

Year End Update on the Fibrous Dysplasia Support Society

Hello Everyone,

I hope that you have all had a good year with no, or not too many, health problems.

It has been an exciting year for the Society. As most of you know, a team at Oxford have set up a research project called RUDY, which is trying to obtain data from those of us with rare bone conditions. There was an initial kick off meeting in March to which three of us went to represent FD/MAS, two patients and a parent of a patient. There were patients and representatives of other bone conditions there too. The most exciting thing, for me, about the day of presentations and playing with the data base was the number of senior health professionals there, their enthusiasm for the project and the high regard they had for, I quote ' These fantastic patients'.

RUDY went live for patients with FD in September and by the end of November there were 27 of us signed up. For those of you who haven't signed up, please consider it. Especially as yesterday the Genome 100,000 project was announced by the Department of Health. Dr Javaid, the lead in the RUDY project, sent me this note (Genome information) – see <http://goo.gl/K26ad6>.

We had our annual meeting on the 11th of October in Oxford. Dr Javaid attended and gave a presentation on RUDY. It was a successful meeting and a lot of fun was had by all as we tried to find our missing lunch. We got it in the end! I know that for many who attend these meetings it is the first time that they have ever met anyone else with the condition and several of the attendees had travelled long distances to get there. I hope that they found the day rewarding and look forward to meeting them again.

Several of us, over the years, have been in contact with Christoph Kloth, a young German doctor training to be a Maxillo-Facial Surgeon, he sent me a note which he asked me to forward to you all – see <http://goo.gl/zQc3UE>.

There were some comments at the meeting that our web site is not interesting enough. One suggestion was to have more photos. Our web site man can put photos on a rolling phase so if any of you have any action shots of yourselves that you feel could encourage other patients, and are happy to let the world see them, please let me have a copy and we will put them out there. I would welcome any other suggestions on how to make the web site more appealing so, if you can think of anything please let me know.

It's a beautiful day here today and the forecast for Christmas Day is that it will be lovely too. I hope that you all have a great day and wish you a healthy and happy 2015.

With best wishes,

Ann Underhill (Chair, FDSSUK), 23rd December 2014