Welcome to our 2nd Annual

BethanysHope
FOUNDATION
Research Leukodystrophy. Live for the Cure.

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The little faces of Leukodystrophy

Our Research

Dr. Tony Rupar

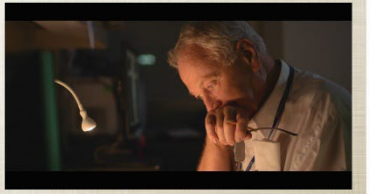
The Bethanys Hope Leukodystrophy Research Laboratory was established by Bethanys Hope Foundation to conduct research to find a treatment and cure for Metachromatic Leukodystrophy (MLD). Dedicated on November 5th, 1999, it is the only lab conducting research into the treatment of MLD in Canada and one of very few in the world. MLD is characterized by the deficiency of an enzyme identified as arylsulfatase A (ARSA). A child with MLD has an error in the gene that codes for ARSA, causing a naturally occurring chemical (sulfatide) to accumulate in the child's brain resulting in MLD.

The treatments that have been developed include those designed to replace the missing enzyme in tissues that are affected by this deficiency, specifically the brain.

The main objective is that this approach will lead to a treatment for MLD and be applicable to some other pediatric neurodegenerative disorders. The long path to developing a treatment has several stages that include basic research, prototype design or discovery, pre-clinical development, and clinical development including clinical trials.

We are excited to have completed the first steps of this process and are now finishing the pre-clinical stages of treatment. This step has included meeting with Health Canada staff to discuss research findings and the design of a clinical trial. Research has focused on developing treatments that provide arylsulfatase A through gene replacement therapy. The laboratory has focused on developing several gene transfer vectors to treat MLD that are currently being used in pre-clinical trial testing. We also have other research projects to develop therapies that target the peripheral nervous system and specific cell targeted therapies that will likely have future therapeutic benefit.

Regulatory authorities in Canada and elsewhere are most concerned that new treatments are primarily safe as well as being effective in treating disease. Data is continuously being collected to demonstrate both safety and efficacy of this treatment. These experiments are designed to meet the requirements of Health Canada to proceed with the clinical trial.



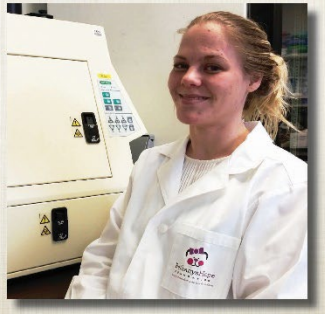
Dr. Stephanie Newman

Stephanie has completed her PhD from the University of Oxford, UK. The University of Oxford is rated as the best University in the world and has a long-term reputation of excellence.

Dr. Newman has joined Dr. Rupar to establish data that focuses on developing a treatment for metachromatic leukodystrophy. Her work has focused on moving the MLD clinical trial forward, as well as developing new therapeutic approaches that work alongside Dr. Rupar's established gene therapy approach. She has developed a project that targets treatment of the peripheral nervous system in MLD that will complement the gene therapy currently being worked on.

She also works with CRISPR/Cas-9 gene editing to establish neuronal precursor cells from MLD patient fibroblasts. Both projects are aimed at developing and enhancing treatment options for MLD.

Her career goals are to remain in the field of rare isease research, continuing to focus on the MLD clinical trial as well as focusing on discovery of new therapeutics for other rare pediatric disorders.



