

# A decade of continuous improvement in cadaveric organ donation: the Spanish model

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## GENERAL DESCRIPTION OF THE SPANISH MODEL

Everybody is agreed that organ shortage is by far the greatest obstacle to meeting the full demand for transplants, at least in Western countries. The supply of organs cannot keep pace with the ever-increasing demand for donated solid organ donors in the United States and in most European countries. There are many countries trying to increase organ donation by the «Classic Approach» which includes publicity campaigns, donor registry, donor cards distributed with driving licences, and changes in legislation and are many discussions about «presumed consent» or «opting out» laws.

In 1989, when the ONT was created, there were many people in Spain who believed that the main solution to solving the problem of organ shortage was to change the legislation and apply a strict presumed consent law. However, we found little evidence to suggest that the style of legislation influences the organ donor because regardless of how the donor might become available, relatives are always consulted, as in most European countries, and their wishes are always respected. In Spain, despite the very large increase in organ donation, over 20% of families refuse to allow organ donation to take place. This has fallen from 30% in the early 1990's but it is still high. In an annual Spanish census, two thirds of the Spanish population are against a presumed consent approach as they consider this kind of legislation an abuse of authority and offensive to relatives. Most of the Spanish people are in favour of organ donation but they want to be consulted.

When reviewing the way forward for Spain, back in 1989, we consulted and endorsed a report from the American «Partnership for Organ Donation», which concluded that legal approaches to increase organ donation led to unpredictable results and could be potentially dangerous. Educational campaigns can be of benefit but they are expensive and provide questionable and very late results. One of the most important things to understand from the

Spanish system relates to the health professional. For the physician in charge of the potential donor the easiest thing is to find an excuse for not considering him/her as a donor, which will allow the physician to close the case as quickly as possible thus avoiding a long and complicated procedure. The physician has a natural reluctance to approach the grieving family and that is the same in Spain as in most other countries.

The basis of the Spanish Model rests on the creation of a transplant co-ordination network at three levels - national, regional and hospital co-ordinators; there are 17 regions in Spain and a Regional Co-ordinator was created for each one. In 1988 there were less than 20 transplant co-ordinators, three years later we had 118 transplant co-ordination teams and now there are 139 (fig. 1). This includes approximately 150 doctors and 79 nurses so it is very important to recognise that when referring to transplant co-ordinators in Spain, we were talking about a different job, a different person and profile from transplant co-ordinators in some other countries.

The majority of Spanish transplant co-ordinators are physicians with one in every hospital, supported by nurses, particularly important in the larger hospitals. They are usually part-time contracted staff as opposed to full-time, and totally independent of the transplant team. This is the main difference with what is happening in other countries. There will be someone working inside most hospitals whose main role is organ procurement.

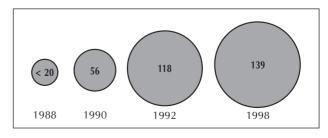


Fig. 1.—Number of transplant coordinator teams in Spain.

A very important aspect is the family approach. An interesting study was performed in Alicante, undertaken by a nurse co-ordinator, which demonstrated that of families who had initially refused consent, 78% changed their mind after having had discussions with the transplant co-ordinators. This portrays the professionalism and skills of the transplant co-ordinator, which is so important to the final result.

In the early years, we also observed the so-called «burn out syndrome» of the transplant co-ordinators. It is quite clear that the role of a transplant co-ordinator is a difficult one, involving direct contact with the grieving family and asking for organs. We find that after three - four years, they have had enough.

It was particularly interesting in the Madrid region during 1988/89 where there was a decrease in renal transplants and organ donation about 20%. In order to try to solve this problem, the ONT introduced new transplant co-ordinators into the hospitals of Madrid, which resulted in a 50% increase in renal transplants in only one year. There was then a plateau and in 1992 a new road traffic law was introduced, which imposed a reduced maximum speed and mandatory helmets for motor cyclists, so there was a very rapid decrease in road traffic accidents. In most hospitals in Madrid, the number of organ donors reduced still further, probably as a direct result of this change in the law.

