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The National Institutes of Health is looking for children with young age of onset strokes, with first stroke occurring after age 3 months. The patients we have seen so far have had recurrent strokes over the years. All have evidence of inflammation with elevated sedimentation rate and C-reactive protein. Most have intermittent fevers and a mottled reddish appearance to their skin (livedo reticularis). Some have other rashes as well and some have joint pain, often misdiagnosed as juvenile arthritis.

We have recently discovered a gene that is mutated in our cohort of patients and are looking for more patients that fit this description. We have a potential therapy that we will be starting soon, based on the known genetic defect. While this is a genetic disease, it is autosomal recessive – meaning the child receives one mutated gene from each parent. People who have only one mutation are asymptomatic – so no family history of childhood strokes is the frequent story we hear.

Evaluation and treatment at the National Institutes Health is of no cost to the patient. There is a Children's Inn on campus where patients and their families can stay.

Please contact me if you think that your child fits this description

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