Global Registry for COL6-related dystrophies

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The **Global Registry for COL6-related dystrophies** ([www.collagen6.org](http://www.collagen6.org)) was launched in English in August 2018 as part of a project funded by the Collagen VI alliance to increase the trial readiness of this group of conditions.

The registry aims to:
- Help identify patients for relevant clinical trials as they become available.
- Encourage further research into Collagen 6-related dystrophies.
- Provide researchers with answers to specific questions to support research.
- Assist doctors and other health professionals by providing them with up-to-date information on managing Collagen 6-related dystrophies, to help them deliver better standards of care for their patients.

And welcomes the registration of:
- All patients, with a diagnosis of Bethlem Myopathy, Ullrich Congenital Muscular Dystrophy (UCMD) or Intermediate form of these conditions.

The registry is currently being translated into a number of languages: Italian, Spanish, German, Polish, Dutch, Swedish, French.

The registry has the following approvals: HRA Research Ethics Committee, Newcastle University Ethics, Newcastle upon Tyne Hospitals Trust (NuTH) R&D, NuTH Caldicott Guardian approval, Royal Children’s Hospital Melbourne Research Ethics Committee (HREC), Governance authorisation at Melbourne Children’s Campus.

The registry is a flexible tool for trial readiness and research in the COL6-related dystrophies.

If you are a clinician or patient who would like to take part, or a researcher who would like to learn more about how registries can support research, please contact the registry curator at: collagen6registry@ncl.ac.uk

Selected clinical features

Wheelchair use
- No
- Full time wheelchair use
- Part time wheelchair use

Current best motor function
- Cord walk
- Cerebellum
- Cerebral palsy
- Non-ambulant
- Cannot walk due to contractures

Non-invasive ventilation use
- Does not use
- Uses regularly
- Uses on occasion

Imvasive ventilation use
- Does not use
- Uses regularly

Contractures
- Currently has contractures
- Does not currently have contractures

Surgery to correct contractures?
- Yes
- No

Unplanned hospital admissions
1 out of 25 registry participants have had an unplanned hospital admission in the past year.

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