In the rest of Spain this did not happen at the same time. There were some other hospitals, which in fact had the same number of donors due to better donor detection. By changing the transplant co-ordinators, even with less traffic road accidents, we managed to increase the number of renal transplants from 200 to 335, nearly a 70% increase. It seems that there is a direct relationship between the activities of the transplant co-ordinators and the number of organs retrieved.

There are many who feel that adverse broadcasts from the media can have a negative effect on attitudes to organ donation in the general population and among health professionals not involved in transplantation. That is true and there is a phenomenon called «The Panorama effect», named after

the British television programme which cast doubt on the validity of the criteria for brain death and was followed by a sharp decline in organ donations in the UK during the seventies. In Spain we dedicated a lot of time and effort in this area with specific media training courses for transplant co-ordinators in which we show what to do and what not to do with journalists; how to explain the sensitive topics of brain death and organ trafficking, how you should dress when speaking to a journalist etc.

When the ONT was created in 1989, we had 14 organ donors per million population (pmp), which have increased over the past twelve years to 33. Compare this with the rates in other countries, such as the USA, and Italy which was very low in the early 1990s and is now 16 pmp. Western Europe appears to be going down during the 1990s. In the UK, it is only 13.5 pmp in contrast to the 17 regions of Spain, 12 of which now achieve more than 30 pmp and two of them are over 50. This is very important because probably the upper limit of organ donation is nearly 60 donors per million (table I and fig. 2).

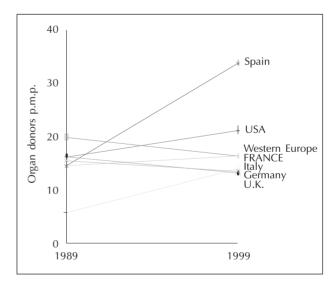


Fig. 2.—Trends in organ donation during the nineties.

**Table I.** Trends in organ donation during the nineties

Donors pmp	1989	1999	Difference		1989	1999	Difference
Spain	14,3	33,6	+19,3	Austria	25,8	25,9	+0,1
Italy	5,6	13,7	+8,1	Holland	12,4	10,9	-1,5
Portugal	13,1	19,1	+6	Scandinavia	15,6	14,0	-1,6
USA	16	21	+5	Germany	15,1	13,2	-1,9
Belgium	20,9	25,2	+4,3	United Kingdom	16,2	13,0	-3,2
Western Europe	14,4	16,2	+1,8	France	19,7	16,2	-3,5

Looking specifically at renal transplants, there was a decrease across Spain in 1986. However, after the ONT was created in 1989, there was an increase from 1,000 to 2,000 transplants over 10 years. 99% of renal transplants are cadaveric, with «living donation» in Spain less than 1%. This is probably because there is no real pressure within dialysis units to ask a living person to donate a kidney and there are not many young people on dialysis who stay for more than six or eight months, so it is very difficult to ask the parent or sibling to give a kidney in this situation.

Spain is the only country in the world with a progressive decrease in the renal transplant waiting lists and these include some patients who are not quite sure that they want a transplant so there are even fewer patients who can receive a renal transplant that the waiting list suggests. There is the same evolution with all other organs, for example hearts. For livers, we perform about 1,000 in Spain, with a population of 40 million people. Spain has 0.7% of the world population but performs about 11% of all the liver transplants worldwide. Our rate of 24 pmp is very much higher than that of the United States or any other country. We also perform 10% of the cardiac transplants in the world.

# PROS AND CONS OF THE SPANISH MODEL. CAN WE TRANSLATE IT TO U.K.?

This is what we can call a short classic exposition of the Spanish model.

I am now going to discuss the pros and cons of the Spanish model, what is the possibility of translating some of these approaches to the UK and what are the differences between the two countries. There are differences in road traffic accidents, the number of doctors, the number of ICU beds, the relevance of non-heart beating donors, the topic of paying for donors and the role of the wider use of marginal donors.

