

My child has an auto-inflammatory disease

INFORMATION SHEET FOR KINDERGARTENS & SCHOOLS

Autoinflammatory diseases are a group of rare, genetic diseases. The hyperactive immune system triggers a generalized inflammatory reaction in the body without any evidence of underlying infections, allergies or autoimmune diseases. Autoinflammatory diseases can't be cured, and the therapies only serve to alleviate the symptoms. PFAPA syndrome is the only syndrome that will usually resolve by itself usually between the ages of 8-10.

Possible complication (i.e. Familial Mediterranean Fever, TRAPS): Amyloidosis. It is a condition that occurs when an abnormal protein, called amyloid, builds up in the organs, especially the kidneys and liver, interfering with their normal function. If untreated, it can lead to organ failure and even death.

Symptoms my child may have:

- high fever or low-body temperature
- severe abdominal pain, sometimes daily for a longer period of time
- headaches, sometimes with eye pain
- joint pain, sometimes with swollen and inflamed joints
- body aches and muscle pain
- dizziness and tremor
- sore throat, including mouth ulcers
- severe fatigue, making it almost impossible to wake up or to stay awake/insomnia
- various rashes, especially hives (sometimes itchy or painful)
- bloated stomach, nausea, vomiting, diarrhea
- swollen and painful lymph nodes
- seizures
- forgetfulness and lack of concentration
- loss of appetite

A flare (a period of increased symptom severity) can occur from one second to the other and without any warnings. Triggers can be any emotions (good or bad), stress, nervousness, but also cold, hot or weather changes. Physical exertion (long walks or sports) can also trigger a flare. Often a flare-up will start without any apparent reason and is simply caused by the disease.

The impact the disease has in school

- ❖ tired/sleepy during class, which is very different from being uninterested/bored in class!
- ❖ restrictions in sport class due to joint pain, body-aches, abdominal pain, fatigue
- ❖ forgetfulness and lack of concentration
- ❖ cramping when writing - aching fingers
- ❖ frequent trips to the bathroom
- ❖ frequent or extended absences from school

How to help the child

- ✓ More time for tests and homework
- ✓ In sports, depending on the types of exercises, the child may be excused class
- ✓ By showing understanding (i.e. allowing the child to get up and leave the class whenever necessary without asking permission).
- ✓ It is important that children are taken seriously in class, if they suddenly complain about some of the symptoms mentioned above. If the child is in great pain, we require that the parents are notified immediately.