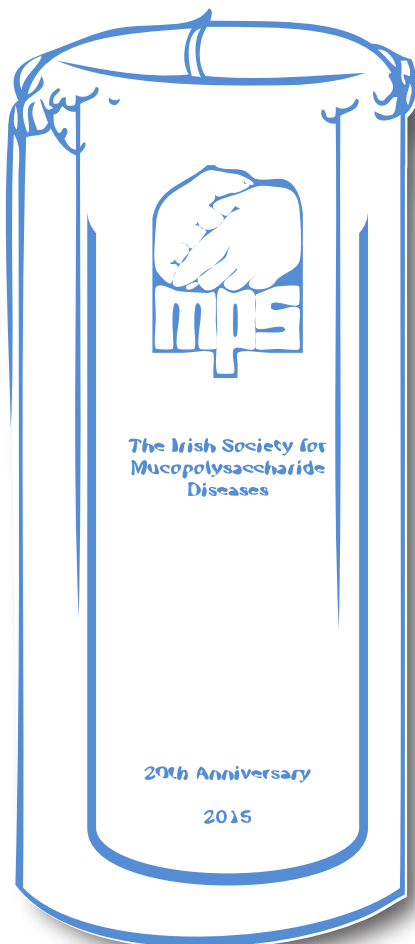




Irish Society
for
Mucopolysaccharide
Diseases

All Ireland Conference
11th – 12th September 2015

Celebrating 20 Years



Clarion Hotel,
Liffey Valley
Dublin 22



ALL IRELAND MPS CONFERENCE

11/12TH SEPTEMBER 2015
CLARION HOTEL, LIFFEY VALLEY

THIS CONFERENCE offers adults, parents, partners, carers and professionals the opportunity to hear state of the art talks on the clinical management of those affected by MPS diseases. As well as learning about the latest research developments, and current and future therapies we will have members share their personal experiences.

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 ;

As no children under 18 years or young adults who are unable to benefit due to their neurological disease are permitted into the conference we have made alternative arrangements for children and vulnerable adults. All parents and carers will be consulted over their child/children's needs. In house entertainment will be supplied while the conference is in progress

We would encourage you to please bring a family member or your regular carer with whom your child is familiar. Alternatively we will supply a volunteer but as there is a very limited number available they will be allocated on a first come first served basis.

THE FOUR STAR CLARION HOTEL LIFFEY VALLEY is located just off M50/N4 intersection at Liffey Valley. Secure car parking is available for all guests. Free WiFi is available throughout the hotel SanoVitae Health & Fitness Spa facilities include 20m heated indoor swimming pool, children's play pool, sauna, steam room Jacuzzi and gym.

20 YEAR HISTORY OF THE IRISH MPS SOCIETY

The Irish Society for Mucopolysaccharide Diseases, founded in 1995, is a voluntary support group and registered charity. It is managed by the members themselves and supported by voluntary donations with fundraising by the members.

The Society supports thirteen different diseases:

Hurler	MPS 1H	Hurler Scheie	MPS 1HS
Scheie	MPS 1S	Hunter	MPS 11
Sanfilippo	MPS 111	Morquio	MPS 1V
Maroteaux Lamy	MPS V1	Sly	MPS V11
Natowicz	MPS 1X	Mucopolidoses	ML 1, 11, 111, 1V

These are ultra rare metabolic diseases which are referred to as MPS I- IX or more commonly by the name of the doctor who first described the condition.

They are multi-organ storage diseases which cause progressive physical disability and in many cases neurological deterioration and can result in death in childhood.

There are about sixty-five people living with a MPS disease today in Ireland.

At present there is no cure for MPS and related diseases but much can be done to improve the care and treatment of sufferers. Bone marrow transplant and enzyme replacement therapies are now available for some of the diseases but even with this treatment, there are still significant problems remaining requiring ongoing management.

The Society operates a network of area families, offering support and links to families. We offer an information service to assist contact and co-operation between parents and professionals and develop and maintain links with sister societies in Europe and world-wide.

We advise on benefits, education and housing. Thanks to the U.K. MPS Society we have benefitted in recent years from the appointment of an All Ireland Advocacy Support Officer.

We support an annual four day clinic divided between Our Lady's Hospital for Sick Children, Crumlin, Temple Street Children's University Hospital and Mater Misericordiae University Hospital.

Annual events include a family weekend break on the May Bank holiday in Clarenbridge , Christmas parties and a Memorial Day to remember our beloved departed family members. The latter is held at Belvedere House & Gardens, Mullingar where we have an inscribed limestone table and seat. We also have a number of oak trees planted in memory of our loved ones.

We make substantial monetary donations to research projects in the U.K.

We partially fund families attending International Parent and Medical Conferences. We also fund delegates to attend The International Network Meetings.

We produce an annual Review aptly named "Dréimire an Dóchais" which means "Ladder of Hope".

