

ALS Ophthalmology Study – Northwestern Medicine

The eye is an extension of the brain, and contains nerve tissue in the light sensitive layer, the retina. Compared to the brain, the retina of the eye offers the distinct advantage of being accessible to high resolution imaging using advanced light and optical technology. These imaging devices are able to detect subtle changes in the order of several microns, a really amazing level of resolution (1 micron= 1/1000 of a millimeter). In order to better understand the ocular involvement in ALS, we have initiated a collaborative study with the ophthalmology department at Northwestern. Interested patients undergo a detailed neuro-ophthalmologic examination by Dr. Nicholas Volpe, followed by high resolution imaging of the retina using optical coherence tomography and photography. In addition, for interested patients, we are also hoping to extend this study to examination of the eye tissue from deceased subjects, which will be performed in the laboratory of Dr. Amani Fawzi and Paul Bryar) in the Ophthalmology department (Study number: STU00017021 – Eye Donor Study). These detailed studies of the eye will allow a comprehensive understanding of the involvement of the visual pathway in patients with ALS in a more detailed and comprehensive manner than ever before, with the goal to gain better insights into this complex disease and its impact on patients' vision and overall function. Our ultimate goal is to use the eye as a window to the brain, as an avenue for early detection of nerve tissue degeneration in asymptomatic patients. We hope our studies may lead to a better understanding of the mechanism of early disease development and potentially lead to earlier detection and thereby inform more effective treatment approaches for this debilitating disease.

For more information about these studies, please contact either Nailah Siddique RN MSN at 312-503-2712 (nsiddique@northwestern.edu) , Lisa Kinsley MS CGC at 312-503-0154 (lkinsley@northwestern.edu), or Anna Castro-Malek BA, CCRC at 312-695-0252 (acastro@nmff.org).