

British Myology Society
First Annual Meeting

2nd – 3rd July 2009

St Anne's College, Oxford

MRC | Centre for Neuromuscular Diseases

Contents

Welcome from the BMS organising Council

Dear Member,
We are delighted to welcome you to this first meeting of the British Myology Society at St Anne's College in Oxford.

The BMS background

The object of the BMS is to act as an independent multidisciplinary professional body of experts to promote the clinical practice, education and advancement of knowledge relating to muscle diseases, myasthenia gravis and spinal muscular atrophy in the British Isles and Ireland. The BMS was established in London in April 2008 and has registered for charitable status. Some rules have been drawn up and are contained in this brochure. 84 colleagues have accepted invitations to be members and we are very pleased that 56 are attending this first meeting in Oxford.

The specific aims of the BMS include:

- Agreeing best practice and standards of care for clinical and diagnostic pathology services
- Agreeing standards for training in clinical myology and clinical muscle pathology
- Promoting translational research
- Establishing clinical networks to improve standards of care and promote registries and clinical trials.
- Facilitating collaborations with patient organisations
- Providing a forum to improve recognition of rare conditions or their complications

Running the BMS

The BMS is a new venture which is untested. It has come together as a result of discussions and some meetings of the colleagues listed at the end of this introduction. At present the secretariat for the BMS is located at and sponsored by the MRC Centre for Neuromuscular diseases in London. The organising group have agreed that initially there will be no subscription to be a member for the BMS. At this meeting we will hold a brief AGM. Since this is a new venture, and we need to assess if it will be useful to colleagues, we considered it reasonable to simply ask colleagues if they are content for the initial organising group to continue to organise the next two meetings and to have a show of hands. If they are content, and the BMS proves to be useful, then elections will be held prior to the second of the two meetings and announced at the second meeting. If colleagues are not content of this arrangement then an email vote will be arranged. It was also considered

reasonable that over the next two years, should members currently in the organising group wish to stand down, expressions of interest will be requested by email and if required an email vote will be undertaken.

This first BMS meeting

Some months ago a questionnaire was sent to all members requesting views on what were considered to be the key current issues/challenges in myology practice. Based on the 45 responses we have devised a programme of interactive sessions which we hope will be of interest and which will stimulate debate. Furthermore, we hope that the conclusions and consensus from the sessions may allow us to develop a plan of work with all partners to start to advance and improve some of these areas.

The key themes that will be covered in interactive sessions include:

Commissioning neuromuscular services
Planning muscle pathology services
Developing networks for clinical practice and clinical trials
Update on UK neuromuscular workshops and clinical trials
Interesting-difficult cases supported by the NCG services.

Finally, we are delighted and honoured that Professor Robert C Griggs, President of the American Academy of Neurology, will be attending this meeting as our guest speaker. Professor Griggs established the North American Muscle Study Group which has successfully facilitated neuromuscular translational research and delivered clinical trials.

We hope you have an enjoyable and stimulating two days in Oxford!

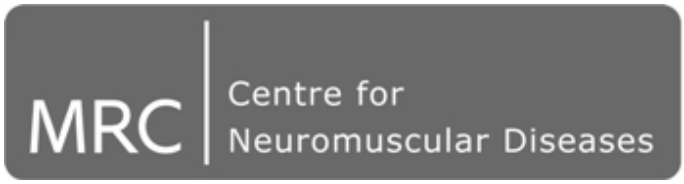
Michael Hanna, David Hilton-Jones, Francesco Muntoni, Kate Bushby,

Doug Turnbull, Janice Holton, Caroline Sewry,

Helen Roper, Mike Rose, Peter Baxter, Doug Wilcox

Professional Academic sponsor

The Secretariat for the BMS has been provided by the MRC Centre for Neuromuscular Diseases.



About the MRC Centre for Neuromuscular Diseases

Genetic and acquired neuromuscular diseases represent an important cause of mortality and morbidity in children and adults. In the UK there is a large gap between major science discoveries and patient benefit in these important disorders. This gap is larger in the UK than in other countries such as Germany, France and the USA who have already moved forward with translational research initiatives. The new MRC Centre aims to reduce this gap by establishing a multidisciplinary translational research activity in these disabling diseases.

This is a joint centre between the UCL Institute of Neurology and the UCL Institute of Child Health, London and the University of Newcastle. The Centre is building on long-established UCL-Newcastle research and clinical links. ***The centre is committed to form reciprocal clinical and research links with other neuromuscular research groups and patient organisations throughout the UK.***

Our mission is to translate basic science findings into clinical trials and new treatments for children and adults with disabling neuromuscular diseases. Current world-class science programmes in London and Newcastle attracting in excess of £20m of grant income underpins the activities of the Centre. The Centre aims to develop new cross-cutting collaborations. We have identified five key areas which we consider to be current obstacles to effective translation of basic science findings into patient benefit. These are: clinical trials support/networks, availability of patient tissues and cells, assessing animal models, applying MRI to humans and animals and developing expertise capacity for the future.

Professional and patient organisation partners

THURSDAY 2nd JULY 2009 - Day 1

16.30 Welcome and Introduction

The BMS and outline of the meeting — Prof Michael Hanna

16.45 UK Neuromuscular services, training and networks

This session will include presentations relating to key areas which influence and impact upon the delivery of neuromuscular services. There will be a brief discussion after each presentation. Full discussion on each topic will be facilitated at the breakout session on Friday morning with the aim of developing actions/ activities that the BMS could pursue with partners.

