I'm not sure whether I'm on the right forum for my concerns but if not could you please forward on to the correct team urgently, as apparently any representations need to be made by 5PM today.
My 15 year old son has suffered his whole life with epilepsy & mild autism and when he first contracted ulcerated colitis this was further aggravated by the stress he suffers due to his underlying health problems. His ulcerated colitis is now acute and is not only in his bowel, but also in his stomach and esophagus too. Great Ormond Street hospital has recommended treatment with the use of infliximab as a last resort, and the consultant believes that this has a high possibility of alleviating my son's symptoms, the only other option would be to have colostomy bag. My son has been through enough during his short life, with the other medications provided (steroids, Salofalk, Imuran) giving him so many side effects, and he is now losing his hair He has the most miserable of existencies when he is suffering a flare up of his symptoms, (which occur whenever he's not on steroids) and he deserves the chance to have as normal life as is possible. If the infliximab treatment successfully treats the symptoms then he should have every entitlement to continued treatment once he can no longer be seen at Great Ormond Street (when he's 16 ?). It is a disgrace that the NHS do not intend to support this treatment on account of the cost, especially since they do so for Chron's disease where the symptons are identical and as life changing as those suffered by my poor son. I would urge you to rethink. Thank you.