

[REDACTED]

Tel, [REDACTED]

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SUMMARY FOR NICE APPRAISAL.

I am mum and carer to Leanne who is 18 years old at present.

Leanne was born in 1988 and was a normal healthy infant. As Leanne grew she took up many sports and some were at county level. She was a 6000 metre swimmer, Competed for the Southwest on the Gymnastic circuit and even made nationals. She snorkelled, scuba dived, surfed. Played beach volley for Exmouth and also East Devon Tag rugby league, finally she was a brown belt in Kick-Boxing. We were a very active family with plenty of outdoor interests. Leanne was very fit and healthy until March 2002. She was 13 years old and just competed in the inter school gymnastic championship for a place in the nationals.

Leanne woke up on a Monday morning in March 2002 unable to breath, quite literally. She had been fine the night before. It was first thought that it was a chest infection and treated accordingly. By the following day Leanne had been admitted to our local hospital. At this point Leanne was unable to walk across the room and couldn't climb the stairs without help. She was coughing, vomiting and struggling to breathe on any exertion. Leanne was also having frequent episodes of turning facially blue. At this point Leanne went on to very part-time school if she went in at all as she just could not cope with the exertion and demands that school had on her. Leanne became some what house bound unless we took her out in the car. She couldn't do any of what her peers were doing as she had become physically unable. Parties and activities went out the window for Leanne as she was not physically able at this point. Life for Leanne and us had changed over night. We were an active family and weekend day trips were the norm. This all stopped from the day she became ill with Pulmonary Hypertension.

It took 1 year almost to the day to get a diagnosis of Primary Pulmonary Hypertension for Leanne and being told at that point that there was no medication to help her. The disease was progressive and other then using oxygen 24/7 there was nothing that they could do. Take her home and enjoy what time that she has left. Our world had fallen apart. There we were one year on and my daughter was still finding it hard to walk without becoming increasing breathless and had just been given a death sentence. At this point she was fully dependant on us to do everyday simple tasks for her. Like getting dressed, washing her hair. She had to give up on all her social activities and sports as she was unable to take part. I gave up my job as a terminal care nurse to look after Leanne. I still could not

believe that Leanne had been competing at sport across the county and now 12 months on was struggling to walk across the room.

After a many visits to different hospitals we finally managed to get a referral to Great Ormond Street Hospital for sick Children. Leanne under went numerous investigations and also had a lung biopsy. It was then that we were given our first glimmer of hope. There was medication available. There is no cure but the medication would help relieve some of the symptoms or even slow down the progression of this disabling disease. Leanne was started a drug called Tracleer which had just been made available for treatment in children with Pulmonary Hypertension. Within days Leanne was doing more and feeling more able. She was able to cross the room and not be heard breathing heavy. Leanne started to attend school more frequently and mix with her peers. This was the first signs that Leanne was responding to the Tracleer medication. Since then Leanne has had other drugs added to her mix over the years as they have become necessary and available.

Leanne is currently on Tracleer, Sildenafil, Remodulin and Inhaled Ventavis. Each one of these drugs had helped her to achieve an independent lifestyle. Prior to meds Leanne was very dependant, now it is fair to say that Leanne is independent of me for the majority of the time. She has been able to complete her GCSEs gaining As and Bs. She went on to study A Level Psychology and Sociology. Leanne has now just finished college, awaiting A Level results, and has been offered a voluntary position with in the college mentoring other A Level Psychology students. Prior to medication Leanne was as I said dependant upon us for everything. We never thought she would have achieved so much given her earlier prognosis. She has now reached the stage that I can leave her at home or I can go away over night and feel confident that she will be able to cope. None of this could have been achieved without the support of the medication that has been made available to her.

Since Leanne has now turned 18 years old we are in the midst of transitioning over from Great Ormond Street to adult care at the Hammersmith Hospital in London. I am now deeply concerned as within the paediatrics centre Leanne was funded for meds relatively easily, Now I am very concerned that if Leannes illness starts to progress again that there will be this huge funding issue. At this time in her and our lives we should be able to relax a little and thank god for medical science. Sadly I spend much of my time fretting about what will happen. The medication that has been made available to Leanne has made such a huge difference to her and our quality of life. I couldn't bear to think that maybe other medications that would ease her symptoms and suffering and they not be available because of cost.

I also have a 16 year old son and we are now able to go out with him and do things that he wants to do, which was not possible previously. Sadly his life was put on hold also as we were so very busy helping Leanne with her daily life. He was only able to go out with either me OR his dad, never all of us like a family... Someone had to be home for Leanne. Now we go out for day trips and Leanne can come sometimes or not if she would rather do her own thing. We feel like the medication has not only given us all hope for Leannes future but it has given us all freedom to be a family and also independent of each

other. Leanne has her life back, yes she has limitations but she still can maintain independence and be an 18 year old.

Back last year we were approached by Great Ormond Street Hospital and asked if we would take part in a documentary programme being made called Child in a Million. It was aired earlier this year on channel 5. Leanne's story is a positive story and many many people have gained so much from it. Our local community nurses have made copies and are using it to show other families with teenagers that have become ill. They have found it a useful tool in showing others Leanne's positive out look on life and her achievements. Leanne's story has made many people sit up and think about how they are dealing much lesser problems. Leanne has taken part in numerous Newspaper, TV and Radio interviews. She is a true inspiration to many many people. Leanne will never give up, and as long as the medication is there to help her she will remain here telling her story and inspiring others with her positive story that was so nearly a negative.

Life for our family before medication was hard. We had to plan everything, down to who would be home, who would help Leanne, who was contactable by phone in emergency. Absolutely everything we did had to be planned like a military operation. Family day trips ceased, due to the fact that Leanne could not part take. My son suffered also, as he was only 11 and his big sister who was competing at high level in sports had suddenly become very ill and dependant on us and he missed out on much of those years. He spent many days, nights in hospitals with us. Now he also feels comfortable with how well she is doing and not guilty for living his life. It was terribly hard for him. He refused to go out with his friends as she was unable to do this. The guilt he suffered for being able. He now feels comfortable knowing if she wants to go out she can, because her medication makes her able to take part.

Please do not misunderstand me, Leanne is not normal and will never be whilst she has Pulmonary Hypertension but she is far more able and independent of us now with medication then she was in the year that we waited for a diagnoses. I am also now considering returning to work as I feel she does not need me constantly.

If medication had not been available our lives would almost certainly deteriorated further. We would have become permanent full time carers and would have not just lost Leanne to this awful disease but my son would have lost his family life. So you see, the medication is invaluable, you can't put a price on a persons life when medication like this makes such a huge difference to each and every member of the family not just the patient.

This is not the life we planned for us or our children but it is a far better option then the one prognosis at the beginning. Quality of life is about independence freedom and enjoyment. The medication that Leanne now takes allows us all to achieve this. My family has a good quality of life now and a brighter future.

Take care

Tracie Pannell