Belfast Health and Social Care Trust
caring supporting improving together

FOI/35410

20 November 2025

Pompe disease Patent numbers and treatment

I would like to submit a Freedom of Information (FOI) request for the following data for Belfast Health and Social Care Trust relating to Pompe disease for the period 1 July 2025 to 30 September 2025.

For reference, Pompe disease may be coded under:
*** ICD-10: E74.0 (Glycogen storage disease), or more specifically noted as Acid Maltase Deficiency / Pompe disease**

*** SNOMED CT Concept ID: 86651009 - Glycogen storage disease type II (Pompe disease) If exact matches are unavailable, please provide the nearest equivalent coding used by your Trust and specify the codes applied.**

Table 1 - Patients Treated and Diagnosed (Jul-Sep 2025)) Product Number of Patients Treated Number of Patients Diagnosed with Pompe (ICD-10 E74.0 / SNOMED 86651009) Avalglucosidase Alfa (Nexviazyme)

Alglucosidase Alfa (Myozyme)
Cipaglucosidase Alfa + Miglustat (Pombiliti)

Table 2 - Patients Treated and Volume Used (Jul-Sep 2025) Product Volume Used (IUs or mg) Avalglucosidase Alfa (Nexviazyme)

Alglucosidase Alfa (Myozyme)
Cipaglucosidase Alfa + Miglustat (Pombiliti)

Table 3 - New Patients Treated by Product (Jan-Mar 2025) Product July 2025 August 2025 September 2025 Avalglucosidase Alfa (Nexviazyme)

Alglucosidase Alfa (Myozyme) +
Cipaglucosidase Alfa + Miglustat (Pombiliti)

Table 4- Patients Treated by Age Group and by Product (Jul-Sep 2025)

Product
Age Group
Number of patients treated

Avalglucosidase Alfa (Nexviazyme)
0-11
12-17
18+

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Alglucosidase Alfa (Myozyme)
0-11
12-17
18+

Cipaglucosidase Alfa + Miglustat (Pombiliti)
0-11
12-17
18+

Table 5: Naïve (New Start) and Switch Patients by Product (Jul-Sep 2025)

Product
Number of Naïve (New Start) Patients
Number of Patients Switching To this Product Number of Patients Switching From this Product Avalglucosidase Alfa (Nexviazyme)

Alglucosidase Alfa (Myozyme)
Cipaglucosidase Alfa + Miglustat (Pombiliti)

Paediatrics
We have no paediatric patients under treatment for Pompe.

Adults
Belfast Health and Social Care Trust has no patients diagnosed with or being treated for Pompe disease.