Multiple technology appraisal

Colistimethate sodium powder and tobramycin powder for inhalation for the treatment of pseudomonas lung infection in cystic fibrosis [ID342]

Personal statement submission

Nikki Samsa

Cystic Fibrosis Trust

I am a carer of a patient with the condition for which NICE is considering this technology.

I am an employee of a patient organisation that represents patients with the condition for which NICE is considering the technology. I am the Clinical Care project lead, currently dealing with Peer Reviews of CF Services.

What is your background and experience of the condition and therapy which is being appraised?

- **When did you first come into contact with the condition and/or therapy?**

I first came into contact with the condition when my daughter was diagnosed in August 2000. She has had regular nebulised antibiotics since 2005 but has not benefitted from the technology under appraisal.

I started to work at the Cystic Fibrosis Trust in 2003.

- **What impact have the condition and therapy had on your life?**

This condition has had a major impact on my life, but more importantly on the life of my daughter, who, at the age of twelve, understands that she has a life limiting condition, spends hours of her day administering her huge quantity of medications which will only increase over time and accepts that this will always be a part of her daily routine if she wishes to continue with a good quality of life into adulthood.

I work for the Cystic Fibrosis Trust to make a difference and aim to prolong the life of my daughter and all those living with CF, and those yet to be diagnosed.

- **If you are yourself a patient or carer, think about significant events such as when treatment was started and completed, onset of adverse or beneficial effects, and changes in quality of life. In the meeting you should be factual and precise - for example, if you experienced pain, think about how severe it was and how long it lasted.**

Once long term nebulised antibiotics began life changed for my daughter and my family. Daily treatment increased by around an hour every day and we were fully aware that this will only increase. With current technologies and medication treatment has to be carried out near to a power supply and equipment has to be cleaned thoroughly. This makes normal life events difficult to plan and structure, for example sleepovers with friends.

- **In your view, what are the benefits and downsides of the therapy under appraisal?**

Please see submission from Emma Lake, Cystic Fibrosis Trust, points 1,2,3,4 as I wish to agree with her submissions on this question.

- **How does the therapy compare with other therapies?**

Please see submission from Emma Lake, Cystic Fibrosis Trust as I wish to agree with her submission on this question.

- **What difference (if any) has the therapy under appraisal made to you?**

None as yet, but please see Emma Lake's submission on 'Availability of this technology' as I wish to agree with her submission on this question

- **What would be the implication if the therapy was not available?**

Please see submission from Emma Lake, Cystic Fibrosis Trust as I wish to agree with her submission on this question.

- **What is the impact on your life at home, socially and ability to work?**

Daily life is difficult and normal daily life has long been forgotten. Treatment always has to be planned and included into the routine and there is no respite as medications are required twice daily, every day of the year.

Each day around two hours of treatment have to be completed and in the long term we hope that technology will reduce these timescales while medication increases.

- **What is the impact on your family and friends?**

While the day to day impact on family and friends has been minimal they are all aware of [redacted]'s additional needs and offer support where they can. I have often been told that the knowledge of the burden of care for people living with CF has made them appreciate the ease of their life.