Gérard Raymond – President, FFD, France

Diabetes has multiple pathologies: we count approximately 20,000 hospitalizations due to stroke, 8000 heart attacks 4,400 patients with chronic renal failure

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Gérard Raymond, president of the Fédération Francaise des Diabétiques (FFD - French Diabetes Federation), gives an update on the situation of diabetes in France and explains the challenges for patient associations in the country. He also shares his vision on how the FFD has to evolve to remain a relevant entity in the French health care ecosystem.

Let's start by giving an update on the technology and numbers on diabetics in France: what are the main concerns today?

We are in a period that we consider crucial for the upcoming years and we just celebrated the International Day of Diabetics on 14th November, and this is always an important event for us. In 8 days, we will submit the restitution of our research on the state of the art on diabetics and the care of the diabetics-affected patients in France and provide respective recommendations to the French National Assembly. Decided last year to organize the "Etats Généraux du Diabète et des Diabétiques". We have since engaged in huge consultations among all stakeholders, and now we can share the results. So, it's a crucial moment for us as we believe that these results will have a strong impact on the work of our association.

Concerning numbers and figures on diabetics and on the state of the art of the care of diabetic-affected patients, well, we have today exactly 3.700.000 people that receive care. If we add those that do not receive care but treat themselves on their own and in addition those who don't know yet that they have diabetes, we exceed largely 4 million people. Being considered diabetic means having a blood glucose level of 1.26g during the day and 0.80g when being ‘sober’. But there are people who, when waking up in the morning present a blood glucose level of 1.0. Those people are not considered diabetic even though their blood glucose level is higher than normal. We consider them a chronic hyperglycemia, a kind of pre-diabetic condition. This category of people may count up to 500,000, and they are at risk of developing diabetes in a near future.

We hence count 4 million people with diabetes and the rate is increasing at 2.8% every year. Diabetes cost EUR 20 billion each year to the French national health insurance. This presents one of the biggest expenses of the French health care system. Diabetes has multiple pathologies: we count approximately 20,000 hospitalizations due to stroke, 8000 heart attacks 4,400 patients with chronic renal failure. We observe an important increase in the number of hospitalizations concerning neuro-pathological problems of the foot. 26,700 people per year are hospitalized for foot wounds and 8,400 undergo an amputation of a lower limb every year. Diabetes is, therefore, a major public health concern in France.

In France, there are national plans for cancer, autism, rare diseases… and unless I am mistaken, I have never heard of a diabetes plan in France. How do you explain this?

We had a diabetes plan back in 2000 when Bernhard Kouchner was Minister of Health. This plan gave some results, and we came to understand that the Diabetic Foot issue was a real problem. Moreover, the Kouchner Plan helped chiropodists to be recognized as true health professionals with a convention that allowed them to claim reimbursements. They finally got rights.

This brings up the question of why there was no other plan following that one? One and a half month ago, President Macron presented three key strategic pillars in the National Transformation of the French Healthcare System, of which diabetes is included. The outcomes of this new strategy will be measured on how better diabetes and diabetics are taken care of. So, we see an interesting perspective of making diabetes an experimental pathology for transforming the health system into a much more supportive and humanistic system, of course, based on technical evidence.

What are the areas of improvement that need to be worked on?

We have submitted 15 proposals to the Minister of Health and to the French President, which range from prevention to healthy democracy. We think that we need to put in place, coordinate and evaluate a real health education policy. Every citizen must be able to preserve his health capital. This is extremely important. Our proposals and actions make health education compulsory in nursery, primary, elementary, and high schools. A second proposal focuses on the improvement of the quality of industrial products. Moreover, we could use the soda tax to finance health education. The government has already started to propose activities for a nutri-score agreement at the European level. There is also the question of how to measure the impact of genetics. We know that diabetes is a genetic anomaly. We know that these are genetic transformations, and we thought that "genetics" + "genetics" are the determinants of diabetes. So, why not take an action at European level to agree on a regulation on chemical products and on educational measures. We need to do more research on chemicals; it seems to us extremely important.

