

GOALS OF THE NOMID ALLIANCE

1. To continue increasing awareness about Cryopyrin-Associated Periodic Syndromes (CAPS) and other autoinflammatory diseases.
2. Act as a united voice worldwide to promote improved collaboration amongst healthcare professionals dealing with autoinflammatory diseases; so that all people suffering from these rare syndromes can have an accurate diagnosis, and improved access to the most beneficial care and treatment available.
3. To serve as a resource and advocate for individuals, families, and friends that are dealing with CAPS, and other autoinflammatory diseases.
4. Encourage medical and pharmaceutical groups to continue researching treatments for autoinflammatory diseases.
5. Increase collaboration on projects and awareness efforts with other organizations that deal with autoinflammatory diseases. We are also interested in working with organizations that are helping to improve research, care, awareness and quality of life for patients with rare diseases worldwide.

We need your support to fulfill our goals! Donations are fully tax deductible in the USA. You can donate online at nomidalliance.org via paypal, or by mail. Thank you!

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 NOMID Alliance  NOMIDAlliance

We also have some private patient groups on facebook for CAPS and autoinflammatory diseases.

What People Are Saying About Our Organization

“The NOMID Alliance has been such a valuable asset to those of us who suffer from these syndromes, and also to the families and friends of those affected. The NOMID Alliance has brought information to many all over the world and educated patients, families, and doctors. As a patient myself and my daughter also, it has been wonderful to direct various doctors of differing specialties to this website for further information. I cannot even describe how valuable it is to have a website like this for doctors to go to. These are fairly rare syndromes and even the doctors are grateful for the opportunity to have this wealth of information in one location. Great tool for patients, caregivers, families, and doctors!” —*J. patient from the USA*

“It was through the NOMID Alliance that we had the chance to connect with families affected with NOMID and found out so much about the condition, no doctor could give have given us this information. The Nomid Alliance brochures have been extremely helpful and we have shared them with doctors in India.” —*P. a parent in Canada with family in India*

“The NOMID Alliance is an exemplary organization in the area of providing quality support and information to patients and families living with auto-inflammatory diseases. Through direct experience in working with them I have found their commitment to their work second to none. They also have an international outlook which I find a breath of fresh air and consistently work with groups and people from several countries to try and raise awareness and build an international patient network to work with stakeholders from the medical corps, research, academia and the pharma, medical devise and biotech industry. I really can't recommend them highly enough, and I'm not just saying that. I've worked with many organizations and the NOMID Alliance really stands out from the crowd.”

—*Denis Costello, Web Communications Manager EURORDIS – Rare Diseases Europe – eurordis.org*

NOMID ALLIANCE

nomidalliance.org

Dedicated to promoting awareness, care, and treatment for patients with Cryopyrin-Associated Periodic Syndromes (CAPS) and other autoinflammatory diseases.



“I am free. I am no longer a prisoner of pain.”

said a 33 year old Muckle-Wells Syndrome patient after being diagnosed and started on medications for CAPS. Butterfly painted by a 10 year old CAPS patient.

What Are Autoinflammatory Diseases?

Most autoinflammatory diseases are caused by genetic mutations in molecules that are involved in regulating the innate immune response – a "hard wired" defense system that evolved to quickly recognize and act against infectious agents and other danger signals produced by our bodies. Genetic mutations are either inherited, or occur spontaneously at conception.

It is important not to confuse autoinflammatory syndromes with autoimmune diseases, such as: Lupus, Rheumatoid Arthritis and others that are caused by the body's adaptive immune system developing antibodies to antigens that then attack healthy body tissues.

Are There Any Treatments or Cures?

At this time, there are no "cures" or ways to halt the development of an autoinflammatory disease.

A few autoinflammatory diseases have FDA-approved medications that help to target the cause of inflammation, or help to control symptoms, but more research and treatments are needed for all autoinflammatory diseases.



"I bought my first sleeveless dress now that I don't have a rash to hide!"

said a 50 year old CAPS patient finally on treatment. CAPS rash is on the left. Painting on the right was made by a 10 year old friend of a different CAPS patient.

How Do These Diseases Affect People?

Some of these diseases are also known as periodic fever syndromes. Episodes of increased inflammation, often called "flares" can include: fevers, rashes or skin conditions, pain in the joints and/or bones, and sometimes eye inflammation.

Many autoinflammatory diseases have symptoms that are present from childhood or infancy. A few syndromes have symptoms begin in adulthood, or late childhood. Every autoinflammatory disease presents with it's own distinct characteristics. Some of these diseases cause systemic inflammation that can harm multiple organs over time, but other syndromes do not cause permanent damage.

LEARN MORE ABOUT AUTOINFLAMMATORY DISEASES AT WWW.NOMIDALLIANCE.ORG

Cryopyrin-Associated Periodic Syndromes (CAPS), such as:

- Familial Cold Auto inflammatory Syndrome (FCAS)
- Muckle-Wells Syndrome (MWS)
- Neonatal-Onset Multisystem Inflammatory Disease (NOMID)-also known as Chronic, Infantile, Neurological, Cutaneous and Articular Syndrome (CINCA)

Familial Mediterranean Fever (FMF)

TNF Receptor Associated Periodic Fever Syndrome (TRAPS)
Hyperimmunoglobulinemia D Periodic Fever Syndrome (HIDS)

Periodic Fever, Aphthous Stomatitis, Pharyngitis & Cervical Adenitis (PFAPA)

Deficiency of Il-1 Receptor Agonist (DIRA)

Chronic Recurrent Multifocal Osteomyelitis (CRMO)

Pyogenic Arthritis, Pyoderma gangrenosum and Acne (PAPA)

Chronic Atypical Neutrophilic Dermatitis with Lipodystrophy & Elevated Temperature Syndrome (CANDLE Syndrome)

Systemic Juvenile Idiopathic Arthritis (SJIA)

Schnitzler Syndrome

Majeed Syndrome

Pediatric Granulomatous Arthritis (PGA) aka Blau Syndrome

Behçets

NLRP12 Familial Cold Autoinflammatory Syndrome

Plus many other newly identified autoinflammatory diseases

What Does The NOMID Alliance Do?

- The NOMID Alliance helps people of all ages with autoinflammatory diseases. We are based in the United States, but also assist patients from around the world.
- We provide free materials in various languages for patients and medical professionals to use to increase understanding and awareness about various autoinflammatory diseases.
- Our multi-lingual website provides information about autoinflammatory diseases for patients, doctors and caregivers in various languages, with links to online patient groups, research and helpful resources.
- Board members do a number of outreach and awareness efforts yearly to increase awareness about these diseases in the medical community and the public.
- Patients and medical staff contact us frequently to find specialists in their region of the country, or the world, to help aid them in diagnosis and treatment. We also refer people to clinical trials and research programs for various autoinflammatory diseases.
- We advocate for patients on a local, national and international level to promote more research, legislation and better access to care and beneficial treatments for autoinflammatory and other rare diseases.
- We refer people to patient assistance programs for medications, so patients can have access to treatments.
- Our efforts to empower patients with understanding of their disease, available programs, treatments and way to connect with other patients include:
 - Moderated public & private online forums
 - Coordinating patient gatherings to facilitate people meeting others with these rare diseases
 - Collaborating with other rare disease and auto-inflammatory disease organizations worldwide.