

# Nurse helps to make things better

## Rapid expansion for a new Croatian brain tumour patient and caregiver group

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AS a nurse Valerija Korent knew quite a lot about illness and the problems it brought for both patients and families. But when her husband was diagnosed with a brain tumour she discovered exactly what it meant to face such a life-changing disease.

In her home country of Croatia there was no support organisation for the 640 new cases every year. Patients and families had no-one to explain the condition in layman's terms and offer advice and guidance on treatments available.

Valerija discovered that patients had to find their way through complicated healthcare systems, and there was limited support. For example psychological support in Croatia was not a standard part of treatment for patients with brain tumours. It was important to raise public awareness, to help patients return to daily life, and also to raise the standards of treatment.

### More challenges

There are other problems too. Croatian neuro-oncologists have limited availability of medicines. Molecular diagnostics are not available and for certain tests patients often have to travel to Slovenia or Italy. In Croatia, with a population of 4.2 million, there are just six neurosurgical centers. Three are located in the capital and treat the vast majority of patients. There are five radiotherapy centers in which there are neuro-oncologists - mainly specialists in the field of radiotherapy/clinical oncology.



**Above:** Valerija Korent, nurse and the author of the Croatian-language brochure *Living with a BrainTumor*, who is also the president of the Glia Association, the Croatian organisation for brain tumor patients.

Because of this distribution, availability of treatment and rehabilitation is not ideal. Currently there are no clinical trials in Croatia for brain tumours and unfortunately, Croatia has not yet achieved the desired level of cooperation with European and international professional organizations such as the EORTC, ESTRO, etc which would allow Croatian patients to participate in multicenter trials.

Medicines, supportive therapy and rehabilitation costs represent a challenge for hospital funds and the economic standard of patients. Many nurses and doctors leave the country to work abroad, and it is difficult to recruit the necessary new staff.

### Valerija's inspirational initiative

Valerija decided to set up her own group

to help others with the problems she had faced. Now she is president of the Glia Association which has 60 members and is growing rapidly. One of her first jobs was to write a brochure in Croatian, called *Living with a Brain Tumour*.

This brochure was released in 2013 and was the first to explain the disease in plain language. It offers basic information about the disease, symptoms, diagnosis and treatment.

In the brochure Valerija writes about her experience of living with a person affected by a brain tumour. She said: "It was very difficult to cope with the diagnosis and the fact that a loved one is suffering from a malignant disease, but this fact you cannot change. It is vital to adjust quickly to the new situation and try to live with it, because it is the only way we can help an ill person."

### The Glia Association is launched

Two years after her husband died, Valerija got together with two oncologists at the Clinical Hospital Centre in Zagreb, Ana Misir Krpan, and Kresimir Loncar. Together they launched Glia with the aim of bringing together not only those being treated for a brain tumour, but all those who involved in their treatment and recovery.

The first meeting was held last June and the group has been very active since then. They are currently looking for an office and have already held two meetings for patients, their families and the medical staff, with a very good response and interest. In addition to lively exchange of experiences, meetings included lectures by experts from different disciplines.

The association has set up a website



Above: Members of the Glia Association in Croatia

which is the main communication channel with members and other patients. Recently there was an article published about the association in the national daily newspaper. Glia's main objective is informing patients and their families about the disease, and getting the best

treatment taking into account the current situation in Croatia. ■

For more information about the Glia Association, visit their website at [www.glia.hr](http://www.glia.hr)

## The Croatian history professor: one academic's brain tumour experience

WHEN I was a child I listened to comments about being healthier than all my friends. I had no childhood illness, had the flu three times in my life, and only visited the doctor about once a year. Therefore it was an even greater shock when I was diagnosed with a brain tumour. And the first results showed it was the worst kind.

Scared and startled by this difficult diagnosis, at first I experienced it as a death sentence. As a professor of history, which is quite different from the profession of medicine, it was initially very difficult to keep track of what the doctors were saying and decipher their findings. I spent hours and hours on the Internet trying to get information about the disease and trying to translate and explain to myself many of the unfamiliar medical terms. In a short time many beliefs about the cancer and medicine in general collapsed. I thought it was a disease only for the old and otherwise ill people. How

could something like that happen to me at the age of 35?

I was not aware that the brain is still a mystery for modern medicine and that the choice of drugs for brain tumours is very limited. I was happy that I got to the best hospital in Croatia, but then I realised that even the best doctors in our country do not have optimal working conditions.

In Croatia, I could not have molecular diagnostics, so I decided to look for a second opinion abroad, at my own expense. The news, fortunately, was good: I did not have the most malignant tumor. This finding properly directed my therapy.

Today, years later, my medical record says "no reliable signs of disease activity," and my 12-letter diagnosis in Latin I pronounce with ease.

I'm still shaking days before each MRI, but now I'm a better informed patient and ready for medical challenges in the future.

*(Patient BN, age 39)*