Road Traffic Accidents: It is true that in Southern European countries, the road traffic accident rates are higher than in the United Kingdom and other countries, for example some Middle and Northern European countries like Sweden. But as a result of the road traffic regulation mentioned earlier, there was a decrease of about 40% in Spanish road traffic accident deaths until 1994 and 1995. After that, unfortunately, there is a plateau and we cannot further reduce this tragic rate, which is higher than that of the United Kingdom (fig. 3). But we can analyse the contribution of road traffic deaths to the organ donation rate. In 1992, which is the first year we

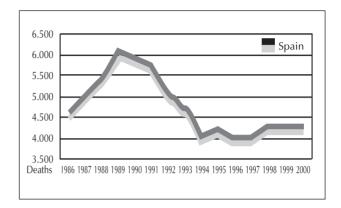


Fig. 3.—Road traffic accident deaths in Spain.

have the data from all donors in Spain, road traffic accidents accounted for 35% of organ donors, that means 7.6 donors pmp.

In 2000, road traffic accidents accounted only for 20.7% of organ donors, that means 7 donors per million. If you exclude the 7 donors per million from the total of 33 per million, we are left with 26 donors per million due to causes other than road traffic accidents. This rate, 26, is still the highest in the world, the nearest being Austria with 25 per million.

Type of donors and graft survival. Through the 1990's, cerebrovascular accidents have increased from 39% to 56% as the cause of death due partly to the decline in road traffic accidents. As a consequence, the age of the donors has been increasing every year. In fact at this time last year, 31.3% of all organ donors were over 60 compared with only 10% in 1992.so elderly donors suffering cerebrovascular accidents are the reason for this expansion of the organ donor pool. The use of these organs from older donors may reduce graft survival compared with younger donors? Of course it is better to use a kidney, liver or heart from a donor that is 20 years old than from a donor who is 60 or 70 years old, but how serious is this disadvantage?

The Catalan Registry is the only database in Spain old enough to compare the results from the 1980s with those from the 1990s. Our patients' survival from the Catalan Registry from the period 1984 - 1989 and 1990 - 1997 shows that the survival rate is better in the 1990's despite the fact that in Spain, as in other countries, we have not only elderly donors but also elderly recipients. These recipients have more complications and much more pathology. In fact it is clear that in all the Spanish registries of renal patients in Catalonia and other regions, there is a relationship between survival and the age of the donor. Some nephrons are better than no nephrons at all.

Some people say that non-heart beating donors are an important source of organ donations in Spain, but that is not true. There has been an increase in non-heart beating donors during recent years despite a Royal Decree at the end of 1999 which set out strict regulations for non-heart beating donors. Only one hospital, the Clinical Hospital in Madrid, has a real programme of non-heart beating donation that provides 55% of its donations. We had fairly good long term results with these kidneys because they are selected more stringently than beating heart donors, which explains why these results were at least as good as with «beating heart donations».

The reason why we do not have many non-heart beating donors in Spain is that most co-ordinators are intensive care specialists and they are not usually in charge of the Emergency Room. In order to get more non-heart beating donors, it would be necessary to implement an additional network with a very high cost/benefit ratio. At this moment in Spain there is no real pressure to increase the number of organs retrieved, in fact there are, unfortunately some people who say we are transplanting too many!

Structural differences. So what are the structural differences between the UK and Spain that can explain some of the differences in organ donation rates? First of all the number of ICU beds for the United Kingdom has already been shown, but I am not sure that these data are quite correct because it is very difficult to make a strict definition of what is an ICU bed. In Spain we have defined an ICU bed as one in which mechanical ventilations is possible. In the UK there are about 20 additional beds per million which can be classed as «intermediate care» which is probably a similar classification to that of an ICU bed in Spain. It appears there are more ICU beds in Spain but not significantly so (fig. 4).

