# Alain-Michel Ceretti – President, France Assos Santé



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*Alain-Michel Ceretti, president of France Assos Santé (the French Union of the Registered Associations for the Users of the Health System), tells us about his own battle against nosocomial infections and the role of the organization in the protection of patient rights.*



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**Why did you accept the position of President of France Assos Santé one and a half year ago?**

I have been since 1997 strongly involved in the patients' organization side of the healthcare sector. After a surgery in one of the most famous private hospitals in Paris – the Clinique du Sport – my wife contracted an infection due to the multiple-use of what was meant to be a single-use medical device. It was provoked by a very special bacterium called *Xenopi:* an unprecedented event in France. My wife was less than 30 years old at the time, and this event has and will continue to profoundly impact our entire existence and lives. After years not realizing why she was entering into complicated physical discomfort (spiral cord pain and more), we started to ask ourselves the question: why? When did this happen? What went wrong?

After extensive research, questions to the Clinique du Sport, discussions with the American manufacturer of this device, we concluded that the only fault was due to misusage of the device at the clinic. My wife and I however decided not to accept any form of compensation, as the insurance company required us to sign a non-disclosure clause and an agreement not to sue the clinic. Instead, we chose to fight and founded a patient health organization, *Lien* "The Link" [one of the 80 associations now part of France Assos Santé], which would include every patient that had a surgery at the Clinique du Sport between 1993 and 1998. You need to understand that this bacterium might manifest only after years due to its slow development in the bones. To find the other 59 people affected, most of them between the ages of 26-28 years old, we had to scan by MRI at least 25,000 patients.

**What were the first measures that you took with *Lien* in 1997?**

Initially, identifying the affected people was very hard, due to the medical secret (the then Minister of Health Bernard Kouchner changed the law only in 2002). We could not use patients' social security number, hence we created a toll-free number to be called by people treated at the clinic in that period. After, we tried to understand how this happened in Paris, in an internationally recognized private hospital. The reason was simple. At the time they were using a surgical instrument provided by an American company, that costed USD 1000 and was meant for single use. The American producer stopped doing business with the Clinique du Sport because they were

using each instrument up to 15 times a day on different patients.

The last step was about setting up a class action against the clinic and the surgeons. The trial lasted for 15 years, and in the end, the clinic and doctors pleaded guilty.

**What was the effect of this very public scandal on addressing medical malpractice?**

The question was: How could this happen in a private hospital with this reputation? Bernard Kouchner, then Minister of Health, decided to better control medical practices, and the correct use of instruments and sterilization. We inspected 2500 private and public hospitals. In over two years the result was disconcerting, as in the same area you had good and bad structures, with no way of knowing in advance.

**What was the idea behind the creation of France Assos Santé?**

In the words of Bernard Kouchner, it was necessary to organize a *sanitary democracy,* a political representation of patients and taxpayers in general. The question then was: who could best represent such people? While politicians and labor unions were logical first choices, it wasn't enough as 60 percent of the users of health services are not in the workforce anymore. Sanitary democracy could be achieved only through patients' organizations. In 1996, the minister decided to put 2 500 patient representatives from health associations on the boards of the more than 1000 public hospitals. Some were from very well-known organizations, like the *Ligue Nationale Contre le Cancer* (the League against Cancer), others were from family and consumer associations. This was the first time that these groups were working together and it was the very beginning of France Assos Santé, under the name CISS [Inter-associative Collective on Health]. We [the *Lien*] decided to join at the beginning of 1998.

**What was the initial role and achievement of CISS-France Assos Santé?**

Even if we were just 24, we had a fundamental role in the creation the Kouchner law on patient rights in 2002, as CISS represented not only the patients but also families and consumers. Personally, due to the experience with my wife, I decided to put an emphasis on individual rights and compensations on medical accidents. New rights is what Kouchner called *la pierre angulaire* (the cornerstone) of this law.

**What kind of new rights did the 2002 Kouchner law introduce?**

For the first time ever, patients were taking their own decisions for their treatments and the doctor function became an advisory one. Before 2002 the decision was only of the doctor.

