Manuel Abecasis – President, Portuguese Association Against Leukaemia (APCL)

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President of the Portuguese Association Against Leukaemia (APCL), Dr Manuel Abecasis is known as the father of bone marrow transplants in Portugal. He outlines the APCL's activities, including the organisation's role in raising awareness and increasing the number of donars in the Portuguese Bone Marrow Donor Registry, which went from 1,500 to 400,000 donors in just 12 years. He also discusses the country's access issues and delays surrounding bone marrow transplants.

Can you start by giving us an overview of your background and how you became known as ‘”the father of bone marrow transplants in Portugal?”

I qualified as a Doctor from Lisbon University in 1974 and did my general medicine training at several hospitals, including in Madeira as a GP for a year. I then moved to the UK, working in Liverpool and then to Manchester at the Christie Hospital, which is a big oncology centre. From there I moved to the Royal Manchester Infirmary as a registrar and then down to London at the Royal Marsden working as a senior registrar in the bone marrow transplant unit with Professor Ray Poles.

I was then invited to go to the Paoli-Calmettes Institute in Marseille as a Leukaemia Research Fund (UK) fellow and collaborated with Professor Maraninchi to set up a bone marrow transplant unit. Afterwards, I moved back to Lisbon and after a short stay at one of the university hospitals, I was invited by the Portuguese Institute of Oncology in Lisbon to set up its bone marrow transplant unit. When we started back in 1987 we were the first centre in Portugal to do this. After that, I had several positions within the organisation before retiring in 2020, eventually becoming head of the haematology department and director of the institute.

After my retirement, I became the director of the Portuguese Bone Marrow Donor Registry (CEDACE), which aims to attract volunteer donors. It is one of the largest in Europe per capita with around 400,000 registered Portuguese volunteers. We have been able to establish a solid registry operation based on strict operational procedures and a new IT system and received official accreditation by the World Marrow Donors Association in just two years, a big achievement. I am also president of the Portuguese Association against Leukaemia (APCL) while maintaining my own private practice in haematology to actively see patients and discuss clinical issues with my colleagues.

The APCL began in 2002 as a support and awareness group. How has the organisation evolved since then and what are some of its main focus areas?

We started our activity back in 2002 as an initiative from Leukaemia patients and doctors working at the Portuguese Institute of Oncology in Lisbon. We are now a community of patients and healthcare professionals focused on supporting patients with haematological malignancies by promoting research, education and advocacy.

Our first goal back then was to enlarge the Portuguese Bone Marrow Donor Registry as there were only around 1500 donors and there was a lack of resources in terms of equipment and manpower to increase these numbers. Therefore, we put in place public initiatives through the media to make more people aware. Furthermore, there was a well known football player whose son had aplastic anaemia, with the only treatment being a bone marrow transplant. There was a huge appeal to find a donor, and eventually one was found from the US. With this push and other cases attracting the attention of the media, we went from 1,500 to 400,000 donors in about 12 years.

Another aim is to be financially stable, and the running costs of the APCL itself are well contained and our resources are entirely dedicated to fulfilling our mission. We give finantial support to lower-income patients and families who are referred to the APCL by the social services of the treating hospitals.

We regularly organise education sessions for patients and their families on topics such as lymphomas, multiple myeloma (in collaboration with the International Myeloma Foundation), Leukaemia, myelodysplastic syndromes and other related disorders. Haematology experts, nurses, psychologists, social workers and even patients participate in these sessions, often conducted by zoom. This has proved to be an excellent way of disseminating scientifically sound information in a lay language and improving patients’ knowledge about their condition.

For the past 5 years we have organised an annual event where the recent advances in the area are presented in a way that is oriented to patients and their caregivers, with highly qualified speakers in each area. This is made possible by grants from the pharmaceutical industry, and with the generous collaboration of the invited speakers.

The centres treating patients with blood disorders are part of the Portuguese National Health Service and we give grants to health professionals looking after patients with malignant blood disorders, such as nurses and doctors, so they can go and train in other hospitals in and outside of Portugal. Moreover, with the Portuguese Society of Haematology and pharmaceutical companies, we give grants for research projects that are to be developed in Portuguese centres and every year there are 3 or 4 investigation projects who are awarded grants.

Our most recent successful project was to build a house for patients and their caregivers who live far from Lisbon and who need to stay in close proximity to their hospital for treatment. This has assisted disadvantaged families who cannot afford to pay for a place to stay and gives them the opportunity to be treated more comfortably.

