

TRANSCRIPT

LEGISLATIVE ASSEMBLY LEGAL AND SOCIAL ISSUES COMMITTEE

Inquiry into increasing the number of registered organ and tissue donors

Melbourne—Monday 31 July 2023

MEMBERS

Ella George—Chair

Annabelle Cleeland—Deputy Chair

Chris Couzens

Chris Crewther

Gary Maas

Cindy McLeish

Meng Heang Tak

WITNESS *(via videoconference)*

Dr Joannis Mytilineos, Chief Medical Officer, Zentrales Knochenmarkspender-Register
Deutschland.

The CHAIR: Good afternoon. We will now recommence the public hearings of the Legislative Assembly Legal and Social Issues Committee's Inquiry into increasing the number of registered organ and tissue donors.

My name is Ella George and I am the Chair of the Committee, and I am joined today by my colleagues Gary Maas, Christine Couzens, Cindy McLeish and Chris Crewther.

I welcome Joannis Mytilineos, Chief Medical Officer from the National Bone Marrow Donor Registry Germany. Thank you very much for joining us today.

All evidence given today is being recorded by Hansard and broadcast live.

While all evidence taken by the Committee is protected by parliamentary privilege in Australia, comments repeated outside of this hearing may not be protected by this privilege.

I invite you to now make an opening statement of around 5 to 10 minutes, and this will be followed by questions from Members. Thank you.

Joannis MYTILINEOS: Hello, everyone. My name is Joannis Mytilineos. It is a pleasure and a great honour for me to be invited to be part of this process. As my name justifies or admits, originally I am from Greece, but I have been living in Germany for my whole professional life. After school I went to Germany and I studied medicine at the university of Heidelberg, where I also did my Adjunct Professor's Degree in immunology. After that, I worked as a transplantation immunologist at the university hospital in Heidelberg, and I was there as lead of the HLA laboratory for several years. At that time I had been working with Gerhard Opelz in Heidelberg, who is one of the very known transplantation immunologists in the world, focusing basically in the field of solid organ transplantation, which was also my expertise in these days. Later on, around 2004, I moved over to the University of Ulm, also in Germany, in south Germany, where I took over the transplantation immunology department there, basically doing the diagnostics for transplantation patients in this area. The focus in this second place that I worked in was rather in the stem cell field, so the organisation for which I was working operated a relatively large regional bone marrow donor centre. Through that involvement in the field of stem cell transplantation, I was asked back in 2020 to take over the lead of the National Bone Marrow Donor Registry in Germany, the ZKRD, which I am leading currently. So this is a short summary of my own person.

My organisation, the ZKRD, is the largest national bone marrow registry worldwide. We have currently more than 10 million donors being registered in Germany. The structure is such in our country that there is a law that basically covers the activities of the national registry in so far that all the searches for patients in Germany have to go through the national registry. The donors can be registered in different organisations and donor centres, but all the information about the German donors and the donors registered in Germany has to be, in an anonymous way, provided to the national registry so that the search can be accommodated. In fact there are more than 25 different donor centres in Germany that are doing the registration work for new donors and who also have the personal information of all those donors. But the search process goes electronically through the ZKRD, so we provide a platform that allows the searching staff to identify the best national and international donor through of course our networks and the connections abroad that also allow a listing of all the international donors through our platform.

So that is my background and the background of my organisation. That is where I am standing at the moment, and I am happy to respond to any questions you might have, which hopefully basically will cover the field of stem cell transplantation, but since my past has been very much influenced from the area of solid organ transplantation, I may be able to give you some answers to questions you could have about solid organ transplantation and increasing the donation rates in this field as well.

The CHAIR: Great. Thank you very much, Joannis. Before I continue, we have been joined by our colleague Meng Heang Tak via Zoom. Thanks for joining us, Heang.

One of the things that has struck me as we have been receiving evidence from our witnesses is that three out of four stem cell donations in Australia are coming from overseas—largely from Germany, we understand. So obviously Germany is doing a fantastic job in terms of really high numbers of donor registrations but also being

able to provide that to the rest of the world, so thank you for all of the work you are doing in that space. Do you have any advice for us here in Australia about how we can increase the number of registered stem cell donors?

