



Society for
Mucopolysaccharide
Diseases

PROGRAMME

All Ireland
MPS and Fabry Conference

14-16 May 2010
Hilton Templepatrick

All Ireland MPS and Fabry Conference

The two conferences, one on Mucopolysaccharide diseases and the other focussing on Fabry disease, offer individuals, parents, partners, carers and professionals the opportunity to hear state of the art talks on the clinical management of those affected by MPS and Fabry and members' personal experiences, as well as finding out more about the latest research developments and current and future therapies.

The conference programme offers the opportunity to meet and talk informally with professionals, and for individuals, parents, partners and carers to share their own experiences with others.

Children and Vulnerable Adults Programme

As no children under 18 years are permitted into the conference, the Society has made alternative childcare arrangements for the care of children and vulnerable adults so you can attend the conference in a relaxed manner knowing your children are safely cared for and entertained.

Children suffering with MPS and Fabry disease and their siblings aged 17 and under will have their own social programme. This programme will also accommodate young adults who are unable to benefit due to their neurological disease from the conference programme. Whatever the age or ability of your children the social programme will allow them to have fun whilst giving them the opportunity to be with others in similar circumstances.

Volunteers will be at the conference on Friday evening to meet individuals they will be supporting. The volunteers will then be available throughout Saturday to support the children's programme. Each volunteer has completed an application, two references and undergone a CRB check. Each volunteer is allocated a child/children or vulnerable adult and given all the information needed about the individual's needs. All parents/carers will be consulted over their child/children's needs and a care plan drawn up where needed. Volunteers receive training on moving and handling, advice on child protection, the safeguarding of vulnerable adults and the Society's policy on Volunteer Conduct and are informed about the importance of respect, encouraging independence and managing challenging behaviour.

The crèche is located in the Hilton Templepatrick meeting rooms and is run by volunteers who care for the under 3s and those affected by MPS diseases whose care needs mean they are unable to participate in the outings or conference. It is therefore likely that there will be a wide age gap in the crèche with a wide range of ability and needs. The crèche is equipped with mattresses, toys, television and a hoist for moving and handling.

Childcare volunteers will be allocated on a first come, first served basis. If your child has complex healthcare needs please contact us before booking to discuss needs and resources required. We will endeavour to meet the needs of all children and vulnerable adults and we will try to provide a qualified paediatric nurse to provide medical support. However, this cannot be guaranteed. Please also note that the care provided within the creche is limited due to the limitations of the hotel. It is therefore important that if your child requires qualified nursing support, that you make us aware of this as soon as possible. In discussion with parents, the Society will advise whether or not an MPS sufferer with complex care needs can participate in the outings or whether they should remain in the crèche.

Evening Children's and Vulnerable Adult Care and Entertainment

Volunteers will be providing care on the Saturday evening to allow parents to attend the gala dinner. Please note that at this stage we cannot guarantee we will be able to provide care in individual bedrooms and we may have to provide some form of entertainment within the hotel.

The Venue

The conference is the Hilton Hotel Templepatrick, which is an open plan, spacious hotel. The hotel is ideally located just off Antrim Road on the Castle Upon Estate. It is set in wooded parkland, 15 minutes from Belfast International Airport and 20 minutes from Belfast city centre. **The bedrooms are spread over two levels and the ground floor bedrooms will be allocated on a first come first serve basis, with priority for ground floor access given to the more severely disabled.** The bedrooms at the hotel can take between 2 and 5 people per room.

The hotel benefits from its own golf course as well as an indoor, heated swimming pool and Livingwell Health Club consisting of Sauna, Steam Room and Spa. Guests arriving on the Friday will be able to use the hotel facilities, however bedrooms are not guaranteed to be ready until 3pm.

Hilton Templepatrick

Castle Upton Estate
Templepatrick
County Antrim
Northern Ireland
BT39 0DD
Tel: 028 9443 5500
www.hilton.com

Deadline for bookings

Friday 9 April 2010

Please note that the above deadline will apply to all MPS Society members with the exception of new members and families that have just recently joined the Society's membership.

Friday 14 May 2010: MPS Conference

- 15.00 Registration
- 17.30 Family Social Get Together including hot buffet dinner
for all family members with children's entertainment

