






Patient associations

Patient Associations exist for many of the Lysosomal Storage Disorders. They are usually voluntary groups of people who can provide invaluable information, advocacy and support.

For the most recent up to date list of LSD patient organisations please visit the LSD collaborative website

<https://www.lsdcollaborative.org.uk/#members>

Disease	Patient Support Group	Telephone	Email	Website
 Pompe	Association of Glycogen Storage Disorders	0300 1232790	info@agsd.org.uk	www.agsd.org.uk
 Batten	Batten Disease Family Association	0800 0469832	admin@bdfa-uk.org.uk	www.bdfa-uk.org.uk
 Tay Sachs and Sandhoff	Cure and Action for Tay Sachs Foundation		info@cats-foundation.org	www.cats-foundation.org
 Gaucher	Gaucher Association	01453 549231	ga@gaucher.org.uk	www.gaucher.org.uk
 Krabbe	Krabbe Uk			https://www.krabbeuk.org/

Mucopolysaccharidoses (MPS), mucopolysaccharidoses (ML), metachromatic leukodystrophy (MLD), Fabry and related lysosomal disorders (including lysosomal acid lipase deficiency/LAL-D)	MPS Society	0345 3899901	mps@mpssociety.org.uk	www.mpssociety.org.uk
Niemann-Pick	Niemann-Pick UK	0191 4150693	info@niemann-pick.org.uk	www.niemann-pick.org.uk

Additional resources

Alex The leukodystrophy charity

Helpline 020 7701 4388

<https://www.alextlc.org/>

Registered charity number 1106008

Cambridge rare disease network

<https://camraredisease.org/>

Registered Charity Number: 1166365

Contact - for families with disabled children

Helpline 0808 808 3555

<https://www.contact.org.uk/>

Registered charity number 284912

Genetic Alliance UK

<https://www.geneticalliance.org.uk>

Registered charity number 1114195

Metabolic Support UK

Helpline 0845 241 2173

<https://www.metabolicsupportuk.org/>

Registered charity number 1089588

Rare disease UK

<https://www.raredisease.org.uk/>

Registered charity number 1114195

SwanUK (syndromes without a name)

020 7831 0883

<https://www.undiagnosed.org.uk/>

Registered charity number 05772999

Addenbrooke's Charitable Trust ACT

Tel: 01223 217757

<https://www.act4addenbrookes.org.uk/>

Registered charity number 1170103

PALS

<https://www.cuh.nhs.uk/have-your-say/patient-advice-and-liaison-service-pals>

please link directly to PALS website