The 9th International Conference on Frontotemporal Dementias (ICFTD) recently took place at the Sheraton Vancouver Wall Centre from October 23-25 and was hosted by the University of British Columbia. The ICFTD is held every two years and is the only regularly scheduled international conference devoted to frontotemporal dementia (FTD), making it an important opportunity for FTD clinicians, researchers, trainees and caregivers from around the world to share knowledge with the goal of improving care for patients with this neurodegenerative disease. Over 550 of the world’s leading scientists and researchers were in attendance, representing 30 different countries and 5 different continents. On Friday October 24, the Caregivers Session of the conference was held. In September, I was privileged to have been asked by the Caregiver Program Committee to be a part of the caregiver panel that afternoon.

Before the opening of the day’s conference, there was an early-morning meeting for those interested in learning more about the status of the TauRx’s Phase III clinical trial (TRx-237-007). This session was of extreme relevance for us as my wife Lisa was recently accepted into the study at the clinical site in Montreal (McGill Centre for Studies in Aging). Dr. Claude Wischik, Chairman of TauRx, gave a current update on the status of the clinical trial which will test a treatment for behavioural variant Frontotemporal Dementia (bvFTD).

“The company is testing their LMTX drug, a compound expected to be able to target the brain process in which the tau protein starts to self-aggregate and bind neuronal waste-products. This process creates aggregates that have the ability to reproduce indefinitely, through the tau protein, which is then converted into more toxic aggregates. Therefore, the drug blocks the aggregation, releasing the protein by clearing it to the nerve cells. In addition, it also acts on the binding protein TDP-43, which also participates in the development of the disease” (Alzheimers News Today, October 29, 2014).

Medical and scientific experts attending the main conference began the day by providing FTD patients and their caregivers with up-to-date information about FTD research, diagnosis and treatments, as well as practical topics related to patient care and family support. Two of the world’s leading neurologists, Dr. Bradley Boeve (Mayo Clinic, Rochester) and Dr. Adam Boxer (University of California, San Francisco), started off the morning session by speaking about the importance of a correct FTD diagnosis. This included its clinical features, subtypes and pathology. Dr. Boeve highlighted the fact that, in the past 10 years, more progress and advances have been made in FTD research than with Alzheimer Disease. He also reiterated what I believe to be the most important lesson in the FTD journey to date – the fact that the symptoms and behaviours reflect the disease, and DO NOT define the person diagnosed with FTD. I certainly appreciated hearing Dr. Boxer articulate how treatment of FTD is different than AD, and that caregiving strategies should reflect this.
Emily Dwosh, a genetic counsellor at UBC, outlined the genetical ramifications for both a sporadic (meaning no known family history) and a familial FTD diagnosis. Approximately 40% of frontotemporal dementia cases appear to be hereditary, meaning that a mutation in a specific gene is known to cause that individual’s frontotemporal dementia (which can then be passed down from generation to generation). The sporadic occurrence rate is approximately 60%. Emily’s presentation was very timely given that, two days after returning from the conference, we were asked to participate in the ‘Care for Rare’ research project which utilizes a new technology (called Next Generation Sequencing), thus allowing a person’s entire genetic code to be analyzed. Dr. Tiffany Chow (formerly Baycrest, Toronto) spoke about medication management, stressing to those in attendance how the focus should be more on behavioural management and less reliance on medication, as there’s been no significant improvements in dementia drugs in the past 5-10 years. When asked how this could be accomplished amidst a cultural “drug mindset,” she bluntly answered that the phrase “responsive behaviours” must be repeated over and over again by caregivers advocating on behalf of those with FTD. She also stressed the importance of having caregivers prioritize ahead of time (i.e., fax, email) the one target symptom they wish to address with the neurologist since their last visit. Dr. Chow added that having more information from caregivers is most helpful as doctors need to see FTD patients more than AD patients, owing to the fact that their landscape is constantly shifting (more so than those with AD). Dr. Howard Feldman (UBC) concluded the morning session by speaking about the current research which seeks to map out the asymptomatic stages of FTD (i.e., what the disease looks like before the manifestation of clinical symptoms). Once these stages can be identified and mapped out, the goal would thus be to delay the on-set of symptoms. Dr. Feldman also spoke about the latest research developments, including tau immunotherapy, oxytocin, and the impending research focusing upon Progranulin gene mutations.

The first afternoon session examined disease management and helped to add more insight and clarity to Dr. Chow’s presentation. Here, Dr. Philip Lee (UBC) discussed the management of behavioural symptoms. I found it rather interesting to hear him say that not all behaviours associated with an FTD diagnosis will be experienced by the patient. The reason being that many patients lack insight into their own behaviours (known as anosognosia), so it is the people around them who are affected by the changes, not the patient him or herself. Next, Claire O’Connor’s (University of Sydney, Australia) presentation on her use of the Tailored Activities Program (TAP) garnered much attention and interest from those in attendance, including myself, as it outlined the “hands-on” behavioural management approach Dr. Chow said was so urgently needed. Finally, audience members (especially those dealing with a Primary Progressive Aphasia diagnosis) were privileged to hear about the latest research governing the management of language symptoms. This included a presentation by Dr. Emily Rogalski (Northwestern University) outlining the use of internet-based speech therapy to help improve quality of life and access to care.

