



# HyperIgM Foundation

1 in a  
Million

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*Hyper IgM Foundation is a not-for-profit 501(c)(3) corporation devoted to improving the treatment, quality of life and long-term outlook for children and adults living with Hyper IgM Syndrome and their families through research, support, education, and advocacy.*

## About Hyper IgM

Hyper IgM Syndrome is a very rare and potentially life-threatening immune deficiency disorder. The most common form of the disease is X-Linked Hyper IgM Syndrome (CD40 Ligand Deficiency), which primarily affects boys. Other forms of Hyper IgM are inherited as autosomal recessive traits and can affect both boys and girls. Patients with Hyper IgM are at significant risk for opportunistic infections, recurrent bacterial and viral infections, and cancer. The median life expectancy for a person with X-Linked Hyper IgM is less than 30 years.

## Diagnosis

Patients with recurrent infections, opportunistic infections (such as PJP/PCP) and low to absent IgG, IgE and IgA antibodies should be tested for Hyper IgM. A confirmatory CD40 ligand flow cytometry test and/or genetic testing should be performed.

## Treatment

Immunoglobulin replacement therapy and antibiotics to prevent *pneumocystis jirovecii* pneumonia (a deadly lung infection) are critical to maintaining health and quality of life. A stem cell transplant (also known as a bone marrow transplant) is the only known cure. Research into new techniques such as gene editing or T-cell therapy is still in early stages.

## VISIT US AT:

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

[www.fb.com/hyperigmfoundation](http://www.fb.com/hyperigmfoundation)

## CONTACT US:

Tel: (646) 883-HIGM

Email: [info@hyperigm.org](mailto:info@hyperigm.org)

**WE BELIEVE THAT A RARE DISEASE  
REQUIRES A REAL CHAMPION.**

**ADVOCATE. SUPPORT. ADVANCE RESEARCH. EDUCATE. EMPOWER.  
SAVE LIVES.**



# HyperIgM

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# Foundation

WE BELIEVE  
"RARE"  
SHOULD NEVER  
MEAN "ALONE"

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*"The Hyper IgM Foundation has been a great place for everyone to connect, get up to date information and have the ability to get in contact with some of the most knowledgeable experts on Hyper IgM."*

*"We have all joined hands, and all of a sudden, one voice was replaced by one hundred voices. We have supported each other through bone marrow transplants, infections, even cancer and death. We are not alone anymore."*

*"Before connecting with the Hyper IgM Foundation I knew no one outside of my family with this, and now I have a bunch of friends around the world who understand what I am going through."*

## Connect With Others With Hyper IgM

Hyper IgM may be an extremely rare disease, but know that you are not alone! You can connect with other patients, parents and caregivers in our Hyper IgM Support Group. We provide an active and supportive global community that can provide emotional support and advice.

## Read Stories, Share Yours

The Hyper IgM foundation provides a platform to share your Hyper IgM patient experience. Read about other patients and families living with Hyper IgM and consider sharing your story. To be featured on our blog, contact [info@hyperigm.org](mailto:info@hyperigm.org).

## Learn More About Hyper IgM Syndrome

Knowledge is power. Learning all you can about Hyper IgM will empower you to make better health decisions for you and your family. Visit the Hyper IgM Foundation's website for simplified information about Hyper IgM Syndrome, treatments, lifestyle changes, the latest research developments, and more so you can better advocate for yourself when facing tough decisions.

## Support our Cause

Donate online at [www.hyperigm.org/donate](http://www.hyperigm.org/donate) to make a difference and support our mission. Your donation goes towards funding research into cutting edge treatments such as gene editing, sponsoring a Hyper IgM Foundation Care Package for our little superhero's with Hyper IgM Syndrome, supporting families living with Hyper IgM, and advocating in the medical community on behalf of Hyper IgM families. Contact us for more ways to support our cause.

## About the Foundation:

The Hyper IgM Foundation was founded by dedicated parents and healthcare professionals. Our mission is to improve the treatment, quality of life and long-term outlook for children and adults living with Hyper IgM. We provide information and resources to patients, families, and their physicians, support research efforts around the world, and connect patients with each other and with physicians with relevant expertise.

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