**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**

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.

Stage One
Identifying, appraising, and analysing current PROMs and studies of individuals with ION

Stage Two
Concept elicitation and development of a conceptual framework

Stage Three
Draft questionnaire development and qualitative evaluation

Stage Four
Piloting and validation using psychometric methods