



LYSOSOMAL STORAGE DISORDER SUPPORT

NEWSLETTERS

Available online and in print

A patient support group is available for your condition; their friendly teams are always happy to work with you and to answer any questions you may have. They can offer help in many ways. Please see overleaf for more details.



Have questions?

- Providing up-to-date information and advice
- Support for newly diagnosed people
- Providing information on housing, education, work and respite care
- Help with information about travel and insurance
- How to set up a care plan with your GP and/or social services
- Dealing with homecare issues

Feeling alone?

- Putting you in touch with other people with the same condition
- Visiting you at home or attending clinic appointments with you
- Simply being there if you need to talk

Know your rights?

- When you need someone to join you at an important meeting
- When you want to make a complaint
- Writing letters to support your case
- Advice on mobility and transport issues

Know what to ask?

- Completing benefit claim forms and making appeals
- Getting your home adapted for your needs
- Accessing specialist equipment
- Completing grant applications

On the next page is a list of support groups; ask your medical team to highlight the group that is appropriate for your condition.



AGSD-UK
PO BOX 1233
Bristol
BS48 9DD

Tel: 0300 123 2790
info@agsd.org.uk
www.agsd.org.uk
Pompe Disease
McArdle Disease
Glycogen Storage Disease



Registered Charity
No. 1084908 -
Scotland SC047408

Batten Disease Family Assn.
209-211 City Road
London
EC1V 1JN

Tel: 07876 682 589
support@bdfa-uk.org.uk
www.bdfa-uk.org.uk

Batten Disease



Registered Charity
No 1144543

Cure and Action for Tay-Sachs
94 Milborough Crescent,
Lee, London,
SE12 0RW

info@cats-foundation.org
www.cats-foundation.org

Tay-Sachs Disease
Sandhoff Disease



Registered Charity
No 1095657

Gauchers Association
8 Silver Street, Dursley
Gloucestershire
GL11 4ND

Tel: 01453 549231
ga@gaucher.org.uk
www.gaucher.org.uk

Gaucher Disease



**Krabbe
uk**
Registered Charity
No 1174472,
SC047927

Krabbe UK

Tel: 07766 558 480
info@krabbeuk.org
www.krabbeuk.org

Krabbe Disease



Registered Charity
Number 1150542

MLD Support Association
Floor 5
Amphenol Business Complex
Thanet Way, Whitstable
CT5 3SB

Tel: 07977 440809
admin@mldsupportuk.org.uk
Metachromatic Leukodystrophy
Disease



Registered Charity
Nos 1143472,
SC041012

MPS Society
MPS House, Repton Place,
White Lion Road, Amersham
HP7 9LP

Tel: 0345 389 9901
mps@mpssociety.org.uk
www.mpssociety.org.uk
Mucopolysaccharide, ML, MLD,
Fabry and related Lysosomal diseases



Registered Charity
No 1144406

Niemann-Pick UK
Suite 2, Vermont House,
Concord, Washington,
Tyne and Wear,
NE37 2SQ

Tel: 0191 415 0693
info@npuk.org
www.npuk.org
Niemann-Pick Diseases



Registered Charity
No 1186383

Pompe Support Network
43a North Lane, Buriton
Petersfield
Hampshire
GU31 5RS

Tel: 01730 231554
hello@pompe.uk
www.pompe.uk
Pompe Disease

