

Desperately seeking a bone marrow match

The media campaign that made things happen in Romania

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CRISTINA NICHITUS

A powerful media campaign that is set to transform the prospects of Romanian patients in need of transplant treatments won TV journalist **Paula Herlo** an ESO Best Cancer Reporter award. The €5000 prize is the first in a new Campaigner category. She talked to *Cancer World* about how her Pro TV broadcasts mobilised public opinion behind the call for a national stem cell donor registry.

When TV journalist Paula Herlo travelled abroad to research a story on advanced treatments for patients with blood diseases, she discovered something about her own country that shocked her.

While looking at transplantation treatments for leukaemia at La Fundació Josep Carreras in

Spain, Herlo was shown the European network for registries of bone marrow and T-cell transplant donors. One researcher offered to help her localise her story for her Romania Pro TV viewers. “She asked me ‘Do you want to know how many donors Romania has on the registry?’ When I said yes, she tried to find it on her computer. Then she told

Result. Former Health Minister Ioan Bazac (*opposite*) and Paula Herlo (*right*) were the first to be tested to be registered donors, under an approving media spotlight at the Ministry of Health, September 2009



me ‘I can’t do it; you don’t have a registry.’”

Without an approved registry, neither the Romanian health system nor the patients waiting for treatment could link to the European Marrow Donor Information System (EMDIS), an international computer network of registries that covers more than 85% of stem cells donors worldwide. And without being part of the global network, the only chance that Romanian patients had of finding a bone marrow match was from close relatives.

When Herlo returned home she found that about 150 leukaemia patients a year were waiting in Romania for transplants, without much hope. There were also 3500 people with Hodgkin’s disease and 3700 Romanian children with thalassemia major, many of whom could be treated with T-cells from bone marrow. Meanwhile, the three centres in Romania that carry out bone marrow transplants could only do so if they found donors within the patient’s family.

“I realised at that moment that I must do a campaign, because in our country, if a patient has leukaemia and does not have a donor in his family, they are condemned, unless they have the money for treatment in France or elsewhere.” To get treatment abroad costs anything from €75,000 to €150,000 – out of the question for most families, given that the wage for a teacher is about €350 a month.

Herlo’s team at Pro TV agreed to launch a campaign, and haematologists in the country

enthusiastically agreed to support them. In March 2009 Herlo began a series of interviews with families and patients that grabbed the attention of the public.

She highlighted cases like that of 18-year-old Dragos Croitoru, who waited three months while the health bureaucracy in Romania considered whether to send him abroad for treatment. Approval arrived on the day that doctors told his mother that he had only a week to live. “I don’t even know if I have the strength to get out of bed anymore,” he told Pro TV. “I feel that it’s all over. I don’t even have the strength to pick up a glass of water and drink.”

Herlo’s reports detailed unbearable foot dragging – including the five days it took the Bucharest Public Health Directorate to find a driver to deliver Dragos’ papers to the Ministry for approval. She told her audience: “Dragos’ story is illustrative of a flawed system that puts people’s fate in the hands of bureaucrats for whom the lives of these patients don’t mean anything. They are just files.”

Dragos got to Israel for treatment where sadly he died. For him, the treatment had come too late.

A SUSTAINED CAMPAIGN

Over the next two months, Herlo and Pro TV ran 25 stories highlighting the need for a national registry under a slogan “Avem viata in sange” – “there is life in our blood”. “We showed how patients are dying – abroad the survival rate is 80%, and in Romania it is 20%.”

Out of the many tragic stories, it was the first that caused Herlo most heartache. Caludiu Voicu, an eight-year-old boy from Slatina, had waited a year for approval to be sent abroad for treatment, at a cost

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of about €100,000. As a result of the campaign, he made it to Hungary, but his leukaemia was too far advanced. “He passed away last year – it was very hard. I helped his family get him treatment, but it was too late for him.”

The campaign was taken up by newspapers and blogs, and 36,000 people signed up on the Pro TV website saying that they were prepared to become donors. After two months, the then Health Minister Ioan Bazac announced that Romania would set up a registry that would meet international criteria. In September 2009, live on TV, Herlo and the Minister became the first two people to be entered on registry as potential donors.