At the APCL we collaborate closely with similar associations in other European countries, such as the International Myeloma Foundation, the CML advocacy group, the Italian Association against Leukaemia and also with other associations that are not strictly European.

As an expert in the field, in your opinion, how accessible are bone marrow transplants in Portugal?

Portugal has six units throughout the country, with three of them in Lisbon, two in Porto and one in Coimbra. There are around 550 bone marrow transplants done in the country annually, but we have a bottleneck in allogeneic transplants, or procedures with a healthy donor, and we are well behind where we want to be. There are waiting lists in every centre, and despite introducing advancements in the field, we cannot fully reach the demands of patients that are suitable to receive transplantation. It is a problem.

We have spoken several times with the authorities and shown them the numbers, and we believe there is an urgent need to increase the capacity of bone marrow transplants in Portugal. Delaying a transplant presents several issues, such as the disease progressing in the future, or the patient receiving the treatment when they are in worse physical condition, such as after extended intensive chemotherapy. Furthermore, this delay causes tremendous stress for the transplant teams, patients, and their families. Sometimes the delay can be over six months.

You mentioned the large number of donars that are now a part of the PCEDACE. If finding donars is not an issue, what are factors behind transplant delays?

Finding donors is not a problem as we can tap into the registries across the globe with around 40 million volunteers worldwide currently. The problem is actually the capacity of the transplant centres in Portugal to treat patients. We need at least two more transplant units and at least one that is specialised in paediatrics as there are conditions that are very specific to younger age groups. For example, in some severe immune deficiencies if a child does not receive a transplant urgently, he will die.

It can be a little frustrating at times, but we are moving ahead. Each centre is part of the European Bone Marrow Society, and our results are shown internationally. We have an excellent team of nurses and doctors that are dedicated and well-trained and many new and young doctors moving into the field.

I will say that being a clinical haematologist you require a very strong general medical background, and it is hard work. I was driven by the death of my cousin from Leukaemia at a very young age as well as my interest in the reports of bone marrow transplants in the 70s and 80s and being able to see the light at the end of the tunnel for Leukaemia patients and other haematological conditions.

Bone marrow transplants were a breakthrough in the 1970s and 80s, and now we can see CAR-T therapy stepping into the limelight. What do you see as the potential of personalised CAR-T therapy for Leukaemia patients?

Together with my team, we actually began a CAR-T programme for lymphoma patients in Lisbon in 2019, but it hit a snag with the COVID-19 pandemic, though today we are again back and running at full speed.

We were curing around 60 percent of our patients with traditional chemotherapy and around 20 percent were being saved by bone marrow transplants. But what about the rest who are on their last legs and going into palliative care? In fact CAR-T cells are able to save around 40 percent of these patients at the end of the road and it is an amazing achievement and a real medical revolution. It is hard to believe how treatment works, using the patient’s own T-lymphocytes that are genetically modified to recognise the tumour cells and kill them. Of course, CAR-T comes with its own unique toxicities, but still it is incredible and a major advancement. CAR-T will very much be a part of our treatment algorithms going forward.

What is the downside of CAR-T, apart from the fact that it is only used as a second-line treatment?

For lymphoma patients it was a third- or fourth-line treatment in the past, but now it is a second-line treatment and has moved ahead of bone marrow transplants. Clinical studies have been done to show the safety and efficacy of CAR-T cells as a second-line treatment and they compare very favourably to bone marrow transplants. In fact, when transplants first began they were seen as too toxic, so it is a natural progression that as we understand and study a treatment, it finds a more secure position in the patient’s treatment plan.

The other aspect of CAR-T is that it is expensive, and prices will have to come down to give more access to patients. For the time being it is a difficult to choose which patients will be able to receive treatment and which will not, especially in a resource-strained healthcare system.

How involved is the APCL in influencing government policy making decisions?

We have a national authority, the INFARMED, which is the Portuguese regulatory body, and our medical experts sit in with the committees and now even the patient advocacy organisations are a part of the process. The APCL is collaborating with INFARMED to gather feedback on patients’ rights and thoughts.

Recently I was at a meeting on the European Health Technology Assessment (HTA) regulation and there is a real need to deliver fast access to medications by speeding up the process leading from European Medicines Agency (EMA) approval to acceptance by the Portuguese national authorities. We hope that this will be in place by 2025 and that it will create a more even playing field for countries receiving new technologies across Europe.

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