



The Myotubular and Centronuclear Myopathy Patient Registry

6-MONTH DATA SUMMARY

February 2025

554

registered individuals

57

countries

54%

genetically verified registrations

438

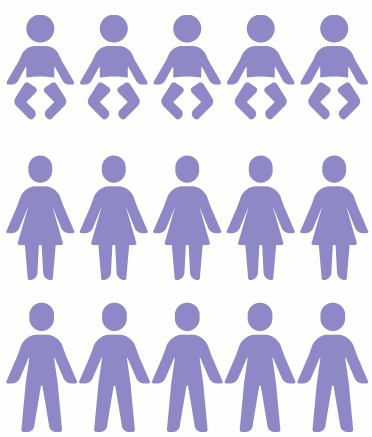
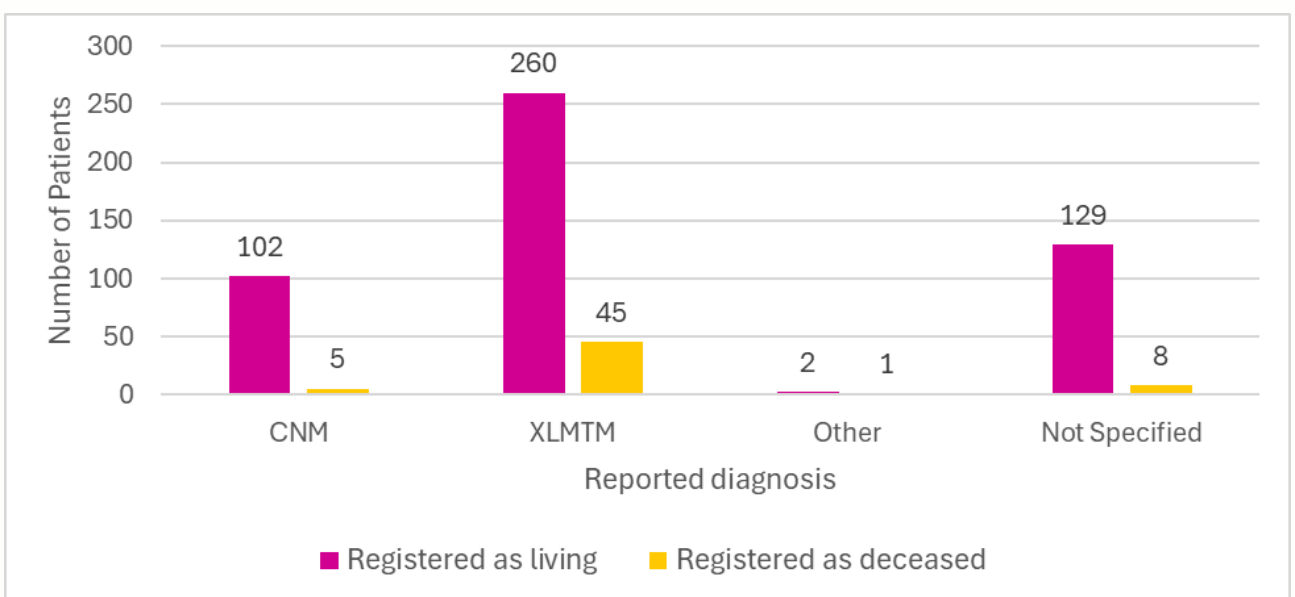
patients

219

liver questionnaires completed

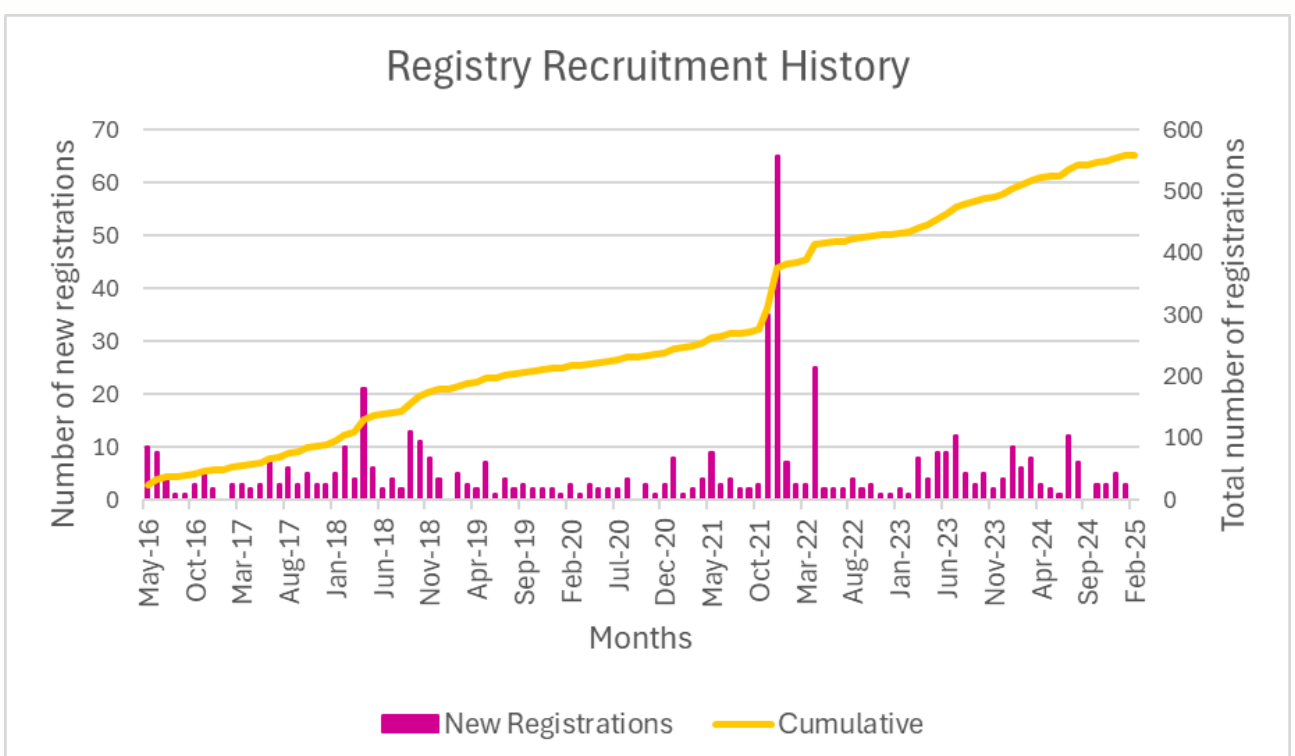
116

female carriers of XLMTM



285 ADULTS (58%)
210 CHILDREN (42%)*

351 MALES (63%)
203 FEMALES (37%)



* Adult/child split provided for patients who registered as living only