16.45-17.25	Introduction	Prof Michael Hanna
	Commissioning new services - How it happened in the Southwest	Robert Meadowcroft Rod Walsh Dr Andria Merrison
17.25-18.10	Muscle pathology services in the UK	Dr Janice Holton/ Dr Caroline Sewry
18.10-18.25	Coffee	
18.25-18.45	Training neuromuscular specialists Dr Michael Rose	Prof Kate Bushby/
18.45-19.25	UK nm networks and the BMS-MDC-MRC clinical database initiative	Prof F Muntoni/ Dr A Manzur/ Dr Peter Baxter
	TREAT-NMD - European/global network	Prof Kate Bushby
19.25-19.45	The Scottish Muscle Network Does it work? What can we learn?	Dr Richard Petty
19.45-20.00	Drinks and AGM Prof Michael Hanna/Prof Francesco Muntoni	
20.15	Dinner St Anne's College Professor Robert Griggs AAN President	

FRIDAY 3 JULY 2009 - Day 2

08.00-08.45	Breakfast	
08.45-10.30	**UK Neuromuscular services, training, networks break out discussions**	
09.00-09.45	1. Commissioning led by Hanna/Hilton-Jones 2. Pathology led by Holton/Sewry 3. Training led by Bushby/Turner/Norwood 4. Networks led by Muntoni/Manzur/Wilcox/Baxter	
09.45-10.30	Round table discussion and suggested workplan for BMS	
10.30-11.00	Coffee	
11.00- 12.30	**Interesting adult and paediatric cases supported by NCG services** **Chair: Dr Helen Roper**	
	1. A boy with congenital muscular dystrophy and plectin deficiency	Dr Elizabeth Wraige
	2. A woman with anti-SRP myopathy	Dr Aleks Radunovic
	3. A man with limb girdle weakness and a cardiomyopathy	Dr Matt Parton
	4. A man with muscle pain and contractures	Dr Simon Hammans
	5. A child with a progressive myopathy and cataracts	Dr Heinz Jungbluth
12.30-13.30	Lunch	

13.30-16.30	**Trials and translational research** **Chairs: Prof Michael Hanna / Dr David Hilton-Jones**	
13.30-14.10	UK NM workshops and trials update/Quality of Life in NM disease (Michael Rose)	Prof Michael Hanna
14.10-1450	USA Translational Research & The Muscle Study Group	Prof Robert Griggs
1450-15.15	Coffee	
15.15-16.15	Care standards in DMD	Prof Kate Bushby
16.15-16.30	Next steps and close	Prof Michael Hanna/ Dr David Hilton-Jones

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*Attending the BMS annual meeting

Rules of the BMS

Name

1. The Society shall be called the British Myology Society.

Object

2. The object of the Society is to act as a multidisciplinary professional body of experts to promote the clinical practice, education and advancement of knowledge about muscle disease, myasthenia gravis and spinal muscular atrophy in the British Isles.

This will include:

- Agreeing best practice and standards of care for patients with muscle disease
- Agreeing standards for training in clinical myology and clinical muscle pathology
- Promoting translational research
- Establishing clinical networks to facilitate and promote clinical trials and patient registries
- Facilitating collaborations with patient organisations

Membership

3. The Society shall consist of Ordinary, Associate and Honorary Members.

4. Those appointed to consultant posts, or senior lectureships or equivalent, in the neurological sciences, genetics, paediatrics, physiotherapy, nursing and neurorehabilitation who undertake specialised muscle clinics or pathological examination of biopsy material from muscle shall be eligible for Ordinary Membership.

5. Persons of distinction in Medicine or related paramedical disciplines who have contributed to the advancement of muscle disease shall be eligible for the Honorary Membership. Foreigners of similar distinction shall be eligible for the Honorary Foreign Membership. The number of Honorary Members shall be limited to 10 and of Honorary Foreign Members to 10; they shall be elected by the Society on the recommendation of the Council.

6. All specialist registrars and others pursuing clinical practice or research in muscle disease within the British Isles or the Republic of Ireland shall be eligible for Associate Membership. On appointment to substantive consultant or senior lecturer posts, Associate Members will automatically become Ordinary Members at the next Annual General Meeting.

8. Ordinary members on reaching the age of 65 or on prior retirement from paid employment , shall cease to be Ordinary Members at the next Annual General Meeting, and may become Senior Members, enjoying benefit of membership without payment of subscription.

9. Candidates for Ordinary, Membership shall be nominated by at least two members of the Association in writing to the Honorary Secretary by the time of the last Council Meeting prior to the Annual General Meeting.

10. The Council shall recommend candidates from those nominated as Ordinary or Honorary Members to the Annual General Meeting.

Subscription

11. The annual subscription shall be decided by Council on a yearly basis in the light of the financial situation of the Society and after taking advice from the Treasurer. The subscription shall then be ratified at the next Annual General Meeting of the Association. It shall be paid by Deed of Covenant, or Direct Debit, or Banker's Order.

12. Non-payment of the subscription within twelve months may be considered by Council as equivalent to resignation.

Officers and Councillors

13. The Council shall consist of the Chairman, Honorary Secretary, Honorary Treasurer, and eight council members. All members of Council shall be Ordinary Members of the Society. Officers of the Society shall be elected at the Annual General Meeting. The chairman shall be responsible for organizing a suitable secretariat.