Saturday 15 May 2010: MPS Conference

Chairs: Fiona Stewart and Eileen Treacy

- 9.30 Welcome and Introduction: Fiona Stewart & Eileen Treacy
- 9.45 Clinical Management and Treatment Options for Sanfilippo and Morquio Disease: Simon Jones
- 10.05 We are Living with Sanfilippo Disease: Naomi Shannon
- 10.15 Clinical Management and Treatment for Hunter Disease: Chris Hendriksz
- 10.30 Our Son has Hunter Disease: Ger Smyth and David Renton
- 10.40 The Dublin Outcome Experience of Bone Marrow Transplant for MPS I Hurler Disease: Anne O'Meara
- 11.00 COFFEE**
- 11.20 MPS I Hurler Scheie, Scheie and Maroteaux-Lamy Disease
- Clinical Management and Treatment Outcomes: Simon Jones
- 11.40 Mucopolidosis and the Rarest of the Rare: Gillian Rae
- 12.00 Orthopaedic Approaches in Managing Carpal Tunnel, Knees and Hips in MPS Diseases:
Speaker (tbc)
- 12.20 The Challenge of Patient Access to New and Emerging Therapies for MPS Diseases:
Fiona Stewart & Eileen Treacy
- 12.45 LUNCH**
- Chair: Simon Jones**
- 14.00 Managing the Eyes in MPS Patients: Colin Willoughby
- 14.20 Surgical Management of the Cervical Spine and Clinical Outcomes: Richard Cowie (tbc)
- 14.40 Neuropsychology Difficulties and Developmental Testing in the MPS Diseases: Richard Ziegler
- 15.00 The Importance of a Multi-Disciplinary Approach in Managing Children and Adults with MPS:
Joanne Hughes
- 15.15 Transitioning from Paediatric to Adult Health and Social Care: Sophie Thomas
- 15.30 Living with Morquio Disease - the Challenges: Elena McGauran & June Elliott
- 15.40 Emerging Therapies for MPS Diseases: Brian Bigger
- 16.00 Questions and Answers

Saturday 15 May 2010: Fabry Conference

Chair: Atul Mehta

- 10.00 Welcome and Introduction: Atul Mehta
- 10.10 Clinical Management, Treatment Options and Clinical Trials in Fabry Disease: Atul Mehta
- 10.40 The Eye in Fabry Disease: Colin Willoughby
- 11.00 Early Indications of Disease in the Kidney and the Clinical Management: Stephen Waldek
- 11.20 COFFEE**
- 11.40 What do we Understand about the Heart in Fabry disease?: Pascal McKeown (tbc)
- 12.00 Early CNS Indicators in Fabry disease: Lionel Ginsberg (tbc)
- 12.30 LUNCH**
- 13.30 Current Experiences of ERT in Children and the Role of Early Intervention:
Uma Ramaswami
- 13.50 Advocating for Individuals with Fabry Disease: Sophie Thomas
- 14.10 Our Child is on ERT for Fabry Disease: Family Speaker (tbc)
- 14.20 Genetic Counselling for Fabry Disease: Aoife Bradley
- 14.50 Fabry Disease in our Family: The Delargy Family in Conversation with Fiona Stewart
- 15.00 What can we learn from the Fabry Outcome Survey and the Fabry Registry?:
Atul Mehta and Stephen Waldek
- 15.30 Questions and Answers
- 15.40 FINISH**

Sunday 16 May 2010

- 9.30 Ecumenical Service
- 10-12 MPS type and Fabry break out sessions with coffee
- 12.00 FINISH**

Republic of Ireland Resident MPS Society Family Registration

Surname	First Name	Conference MPS or Fabry	Special Dietary Requirements	Wheelchair (Tick)	DOB If under 17	MPS type

ACCOMMODATION

The MPS Society has subsidised the prices below for MPS members based on a maximum of two adults. Additional adults are welcome at a charge of €270. Please see professional and additional adults registration.

Family rooms accommodate a maximum of five persons per room and comprise of two double beds and one single foldaway bed. The family price is for two adults, MPS sufferers and siblings under 18 years of age.

Single room comprises of an adult/MPS member 18+. Single rooms can only be offered at this price to those members attending the weekend alone and cannot be offered to additional adults who are accompanying other family members. Please see professionals and additional adults registration for additional room rates.

Double/twin room a double room comprises one double bed and a twin room comprises of two beds. (Maximum two persons, must include one adult).

If you are unsure or this doesn't fit your requirements, please contact MPS before completing your form.

RESIDENTIAL* WEEKEND PACKAGES

Single €110 Double €157 Twin €157 Family €180

*Residential weekend comprises Friday and Saturday night accommodation, Saturday breakfast and lunch, Saturday gala dinner, Sunday breakfast and lunch and Saturday conference and Sunday ecumenical service and break out sessions.

SATURDAY CONFERENCE ONLY

MPS/Fabry Sufferer 18+ €17
 Adult €34

SATURDAY CONFERENCE & GALA DINNER

does not include accommodation €68

Please note that the Saturday conference is for adults only.
 We are unable to accommodate non-resident children on the childcare programme.

Additional information/comments to assist us with your booking.

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Methods of Payment

Please tick one of the boxes below to indicate which method of payment you wish to use.

- Pay the full amount by cheque or credit card when sending in the booking form.
- Send in the minimum deposit of €40 with the booking form, and then pay the rest of the amount owed in a lump sum no later than **Friday 9 April 2010**.

