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FRENCH ASSOCIATION OF **FAMILIAL MEDITERRANEAN FEVER**
AND ASSOCIATED PERIODIC FEVER DISEASES

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with the support of

fondation française pour la santé
Vaincre les maladies rares

GONE ARE THE DAYS OF **INCORRECT DIAGNOSES**

"The genetic results come in: your son Jeremy has the MEFV genetic mutation at protein position 694. He has FMF and will need to follow a daily treatment, based on the drug Colchicine, for life. We tried to explain this in simple terms to Jeremy, aged 7 at the time of his diagnosis. He started taking the medicine on the very same day. Interestingly, weeks and months later, Jeremy no longer suffered from any flare-ups. A year later, he still did not have any outbreaks. Since Jeremy was born, he never really stopped being sick. Until now, we had incorrectly diagnosed his illness."
The father of Jeremy, who is now 13 years old

SOMETIMES IT IS DIFFICULT TO DECIPHER **THE SYMPTOMS**

"An enormous fatigue overcame me, it felt as if my legs were being cut off. From one minute to the next, I had no more energy. The outbreak can last anytime from 3 days to a week. The pain is never in the same exact area, so sometimes I do not even recognize my own disease. Sometimes I think I am coming down with a cold, or a stomach flu, or I get an attack of rheumatism, sudden joint pain, violent headaches, pain in my jaw..."
Véronique, 49

NOT EASY **FOR THE PEOPLE AROUND**

For a long time, we had incorrectly diagnosed the disease. During a period of five years, we went for multiple consultations with various doctors in different hospitals, took blood tests, underwent x-rays and other nuclear testing, took courses of antibiotic treatments. The flare-ups could suddenly disappear after 3 or 4 days. Not knowing what is going on is quite difficult for the patient, of course, but it is also very hard for all those around him.
Karine, has 3 children; her 7 year old boy is sometimes ill

WE HAVE 2 DAUGHTERS, **AGED FOURTEEN AND TWENTY YEARS OLD**

Bouts of abdominal pain began for our youngest daughter when she was 5 years old, at a rate of about once a month. They were accompanied by shoulder pain, fever and extreme fatigue. We were taken aback by the intensity of her pain and our inability to do anything to relieve our child. Shuttling from hospital to hospital, our daughter underwent multiple examinations, hospitalizations and even an operation for appendicitis. She was going to school part time under the incredulous eyes of teachers who saw her as a child who refused to grow up. Slowly, she withdrew into herself. After six years of drifting in the unknown of her illness, we went to a homeopathic doctor who brought up the hypothesis of FMF. At that point, everything moved along quickly: a positive genetic test for the illness, a correct diagnosis and finally, the prescription of Colchicine. Our daughter finally felt relieved. An answer to her illness did, in fact, exist!
Claire, 42 years old

STOP CALLING THE SYMPTOMS **"PSYCHOSOMATIC"**

It has been ten years since my FMF was diagnosed. What a relief to finally put a name to my health problems.
No more having to hear from doctors that my symptoms were "psychosomatic." It's also a relief to not have to spend endless nights in the emergency room. All this cost me too many pointless medical interventions....
Jérôme, 28 years old

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IT IS NOT BECAUSE YOUR DISEASE IS RARE **THAT YOU SHOULD FEEL LONELY**

WHAT ARE THE RELEVANT DISEASES?

Familial Mediterranean Fever ("FMF") Tumor Necrosis Factor Receptor-Associated Periodic Syndrome ("TRAPS"), Cryopyrin-Associated Periodic Syndromes ("CAPS"), Hyperimmunoglobulin D Syndrome ("HIDS"), and Marshall 's Syndrome, among others, all belong to a new category of diseases known as " autoinflammatory diseases." All these diseases come under the umbrella of the French Association of Familial Mediterranean Fever and Associated Periodic Fever Diseases.

These syndromes belong to a class of rare diseases which affect less than 1 in 2000 people in France. They usually begin during childhood, but may also appear for the first time in adulthood. Fever, fatigue, abdominal, joint and muscle pain and, for some of these syndromes, nausea, aphtosis, pharyngitis, skin and eye problems, are some of the common symptoms these diseases present, which symptoms may vary from patient to patient.

How do these symptoms manifest themselves? They can appear as outbreaks lasting anywhere from 2 days to several weeks, and they are usually provoked by stress and fatigue.

The mere fact that the symptoms presented by these diseases are so varying and even commonplace only increase the difficulty in properly diagnosing any one of these rare disorders.

Our mission is to support research towards a cure that will not only correctly diagnose patients with such symptoms, but also suppress and slow down the manifestation of detrimental episodes by coming to correct diagnoses before such things as renal failure by amyloidosis, a potentially life-threatening condition which often requires dialysis, can occur.