“It was a big surprise when they responded. It was like a dream. But when I had spoken to the Minister I told him that we would continue this campaign for a year or two years if necessary.”

One of those who had been watching the campaign was Olga Cridland, president of the PAVEL Association Against Childhood Cancer in Romania. She says that scarcely a week goes by when she does not hear of a new patient who needs to be sent abroad for treatment. The campaign got patients and families talking and they became active supporters. Hugely impressed, Olga nominated Herlo for the Best Cancer Reporter Award.

“I think that the media has a big power in influencing things, depending on who is doing the campaign. If it is made in a really good and, how can I say, stubborn way, I think this can change many things regarding health, and changes in the laws. Our attitude as organisations is to try to work together with the media. When we heard Herlo’s campaign I thought it was a very good way to do it.”

ETHICAL PITFALLS

Herlo recognises the potential ethical pitfalls in running a campaign based on highlighting tragedy and hope in people’s lives, and stresses the importance of having a good team to take decisions. “My colleagues are very receptive to my ideas and support

me very much – my boss is a great woman. Of course, there were discussions about ethics and I treated every case very carefully. But I admit that along the campaign there were very emotional moments, when families who lost their loved ones spoke about their drama and the chance that every Romanian patient should have.”

Herlo says she would prefer to avoid these sorts of highly emotive, dramatic stories, “but experience showed me that the Romanian authorities react only to pressure from public opinion and the mass media. Sometimes we have to call things by their names and show that people suffer, so that the ones who can change their destinies react.”

Media campaigns, she adds, can get things done, because the public becomes a partner. “They can ask the authorities to change things. I strongly believe that a media campaign can change laws and even mentalities.”

Herlo, who has won awards for her reports on economic and social issues before she turned to health, is now running a series on the crisis in the Romanian health system, campaigning for a change in laws and funding. “Romania has an under-financed health system. The funds are going into black holes, without anyone paying for it. The hospitals are going bankrupt one by one, and the patients are paying for treatment although they already pay the health insurance.”

The implications for anyone diagnosed with cancer can be dire. “Cancer patients are somehow condemned in Romania. For example, once a patient is diagnosed he must wait for months sometimes for the treatment to be approved by Health Insurance Office.”

Olga Cridland says that organisations like hers are learning to work more effectively with the media, inviting reporters to come and speak to patients directly. PAVEL has formed a partnership with the health channel Sanatatea TV and is also working with *Adevarul* newspaper (“The Truth”) to highlight the need for early referral of children with

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Inspiration. Paula Herlo with Ramona Ilian, a little leukaemia patient she met on her visit to Barcelona's Vall D'Hebron hospital while researching her story on blood transplantation treatments

cancer, backed by the UICC 'My Child Matters' campaign.

PAVEL also appreciates the part of Herlo's latest health campaign that is pressing for government action to ensure that common cancer drugs are available on the Romanian market. Because the number of patients is relatively small, lower-cost drugs such as Cosmegen (dactinomycin) used in the treatment of Hodgkin's lymphoma, cannot be bought in Romania. “Unfortunately, we have a big economic crisis now affecting the entire health system,” says Cridland. “Many people are suffering and we have tried to alert the authorities but it has not changed the situation. It is a tragedy because people have to travel abroad to buy this or that drug.”

These are issues, she says, where a campaigning media can wake people up. “Not all media are good,” she says. “I want to make a distinction. But if you speak to a proper journalist, sometimes they help you to express clearly what you want to say. I don't know about other countries, but I have a good impression about media in our country. When reporting on children, mostly the journalists are very sensitive.”

While she campaigns on these broader health



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issues, Herlo has not given up the bone marrow registry. Of the 36,000 people who volunteered to sign up, so far only about half have actually done so. The registry is due to be linked to other international registers in February 2011, when it will finally become a resource for hope and treatment – and Herlo is not ready to let the matter drop. “This campaign will continue next year with a series about the importance of becoming a donor. I will prepare another campaign to sustain this register.”

Given her record so far, Romanian patients in need of a transplantation treatment will soon be facing a much brighter future.

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