

MDSG

14th Annual Conference 2003

Learning and



Sharing Together

4th International Conference

IDMC4

Advisors

We give grateful thanks to the Medical Advisors of the Myotonic Dystrophy Support Group

Prof. J. David Brook

Director of the Institute of Genetics, Nottingham

Prof. Peter Harper

Professor and Consultant in Medical Genetics, University Hospital of Wales, Cardiff

Dr David Hilton-Jones

Consultant Neurologist, Radcliffe Infirmary, Oxford

Dr Margaret Phillips

Consultant in Rehabilitation Medicine, Derby City General Hospital

Dr Mark Rogers

Senior Lecturer, Medical Genetics Department, University Hospital of Wales, Cardiff

Dr Ian Bowler

Consultant Anaesthetist, Cardiff

Dr Marion Hamshere

Lecturer in Life and Environmental Sciences.
(Web site facilitation)

Dr Alison & Dr Douglas Wilcox

Scottish Muscle Centre, Glasgow

IDMC4

4th International Myotonic Dystrophy Consortium Meeting

Thursday 10th to Saturday 12th April 2003 – Glasgow

**Are you wondering why we have moved the Myotonic Dystrophy
Support Group Annual Conference from June to April?**

The answer is to share with the IDMC

The International Myotonic Dystrophy Consortium is an informal group of individuals with a shared interest in understanding all aspects of Myotonic Dystrophy with the long-term aim of providing improved treatments for affected patients. In order to discuss all the latest developments in the field, the IDMC organises biannual meetings. The next meeting, IDMC4, will be held at the University of Glasgow from Thursday 10th to Saturday 12th April 2003. If you have an interest in any facet of Myotonic Dystrophy research, please plan to attend. Subjects that will be covered will include all aspects of the clinical presentation and the molecular biology of the disease process. In addition to the scientific discussions, the meeting will overlap with the UK Myotonic Dystrophy Support Groups Annual General Meeting providing the opportunity for increased interaction between clinicians and scientists and patients and families.

The Myotonic Dystrophy Support Group feel very privileged to be invited to join the Researchers Conference. IDMC4 is the first time families have been invited to join this Conference of World Wide Colleagues who are working to find a cure for Myotonic Dystrophy.

I am pleased you are going to be part of this new experience.

We will benefit from meeting each other.

Margaret Bowler

Information about Conference Speakers

Patron - Professor J. David Brook

*Professor of Human Molecular Genetics,
University of Nottingham.*

Prior to this appointment, Prof. Brook had a Post doctoral research position in Massachusetts USA, and Cardiff, and came to Nottingham in 1992 as Senior Lecturer in Molecular Genetics. David was instrumental in isolating the gene that causes Myotonic Dystrophy. Prof J. David Brook is Patron of the Myotonic Dystrophy Support Group.

Dr Maxine Power PhD, MRCSALT

*Senior Lecturer/ Speech Language Therapist at
Department of Gastrointestinal Science,
University of Manchester.*

I am Speech and Language Therapist with a particular interest in swallowing and its disorders. My research interest is in defining the features of 'normal' swallowing using a range of assessment techniques, e.g. video fluoroscopy. In particular I am interested in the relationship between bolus flow through the pharynx and its relationship with airway closure.

I have used the information gained from my studies in health to determine key abnormalities in a range of clinical conditions. I am currently participating in a research protocol to identify the key swallowing abnormalities in patients with Myotonic Dystrophy.

Dr Jane Fenton-May

Jane is co-ordinator for the Wales Muscle Network, which links services and personnel involved with muscle disorders across Wales.

The Network is co-ordinated by Professor Mark Wiles (Professor of Neurology) funded by the Muscular Dystrophy Campaign. Dr Fenton-May is also part of the Cardiff Muscle Clinic team and has extensive experience of Myotonic Dystrophy, including cardiac aspects.

Other speakers at IDMC4 include **Shannon Lord, Jacqueline Donachie, Tetsuo Ashizawa** and our very own **Margaret Bowler.**

Please Note!

No video recording allowed
during the conference

Programme

Friday 11 April

- 8.00pm to Ceilidh at Grosvenor Hotel
11pm We are invited to join the international delegates to IDMC4 as they enjoy a special social evening 'Scottish style'.

