

World Congress of Nephrology 2019 – My report

I found the World Congress of Nephrology 2019 innovative and inclusive.

I appreciated the attention towards disadvantaged people like patients requiring dialysis and living in remote areas or in highly populated countries where haemodialysis cannot be performed more than 2 times per week as it should.

However, in my view the highlight of the congress was the effort that the scientific community is making in involving patients in the design of research. The SONG initiative is doing an extraordinary job in identifying core outcomes for patients treated with haemodialysis or peritoneal dialysis, as well as patients receiving transplant and patients with glomerulonephritis, by asking directly patients what their priorities are. Allison Tong gave a brilliant talk explaining the standardized process leading to the identification of the core outcomes, starting from a systematic review of all the outcome measures for each field of interest and following with Nominal technique, Delphi survey and consensus workshop procedures. Interestingly, and not surprisingly, patients prioritised outcomes that were different from the usual ones considered important by clinicians, including ability to travel, dialysis free time and fatigue. Along similar lines, Adeera Levin gave an inspiring talk about the Can-SOLVE CKD project showing how patients can actually learn about technical aspects of research, and can actually provide important input in developing a research protocol or evaluating grant applications.

During the congress, I had also the privilege of helping out with the SONG-kids workshop aimed to standardise outcomes in nephrology for children and adolescents. It was touching listening to few kids who wanted to share their view with courage and gave adults a lesson of what matters in a very powerful, straight to the point, communicative way.

I was also impressed by the movies' night that confirmed this focus of the congress on giving patients voice and trust.

Finally, I appreciated the plenary talks emphasising that, despite the importance and progress of technology, the human touch of clinicians and trainees cannot be replaced, and that the future of medicine is personal.