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Elizabeth Bray
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26th June 2015

Dear Elizabeth, Trustees and members

Re: Travel Scholarship for ATS 2015

I would like to express my sincere thanks to Action for Pulmonary Fibrosis for supporting my attendance at ATS through the award of a travel scholarship. Attending international conferences is exceedingly important for me at this stage of my research career. Travelling to ATS in Denver provided an invaluable opportunity to network, in addition to academic learning, which was twofold: disease specific in relation to IPF; and methodological, in terms of the development and analysis of Patient reported outcome measures.

I did not arrive in Denver until the Saturday evening. Sadly it was a somewhat wet and windy city for the duration of the conference. I started my morning on the Sunday with a session co-chaired by my esteemed leader Professor Athol Wells. Professor Talmadge King was the featured speaker for this session and presented data from the Panther, ASCEND and INPULSIS trials. He spoke of the challenges of the molecular targets of existing therapies remaining unknown and the need for new paradigm for effective management of IPF. He estimated that it would be 5 years before the next new drug treatment for IPF would emerge and that in the interim there was a need to manage IPF and symptoms associated with it more aggressively and at the earliest possible opportunity. He also mentioned in brief the challenges of defining exacerbation in IPF and the importance of collecting data on the impact of exacerbations on quality of life to gain greater insight.

Steven Nathan, an exceedingly eloquent and engaging speaker, discussed the reliability of FVC as a predictor for disease progression o IPF and the challenges of imputing missing FVC data. He argued that patients with a 10% decline in FVC predicted taking Pirfenidone should be allowed to continue.

Lisa Lancaster discussed the tolerance of side effects of Pirfenidone in patients on therapy reporting just a 15% discontinuation rate in data presented form 5 clinical trials which included 1,229 participants. She spoke in favour of the compassionate use of Pirfenidone.

I missed the discussions on Nintedanib in order to attend the ILD clinical year in Review presented by Toby Maher. Toby presented the landmark studies of ASCEND and INPULSIS against the back drop of the PANTHER study – he spoke of the challenge of selecting the appropriate and most meaningful endpoints in clinical trials in ILD and specifically IPF. Toby then went on to present the paper published in Lancet Respiratory Medicine [doi: 10.1016/S2213-2600(14)70069-4] which discussed the lung microbiome and disease progression in idiopathic pulmonary fibrosis in the context of an analysis of the COMET data. He cited the challenges of studying anti-microbial agents and the need to repeat the work done by Andrew Wilson et al on co-trimoxazole with lower dosing regimens. Toby also presented the retrospective large multicentre UK study undertaken by the BRILL network which reported on associations, prognostic factors and physiological and radiological characteristics of Rheumatoid arthritis-related interstitial lung disease. Toby highlighted diagnostic challenges and the need to think laterally to assist with early diagnosis. The final paper that he presented was from Nature on pulmonary macrophage transplantation in mice. Toby described GM-CSF signalling and reported that this study made an important contribution to understanding homeostatic processes in the human lung.

I attended an additional Meet the professor Seminar with Professor Andrew Limper from the Mayo clinic Rochester on Case management studies in symptom control in IPF – He focussed primarily on cough followed by breathlessness and hypoxemia and then “loss of personal control” encompassing depression. He cited the key studies that have been published on cough (Key et al 2010; Hope Gill 2003; Lee 2013) – he was critical of the sample size in the Hope Gill study and spoke of the challenges of using thalidomide, not only the teratotoxicity but side effects of constipation and dizziness. The Mayo clinic uses nebulised lidocaine for dry irritating cough and nebulised saline and physio for productive cough. Prof Limper acknowledged the need for new therapies and expressed interest in the Effect of Pirfenidone on Cough in Patients with IPF study hosted by ERASMUS and soon to be recruiting at the Brompton [https://clinicaltrials.gov/ct2/show/NCT02009293].

In relation to breathlessness Prof Limper discussed the need for evidence on the benefits of Pulmonary Rehabilitation. He cited the studies by Mahler on physiology of breathlessness and Nishyama. He spoke about the benefits of optiflow (high flow nasal oxygen) and the positive benefit this brings to palliative care. He presented a synopsis of the literature but advocated the use of opioids should be specific to each patient in terms of their individual needs and tolerance. There was some off the record discussion about marijuana.

At the Mayo the PHQ9 is used as a screening tool for depression – the focus on therapy is to enable the patient to regain control. Psycho social interventions are offered including CBT; psychologist or psychiatric assessment; exercise +/- pulmonary rehab with judicious use of anti-depressants. Mindfulness is offered for stress reduction. Overall a multi modality approach is advocated.

