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Helpful Websites:

Our NOMID Alliance website (this chart, the CAPS medical guidebook and other materials are on the site) http://www.nomidalliance.org

The International Society of Systemic Auto-Inflammatory Diseases http://fmf.igh.cnrs.fr/ISSAID

The Registry of Hereditary Auto-inflammatory Disorders Mutations http://fmf.igh.cnrs.fr/ISSAID/infevers

The Diagnostic Score for Periodic Fever (online diagnositc tool, resources & flow chart for pediatricians to use) https://www.printo.it/periodicfever/index.asp

The EUROFEVER Registry for Autoinflammatory Diseases http://www.printo.it/eurofever/eurofever_registry.asp

La Unidad de Enfermedades Autoinflamatorias (disease information in Spanish): Enfermedades hereditarias http://www.autoinflamatorias.com/pacientes/?page_id=391

PRINTO information on pediatric rheumatologic diseases (including many autoinflammatory diseases.) http://www.printo.it/pediatric-rheumatology

The French Centre de Référence des Maladies Auto-inflammatoires http://asso.orpha.net/CEREMAI/CEREMAI.html

Translational Autoinflammatory Disease Section at NIAMS at the NIH http://www.niams.nih.gov/Research/Ongoing_Research/Branch_Lab/Pediatric_Translational_Research/tads.asp

The American College of Rheumatology site has a search for a rheumatologist feature, & helpful disease information at http://www.rheumatology.org

Genetics Home Reference–a service of the US National Library of Medicine http://ghr.nlm.nih.gov

Genetics Testing Registry (GTR) to search for any genetic test that can be done at laboratories worldwide: http://www.ncbi.nlm.nih.gov/gtr/

Pub-Med: The US National Library of Medicine National Institutes of Health (NIH) http://www.ncbi.nlm.nih.gov/pubmed

The HUGO Gene Nomenclature Committee (HGNC) http://www.genenames.org

Club Rhumatismes et Inflammation Image Library and other resources http://www.cri-net.com/base_image/default.asp

Dermatology Online Atlas. DermIS Dermatology Information System http://www.dermis.net/dermisroot/en/home/index.htm

Interactive Dermatology Atlas http://www.dermatlas.net

The Childhood Arthritis and Rheumatology Research Alliance (CARRA) https://www.carragroup.org

Moderated online international patient & medical community, including communities for CAPS, TRAPS, FMF and Behçets–a NORD and EURORDIS initiative (The NOMID Alliance is a moderator for some of these communities.) https://www.rareconnect.org

Sterol & Isoprenoid Research Consortium http://rarediseasesnetwork.epi.usf.edu/stair

HIDS info and registry: http://www.hids.net

American Behçets Disease Association http://www.behcets.com

National Organization for Rare Disorders has a helpful rare disease database http://rarediseases.org

Rare Diseases Europe has a lot of information for patients at: http://www.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.

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.

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.

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*

"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 device 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

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 treaments.

- 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 autoinflammatory disease organizations worldwide.

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