14. Council may co-opt others, without voting rights, to attend its meetings.

15. A quorum of four voting members will be necessary for decisions made by Council to be valid.

16. The Councillors shall hold office for three years following which there will be re-election..In order to avoid a complete change of council members at once a staggered re-election of council members will be agreed.

17. If an Officer or Councillor of the Society be unable to continue in office for any reason the Council
shall have the power to nominate a successor to hold office until the next Annual General Meeting.

Meetings and the Annual General Meeting

18. At least one and usually two or more meetings shall be held each year, one of which shall include the Annual General Meeting. Associate members shall be entitled

to attend these meetings and the Annual General business meetings of the Association as non-voting members. 19. At least two months prior to the meetings the Honorary Assistant Secretary shall send a notice to each member and shall invite communications to be presented at the scientific meetings.

20. At each clinical meeting time there will be time available for members to discuss management and research issues of general interest to the Society. The agenda for these items will be decided by the Council and will generally focus on the main aims of the Society across all muscle diseases.

21. The programme for the Meetings of the Society will be organised by the local organiser in discussion with the Honorary Secretary and Chairman.

22. The programme for each clinical meeting shall be sent by the Honorary Secretary to each member of the Society at least one week before the meeting is held.

23. The agenda for the Annual General Meeting of the Association shall be sent to Ordinary and

Honorary Members by the Honorary Secretary at least one week before the meeting is held.

24. A majority vote of those members present will be required to ratify decisions at the Annual General

Meeting.

Other Rules

24. No alteration shall be made in the rules except at the Annual General Meeting and unless proposed by the Council or by at least ten members in writing. In the latter case, the proposal must reach the Secretary at least four weeks before the date of the meeting. Notice of the proposed change shall be circulated to each member at least one week before the meeting at which it is to be brought forward, and it shall be decided by vote of those present at the meeting.

25. The income and property of the Society, whencesoever derived, shall be applied solely towards the promotion of the objects of the Society as set forth in the Rules, and no portion thereof shall be paid or transferred directly or indirectly, by way of dividend or otherwise howsoever by way of profit to members of the Society. Provided that nothing herein shall prevent the payment, in good faith, of reasonable and proper remuneration to any officer or servant of the Society, or to any member of the Society, in return for any services rendered to the Society.

26. If upon the winding up or dissolution of the Society there remains, after the satisfaction of all its debts and liabilities, any property whatsoever, the same shall not be paid or distributed among the members of the Society, but shall be given or transferred to some other institution having objects similar to the objects of the

Society, and which shall prohibit the distribution of its or their income and property among its or their members to an extent at least as great as is imposed on the Society under or by virtue of the last preceding Rule, such institution or institutions to be determined by the members of the Society at or before the time of dissolution, and if and so far as effect cannot be given to such provisions, then to some charitable object.

27. The Association shall be independent and its views shall not be compromised as a consequence of its relationships with commercial sponsors or any other organisation.

Previous minutes and meetings

Monday 28th April 2008

Present:

Mike Hanna, Francesco Muntoni, Caroline Sewry, Janice Holton, Doug Wilcox, Michael Rose, Helen Roper, Peter Baxter, David Hilton-Jones

Apologies:

Doug Turnbull, Kate Bushby

The following points were agreed:

All people present agreed to the establishing the BMS on the 28th April 2008.

All present agreed to act on the initial council of the BMS.

Mike Hanna will amend the rules of the society to incorporate the provision of staggered re-election of council members.

All present agreed the preferred meeting arrangement was to hold an annual BMS meeting over two days, with an overnight stay. It was anticipated that this meeting would cover a BMS specific agenda including reports from BMS working groups and workshops.

All present agreed to MH amending the rules to correct the error and add consultant paediatricians in the list of eligible people to be members.

It was agreed that the BMS will collaborate with charities and patient organizations but it is very important the society should be an independent professional society.

It was recognised that although there are many scientific and clinical muscle meetings held in the UK, there is currently no forum to address the specific aims of the BMS as outlined in the rules including implementation.

It was agreed that the first annual meeting should be held at the end of March/start of April 2009 to avoid the school half-term breaks, and that Mike Hanna and David Hilton-Jones would look at venue options.

It was agreed the initial secretariat would be provided by the Senior Administrator at the MRC Centre for Neuromuscular Diseases in London.

It was agreed that Mike Hanna would contact the appropriate professional associations to seek affiliation including BPNA, ABN and BSHG.

It was agreed that the BMS would not supplant current muscle meetings. Thus for example the Muscle Interest Group would continue unchanged as a diagnostic forum for paediatric adult muscle disease and the Oxford summer meeting would also continue unchanged. There would be a series of Disease related workshops held by the MRC centre and summaries of key outcomes from such workshops will be made available at the annual BMS meeting (the first workshop on IBM will be held on 13th June 2008). BMS working parties might be set up to tackle specific issues such as agreeing standards of care relating to diagnosis, treatment and training.

It was agreed that the BMS would potentially be a valuable implementation forum for standards of care.

It was agreed the BMS should include all acquired and genetic muscle disease and acquired and genetic myasthenia gravis and spinal muscular atrophy.

It was noted the BPNS addressed all peripheral nerve diseases.