The multi-modality approach was picked up as a theme in the Nursing Year in Review. This was not focussed on ILD but rather breathlessness in obstructive lung diseases and sleep disordered breathing. Professor Ginger Carrieri-kohlman presented research on breathlessness from 1985 to the present day noting that an ATS statement on the management of breathlessness in Palliative care was not published until 2012. There was discussion on the language of breathlessness, contemporary tools used to quantify breathlessness and treatment including non-pharmacological approaches. The need for more research, specifically nurse led research was discussed.

I presented my work on Monday morning and on Tuesday Afternoon. Both posters generated discussion and interest – the need for an IPF specific PROM is acknowledged. I received some helpful suggestions and valuable critical feedback. In the immediate future I have had abstracts accepted at international conferences in the autumn to keep this work alive and need to focus on writing papers over the next few months.

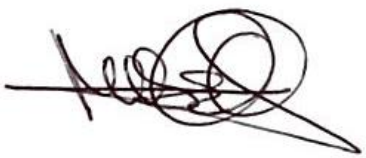
I was invited to join the American thoracic Society Nursing Assembly Program Committee and commenced a 3 year term of office commencing on 18th May 2015. This will give me the opportunity to influence programme content in relation to nursing and allied health professional intestinal lung disease research.

After ATS I travelled to New Orleans where I had been invited to talk about Symptom Management and Quality of Life at an Autoimmune Lung Symposium facilitated by Tulane University. This was the first regional conference on the new classification of *Interstitial Pneumonia with Autoimmune Features* (IPAF), now a designated ATS/ERS classification for Idiopathic Interstitial Pneumonitis (IIP). The symposia provided education and skill-building for the recognition of current and prospective treatments of IPAF, and appropriate outcome measures. Attendees were patients, medical students / trainees and nurses. Whilst in New Orleans I had the opportunity to co facilitate a focus group of patients who are participating in a transatlantic study to explore perceptions of death / survival vs quality of life in IPF. I am busy transcribing audio recordings but this is interesting work in terms of similarities and differences across cultures which appear to be emerging.

I finished the trip with a visit to Professor Virginia Steen's clinic at Pascarella Health Centre Georgetown Washington DC and took the opportunity to attend the Pulmonology / Rheumatology Conference where amongst diagnostic challenges there was much discussion on patient reported outcomes.

There is a perception that the IPF PRoM study will contribute positively to the IPF community and so I again thank you for your support. I have strengthened my collaboration with Tulane University and I am nurturing others so this was an exceedingly worthwhile trip.

Sincerely



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Abstract Detail:

Russell AM, Sanderson TC, Wells AU, Fleming S, Maher TM, Cullinan P (2015) Developing a Patient Reported Outcome Measure (PRoM) in Idiopathic Pulmonary Fibrosis (IPF): an Iterative Process" In American Thoracic Society International Conference Denver Poster Discussion AJRCCM 191:2015; A2504 http://www.atsjournals.org/doi/abs/10.1164/ajrccm-conference.2015.191.1_MeetingAbstracts.A2504

Russell AM, Doyle AM, Fleming S, .Burdett C, Ross D, Gane J, Aden Z, Foody M, Maher TM, Cullinan P (2015) Development of a Patient Reported Outcome Measure (PRoM) in Idiopathic Pulmonary Fibrosis (IPF): Incorporating a Research Partnership with Patients" In: American Thoracic Society International Conference Denver Poster Discussion AJRCCM 191:2015; A5190 http://www.atsjournals.org/doi/abs/10.1164/ajrccm-conference.2015.191.1_MeetingAbstracts.A5190

Saketkoo LA, Escorpizo R, Keen KJ , Fligelstone K, Lammi MR, LeSage D, Russell AM , Birring SS, Sarver C , Varga J , Distler O (2015) The World Health Organization (WHO) International Classification of Functioning, Disability, and Health (ICF) Core Sets for Connective Tissue Disease Interstitial Lung Disease (CTDILD) &Idiopathic Pulmonary Fibrosis (IPF) A Necessary Map to Health Care Provision in the Era of ICD11 In: American Thoracic Society International Conference Denver Poster Discussion AJRCCM 191:2015;A65478 http://www.atsjournals.org/doi/abs/10.1164/ajrccm-conference.2015.191.1_MeetingAbstracts.A2514