

# What is MLD?

Leukodystrophy is an inherited, progressive disorder of the central nervous system and the peripheral nervous system.

Metachromatic Leukodystrophy (MLD) is a disease in which fatty substances build up in the brain and spinal cord. This buildup happens in the part of the brain and spinal cord called the white matter, affecting a person's mental development and the ability to move in a coordinated way. Most forms of MLD appear in early childhood, but this disease also affects adults. It usually leads to progressive paralysis and in children, early death.

Scientists have traced the development of MLD to a defect in the gene that tells the body how to make an enzyme called Arylsulfatase A (ASA). This is the enzyme that is responsible for breaking down sulfatide into smaller, harmless chemicals that can be eliminated or reused by the body. The lack of proper ASA enzyme leads to a buildup of sulfatide which in turn causes a process called demyelination. This demyelination causes the symptoms of MLD by affecting communication between nerves in the brain.



## OUR MISSION

Bethanys Hope Foundation is committed to:

1. Conducting research into the cause, control and cure of MLD
2. Undertake public education and publication about MLD
3. Continue to give "Hope" to children and their families who suffer with the devastation of leukodystrophy.



### Bethanys Hope Foundation

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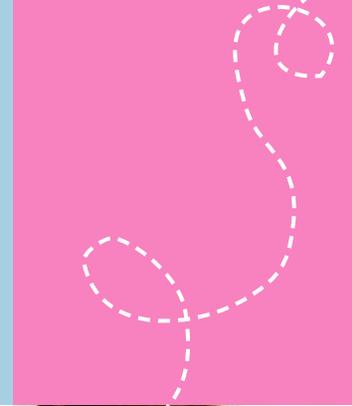
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Supporting  
Research and  
the families of  
Leukodystrophy





Since that fateful day in August 1995 when the seed of hope was planted Bethanys Hope Foundation has reached out to many families of Leukodystrophy. The power of the internet has allowed families to reach out and know that cutting edge research is being conducted at the **"Bethanys Hope Leukodystrophy Research Laboratory"** in London, Ontario, Canada.

The Foundation is touched daily by families from around the world, including countries like Australia, India, England, Ireland, South Africa, Mexico, Japan and the United States.

Gill Smith from South Africa wrote, *"MLD must be one of the cruelest illnesses as so little is known about it. To watch your child having seizures and choking is so painful to endure. Perhaps the cruelest pain is that which the unknown brings, we don't know how Claire is feeling and we don't know what we can do...we don't know anything."*

*"I know at this stage Claire cannot be cured because of lack of medical research. I feel strongly that parents like us have an enormous duty to help future children with MLD"*

*"This is where the Bethanys Hope Foundation is so important. Although oceans separate us, our journey with our MLD children unites us. Thank you for your willingness to share your experience and advice with us, it has meant the world."* Gill and Grant's daughter Claire sadly lost her battle with MLD in March of 2002.

Traditional forms of treatment have not been successful at combating MLD. However, the commitment of this community, as well as our many partners, has made it possible to form a collaborative research program at **"Bethanys Hope Leukodystrophy Research Laboratory"** to explore the treatment of genetic diseases such as MLD.

Dr. John Barranger, MD, PhD of The University of Pittsburgh, Yale University and McGill University have joined forces with Dr. Tony Rupar, PhD, FCCMG, Chairman, Division of Clinical Biochemistry, the University of Western to conduct cutting-edge research into innovative "gene therapy" and cell transplantation treatment for these genetic diseases. These promising new approaches provide hope for the future.



"Hope is never lost...only found."

Clyde W. LeFevée

# There is Hope. Please help!



Name: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ Province/State: \_\_\_\_\_

Postal Code/Zip Code: \_\_\_\_\_

Telephone: Home \_\_\_\_\_

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**Here is my tax deductible gift of:**

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Cheque     Post-dated Cheque     Money Order   
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Credit Card # \_\_\_\_\_

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Signature \_\_\_\_\_

I would like to send my donation "In memory of":  
 \_\_\_\_\_

**Please 1.** Print clearly in the memo of the check who the donation is "In memory" of. **2.** On a separate piece of paper, please include the name(s) and mailing address of either the person or family that you would like acknowledgement letter sent to. *(The amount of your donation will not be disclosed in the acknowledgement letter.)*

**Please fill out form, insert into an envelope and send to the Bethanys Hope Foundation.** 1519 Shore Road, London, ON, Canada N6K 4Z5. For more information about donations, please contact us by e-mail at [dmcintyre@bethanyshope.org](mailto:dmcintyre@bethanyshope.org) or phone (519) 858-HOPE (4673).