



**Wilhelm
Foundation**

**Undiagnosed
brain diseases**



Children of all ages are affected

3 out of 10 000 children have an undiagnosed brain disease. That means that about 21.000 children in the USA (within the EU about 27.000 children) suffer from a brain disease the doctors can't diagnose. The only thing the doctors know is that it is a disease which causes the brain to degenerate. Some of these children die much too young, since nobody can stop the degeneration of the brain.

The diseases are separated into 2 main groups: the progressive (degenerative), which is when the child is healthy from birth only to be worn down by the disease later on; and the stationary, when the child is very ill from birth or falls ill shortly thereafter.

Symptoms

Children with undiagnosed brain diseases show a number of symptoms. Common symptoms are different stages of development disorders, epilepsy, impaired motor skills and impaired vision and speech. They can also suffer from digestive problems and/or difficulties with getting enough nutrients. Different stages of autism are common with these children as well, and there are many more symptoms that can affect these children.



No tests

There is no cure and no one knows how it is inherited since there is no description of the disease. There are no tests to determine which children will be affected or already are affected, since the doctors don't know what to look for. First it has to be established what kind of disease the child suffers from.



Global congress

The Wilhelm Foundation's goal is a global congress with the world's top specialists within brain research, as well as participation from different areas of medicine: neuropathologists, geneticists, molecular biologists and biochemists, to name a few. But veterinarians should also attend, since there are some diseases among animals (mad cow disease for example), that are similar to the degenerative diseases that affect humans (Creutzfeldt Jakob Disease for example).

Each year many children die from their disease, which is why we are trying to reach out to the families now and offer them the opportunity to present their child on our website. This way they may make contact with other parents or, hopefully, doctors!

The Silver-Lining

The Silver-Lining was created for the children of the Wilhelm Foundation. What makes a Silver-Lining is for the family to decide. It's meant to be something special, something that makes life a little more fun or easy, despite being so ill – something to put a silver lining onto one's cloud!



The Wilhelm Foundation has managed to put undiagnosed brain diseases on the map!

The Foundation has together with RareConnect created a global community for undiagnosed brain diseases. At the community parents can add pictures of their children as well as share their stories. It includes information about the diseases, a forum, as well as other organizations who work with children with undiagnosed brain diseases. We hope in the future to include more specialists. It is a dream come true and a perfect way to help parents in their pursuit of a diagnosis! RareConnect.org include about 40 diseases and we can be found at Undiagnosed Brain Diseases. Everyone is welcome to become a member – you don't have to be a parent, all it takes is a wish to learn more about these diseases.



Parents run the foundation

Mikk and Helene Cederroth from Sweden, have founded and are running the Wilhelm Foundation. Their 3 youngest children suffered from a degenerative brain disease. They were never diagnosed. Even though they searched all over the world, no one could solve the mysterious disease of their children. Wilhelm died at 16 years of age, little Emma at 6 years of age and Hugo became 10 years old. Now they are passionate to help families who have children of their own with undiagnosed brain diseases.

The Wilhelm Foundation
needs YOUR help!

Don't wait until tomorrow.

Give a donation on www.wilhelmfoundation.org
or through our web shop at shop.willefonden.se
We also sell cards, table mats and photos, as well
as Wilhelmgrams and memorial letters.

Let your company become business
buddies with the Wilhelm Foundation!

The Wilhelm Foundation is a 501(c)(3) nonprofit and voluntary international organisation headquartered in Sweden, dedicated to helping children with undiagnosed brain diseases.



Infobox

- 3 of 10 000 children suffer from an undiagnosed brain disease:
- 2/3 of these children suffer from a stationary disease. They are already very sick from birth.
- 1/3 of these children suffer from a degenerative brain disease. They are healthy at birth but their health slowly deteriorates by the disease as they get older.
- Every year children fall ill due to undiagnosed brain diseases.
- There is no prognosis for the disease.
- Lacking a diagnosis means that there is no cure, since no one knows what the child is suffering from. The doctors can ease their symptoms, for example by giving those suffering from epilepsy medication for this, or by giving painkillers to those in pain.
- Many children die much too young.
- No prenatal tests can be taken, no one know how the diseases are inherited or whether a seemingly healthy child will fall ill.
- In Sweden about 500 children are affected, in the EU about 27.000 and in the USA about 21.000 children suffer from an undiagnosed brain disease.

The goal of the Wilhelm Foundation is to gather the best that the world has to offer within brain research. Specialists will together try to help the children who suffer from an unknown brain disease to receive a diagnosis. Getting a diagnosis can, at best, help the child to live!

The Wilhelm Foundation's Silver-Lining is granted to children with undiagnosed brain diseases to bring a silver-lining to their otherwise difficult existence.

The Wilhelm Foundation also works to spread information about these diseases and increase healthcare for the children affected.

Children with
undiagnosed brain diseases
exist all across the world!



Wilhelm
Foundation



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