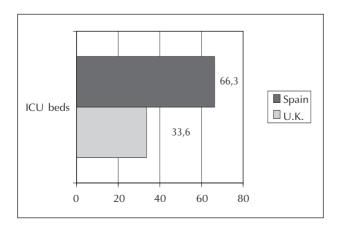


Fig. 4.—Number of Intensive Care Beds pmp.

The present proportion of the Gross National Product dedicated to medical care in the UK is more or less the same as in Spain, with similar proportions between public and private healthcare. The life expectancy at birth in the UK is 77 and in Spain 78, both are amongst the highest in the world. The cost of living, which is important in order to compare the amount of money being dedicated to healthcare is much higher in the UK than in Spain. Comparing the cost of living in Spain to that of the UK there is at least a 25% difference so every economic calculation made should be adjusted by approximately 25% in order to compare what is happening in both countries.

There are many more doctors in Spain than in the UK, with 4.1 doctors per thousand persons - the second highest rate after Italy - compared to only 1.7 in the UK, with the UK dedicating more doctors to primary care than Spain. Data from the Lancet shows 60% of medical doctors in the UK are primary care doctors compared to just 37% in Spain. But on the other hand the UK has more nurses. Spain has 4.1 nurses per 1000 inhabitants, whereas the UK has 5.2. Average pay for UK doctors is also much higher than in Spain. In the UK everything is included in a junior doctor's basic pay whereas in Spain there is a very low basic pay with an opportunity for extra money which can in fact increase this amount to more or less the same as a junior UK doctor.

This is not the same with the senior doctors, and in fact there is a very important difference between the Spanish and British. In essence than, there are fewer doctors receiving a higher basic salary the Spaniards who receive a fixed, lower salary but with more possibility of extra wages linked to results (fig. 5).

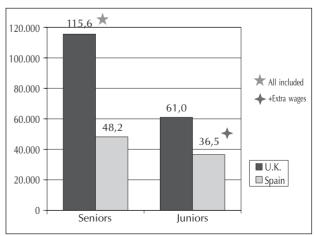


Fig. 5.—Average pay per year for doctors Spain vs U.K. (€).

Furthermore, it is important to understand that it makes no difference whether a transplant co-ordinator is a doctor or a nurse. In fact many of the first class transplant co-ordinators in Spain are nurses and what makes the difference is the role given to this profession and to the transplant co-ordinator - the responsibility, the job, and the power inside the hospital. Transplant co-ordinator is possibly not even the correct name to use and a better description would be «Transplant Managers».

In Spain the hospital coordinator is directly involved in organ and tissue donation and transplantation. There is an increasing amount of research and budget management responsibility and, of course, they need more specific training to do all this. They belong to the management team of the hospital, so they have much more responsibility. This means the management of organ donation is at the same level as organ transplantation.

#### THE QUALITY IMPROVEMENT PROGRAMME

It is very important that we look at the organ donation Quality Improvement Programme that is being carried out across the whole country. The Quality Improvement Programme audits every hospital brain death - not retrospectively but at the time. The brain death audit is not easy to implement in a hospital but we realised that it was very important we included it in the job description of the transplant coordinator, in Insalud: part of the Spanish National Health Service still managed by the Central Government. It accounts for 10 out of the 17 regions and 38.5% of the Spanish population, since 1997.

The Quality Improvement Programme is an analysis of the donation process step by step - its purpose was a provision of break points in every hospital and to define areas for improvement. It is based in the studies performed in the early 1990s in Madrid, in the Basque Country and in Catalonia.

Since 1998, a common process control methodology was established. In this way we can define the theoretical capacity of organ donation of every hospital together with their characteristics and mortality. This programme is in fact a continued self-evaluation process performed by transplant co-ordinators. A clinical records audit has been included as an institutional objective of Insalud and is also an important part of this programme. There is also the possibility of an external evaluation.

