



International Pompe Day 2026

The goal of International Pompe Day, 15th of April, is to foster international awareness of Pompe Disease, a life-changing inherited condition. It's estimated that there are 35–40 children living with infantile-onset Pompe in the UK. This especially rare and most severe form of the disease particularly affects the heart and skeletal muscles.

The parents of baby Arla from the Wirral are keen to help raise awareness of the condition.

They first became concerned about Arla when she was repeatedly becoming unwell with chest issues. She was very weak; her parents were worried she was not feeding properly and was losing a significant amount of weight.

Arla's Mum, Emmie Wood said;

“We knew something wasn't right, so we kept taking her back to the doctors. Eventually, our GP referred her to the hospital, where further tests were carried out. During these tests, they discovered that her heart was enlarged, which was a huge shock for us. Following this, genetic testing was done, and that's how we finally received the diagnosis of Infantile Onset Pompe Disease (IOPD). While it was devastating news, it also gave us some answers after a very worrying and uncertain time.”

Daily life for the Wood family requires constant adjustment, resilience, and planning. Much of their routine revolves around managing medical needs — appointments, treatments, and monitoring Arla's health.

Emmie went on to say; “Emotionally, it can be very challenging. There are moments of anxiety and exhaustion, but we try to focus on the positives and carry on day by day.”

AGSD-UK is a charity that supports this rare disease community offering invaluable services for families. Emmie said, “From the moment of diagnosis, they provided clear, reliable information that helped us understand Pompe Disease and what to expect.

“They helped us apply for grants during Covid when things were hard with money as Arla was an inpatient in Manchester hospital and I was at home with three other children. They have been amazing and helped us along the way with anything we have needed. They have really been there for us.”

AGSD-UK commented:

“Families affected by Pompe can face huge challenges and it’s vital they get the early support they need. We want to see consistent signposting at diagnosis to organisations like AGSD-UK, so no family misses out on the range advocacy and support services we offer.

“People affected by Pompe and other glycogen storage disorders tell us just how isolating life with this rare and a little-known condition can feel. We’re here to provide a listening ear, connect people to others who understand their experiences and make sure all-round help and information is available to enable them to live positively.

“While pushing for greater awareness, along with continued research into better treatments and ultimately a cure, we want to ensure families living with Pompe feel supported, informed, and empowered from the very beginning of their journey.”