Joannis MYTILINEOS: Well, the system in Germany is basically not based on the state. That means the registration of new donors is not financed by the state. It is fully privately managed insofar as the funds for the typing of new donors and the registration costs that may be associated with the whole process are covered through money donations. The organisations in Germany are sort of competing a little bit to each other. There is one large vendor, I would say, which probably you would know, DKMS, that has more than half of all the donors that are being listed in Germany. The head of that organisation originally came from the cosmetics department, so marketing was a large part of it. So they knew how to market the issue. They pushed the field very, very much ahead, and all the other 24 donor centres tried very hard to be able to stand in this field. So my recommendation would be: do not over-regulate but create the background so that facilities that would register donors can be creative and of course inform people. So that is the other point. In Germany, the altruistic thought is quite prominent. Germans, or people living in Germany at least, get inspired by the fact that they could save some other's life by donating just blood or cells. That creates a lot of motivation for them to get registered. Once the marketing structure is there, that brings that issue closer to them, and if they have the options and the opportunities to easily get registered—that make it easy for them to approach the registry and get registered—that is very helpful and that I think increases alone the numbers.

In Germany, very often the new registrations are associated with a particular case. So there is a child or somebody, a fireman or a policeman or a popular member of the society, that has suffered leukaemia, and very often they use such a person in order to organise a donor drive. And people go and donate, basically because of this person but not exclusively for this person, because everybody knows then that once registered they do not donate for that person only but they would be available for every patient worldwide who may be in need. So education, marketing and making it easy for them—I think those would be the main three points that I would like to raise.

There is also another issue that does not really make it easier for people to register, but it is an important parameter when it comes to the success of the German system, and this is the national policy that exists in Germany where people have to register with authorities. That means authorities have to know where people reside—this is by law—and when new donors are registered to the registry they have to give their consent that if they have moved somewhere else and we cannot trace them we are allowed to go to the authorities and ask for the new address. That makes it easier for us to find people, in particular young people who move around the country, and contact them in case they are needed.

The CHAIR: That sounds like a very sophisticated system that you have operating in Germany. Just one quick question about the 25 donor centres: do they all operate individually of each other and receive different sources of funding?

Joannis MYTILINEOS: There are some larger ones—like I said, the DKMS, then the second largest has half a million donors, the third largest has 300,000 and so on and so forth. There is a large number of smaller ones with less than 50,000 donors being registered, and they can be either part of private organisations or they are associated with university hospitals or blood donation services—all kinds of different organisations are involved in that. As I said before, they all have their own funding. They try to find support either from, different organisations, like Lions Club, Rotary etc, or larger regional companies that are in the area where they are operating—many different ways, so they are very creative in finding funds. Having said that, the state supports the system by giving a symbolic amount per registered donor, okay? So on an annual basis the donor centres receive a symbolic amount for sustaining the system, but there is no money coming in for new registrations.

The CHAIR: Great. Thank you. I will hand over to Cindy now.

Cindy McLEISH: Thank you. And thank you very much for your time. It is greatly appreciated, certainly for us to speak with somebody with your experience and be able to do it so easily over Zoom when you are in Germany and here we are in Melbourne. Can you tell me, when somebody makes a stem cell donation, how long do they spend there and do they get paid for it? Is there any reward for them when they are doing that?

Joannis MYTILINEOS: No, it is absolutely voluntary. They do not get any money but of course they get, if they lose their income for a couple of days or for the period they need to be active as a donor for the whole preparation—they obviously need to go to the doctor and get what they call the donor clearance. That implies a full check-up, and usually a donor would be away from work two to three days for the whole process. Let us say three days. Sometimes they would have problems afterwards; they may have felt ill or something. Let us put it like this: they could be away from work for a week or something, and these expenses are being covered by the donor centres. So the donor centres are reimbursing the income loss that a donor may have, but the donor needs of course to justify that. He needs to provide documentation about the loss of income. Usually, his or her employer would issue a certificate saying that that amount of money has not been paid to that particular person, and with this certificate or with this document the donor centre would reimburse the donor. But apart from that there is no other remuneration, and very often actually the employers would step in and continue to pay and then declare that as a donation, if you know what I am saying.

Cindy McLEISH: Ah, tax deductible.

Joannis MYTILINEOS: Exactly. It is then considered a donation, so they need to declare that separately somehow.

Cindy McLEISH: Well, that is pretty interesting, and I think it is really impressive to think that with a population of, like, 83 million you have got some 10 million donors. That must mean it is working really effectively. With the centres, how do they make ends meet? You mentioned that they do get paid by registration. But there is a lot of work involved, and I would imagine that they have a lot of costs. So what else is there that helps them make ends meet?

