disorders(IMD)

- **Newborn screening**
  - Phenylketonuria (PKU)
  - Medium chain acyl CoA dehydrogenase deficiency (MCADD)
  - Other IMDs
- **Clinical investigation**
  - Acutely sick newborn/infant
  - Developmental delay
  - Liver, Renal, CNS
  - Adults
- **Prenatal diagnosis**
- **Clinical management**
  - Monitor Tx
  - Disease progression

# Metabolic Biochemistry

- **Metabolites**
  - Amino acids
  - Organic acids
  - Acyl carnitines
- **Enzymes**
  - Plasma
  - Leucocytes
  - Tissues ( skin/liver etc)
- **DNA**
  - 'biochemical' disorders

# The Project

- **Background**

- major developments in IMD and Newborn Screening to respond to
- services under increasing pressure
  - increasing workload
  - demands for new tests
- services – issues of robustness
  - staff
  - equipment
- poor recruitment of clinical scientists
  - Vacancies
- no manpower or training plan (**retirements & succession planning**)

# The Project Aims

- **Form a network of stakeholder laboratories across UK**
  - Communication
  - Sharing of information
  - Common practices
- **Address key issues**
  - Manpower plan
  - Training strategy
  - Testing for rare disorders
  - Develop guidelines
  - Quality initiatives

# Genetics Development Project

- **2 year project**
  - Oct 2002 - Oct 2004  
(extended to April 2006)
- **Hosted – Birmingham Children's Hospital**
- **Lead Scientist**
  - 0.4 wte
  - A/C support

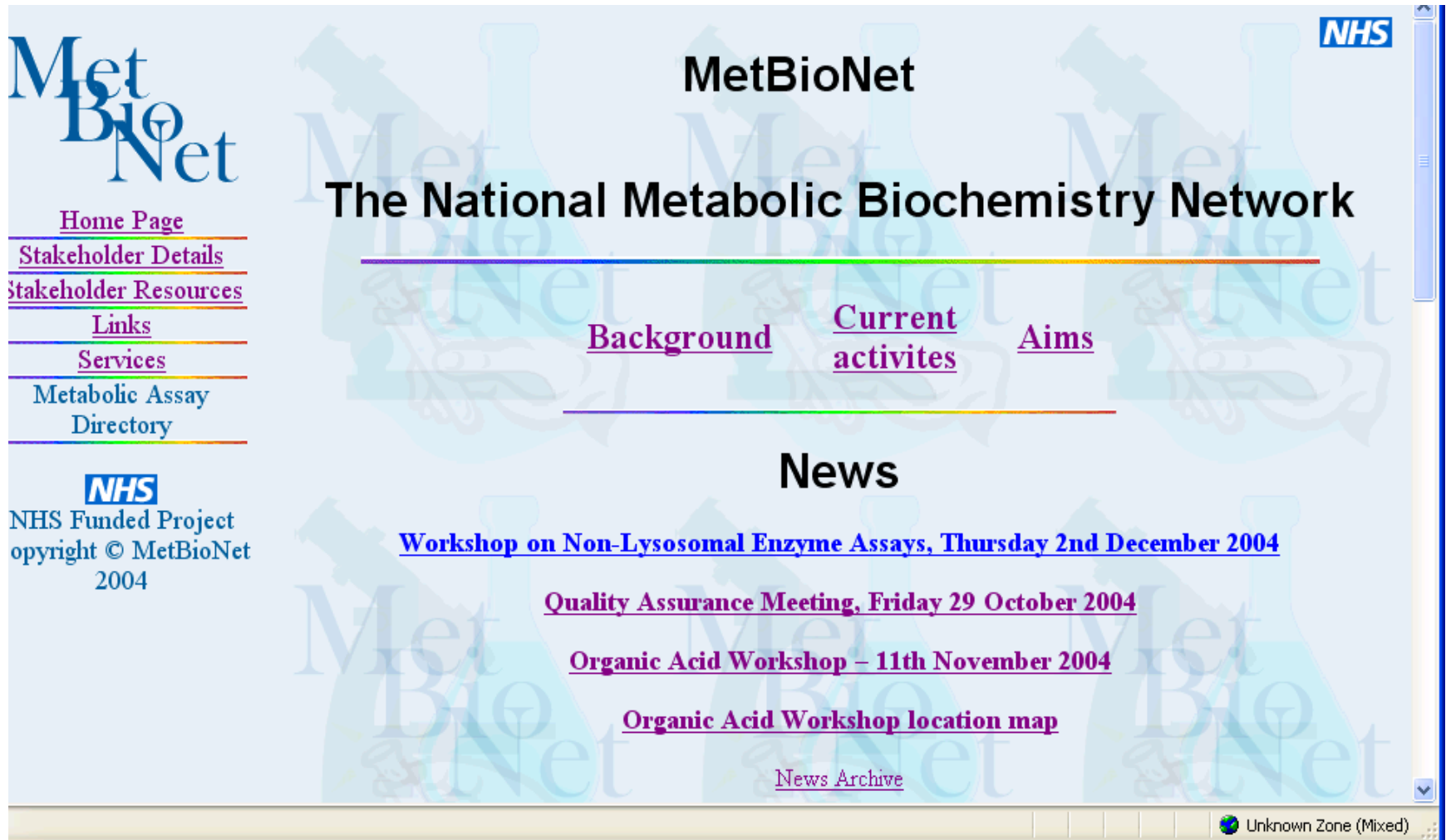
# Stakeholders Laboratories(17)

