

How can the child be accommodated?

Children with AID may miss school for medical appointments, illness, disease flare-ups, or treatment side effects. To help children achieve their academic goals, schools must be willing to make the following accommodations:

- * Extended time and due dates for tests and homework.
- * Excused absences in PE, should be accommodated to the child's ability or wellness, based upon the difficulty of exercises and activities presented in a particular unit of the curriculum.
- * Allowing the child to leave the class as needed for bathroom breaks and nurse visits without asking for permission.
- * Notification to parents, should be made immediately by the teacher or the school, should the child complain and begin to express AID symptoms.
- * Request via accommodation that the school supply extra set of books or online materials so that the child may continue class work from home.
- * Provide the child with a place to lie down if necessary during the school day.
- * The school should accommodate in writing a plan for AID child to not be penalized for tardiness or absences regardless of reason, due to illness.
- * The child shall be permitted to carry a cell phone to contact his or her parent(s) or legal guardian solely for medical reasons. This accommodation should be made in writing.

Living with an invisible disability

Disability comes in many forms, and although a AID child may not require a wheelchair or have an obvious physical impairment, autoimmune patients may often need special accommodations. It is important that AID children's limitations be recognized by their schools, and appropriate measures are put into place to ensure they have an equal and productive educational experience.

Some disabilities look like this



others look like this



not all disabilities are visible

504 Plan & Individual Educational Plan (IEP)

If your child suffers from a chronic illness, they may qualify for two types of school accommodations that will be updated annually: 504 plan and IEP.

The 504 Plan is for children who have a disability identified under the law and are attending school receive accommodations that ensure their academic success and access to the learning environment. This plan, specific to your child's needs, governs education through college. The plan is designed by a team of health care and education professionals involved in your child's life, and is a legally-binding document.

An IEP is a plan for children who have a disability identified under the law and are attending school receive specialized instruction and related services. It requires documentation detailing a child's needs outlining their specific requirements with measurable goals to ensure accessibility for and equal education. This legally-binding document also governs education through college and is designed by a team of professionals.

Homebound Instruction

Academic instruction is provided to students who have an injury or illness, and are confined at home or in a health care facility, that would prevent normal school attendance. The treating physician and the school professionals will assist developing this type of accommodation.

Important for parents to consider

You are your child's best advocate. Take an active role early to work with your child's school and educate them about your child's disease and specific needs. Involve your child in the accommodation process as one day they will need to advocate for themselves. It is essential to enlist the help of your child's healthcare provider, to address their limitations so that appropriate accommodations may be made. Should the school be unwilling to cooperate, it may be necessary to seek guidance from an educational advocate or law firm.

FMF & AID Global Association

a Swiss registered non-profit organization

CHE-400.064.574

www.fmfandaid.org

E-mail: info@fmfandaid.org

facebook.com/FMFandAID

The brochure has been reviewed and endorsed by PD Dr. Juergen Rech, Senior Physician and Head of the Autoinflammation Clinic, University of Erlangen, Germany.



FMF & AID Global Association

Familial Mediterranean Fever & Autoinflammatory Diseases

KINDERGARTEN & SCHOOL



ENGLISH

What are autoinflammatory diseases (AIDs)?

Autoinflammatory diseases, also called Periodic Fever Syndromes, are a group of inherited disorders caused by genetic abnormalities and overactivity of the innate immune system, resulting in recurrent episodes of spontaneous inflammation affecting multiple organs. These recurrent flares are often accompanied with fever and other associated symptoms. Each syndrome has distinctive clinical features. These diseases can be very painful and debilitating.

What are the most common AIDs?

- PFAPA syndrome
- Familial Mediterranean fever (FMF)
- Cryopyrin-associated periodic syndromes (CAPS):
 - Familial cold autoinflammatory syndrome (FCAS)
 - Muckle-Wells syndrome (MWS)
 - Neonatal-onset multisystem inflammatory disease (NOMID)
- TNF receptor-associated periodic syndrome (TRAPS)
- Hyper IgD syndrome (HIDS)
- Deficiency of IL-1-receptor antagonist (DIRA)
- Deficiency of adenosine deaminase 2 (DADA2)
- Yao / Blau syndrome
- Behçet's disease
- sJIA (systemic Juvenile Idiopathic Arthritis)
- CRMO (Chronic recurrent multifocal osteomyelitis)

What is a flare?

