

## What is ZARD?



ZARD stands for “ZC4H2 Associated Rare Disorders”. It’s an extremely rare neurologic and neuromuscular condition that can profoundly affect the quality of life of patients and their families.

It is caused by a change (mutation) in a gene called ZC4H2. Although little is known, the ZC4H2 gene plays a crucial role in early life development. The condition can be inherited or happen spontaneously.

ZARD is a congenital condition, meaning people are born with it. Symptoms start very early in life, as soon as in the embryo, and continue throughout the patient’s life.

To date, there are only about 250 known cases in the world, varying from different ages, from newborns to elderly.

Boys and girls can be affected in various ways and severities.

## The most common symptoms are:

- Motor planning impairments
- Impaired mobility
- Joint problems (usually Arthrogryposis Multiplex Congenita)
- Other orthopedic issues
- Various different neuromuscular and neurologic manifestations
- Respiratory issues
- Speech difficulties
- Developmental delay



ZARD can affect the whole body and its functions or only part of it. Organ function and general health can also be affected in patients with ZARD.

ZARD is not known to be a primarily progressive condition. However, without the appropriate and frequent medical and therapeutic interventions, the quality of life of an affected patient can deteriorate significantly.

With over 200 possible symptoms, ZARD presents as a spectrum rather than a defined condition.

No two patients are the same, even those within the same family.



## Treatment

There is currently no cure for ZARD. Treatment consists of frequent medical care and supportive therapies such as physical, occupational and speech therapy.

It is known that early and frequent supportive therapies result in better outcomes.

## You can help us!

Hope for a better quality of life for those living with ZARD starts with scientific and medical research. Research is long and very expensive but our patients and families can't wait...

You have the opportunity to give hope to those by donating for scientific and medical research projects on ZARD through the ZC4H2 Foundation.



The ZC4H2 Research Foundation is a non-profit organization registered in The Netherlands and in the USA.

It is recognized by the USA Internal Revenue Service as a 501(c)(3) organization. EIN: 87-4577599.

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## The ZC4H2 Research Foundation

As a parent-led, non-profit organization, the ZC4H2 Research Foundation advocates for those living with ZARD through advancing the development and execution of scientific and medical RESEARCH on this condition, creating AWARENESS and offering SUPPORT in the form of accurate information to the ZARD patient community worldwide.

The ZC4H2 Research Foundation works in partnership with the Orphan Disease Center from the University of Pennsylvania. Under their JumpStart Program, our Foundation counts on the highest levels of scientific advice, guidance and counsel.



the orphan disease center



the jumpstart program

To find out more about our work and how you can support someone living with ZARD, please visit:

[www.ZC4H2foundation.org](http://www.ZC4H2foundation.org)