

Comments on: Ophthalmic registries for rare eye diseases

Dear Editor,

We read with interest the systematic review by Sharma *et al.*^[1] that highlighted the value of rare disease registries as important clinical and research resources to attain better patient outcomes. As the authors report, there are few rare eye disease registries: they identify a total of 26 registries, of which almost half are devoted to hereditary diseases. Notably, most registries are nationally based and have been established in high-income countries or regions spanning western Europe, the United Kingdom, and North America. We agree there remains an unmet need for registries that have international reach for a broad spectrum of rare eye conditions. To this end, we recently established the *International Vitreoretinal B-Cell Lymphoma Registry*.^[2] This multinational initiative, which was not included in the author's list of rare eye diseases, aims to provide the medical and general communities with real-world information about outcomes of standard diagnostic and therapeutic practices.^[2] Vitreoretinal lymphoma affects an estimated one in two million persons annually, typically older adults.^[3] Its etiology is unknown, and it may occur as an isolated—or primary—condition, or in association with primary central nervous system lymphoma. Its five-year survival rate is low (approximately 30%)^[3,4]; yet, this cancer often “masquerades” as uveitis, delaying a diagnosis and the initiation of appropriate treatment. The rarity of vitreoretinal lymphoma, along with historical and current limitations related to inconsistent reporting in the literature and classification systems, have challenged efforts to improve outcomes.^[3,5] Ophthalmologists across the globe contribute to the *International Vitreoretinal B-Cell Lymphoma Registry* by lodging retrospectively collected, management-focused data without patient identifiers via a secure online platform. We echo the call by Sharma *et al.*^[1] to increase the number and scope of registries for rare eye diseases and applaud the efforts of the

Women Ophthalmologists Society to establish the first rare eye disease registry in India.

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Conflicts of interest

There are no conflicts of interest.

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