



UNITED KINGDOM THALASSAEMIA SOCIETY

19 The Broadway · Southgate Circus, London N 14 6PH

Tel: 020 8882 0011 · Fax: 020 8882 8618 · Email: office@ukts.org · www.ukts.org

National Institute for Health and Care Excellence
10 Spring Gardens
London
SW1A 2BU

20 November 2014

Dear Sir or Madam

Re: NICE evaluation of new drugs to combat hepatitis C virus

I am writing to you on behalf of thalassaemia patients in the UK, to request that NICE expedite the appraisal of the drugs Sofosbuvir, Simeprevir and Daclatasvir; including the combination of Ledipasvir with Sofosbuvir which is licensed in Europe under the name Harvoni.

Thalassaemia is a genetic blood condition which requires patients to receive red cell transfusions every 3 to 4 weeks, usually from babyhood and throughout their lives. Many thalassaemia patients in the UK were infected with HCV by blood transfusions administered by the NHS before screening for the virus was available. Some have already died and many of the others are suffering from chronic and worsening liver disease which has not responded to treatment using currently licensed therapies.

The above named drugs have been shown to be safe and highly effective in clinical trials and there is growing evidence that they can be life-saving. Furthermore the drugs have been shown to be safe and effective in all genotypes of HCV.

Many of our patients are caught in a desperate race against time; hoping that new drugs to treat their condition will become available before their liver disease reaches the final, fatal stage. In most cases these drugs are their last hope. These drugs are now licensed by the EMA but are not yet funded by the NHS while they await appraisal for cost effectiveness by NICE. We believe that the NHS owes a special duty of care to thalassaemia patients with HCV; having (albeit unknowingly) caused them to be infected with the virus.

I would be grateful to receive a reply indicating when NICE will be considering the evaluating of these drugs, what factors will be taken into consideration; and how the UK Thalassaemia Society can take part in any consultative process.

Yours faithfully

Gabriel Theophanous
President, UK Thalassaemia Society

Living with Thalassaemia

A Charity Organisation · Registered charity number: 275107

Patrons: Lady Diana Brittan (BE, Baroness Shreeela Flather JP, DL, Mr George Michael, Mr Panko) Udhas, Mr Peter Polycarpou, Mr Mark Tully