Fanconi Anemia: An informative webpage on a rare disease.

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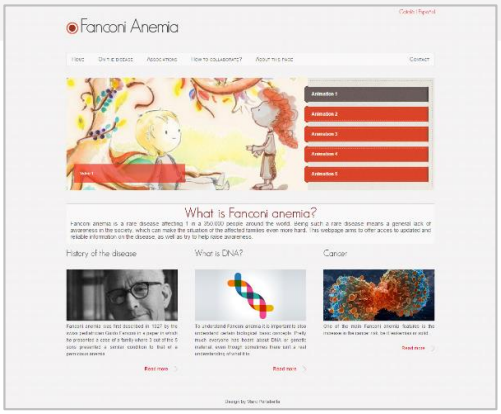
Introduction

Rare diseases may not seem a major health concern if you look at each one separately, but if you look at the bigger picture, the estimations on the number of rare diseases are in the 6000s and the number of affected people around the world might be counted in millions. Every shred of help to fight these diseases counts and the presented work exists for this exact reason, divulgation. This work consists of a webpage about Fanconi anemia, a very rare disease that affects some thousand people around the world.



Goals

- Spreading the awareness on the disease.
- Providing understandable, updated and accurate information.
- Creating a modern, minimalist and user-friendly webpage.

Social interest

Scientific divulgation is key if we aim to create a more informed society, where diagnosis of rare diseases wouldn't be delayed just because there's a general lack of information on them. And it's also key to help people understand that rare diseases are not a slight problem, as they affect as much as 6% of Europe population.

Basics on Fanconi Anemia

Fanconi anemia is a recessive rare genetic disease caused by a mutation in one of the 17 genes known as FANC, and affects around 1 in a 350,000 people around the world. These FANC genes are involved in the Homology Directed Repair system. The main traits are an aplastic anemia affecting all the blood cell lines (caused by a bone marrow failure) and a higher cancer risk.

Symptoms

Besides the pancytopenia, the range of symptoms includes congenital defects (such as skeletal abnormalities, deafness or café-au-lait spots) and endocrine problems (such as growth retardation or thyroid dysfunction).

Treatment

Currently, the only efficient long term treatment is a stem cell transplant which allows us to heal the hematologic part of the disease. Of course, this comes at some risk, although it's been greatly diminished in the last years. There are also, however, hormonal short term treatments to treat some symptoms.

The Website

The website is structured in 3 main parts: On the disease, Associations and Collaborate. It is written in English, Spanish and Catalan to reach a wider audience.

On the disease

In this part of the web you will find information regarding what is Fanconi anemia, its symptoms, diagnosis, genetics and molecular base. You will also find info on the current treatments as well as perspectives on new ones.

Associations

Because Fanconi anemia is such a rare disease it is important to know about the existing associations. What kind of support can they give? All the information about the American and Spanish associations can be found in this part.

Collaborate

Can we help in any way? We can. One of the most direct ways to help is to donate to any of the associations around the world. Another way, more complicated but equally important, is to become a bone marrow donor.

Access the website from your smartphone!

http://www.anemiafanconi.com

Webpage created with Adobe Dreamweaver