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Donna Barnes
Administrator - Technology Appraisals Committee D
National Institute for Health and Care Excellence
Level 1A
City Tower
Piccadilly Plaza
Manchester M1 4BT

16th October 2013

Dear Donna

Re: **NICE STA: Hepatic encephalopathy (maintenance treatment) - Rifaximin [ID496]**

In response to NICE's Appraisal Consultation Document I am writing as a representative of people with, and affected by, liver disease to express concern that you are not recommending Rifaximin as a treatment for hepatic encephalopathy (HE). As previously expressed, in responses and at the appraisal committee meeting, Rifaximin offers significant improvement in the treatment of people with HE with the stabilization and potential improvement in their health but also a significant improvement on current treatment with laxatives.

As evidence shows treatment with Rifaximin has shown a very positive effect on the patient's, and their families, quality of life.

HE has a significant detrimental effect on both the patient and their families symptoms include:

- Confusion
- Forgetfulness
- Personality or mood changes
- Poor concentration
- Poor judgment
- Stale or sweet odored breath
- Change in sleep patterns
- Worsening of handwriting or small hand movements

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But more severe symptoms may include:

- Unusual movements or shaking of hands or arms (also known as "flapping")
- Extreme anxiety
- Seizures
- Severe confusion
- Sleepiness or fatigue
- Severe personality changes
- Jumbled and slurred speech
- Slow movement

Many patients with HE maybe at an end of life stage of their disease and dying with most of these symptoms significantly decreases their quality of life. Current treatment with lactulose can add to the indignity and poor quality of life causing

- Bloating
- Diarrhoea
- urgency to defecate
- flatulence
- and sometimes constipation / lazy bowel

Clinical evidence presented at the recent British Association for the Study of the Liver conference has shown that Rifaximin can have significant improvement in all of these symptoms of HE, better quality of life and decreasing the burden on care givers and in some cases significantly improve their prognosis.

Following further evidence and due consideration I hope that the appraisal committee will review it's decision and approve Rifaximin as a NICE recommended treatment for HE.

Thank you for consulting with us.
Kind regards

[redacted]

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