

Facebook testimonials following very successful FDSS meetings on 18/19 November 2017



20 November at 08:08: Congratulations to all involved in arranging such an informative event & to the Doctors who gave us their time. Thank you again all.

20 November at 08:22: Am very grateful and appreciative of the opportunity to talk to these doctors directly and keep up to date with a rare disease. It makes SUCH a difference. I feel supported. Thank you for all your hard work in arranging this and to doctors for giving us their valuable time.

20 November at 08:27: Well done for organising such a fantastic event. So important to keep in touch, share experience and have the opportunity to listen to and speak with experts. ·

20 November at 08:43: It was so good. Thanks to the organisers.

20 November at 09:00: Very informative and great to meet new people and to meet the doctors.

20 November at 09:01: It was fantastic. Thank you! So sorry I couldn't stay for longer.

20 November: Amazing work everyone sorry I could not attend

20 November at 11:32: CONGRATULATIONS!!! It's been a pleasure to take part in such an interesting and well-organized event. Thanks a bunch to the organizers (Jamie, Michael, Heather...). You've made us feel at home.

Thanks so much to the doctors Collins, Boyce and Stanton, always so helpful, sensitive and close to patients. Can't forget to mention Valter Dal Pos (EAMAS) and Deanna Portero (executive director of FD Foundation) for sharing and giving us some useful and practical information. We are really proud to be part of this great family (FD).

I'll translate it into Spanish for the Spanish speaking community:

ENHORABUENA!!!

Ha sido un placer haber tomado parte en un evento tan interesante y bien organizado. Muchísimas gracias a los organizadores (Jamie, Michael, Heather,...). Nos hemos sentido como en casa. Muchas gracias a los doctores Collins, Boyce y Stanton, siempre dispuestos a ayudar, tan sensibles y cercanos a los pacientes. No nos podemos olvidar de Valter Dal Pos (EAMAS) y de Deanna Portero (Directora ejecutiva de FD Foundation) por compartir y aconsejarnos tan sabiamente. Estamos realmente orgullosos de formar parte de esta gran familia de FD.

20 November at 20:00: Thank you so much to all that had any part to play in organising the day from the venue, food, speakers, one to ones it was all so well put together and what a privilege to have a personal meeting with a team of experts in FD!! Absolutely makes a huge difference to feeling we are not so rare and alone we are getting somewhere! Onwards and upwards thanks to you guys x Was Lovely to see Ann appreciated for starting it all too so many years ago!👏👏

20 November at 20:27: My thanks to one and all for organising such a fantastic event. The information sharing by the drs was enlightening and answered a lot of questions for us as a family. I felt proud to be amongst you all; as a parent I thank all who took time out to speak to me and for your patience in listening to me. To all the FD warriors I wish you well and I hope to see you all again in the future.

20 November at 20:51: Well done x any answers s please to my questions?

21 November at 08:19: Thanks you so much Jamie, Michael and everyone involved in organizing this event. It is amazing what you have achieved and I cannot thank you enough. It was my first time ever meeting experts on the fd and other patients and I still can't stop thinking about it. I've made an appointment with my gp as I need to put things in place and make sure I am getting the right treatment; before this weekend I thought there is nothing I can do but now I feel more empowered to get the help I need.

Response from Jamie Watson: Thank you all for your lovely comments it really means a lot. It really is all down to Ann though who started this all in 2007. We could use all the help we can get to keep things going and arrange more meetings like this in the future and support the International Consortium that are doing such great work in creating a medical pathway for use by all newly diagnosed as well as current sufferers. You all remember that initial fear of not knowing what we are dealing with. So if anyone feels like getting more involved in the future we could sure use some help :-)