Saturday 12 April

- 9.30 am Welcome to Glasgow - **Margaret Neil**, Aberdeen
- 9.35 Welcome to the Conference - **Margaret Bowler**, Nat. Co-ord. MDSG
- 9.45 Annual General Meeting - chair **Prof. David J Brook**, Patron
- 10.15 Speaker - **Dr. Maxine Power**, Hope Hospital, Salford
Swallowing Disorders
- 10.45 Comfort break, Tea/Coffee
- 11.15 Speaker - **Dr Jane Fenton-May**, Clinical Assistant Cardiff Muscle Clinic. General questions about Myotonic Dystrophy
- 11.45 Morning session closes
- 12.00 noon Travel to **Western Infirmary Lecture Theatre** for lunch
prompt with IDMC delegates
- 12.30pm Lunch
- Afternoon session chaired by **Darren Monckton**
- 2.00 My family has Myotonic Dystrophy - **Shannon Lord**
- 2.20 Recent scientific advances in Myotonic Dystrophy - **David Brook**
- 2.40 Living with Myotonic Dystrophy - **Margaret Bowler**
- 3.00 Tea/coffee
- 3.40 Science, art and Myotonic Dystrophy - **Jacqueline Donachie**
- 4.00 Towards treatments for Myotonic Dystrophy - **Tetsuo Ashizawa**
- 4.30 Close
- 7.00 Civic Reception at **Kelvingrove Art Gallery**
- 8.00 Scottish Buffet at **Kelvingrove Art Gallery**

Venue

The conference is held at the Holiday Inn Hotel (Glasgow City West)
Bothwell Street Glasgow. Tel.No: 0870 400 9032,
E-mail: glasgowcity@gc.com on 12 April

Accommodation

The accommodation will be paid for by the Myotonic Dystrophy Support Group only if you are a member. (A member is an individual or couple who live at the same address and who have paid their MDSG subscription for 2003)

People who live near the venue please sleep at home.



Travel on the Day

Arrangements for travel from the Hotel to the Western Infirmary Lecture Theatre will be arranged. If you need wheelchair transport please telephone **Margaret Bowler** on **0115 987 5869**.

Travel back to the Hotel after the conference will also be arranged.

If you are going to the Civic Reception at Kelvingrove Hall return transport will be provided.



M.D.S.G. Logo

The logo was designed by an acquaintance in Nottingham. It shows a hand, chosen to represent a clenched fist. Anyone with Myotonic Dystrophy will know that medical students will be encouraged to shake the patients hand. The handgrip is an aid in clinical diagnosis as it demonstrates the myotonia. The lines of the D are the "fingers", with the "thumb" at the top.





Website

The website has been upgraded and made a friendly interactive site. Grateful thanks to **Vicki Lacey** and **Dr Marion Hamshere** both at Nottingham University for their work on the web site.

Childcare

Childcare will be arranged at both venues, further information on the day. Please complete registration form. Young adults will join in the main conference this year.

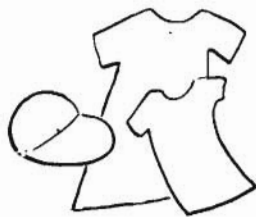


Bring and Buy table

We are asking all delegates to contribute a small gift that someone else may like to buy. Perhaps it could be from the geographical area where you live. Please make your contribution of a gift to be reasonably priced and not too large. All proceeds will go towards Research into Myotonic Dystrophy.

For Sale

Our sweat shirts, polo shirts and baseball caps are selling well. They are very good quality and reasonably priced, and the support group still makes a small profit from the sales. Order forms will be provided. Pens, and badges will also be on sale



Refreshments

If you are staying at the Holiday Inn Hotel Friday 11th and Saturday 12th, breakfast is included, paid for by Myotonic Dystrophy Support Group.

All light refreshments and lunch are included on the Conference day.



Collection Boxes

Please empty your boxes and any film cases and bring a cheque to give to Julie Murray. Thank you.

Information Stall

Members of the Support Group will be available to advise and answer any queries you may have. Our literature, including Care Card and Alert Card can be found here.



On the 7th January 1999 the Myotonic Dystrophy Group became a registered charity No. 1073211.

This status helps us to increase awareness of the condition of Myotonic Dystrophy.

The important people in the Support Group are the families who have Myotonic Dystrophy.

The Support Group has a reputation of friendliness and warmth along with professionalism. Our desire is to continue in this way in the future.

The Support Group Helpline Telephone No: 0115 987 0080 – Office: 0115 987 5869 – Fax: 0115 987 6462
– Web site: mdsguk.org – E-mail: mdsg@tesco.net

We say thank you to Dr Marion Hamshere and Vicki Lacey, who have redesigned the new, interactive web site.

