



**National Metabolic Biochemistry
(Biochemical Genetics) Network**

**ACTION PLAN
2004/5 and 2005/6**

An NHS/Department of Health funded project
Genetic Services (Specialised Services, Definition Set No. 20)

Host Trust – Birmingham Children’s Hospital (BCH)

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Version: 1

Anne Green (AG), Lead Scientist
Mary Dowling (MD), Admin. Support

Abbreviations used

ACB	Association of Clinical Biochemists
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ACS	Association of Clinical Scientists
CPA	Clinical Pathology Accreditation
GenCAG	Genetics Commissioning Advisory Group
GTN	Genetics Testing Network
HST	Higher Specialist Training/Trainee
IEM	Inborn Errors of Metabolism
IMD	Inherited Metabolic Disorders
JMC	Joint Medical Committee
MAD	Metabolic Assay Directory
QA	Quality Assurance
RCPATH	Royal College of Pathologists
UKNSLN	UK Newborn Screening Laboratory Network
VLCFA	Very Long Chain Fatty Acids
WDC	Workforce Development Confederation

ADMINISTRATION AND INFRASTRUCTURE

OBJECTIVE	ACTIONS	LEAD/PROCESS AND TARGET DATE(S)	OUTCOME
♣ Improve the accounting system and budgetary monitoring	Network budget - set up accounting for 2004/5 - set up budget statements with Finance - produce end of year statements	MD Statements, BCH Finance - April 2005 - April 2006	Timely, accurate accounts

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COMMUNICATION

OBJECTIVE	ACTIONS	LEAD/PROCESS AND TARGET DATE(S)	OUTCOME
♣ Agree objectives for 2004/6	Meeting of Stakeholders to agree objectives and priorities	AG End June 2004	Meeting 22.06.04. Objectives and work plan agreed for 2004/5/6
♣ To communicate regularly with Stakeholders	Newsletters	Twice yearly newsletter	Newsletter - October 2004 - March 2005 - October 2005
♣ To communicate and liaise with related organisations (GenCag/GTN/ACB)	Updates	Regular updates	Updates for GTN - April 2004 - October 2004 GenCAG - as required for meetings Update for ACB Newsletter – July 2004

**SERVICE PROVISION
Questionnaire**

OBJECTIVE	ACTIONS	LEAD/PROCESS AND TARGET DATE(S)	OUTCOME
To review service provision across Stakeholder laboratories	Present summary to stakeholders: - prepare summary - discuss outcome - agree further actions	AG Stakeholder meeting June 2004	Further action agreed for 2004/5
	Prepare report	AG August 2004	Report circulated to Stakeholders
To progress issues	Engage with GenCAG/DOH Commissioning on needs	AG October 2004	Agreed process/way forward

TRAINING and EDUCATION

OBJECTIVE	ACTIONS	LEAD/PROCESS AND TARGET DATE(S)	OUTCOME
RCPPath	To continue to liaise with the College to provide Qs for MRCPPath examination	Mick Henderson (Lead) Ongoing	
ACB/ACS - Paediatric Metabolic Biochemistry submodality	To monitor registrations	AG ongoing	
HST posts/WDCs	To agree advert, job description, personal specification To advertise and appoint	AG July 2004 AG/Lead Trainer September 2004	HST posts appointed to October 2004
National training strategy	To appoint Lead Trainer To progress 'local' trainer posts	AG June 2004 Lead Trainer/AG July – September 2004	Lead Trainer in post June 2004 Local Trainers in post

SPECIFIC PROJECTS
Working Groups

OBJECTIVE	ACTIONS	LEAD/PROCESS AND TARGET DATES)	OUTCOME
Best practice guidelines	To produce guidelines:- Metabolic autopsy (SUDI) IEM and hydrops IEM and cardiomyopathy postmortem Hypoglycaemia Hyperammonaemia Developmental delay Fits and seizures Prolonged neonatal jaundice Lactic acidosis Rhabdomyolysis	See Appendix for details	IEM and Hydrops on Web (March 2004) IEM and Fits and Seizures on Web (June 2004)
Web Site	To provide a metabolic assay directory (MAD) as part of web site To monitor and keep updated	AG/Janet Stone – November 2003 To pilot MAD July 2004 To launch MAD August 2004 MD	Input completed Pilot completed Launch of site Up-to-date details on site

SPECIFIC PROJECTS
Working Groups contd..

