

Why join the registry?

A patient registry is essentially a **research database**. For rare conditions, they play a particularly important role in the pathway to therapy development. **Your participation is valuable!**

The **Global Registry for COL6-related dystrophies** aims to:

- ✓ Help identify patients for relevant clinical trials as they become available
- ✓ Encourage further research into COL6-related dystrophies
- ✓ Encourage drug development by providing feasibility information for pharmaceutical companies
- ✓ Provide researchers with specific patient information to support their research
- ✓ Assist doctors and other health professionals by providing them with up-to-date information on managing COL6-related dystrophies, to help them deliver better standards of care for their patients

Global Registry for COL6-related Dystrophies

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Join Today
www.collagen6.org
Or email us at:

collagen6registry@newcastle.ac.uk

A paper form can also be requested via the contact form on the project website:

www.collagen6.org
or by email:
collagen6registry@ncl.ac.uk



Global Registry for
COL6-related
dystrophies



www.collagen6.org

Who can register?

We welcome the registration of

All patients **with a confirmed diagnosis of a COL6-related dystrophy:**

- ✓ **Bethlem Myopathy**
- ✓ **Ullrich Congenital Muscular dystrophy (UCMD)**
- ✓ an **intermediate form** of these conditions.

Our aim is to make the registry the most comprehensive there is for this group of conditions, to give us a good insight into the numbers of people affected and to help us understand more about their natural history.

How will my information be used?

Your data will be stored on a secure server managed by a curator under the supervision of the Principle Investigator, Professor Volker Straub

No unauthorised people will be able to access information about you.

When planning a scientific study or clinical trial, researchers may make enquiries to the registry to obtain anonymous information about the numbers of patients who may be eligible for their studies. **Release of such anonymous information must first be approved by the registry steering committee.**

If you meet the criteria for a study or clinical trial you may be contacted by the registry and given the contact details of the trial/study site so that **you may contact the site if you are interested in the study.**

You can choose whether you would like to be contacted about involvement in studies and **you are free to withdraw participation in the registry at any time by contacting the registry curator (contact details on back of this leaflet)**

What information is collected?

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- Personal details, such as name, address, date of birth and gender, so that individuals can be identified and contacted.
- Individual's experience of daily life, their activities and quality of life (also known as patient-reported outcome measures or PROMs).
- Clinical and genetic information to inform researchers in their development of treatments, to aid recruitment to clinical trials and to assist access to new treatments.