

# "The humane dimension of the rare"

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So I shall start from this, because sometimes, as you know in this field more or less they explain to us, that when the illnesses are rare, we wish we would be many more. If we were many more they would attend to us, but for us to be many more they would have to give us the right to become again. But they tell us it is not good to become again, therefore we are not many and as we aren't many then we are not of great interest. So it is a vicious circle which medicine finally explains to you, and you very correctly said it earlier, only you said it very modestly even if I don't know how modest this thing can be - More or less we attend to the large percentage. So, you will tell me how can we change things in this field when we belong anyway in a category where the percentage is small. So now I will give you paradigms, you shouldn't be irritated immediately, anyway you have endured worst in reality, because what I will do now will be 0% fatal. Because as you know I am a mathematician, when I was looking at the numbers I said: ok...So, God is great, but we expect him be even greater from what. φαίνεται. he seems. I would like you to think, what could happen when you have let's say 10 patients, 100 patients, 1.000 or 10.000, You will tell me: Very simple they will attend to the 10.000. Now I'll change it, the 1st who is alone, is President of America. This way we make it even simpler, so that you don't have local problems and you don't think that it concerns a specific party. You will see suddenly that if it concerns one patient and he is very special, everyone will attend to him, even if they cure one person. Because what we need to understand, and at a strategic level is if you cure this person, then in your laboratory it will be written all over that you did this. If you cure 2.000 people and another lab has 5.000, they will go to the 5.000. So the question is, it was a very nice observation, είναι να προσέξετε πού be careful on how you will choose. I would choose there where they cured a President. What do I mean, it is related to mathematics all this we are saying and only with society's data. Society will examine things socially, and always cynically. So if the expenses are too many for a company it makes them less. If it is less and it can cure the same it will be the same or it will go towards the other strategy. If society believes that curing people is more expensive than letting them die, it will let them die. Yes, I am serious, it may seem to you simple, but they are the issues of epidemiology. I'll give you another paradigm because you spoke about smoking. Smoking in France is prohibited, I am taking France's paradigm because I am in Greece, so it doesn't seem it. Of course there is the law but it doesn't seem so. So in France, they made the decision to prohibit smoking. Now you will all tell me that it is very good because they certainly studied and realized it is not good that for osteoporosis etc. Nothing like that. It is very simple

what they did. They did epidemiology, they looked at how many have illnesses from passive smoking. And said, ok those that smoke, it doesn't matter, there is nothing we can do. They will die anyway. Since they have an issue. The others though that do not smoke, but who smoke due to the others, if we prohibit them to smoke anywhere, then we won't have the others. If you now look at the cost analysis, you will understand why the law was passed. Because they don't change anything for the others, Because all the rest that have these illnesses and society has to pay, it is understood that if you isolate the smokers, then we are ok. These approaches, they astonish us initially, because we don't understand them. While strategically they are more rational. So, at some case where I was in a convention which concerned blood donation, and before I stepped up, to speak I was like this, they explain to me in a diplomatic manner that if I could say that for those who have thalassanemia should not enter. Do you understand? No, I probably said it very modestly. They said that rationally when we give blood when the other doesn't have a problem it is worth it. If he has a great problem it is not worth spending so many bottles for someone we know that he already has an issue. So if you could tell them could those who have a great issue to no longer exist so that we have less problems for those who provide it? We say this because that was a true incident. I explained then, because in my CV which you finally managed to read it, there was the reference to Karatheodori. My friend Sakis, is the President of the Karatheodori Museum. If Sakis didn't exist, nobody would know about Karatheodori, except from the Germans, οι Γερμανοί τον θεώρησαν από την αρχή ότι ήταν δικός τους. Στην Ελλάδα who considered him from the beginning of being one of their own. In Greece we have to wait 50 years to discover that he is called Konstantinos, Karatheodori, that it certainly says something. This work was completed in a decade. Within a decade the programs have changed, in mathematics, in the museums, there are schools that have been named after Karatheodori, there are research, programs all this is due to one person. Due to Sakis. And Sakis has the disorder. So normally, if the previous ones were right, Sakis shouldn't had been born. because he is problematic, Because he has problem with the iron levels, etc. and actually with Sakis very often laugh when we say in Greek "Be iron-headed" he says, me don't worry, I have it everywhere. So, I want to say this because many times we are under the impression that patients are always humans that are miserable. Sakis is happy because of Karatheodori. He does nothing else as a mathematician than to highlight the work of a man who died in 1950. The issue is that this man, actually he was in mathematics what Einstein was in physics and you understand then that a simple man has this disorder and it is very funny, I'm saying this to the two doctors. When Sakis went to the hospital, and they perform measurements. They tell him, "You should have been already dead with such levels." Normally there is no patients that comes and do this. So you should see now the gratitude for Sakis because experiments are being done that hadn't ever been done. I say this in a sense that for the rare, the rare is not rare. I can say it again. Actually, the rare is rare for the regular. So we believe that Sakis is rare, but Sakis believes that it is his life. Initially what happens? Medicine believed that there is only illness, afterwards the model changed and we made it patients,