Third, there is also a need to improve the knowledge of and identification of people at risk for diabetes. We have personalized questionnaires that help identify this risk. Yet, the real question is how can we use health education and mobilize the different actors such as charities and others that are in contact with those people, to identify those at risk of diabetes, and how can we include them in a program that improves their quality of life? We need to put those people in a more favourable context so that they can benefit from their health capital. The CNAM (Caisse Nationale d'Assurance Maladie – National Health Insurance Fund) is funding a program called "Say NO to Diabetes". We need to support and strengthen this program through recruitments other than the general practitioner because these people are not 'sick'. They won't go and see the GP – these people simply need health education and prevention.

Fourth, we have proposals against the discrimination of diabetics in the workplace and regarding employment. We consider those regulations to be completely obsolete and need to be revised by means of an inter-ministerial committee that we have proposed to create. The same goes for employment: in France, disabled workers have a special status and employers have an obligation to include disabled workers in the workplace. Our proposal is to create an intermediate status between disabled and normal workers, that enables to get into long-term employment. Why can't we create, on the one hand, an intermediary status that allows diabetics to leave their workstation to go to see the doctor, while on the other hand, employers are rewarded for hiring these people through tax benefits? That's an idea we're going to bring to the National Assembly.

We also consider information sharing and training of patients as vital. Most of the time, they are informed about their health status and of the decisions made by their health professional. As FFD, we want to train and empower patients to become responsible for their own health. Every patient should be able to become an expert of his own illness.

Don’t you think that patients already use the internet to search for the information they need, but that the real problem is to sort out between the right and fake information?

Of course, but the real revolution of the 20th century is the “discovery of the patient”: a patient who speaks, who challenges and questions his GP, who wants to live and who wants to be an actor of his own health. No one is contesting this. There is a lot of information on Facebook and other social networks and I think it is in our own interest to tell patients how to sort out the information. Our website counts more than 200,000 visitors monthly because we only publish validated information. Nevertheless, it appears even more important to accompany and train our chronic patients similar to what is done within the context of therapeutic education. This support should be as flexible as possible, more democratic and closer to people to avoid hospitalization because of therapeutic education. We know that a diet and physical activities are most important for a type II diabetic; so we want both nutrition and physical activity to be considered as an entire therapy that is prescribed and reimbursed.

We advocate for a comprehensive and personalized medical care, so we need to go for lump sum payment by regrouping health professionals of the first instance and elaborate evaluation indicators jointly with hospitals. We need to provide GPs with practical tools to help them adopt a more global and preventive approach for poly-pathological people, and the Haute Autorité de Santé (French High Authority of Health) needs to publish relevant guidelines. Our proposals are on the table. Also, there is a need for clarification of the role and responsibilities of each actor. Very important would be to empower the pharmacist regarding the delivery of drugs in partnership with the patient and the prescriber. Yet, this also means that the pharmacist is responsible for pharmacovigilance.

Lastly, we recommend including the improvement of the quality of life as an indicator of evaluations of our health care programs. To make the care and empowerment of patients efficient, we need to give patients a voice and participate in the assessment. This is what we consider as sanitary democracy.

Let’s talk a little about the “centricity of the patient”, as it is promoted by the industry leaders such as Sanofi or Pfizer. Over the past 10 to 12 years, they have changed their discourse and approach. Now, they all spread out the message that the patient is at the centre of their concerns. Is this a reality for you?

I think there are two different levels to be considered. The first one is the individual patient. Indeed, nowadays, we listen and want to be closer to the patient. We consider the patient as a whole with all his fears and denials. The second concerns the representing associative structures. Health democracy is not a direct democracy. It is a democracy by representation. So, the associative structures that represent their patients are patient associations; they must be independent, transparent, and have a real strategic associative project. There are hence the individual notion and collective rights, and these two cannot be mixed. Collective rights are assumed by representation, government instance and when developing further the French healthcare system. They are “political bodies”. Yet, there are also structures such as ours, patient associations that bring up proposals to the Ministry of Health.