**Sounds funny to hear this in 2018…**

Honestly, today, there are still a vast number of doctors who still do not understand why the patient makes the decision, as this decision for them takes 15 years of study! We call it ‘paternalism’. In terms of rights, this law has several important implications. The patient is now free to decide about his own life, and it is the responsibility of the doctor to provide all necessary information to the patient and explain all potential associated risks of a treatment. Thus, the patient is correctly informed and can make his own decision. Currently, for each surgery, the doctor writes down a document illustrating all the risks of the intervention: it must be read and signed by the patient to avoid any possible suing for non-information in case of a negative outcome.

**How did the situation of nosocomial infections change?**

The other great victory of the 2002 law regarded nosocomial infections. The faults at the Clinique du Sport were huge. Yet all of the affected patients going to court individually lost before the scandal was unveiled in the press. Why? Because they had to prove the fault of the clinic. Twenty people lost on the worst story in the history of France, which meant that winning was impossible. It is hard to provide evidence of malpractice on infections, as only 60 percent of nosocomial infections are avoidable. A judge in front of a nosocomial infection has roughly 50 percent of chance of taking a bad decision, whatever that is. Finally, in 2002, we created a fund to compensate medical accidents due to no fault. It is still the way it is working today: 50 percent of the cost of nosocomial infections would be paid by insurance companies and the remaining by the government. In a nutshell, we now have individual rights, where the patient 1. takes his/her own decision 2. can be compensated quickly, in maximum one year, 3. is represented inside all of the health organizations.

**Is France Assos Sante really just about being the voice of the patients towards healthcare authorities, or do you have the intention of becoming like the UK charities, financing research and development?**

We have nothing to do with that. We are a political organization: we do what the law is asking us to do. The law is saying that France Assos Santé represents all the patients' organizations, at least those receiving an agreement (around 120). We have representation in the whole territory and our main expenditure is the training of the voluntaries going on hospital boards. The government consults us for any action regarding health. Last but not least, we help our member associations in the organization of class actions, something very new for France and very normal for the UK and US.

**What are your top priorities in the discussion with the cabinet of Agnès Buzyn, Minister for Solidarity and Health?**

We have many points. When I started in the health area I was upset, because of what happened to my wife and I fought a lot to change things in terms of patient safety. Now we have to put a lot of energy on the table just to save what we have. The risk is that in ten years' time, public hospitals will be used by people only when they cannot afford private structures, like it happens almost everywhere else in the world. Last February, I met Mrs. Buzyn herself: she wanted our contribution into the *Stratégie de transformation du système de santé* (the Transformation Strategy for the Health System) by the end of June. We hence worked on proposals on hospital rating by patient – always from a patient centricity side – and the new plan is to be announced by President Emmanuel Macron on September 18th.

**Pharma companies have a very bad image among the public in France. What could be your role in establishing a relation of confidence between the patients and the pharma companies?**

For the majority of the French people, doing business on health is not ethic, and this is very much a cultural issue. French do not like private hospitals, they do not like any private organization making profits on health. While public hospitals are losing money, the attention of some governments are

towards the modest margins made by private hospitals which are tied by regulatory constraints. In 2016, the then Minister of Health Marisol Touraine made a proposal that would have impacted negatively private hospitals. She presented a tax on the profits of private hospitals when their profits were unfair. The law however did not specify what was ‘unfair’. The situation today is as follows: while the law has been passed, the decrees are still pending, which means that it is still not in a situation of being applied and may never be. But imagine the meaning in terms of public attitude towards private health investment. Doing business in this area is very difficult… but one must not forget that the vast majority of innovations actually comes from the private sector. France would have everything to lose if private healthcare companies leave. Hence, as an association we have to create a dialogue with the industry, we have to see what they need, and denounce the unfair prices when they happen.

**What is the reason behind the unfair pricing you mentioned and the antidote to it?**

The reason is that we are not good at negotiating, and negotiation with industry is fundamental. Obviously, pharmaceutical companies will want to sell as high as possible, like in any industry! It is our task to face this issue. Right now, each European country is negotiating its own drug prices. Organizing global negotiations would be a big gift for the industry, as we need more bargaining power. We hence need to join our forces. It is no longer conceivable and acceptable that the State defines healthcare policies for its people without its people. Healthcare matters are just too important to leave into the hands of only doctors and politicians.

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