

5th European Alpha1 Congress

Friday the 9th July saw representatives of the 11 member countries of Alfa Europe Federation, gather at the Kensington Hilton Hotel, London for the Federation's Annual Meeting. The meeting was the coming together of representatives of the various European Alpha 1 patient associations, we come together to review the year, plan for the coming year and share knowledge and experiences. At this year's meeting we again had an election for the Federation President, as last year's election was held mid way through the previous President's term of office. I am pleased to say the Alpha 1 Awareness UK's Chairman Alan, was elected once more to the position of President, this time for a full 2 year term of office.

Once the official business of the AGM was over it was time for delegates to come together with old friends and make new ones.

This year was special for us at Alpha 1 Awareness, because we were the host country, this meant we were joined by a large number of our members, who arrived in time for dinner on Friday evening. Quite a mixture of people, but so it was that over 100 people sat down to dinner, European Federation delegates, AAW members, representatives from Talecris and some of our speakers, who had arrived for the presentations on Saturday, many strangers to each other, but if you had walked in to the room during dinner you would have thought it was a gathering of old friends, so great was the talking and laughter.....a quote about the evening summed it up "*...Alphas are so friendly have wonderful sense of humour and enjoy life to the full, that was so obvious....*" Certainly when one went around the tables during the evening, there was not a silent table in the room, everyone had introduced themselves to each other and were getting along like old friends.



This was an opportunity to get to know one another and to chat about experiences of diagnosis, treatment and generally of the problems of living with Alpha1. It may seem that the programme of presentations is the key event of a congress but the social gathering is of equal importance.

PRESENTATIONS

The scientific programme started on Saturday morning. After the formal opening the young children who came along with their parents were introduced to the nannies of the child-minding service and they left the hotel to spend the day in London. The weather was warm and sunny and they passed an enjoyable day at London Zoo.

The first speaker was **Professor Sabina Janciauskiene**.



Sabina has a special relationship with Alpha1 Awareness: she was the first speaker at our first Information Day held in Bristol in 2009. She continues to support our efforts and it was a great pleasure to introduce her yet again to our members. Her presentation covered the period over which Alpha1 Antitrypsin Deficiency was first identified and the genetic causes

explored. She went on to outline what is known about the physiology of the degradation within the lungs.

Next we heard from **Doctor Dino Hadzic** from King's College Hospital in London.

Dino spoke about the liver damage that can occur in Alpha babies. Most Alpha babies do not have liver problems – other than a certain amount of jaundice which is found in non-Alpha children. There were a number of parents of Alpha children and Dino answered their many questions.



After a coffee break **Professor David Lomas** from Cambridge University spoke about *The Cure*.



David has done some of the ground-breaking scientific research into AATD and it was encouraging to hear his views and his prediction that a cure will be found in the next ten years. He was pleased that this was the first opportunity that he had to give his insights to a large group of UK Alphas.

The final presentation of the morning was from **Doctor Heinz Steveling** from Essen in Germany.

Doctor Steveling was one of the first doctors in Germany to treat Alphas with Prolastin to replace the missing alpha1 antitrypsin in their blood stream. He showed figures, based on his clinical experience over twenty years, which showed the benefit of replacement therapy in extending life. Studies in other countries confirm these findings.



After lunch **Melissa Hillier** from Genetic Alliance UK gave us in insight into the workings of her group.



Melissa also has a special relationship with the charity; she too spoke at our first Information Day in Bristol. She explained how the Genetic Alliance lobbies politicians and decision makers to reform the health care system and give patients more powers. As in Bristol the thorny issue of insurance for Alphas was discussed.

The next speaker was to have been **John Walsh** who is the Chief Executive Officer of the Alpha-1 Foundation in the USA. John was one of the founders of the Foundation and has been the driving force behind its growth and success. The Foundation funds many research programmes. Sadly for us, John contracted a lung infection shortly before he was due to fly to London. We were denied his views on patient empowerment and his experiences of pressing for better treatment. We hope to see John in the United Kingdom in the not-to-distant future. We sent John our best wishes for a speedy recovery and have posted to him the Thank You Gift that we give to all our speakers. The gift was a piece of glassware from the famous Bristol Blue Factory.

We had a very powerful and personal speech from a UK Alpha, **Neil**. Neil spoke of his experiences with GPs and of going to ADAPT. However, he directed his stinging comments at our health care system that spends millions on treating drunken Saturday night revellers but ignores people with serious illnesses. The revellers choose to put their health at risk; Alphas have no choice in the matter.

Lin spoke of her experience as a carer.

We all are carers at some points in our life; parents for children, adults for ageing relatives, more often than not it is to the people who mean the most to us, our partners or spouses. But Lin spoke primarily about carers for Alphas, and carers for our community for Alphas. There were light moments in Lin's talk, but the sincerity of her speech left few dry eyes in the room.

Professor Sabina Janciauskiene Closed the scientific programme by summarising what we know about Alpha1, what we don't know and possible future directions.



CLOSING

On time with the end of the presentations the children of attendees returned from London Zoo. Members of the AAW board presented each child with a Teddy Bear complete with his tee-shirt showing his name: 'Alphie'.

The congress was widely acclaimed as a great success.