because with one illness we gave the same medication and one was fine and the other not, but they had the same illness. Then we understood that we had many factors and it wasn't exactly the same illness, it was different, so then we named them patients. So gradually medicine understands that the patients we have to name them, you will see it is very innovative, humans. Yes, in between we passed on to clients. And pay attention the clients are very dangerous for what reason. The laboratory when it receives funds, it will depend on the number of clients, to which it provides a service. Here we spoke about the companies, there are companies that are worst, that are behind those companies, which are investors' companies. You should see the cynicism there. There they speak only about weight. For those of you who are fat, don't worry it doesn't concern that weight, it concerns the weight in dollars. The questions are "your illness how much does it weigh?". Namely here even if it is , we don't even mean the lab, the doctors, we mean beyond that. So gradually we understood that this approach is a little problematic and most importantly we understood that medicine can have better results if it has a more humane approach towards the patient. Which seems extraordinary initially. Namely we understood that the environment, his family, his mother, even the psychological support can change the situation, while we have given exactly the same things. So we pay attention to that and we see it for everyone who goes to the hospitals. In the older days, the doctor was the professor in the University . Namely the fact that you spoke to him made you lucky. Normally you had to speak to the third level if he had time, because he runs around everywhere. The professor walks very slowly. It's like in the University, professors in the University don't answer to questions, because there are no questions. Because no one dares in an auditorium with 500 individuals to say " I am sorry, I didn't understand what you said". So it is all the others that explain in the labs what the previous had said. I tell you this so that we understand the following. More or less it happens also with the links. For this disorder some years ago-maybe even some decades ago -the target wasn't the medical offices of the patients, but their disappearance. Namely, the target if you look at society's perspective, it believed that hopefully these patients didn't exist better than to cure them. Even the associations had an approach of how could we be less, so that we are less problematic for society. And my issue is this: if you prove- not to society, but to Humanity that there are humans that have this disorder , which for centuries get into a process that indeed may decrease the quality of their life-there is a difficulty, but they do generate work for the entire Humanity. I will give you a simple paradigm, I imagine that you all know Stephen Hawking. They had told Hawking that he will die soon. So what is interesting is while they told him that he will soon die, he has children. Tthere is only one with his disorder and for those who have difficulty with their keyboard, if you look at the keyboard of Stephen you would see that it is one mouse only and by making a move only with one finger only he creates the entire alphabet and they have made an application only for him, who is involved especially with cosmology. Namely, for example, they are not even a few that can use this, there is only one. An entire computer company has done all this to prove what? To prove that, for this man we are capable of doing all this. So our issue is this: If the patients

of this disorder prove that there are only some elements, not everyone it is not necessary, that are capable to change the world, then society will look at these elements. I'll give a tangible paradigm. You said it very nicely for osteoporosis. In the beginning you said more or less we go through the same therapy like the others. Myself, with what I hear after the innuendoes, I say thankfully they go under the same category, because if they weren't placed under the same category, everyone would all deal with osteoporosis, but not for this disorder, but for all the others. Then you perplexed me, because indeed there haven't been many studies and essentially you act like strategy does, you use what you have, because you have nothing else and then that will become an issue. Because maybe, you said it afterwards you made me a good person again and I was pleased, with this new medication we may have may two good things. I want to tell you this then, that one way of winning mass is uniqueness. I'll give you another paradigm. The two spokesmen are good fellows, they went also to Germany and to France, they had all this, they were assisted, they became what they became. Now I will take Albert Einstein. Albert Einstein at one stage they told him if you would like to come to Princeton. So everyone now believes, especially the Cypriots, that surely they located him, they gave him a scholarship etc because he was a very good student. Of course nothing like such. The best thing is they invited him to go to a building that didn't exist. So they said to him "if you come, we'll make it". And that is the Institute for Advanced Studies in Princeton. Princeton. Many of you, especially the Greeks, I include in this the Cypriots and the Greeks from Greece, believe that Harvard is important, MIT etc. but they forget that these are private. Of course suddenly our politics remind us that they are private and suddenly we hear about politicians that have gone through these and you say God help! Of course you don't know how they passed, but of course I can give you an indication (money). For Princeton as much as you may have you are not accepted, because no one makes an application, they call you. Therefore the situation is completely different, I'll give an analogy with the College of France. In the College of France the one who are inside choose you and they choose you to give courses just and only for work you have generated. You will not speak about the others, you will be speaking for what you do. Which is very good, because all of us, we like talking about ourselves. μάζ. The issue is that if you were actually given the capacity to speak for yourself you will see that the time frame is small on a scientific level, because how much could you say. Think that in College of France there are people who stayed for forty years and spoke about their researches, which of course they continued them at the time they would go there. This College gives lessons for free. There is no registration, you cannot certify that you followed the lessons, but inside if you look at the professors it is full of Nobel prizes, Fields medals, because they say to them "you do the lesson and we pay, the others, whoever pleases let them attend". What I want to say is this. These are approaches that concern the rare, they don't concern the majority, we know that it is not possible. Now if I give you a theorem and I tell you do you agree or not, most likely, if you are not mathematicians, you disagree that it exists, afterwards I will give the proof and you will say "aha, it exists indeed". Namely if we proved the theorems