4th July 2008, Worcester College Oxford

Present

Mike Hanna-MH, Helen Roper, Caroline Sewry, Janice Holton, David Hilton-Jones

Apologies

Doug Wilcox, Kate Bushby, Michael Rose-MR, Francesco Muntoni, Peter Baxter, DougTurnbull

Previous meeting minutes

Minutes of the meeting 28th April 2008 London, as updated 18th May 2008 were accepted as a correct record.

Matters arising

Rules adjustments:

MH had updated the Rules as agreed and minuted 28th April.

MH gave a brief update on the recent IBM workshop organized by MH, DHJ, Matt Parton and MR and held in the MRC Centre Queen Square 13 June 2008.

The workshop was attended by 49 colleagues, mainly adult neurologists, interested IBM. There was agreement to establish an IBM database, an IBM DNA bank and natural history studies. Revised clinical and pathological criteria were discussed. A workshop report is in progress. The BMS was discussed and 37 written expressions of interest to join were received on the day.

MH had met with ABN representatives who were supportive of the BMS initiative and agreed to advertise the first annual meeting in ABN newsletter.

Membership of the BMS

It was agreed that this should be an expert professional body that includes ordinary members as outlined in the revised rules.

It was agreed that trainees in myology should be associate members.

It was agreed that the BMS should be an independent professional body.

It was agreed that an annual BMS meeting would take place at which there would be an AGM.

Invitation to be members:

It was agreed that a standard email should be sent to all colleagues potentially interested in being members of the BMS.

This email should be accompanied by the latest version of the rules.

Actions

MH will draft an invitation from council with instructions to reply to Zoe Scott [MRC Centre administrator]. MH will circulate the invitation to all members of the council for approval and so they can invite colleagues who they consider might be interested.

HR will circulate to the MIG members

JH will circulate to members of the RCP who might be interested [neuropathologists]

MH will circulate to all adult neurologists through the ABN, to the BPNS membership and to MDC colleagues.

MH will ask FM to circulate to BPNA members and BSHG members.

All present agreed they would let MH know if there were other groups of colleagues that should be invited.

It was agreed that a subscription would not be requested for the first year.

Replies to the invitations for membership will be collated by Zoë Scott

Annual BMS meeting possible date: 23rd and 24th April 2009

An annual meeting of the BMS over two days with an overnight stay for socialising and networking was agreed as the preferred format.

Broad discussion took place about the content and aims of the annual meeting which would be within the remit of the aims outlined in the rules. DHJ indicated it should be a varied format including service issues, training issues, interesting cases and difficult diagnoses, as well as updates on trials and clinical research. MH and HR suggested that parts of the meeting could be given over to specific topics/mini-workshops.

It was agreed that the BMS meeting should stand alone from science meetings such at the MRC centre annual meeting.

The provisional date set in the previous meeting was agreed ie 23 and 24th April 2009.

It was agreed that costs would be covered by individual attendees.

Action

MH will identify venue in Cambridge. DHJ had obtained details of Clare College and MH will pursue this and other Colleges.

AOB

None

Date of next meeting

It was agreed this should be during the WMS in Newcastle in October 2008. Date to be confirmed.

WMS meeting of BMS council Newcastle 1 October 2008

Present: David Hilton-Jones, Caroline Sewry, Mike Hanna, Helen Roper, Francesco Muntoni.

Apologies: all other council members

Main action point agreed- No availability identified in Cambridge. The first annual BMS meeting would be Oxford on 2nd and 3rd July 2009 and Mike Hanna would take forward the organizational details.

BMS council telephone conference 11 March 2009

All council members called in and programme agreed.

Recent workshops in past 12 months and other regular meetings/groups

IBM Workshop

13th June 2008, NHNN, Queen Square

For more information contact z.scott@ion.ucl.ac.uk

The first UK IBM workshop was supported by the MRC Centre for Neuromuscular Diseases and the new British Myology Society. It was the first in a series of CPD approved practical workshops covering major muscle diseases which it is hoped will engage the clinical and scientific muscle community from throughout the UK, Ireland and beyond. We aimed to invite colleagues who are actively involved any aspect of IBM. The format for each of the workshops will be similar with the following broad aims:

- To establish or build on networks of clinicians, pathologists, geneticists, therapists, clinical nurse specialists, scientists, patient groups and other expert disciplines interested in specific muscle diseases that will work together on a long term basis.

- To agree network activities that are relevant to clinical practice and to which network members can contribute with minimal effort in the course of routine muscle practice.

- Consider current practice regarding diagnostic criteria and treatment and to form a consensus current view from the workshop experts present.

- Update re key current research that has potential for translation into clinical trials and clinical practice.

- Establish disease specific registries and databases held on web accessible server.

- Update re pending natural history studies/ new clinical trials that network members can participate in.

- Publish a summary of the consensus views of the experts present at the workshop in Neuromuscular Disorders.

- Updates re outputs from the workshop at annual BMS meeting and reconvene workshop at agreed intervals.

Planned MRC BMS workshops 2009-2010

Exercise therapy in Neuromuscular Diseases- Newcastle 4/5 Nov 2009

Doug Turnbull, Mike Trenell, Mike Hanna – contact Caroline Hodgson c.hodgson@ncl.ac.uk.