The first results of this programme showed a very important increase in the number of donors, mainly due to a great improvement in potential donor detection. Most studies today were carried out to establish the potential of donation and to quantify the losses during the process and then after detecting the weak points, we established new continuous training programmes for this profession. In all the studies, the pilot studies and then the general studies, we have discovered that in the general hospital, between 2% and 3% of deaths and 12% or 14% of ICU deaths are brain deaths. This is a gold standard, which is repeated in all the studies. This slide shows the complete data from 1999. 12 out of 17 regions participated. During 2000, 16 of the 17 regions participated. The population covered in 1999 was 23 million. The number of hospitals beds for acute patients in this study was 1.67 public beds per thousand inhabitants.

The number of ICU beds are 1,535 - 4% of acute beds, 66.3 ICU beds/pmp.

The figure shows the number of hospital deaths that were studied, the admission in ICU, where 10,000 deaths were analysed. 1,387 brain deaths were analysed - 13.7% of ICU deaths and 2.4% of all hospital deaths. These facts are important in order to compare what is happening in Britain and what is happening in Spain (fig. 6).

Real donors from all these regions were 676, nearly 50% of brain deaths, about 6% of ICU deaths and 1.2% of hospital deaths. This means that if the

- Brain deaths/hospital deaths (2.5%)
- Brain deaths in ICU/deaths in ICU (13.1%)
- Deaths in ICU/hospital beds (3.6%)
- Brain deaths in ICU/ICU beds (90.4%)
- Brain deaths in ICU/patients in ICU (1.3%)
- Brains deaths unreported («escape»)/brain deaths (1.7%)
- Cardiac arrest/brain deaths (4.0%)
- Legal refusal/brain deaths (0.1%)
- Problems in brain death diagnosis/brain deaths (0.4%)
- Family refusals/family interviews (23.6%)

- Real donors/hospital deaths (1.2%)
- Real donors/deaths in ICU (6.4%)
- Real donors/hospital beds (1.7%)
- Real donors/ICU beds (44.0%)
- Real donors/patients in ICU (0.6%)
- Medical contraindications/brain deaths (27.4%)
- Family refusal/brain deaths (16.4%)
- Problems organization/brain deaths (0.7%)
- No recipient/brain deaths (0.6%)
- Legal refusals/legal diligences (0.7%)

number of donors is much less than 1.2, then something is not working as well as it should.

For instance in Insalud this study was performed in 1998 and 1999 so we can compare what was happening in these two years. Under-detection went from 4 to 2.1 but this is slightly inaccurate. Under-detection is always the main cause for losing donors - if the population of the Basque country or Cantabria is approximately 60 donors per million then there is some other reason why 20 - 25 more of these donors are not detected. In fact, an external evaluation in this hospital detected 15 - 20% more donors. This is a self-evaluation process but when it is subjected to an external evaluation, 15 or 20% more donors are often found - this is a very critical point.

The main lesson we learned from this study is that once you know the percentage of hospital brain deaths, real donor hospital deaths, brain deaths in ICU, deaths in ICU, real donor deaths in ICU and so on, you can compare this with other hospitals in order to detect what is happening in every hospital not providing an adequate number of donors.

The conclusion of this study is that the maximum potential organ donor rate can be estimated as at least 60 donors per million bearing in mind that in some regions, there were close to 80 brain deaths per million. Disregarding medical complications, the maximum potential is not very far from 60 and faults in the detection process are almost always the main reason for losing potential organ donors. This is very dependent on the infrastructure of the health professional's attitude. It is true to say that if there are not enough ICU beds, you cannot have donors but under-detection remains the main problem.

The next step should be to develope the best way to improve cadaveric organ donation in every hospital in a process known as «bench-marking» - finding out the best results in order to define the process and to define the clinical pathway for organ donation. Having found out the best, we try to compare the result with other hospitals that were not in that category. This is the next step for improving organ donation.

#### **HOSPITAL REIMBURSEMENT**

There is another critical point in understanding the Spanish model, which is hospital reimbursement. If the hospitals do not receive enough money, they will get the first and second donor but not the third. This is especially true in a small hospital where the interest of the transplant surgeon or transplant commission is not as evident as in the bigger hospitals.