in referendums, surely we would have killed Pythagoras, Archimedes...In reality the history of Humanity shows us that only some individuals have made all of our history. And I ask now, what if Archimedes had your disorder? You would tell me that he is one, an entire pharmaceutical company for Archimedes? Yes, but they would say immediately, yes, but it is Archimedes. What I want to tell you is this, as long as you are just and only patients, we will be indifferent. If the patient has a CV then suddenly he becomes a human being and you show the CV, then you will see that you have an issue, they cannot weigh you in percentages. That is very significant for this field, because we βλέπουμε και για τους μικρούς. see it also for the young ones. Namely, very good, there are experiments that go much better with the younger ones than the older ones etc. The issue is how do the parents decide if the young one will go and do it. Because I could see the ladies here that were resentful, especially when they saw the numbers. Because this is a different issue which I will present to you as game theory. If you go to the casino, I give you the money, don't worry. So, I give you one thousand Euro and tell you, you will bet all at once the 1000 Euro or 10 times over 100 Euro. It is very simple, all of you would go to the category 10 times. In game theory this is called the catastrophe of the player. The more times you play, the more often you lose. Therefore the theory says that when the game is unfair, there are two ways to win. You either don't play, and indeed this works. Sun Tzu says "in strategy the great victories are those that have not occurred by war", so you didn't play. Because you have to choose when to play. Here you must choose if you will do the surgery or not. And what the game theory tells you is that what is rational because of the theory, it is not normal for us. μας. Here from what it seems the results we have so far, we have difficulty making the other decision which would have a cure at once, because we see that we have fatal incidents. Good, so now I will play devil's advocate and I will ask you what is your problem? The fatal incidents were only 12%. You see though that 12% because it is fatal and irreversible as a result, it affects you much more than that which have been succeeded. Good, so we'll make it even worse, there will be sadness now because that someone will tell me that it will be in 10 years that we will achieve it, I will make it 1% fatal. Not 12, 1% twelve times better and I ask you would you go? As long as you cannot give us zero, then you can tell us various things. Chemotherapy, we will do this too, and the other and the other. But if in one of all these you place 'fatal', ouch! And I try to tell you this: In reality when you think in that manner it is the correct way and it is because you evaluate the rare more than the mass. Because the rare has a problem, it is irreversible. Namely, more or less it gives you the choice to say I don't do it now, I will do it in two years. It can be done. If you did it though and you are dead, you cannot say that I will do it in two years. So in our life we make many moves, most of them are useless and they are reversible. We make them or not it doesn't matter. And there are some acts, these are irreversible. If you recall your age from the beginning you will see that you will remember a few things. These few things define you from the whole. All the rest is fill up. There are days that you haven't done something special, Μία even for the laboratory. And there is one day you make a discovery. One day, one. Us in mathematics we are worst,

