Rare diseases are a global issue which transcends borders, and is a huge problem affecting a relatively small group of people. It is estimated that about 30 million Europeans are affected by one of 6000 existing rare diseases.

Their scale and variety makes it difficult for efficient research, diagnostics and therapy to be conducted at national level. However, at the European or global levels, we can certainly do much more.

One of the biggest problems for people affected by a rare disease is that correct diagnosis frequently
takess place after many expensive and unnecessary examinations, often accompanied by damaging
treatments.

This is even more tragic when you consider that 50 per cent of rare diseases affect children. Additionally, those suffering from rare diseases and their families are very often unable to get appropriate support, and face multiple barriers, making it very difficult to develop skills, learn, work or fulfil social functions.

Therefore, it is very important to spread knowledge and awareness of rare diseases both in the medical and public spheres, to reach those affected people and their families.

This sort of action can easily be taken at the European level with the communication tools available to us today; for instance, the creation of the NGO Committee for Rare Diseases, established under the umbrella of the Conference of NGOs in consultative relationship with the United Nations, will certainly help achieve that goal.

Organisations such as the United Nations and the European Union should be engaged in conducting research on these diseases, as well as on how to prevent and cure them.

I have very high hopes for projects such as the European reference networks, facilitating cross-border healthcare and research, or the international rare diseases research consortium, which teams up researchers and organisations investing in rare diseases research. Such initiatives to help develop the much needed international cooperation of experts, researchers and medical professionals.

Differences in national funding systems constitute an important barrier to the use of therapy and diagnostics abroad, as well as access to expensive medication. I have been thinking about how to manage these barriers. Perhaps a special European programme, or some sort of European patient’s card for people with rare diseases could be useful?

I think that the true measure of our civilisation is the extent in which we can guarantee a dignified, full life to our citizens, to enable them to develop their talents, fulfil social functions and contribute to common welfare.

In order to illustrate this last point, allow me to share my positive experience with you. I learned that a disease constitutes a great challenge, which I need to overcome every single day. But the efforts to overcome it have immense value. They provide faith and the strength to act.

As it turned out, my disease didn’t prevent me from being a parent and a happy husband. It didn’t stop me from developing my professional career and helping others.

In my life I went through different stages. I never went to primary school - teachers came to my
parents’ house. I learned from books but I lacked social skills. Then I moved to a social welfare home.

At first there was happiness from having colleagues, social interactions, and first duties. But then came a reflection that this was a path to nowhere and that without entering normal life, with normal duties and responsibilities, my life would be empty. It was an important decision and a difficult path with many obstacles. But I went to university, I worked, helped others and started a family and, now, I am an MEP.

Today, I fight among other things for inclusive education systems, and for the introduction of the EU accessibility act, so that our cities, institutions, schools, work places, services and products become accessible for all.

In addition to this framework, I would like to highlight the great importance of supporting people affected by rare diseases, as well as their relatives, whose valuable, albeit often difficult task is to care of them every day and bring them strength and faith.

I believe that we can be proud of our civilisation’s progress, the incredible achievements of the human mind, the developments in technology and science. Humans reach the stars, subjugate nature, create works which continue to amaze. New communication technologies make it possible to be in touch even though we are separated by thousands of kilometres.

Our challenge today is to channel our great potential towards the common goals of eliminating poverty, hunger, disease, epidemics, and restoring balance in our environment, in order to improve the world in which we live.

28 February is Rare Disease Day. The theme next year is research. I hope that the year ahead will be marked by new advances in the study of rare diseases, and increased EU engagement in this area.

About the author

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