



Parley

Parents And Relatives
Listening and Empathising
with You

Baileys's Story

Nephrotic Syndrome

In October 2006 Bailey had what we thought was a sickness bug for a round a week we kept taking him to the Dr's saying there's something wrong because his tummy was swollen and 3 drs told us its just a bug we went back for the 4th time and the dr told us to get him to the hospital straight a way,

When we got there they ran lots of tests and said he has to stay because they think he has Nephrotic syndrome we were moving the next day so we went home for the night and went back first thing in the morning as they weren't going to do any thing till the morning any way and i wouldn't leave him there but was also in shock they gave me a print out from the net explaining it and didn't even explain it themselves or let me ask questions it was all very scary while we was at the hospital for 3nights he got really badly swollen they let him home then called and said he needs to go back in. So he was there for another 3nights when the steroids started to work he started to get back to normal but since then he's had 6 replaces the last one was the worst leaking protein/relapsing while on the steroids he has never done before we don't know if its because it was a worse relapse or if it means some thing hes also had lots of side affects this time hes seeing a kidney specialist from Great Ormond Street so hopefully we will get more help and be able to try some different meds to stop him relapsing,

While hes on steroids he can get very ill from things like chickenpox so we have to be very careful and hope that a cure is found because as people with kids or with out know your kids are your life and you'd do anything to keep them safe and well but with things like NS etc its out of are hands until a cure is found we hopefully if his ns stays as it is now his future is bright but if it goes the other way he will need a kidney transplant as his kidneys will fail in the end and sometimes even that doesnt cure it. At the moment bailey is doin well and has been for in remission for 5 months and he responds well to steroids.