- **Belfast**
- **Birmingham**
- **Bristol**
- **Cambridge**
- **Cardiff**
- **Dublin**
- **Edinburgh**
- **Glasgow**
- **Leeds**
- **Liverpool**
- **London (2)**
- **Manchester(2)**
- **Newcastle**
- **Sheffield**
- **Southampton**

# Outcomes

- **Web site**

# MetBioNet Home Page



The screenshot shows the MetBioNet website interface. At the top right is the NHS logo. The main heading is 'MetBioNet' followed by 'The National Metabolic Biochemistry Network'. A horizontal rainbow bar is positioned below the heading. On the left side, there is a vertical navigation menu with links: Home Page, Stakeholder Details, Stakeholder Resources, Links, Services, and Metabolic Assay Directory. Below the menu is the NHS logo and copyright information: 'NHS NHS Funded Project copyright © MetBioNet 2004'. In the center, there are three links: Background, Current activities, and Aims, separated by a horizontal rainbow bar. Below this is a 'News' section with four links: Workshop on Non-Lysosomal Enzyme Assays, Thursday 2nd December 2004; Quality Assurance Meeting, Friday 29 October 2004; Organic Acid Workshop – 11th November 2004; and Organic Acid Workshop location map. At the bottom center is a link for 'News Archive'. The bottom right corner shows a system tray icon for 'Unknown Zone (Mixed)'.

**MetBioNet**

**The National Metabolic Biochemistry Network**

[Home Page](#)  
[Stakeholder Details](#)  
[Stakeholder Resources](#)  
[Links](#)  
[Services](#)  
Metabolic Assay Directory

**NHS**  
NHS Funded Project  
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2004

[Background](#)   [Current activities](#)   [Aims](#)

**News**

[Workshop on Non-Lysosomal Enzyme Assays, Thursday 2nd December 2004](#)  
[Quality Assurance Meeting, Friday 29 October 2004](#)  
[Organic Acid Workshop – 11th November 2004](#)  
[Organic Acid Workshop location map](#)

[News Archive](#)

Unknown Zone (Mixed)

# View Stakeholder Details

**BIRMINGHAM**  
West Midlands Laboratory for Inherited Metabolic Disorders and Neonatal Screening  
Department of Clinical Chemistry  
Birmingham Children's Hospital NHS Trust  
Steelhouse Lane  
Birmingham  
B4 6NH

Fax No: 0121 333 9911  
Web Site: <http://www.bch.org.uk/departments/imd/laboratoryservice.htm>

For Metabolic Queries Contact Duty Metabolic Biochemist	Tel No: 0121 333 9864
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Dr. George Gray

ERNDIM Urine organic acids

# Metabolic Assay Directory

Google Search Web 19 blocked AutoFill Options

Met Bio Net **Search Results - Registered Analytes** NHS

[New Search](#)

Acyl carnitines (by tandem MS)

Lab name
<a href="#">Addenbrookes Hospital</a>
<a href="#">Freeman Hospital</a>
<a href="#">Institute of Child Health - Great Ormond Street Hospital</a>
<a href="#">Royal Group of Hospitals Belfast</a>
<a href="#">Royal Hospital for Sick Children</a>
<a href="#">Sheffield Childrens Hospital</a>
<a href="#">St. James University Hospital</a>
<a href="#">Willink Biochemical Genetics Unit</a>
<a href="#">Birmingham Childrens Hospital</a>
<a href="#">Guy's and St. Thomas' Trust Chemical Pathology</a>
<a href="#">University Hospital of Wales</a>

