

Who are we?

The Familial Mediterranean Fever and Autoinflammatory Diseases (FMF & AID) Global Association was established by a group of patients, family members, physicians and researchers, all working together for the same cause.

The idea was born when patients started to connect online, looking for answers. The patient and medical community joined forces and started to share their experience and knowledge to help others with autoinflammatory diseases.

We are a global umbrella organization that aims to raise awareness for all autoinflammatory diseases, and hopefully help to contribute to early diagnosis and easier access to treatments. A place where people meet to help each other, regardless of race, language or religion. We are like an extended family who cares deeply for all its members. We have incredibly strong people, all working for the same cause: rights, awareness, understanding, acceptance, research, new treatments and patient advocacy.

What is our mission?

We are the voice of the people who suffer from autoinflammatory diseases. We aim to support patients and their families, guide them and advise them as much as possible.

What are our goals?

- Provide a 24/7 helpline
- Provide patients with social and emotional support
- Help to get patients promptly and correctly diagnosed
- Assist patients, who find our online services, and educate them so that they can be their own advocate
- Help patients' families to cope with these diseases in dealing with local authorities, educational establishments, employers and the disability itself
- Raise awareness especially within the medical community
- Provide valuable and relevant information to patients
- Participate at relevant conferences to bring patients the latest information
- Connect with researchers and scientists
- Organize/offer continuing professional training for health professionals

How are we helping?

We are very active in our online help groups, providing important information to AID patients worldwide. We also have a social media helpline, where patients can contact us 24 hours a day, 7 days a week, in multiple languages. We count on the help of a medical board.

We organize meetings and workshops for patients and produce informative materials which can be of help for patients. We also aim to organize workshops for doctors.

Treatment

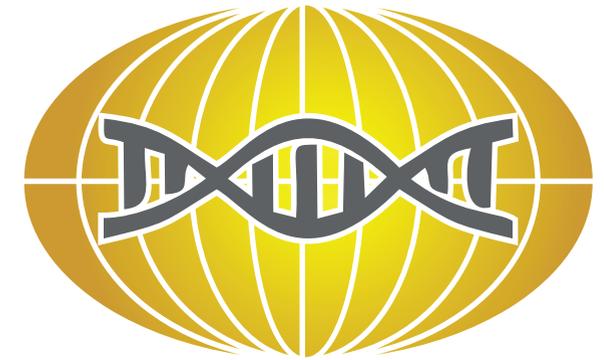
Since these are genetic diseases, there is NO cure. However, a good control of symptoms can be achieved in many cases.

All diseases have a good response to corticosteroids. However, due to the serious side effects of corticosteroids, other options need to be considered. In the case of FMF, it is colchicine and biological agents. Other autoinflammatory diseases do not have a great response to colchicine and a biological agent has to be used. Unfortunately, biological medications are costly and not available everywhere.



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FMF & AID Global Association

Familial Mediterranean Fever & Autoinflammatory Diseases



Rare but real!

**Alone we are rare, together
we are stronger!**

What are autoinflammatory diseases?

Autoinflammatory diseases (AIDs) are caused by an abnormal activation of the innate immune system. They are characterized by intense episodes of inflammation that result in fever, rash, or joint swelling. These diseases also carry the risk of amyloidosis, a serious health problem that can lead to life-threatening organ failure. They are difficult to diagnose and often remain unrecognized, misdiagnosed or undiagnosed, even for decades.

Autoinflammatory diseases affect both children and adult alike. Familial Mediterranean fever (FMF) and PFAPA are the most common diseases in the autoinflammatory category. However, it should be mentioned that, PFAPA is the only condition which is not hereditary and where children can actually grow out of it.