Workshops and other meetings continued

- There is a planned workshop on management of foot deformity in CMT, sponsored by the MDC (will be in September 2009).
  Contacts: Adnan Manzur ManzuA@gosh.nhs.uk and Stephanie Robb RobbS@gosh.nhs.uk

- Muscle Interest Group MIG occurs every 6 months, next meeting 13.11.09 at ICH (previous meeting 7.5.2009 in Leeds), date for 2010 not decided as yet
  Contact: Helen Roper helen.roper@heartofengland.nhs.uk

- Myasthenia Interest Group
  Contact: Marguerite Hill marguerite.hill@swansea-tr.wales.nhs.uk

- Optimal management of children with congenital myopathies
  Contacts: Stephanie Robb RobbS@gosh.nhs.uk and Anita Simonds a.simonds@rbht.nhs.uk

- British Peripheral Nerve Society meets twice a year
  Contact: Mary Reilly m.reilly@ion.ucl.ac.uk

UK Databases/Registries

North Star
Contact: Adnan Manzur ManzuA@gosh.nhs.uk

SmartNet
Contact: Adnan Manzur ManzuA@gosh.nhs.uk

Ibm-NET
Contact: Matt Parton matt.parson@uclh.nhs.uk

Current UK Neuromuscular Clinical Trials

Clinical trials linked to the MRC Centre and supported by different funding agencies including the Medical Research Council, Muscular Dystrophy Campaign, UK Department of Health, National Institutes of Health (USA), Food and Drug Administration (USA), AVI Biopharma and PTC Therapeutics.

Open Trials

RANDOMISED DOUBLE-BLIND PLACEBO CONTROLLED TRIAL OF LONG-TERM ASCORBIC ACID TREATMENT IN CHARCOT-MARIE-TOOTH DISEASE TYPE 1A

Status: Follow-up phase. Closed to recruitment
Sponsor: University College London
Funder: Muscular Dystrophy Campaign (MDC)
PI: Dr. Reilly

Charcot-Marie-Tooth disease 1A (CMT1A) is associated with a duplication of the peripheral myelin protein 22 (PMP22) gene. To date there is no pharmacological treatment for CMT1A patients. Treatments and therapy for CMT is restricted to symptomatic treatments such as physiotherapy and surgery for skeletal deformities.

Recently, treatment with ascorbic acid (AA) has been shown to be effective for transgenic mice over-expressing PMP22, a model of the human disease. Treated animals had much less severe neuropathy as compared to untreated controls as shown by clinical and histological findings. Some clinical parameters even improved during treatment.

This is a phase III prospective, multi-centre, randomised, double-blind, placebo-controlled study aiming to evaluate the efficacy of AA treatment in CMT1A.

The study has been running now almost for two years and it is now in the follow-up phase. Fifty participants were enrolled in the UK site at the National Hospital for Neurology and Neurosurgery.

For information about the study please contact Dr. Matilde Laura at m.laura@ion.ucl.ac.uk.

A PHASE IIb EFFICACY AND SAFETY STUDY OF PTC124 IN SUBJECTS WITH NONSENSE MUTATION-MEDIATED DUCHENNE AND BECKER MUSCULAR DYSTROPHY

Status: Closed to recruitment
Sponsor: PTC Therapeutics
Funder: PTC Therapeutics
PIs: Prof. Muntoni, Prof. Bushby

Duchenne muscular dystrophy (DMD) is an X-linked genetic disorder affecting young boys. The condition is disabling and life-threatening. A small subset of boys are classified as having Becker muscular dystrophy (BMD), a phenotypically milder form of the dystrophic muscle disease.

In approximately10 to 15% of boys with DMD and BMD the causative defect is the presence of a nonsense mutation in the dystrophin gene that truncates dystrophin protein production by introducing a premature stop codon into the dystrophin messenger ribonucleic acid (mRNA).

PTC124 is a novel, orally bioavailable, small-molecule drug that promotes ribosomal read-through of mRNA containing a premature stop codon. Through this mechanism of action, PTC124 has the potential to overcome the genetic defect in boys for whom a nonsense mutation causes DMD/BMD.

In vitro studies in cell lines with dystrophin nonsense mutations have shown that PTC124 can restore production of the missing dystrophin gene.

This is an international, multi-centre, randomised, double-blind, placebo-controlled, dose-ranging, efficacy and safety study.

The study primary aim is to evaluate the effect of PTC124 on ambulation as assessed by the distance walked during a 6-minute walk test (6MWT).

The double-blind arm of the study randomised 174 participants worldwide which are to be followed for a period of 12 months. At the completion of the blinded treatment, all compliant participants will be eligible to receive open-label PTC124 in a separate extension study.

(Ataluren is now the non-proprietary generic name for PTC124).

ANTISENSE OLIGONUCLEOTIDE INDUCED EXON SKIPPING IN DUCHENNE MUSCULAR DYSTROPHY

This initiative is led by the MDEX consortium (The MDEX consortium led by Professor Muntoni, is a multidisciplinary enterprise to promote translational research into muscular dystrophies, and is formed by the clinical groups of Professor Francesco Muntoni (UCL Institute of Child Health) and Professor Kate Bushby and Professor Volker Straub (Newcastle University), and scientists from Imperial College London (Professor Dominic Wells), UCL Institute of Child Health (Dr Jennifer Morgan), Royal Holloway University of London (Professor George Dickson and Dr Ian Graham), Oxford University (Dr Matthew Wood) and University of Western Australia (Prof Steve Wilton). In addition, the charities Muscular Dystrophy Campaign (MDC), Action Duchenne and Duchenne Family Support Group also participate in the Consortium, www.mdex.org.uk).