because we have centuries of defeat and now and then we find one thing, so we are used to losing, but when we win, we win the whole package. There are some mathematicians who we know because of one theorem. Namely, the man had 70 years, one theorem. But it has remained and it is his name. Now the question is this. if we think only in terms of percentages, we will not get through. If we think in terms of rareness, then we will change the circumstances. We should now think that the rare, is rare for the regular and it is normal for the others. Now you have to think what it means that I live in Cyprus. Because I don't know if you noticed, but you said it to us a little discretely, almost with humor, that before in Syria we already had a problem. So there are some of you that think that to be here with this disorder in Cyprus is awful. They are thinking that because Cyprus is small and because its population is small, the patients are little, so who will pay attention to us. But Panos, said something very good, which was "if the others have the same, for example Italy, because Italy is so large, 40% of Italy is not a small size. So you see that here you are networked. Namely it doesn't matter that you are only here and think you are isolated. Is it maybe that you don't look at the networking with other categories which allow you to look at you entirely and not only here. Myself many problems that I see also in the approach of the Cypriots is that they look at the problems locally. This disorder has proven that it has no locality. You have to look at it in a Mediterranean manner the word speaks for itself, and there, a Mediterranean network be created. Then there is a diversity in the approach. However what we always need to have in mind is the phrase of Poincaré. Poincaré says "in the history of the universe our galaxy is nothing, in the history of our galaxy our solar system is nothing, in the history of our solar system Humanity is nothing, but it is everything for us because we have nothing else. Suddenly he who tells you "I make theories of everything, but then I don't forget that inside everything I am only an ant and my entire life will be an ant, so I will deal with ants and from the ants I will bring out things". Take out fat also from the fly (idiom). Here the idea is that the people of the disorder have to understand that they are only humans that have this disorder and they are not patients who are by the way human beings. Because sometimes you may feel like this. Namely, you go to the Social Security office. There you are a number. So suddenly you become a number. As long as you are a number, you are as much as a number. Now the police pulls you over and you are on the highway, the first thing a Greek says, what is it?

(Audience)

-I wasn't speeding.

That is the second thing. The first is "do you know who I am?". The officer can't see with his radar who you are, you are you, so he stops you. At the time he sees you, you say "do you know who I am?" Then if he gives you distress, you say, write it. I will remove it. That of course irritates them. Then in Cyprus you are more honest than in Greece, in Cyprus you speak of connections. In Greece we don't say it, we only use it. So a regular Greek in Greece he hides the connection, but when it succeeds we say God is great. In Cyprus it is "you have an MP, I have a Minister". As raw as that. I

like it, it is quite funny. It's like playing poker with the cards down. If you want bid. So what do I want to say by this, why don't you suddenly say there the social security number? In reality you are networking. And you explain to the other that I am not merely a car driver, I am so and so. How many times do the patients when they go to a place they say that they are so and so. They don't have time, since they are a number. In reality, if we look at the humane approach of medicine, gradually we will understand that there is something a little higher and it is the approach of Humanity. Therefore, I'll give you a different paradigm. What is the percentage we have for the left-handed? 17%. This doesn't bother us. In fencing to be left-handed you have a huge advantage. Two advantages, the brain due to the structure, it belongs to the rare sports that is useful here and the second is that most pull the sword with a right-handed. So the right-handed ones are used to fight with right-handed. When you come about with left-handed, they see everything reversely. The worst for a left-handed, what is it? A left-handed. Because he is used to pull the sword only with right-handed. And now I say it to you differently, now you are the coach of the team and you have different kids and have exactly the same talent. Damn me if you don't get a left-handed one. Because you know that for the same talent there will be a small difference. And you see that within a field something that is a minority it can be transformed to an advantage. Here it is the same, you just don't see the advantages. I explained to you in the beginning that I dedicate this discourse to Sakis, because he was a problem for the parents and the children. I am not thinking only of Sakis, I am thinking of other individuals as well, but I cannot say their names, because then you might tell me we know them. So there is an issue, again a probability issue, if you have the stigma whether you can have children. Society tells you that if you both have the stigma don't have them. I would like you to tell me for what reason does society says that? It does it for your benefit or because it believes that per capita you will spend more money than the others? Because you are not a cancer patient. It is a completely different approach. Unfortunately you get into the patient category on your own, but there are illnesses that you cannot live with and there are illnesses that you can. The other who has serious cancer and has to constantly take him in for chemotherapy etc. we no longer speak about quality of life, at one point we speak of survival. Here we don't speak of survival, we speak of quality of life, there is a difficulty but we have to understand this. Those who decide to do what they are told not to don't have mental retardation, The issue is what will they do with what they created, namely with their child. Will they attend to their child as a patient and will do the same that society does or will they handle their child as a little human that generates work and will be justified with their choice? Because afterwards the others will say "gladly you didn't listen to society and you made this child." So all this I am telling you is for these children. So we are the Just -and we cannot be innocent-we are always on the side of the innocents. So don't listen to society, which looks only at the percentages for what happens. Look at what Humanity wants and you will see that it only pays attention to rareness. If we realize this and understand that we are not in the

same category, then you will see that the target is not disappearance. but it is life. This is what I wanted. Thank you very much.