Joannis MYTILINEOS: Again, there are many different organisations that have different backgrounds. As I said before, there is a calculated cost for ‘donor registration’, they call it now, and that is something between €35 and €50. The different donor centres have calculated that on a different basis, obviously, so there is a little difference. Some would claim €35, some would claim €50 and this is what they do in order to receive funds. When they are applying for funds, they are calculating something between €35 and €50 per registration. In the old days they called it money for typing, so that covered only the typing. But as the typing procedures have become more affordable currently with all the new technology that has come up, this has now been called a registration fee, and it covers all the process of registration and of course the operation of the registry. Also, I must say that a large amount of the income that the donor centres have comes from the donations themselves. Once a donation happens, the majority of that income stays with the donor centre. Of course a certain amount goes to the collection centre or to other organisations that are involved in the donation process. But the vast amount of the money that comes in after the donation has taken place stays with the donor centre, and that helps them to finance their operations.

Cindy McLEISH: Okay. So when Australia uses or gets some stem cells, we pay you for that.

Joannis MYTILINEOS: That is true, and we are charged by the donor centre. Almost 95% of the amount that you pay us goes actually to the donor centre. The donor centre also pays the collection centre or whoever was involved. That is also part of the law basically—that the finances of the search are managed by the national registry. The financial conduct with international organisations goes through us. We get the money from you. We pay almost the whole amount to the donor centre, and any expenses the donor centre have had on a local basis and a regional basis they have to deal with themselves.

Cindy McLEISH: Thank you very much.

Joannis MYTILINEOS: You are welcome.

Cindy McLEISH: Chair, thank you.

The CHAIR: Thanks, Cindy. Gary.

Gary MAAS: Thanks, Ella, and thank you, Joannis, for your time today. It is very much appreciated by us. I would just like to move the focus to pre pandemic and post pandemic in terms of the numbers of registered donors. Is it fair to say that, similarly to other jurisdictions, donor numbers were affected during the pandemic?

Joannis MYTILINEOS: As I mentioned before, in Germany it has been quite peculiar, I would say, because I have been following that with the other national registers as well. I remember, for instance, that in the UK a large amount of the new registration, even prepandemic, was going on online through online recruitment, and that was not the case in Germany. Prepandemic in Germany the vast majority of new registration was through physical donor drives. As I said before, somebody became ill and that was sort of used as a marketing tool in order to attract new donors, and people gathered somewhere and registered as a new donor. Even if it was possible to do it from home with the swabs, still people preferred to go somewhere and go through the registration process. With the pandemic, all this ceased completely. It was not possible to do donor drives anymore. The donor centres all still had this online registration, but it was not really very much used. Through the pandemic that shifted almost exclusively to online, with the effect that the numbers of new registrations went down dramatically—a very low number of new registrations in those years. The numbers have come back now after the pandemic but are still not at the levels that we had prepandemic. Although in the meanwhile we have had more than a year almost where the pandemic has been declared as ended and donor drives have been organised routinely, the number of registrations in the last 12 months has not reached the numbers that were experienced prepandemic.

Gary MAAS: In terms of the method of registering, though, it sounds like online registrations increased. Are the online registrations higher now than they were prepandemic?

Joannis MYTILINEOS: Yes.

Gary MAAS: They are?

Joannis MYTILINEOS: They are definitely higher now than they were prepandemic, but I honestly do not have a figure with me. I cannot really tell you what the percentage is of online versus physical because we have 26 different donor centres, and every donor centre has its own dynamics. Some are more active online, some are less active online. The largest donor centre is the DKMS, and I know that the DKMS has a substantial number of their registrations online in the meanwhile.

Gary MAAS: Thank you. You have spoken about some of the donor drives that you have and some of the public campaigns. I know this extends a little bit beyond your field of expertise, but what are the sorts of public campaigns that are run, and how successful have they been?

Joannis MYTILINEOS: There are different ways, and again as we get more and more electronic, social media plays a very important role in that. I would guess that social media are extremely important in the meanwhile. Whenever there is a new drive, just make it public through social media. But still there are other means of marketing, like, for instance, in the local radio and TV stations or if there are local and regional newspapers or any posters that can be mounted in public places—schools, universities. Obviously, the new recruitment is very much focused on young people. So you want to attract as many young people as possible, and not necessarily people that are beyond 35—40 or 50 for sure—because all the donors are automatically taken out of the register once they have reached the age of 60. So there is no need to basically register people that are older than 50, and some of the donor centres in Germany have already declared that they would not register new donors that are above an age of 50. Anyway, so you want to focus on young people, and you need to go where the young people can get your message—social media, universities, schools and any other places where young people gather or have a chance to get your message.