One of the critical things we did in Spain during the 1990's was to establish an adequate and general framework for reimbursement for organ donation.

The figure 7 shows the amount of money we receive at present in Insalud hospitals— (in Euros, therefore multiply by 0.65 to convert into British pounds). It is estimated that the cost for one hour of an operating room in a big hospital of Insalud is about £1,000. This is the case whether the organ is going to be transplanted or not. Even if the organ is not always useful, it costs money and these costs should be provided by Insalud or another authority, otherwise the hospital will not continue doing such work.

The figure 8 slide shows the cost calculated for cardiac, renal or liver transplant, giving an estimated cost of all solid organ transplants performed in Spain during 1999, in Euros. The structure of the ONT and all the transplant co-ordinators costs approximately 5 million Euros - a mere £3.2 million. This represents 3.8% of the total cost of solid organ transplants in Spain. If the level of renal transplantation had remained the same as in the early 1990s, 6,400 patients would not have received a renal transplantation. This would have cost the same amount of all solid organ transplantations performed in Spain. So the reduction in the cost of end stage renal transplantation, thanks to the ONT and transplant co-ordination at work, is equivalent to

	Spanish pts.	EUROS (€)
Multiorgan procurement	1,000,000	6,000
Renal procurement	750,000	4,500
Multiorgan + tissue	1,250,000	7,500

Fig. 7.—Hospital reimbursement 1999. Hospitals of INSALUD.

	Per unit	Total
Organ procurement Renal transplants Liver transplants Heart transplants Lung transplants Other (pancreas, etc.)	16,537 62,995 59,898 45,181	$\begin{array}{c} 8,975,903 \in \\ 33,433,735 \in \\ 56,626,506 \in \\ 20,126,506 \in \\ 6,096,385 \in \\ 674,699 \in \end{array}$
ONT structure  Total		4,939,759 € 130,873,493 €

Fig. 8.—Estimated costs of solid organ transplants in Spain during 1999.

all solid organ transplantation in Spain, which is very important.

Finally, how do these methods translate to other countries? Tuscany, in Italy, is using some of the points from the Spanish model. They are implementing transplant co-ordinators, not in such an organised way but they have adopted some of the points of the Spanish model. In the early 1990s, there were 5 donors per million, 13 donors per million in 1998, 26 donors per million in 1999 and the projection for the year 2000 after the first months is 38.5 donors per million. That is even better than in Spain. Even in the north of Italy, most of the regions are over 20. The results speak for themselves - this model can be translated to other countries with some conditions attached.

We collaborated with Australia since 1994/1995, and this is the summary performed by Bruce Lindsey, Director of Australia Donate Inc, an agency that comprises representatives of the Gold Coast Session and the National Donation and Transplantation infrastructure. In Australia, there are five state agencies responsible for the investigation and management of donors, care of the family and organ sharing. We were partly involved in the creation of the South Australia agency, which was to open in 1996. There are also some contacts in Western Australia.

The state agency which replicated most elements of the Spanish model in South Australia and enjoyed the greatest improvement in cadaveric donations and have now been able to double the national donation rate resulting in 20 donors per million. The New South Wales agency, which has not adopted the Spanish model, has only 7 per million. Queensland and Western Australia have adopted some aspects of the Spanish model but they only started last year or in 1999 and we have no reliable data about the results to date.

There are a lot of countries within South America that have been influenced by the Spanish model, but the ideal conditions required to implement this model within another country necessitate having a national health system. Without this condition you can improve the organ donations in hospitals and regions, but not throughout the whole country. The best place to implement the Spanish model is in countries with a national health system, such as Australia and some European countries.

In conclusion, the Spanish model has, through the tenacity of many people, overcome obstacles such as training under-trained staff and identifying donors by tightening up the approach and through the screening of family members.

