# Maria Begona Barragan Garcia – President, GEPAC, Spain

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*Maria Begona Barragan Garcia, president of GEPAC – the Spanish Group of Patients with Cancer – discusses the necessity of the group and its role in Spain's healthcare system, in addition to how the voice of the patients is now stronger than ever.*

**What is the story behind the creation of GEPAC?**

GEPAC was formed out of necessity in Spain's healthcare system. After being diagnosed with lymphoma in 2001, I helped to create AEAL (Spanish Association for Lymphoma) two years later, focusing primarily on representing cancer patients with lymphoma. Later, we expanded and welcomed patients to the association with different forms of blood cancer, such as leukemia and myeloma. As the years passed, we continued to grow however those directing this association felt that our voices lacked in strength and we were still not properly recognized by the key stakeholders in the industry. Thus, GEPAC was born through the collaboration of AEAL with six other cancer associations. Now, nearly eight years later, GEPAC represents 88 different cancer organizations and we now have a strong voice in Spain's healthcare society with the recognition of the Ministry of Health, Social Services and Equality. This recognition strengthens the voice of the patients in the healthcare system which is important because now we have much more visibility than before.

**Can you please elaborate on the main goals of the patient association?**

The main goal of GEPAC is to represent the voice of the cancer patients not only nationally, but also internationally. Spain has strong links to Latin American and Europe, allowing cancer patients to expand their voice and have their needs addressed. At GEPAC, we focus mainly on training other patient organizations in the country because of our years of knowledge and experience. However, most of the patient organizations in Spain are young, because before democracy in 1978 we were not allowed to collaborate and stand together. Therefore, these young organizations need the right information and training to become relevant in the healthcare system with the goal of being nationally recognized, and this is one of our main goals.

In addition to providing training to other organizations, we offer services to patients ranging from physical rehabilitation to providing psychiatrists and cosmetic workshops. More recently, we have begun offering a service to patients where they can undergo real-time information from a phycologist, who speaks to them during their day to day activities and offers support and advice to the patient regarding different areas such as nutrition, exercise, and medication.

Finally, we help to organize many different events to celebrate the numerous international days recognizing different cancers. This enables GEPAC to continue the dialogue between the patients and the professionals in the industry. In November, we have our biggest event in Madrid, a Congress which last year had 2400 patients and their families in attendance, in addition to more than 100 professionals, bringing together all the different corners of those affected by cancer with the aim of improving the needs of the patient

**In Spain, there has been a recent increase in the number of patients diagnosed with cancer. What is your assessment of this?**

There are several factors associated with the increase of diagnosis in the country, the most notorious being the advancements in technology. In Spain, we can now diagnose a patient with cancer much earlier than before. Although this affects the numbers of those diagnosed, this offers the patient the best chance of survival. In addition, the country has the highest life expectancy in Europe, with a child born this year having a life expectancy of 83. Thus, an ageing population paves the way for more cancers to become prominent in a patient.

Furthermore, despite this increase Spain has more than 1 500 000 cancer survivors, keeping the country in line with other European countries. Following on from this, GEPAC conducted a study looking into the needs of cancer survival patients. As a survivor myself, the quantity of survivors in the country is a positive number to see but sometimes society is lacking in the tools for treating those who have recovered from cancer and more needs to be done to introduce the necessary social and economic elements for a survivor to be reincorporated back into their original lifestyle.

**There are some cancers which can be prevented by a change in lifestyle. Do you believe enough is being done to promote the prevention of cancer?**

Unfortunately, we do not have many strong prevention programs in Spain. The government's priorities are not yet looking towards prevention and this is an issue when some cancers can be prevented. Therefore, GEPAC has taken the initiative of educating, and recently we have visited schools on Melanoma Cancer Day to explain the importance of protection against the sun to prevent skin cancer. It is important to have these habits as a child because otherwise, it becomes very difficult to keep this up as an adult. Therefore, GEPAC always tries to educate the younger generation on prevention where we can, but we do not always have the funds or the tools to do so and thus this should be a priority for the government to focus on prevention activities in schools.

**What is the role that pharmaceutical companies play in the field of oncology in Spain?**

GEPAC and many other patient associations have strong relationships with Pharmaceutical companies. We both understand the rules and the limits of these partnerships and we all respect this. Recently, we are seeing more and more investment in oncology from these companies.

More recently, GEPAC created the initiative GEPAC VIDA, an incentive orientated towards giving back to the society through the companies we collaborate with. It has only recently advanced in terms of effectiveness, with the idea of giving back to the companies' information and advice when they donate money to our cause. For example, companies that invest in GEPAC VIDA will receive vital information on how to treat employees who have cancer and the best options for them both. This is essential in modern society because some companies are blind in this matter and do not know how to accommodate their employees affected.

**Looking to the future, what role do you think Spain can play in the fight against cancer?**

Spain can play a very important role in Europe regarding clinical trials. The next steps are for the patient organizations to educate patients on the need for their participation in clinical trials right from the beginning. Without this early participation, our patients cannot receive the best medication in the long term. Patient associations need to bring to the table different tools for both the patients and the professionals involved.

**Where do you hope to see the future of GEPAC and its evolution in Spain's healthcare system?**

Looking back, I never thought in 2010 when GEPCA was created that eight years later we would be representing so many different patient organizations and have become a voice for the patients. My dream is that a patient's voice will be recognized regardless of their geographic location and to see more patient associations promoting the need for participation in clinical trials across the whole spectrum

The motivation for this is my enthusiasm for the work that I do for other patients with cancer, but more importantly for myself. I am a cancer patient but also a cancer survivor, therefore I am dedicated to improving the lives of others in Spain. The philosophy that we should all follow is to give back to society and make the country better step by step.

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