Gary MAAS: My last question is on what that demographic spread looks like in terms of age group. So have you found that those public campaigns have been successful at attracting that 18- to 34-year-old group and potentially up to 50?

Joannis MYTILINEOS: Yes. We have graphs in our registry that show the dynamics of new registrations, and almost 85% of the new donors that are recruited are in the ages between 18 and 23, 24. So that is the vast majority. There are very few donors that are really registered that are beyond that, in the meanwhile. It is very strongly focused on the young people, in Germany at least.

Gary MAAS: That is helpful. Thank you very much.

Joannis MYTILINEOS: You are welcome.

The CHAIR: Thanks, Gary. Chris?

Chris CREWITHER: Thank you, once again, for your evidence all the way from Deutschland. The Zentrales Knochenmarkspender-Register Deutschland 2021 annual report states that:

for ... 90 % of patients in Germany, a suitable donor can usually be identified within a few weeks.

What technologies and strategies did you implement to lead to such an impressive and efficient search process?

Joannis MYTILINEOS: Thank you for that question. I assume you speak some German. At least it came over very professionally.

Cindy McLEISH: It sounded like it.

Chris CREWITHER: I used to.

Joannis MYTILINEOS: Okay, you see? So as I said before, in Germany we have a central system for identification of the most suitable donor. That goes through my organisation. So all the hospitals that need to find a donor have a local coordinator. We call that the search unit. And the local coordinator is trained by the ZKRD and uses the platform of the ZKRD in order to find the most suitable donor among the pool of donors that is available worldwide, which is provided through our platform. So there is an electronic platform. It is like an Amazon thing, where basically all the donors of particular patients are listed. They are listed according to their tissue type, so the matching probability plays a role in the way the donors are listed, and the donor search coordinators have an easy job to select the donors that are most suitable for a particular patient. That is number one.

Number two is of course, as I said before, donors are available in Germany, so the dropout rate is rather small. It is less than 25%. So we are able to identify the donors, and the commitment of the donors is probably culturally a high one. We have very few dropouts just because people do not want to donate anymore. Of course there are always reasons—like if somebody is on holidays or somebody has an exam to take—there are many, many reasons that lead to an exclusion of a donor, but in the majority of the cases, we are able to locate the donor and the donor is committed.

Another reason is that the donors in Germany, the majority of the donors, are very well typed, so you have very few surprises. I do not know if you are familiar with the process. What happens usually is the donor is being registered and typed, and then whenever he is being selected a new blood sample has to be sent to the hospital with the patient in order to confirm that the tissue type of the donor is what he was selected for, because in donor drives you can experience all kinds of things—mixed up samples and this and that, or mistypings in the laboratory, so in order to make sure that the donor that you have selected is really the one that you wanted to have confirmation of the donor has to be done. Because of the high-resolution typing that is now being routinely done in Germany for all the loci of all the different parameters that are of importance for the selection of a donor we have very few surprises, and therefore the success rate in terms of finding the donor you really wanted to have is relatively high. Also, the technologies nowadays that allow a quick confirmatory typing, as we call it, also have improved so technology is quicker. Logistics are also important—how to get the samples from one place to the other is streamlined, so we have been working together with companies that take those blood samples and transport them and they know what to do; they know where the recipients of those samples are, and that also helps a little. I think that is all. I cannot think of something else.

Chris CREWITHER: Thank you. Now, in Australia and in –

Joannis MYTILINEOS: Sorry, sorry, there was one thing, the population in Germany. Of course we are living in a big world and there is a lot of coming and going, in particular nowadays with all the refugees that are coming from the Middle East, but in general the population of Germany is quite central European in terms of genetics. It is not as diverse as you have in other large countries like in Australia or in the United States. It is more homogeneous, and I think that also plays a role in being able to find a suitable donor for most of our patients. So that was an important point. I missed that.

Chris CREWITHER: Thank you. That links in to my next question, which is: in Australia and in a number of other countries we sometimes have a shortfall in donations for minority groups or those from culturally and

linguistically diverse backgrounds. Do you have a similar struggle in Germany, and how do you target those individuals and groups to ensure there is not a shortfall?

