

INTERNATIONAL MPS SOCIETIES AND RELEVANT PATIENT ORGANISATIONS

List put together by the UK MPS Society
August 2008

For each country, where there is an MPS Society/Association it has been listed. Where there is no MPS Society, an organisation which supports those with Lysosomal Storage Diseases has been listed. If a country has neither of the above, an umbrella organisation such as one supporting those with Rare Diseases has been listed where there is one.

MPS Societies are shown with "[MPS](#)"

ARGENTINA

Contact Name:
Position:

Organisation: Asociación de Pacientes de Enfermedades Lisosomales de la Republica Argentina (APELRA)

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ARGENTINA

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Website: <http://web.apelra.org.ar>

AUSTRALIA

MPS

Contact Name: Wendy Boon

Position: Board President

Organisation: Mucopolysaccharide & Related Diseases Society Australia Ltd

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Officer

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AUSTRALIA

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AUSTRALIA

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Email (Committee of Management): committee@mpssociety.org.au

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AUSTRIA

MPS

Contact Name: Michaela Wiegl

Position: Board President

Organisation: Gesellschaft für Mukopolysaccharidosen

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AUSTRIA

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Fax:

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BELGIUM

Contact Name: Lut de Baere

Position: Board President

Organisation: BOKS Belgium

Address: Alice Nahonlaan 7
9120 Melsele
BELGIUM

Tel: + 32 (0)498 70 15 03

Fax:

Email: info@boks.be; lut@boks.be; ludeba@skynet.be

Website: www.boks.be

BRAZIL MPS

Contact Name: Prof. Josué Félix de Araújo

Position: President

Organisation: ABMPS - Associação Brasileira de Mucopolissacarídeos

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Nazaré- Salvador -Bahia,
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Fax:

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BULGARIA **MPS**

Contact Name: Desislava Pavlova Hristakeva-Atanasova

Position: President

Organisation: National Association of MPS Bulgaria

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BULGARIA

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Fax:

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Website:

CANADA **MPS**

Contact Name: Kirsten Harkins

Position: Executive Director

Organisation: The Canadian Society for Mucopolysaccharide & Related Diseases Inc. (The Canadian MPS Society)

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CHILE

Contact Name:

Position:

Organisation: Fundación Chilena de Pacientes de Enfermedades Lisosomales

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CHILE

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Fax:

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COLOMBIA

Contact Name: Luz Victoria Salazar

Position:

Organisation: ACOPEL (Asociación Colombiana de Pacientes con Enfermedades de depósito Lisosomal)

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CROATIA

Contact Name: Nataša Bijelić

Position: Secretary

Organisation: The Croatian Society of Patients with Rare Diseases

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CROATIA

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CZECH REPUBLIC MPS

Contact Name: Prof. Jan Michalík, PhD

Position: Chairman

Organisation: Spolecnost pro MPS (Czech Society for MPS)

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Olomouc
772 00
CZECH REPUBLIC

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Email: spmps@seznam.cz

Email (Jan): janmichalik@email.cz

Website: www.mukopoly.cz

DENMARK

Contact Name:

Position:

Organisation: Sjaeldne Diagnoser (Rare Disorders Denmark)

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København K
DENMARK

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ECUADOR

Contact Name: Eliecer Quispe Fray & Carmen Mayorga

Position:

Organisation: FEPEL (Fundación Ecuatoriana de Pacientes con Enfermedades de deposito Lisosomal)

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Las Caudras
ECUADOR

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Website:

ESTONIA **MPS**

Contact Name: Ande Martin

Position:

Organisation: MPS Society Estonia

Address:

Tel:

Fax:

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Website:

FRANCE

Contact Name: Delphine Genevaz

Position: Deputy Director

Contact Name: Jean-Paul Lebarbenchon

Position: Board Member

Organisation: Vaincre les Maladies Lysosomales (VML)

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91300 Massy

FRANCE

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Email: scientifique@vml-asso.org; jplebarbenchon@vml-asso.org

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GERMANY MPS

Contact Name: Thomas Baum
Position: President

Contact Name: Bettina Wildi
Position: Board Member, Vice President?

Organisation: Stellvertretende Vorsitzende der Gesellschaft für MPS e.V.