AMOUNT ENCLOSED (Minimum deposit €40): €

BALANCE TO PAY BEFORE FRIDAY 9 APRIL 2010: €

Payment Details

Payment by cheque, bank draft or postal/money order

Address Details

Name

Address

Post Code

Telephone

Email

Professionals and Additional Adults Registration

Name/s	<input type="text"/>	
Organisation	<input type="text"/>	
Address	<input type="text"/>	
	<input type="text"/>	
Telephone	<input type="text"/>	Fax <input type="text"/>
Email	<input type="text"/>	

Residential Weekend Packages

Friday to Sunday: Package comprises Friday evening buffet dinner, Friday night accommodation, Saturday breakfast, lunch and evening Gala Dinner, Saturday conference and Sunday ecumenical service.

Price is per person

Single occupancy

€337

Friday to Saturday: Package comprises Friday evening buffet dinner, Friday night accommodation, Saturday breakfast, lunch and Saturday conference. If you want to book for the Saturday Gala Dinner please do so below.

Price is per person

Single occupancy

€152

Saturday Gala Dinner €51

Non-Residential Conference Options	
	MPS or Fabry
Saturday Conference Only (including lunch)	€73 <input type="text"/> <input type="text"/>
Saturday Conference Only (including lunch and Gala Dinner)	€112 <input type="text"/> <input type="text"/>

Special Dietary Requirements..
Any other requirements...

TOTAL AMOUNT DUE: €

Payment Details

Payment by cheque, bank draft or postal/money order

Please Invoice Hospital or Institution (Please Tick)

Name	<input type="text"/>	Organisation	<input type="text"/>
Address	<input type="text"/>		
	<input type="text"/>		
Telephone	<input type="text"/>	Email	<input type="text"/>

Completed forms with payment to:

David Hackett, 20 Wrenville, Pipers Cross, Carrigaline, Co. Cork or Mary Elliott, Grangegeeth, Slane, Co. Meath

Join our Awareness Day Celebrations!

Book your place at the Conference and join the celebrations for MPS Awareness Day at the Gala Dinner on Saturday evening. The children will be celebrating with a party and Grand Balloon Release!

MPS Awareness Day

15 May 2010

One baby every eight days in the UK will be born with an MPS or related disease

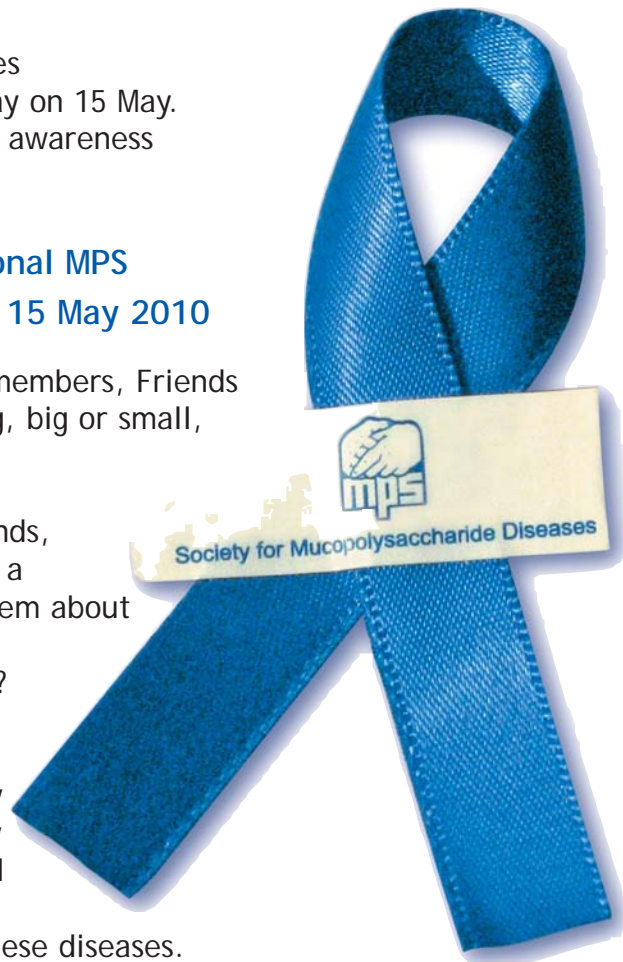
Each year the Society celebrates International MPS Awareness Day on 15 May. This is a day devoted to raising awareness of MPS and Related Diseases

Help us celebrate International MPS Awareness Day on Saturday 15 May 2010

This year we're asking all our members, Friends and supporters to do something, big or small, to mark MPS Awareness Day

Does your workplace, your friends, relatives or neighbours support a chosen charity? Why not tell them about MPS? Or perhaps you'd like to organise a fundraising event? Look inside for some ideas

Use MPS Awareness Day, 15 May 2010 to tell everyone you know about MPS and spread the word that we are working hard to support those affected by these diseases. Let us know how you're planning to celebrate MPS Awareness Day, maybe we can help...



www.mpsociety.co.uk