Yusuf

Yusuf, was born in 2019 and lives in Istanbul, Turkey. He has the early infantile form of Galactosialidosis and has chronic kidney failure as a key symptom of his condition.

There were concerns even whilst his mother was pregnant and there were some signs in utero, at around 5 months which were spotted.

Yusuf was born premature at 8 months and remained under hospital care in an incubator for the first two months of his life due to fluid overload. He was discharged once the fluid retention was brought back under control. However at 6 months of age he had significant oedema again and was admitted to hospital for fluid management and genetic testing. Yusuf was finally diagnosed with Galactosialidosis before the age of 12 months.

Yusuf's main symptoms impacting his quality of life relate to his chronic kidney failure and regular dialysis. His other symptoms include short stature, mild skeletal deformities, muscle weakness and delayed gross motor skills. There does not appear to be any cognitive impact on Yusuf however he does not yet speak or walk.

He demonstrates understanding by taking instruction and communicating effectively non-verbally. He has good fine motor skills and enjoys playing with his dad and going around malls.

It is suspected that his development could also be slow in some areas due to the side effects and chronic fatigue as a result of dialysis.