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GERMANY

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Website: www.mps-ev.de/index.php

GREECE

Contact Name: Mrs. Marianna Lambrou
Position:

Organisation: The Greek Alliance of Rare Disease (PESPA)

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GREECE

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HONG KONG **MPS**

Contact Name: Stephen Ma On Tat

Position: Chairperson

Organisation: Hong Kong Mucopolysaccharidoses & Rare Genetic Diseases Mutual Aid Group

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HUNGARY **MPS**

Contact Name: Zsuzsanna Roman

Position: President

Organisation: Magyar Mukopoliszaccharidózis Társaság (Hungarian Society for Mucopolysaccharide Diseases)

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HUNGARY

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INDONESIA

Contact Name: Mrs Peni Utami

Position:

Organisation: Indonesia IEM Parent Society

Address:

Tel:

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Website:

IRAN

Contact Name:

Position:

Organisation: Charity Foundation for Rare Diseases (CFSD)

Address: No 12 15/1 st. sshahid akbari st, valia st
PO Box 15815 - 3333
Teheran
IRAN

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Website: www.cffsd.org

IRELAND **MPS**

Contact Name: David Hackett

Position:

Organisation: The Irish Society for Mucopolysaccharide Diseases

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REPUBLIC OF IRELAND

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ITALY **MPS**

Contact Name: Flavio Bertoglio

Position: Board President

Contact Name: Giovanna Pavan

Position: Vice President

Contact Name: Sonia Colombo

Position:

Organisation: Associazione Italiana Mucopolysaccharidosi Per Le Malatie Affini

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ITALY

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sonia@mpssociety.it

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JAPAN**MPS**

Contact Name: Ushio Fujita

Position: President

Contact Name: Nobuhiro Kasa

Position: Vice President, Foreign Contact

Organisation: The Japanese Society of the Patients and the Families with MPS

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TANO-gun, GUNMA-ken
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JAPAN

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KOREA**MPS**

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Position:

Organisation: MPS Patient Organisation

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KOREA

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Fax:

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LUXEMBOURG

Contact Name:

Position:

Organisation: Association Luxembourgeoise d'aide pour les personnes Atteintes de maladies Neuro-Musculaires et de maladies rares (ALAN asbl)

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LUXEMBOURG

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MALAYSIA

Contact Name: Mr Lee Yee Seng

Position: Secretary

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MALAYSIA

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NETHERLANDS

Contact Name: Hanka Meutgeert

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Organisation: VKS

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NETHERLANDS

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NEW ZEALAND

Contact Name: Jenny Noble

Position: Secretary / Treasurer

Contact Name: John Forman

Position: Chairman

Organisation: Lysosomal Diseases New Zealand

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Ohauti
Tauranga
NEW ZEALAND

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NORWAY **MPS**

Contact Name: Rita Barkhodaee
Position: Representative for parent group

Organisation: Foreldregruppen for MPS sykdommer
(the parent and family organisation for MPS disorders in Norway)

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NORWAY

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Email: rita.barkhodaee@upstreamonline.com
Fax:
Website:

Second Contact: Kaja Giltvedt
Position: Contact person for MPS disorders

Organisation: Frambu (a national centre for rare disorders)

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1404 Siggerud
NORWAY

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Email: kaja.giltvedt@frambu.no; info@frambu.no
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PERU

Contact Name: Cesar Augusto Mostacero Venegas

Position: President

Organisation: Asociación Peruana de Pacientes con Enfermedades de deposito Lisosomal (APPEL)

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Jesús Maria

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PERU

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PHILIPPINES

Contact Name: Cynthia K Magdaraog

Position: President

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PHILIPPINES

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POLAND

MPS

Contact Name: Teresa Matulka
Position: President

Contact Name: Meg Kaflik
Position: Foreign Administrator

Contact Name: Natalia Pawlowski
Position: Foreign Administrator

Organisation: Polish Society of Mucopolysaccharidosis (MPS) and Rare Diseases

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POLAND

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PORTUGAL

Contact Name:
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PORTUGAL

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ROMANIA

Contact Name: Teodora Dumitriu
Position: Member & Contact Parent

Organisation: Fundatia Romana pentru Boli Lisosomale - FRBL (Romanian Foundation for Lysosomal Diseases)

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ROMANIA

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SINGAPORE

Contact Name:
Position:

Organisation: Rare Genetics Network (Singapore)

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SPAIN **MPS**

Contact Name: Jordi Cruz
Position: President

Organisation: Asociación MPS España

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SPAIN

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SWEDEN **MPS**

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Position:

Organisation: Swedish MPS Society

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SWITZERLAND

MPS

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Position: Board Member

Organisation: MPS Schweiz (MPS Society Switzerland)

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TAIWAN

MPS

Contact Name: Virginia Tsai

Position: President

Organisation: Taiwan MPS Society

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Website: <http://tacocity.com.tw/cks49/>

TURKEY **MPS**

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Position: Co-ordinator

Organisation: Turkish MPS Society (lives in UK)

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Fax:

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Website:

UK **MPS**

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Position: Chief Executive

Organisation: Society for Mucopolysaccharide Diseases (MPS Society)

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Website: www.mpsociety.co.uk

URUGUAY

Contact Name:

Position:

Organisation: AUPEL (Asociación Uruguaya de Pacientes con Enfermedades Lisosomales)

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Fax:

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USA

MPS

Contact Name: Barbara Wedehase

Position: Executive Director

Organisation: National MPS Society

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