[redacted]
Telephone: [redacted]
Helpline: [redacted]
Fax: [redacted]
Email: [redacted]
www.britishlivertrust.org.uk

BRITISH LIVER TRUST

Pioneering Liver Health

Kate Moore
Project Manager - Technology Appraisals Committee D
National Institute for Health and Care Excellence
Level 1A
City Tower
Piccadilly Plaza
Manchester M1 4BT

Sent by email

24th October 2013

Dear Kate

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

Thank you for sending me the additional papers for the 2nd committee meeting and for allowing me to send in this written statement as I am unfortunately unable to attend as I am co-chairing the oral session of the All Party Parliamentary Group on Hepatology's Liver Inquiry when your meeting is taking place.

I would like to reiterate previous submissions that the British Liver Trust has made that highlights the significant improvement in patient care that Rifaximin has when used as a treatment for Hepatic Encephalopathy. I won't repeat all of the issues that affect people with HE but would ask that the committee do consider those listed in the last submission.

For the patients and families that I have spoken with Hepatic Encephalopathy (HE) is by far the worst fear they have, much more daunting and scary than death itself. The fears that we all hear about people developing dementia / Alzheimer's disease are the same for people who may get or be affected by HE. Many who have been admitted to hospital during the course of their liver disease will have seen other patients with HE and the mental and physical symptoms that are obvious and are consequently very fearful of whether this may happen to them. In addition many will have seen the side effects many people suffer with from the current treatment with laxatives.

Registered Charity England and Wales 298858, Scotland SC042140
Company Limited by Guarantee Registered in England and Wales, Company No 2227706
Registered Office [redacted]

Charity Staff Foundation
CSVA 2013 Campaigner of the Year

Love Your Liver a British Liver Trust campaign

[redacted]
Telephone: [redacted]
Helpline: [redacted]
Fax: [redacted]
Email: [redacted]
www.britishlivertrust.org.uk

BRITISH LIVER TRUST

Pioneering Liver Health

Many patients that have benefitted from Rifaximin have had significant improvement in both their mental and physical health – some of whom who have been considered critically ill have gone on to live longer much more enjoyable lives with minimal or without HE. A woman whose husband was treated with Rifaximin for his HE before he did die of liver cancer commented "Thank God he didn't die when he had dementia (encephalopathy) it was great we got him back and saw him die as himself rather than that other unrecognisable thing he became."

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

.
Kind regards

Andrew Langford PhD
Chief Executive

Charity Staff Foundation
CSVA 2013 Campaigner of the Year
Love Your Liver a British Liver Trust campaign

Registered Charity England and Wales 298858, Scotland SC042140
Company Limited by Guarantee Registered in England and Wales, Company No 2227706
Registered Office [redacted]