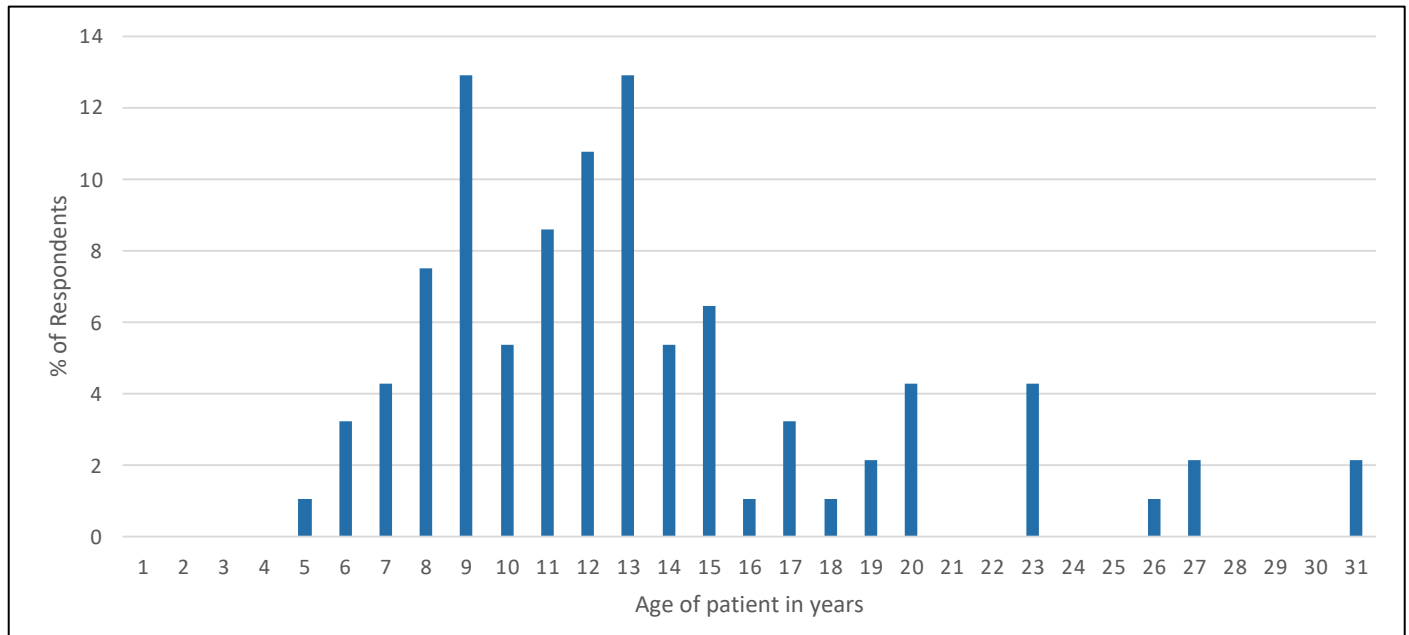
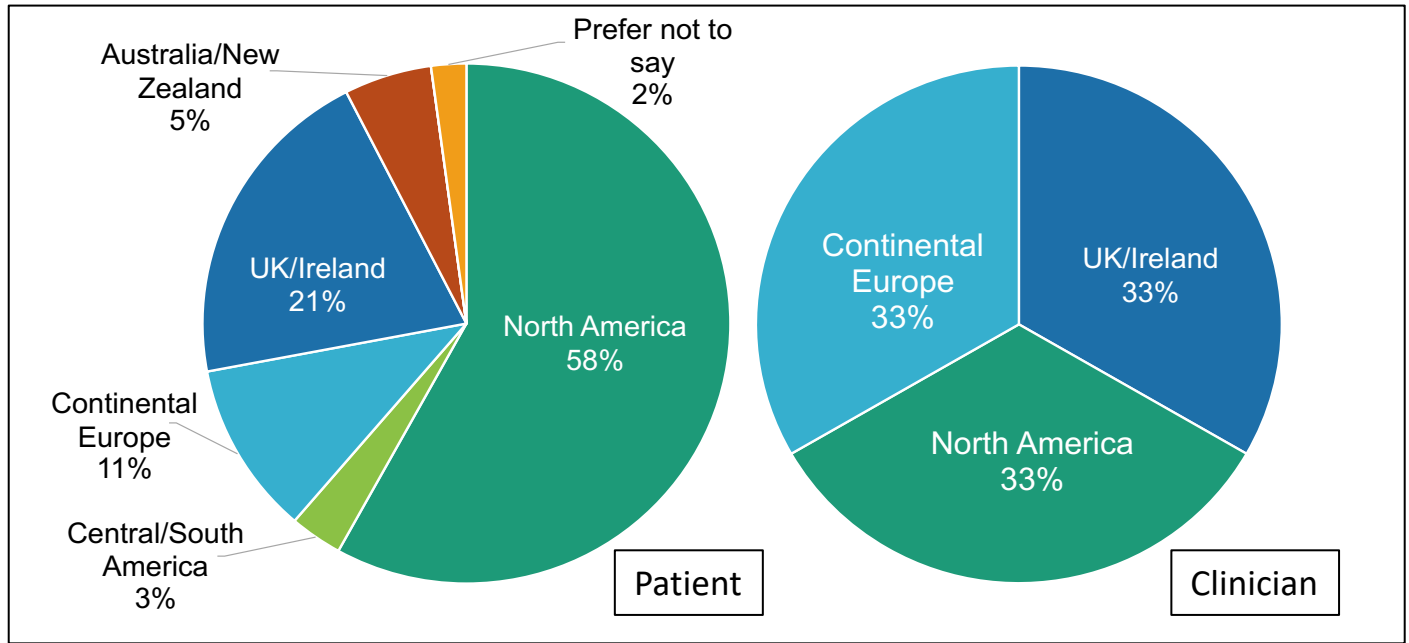


A



B



Supplement 3: Survey demographics. A) There were 93 responses to the patient questionnaire, 23% (21/93) were from children and young people (CYP) affected by CNO, and 77% (72/93) were from parents/carers. The ages of the patients ranged from 5-31 years (Median: 12). B) Of patients/carers, 58% (54/93) were from North America, 21% (19/93) were from the UK and Ireland, 11% (10/93) were from continental Europe, and 10% (10/93) were from other regions (including Australia, New Zealand, Central and South America). Responses from clinicians/clinical academics were equally distributed between North America, the UK, and continental Europe (all 7/21, 33.3%).