Specimen: blood spots Sample requirements: liHep

javascript:shortPopup('sh lbdet.jsp?lab=uwcm', 'lab', 600, 500) Trusted sites

# Stakeholder Resources

## Stakeholder Documents

### National Metabolic Biochemistry Network

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

**Present:**

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

## Strategy and Action Plans

# Outcomes

- Web site
- **Manpower & Training**

# Manpower

- **Provision of Service (2001 Questionnaire)**
  - Grade C and Grade B clinical scientists
    - 62 established posts
    - 14 planned ( new service developments)
    - **24 posts required over next 5 years**

# Manpower & Training

- **Training Survey ( Questionnaire 2002/3)**
  - 83 Grade As in training ( England 2003)
  - 54% inadequate training
  - 23% **no** plans for training ( esp London)
  
  - **1** Higher specialist training post !

# Training Strategy ( 2003)

- Paediatric Metabolic Biochemistry – recognised Sub modality
- Trainers
  - Lead trainer
  - ‘local’ cluster trainers( North, Midlands and South)
- Higher Specialised Trainees
  - 10 posts

# Training Update

- **Paediatric Metabolic Biochemistry**
  - recognised sub modality **(HPC)**
- **Lead Trainer**
  - Dr Mick Henderson – June 2004
- **Local Trainers**
  - London (Dr Colin Samuels)
  - Sheffield (Dr Rodney Pollitt/ Dr Jim Bonham)
  - Birmingham (appts Nov 3<sup>rd</sup>)
- **HSTs**
  - 2 posts funded WDCs
  - 8 from DH Genetics

# Outcomes

- Web site
- Manpower & Training
- **Workshops**
  - 2 – 2003/4
  - 3 – 2004/5

# Outcomes

- Web site
- Manpower & Training
- Workshops
- **Best Practice Guidelines**
  - 2 completed
  - 8 in preparation

# Outcomes

- Web site
- Manpower & Training
- Workshops
- Best Practice Guidelines
- **Quality**
  - Oversee QA ( annual meeting)
  - CPA
  - Audit

# Outcomes

- Web site
- Manpower & Training
- Workshops
- Best Practice Guidelines
- Quality
- **Service Provision** ( Questionnaire)
  - accomodation
  - equipment
  - rationalisation/development

# Has it made a difference ?

- Appointed to 8 new clinical scientist posts  
( 2001/2 - unfilled vacancies across UK)
- Paediatric Metabolic Biochemistry is recognised sub speciality ( HPC and CPA)
  - more flexible recruiting
- Common practices promoted
  - Best Practice guidelines
  - Workshops
- WEB site
  - communication & information
  - assay directory ready for launch

# Experiences

- **Highs**

- Support from colleagues/spirit of cooperation
- Metabolic Biochemistry - recognised
- Platform to go forward
- **\*\*\* Training strategy –support & £**

# Experiences

- **Lows**

- **We are too late?/tight time frame for training**
- **Same few people/time!!**
- **NHS structure or lack of for specialised services!**
  - Frustrating!
  - Depressing!

# 'Lessons Learnt'

- **Do not expect anyone to understand what we do**
  - Keep repeating same message
  - Be patient
  - Don't expect too much too soon
- **DH staff are very busy**
  - we may be a 'blip' on their agenda/not highest priority
  - may need to feel a nuisance
- **Know what you want and keep focussed !**

# What Next/Issues

- Implementation of CS training
- Manpower planning for BMSs
- Service issues ? How to take forward
- National coordination for whole IMD (clinical & lab)
  
- Links with newborn screening (NSC)
- Commissioning process
- WDCs role?
- Longer term role/future for the network

# Summary

- Network infrastructure & communication links established
- Paediatric Metabolic Biochemistry recognised sub modality for registration of clinical scientists
- Web site established – assay directory ready for implementation
- Overview of service provision completed
- National Training Strategy developed , funded and now being implemented

# Acknowledgements

- Jim Bonham , Sheffield
- Mick Henderson, Leeds
- Stakeholder Colleagues
- Genetic colleagues
- Mary Dowling Birmingham
  
- ACB Training Committee (Trainees)
- Royal College Pathologists (SAC Clin Biochem)
- Joint Committee Medical Genetics
  
- Birmingham Children's Hospital
  
- DH colleagues