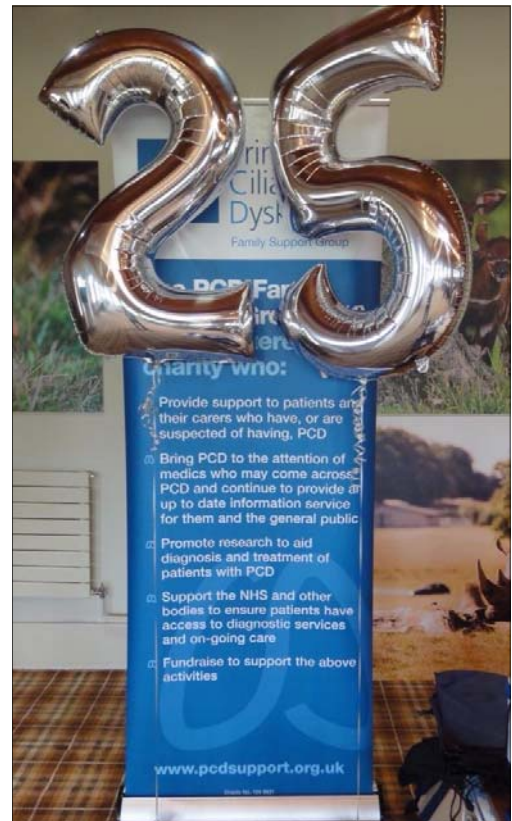
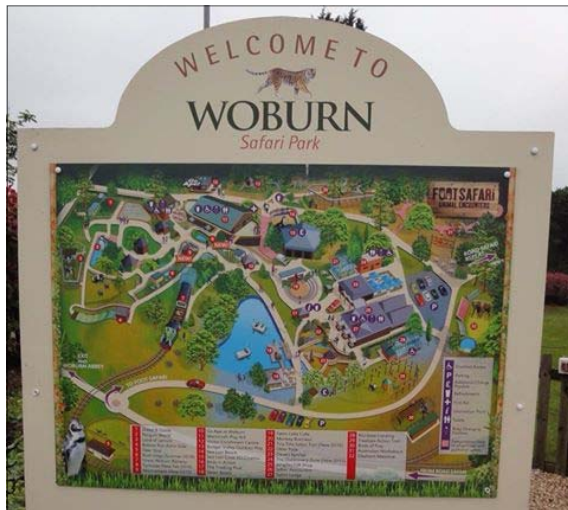


# PCD Family Support Group Celebrates 25 years!



We celebrated our 25<sup>th</sup> anniversary of the founding of the PCD Family Support Group at Woburn Safari Park, on 4<sup>th</sup> June, with more families attending than ever before. It was a great success! The children had a wonderful time seeing all the animals, especially the monkeys who hitched rides on our cars as we drove around. We then had a delicious lunch, where everyone had an opportunity to chat to others with PCD, researchers and medics, followed by our AGM.

*One of our young PCD patients said “ I don’t know anyone at school with PCD, and it is nice to meet other people with PCD so I don’t feel so alone”*

Fiona, our Chairman since 2004, welcomed everyone and outlined our activities. She



explained that we have continued to support families via the website, email, newsletters, telephone and social media. We have raised awareness of the condition and hosted the PCD Medical Board Meeting, attended the BTS Conference, the House of Commons Rare Diseases Day, and various other events including supporting Jeans for Genes Day. We have supported and promoted research by helping to recruit patients for PCD research, continued to work as part of CAUK, and represented patients at the Brompton Biomedical Research Unit for the

Chronic Suppurative Lung Disease Consortium, BestCilia and the British Lung Foundation. We have worked towards obtaining the best care for our patients by supporting the diagnostic and paediatric management service, and we are working with the

Scottish NHS to improve access to diagnostic testing and management of the condition. We have also helped to obtain adult funding which we hope will be in place in 2016. We are very excited about this, as it will be a major improvement in the care of adult PCD patients.



We have held various fund raising events to support these activities including, marathons, sponsored walks, company charity of the year, jewellery sales and regular giving through direct debits. Mick Wilkin, Treasurer, then gave us a financial review and explained that we are a going concern with cash reserves of around £31k. The accounts were approved and the independent examiners, Dove Naish, were re-appointed.

Fiona outlined the plans for 2016/17 which include continuing to work with the NHS in supporting the diagnostic and paediatric service, the development of the service in Scotland and Wales, helping with transition and the adult service. The Chairman, Secretary, Treasurer and Committee Members were re-elected. Fiona welcomed our newest committee members including Nhu Tran, Jacob Fries, Lucy Dixon and Charlotte Kewell. Fiona asked for more volunteers and new committee members.

Fiona explained that the group is very proud of the small part they have made in improving the lives of people with PCD including the introduction of the diagnostic service, paediatric management service, research, and the adult service in 2016. Fiona thanked Carol Polak for founding the family support group in 1991 and chairing it until 2001. They then cut the cake together!



This is the PCD Family Support Group Committee 2016 celebrating 25 years with Carol Polak!



When the cake had been eaten, everyone went back to see more of the animals!



By Myra Tipping, 10th June 2016