### QUESTIONS AND ANSWERS TAKEN FROM THE PRESENTATION GIVEN BY

#### **Audience questions**

Professor Roger Williams, Institute of Hepatology

Q.: What interested me was the relationship between the co-ordinator in Spain and the doctors who are looking after the patients. The doctors looking after the patients are still in charge, but how do you improve the relationship?

Dr. Matesanz: There can sometimes be a conflict within intensive care because both doctors are caring for a patient and sometimes it is a member of the team who performs the role of transplant co-ordinator. However if you want more donors, you should involve intensive care specialists in the process of organ donation. If they are not involved, you will not get donors. In the past when there were not so many transplant co-ordinators, if a nephrologist wanted the kidney, he just went directly to the family. Now the situation is much better in that whenever there is a new donor, even though the heart specialist would have as much reason to want the heart as I the kidney, there is a need for an independent health professional who can act as mediator. At this moment there wasn't sufficient money for a full-time dedicated doctor or even a dedicated nurse in every hospital. So the best compromise was to have a part-time doctor. We realised it was much better economically but even so there wasn't initially enough money to put a doctor in every hospital.

What kind of doctor would be ideal? Someone who is highly motivated and able to get many more donors. There is no problem if the nephrologist wants to be a co-ordinator. At this moment 25% of the co-ordinators are still nephrologists but there has to be a clear delineation between their roles to avoid a conflict of interest. The motivations of the transplant team and the organ donation team are quite different. Our motivation was to get more organ donors but the intensive care specialist is concerned with keeping those patients in post operative care, as well as they can. It is one thing to try to get more donors, but it is likely there will be one patient needing a liver and another who isn't yet brain dead and who has a useful liver, so you should give this patient the best treatment that you can.

In Spain, we have never had such a conflict of interests, because the diagnosis of brain death is performed by independent teams including a neurologist, and I think that the process of getting organ donors is so public a process that there are many

people who are involved in this complicated process who feel something like this is not correct.

#### Ms Alison Crombie, Transplant Co-ordinator

Q.: Five years ago I was lucky enough to spend some time in Spain with some colleagues. We were immensely impressed with the national and regional system and structure that's in place, and I do understand in the UK we are moving towards that through UKT. One of the issues for us was the local implementation and, as much as we can sweep aside the ICU bed position, I think that is one of the things that is very clear. For instance in Barcelona, where one of the hospitals has a very similar population to the Royal Free, we were looking at 1,000 acute beds with 40 ICU beds and the Royal Free has 1,000 acute beds and only 16 ICU beds. I think the other crucial point was the length of admission. What we witnessed was that with a patient who became brainstem dead, the family might well refuse on the first day. They would then have a second interview where the family might reconsider the proposition and on the third day the family might come round to agreeing. So I think there were differences in terms of practice. I also want to make the point that, much as I think that Spain is truly very good and very experienced, to try and implement a system that has such a different infrastructure, from the national and regional levels, is absolutely right, but nursing in Spain and nursing in the UK, are different. What we got from the course in Spain, and what the people who run those courses have been able to say to us, is that we have expertise and experience that they haven't witnessed in Spain. So in all this, we shouldn't lose sight of what we have in the UK. But I agree that the best things about the Spanish system are the support and the financing and the way in which co-ordination has become an independent professional practice. I think that in the UK we have been held back enormously for lack of that structu-

#### Mr Gordon Nicholas - National Kidney Federation

*Q.:* I speak as a patient. You touched in your presentation on an education campaign. Can you elaborate on that please? How did you go about changing the culture in Spain and did you go into the schools and colleges to bring that about?

*Dr. Matesanz:* During the 1980's, Spain was in the middle to low level of organ donation rate and blood

donation rate in Europe. Now in 2000, we have the best rate in the world for organ donation but we still are in the middle to low for blood donation. Does this mean that we have not been able to change and educate the Spanish population to be open to something like this? This reinforces the idea that educational campaigns can only change the mind of the population, after many years. In fact, we did not perform any kind of education or publicity campaign or direct publicity campaign in Spain in order to improve programme donation - we had no money to do so.

