THE HEPATITIS C TRUST

27 CROSBY ROW, LONDON SE1 3YD

Tel: +44 (0)20 7089 6220 Fax: +44 (0)20 7089 6201

Website: www.hepctrust.org.uk

Submission to NICE for Multiple Technology Appraisal of peginterferon alfa and ribavirin for the treatment of chronic hepatitis C in children and young people aged 3-17 years

The Hepatitis C Trust, as a patient organisation, is making this submission to represent the views and concerns of children living with chronic hepatitis C and their parents. It does not address the issues of clinical effectiveness or cost effectiveness, except peripherally, but seeks to present the patient/carer perspective on issues that bear on the advantages and drawbacks of the treatments under consideration.

Children have higher rates of spontaneous clearance of hepatitis C and lower rates of advanced liver disease than adults so it could be argued there may be less clinical need for treatment in children than in adults. Nonetheless, cirrhosis has been observed in adolescents so there will be cases of children approaching cirrhosis where there is clear and important clinical need.

However, there are other reasons than clinical need for wanting to do treatment. In the case of children and their parents in our experience the primary one is stigma and discrimination. Children have the capacity to single out, tease, bully and otherwise make life miserable for anyone different and that very much includes a child with an infectious disease. Parents in our experience have a tendency therefore to keep a child's infection as secret as possible. This can be hugely stressful. One of our service users is a single mother with a hepatitis C positive son. When his hepatitis C status became commonly known at his school, his life was made so intolerable by his peers that she felt she had to move him. At his new school, she told only the headmaster. One day one of his new peers picked up a pair of compasses, stabbed her son in the arm and then stabbed 3 other children. The stabs did little damage through clothing but they broke the skin of course. His mother called us in high anxiety about whether she needed to tell the parents of the other stabbed children about her son's hepatitis C. She was absolutely convinced that, if she did that, she would have move to him again and that that would so unsettle him that it might effectively destroy his chances of good grades. Removing the fear of stigma and discrimination can therefore be an important reason for parents to want to put a child on treatment.

Since pegylated interferon and ribavirin has been shown to be at least as effective and well-tolerated in general in children as in adults, we would like to see NICE recommend

this treatment. Indeed, some evidence from Birmingham Children's Hospital suggests that it may be even more effective and well-tolerated in children aged 3-7 years.

However, recent data in June 2012 *Hepatology* has highlighted the effects of the treatment on height, weight and body mass. Mostly this returns to normal after treatment but not always. This has been the case with the daughter of one of our service users whose height has remained significantly below normal (and indeed whose general health has been significantly worse) since her successful pegylated interferon and ribavirin treatment.

A further issue we have encountered is the psychological effect of treatment on teenagers already experiencing the hormonal changes of that period. Interferon and ribavirin treatment is known to cause both depression and rage in some adults and we have seen this in teenagers. The son of one of our service users oscillated, in his mother's words, between a state of almost comatose inactivity and negativity and such an anger that he regularly destroyed the furniture in his bedroom during his one year of treatment.

We feel therefore that, while this treatment should be available to children and young people, they and their parents should be fully informed of the risks and side effects. This applies particularly to effects that may persist after the end of treatment such as height, weight and body mass issues. In our experience, clinical staff almost never discuss the possible long-term effects of interferon and ribavirin treatment, despite the fact that research we have done suggests significant numbers of patients experience long-term effects.