The current two trials led by the consortium are mentioned below.

RESTORING DYSTROPHIN EXPRESSION IN DUCHENNE MUSCULAR DYSTROPGY: A PHASE I/II CLINICAL TRIAL USING AVI-4658

Status: completed. Closed to recruitment
Sponsor: Imperial College London
Funder: Department of Health (DoH)
PIs: Prof. Muntoni

The primary scope of the trial is to assess efficacy (dystrophin production) and safety of intramuscular administered morpholino oligomer directed against exon 51 (AVI – 4658 PMO).

Antisense therapy with the use of antisense oligomers has the potential to restore effectively the production of dystrophin, the defective protein, in >70% of DMD. This could result in increased life expectancy through improved muscle survival and function. Recent scientific research has demonstrated the potential of this technique to skip mutated dystrophin exons, restore the reading frame and generate functional dystrophin protein. Having demonstrated proof-of-principle in human cell culture and animal model studies, we now intend to determine efficacy and safety of this approach to induce dystrophin exon skipping in children with DMD. This study is aimed at children with Duchenne muscular dystrophy above the age of 10 years with mutations than can be rescued by the skipping of exon 51 [45-50; 47-50; 48-50; 49-50; 50; 52; 52-63].

DOSE-RANGING STUDY OF AVI-4658 TO INDUCE DYSTROPHIN EXPRESSION IN SELECTED DUCHENNE MUSCULAR DYSTROPHY (DMD) PATIENTS – (Systemic study)

Status: Open to recruitment
Sponsor: AVI Biopharma
Funder: Medical Research Council (MRC) and AVI Biopharma
PIs: Prof. Muntoni

This is a safety study of AVI-4658 (a 30-base phosphorodiamidate Morpholino oligomer [PMO]), to skip exon 51 of the dystrophin gene in relevant subjects with DMD.

This is an open-label, two-centre, dose-ranging comparative clinical study of duration twelve weeks.

The objectives of the study are to assess safety and to select the optimum dose that elicits at least 10% *de novo* dystrophin-positive fibres and dystrophin in a sentinel muscle group after an intravenous AVI-4658 dosing regimen.

A total of up to 16 subjects (ambulatory paediatric males, aged ≥5 and ≤15 years of age) will be enrolled in this study, consisting of four treatment cohorts and four subjects per cohort. It is expected that there will be four treatment arms ranging from 0.5 mg/kg to 4 mg/kg. All subjects will receive 12 weekly intravenous infusions of AVI-4658.

Precedent studies have demonstrate that AVI-4658 might have therapeutic relevance in managing DMD for boys whose frame-shifted dystrophin gene lesion could be restored after excision of exon 51 if sufficient drug is translocated into the nucleus of the afflicted muscle cell.

This trial is being conducted in London and Newcastle.

For information on the status of recruitment please contact Gisela Barreto, Trials Coordinator (MRC centre London site) at Gisela.barreto@uclh.nhs.uk or Geoff Bell, Trials Coordinator (MRC centre Newcastle site) at geoff.bell@nuth.nhs.uk.

Planned Trials

HYP HOP: DICHLORPHENAMIDE vs. ACETAZOLAMIDE FOR PERIODIC PARALYSIS

Status: Set-up Phase
Sponsor: University College London (UCL)
Funder: National Institutes of Health (NIH - USA)
PI: Prof. Hanna

This is a phase III trial into Periodic Paralysis planned to start in 2009. This proposal involves a multi-centre, double-blind, placebo-controlled parallel group, nine-week studies comparing the effects of acetazolamide (ACZ) vs dichlorphenamide(DCP) vs placebo in patients with period paralysis (Hyper, Hypokalemic periodic paralysis). The 9-week studies will investigate the prevention of attacks of weakness and it will be followed by 1-year double-blind extensions without placebo to compare the long term effects of DCP vs ACZ on the course of the diseases and on inter-attack weakness. Approximately 40 participants will be recruited from the United Kingdom.

For information on the status of recruitment please contact Dr. James Burge at James.burge@uclh.nhs.uk or Gisela Barreto, Trials Coordinator at Gisela.barreto@uclh.nhs.uk.

THERAPEUTIC TRIAL OF MEXILETINE IN NON-DYSTROPHIC MYOTONIA

Full Title: A Phase II Randomised, Double-Blind, Placebo controlled, Cross-Over Study to Investigate the Efficacy of Mexiletine in Patients with Non-Dystrophic Myotonia

Status: MHRA pending/REC approved
Sponsor: University College London (UCL)
Planned Start date: July 2009
Funder: Food and Drug Administration (FDA – USA)
PI: Prof. Hanna

The non-dystrophic myotonia (NDM) is a group of rare neuromuscular disorders that causes episodes of muscle stiffness (known as myotonias) and paralysis. Predominantly the muscles of the face, hands and legs are affected. In addition to these episodes a permanent and debilitating muscle weakness can develop. The optimal treatment for these disorders is unknown.

Non-dystrophic myotonias are due to abnormalities of ion channels present in skeletal muscle membranes. There is experimental evidence that drugs like mexiletine which block the abnormal function of these ion channels allow the muscle to perform normally.