A flare is a period of increased symptom intensity and severity. It may occur from one minute to the next without any warning. Depending on the disease, the flare may last from a few hours to a few days or weeks. The flares are unpredictable and they vary in intensity and frequency. Often a flare-up will start without any apparent reason and may not always be attributed to a specific trigger.

Common triggers

Triggers can be emotional or physical reactions to external factors that can cause a patient to flare.

Triggers may be caused by positive or negative events, stress, nervousness, cold/hot temperatures, weather fronts, accidents, common illness, infections, vaccinations, lack of sleep, and menstruation. Physical exertion, even mild, short walks or athletic participation are well-known triggers.

Symptoms children with AID may experience:

- high fever or low-body temperature, chills
- severe abdominal pain, cramping, bloating
- headaches or migraines often with eye pain
- joint pain often with swollen and inflamed joints
- leg pain (unable to walk)
- body aches and muscle pain
- canker sores and mouth ulcers
- redness (uveitis) and swelling of the eyes
- severe fatigue impacting the ability to wake up or to stay awake
- insomnia and inability to get adequate sleep
- various skin rashes, i.e. hives (sometimes itchy or painful)
- nausea, vomiting, diarrhea, constipation
- swollen and painful lymph nodes
- forgetfulness, lack of concentration, brain fog
- tonsillitis, sinusitis, pharyngitis, sore throat
- anxiety, depression
- flu-like symptoms
- seizures

What impact do these diseases have in school?

Autoinflammatory diseases has a major impact in the child's attendance, school performance, and social skills, depending on several factors, i.e. the severity of the disease, if it is being medically acknowledged and treated, and how effective the prescribed therapy is.

- * FATIGUE: Difficulties with regards to executive function, concentration, memory, and focus are often encountered by the child in addition to lack of sleep. AID and its various treatments may reduce a children's energy reserves, thus impacting classroom performance.
- * LACK OF SLEEP: Sleep disruption may lead to fatigue, attention deficit, brain fog and irritability. Child may appear uninterested or bored in the classroom. However, it may actually reflect on the child feeling tired/exhausted during class time.
- * PAIN: Pain and discomfort can make it difficult for a child to sit in class, ignore flare pain, endure a long day at school and complete homework in the evening.

* PE/SPORTS: Depending on the extent of AID health issues, the child may require restrictions in PE and sports due to joint pain, body-aches, abdominal pain, etc. Forcing the child to participate is NOT an option and may require accommodation. It is appropriate to allow the child to pace themselves to decide when, how and length of time to participate in physical activities. Certain children may need to be permanently exempt from PE via an IEP (individualized education program).

* SCHOOL ABSENCES: Children may require excused absences due to flare-ups, scheduled treatments, medical procedures, or they may need to remain at home for an extended time to manage illness.

* MOOD SWINGS: AID often causes children to have irritability, bad moods, anxiety, or depression.

* ABILITY TO WRITE: AIDs may be linked to hypermobility or arthritis, which negatively impacts the child's ability to write successfully. Allowing the student to use a computer alleviates "hand issues" and provides access to equal participation for completing assignments, either in the classroom or at home.

* FREQUENT BATHROOM BREAKS: Frequent and urgent trips to the bathroom are sometimes necessary to avoid "accidents". The child may require a written accommodation to use the bathroom without permission.

* WEIGHT ISSUES: AIDs may cause variable weight gain and loss issues associated with increased inflammation, use of steroids, medical treatments, and despite dietary intake. Therefore, discussing the child's eating habits and weight must be avoided in the school setting.

Some facts about these syndromes:

- They are lifelong diseases
- They are NOT contagious
- They are NOT curable
- Require a lifetime of medication use
- Very debilitating and painful
- Treatments ONLY alleviate the symptoms
- AID children have an invisible disease
- Require understanding and acceptance by their schools
- AID children may develop life-threatening complications