September – World Autoinflammatory Awareness Month

By Malena Vetterli

Autoinflammatory diseases are rare, little known. It takes on average 5-10 years to diagnosis and few treatments are available.

Maybe you've heard of PFAPA, FMF, CAPS, TRAPS, HIDS, CRMO, BLUE, Yao, Schnitzler, Sweet or Behcet's Disease? These are just a few of the autoinflammatory diseases. As the name itself implies, they cause inflammation in the body. Depending upon the disease, people can be affected at any age: babies to adults. Due to elevated inflammatory markers in the blood, these diseases are usually mistaken for infections, when there is really none present.

This category of diseases is relatively new, and most doctors have to reach out to good old "Google" to find out what these diseases are. The majority of patients have a long ordeal behind them. It is important to raise awareness in the medical community, but also within the general public. A late diagnosis may lead to organ failure and consequently death.

If you have someone in your family or have heard of someone suffering from recurring fevers, swollen or painful muscles/joints, rashes, stomach pain, headaches, red eyes, then contact the referral centre in your country or for more information the FMF & AID Global Association. The FMF & AID Global Association, although based in Zurich, operates internationally (in over 12 languages) & on a global level. We receive many help requests from all over the world. Often, when affected people are examined, nothing is found. As a result, they are frequently accused of “faking” it. The pain caused by these diseases can be excruciating.

The FMF & AID Global Association is a non-profit umbrella organization that relies on donations. Your support helps us to improve the quality of life of those affected. We inform, advise and support those afflicted, their parents, relatives and friends. Funds are urgently needed to carry out the various projects for the benefit of those affected: a yearly meeting so that affected children can get together, direct financial support to cover consultations overseas and travel expenses for children with challenging cases, symposium for medical professionals, just to name but a few. Over 50% of the people helped are children. The association works around the clock on a voluntary basis (no financial compensation) to try and meet the large demand.

The president and founder, Mrs. M. Vetterli, has gone through an odyssey herself with her ill son and that was in Switzerland. Unfortunately, her story of suffering and injustice is not unique. Affected families are frequently treated unfairly, and in some countries, even persecuted and punished instead of being helped. The social and medical systems for rare diseases in most countries are far from prepared or adapted to meet the needs of those afflicted. Every week the FMF & AID is contacted by desperate people. Often the sufferers are on their own and have to fight for survival, as the majority do not receive a disability pension or any type of financial/social assistance.

This year the awareness campaign for autoinflammatory diseases is to have easy access to genetic tests. For example, in the US, a whole genome analysis is done for just USD 250 (including closely related family members at zero cost) and results are often available within 2 weeks. In other countries, the same would cost several thousands. No wonder that many health insurance companies take their time (up to 1 year) before approving such a test. Since 90% of all rare diseases are genetic, it makes sense to simplify access to these tests in order for patients to be quickly diagnosed and correctly treated. In addition, health insurance companies would save a lot of money on unnecessary and useless tests.
For more information or donations, please visit: www.fmfandaid.org.