Other diseases from this category

- Familial Mediterranean Fever (FMF)
- Tumor Necrosis Factor Receptor Associated Periodic Syndrome (TRAPS)
- Cryopyrin Associated Periodic Syndromes (CAPS) (CINCA/Muckle Wells/FCAS)
- PFAPA Syndrome
- Mevalonate Kinase Deficiency (MKD) or Hyper IGD Syndrome (HIDS)
- Deficiency of interleukin one receptor antagonist (DIRA)
- Chronic non-Bacterial Osteomyelitis/Osteitis (CRMO)

The most common symptoms in these syndromes are recurrent fever, abdominal pain, joint and/or muscle pain and/or swelling, diarrhea, vomiting, headaches, swollen lymph nodes, mouth ulcers, skin rashes, to name but a few. Some of these conditions can cause conjunctivitis and even hearing loss. The symptoms vary from patient to patient, as well as the length of the flares. There is no treatment that applies to all. It is adjusted on a case-to-case basis.

In the case of FMF, the fever episodes usually last 1-3 days. Flares, episodes or pain attacks, as they are often called among patients, tend to last anywhere between 3 to 7 days. In severe cases, the patient may experience pain daily, and in others, the patient is completely symptom free between flares. Flares for other autoinflammatory diseases can last a week, a month or even longer.

Diagnosis

Some of these diseases can be diagnosed genetically but not all. PFAPA and Behçet's for example, cannot be diagnosed genetically, only through a clinical diagnosis.

In other cases, like FMF, even though a genetic test can be done, sometimes no significant mutations are found. This is why it is so important that physicians are able to diagnose the patient solely on the basis of clinical symptoms. Ca. 20% of all FMF patients do not have any mutations at all and another 20% have just one mutation. A common misconception is that the patient needs to have two mutations to be diagnosed with FMF.

Invisible Disability & Symptoms

Since these diseases might not always have physical manifestations, we often hear, 'You Look Too Healthy to Be This Sick', when in fact, a huge effort has to be made to appear "normal", even though the patient might be in pain. Unless the patient has extreme pain, swollen joints, high fever, skin rash, vomiting or fainting, it will be difficult to see the invisible disability.

Whether you see evidence of the disease or not, it's important to understand that the pain is genuine and the limitations are real and debilitating. Many patients are not able to live a normal life despite being on treatment. It is important for them to receive a disability pension because it's a lifelong debilitating condition that is beyond their control.

Schooling

Homeschooling or homebound is not available everywhere. Special accommodations should be made for children, like the 504 plan in the USA, which not only gives children with medical limitations the chance to be educated at home. It also protects them from any legal actions against them or their parents due to repetitive school absences caused by the disease. Depending upon the severity of the disease, some will be able to have a virtually normal life, others a partial improvement of symptoms, and severe cases, might not be able to complete their education.

Due to inflammation, patients may also suffer from fatigue, mood swings, lack of concentration, bad memory and brain fog.

Are these diseases psychosomatic?

No, they most certainly are not. Autoinflammatory diseases (AIDs) are a group of rare, genetically defined diseases characterized by recurrent unprovoked inflammation. These very painful diseases are real and cannot be treated with a psychological approach. They are often referred to as an invisible disability.

Triggers

Some triggers can be physical exertion, stress, cold/heat, menstruation, vaccines, some foods, etc.

Who treats autoinflammatory diseases?

They are often treated by rheumatologists or immunologists but they can be treated by any other medical doctor. Some of these diseases are so complicated that they require team work. It usually includes the family practitioner, a gastroenterologist, a cardiologist, a dermatologist, just to name but a few. Since most of these diseases are new and are just recently being recognized, they are not always part of the current medical training. Our organization welcomes doctors who want to learn more about these diseases or get more practice by connecting them with our doctors. If they wish, they can also be actively involved with us. Doctors who collaborate with us and opt to participate in our help groups get to see all sort of cases.

Recognizing these diseases

These diseases are often mistaken with infections, peritonitis, pneumonia, epilepsy, etc. Especially recurrent fevers, frequent infections, acute abdominal pain, should all raise a flag with doctors. Lifelong unnecessary treatments, discrimination and lack of understanding may have a negative repercussion on the patient's educational, social and professional life.

Complications

In almost all autoinflammatory diseases, if left untreated, the patient might develop a condition called Amyloidosis, which damages the organs and can be fatal. In the case of CAPS, the patient might develop deafness or serious mental retardation.