Joannis MYTILINEOS: That is true. That is an issue in Germany as well. In Germany, as I said before, the population is more homogeneous, but of course we experienced an increasing number of patients, and not only patients but also potential donors having a different ethnic and cultural background. The population is getting more diverse in the meanwhile. So we experience differences in the registration of people with an immigration background. I will speak frankly. In Germany we have a large Turkish minority. It is about, I think, 3 million to 4 million people with a Turkish background. They may be German citizens, but they have a Turkish background, and we have experienced that the number of donors registered in the German registry with a Turkish background is lower than the representation in the entire population, so the donor centres have tried to find some incentives for how to approach donors with a Turkish background, and this has been challenging. It is not the same way that you would use in order to approach the average German donor; you would need to go to their cultural gatherings or to announce in their newspaper, those kinds of things. And of course with all the Syrian refugees that came in there are some initiatives to approach those people as well. Again, as I said before, this is very much depending on the means that each donor centre has. It is very much on the donor centre to develop any activities of this kind. But yes, it has been a challenge in our place as well, and it is something that we struggle with. As the community is getting more diverse and you have these mixed marriages, that potentiates the problem because, for the children of mixed parentage, you probably would expect to have less donors whenever they are needed. So that is something that we have to tackle in the future, worldwide, basically.

Chris CREWETHER: Danke schön.

Joannis MYTILINEOS: Gerne.

The CHAIR: Thanks, Chris. Christine.

Chris COUZENS: Thank you so much for your contribution today. It is very much appreciated. I am not going to impress you with German, because I cannot speak it. Most of the questions I had have already been asked. But I just wondered: you talked about the donor centres. Are those donor centres specifically for stem cell donations or for all donations?

Joannis MYTILINEOS: Stem cell donation and solid organ donation are totally separated in Germany. They are absolutely separated, so no mix, not only clinically but also the registration and the finances. They are in two different worlds, basically. So yes, the donor centres are exclusively dealing with stem cell transplantations.

Chris COUZENS: Okay. So where do people go then for other organs to register? Is it something different?

Joannis MYTILINEOS: Yes, it is something different. There is actually no registry for potential solid organ donors. So what happens in Germany concerning that point is that people may carry with them a donation ID card that documents their willingness to be an organ donor if they decease, and then they can check which organs they would consent to donate. They can donate the whole body, or they can donate only the eyes or the kidney or whatsoever. And in fact the health insurances have taken that part over, and they are contacting their members every now and then—I do not know the frequency, but probably every five years I would guess or something—in order to remind their clients that this process is existing of filling out this card. They provide their clients with this card, but it is up to the individual people to fill in that card and to be aware that this process exists. But there is no national or official registry at this point to document the consent of the population when it comes to organ donation.

Chris COUZENS: Thank you. You also mentioned earlier that, if somebody moves, they have got the right to get their address. How have you done that, given confidentiality and all those issues that many of us have to deal with? Is it through legislation that that has been implemented?

Joannis MYTILINEOS: Well, there is this consent form that every registered person has to fill in, and in this consent form there is one sentence where the donors can tick, basically, whether they give their consent that they are traced—actually, no: either they register and they agree with that, or they do not register, because that is essential. It is essential that the donor centre is able to trace the donor through the authorities. So if they do

not consent with that, they do not register, full stop, and that has been always like this. It is not an option. Either you agree and you register or you do not agree and you do not register. And this consent form is actually more or less the same for all the donor centres. They look a little different, but the main parts are the same, and this is a substantial part that is in all the donor centres. The consent form has to obviously be approved by the ethical boards, so it is ethically and data protection wise safe. But I am not an ethicist and I am not a data protection manager, so I cannot really tell you if there are any tricks behind that. I can tell you that this is just how it has been working in Germany for many years, and even after the European law on data protection has changed, nothing changed with that, so that stayed with it. There is a law that says that each person that resides in Germany has to register with the authorities, and after moving to somewhere else they have one month to reregister, you know. That is by law. That is regulated by law.

Chris COUZENS: Thank you very much.

Joannis MYTILINEOS: You are welcome.

The CHAIR: Heang, do you have any questions? No? Great. Thank you. In that case we might wrap it up now.

Joannis, thank you very much for appearing before the Committee today and for your contribution to this inquiry. The Committee greatly appreciates the time and effort that you have taken to prepare and appear before us, and we appreciate that it is early in the morning for you over in Germany, so thank you very much.

Joannis MYTILINEOS: You are welcome. It was a pleasure.

The CHAIR: You will be provided with a proof version of today's transcript to check, and verified transcripts will be published on the Committee's website.

This concludes today's hearings, and I thank all witnesses who have given evidence to the Committee today as well as Hansard and the Committee secretariat. I declare this hearing adjourned.

Committee adjourned.