Have you seen a change in France over the past few years?

I joined the FFD 20 years ago. At that time, the FFD was managed by diabetologists only. Patients just had the right to keep quiet, and FFD was not a patient association at all. When we took the management in 2003, the first thing we did was to kick out all the diabetologists. There is no longer any diabetologist in our governance bodies (board, secretariat) – we only have diabetic patients. There may be some having a medical profession, but they are here because they are diabetic patients. Then, pharmaceutical industries largely abandoned us because we kicked off the diabetologists. We had to find another way of interacting with them, and with others as well to create our new associative project asking fundamental questions such as what are our values? Mutual aid and solidarity. What are our goals? Help all diabetic patients to better live their lives as citizens. What is the way and what are the means we have? Well, we have strategic projects, participate in the evolution of our national healthcare system, and are present at all levels of institutional governance.

And FFD has evolved well?

Of course. We have evolved and people are listening carefully to us. Today, we have recognized for our expertise and patient support thanks to a great team. Today the FFD has become an essential structure, including for issues such as health democracy but especially for the management of diabetes. But, as much all this is important, we also require financial and human resources. The FFD has a budget of EUR 4 million annually, and we have to run it just like any other business. We have employees, and instead of selling croissants, we sell solidarity and mutual aid. The economic model is the same; yet we needed to find a model that would ensure our independence from health professionals, industry, and public power, and which guarantees transparency in governance and financial transactions.

The pharmaceutical industry’s communication strategies are placing the patient right at the centre. Do you see in this strategy a stronger will for cooperation with patients associations?

To say things bluntly, industry understood little by little that patients existed. The latter was usually told to go and see the doctor, to have a medical checkup, etc. but they have also seen that some associations such as the FFD started moving ahead. They hence started thinking of cooperation because they suddenly realized that they need us. Many of them, and even start-ups came to my office proposing this or that, and each time I told them: No. That’s not the way it works here. You just come with a white paper, think of the needs and expectations of patients, and then you come up with proposals. This is the way to go together. Most did not understand, and then one day since I kept on telling them that, some started understanding. We above all understood that we must develop a tool for them to help them understand patients’ needs and expectations.

We, for example, created the “*Diabète LAB* » three years ago starting with a database to provide evidence on patients’ needs, expectations and patients’ habits. This research enabled us to participate in assessments of healthcare programs and systems and to contribute to informed decision-making processes based on evidence. It is actually quite interesting because today industry and other institutions such as the HAS, ANSM, and CNAM are coming to ask us if we could not run a study for them. So, I consider the patient experience to be more and more valuable, and this is one of the major axes of our business model. Today, we have a real partnership relation with the pharmaceutical industry. We sell them patient validated experience, expectations and needs and every single Euro fixed in our contracts is subject to transparency and legal validation.

Where do you see FFD in 10 years from now?

Things will change a lot. Associations created within the framework of the national law 1901 as the FFD was, will soon be gone. The 1901 law was to produce associations that give a good time to a targeted group of people in need, with no intention to participate in changes in the healthcare system. FFD’s membership represents less than 2% of its budget – what is key is the number of patients we have. I think it is our job to change the current associative model to be more appropriate, and able to respond to the realities of the 21st century. Many associations will need to change as otherwise, they lose their mission, the FFD included. We will achieve our objectives within the context of sanitary democracy. On the one hand, we will be a health actor meaning a service provider for patients and patients groups to help them get a better quality of life, while on the other hand, because we have the expertise, we will participle in the decision-making process regarding the development of our healthcare system. A third pillar will be the involvement and leadership of assessments and evaluations.

Yet, to be able to transform ourselves in that direction, we need to find a business model that guarantees the independence of our stakeholders. There are options. Certainly, it’s neither the state nor the industries that will give us the money. It might be a mixture of both, or maybe the democracy in our country becomes more inclusive and makes all stakeholders responsible and accountable? I am however sure of an evolution regarding the relationship between individuals and institutions in France, and I call it humanism. Creating a medical system based on humanism and making it more respectful towards people. This is what guides us every day.

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