For the French Association of Familial Mediterranean Fever, **it is a daily struggle.**

WHAT ARE THE CONSEQUENCES OF THESE DISEASES IN A PATIENT'S DAILY LIFE?

- A long and difficult diagnosis period. It takes an average of 5 years for a correct diagnosis of these diseases.
- **Multiple medical consultations,** surgeries, unnecessary examinations due to unfamiliarity with the disease
- Outbreaks that start in early childhood can be mistaken with viral diseases, sepsis, seizures rheumatic illnesses, peritonitis, etc
- Frequent seizures, acute pain, lifelong treatments which may have negative repercussions on one's educational, social and professional life

FMF TRAPS CAPS WHAT DOES THAT MEAN?

FMF : Familial Mediterranean Fever
Traps : Tumor Necrosis Factor Receptor-Associated Periodic Syndrome
HIDS : Hyperimmunoglobulin D Syndrome
Caps : Cryopyrin-Associated Periodic Syndromes (including FCAS, MWS and CINCA)
PFAPA : Marshall 's Syndrome

WHO ARE WE?

The French Association of Familial Mediterranean Fever and Associated Periodic Fever Diseases was formed by patients and parents of patients. It opened its doors on the **11th of January, 2006.**

The purpose of this association is to connect and inform patients and their families, and anyone else who is touched by FMF or other similar Periodic Fever Diseases.

The AFFMF is a recognized, non-governmental interest group and a member of the French Rare Diseases Alliance (Telethon), Eurordis and Inserm, the National Institute of Health and Medical Research. The AFFMF comprises of a scientific council composed of leading medical specialists in France who are also recognized internationally. These doctors help the Association and its members in its day-to-day activities.

WHAT ARE OUR MISSIONS?

Inform doctors and patients alike on Periodic Fever Diseases, disseminate information on diagnosing the diseases, provide assistance to families touched by these illnesses and so forth. The goals of the Association are many. For example, the AFFMF aims to:

- **Develop information** about the Periodic Fever Diseases, orient patients and their families towards appropriate medical care;
- **Share every day experiences** and practical information with others affected by these illnesses;
- **Help improve diagnosing** and early management of patients;
- **Work in partnership** with community associations; establish a network with foreign associations of Periodic Fever Diseases
- **Contribute to research** on autoinflammatory diseases, in general.

WHAT ARE OUR ACTIONS?

TO REFER PATIENTS TO SPECIALISTS IN THE FIELD VIA:

- Our website at: **www.affmf.org;**
- Our" Book of Hope";
- Our phone hotline.

TO ADVISE, SUPPORT AND SHARE INFORMATION WITH FAMILIES THROUGH:

- A continuously staffed "Drop-in"center at the AFFMF's offices, open every afternoon;
- Organizing informational meetings in Paris and in greater France;
- The establishment of workshops by theme, such as "Fever and School" or "the Long-term Effects of Using the Drug Colchicine"
- Support of consultations with psychologists and other mental health professionals.

TO DISSEMINATE INFORMATION FOR ALL USING:

- A reference book for families and patients;
- A specially conceived album for children explaining the disease and the importance of long-term treatment;
- A collection of information, broken down by subject, having to do with daily life, for example: " There is a student with FMF in my class," "I am pregnant and suffering from FMF," "I am suffering from FMF and have to explain my disease to my friends and family," etc…

All these books are available via our website at: ***www.affmf.org***

TELETHON
Each year the AFFMF participates in the march and fundraiser organized for the cure of rare diseases.

WEBSITE NEWS
practical information, list of specialist consultations, patients' stories, etc. The website, www.affmf.org, overhauled in 2009, provides even more in depth information than before to learn about the disease.

TRIPTYCH COLLECTION
Three brochures for three stages of life with the disease. "Three titles are already available and they are entitled: "There is a student with FMF in my class," "I am pregnant and suffering from FMF," "I am suffering from FMF and have to explain my disease to my friends and family."

DOCTOR DIRECTORY
Gastroenterologists, pediatricians, emergency physicians, rheumatologists, internists; many of these specialists have received the information guide on FMF and other Periodic Fever Diseases.

THE "BOOK OF HOPE
is dedicated to patients and their families. It is a reference tool produced together with the Groupama Foundation, that covers all aspects of daily life while living with the disease.

BOOK FOR CHILDREN
The album for children has been translated into **Italian, Arabic, Turkish, Armenian, English, German and Hebrew.** The goal of this book is to explain to children how to manage the disease on a day-to-day basis and to outline the importance of carefully following long-term treatment. It is a support tool to promote dialogue within families touched by these illnesses.