



Standing from left to right: Stanley Fahn, MD; C. Warren Olanow, MD; Howard Federoff, MD, PhD; Michael J. Fox; Marian Emr; Robin Elliott, Elizabeth Pollard, Congress Manager. Seated: Andrew Lees, MD; Deborah Brooks

Oliver Sacks, MD speaking at the Opening Ceremony in 2006



“Perhaps one of the WPC 2010 faculty members in Glasgow might be the one who cracks the science and finds the cure – wouldn’t that keep you glued to your seat?”

— Elizabeth ‘Eli’ Pollard

Most medical meetings keep those who research and treat the disease separate from those who live with it. But now the World Parkinson Congress could be changing the shape of audiences to come. Rob Spalding reports

And the patients came too...



The well-disciplined line for registration

rally the PD community behind this mission. With the support of nearly 75 high-level researchers, health professionals, patients and caregivers, the inaugural World Parkinson Congress (WPC) was launched in Washington in 2006 and next year will happen again in Glasgow, Scotland.

The WPC is designed and hosted by the World Parkinson Coalition Inc., a legal, non-profit organisation integrating the existing groups within the PD community and housed in the New York office of the Parkinson's Disease Foundation.

“The cross-pollination of everyone in the global PD community allows for an exchange of ideas that we hope will spark innovative relationships and research projects that will ultimately expedite the discovery of the cause and cure for PD,” says Pollard.

Quite often, scientists spend so much time focused on the science that they never actually meet a person living with

PD. The WPC puts a ‘face’ on the disease for these scientists.

“One patient who attended the WPC 2006 said he often felt alone with the disease and angry that no one was doing anything,” recalled Pollard. “Coming to the Congress opened his eyes to all the great scientists who have dedicated their lives trying to find a cure for PD... and it gave him hope.

“Perhaps one of the WPC 2010 faculty members in Glasgow might be the person who cracks the science and finds the cure,” mused Pollard. “Wouldn’t that keep you glued to your seat?”

Attendance fees are charged on a sliding scale. Some 3,150 people from 56 countries found it worthwhile in 2006, more are expected in 2010.

“PD can be a very impoverishing disease, especially if you are diagnosed at a younger age and have to stop working,” states Pollard. “Around 5 per cent of the people diagnosed with PD are under the

age of 50, some in their 20s and 30s. It is a chronic illness that can rob people of the ability to work so we try to make it as reasonable as possible for people who want to attend to be able to attend.”

In Glasgow, Concorde (now Congrex) will act as local PCO and organise housing along with other duties.

Some 37 committee members have contributed to the conference programme and another 40 have guided the logistics. Speakers are nominated and invited based on a number of aspects such as who is the highest ranking expert and who has current research. Another requirement is someone who can speak effectively to a mixed audience of health professionals **and** patients.

In 2006, only 11 out of 284 invited speakers turned down the invitation. “Unless it conflicts with another scheduled event, invited speakers generally say yes,” says Pollard. “We cover registration and hotel expenses and a stipend to help defray flight costs for speakers, but do not give

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Stanley Fahn, MD

honoraria, not even to keynote speakers.”

In 2006 a pre-Congress day featured an hour of speeches (Michael J. Fox and Oliver Sacks, MD included) followed by a welcome reception in the Exhibit Hall. Next year, the final evening will feature a PD Game Night hosted by one of the organisational partners, The Cure Parkinson's Trust.

A hosted dinner to say thank you to the WPC leadership, made up entirely of volunteers, and a reception for the 100 plus organisational partners from 30 countries, are also on the schedule.

What is the new format trying to achieve? “Ultimately, like every other Parkinson's organisation on the planet, we want to put ourselves out of business,” declares Pollard. “We want to help generate collaborative relationships and novel ideas that will expedite the discovery of a cure. But until that happens, we hope to see that those who live with PD have access to the best health care and highest quality of life.” **ami**