

## Report on the APPG meeting of the 11th December 2012 at Portcullis House,

*written by Silvia Lane and Malcolm Smith, LDNNow representatives*

It's happened, our long awaited first APPG (All Party Parliamentary Group) meeting in Westminster has taken place. The 11th of December 2012 turned out to be a beautiful day, a sparkling, though cold, setting for hopefully the start of a very good thing, and the start for some people to begin to take notice of LDN. Five of us LDNers and LDN associates had met outside the entrance and after security checks were escorted into and through Portcullis House and into an office. The whole transferring from the reception area to the office we met in happened in a bit of a rush and my memories are blurred, I know that I would have no chance of finding my way through this maze on my own, nor will I ever have the opportunity to try. There are a lot of safety measures, body scans, photos, coat and bag scanning (and yes, you do need to take your phone and wallet out of your pocket, as some of us discovered) in place and Joe Bloggs is definitely not wanted unaccompanied.



We were kindly collected and escorted up to the office by David Griffin, Nia Griffith's secretary and Nia Griffith MP for Llanelli (Labour) herself, which was very nice of her. Dr Tom Gilhooly was already there, the room was set up and there were a few very young people there, which turned out to be other MPs' researchers. Two more MPs (Annette Brooke MP for Mid Dorset (Lib/Dem) and Julian Huppert MP for Cambridge (Lib/Dem)) were also there, left fairly early on though, presumably because they had to attend some parliamentary function/meeting. The researchers were sent by Stephen Crabb MP for Pembrokeshire, Pauline Latham MP for Mid Derbyshire and John Howell, MP for South Oxfordshire. It was a great shame they couldn't be there in person and after the meeting we just hoped that these young researchers related the information they had heard back to their MPs. Also present, though slightly remote via Skype link, were Jayne Crocker and Andrew Barnet from LDNNow.

Dr. Tom Gilhooly, who had flown down from Glasgow that morning, gave a very good introduction to the problems we are facing with LDN and its acceptance by our doctors. He highlighted the excellent safety case that both Naltrexone and LDN have and the wide range of uses for LDN. He explained that many doctors are reluctant to prescribe LDN because they are not familiar with it and prefer to take the safe option of only prescribing licensed products. He felt that if doctors were aware of the safety record of Naltrexone and LDN there would be less reluctance to prescribe it.

The LDNers then described their experience with LDN and their experiences in obtaining prescriptions for LDN. Malcolm explained that NICE has been tasked with assessing some unlicensed products for the NHS – something that had been mentioned in Simon Burns' response during the adjournment debate last year. Dr Gilhooly was interested in this approach and indicated that a formal report from NICE on safety issues would go a long way to reassuring doctors and encouraging them to prescribe LDN.

Nia Griffith indicated that Lord Saatchi is intending to introduce a private member's bill to change the law to make it easier for doctors to adopt novel and innovative treatments, particularly for cancer. It was felt that his ambitions matched those of the LDN movement in removing the likelihood of censure for doctors who "think outside the white lines".

The conclusion of this auspicious day, the first APPG meeting to discuss LDN issues, is thus: Nia Griffiths MP will lobby some of her colleagues to take on the roles of officers in the APPG. Several names of possible candidates of all parties were mentioned, some of the MPs unfortunately have positions in government which prevents them from belonging to an APPG. Nia also undertook to contact the Department of Health about getting NICE to assess LDN and to contact Lord Saatchi about joining the APPG.