



“It is fundamentally important to live each day in the best way possible; to overcome our fears and to trust in the future, accepting whatever comes with open arms.”



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My name is Ana Paula and I am 34 years old.

I am married and I live in Azeitão, Portugal. In my spare time I enjoy writing, dancing, reading and spending time with my pets or going out with friends. I was diagnosed with juvenile idiopathic arthritis when I was about 3 or 4 years old. One of my biggest passions is writing, so this competition was a big challenge for me. Besides, I think that it is important to raise awareness of rheumatic diseases (arthritis in particular) and that made me send in my contribution.

The great challenge of managing a rare rheumatic disease

I’m going to share a little bit of my story with you and tell you how, since I was a little kid, I have dealt with a rare rheumatic disease in children called Juvenile arthritis!

“Juvenile Arthritis? What is that?” “Poor dear, so young and already in so much pain...”

“Juvenile Arthritis? You know you are going to suffer a lot all through your life, don’t you?”.

“Oh dear, if I were you I wouldn’t risk having children because they might also have diseases... Just look at how bad your arthritis is!...”. “You poor, poor girl...”

These were some of the things I heard as I was growing up which gradually increased my fears and decreased my self-esteem...

Juvenile Arthritis is one of a group of diseases that are not very well known and, as such, most people have very little knowledge of them. This can lead people to say inappropriate things, and sometimes this even applies to health professionals. This, I must say, was a bit of a shock to me!

When I was a child, it was normal to hear the neighbours asking my mother: “How is she? Is she doing better? So small and already like this. Poor girl...” They made me believe that I really was a “poor girl”!

Many times I asked myself: “Why are they saying this? “Poor girl” me? Why is that?” I had so many unanswered questions inside me as I was growing up.

I did grow up, but it was not until I was about 20 years old that I truly realised what was happening to me. I gathered more in-depth information about my disease, started to put more questions to the doctors and was able to understand and face both other people and my disease better.

I have also learned how to protect myself from some of the absurd and intrusive comments other people have made throughout my life.

Once I went to the pharmacy to get some drugs to treat my arthritis. The pharmacist was very curious about my prescription and asked me if all those drugs were for me. When I answered him, he told me: “So young! You know you are still going to suffer a lot due to your arthritis, don’t you?” I just couldn’t believe that such a comment could come precisely from a health professional who should have understood better how harmful these words could be to patients. It would be easier to understand if he was someone without any knowledge about health, but coming from that guy...!

I didn’t know whether I should laugh or just shake my head and pretend I was the “poor girl” they thought I was. That was a role I was used to playing...

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Happily I was strong enough to explain to the pharmacist what my disease was and how I could deal with it, the hopes and trust I had in medicine, and how I thought it could help me change my future. I explained to him that there was no reason to be scared, and told him that one should live fully every day, in the best way possible, and accept with joy everything that tomorrow might bring. It was as if we had changed roles, and I was telling him things that, perhaps, he should have been telling me...

I left him with a smile on my lips, trying to understand that he was only human and, as such, he couldn't be perfect! Besides, probably the problem with what had just happened was due to the fact that there is not enough knowledge about Juvenile Arthritis, even amongst some health professionals because it is such a rare disease.

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There have been many other remarks of this kind that I have had to listen to since I have had this disease in my life! Would you like me to give you another example?

I have always dreamt of being a mother, though many people in my family kept telling me: "Look here... be careful, if I were you I wouldn't have kids because you could get worse or the child might have your disease, or some other condition... Better not to risk it!"

Whenever I heard these things, I used to say to myself, how can they say this to me? Dreams are the inspiration of life and I believe one should fight for one's dreams! I believe I was born to be a mother too, and I'm going to fight for this dream of mine, no matter what! However, some doubts kept growing inside me...

One day, whilst I was waiting for my rheumatologist's appointment at the clinic, I was talking to the nurse about this subject and asked her for her expert opinion on the matter. She said to me, "You know, if I was you I wouldn't risk it because this disease is hereditary." I thought this was absurd because, as far as I know, no one else in my family suffers from arthritis or anything similar.

Well, at the start of my rheumatologist's appointment, I decided to solve these doubts of mine once and for all, and to ask the doctor the same question. He reassured me and told me that the risk was indeed very small. Juvenile Arthritis itself is not hereditary, but special care would be needed, both during and after pregnancy, in order to minimise any possible risks. He also said that sometimes people who have no special knowledge about these matters can speak out of turn. That helped me a lot! Anyway, I heard other rheumatologists' opinions and they all agreed on this subject.

Once again I faced a health professional (in this case, a nurse) telling me incorrect things about my disease and my dreams for the future...! Once again, I had to make an effort to understand that the problem lies in the lack of knowledge about this relatively rare disease and this is something that definitely needs to change in the near future...!

As my life goes on, I understand that I have two choices: either I decided to be a loser and be the "poor thing" that many thought I was, or to be a winner, fighting against my disease and all the nonsense spoken by many people around me.

"I had to make an effort to understand that the problem lies in the lack of knowledge about this relatively rare disease."

As I told the pharmacist during the episode that I mentioned above, as well as taking good care of the diseases of our bodies and minds, it is also fundamentally important to live each day in the best way possible; to overcome our fears and to trust in the future, accepting whatever comes with open arms.

That's what I do, day after day. That's also what I think all of us should do, day after day!

Be happy and "até sempre"...!