Our new office is 35a, Carlton Hill, Carlton, Notts, and is above the Nottingham Offshore Marine shop. Many thanks to June, Averil and Jenny for their help in the office and Elizabeth our Treasurer.

Many thanks to the Trustees and Contact persons for all they have done during the year. Thank you to our Patron, Prof. J. David Brook, and the Advisors, Speakers and Volunteers. We look forward to the coming year with expectancy! Thank you.

Acknowledgements

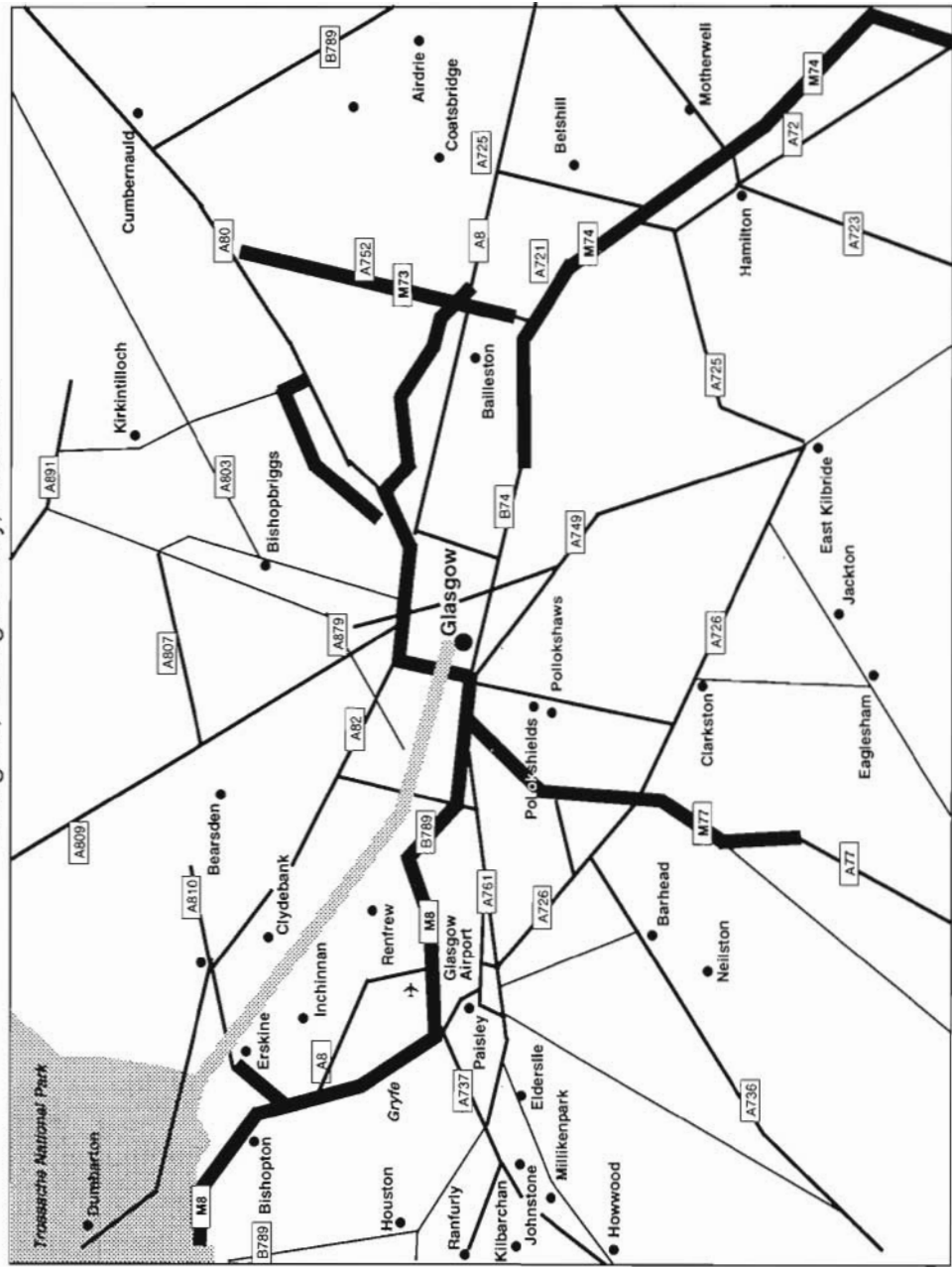
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Dr Alison and Dr Douglas Wilcox
Mike Brackpool MDC

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