

Title: Blood Collection from Patients with Hunter Syndrome Currently Participating in the Hunter Outcome Survey for use in Disease Assay Development, A Hunter Outcome Survey Sub-Study

IRB# 2009-084

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Synopsis:

This is a multicenter blood collection study from patients with Hunter syndrome currently participating in the Hunter Outcome Survey. Hunter syndrome is an X-linked recessive lysosomal storage disease caused by the deficiency of the enzyme iduronate-2-sulfatase (I2S). It is a rare disease with an estimated minimum incidence of 1 in 162,000 live births. The purpose of this study is to collect a one time blood sample from Hunter syndrome patients currently participating in the Hunter Outcome Survey (HOS) and their parents to be used to develop an assay for newborn screening for Hunter syndrome.