

Profile

Vania Hungria—treating myeloma with restricted resources



A love of sport almost saw Vania Hungria become a physical education teacher. “But at university I soon realised doing sport and teaching sport were not the same thing!” Hungria tells *The Lancet Haematology*. She then transferred to a medical degree at the Santa Casa de São Paulo Medical School (Sao Paulo, Brazil), where she realised her interest lay more in clinical medicine than surgical disciplines. “During my residency at Santa Casa Hospital, I got to work with and bond with many young patients with leukaemia. I knew then that haematology would be my career.”

During her residency, Hungria soon noticed some patients were not getting the attention they needed—those with multiple myeloma. “Myeloma then had very few treatment options. Generally, these were older patients, suffering multiple fractures and often in great pain, with anaemia and renal failure,” she explains. “They were passed between specialties. It was not good enough.”

As well as working at the private São Germano Clinic (Sao Paulo, Brazil), Hungria established a clinic for multiple myeloma at Santa Casa Hospital, so that patients had their needs addressed in one location. She intensely studied research from the USA and Europe to provide patients with the best supportive therapy possible. “I then went to the International Myeloma Foundation for help and advice for how to improve things in Brazil,” she explains. “I translated their patient handbook into Portuguese, so that patients across Brazil would better understand all the changes they were going through.”

Hungria was able to form the Latin America branch of the International Myeloma Foundation in 2004, with the help of the daughter of a patient with multiple myeloma. She made many connections with leaders in clinical trials worldwide and was eventually able to include patients at Santa Casa Hospital in a wide range of pharma-sponsored studies. She explains that three quarters of Brazil’s population of 210 million people depend on the public health system, so cannot access the newest treatments for myeloma. This is a life or death issue, since the latest treatments can double survival in myeloma patients to 6 or 7 years. Additionally, although stem cell transplantation is available on the public health system, there is a long and waiting list and many patients will die before receiving treatment.

Hungria’s first clinical trial was sponsored in 2005. She has completed studies including bortezomib, panobinostat, vorinostat, denosumab, carfilzomib, ixazomib, daratumumab, isatuximab, and venetoclax. During the past two decades, these studies have allowed Hungria to treat many hundreds of patients who would not have received these treatments in the public health system. Sadly, in 2015, Santa Casa Hospital ended clinical trials, and she

transferred the studies and thankfully, most of her patients, to São Germano Clinic.

Currently, Hungria’s clinic has patients enrolled in trials on monoclonal antibodies. However, she laments that patients on pharma-sponsored studies are only a very small fraction of the estimated 15 000 patients newly diagnosed with multiple myeloma each year in Brazil. Additionally, the sheer size of Brazil makes it difficult for many eligible patients to travel to trial sites, which are usually in Sao Paulo or Rio de Janeiro. Despite this, Brazil is in a much better position than other countries in Latin America. In Brazil, around 25% of patients can access private health care, and therefore the latest treatments, compared with an average of 12% across the rest of the continent. As an author on the Latin America Haemato-Oncology study, it was clear to Hungria that although doctors in Latin America are well trained to deliver the best therapies, access to them remains a critical issue in every country. “Access to the latest therapies, such as monoclonal antibodies, is almost non-existent in the public health system,” she says. In 2008, Hungria faced her own diagnosis of lymphoma. “At first they thought it was an untreatable aggressive cancer, so I felt lucky,” she recalls. “I used to use the phrase ‘I know how you must be feeling’ a lot with my patients but having had cancer myself I know now that isn’t true!” She confronted her diagnosis head-on, refusing to wear wigs as she lost her hair during chemotherapy. “I went to one myeloma patient advocacy congress completely bald,” she remembers. “I was meant to be talking about myeloma with them, but of course they wanted to know my own lymphoma story when they saw me.”

In the future, Hungria would like to open her own myeloma institute. But for now, she enjoys each day and is known as a joker among her friends and colleagues, often turning up in fancy dress to events. “I have come as Abba, Amy Winehouse, I have been many people!” she laughs. She loves to play tennis and go skiing, and takes advantage of work travel to discover different countries.

“I had the enormous privilege of meeting Vania Hungria almost 20 years ago as she was evaluating three different thalidomide-based regimens in myeloma. She had already started her fight for fair access to drugs in Latin America,” says María-Victoria Mateos (University Hospital Salamanca, Salamanca, Spain). “Since then, I have admired her skill and sensitivity in leading not only Brazil’s myeloma doctors but also those across Latin America. I also know of another of her skills: she plays piano and has delighted me with some songs sent through WhatsApp during the COVID-19 pandemic!”

Tony Kirby



For more on the HOLA study see *Br J Haematol* 2020; **188**: 383–93