MOWAT-WILSON SYNDROME FOUNDATION

www.mowat-wilson.org

Founded in 2014, our mission is to enhance the lives of people affected by Mowat-Wilson Syndrome by providing family support, raising awareness, and supporting research and education.

Each day we become aware of new cases of Mowat-Wilson Syndrome (MWS) around the globe. Most MWS children are in communities with doctors who have never seen a MWS child, and many are not diagnosed until an advanced age. The wide variation of anomalies makes each MWS child a unique case depending upon the severity of the array of physical and mental issues that can be present with the syndrome.

Due to a lack of understanding of the complexity and inter-relatedness of the many MWS symptoms, doctors of all specialties currently treat a child's individual symptoms, but the true need is for doctors who are trained and available to treat the entire child collaboratively, integrating care of the entire child's physical and mental needs.

To advance our mission the Foundation:

- Conducts biennial family conferences to bring patients together with doctors and other medical professionals engaged in the care of MWS patients.
- Funds cell biology research projects through major research hospitals aimed at finding answers and effective treatments.
- Provides a network of virtual community opportunities for families to find education, guidance, and emotional support (*See Life with Mowat-Wilson Syndrome on Facebook and Mowat-Wilson.org*).
- Provides and updates a central repository of educational information, articles, and news.
- Fundraises through individual and corporate donors, donation vehicles on our website, and MWS merchandise sales.
- Promotes awareness of Mowat-Wilson Syndrome through various media outlets and education of medical professionals.

Join our Facebook Community Today

Make a Donation Support the Mowat-Wilson Syndrome Foundation by donating at www.mowat-wilson.org.

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What is Mowat-Wilson Syndrome?

Mowat-Wilson Syndrome is associated with cognitive impairment and with multiple health defects caused by a genetic mutation or deletion on the ZEB2 gene. Major signs of this rare genetic disorder include distinctive facial features, intellectual disability, delayed development, intestinal disorders, seizures, congenital heart disease, Agenesis of the Corpus Callosum, male genital abnormalities (hypospadias), and major expressive language difficulty.

Most Mowat-Wilson children are non-verbal. Speech is absent or severely impaired. Many people with this condition can understand others' speech, however, and some use sign language to communicate. If speech develops, it is delayed until mid-childhood or later. Children with Mowat-Wilson Syndrome also have delayed development of motor skills such as sitting, standing, and walking.

More than half of people with Mowat-Wilson Syndrome are born with an intestinal disorder called Hirschsprung's disease that causes severe constipation, intestinal blockage, and enlargement of the colon. Chronic constipation also occurs frequently in people with Mowat-Wilson Syndrome who have not been diagnosed with Hirschsprung disease.

Although many different medical issues have been associated with Mowat- Wilson Syndrome, not every individual with this condition has all of these features. MWS children typically have friendly and happy personalities, despite their many difficulties. Children born with MWS will need intense medical attention and personal care throughout their entire lives.

It is important to note that MWS was discovered only recently (defined in 1998), and we are still learning about what physical, behavioral, and developmental issues are associated with MWS. We invite you to learn more at www.mowat-wilson.org.

Agenesis of the corpus callosum
Seizure disorders
Speech/Language delays
Developmental delays
Cognitive delays

Distinct facial features
Eye issues

Congenital heart defects

Core strength – delayed motor development

Male genital abnormalities (hypospadias)
Kidney issues
Intestinal disorders/Hirschsprung's Disease