Sent by email to: xxx.xxx@srft.nhs.uk

xx xxxx xxx

Consultant Adult Metabolic Medicine,

Honorary Senior Lecturer, The Mark Holland Metabolic Unit,

Salford Royal Foundation NHS Trust,

Ladywell NW2- 2nd Floor,

Salford, UK. M6 8HD

31 March 2017

Dear xx xxxx

**Final Evaluation Determination: Sebelipase alfa for treating lysosomal acid lipase deficiency (LAL D)**

Thank you for your email of 24 March, to xxx xxx in response to my letter of 9 March giving my initial view on the points in your letter of 1 March. I confirm that those points are not valid.

I understand your disappointment that the points you made will not be going forward to an appeal panel. However, as I expect you know, a number of organisations including the company the four paediatric metabolic units supported by the BIMDG, and the Society for Mucopolysaccharide Diseases have made several points about the process and reasonableness of the Committee’s conclusions which will be heard at an oral hearing on 25 April.

I also understand and sympathise with the point you make about differences between treatments that are subject to appraisal or evaluation by NICE and those that are not. Although NICE manages the process for identifying treatments for appraisal, decisions on what NICE should appraise are made by the Department of Health who must themselves take into account NICE’s own capacity constraints.

I hope you find this letter not wholly disappointing. Your engagement on the issue is most appreciated.

Yours sincerely

Andy McKeon

Vice-Chair

National Institute for Health and Care Excellence