The study aims to test the efficacy of mexiletine in the treatment of the non-dystrophic myotonias.

This proposal involves a multi-centre, double-blind, placebo-controlled cross over trial of total duration nine weeks.

Approximately fifteen participants will be enrolled in the UK at the National Hospital for Neurology and Neurosurgery.

For information on the status of recruitment please contact Dr. Emma Matthews at e.matthews@ion.ucl.ac.uk or Gisela Barreto, Trials Coordinator at gisela.barreto@uclh.nhs.uk

ARIMOCLOMOL FOR SPORADIC INCLUSION BODY MYOSITIS (IBM)

Full Title: A Randomised, Double-blinded, Placebo-controlled Pilot Study Assessing the Safety and Tolerability of Arimoclomol in Adult Patients with Sporadic Inclusion Body Myositis

Status: MHRA pending/REC approved
Sponsor: University College London (UCL)
Planned start date: July 2009
Funder: Medical Research Council (MRC)
PI: Prof. Hanna

Sporadic Inclusion Body Myositis (IBM) is the commonest acquired disease of muscle affecting people aged 50 years and over. This is a progressive and debilitating disease with both muscle weakness and wasting, characteristically of the quadriceps and finger flexors. Over time the condition can lead to severe disability, falls and swallowing impairment. Affected muscle tissue demonstrates inflammation and degeneration.

Arimoclomol is a new compound which acts by enhancing a normal, inbuilt protective cell reaction to stresses. The products of this response are 'Heat Shock Proteins (HSPs) which counteract processes that end up leading to abnormal protein deposition and to damage mediated by inflammation.

This proposal involves a multi-centre, double-blind, placebo-controlled parallel study of total duration twelve weeks.

This study proposal aims to assess the safety and tolerability of Arimoclomol (100 mg TDS) as compared with placebo over 4 months of treatment in patients with IBM.

Recruitment will take place at the National Hospital for Neurology and Neurosurgery and twelve patients will be enrolled.

For information on the status of recruitment please contact Dr. Adrian Miller at a.miller@ion.ucl.ac.uk or Gisela Barreto, Trials Coordinator at Gisela.barreto@uclh.nhs.uk.

TAPP: THERAPEUTIC TRIAL OF POTASSIUM AND ACETAZOLAMIDE IN ANDERSEN-TAWIL SYNDROME

Status: Set-up Phase
Sponsor: University College London (UCL)
Funder: National Institutes of Health (NIH – USA)
PI: Prof Hanna

Andersen-Tawil Syndrome (ATS) is a rare form of periodic paralysis that is associated with serious heart-rhythm abnormalities. ATS is characterized by a triad of episodic muscle weakness, long-QT syndrome with potentially fatal cardiac dysrhythmias and skeletal developmental anomalies. The underlying cause of this potentially fatal condition is only partly understood and there are no established treatments. Mutations in the KCNJ2 gene encoding Kir2.1, an inward-rectifying potassium channel account for approximately 60% of ATS cases (termed ATS1), the remaining 40% are presumed to have an as yet undetermined gene lesion and are designated ATS2. ATS1 and ATS2 are phenotypically indistinguishable.

The treatment of ATS has been largely anecdotal and empirical.

This proposal involves a multi-centre, placebo-controlled 'n of 1' study design of total duration 45 weeks. The expected total enrolment for this multi-centre study is 16 participants.

The aim of this study is to determine whether potassium supplements and/or acetazolamide alter the duration of muscle weakness and potentially life-threatening heart rhythm abnormalities in patients with ATS.

For information on the status of recruitment please contact Dr. James Burge at James.burge@uclh.nhs.uk or Gisela Barreto, Trials Coordinator at Gisela.barreto@uclh.nhs.uk.

Natural History – Longitudinal Studies

NON-DYSTROPHIC MYOTONIAS: GENOTYPE AND PHENOTYPE CORRELATION AND LONGITUDINAL STUDIES

Status: Closed to recruitment
Sponsor: University College London
Funder: National Institutes of Health (NIH – USA)
PI: Prof. Hanna

This multi-centre project involves a prospective, cross-sectional and longitudinal natural history in non-dystrophic myotonias (NDM).

The aim is to collect standardized data from NDM patients, to include clinical symptoms, exam findings, as well as the results of strength, functional, and electrophysiological testing. Genetic testing will permit precise identification of individual NDM subtype. This information will allow for the identification and implementation of appropriate endpoints in studies of potential treatments.

This is a NIH funded study. Twenty patients were enrolled at the National Hospital for Neurology and Neurosurgery.

For more information about the study please contact Dr. Emma Matthews at e.matthews@ion.ucl.ac.uk.

ANDERSEN-TAWIL SYNDROME: GENOTYPE AND PHENOTYPE CORRELATION AND LONGITUDINAL STUDY

Status: Open to recruitment
Sponsor: University College London
Funder: National Institutes of Health (NIH – USA)
PI: Prof. Hanna

Andersen-Tawil syndrome is a neuromuscular disorder caused by a mutation in the KCNJ2 gene which codes for the inwardly rectifying potassium channel Kir2.1. A number of different mutations in this gene have already been identified in affected individuals. This disorder is characterised by the triad of periodic paralysis, developmental abnormalities and cardiac arrhythmias.