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Molecular based testing	To review needs for IMD and input into Genetic Testing Network	Establish Sub-group (Lead Guy Besley – Manchester) Proposals for new tests to GTN	Effective input into GTN
Workshops:- To agree topics and leads To undertake workshops	Topics for workshops:- Urine organic acids Acyl carnitines Carbohydrate disorders Non-lysosomal enzymes Mitochondrial disorders	Leads and dates advertised on web site	To complete Workshops

QUALITY STANDARDS

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OBJECTIVE	ACTIONS	LEAD/PROCESS AND TARGET DATE(S)	OUTCOME
To provide a focus for quality assurance	To review existing schemes and need for new schemes To review performances of specific schemes as part of an Annual Quality Day	Ying Foo (GOS, London) October 04	Annual Quality Day – 29 th October 2004
Accreditation:- Needs for metabolic biochemistry to be recognised by CPA	To continue dialogue with CPA	AG ongoing	
Audit requirements	To review audit needs	To plan audit initiative - June 04 To summarise audit initiatives by Stakeholders – August 04 To discuss at Stakeholder meeting – November 04	Agreed audit initiative for 2005/6

THE NATIONAL AGENDA

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OBJECTIVE	ACTIONS	LEAD/PROCESS AND TARGET DATE(S)	OUTCOME
Workforce planning	<p>To liaise with professional bodies and input into national discussions</p> <p>To obtain workforce data</p> <p>To prepare Workforce Planning document</p>	<p>Ongoing Lead Lesley Tetlow (Manchester)</p> <p>June 2004</p> <p>June 2004</p>	<p>Completed May 2004</p> <p>Completed May 2004</p>
Agenda for Change National Occupational Standards	<p>To input into national discussions</p> <p>To appoint a small working group</p>	<p>Ongoing To prepare job descriptions for posts – Lesley Tetlow</p>	<p>Attended DOH Workshop - December 2003</p> <p>Working Group formed (Jacqui Calvin, Ying Foo and Lesley Tetlow)</p>
Newborn Screening	<p>To input into national discussions on behalf of Stakeholders</p> <p>To undertake questionnaire with UKNSLN</p>	<p>AG</p> <p>AG</p>	<p>Completed questionnaire May 2004</p> <p>Presentation circulated May 2004</p>

WORKSHOPS

(Training for existing or new staff)

Workshop	Organiser	Date
Urine Organic Acids	Jim Bonham	? 6 th October 2004
Acyl Carnitines	Neil Dalton	T.B.A
Carbohydrate Disorders	Jacqui Calvin	T.B.A.
Non-lysosomal Enzymes	George Gray	2 nd December 2004
Mitochondrial Disorders	Jim Bonham	T.B.A.
Quality Assurance	Ying Foo	29 th October, 2004

BEST PRACTICE GUIDELINES

Guidelines	Lead	Target Date

Metabolic autopsy (SUDI)	Mary Anne Preece	?
IEM and hydrops	George Gray/Mary Anne Preece	Completed – on web site (March 2004)
IEM and cardiomyopathy postmortem	Helena Kemp	?
Hypoglycaemia	Helen Losty	Completed 2 nd draft. With reviewers
Hyperammonaemia	Helen Losty	Completed 2 nd draft. With reviewers
Developmental delay	Peter Galloway	First draft received
Fits and seizures	Mick Henderson	First draft received
Prolonged neonatal jaundice	David Isherwood	?
Lactic acidosis	Jim Bonham	?
Rhabdomyolysis	Jim Bonham/Simon Olphin	2nd draft received. With reviewers