The last part of the day honed in on caregiver support. Professor Darby Morhardt (Northwestern University) provided a most riveting account of the issues that arise in families affected by FTD. Using the example of a mobile, Dr. Morhardt expounded upon the lesser known evils which impact the intergenerational family system on a daily basis, especially having to live with ambiguity. This included
the impact on relationships, especially the spouse and children and the complicated role dynamics the diagnosis bring about. Strategies were also offered for ways caregivers can intervene given the various FTD subtypes. Most important for me was the issue of family resiliency and how, with help and support, patients and families can live meaningful lives. Robin Ketelle, a clinical nurse specialist (University of California, San Francisco) addressed the importance of caregiver support, stressing that FTD is a disease of emotion and communication. Like Dr. Morhardt, Nurse Ketelle provided ample research citing the fact that FTD caregivers are more stressed and burdened than other dementia caregivers (including AD). Here, she outlined the vital role support groups can play in helping families throughout the FTD journey. Of particular interest to those in attendance was the UCSF Memory and Aging Center’s LEAF program (life enhancing activities for family caregivers). Both these presentations seemed to put some much-needed wind back in my sails, as they gave me concrete evidence that programs, which are specifically tailored to meet the needs of the FTD caregiver (and associated family members), are in existence.

The last part of the day was the caregiver panel in which both Susan Gustafson and I were the principal speakers. The panel was moderated by Dr. Lynn Beattie (Professor Emerita UBC and current board member of Alzheimer Society of Canada). Susan was an educator and school administrator for 33 years before retiring in June 2013. Her husband Dave was diagnosed with FTD in 2008 at the age of 54. Susan cared for him at home with the support of daily caregivers until 2011 when he entered a personal care home. Dave died in February 2013 at the age of 59. Today, Susan advocates for those with early onset dementias in Manitoba by speaking to local groups of caregivers and health care professionals. My talk was entitled “Finding Peace amongst the turmoil and strife of an FTD Diagnosis – The lesson of Acceptance.” (It was later shorted to” The Journey Forward, not Downward”. ) In it, I drew on my caregiving experience and offered my own “Top 10” list for coming to peace with oneself and learning how to accept all that goes along with an FTD diagnosis. Both of our talks elicited strong emotional reactions from the audience, as they touched upon the human dimension of the disease, a dimension very few people can fully comprehend.

On Saturday morning, approximately twenty-five people were invited to a peer/advocacy meeting by Helen –Ann Comstock, founder of the Association for Frontotemporal Degeneration (AFTD). Delegates looked at ways of starting a new FTD organization, including methods to enhance collaboration and the sharing of information, especially in a digital age. A good deal of time was spent discussing the creation of an FTD patient registry. Among the many benefits listed were the ability to speed up rare disease clinical trial enrollment by identifying and organizing patient volunteers according to location, diagnosis, and stage of disease progression. Lastly, delegates agreed to a coordinated effort to have the first week of October recognized globally as International FTD Week.

Yet, despite the rich learning throughout the entire conference, the most rewarding experience for me was meeting other FTD caregivers and health professionals. They say that expertise doesn’t just come from degrees, but life experience too. The wisdom and insight I left Vancouver with was certainly invaluable, and has left me eager to learn more about my dear Lisa’s diagnosis. I was fortunate enough to have met Katie Brandt, whose heart wrenching story has been garnering global attention, as she endeavours to share her story on the Ellen DeGeneres Show. I was also privileged to have met Lisa Radin, editor of the insightful and highly recommended book entitled “What if it’s not Alzheimer’s? A
Caregiver’s Guide to Dementia.” The book is currently in its 3rd edition and features the latest information on FTD. There was also plenty of rich discussion and wisdom gleaned from my discussions with members of the Association for Frontotemporal Degeneration, whose headquarters are in Radnor, PA. Foremost among these was learning how to champion and have recognized the other “RD’s” (related dementias) in, what seems like, an Alzheimer-dominated world. As the conference drew to a close and I prepared to head back home to Ottawa, I realized how much more I had learned about Lisa’s illness in such a short amount of time. All in all, it was a tremendous experience for me as a caregiver, and I am grateful for the opportunity to have been invited to attend. I am already looking ahead to the 10th ICFTD in Munich in 2016!

**ADDITIONAL INFORMATION**

- Those wishing to learn more about the ICFTD Caregiver Conference can visit the Association for Frontotemporal Degeneration’s website and access the caregiver agenda with links to each of the slide presentations: [http://www.theaftd.org/wp-content/uploads/2014/11/Caregiver-Program-Schedule-2014_.pdf](http://www.theaftd.org/wp-content/uploads/2014/11/Caregiver-Program-Schedule-2014_.pdf)


- Those wanting to learn more about the Tau RX study (TRx-237-007) can visit [www.FTDglobalstudy.com](http://www.FTDglobalstudy.com)

- The 10th International Conference on Frontotemporal Dementias will be held in Munich, Germany from August 31-September 2, 2016. More information can be found at [www.icftd2016.de](http://www.icftd2016.de)

- Those wanting to learn more about Bill C-356 calling for a National Dementia Strategy including ways to get involved can find more information on the attachment.

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