COATS' DISEASE PATIENT NEEDS ASSESSMENT

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Coats' Disease is a rare congenital, non-hereditary eye disorder that results in partial or complete blindness in one eye. It is caused by an abnormality in the development of the blood vessels behind the retina, which becomes twisted and coiled resulting in a leakage of blood in the back of the eye. Due to the rarity, it is more difficult to provide a patient and their family with accurate and trustworthy information, community support, and resources currently available to address their unique needs. Our focus also incorporates the importance of retaining information given by the physician to the patient and family. To assess these specific but different needs of the patient, family, and physician, we conducted interviews using a series of questions that would highlight a common misconception or need. Our data collection overlapped highlighting the need for a thorough overview of Coats' Disease, support groups, current clinical trials, foundation for advocates, and news. After identifying these needs, we concluded that the best method to address all of our goals is to gather already existing, accurate resources to compile into a database. This database would include comprehensible information that would be useful to the patient and their family and alleviate the amount of information that must be retained from the physical all in one organized space. We hope to add on our database to websites that patients and their family are more likely to gravitate towards such as Coatsdiseasefoundation.org or the Moran Eye Center Website.