For many of us times are tight, things are tough, we see it in our own lives and livelihood. Yet in the midst of dramatic changes which we have experienced there are some aspects that remain constant – the need for community, for coming together and sharing, for experiencing certain things as a group rather than as individuals.

One day seminars or a weekend conference is one of those great parts of life which allows us to do this. Our committee have worked very hard to provide families and professionals with this opportunity - to experience together the excellence of first rate speakers giving first rate presentations. Thus we sincerely hope that each of you will enjoy and benefit from this conference which we are proud to present.

For a number of years now we have been celebrating “**International MPS Day**” on May 15th where societies worldwide focus on increasing awareness and raising vital funds for research to progress the search for treatments for all the MPS and ML diseases.

As this is the twentieth anniversary of the founding of our society we are delighted that we have been invited to Áras an Uachtaráin on this special day.

The slogan of our society is:

“Care today – Hope tomorrow”

Committee Officers

Tony Woods	Chairperson
Martin Lynch	Vice Chairperson
Mary McGauran	Hon Secretary
Elena McGauran	Assistant Secretary
Mary Elliott	Hon Treasurer
Mary Boushel	Hon PRO and Delegate to Inter Network
June Elliott	Editor and Assistant Treasurer

We would like to thank our sponsors who have assisted in our All Ireland Conference

B:OMARIN

Shire

genzyme
A SANOFI COMPANY

All Ireland MPS Conference 2015 Saturday 12th Sept 2015

Saturday morning session 9.00am - 1.00pm

Chair: Prof. Eileen Treacy

9.00	Welcome Address	Tony Woods
9.10	Overview of MPS Diseases	Dr. Greg Pastores Mater Hospital
9.40	Mucopolidosis and the Rarest of the Rare	Dr Fiona Stewart Belfast City Hospital
10.00	My Daughter was on Vimizin Trial	Costel Focsa Parent
10.10	Vimizin Availability	Nigel Nicholls Biomarin
10.25	Long Term ERT	TBC
10.45	Home Infusions	Mo Kelly Parent
11.00	Coffee Break	
<u>Chair</u>	<u>Dr Fiona Stewart</u>	
11.30	National Rare Disease Plan	Prof Eileen Treacy Mater Hospital
11.50	Transition to Adult Clinics	TBC
12.20	Genistein Trial	Dr Claire O'Leary Manchester University
12.40	Panel Discussion	
1.00	Lunch	

All Ireland MPS Conference 2015 Saturday 12th Sept 2015

1.00 pm- 2.00 pm Lunch

Saturday afternoon session 2.00pm – 5.00pm

Chair: Dr . Greg Pastores

- | | | |
|-------|--|--|
| 14.00 | Gene Therapy | Dr Claire O'Leary
Manchester University |
| 14.20 | Sensory Dimensions of Care | Julie Whann
Occupational Therapist |
| 14.40 | My sister has Sanfilippo | Gary Woods
Brother |
| 14.50 | Advocacy | Alison Wilson
All Ireland Advocacy
Support Officer |
| 15.20 | Pain management | Dr Conor Hearty
Mater Hospital |
| 15.40 | Panel Discussion | |
| 16.00 | Slide Show of 20 years of the Irish MPS Society | |
| | Tea and Coffee and 20th Anniversary Celebration Cake | |
| | Presentation of 20th Anniversary Candle to each MPS family | |
| 17.00 | Close | |



Booking Form for All Ireland Conference 2015 Family Registration

Surname	Name	MPS Y/N	Dietary needs (if any)	Wheelchair User Y/N	Date of Birth

Friday – Saturday €50.00 per family.

Extended family members €25.00 each

Saturday only €50.00 per family

DEADLINE FOR BOOKING FRIDAY 17TH JULY 2015

Payment to be made by Cheque, Postal Order or Bank Draft made payable to the Irish MPS Society and posted to Mary Elliott, Grangegeeth, Slane, Co. Meath

- Rooms have been reserved in the Clarion Hotel for Friday 11th September 2015
- Anyone wishing to stay on Friday night MUST MAKE THEIR OWN BOOKING directly with the hotel on 01-6258000, quoting “Irish MPS Society”
- Upon presentation of a receipt from the Hotel the society will refund 50% of the cost to MPS families. Early booking is essential.
- **Families may arrive on Friday afternoon and use the facilities in the hotel.**
- **Dinner will be in the hotel restaurant at 7pm.** (Sponsored by Irish MPS Society)



Booking Form for All Ireland Conference
2015
Professional and Non-members
Registration

Name(s): _____

Organisation: _____

Address : _____

Telephone: _____ Fax: _____

Email Address: _____

Special Dietary needs (if any) _____

Professional Rate

Saturday Only €50.00

DEADLINE FOR BOOKING FRIDAY 17TH JULY 2015

Payment to be made by Cheque, Postal Order or Bank Draft made payable to the Irish MPS Society and posted to Mary Elliott, Grangegeeth, Slane, Co. Meath