



LYSOSOMAL STORAGE DISORDER SUPPORT

Video and Telephone Consultations



Information for Parents and Carers

A virtual or telephone appointment is when your healthcare professional will connect with you via video or telephone call instead of you and / or your family attending an appointment at the hospital.

Due to the ongoing limitations for patients in accessing clinic appointments, video and telephone consultations are being widely offered as a way for patients and carers to access their specialist centres and clinical teams. However, if there are clinical assessments due, then a face to face appointment may be booked. If a face to face appointment is taking place, the team will ensure that you are attending a COVID secure environment.

It is up to you whether you prefer to conduct your clinic appointment via telephone or by video link. The benefits of using a video link are that you are able to see the clinical teams face to face, multiple people can join the meeting including other family members, different specialties and interpreter if required. Although not all tests and assessments will be possible, some would be possible virtually.

Your specialist centre will discuss your options with you before setting up your appointment and will send you the video link and instructions for joining. If anything is not clear, please do ask your centre for more information.

If the appointment is for your child, it is important they are present as well as you. The clinician will need to physically see them or ask them a question directly as appropriate.

What equipment will I need for a video call?

You will need access to a computer, laptop, smart phone or tablet and have good access to the internet. Most devices now have cameras and microphones inbuilt, but if not, you may need a separate camera and microphone / telephone.



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What do I need to prepare for my appointment?

- If possible, test out your device to ensure that it is able to connect and you have all the equipment (camera, microphone) set up ready. Let your doctor or the team know if you are experiencing any problems
- Please make sure the device is plugged in or well charged
- Have access to a telephone in case video does not work
- If you have any additional needs or concerns about the call make sure you raise these before your appointment
- Be on time for your appointment (virtual clinic appointments are set up in the exact same way as normal clinic appointments and you may risk missing your appointment if you are late)
- Ensure you are somewhere, private, comfortable and quiet (a supermarket is not advisable)
- Please be mindful of lighting, that the room is not too dark and that lighting is behind the camera (for example do not sit in front of a window)
- You are able to have someone with you, if preferred, as with face to face appointments (please advise your specialist centre if someone is on the call with you)
- Make sure you have any clinic letters, list of current medications and any other medical information to hand for the call
- If you are not able to attend your appointment, please let your specialist centre know so that they can offer it to someone else.

Is it secure?

Each hospital trust has chosen the online platform that is compatible with their own systems and trust policies (main platforms are 'attend anywhere' 'AccuRx' and 'zoom').

Can I record my appointment?

While it is perfectly acceptable to make notes of your appointment, recording the appointment is not allowed.

What if I need more help?

Your patient advocacy group can provide advice and support regarding the different platforms used by each hospital trust, or you can contact your clinical team direct. Video appointments are new to many of us and different types of support are available to encourage effective use.



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



CURE & ACTION FOR TAY-SACHS FOUNDATION
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

