



Awardee: Dr Shane V. Hegarty

Project Title: Brain Research And Individuals Networking for Teaching, Assisting, Learning and Knowledge (BRAINTALK)

Higher Education Institution: University College Cork

About the Research Project

Over 8,000 people in Ireland are living with Parkinson's disease (PD) a debilitating neurological disorder which remains incurable. However, the affected members of the public (patients and their families), the clinicians treating these patients and the scientists researching PD remain relatively isolated from each other. This project, BRAINTALK, developed an informal conference to bridge gaps between public, clinicians and scientists within Parkinson's disease community. The overarching objective of the forum was to encourage interaction between, and contribution from, each of these groups for purpose of exchanging and disseminating knowledge. On 7 September 2015, the 'Parkinson's Community' meeting took place at the Glucksman Gallery in Cork. Over 200 participants, the majority of whom were people with Parkinson's

and their carers, gathered for a variety of presentations by Parkinson's advocacy groups, People with Parkinson's, therapists, neurologists and neuroscientists. The event began with a session on "Living with Parkinson's", which included talks by Margaret Mullarney of Move4Parkinson's Ireland and Dr Jon Stanford of The Cure Parkinson's Trust, UK. The "Understanding Parkinson's" session included talks by Ireland's two leading Parkinson's neurologists, Professor Tim Lynch of the Mater Hospital, and Dr Sean O'Sullivan from Cork University Hospital. The final session involved presentations about the latest research on novel therapies and patient-centered research by Professor Maeve Caldwell of TCD, Professor Aideen Sullivan of UCC and Dr Denise McGrath of UCD. To conclude the event, several people with Parkinson's paired up with neuroscientists for a set-dancing session directed by Pat O'Dea. This dance was a dialogue between those affected by Parkinson's and those working to develop new therapies. After the meeting, the 'Parkinson's Community' art exhibition was launched. This included paintings made by People with Parkinson's in an 'Exploring Parkinson's with Art' workshop held at the Glucksman Gallery on 28 July, as well as photomicrographs showing the ongoing scientific work by Parkinson's researchers in the Department of Anatomy and





Dr Gerard O’Keeffe (L), Professor Aideen Sullivan and Dr Shane Hegarty of University College Cork.

Neuroscience, UCC. Two additional artworks were made at the event on 7 September: the recital of “Live Your Life” was recorded and exhibited by Fearghal Cunningham as an audio waveform in digital print on tracing paper. The dance by People with Parkinson’s and researchers was exhibited in a digital video by Brid Corcoran, with the movement and interaction within this piece exemplifying the spirit of the meeting.

Awardee

“We were overwhelmed by the positive response, interest, participation and feedback we received during this project, which highlights the need for more of these public engagement events in the future. I believe that through this Irish Research Council-funded project, we have significantly contributed to the creation of an active and interconnected Parkinson’s community in Ireland, which together strives to improve the management and research outcomes of Parkinson’s disease.”

Research Impact

The Irish Research Council New Foundations award acted as a platform to support and facilitate this forum, which gathered all members of the PD community together. The ‘BRAINTALK’ public engagement events provided an outstanding opportunity for interactions between scientific researchers from different disciplines, specialised clinicians and non-scientific members of the PD community. At the forum, a ‘Living with Parkinson’s Disease’ community was launched to facilitate long-term maintenance of the networks formed at the forum, as well as future actions within this community.

