



FACT SHEET

WHO IS EYE ON JACOB?

- The Eye on Jacob Foundation was founded in 2008 by Sonia Desormeaux whose youngest son, Jacob, suffers from Usher Syndrome
- The Eye on Jacob Foundation is a 501 c-3 nonprofit whose mission is to fund research for treatment and, hopefully, a cure for Usher Syndrome
- The EOJ secondary mission is to establish support groups for patients and families of patients with Usher Syndrome

WHAT IS USHER SYNDROME?

- Usher Syndrome is a complicated genetic disease affecting children from birth
- Usher Syndrome affects both hearing and vision
- Many individuals with Usher Syndrome also have severe balance problems
- Usher Syndrome is a degenerative disease usually resulting in total vision loss by the teen years

WHY IS RESEARCH SO IMPORTANT?

Currently, there is no cure for Usher Syndrome. At present, the best that patients can expect is a management of their symptoms. Research is necessary to identify effective treatment as well as to find a cure for this debilitating condition. There are an estimated 12,000 children living with Usher Syndrome in the United States with many, many more children in the world also suffering from this genetic disorder.

Through extensive research, Eye on Jacob identified Dr. Jean Bennett of the Children's Hospital of Philadelphia as the leading scientist and research team in this field. It is our belief that funding for this cutting-edge research program will lead to better treatment options and even a cure for Usher Syndrome in our lifetime.

HOW CAN YOU HELP?

We have launched a \$5 million campaign to fund research for the next three years to advance discoveries in the treatment and cure for Usher Syndrome. Please share our enthusiasm by making a meaningful financial contribution to Eye on Jacob. You can make a difference to 12,000 children, and this program can make a difference to the world.