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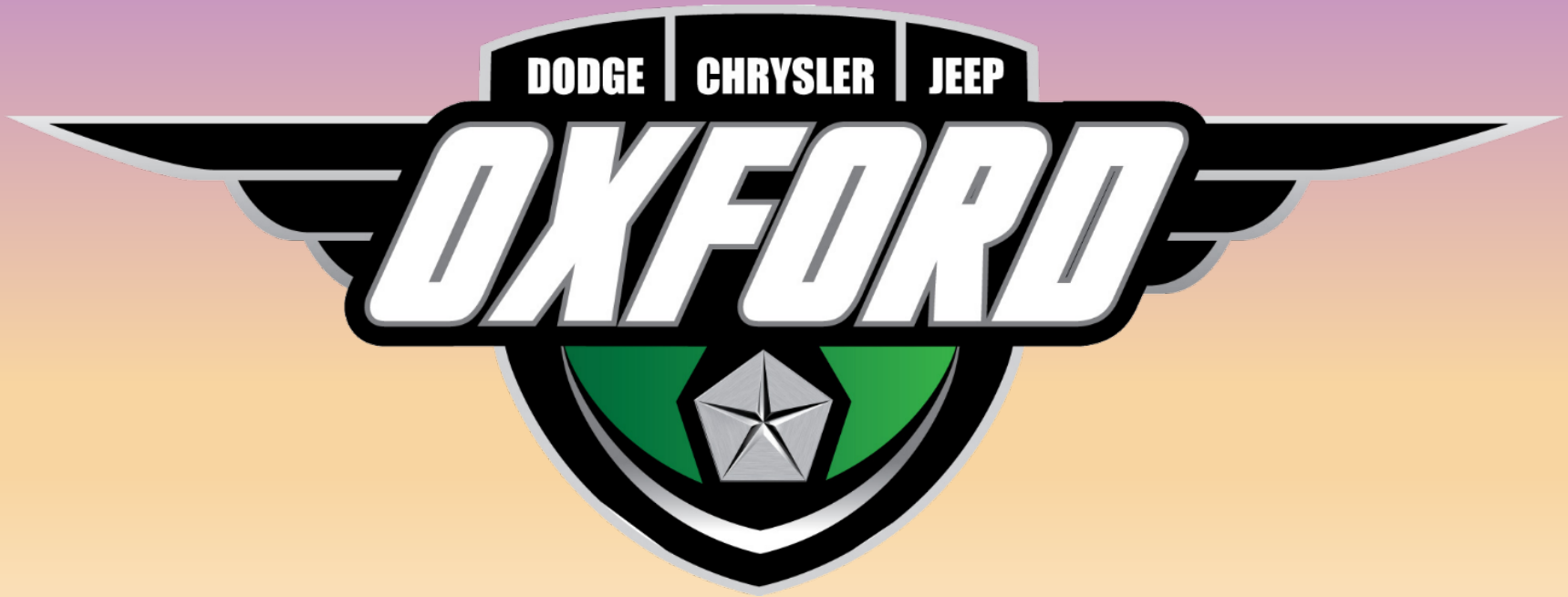

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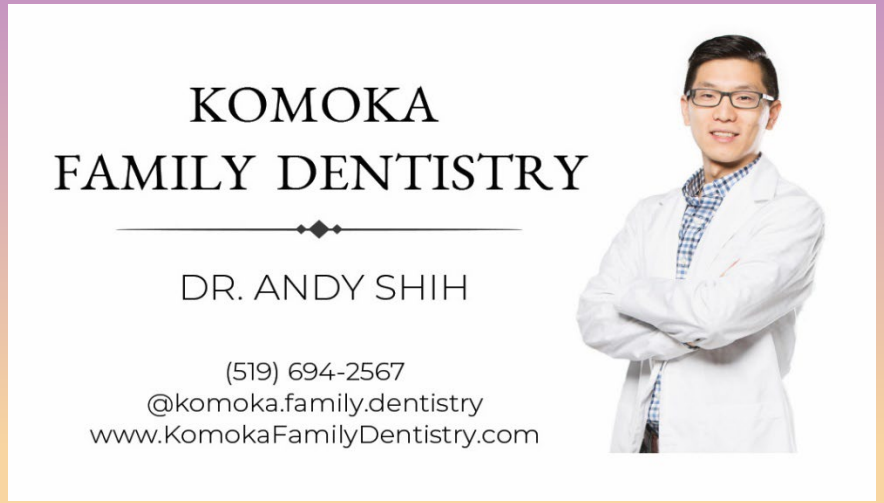

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