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ABSTRACT DETAILS

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| Title | Creating the Global Moyamoya Patient Registry - A Patient Engagement Effort and Preliminary Findings |
| Presentations | S45 - Cerebrovascular Disease and Interventional Neurology: Meta-analyses and Outcomes Research |
| Background | Moyamoya is a rare cerebrovascular disease that is characterized by the progressive narrowing of the internal carotid artery. Moyamoya disease (MMD) is considered idiopathic while moyamoya syndrome (MMS) is moyamoya in the presence of another associated clinical condition. The heterogeneity of moyamoya patients, in combination with the disease's rarity, has introduced challenges to data collection for research. The MoyaMoya Foundation Co 501(c)(3), a non-profit organization committed to patients with moyamoya and their families, has sought to establish the Global Moyamoya Patient Registry (GMPR) in address this challenge. |
| Objective | To establish a global patient registry for moyamoya research. |
| Design/Methods | The Foundation has partnered with GeneticAlliance, another non-profit organization committed to amplifying rare disease advocacy and research, to establish the GMPR. The GMPR will gather global data on moyamoya through GeneticAlliance's HIPAA-compliant platform. The Foundation has authored two questionnaires regarding patients with moyamoya. One questionnaire is to be completed by physicians who treat moyamoya patients and the second is to be completed by patients with moyamoya and/or an appropriate proxy (e.g., legal guardian). |
| Results | The two questionnaires ask about patients' demographics, moyamoya symptoms, moyamoya treatment, family history, history of associated disorders and stroke, and recovery and rehabilitation. The patient questionnaire also features questions about the unique experience of living with a rare disease, such as the time to diagnosis and whether the patient was initially misdiagnosed. Patients may register directly or through their hospital if it is a hospital partnering with the Foundation on this initiative. |
| Conclusions | The Foundation is addressing a critical challenge in moyamoya research by establishing the GMPR. By actively engaging moyamoya patients, we hope to create a larger, living registry for moyamoya research that will be geographically representative. Further, we hope this may act as a model for other rare disease registries. Data collection is expected to begin in January 2023. |

| Authors/Disclosures | |
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| Catherine Stratton, MPH <i>(Yale School of Medicine)</i> PRESENTER | Miss Stratton has nothing to disclose. |
| Roxanne Houle, Other <i>(Moyamoya Foundation)</i> | Mrs. Houle has nothing to disclose. |
| Dean Houle <i>(Moyamoya Foundation Co)</i> | No disclosure on file |
| Samantha Houle | No disclosure on file |
| Sophia Dupre Kocher | No disclosure on file |