

## Personal Story – Jackson’s Journey

### How mum with a needle phobia learns the ropes!

Personal stories are important to us. Not only do we appreciate the time it takes to put thoughts onto paper (or a computer screen these days), it gives us insight into the impacts of families living with Gaucher disease.

Thank you to Jackson's mum Emma on sharing their family Homecare journey with us, please read their story below:

Moving to Homecare treatment has been the best thing for Jackson. We have watched him go from strength to strength since being on infusions the last few years from home. As amazing as the care and support was that we received from Great Ormond Street Hospital (GOSH), Jackson being so little at diagnosis meant the trips to the hospital for infusion became long exhausting days for him that he rarely relished.



When we were told we were able to have infusions at home and that was the goal we were to aim towards, we were so thrilled that this was an option.

Jackson finished his course of infusions at GOSH a week or so before Christmas 2018, age 2, we had our first home care infusion on the 2nd Jan 2019, we had met Lisa one of the health care nurses prior to the infusion where she explained the plan for the visit. She met Jackson, played and made him so at ease with her that when she came for his first infusion they were already the best of friends.

Lisa met with us two weekly in the instance and then started to bring other nurses to meet Jackson in order to familiarise him with the local team that would eventually become his team of nurses.

Jackson over the next few months developed great friendships with our fantastic group of homecare nurses who became members of the family, it was so easy having them in our home, they really were fantastic at working with us and Jackson to ease him into having infusions, watching him and deciding the best way for him and us to tackle normalising the procedure.



Jackson would welcome infusion Wednesday and he would pray for his favourite Lisa, although he was at ease with all our lovely nurses, Lisa just seemed the right fit for him, so when the day came that she asked if I myself wanted to do Jackson's Infusions, she absolutely put me at ease with the idea. We worked on a plan of having a port fitted for Jackson, a decision that wasn't the easiest for us, but both the Homecare team and Gosh team supported us with so much information we decided it was the right path for Jackson and we prepared him for the operation explaining to him as best we could and put an end goal in place for me to be competent completing Jackson's infusions.

The homecare team again supported us with this helping us to make it the new norm for Jackson once he was home and recovered from the procedure.

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So after a year or so of home infusions and Jackson a pro at the whole procedure by now it was time to let mummy loose!

A mum with a needle phobia was now learning the ropes! Without the encouragement and support of our Homecare team there is no way our infusions would be as normalised as they are now. It didn't take long with the help of Lisa and the team for me to get signed off and now a few weeks into lockdown we were free of nurses in the house and running infusions solo!!



Jackson is so at ease having his infusions at home now, it's amazing to see the difference, and he's gone from just wanting to sleep through the entire infusion into the afternoon, to cramming as many activities in as he can! Golf remains the activity of choice at the moment for infusions as well as Lego time but the freedom it's given us means it no longer takes a full day out of our week but just a few hours of the morning.