

IFOND Report 2021

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Academic Progression

Benson started his graduate studies in Cambridge in October 2020. Despite the challenges of the COVID pandemic and periods of national lockdown, he has made excellent progress in his research project. Benson successfully defended his progress panel viva in July 2021 and he was formally accepted as a PhD student with the University of Cambridge (Caius College).

Research Updates

- Benson is aiming to develop a patient-reported outcome measure (PROM) for individuals with inherited optic neuropathies (ION) (Figure 1). Stage One has been completed and the data has resulted in one publication with two more in the pipeline. Stage Two, which is currently in progress, will involve concept elicitation interviews conducted on Zoom Pro with about 20 participants with Leber hereditary optic neuropathy (LHON) and autosomal dominant optic atrophy (ADOA). The interviews are being transcribed and imported into a qualitative software package (NVivo 12) for thematic analysis.
- Benson is also closely involved with a UMDF project led by Rustum Karanjia and Lissa Poincenot to standardize the nomenclature used for LHON.

Publications

- Chen BS, Galus T, Archer S, Tadić V, Horton M, Pesudovs K, Braithwaite T, Yu-Wai-Man P. Capturing the experiences of patients with inherited optic neuropathies: a systematic review of Patient-Reported Outcome Measures (PROMs) and qualitative studies. *Graefe's Archive for Clinical and Experimental Ophthalmology*. Epub Ahead of Print.
- Chen BS, Holzinger E, Taiel M, Yu-Wai-Man P. The impact of Leber hereditary optic neuropathy (LHON) on the quality of life of patients and their relatives: a qualitative study. *Journal of Neuro-Ophthalmology*. In Press.
- Chen BS, Horton M, Yu-Wai-Man P Psychometric validity of the Visual Function Index (VF-14) in Leber hereditary optic neuropathy. Poster presentation at NANOS 2022.

Figure 1. Overview of study to develop a conceptually grounded and psychometrically robust PROM for individuals with an ION to report their experience of living with their condition.