#### Q.: If you did have the money?

Dr. Matesanz: We used the mass media which is so very important. Mass media can work in a detrimental way but also in a positive way and it was very important during the early 1990s when we began to be able to say things are running, that we are getting more and more donors, that we are saving more and more lives, that we are the first in Europe, that we are the first in the world, etc. The Spanish people were really starting to feel very proud of the organ donation and the organ transplantation and the ONT. On the contrary, there have been problems in other countries such as the Liverpool affair, which have the potential to be very detrimental for organ donation. And the opposite is also true - when you give positive news and positive news and positive news and the mass media want to co-operate. at the end everything is positive.

# Dr Giles Morgan - President of Intensive Care Society

Q.: I represent the membership of our society, which is about 2000. We look after about 300 Intensive Care Units in the country. I would like to endorse everything that you have said. I have a couple of comments to make rather than questions. The first thing is that I am very heartened to hear that this is not really an issue about presumed consent. I think that is a secondary issue. The issue is about local empowerment and about local authorities getting things done within hospitals and from this country's point of view, the intensive care doctors are already well on line with that and in fact manage all the donors and all the retrieval procedures that go on. In this country 75% of all the intensive care is actually done in district general hospitals rather than large teaching hospitals and that is by and large from where the retrieval operations come. What is important about the system that you have instituted in Spain is that there is actually a representation of the transplant organisation in every hospital. The difference is fundamental in this country in that, at the moment, the transplant co-ordinator is actually responsible for a group of hospitals and therefore, the devolvement of authority to individual hospitals is not actually that good. I think if we could remedy that, we would be well on our way to having a much better system.

It is very important to have a representative inside a hospital and the better representative is always an intensive care specialist. In the UK there are 845 donors and 250 potential donor hospitals - 4 donors per hospital. But there are very few donors per hospital in Spain, Britain and also in most other countries. If there is no-one inside the hospital who can detect 1, 2, 3 or 5 donors every year, most of these organs will be lost. You cannot therefore have a person who is fully dedicated in a small hospital just to get 4 donors every year, you need somebody who is involved, who is linked to the organisation of UK Transplant and the ONT in Spain and whom, whenever there is a potential donor, you call and inform them.

#### Dr Anthony Issac - Nephrologist in Surrey

Q.: Are patients in Spain ever admitted to the ICU purely as a potential donor?

Dr. Matesanz: No not at all. Elective ventilation has never been performed in Spain as far as I know, but it is a very interesting topic and it depends on the availability of the ICU beds. If there are sufficient ICU beds, it is very likely that every person with cerebral bleeding or someone who really needs ventilation is finally admitted to an ICU bed. The elective ventilation performed in some countries is probably the result of not having enough ICU beds

because there is a social demand that you should do as much as you can to save the life of the patient and there are no doctors in Spain that doubt the need to intubate the patient in order to ventilate. Later they may consider that they can be a donor. In the emergency room these people are intubated and then taken to the ICU. When the neurological work-up is complete the doctors may realise that there is no possibility of saving the patient. But as far as I know, no patients are admitted to ICU solely for organ donation.

#### Dr Liz Lightstone - London

Q.: A particular issue in many renal units in the UK now is the over representation of patients from ethnic minority groups but they are under-represented in the donor population, particularly the southern Asian and Afro Caribbean. Have you had to address those issues in Spain?

Dr. Matesanz: In Spain we haven't had until now many immigrants or different cultures and so not had this problem we are just starting. The only specific group that we had in the past were gypsies of whom we have half a million. We are now starting to have people from North Africa, Latin America and so on. It is true that for people from Northern Africa and Muslims in general, it is more difficult to become a donor but not impossible. In 1989, the organ donor rate in the South of Spain and Andalucia was very low, no more than 5 or 6 donors per million. It was said them that people from Andalucia have a special conception of life and death and so they coul have much more difficulties to donate organs. At this moment Andalucia has 35 donors per million. So the influence of the culture should not be over emphasised.