This project is a natural history trial into Andersen-Tawil Syndrome. The aim of the trial is to study the relationship between the genetic abnormalities underlying the disorder and the diverse clinical features.

Eight patients have been enrolled so far at the National Hospital for Neurology and Neurosurgery.

For information on the status of recruitment please contact Dr. Sanjeev Rajakulendran at s.rajakulendran@ion.ucl.ac.uk.

Exercise Studies

STRENGTHENING HIP MUSCLES TO IMPROVE WALKING DISTANCE IN PEOPLE WITH CHARCOT- MARIE-TOOTH DISEASE

Status: REC Approved. Open to recruitment
Sponsor: University College London Hospitals
Funder: Muscular Dystrophy Campaign (MDC)
PI: Dr. Reilly

Charcot-Marie-Tooth (CMT) disease is a form of hereditary peripheral neuropathy.

People with CMT present with weakness, wasting and sensory loss as a result of degeneration of the long peripheral nerves supplying the distal muscles.

The aim of this study will be to investigate the efficacy of a 16 week home based programme of training to increase hip flexor muscle strength and walking endurance. Additional measures of gait speed, exertion, fatigue, disability and general activity will also be recorded. Baseline impairment measures will be obtained to ascertain predictors of strength gains.

This study will use a single blinded, randomised cross over design to investigate if training the hip flexor muscles will strengthen the hip flexor muscle and improve walking endurance in people with all types of CMT.

The trial will included people, aged between 18 and 70 years, who have been diagnosed with CMT on the basis of genetic tests (where possible), family history and neurophysiology testing. Each subject will be involved with the study for a 40 week period.

For information about recruitment contact Alex Pollard, Research Physiotherapist at a.pollard@ion.ucl.ac.uk.

EXERCISE TRAINING IN PATIENTS WITH MITOCHONDRIAL DISEASE: ASSESSING THE BENEFITS

Status: Recruiting
Sponsor: University Newcastle
Funder: Muscular Dystrophy Campaign (MDC)
PI: Prof. Turnbull

Mitochondrial myopathies are a very important group of muscle diseases associated with weakness, pain and fatigue. At present, treatment options are very limited.

Exercise therapy has been found to have some benefit in this group of patients and we wish to explore this further in terms of both strength and endurance.

The aim of this study is to demonstrate that strength exercise training is an effective approach to therapy in certain patients with mitochondrial myopathy, specifically those with sporadic mutations in mitochondrial DNA. Based on our previous research studies, we believe that such training will improve muscle strength, mitochondrial function, exercise tolerance and overall quality of life.

The main objectives will be:

To confirm that endurance training in patients with mitochondrial abnormalities improves quality of life, exercise tolerance and oxidative capacity.

To determine the ability of resistance muscle strength training to improve skeletal muscle strength and oxidative capacity by incorporation of satellite cells into mature myofibres.

Participants are expected to commit to an exercise training and testing over a period of 4 to 8 months.

The study will include patients between the ages of 18 and 65 years who have had a previous muscle biopsy showing a defect in skeletal muscle mitochondrial DNA that is either in the form of a sporadic point mutation or single large-scale deletion. Patients who have this type of mutation and do not have any family members that are affected and have no major cardiac involvement, hypertension, pulmonary or peripheral vascular disease that may complicate findings.

For information about recruitment contact Geoff Bell at geoff.bell@nuth.nhs.uk or Caroline Hodgson at c.hodgson@ncl.ac.uk.

Future Meetings

Provisional date of MRC Centre for Neuromuscular Diseases / MDC UK translational Research conference Annual Meeting 2010:
Thursday 25th – Friday 26th March
Provisional venue Oxford.

Date of BMS Annual Meeting 2010: tbc

MRC BMS and other Workshops
See earlier

UK Neuromuscular services, training, networks, 9 – 9.45am Friday 3rd July
Breakout groups:

Commissioning led by Michael Hanna / David Hilton-Jones
Helen Roper
Wojtek Rakowicz
Ros Quinlivan
Max Damian
Louise Hartley
Robert Meadowcroft
Charlotte Brierley
Mark Roberts
Andria Merrison
Mark Rogers
Lucy Feng
Rod Walsh

Pathology led by Janice Holton / Caroline Sewry
Tom Jacques
David Hilton
Roger Malcomson
Russell Lane
Liz Curtis
Michael Farrell
Rita Barresi
Jacob Joseph
Kelvin Poulton
Waney Squier
Marinos Dalakas
Richard Charlton

Training led by Kate Bushby / Chris Turner / Fiona Norwood
Richard Orrell
Cathy White
Simon Hammans
Nick Gutowski
Cheryl Longman
Heinz Jungbluth
Emma Matthews
Yvette Easthope-Mowatt
Maria Farrugia
Jane Fenton-May
Jon Walters
Elizabeth Wraige

Networks led by Francesco Muntoni / Adnan Manzur / Peter Baxter

Berch Griggs
Peter Baxter
Aleks Radunovic
Matt Parton
Gabriel Chow
Richard Petty
Angus Clarke
Margaret Phillips
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http://www.cnmd.ac.uk/British_Myology_Society

RCP and RCPCH CPD approval has been applied for

BMS 2009 Conference brochure prepared by
Mike Hanna and Zoë Scott
MRC Centre for Neuromuscular Diseases, UCL London.