“A MEDICAL DOCTOR SHOULD NEVER SAY THAT!”

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“A Medical Doctor Should Never Say That!”

Itinerary of an AIDS Specialist

médical

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To my father Albert, who left us in early 2016, leaving an empty space we cannot fill.

To my mother Eliane, whose heart, goodness and attentiveness continue to shine at the age of 82.

To my beloved son Vincent.

To all the patients and their families I have tried to help using the advances of Science, some of whom are still here, over 25 years later.

And to my beloved chocolate Labrador “Lino”.

Special note

This book is a translation of the French first edition published in October 2017, but with updated and increased data

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Foreword

Monday May 11th, 1981: the first day of the competitive exams for admission to La Timone hospital in Marseille, where I hoped to spend my second year studying medicine. The supervisors and Professors attending the exam week were looking grim: the day before, François Mitterrand had won an historic victory against the French right wing with 51.76% of votes. I'd been waiting for this for years: at the age of 20, it was my first opportunity to vote for "change" and hold a polling station.

Once the exams were over, I found myself in something of a no-man's land, waiting for results, which would "probably arrive in early July". Like most of my "competitors", I called the Faculty of Medicine every two days to see if the results were in. And every time a "no" came back, I said to my parents that I wouldn't pass the exams anyway because the others were better than me. Finally, the secretary told me the results were up, but she couldn't give them to me over the phone. My dad – always ready to face an emergency –

decreed “Let’s go!”… and that’s how I found out I had come fourth in the year out of just under 300 students admitted.

In the Eighties, a medical degree in France included a 6-year common core, followed by general practitioner or specialist studies. I wanted to be a specialist – but I didn’t know what in. Gastroenterologist and see digestive tubes my whole life? Gynaecologist and see wombs and vaginas forever more? It might seem like a cliché, but that’s how I felt. Until I discovered Internal Medicine during a 6-month internship. This speciality is little-known in France, but far more widespread overseas, in America for example. It relates to patients with complex pathologies or difficult diagnoses, often referred to as “second-hand” patients… In fact, they may already have undergone multiple tests and been seen by multiple doctors without a diagnosis: for example, patients with an unexplained fever lasting several weeks, or an inflammatory syndrome, i.e. abnormal blood tests that can’t be linked to a precise problem. After seeing several of these specialists at work in Marseille and Toulon, it became obvious it was the speciality I needed: that of Columbo who works on a single clue to find the culprit – but no haemorrhoids or vaginitis. However, Internal Medicine wasn’t – and still isn’t – considered a ‘noble’ speciality. So, in 1986, after coming 7th in the internship exams, I was

booed in the amphitheatre of the Montpellier Faculty of Medicine when I announced my choice. At the time, the "trendy" specialities were cardiology, radiology and dermatology, which have always been lucrative when practised privately if you can't, or don't want to practise in a hospital.

Organ specialists were considered as "knowing everything about nothing" (surgeons that operated only the big toe were mocked), while Internal Medicine specialists were considered as "knowing a little bit about everything".

My determination not to limit myself to a single organ or disease changed considerably with the arrival of AIDS (Acquired Immune Deficiency Syndrome) and the first cases I had to face. At the time, I didn't know that as an Internal Medicine specialist, I was going to become an "AIDSologist" (a specialist in patients infected with the Human Immunodeficiency Virus or HIV) – a skill that remains unrecognised today as a subspeciality).

Clearly, the first AIDS patients I saw in Marseille in 1984 and 1985 all had something in common: the carers were scared of them and didn't want anything to do with them. In 1986 and 1987, while I was an intern at Toulon General Hospital and awaiting the results of the internship exams, it became clearer and clearer that as an Internal Medicine specialist, I was going to have to

deal with what was looking to be the late 20th century's biggest-ever pandemic, which is still the case today.

It is this 30-year fight alongside HIV patients and my vision of the evolution of our healthcare system and society that I want to share with you through this book.

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35 MILLION PEOPLE HIV INFECTED WORLDWIDE

I'd like to go back over a few historic and biological facts before the next chapters. They might seem obvious to you, but if not, I think it's important to get clear on the situation at the time.

In 1981, the Centers for Disease Control (or CDCs), in charge of monitoring epidemics in the US, reported an increased use of Pentamidine on the East Coast: an anti-parasite drug used to treat a syndrome called pneumocystosis, which only affects immunodeficient patients (those undergoing anticancer chemotherapy for example). Meanwhile, on the West Coast, a rise in skin and mucosa cancers, referred to as Kaposi's sarcoma, was observed. This cancer, which causes multiple wine-coloured lesions, had been described in African populations in 1872. But now, there was a widespread outbreak of cases in homosexual patients, hence the nickname "gay cancer".

So here we were, with an epidemic of infections and cancers mainly affecting the gay population, probably due to an immunity issue of unknown cause. Over the

following 2 years, some people claimed the complications were due to the "immunosuppressive power of sperm", while others put it down to the cytomegalovirus (CMV) – a virus most people catch at some time during their life, which can cause temporary fatigue and fragility – but is systematically eliminated by the immune system.

Meanwhile, the CDCs continued their fieldwork. Although most people affected in the US were indeed homosexual, some had received blood transfusions or were drug addicts who swapped needles. It was therefore becoming increasingly clear that an unidentified infectious agent was at work.

Living beings are characterized by their DNA (deoxyribonucleic acid) and RNA (ribonucleic acid). Generally speaking, DNA gives rise to RNA through the work of enzymes (we say that DNA is transcribed to RNA), allowing protein synthesis: that is how our genetic machinery functions, from the most primitive beings all the way to humans.

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In 1974, the American researcher Robert Gallo discovered a virus that worked the opposite way around (synthesizing DNA from RNA), which allowed him to announce a "retrovirus" family. This first retrovirus,

which he named HTLV-1 (Human T-Cell Leukaemia Virus) is capable of inducing leukaemias or paralyses in certain patients. In parallel, Professor Gallo isolated Interleukin-2 (IL-2), a molecule produced by the immune system and vital to cell proliferation, which went on to become a key ingredient for maintaining laboratory cell cultures. In 1982, he also isolated HTLV-2, a retrovirus at the origin of leukaemia in certain parts of the world. His laboratory at the Bethesda National Cancer Institute in America therefore had all the knowledge needed to confront and characterize the pathogen responsible for AIDS, which had just been recognized by the CDCs.

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A team was forming at the Pasteur Institute in Paris, led by Professor Luc Montagnier along with Jean Claude Chermann and Françoise Barré-Sinoussi, who were also interested in characterizing the infectious agent responsible for AIDS. Françoise Barré-Sinoussi had worked as an intern alongside Robert Gallo, who taught her how to detect a possible retrovirus in a cell culture. In practise, retroviruses all contain RNA not DNA, and when they infect a cell, they bring along the enzymes needed to replicate and become permanent, dormant inhabitants of certain cells. These enzymes are called Reverse Transcriptase, and allow the production of viral

DNA from viral RNA, Integrase allowing the viral DNA to integrate the patient's cell chromosomes, together with Protease, which allows the production of new viral proteins when the integrated virus becomes active. Once assembled, these proteins constitute new viruses capable of infecting other healthy cells. A genuine Trojan Horse as it were. The detection of Reverse Transcriptase activity in cell cultures therefore allowed researchers to suspect that the cells were infected by a retrovirus. The retrovirus at the origin of AIDS preferentially infects T lymphocytes, the surface of which contains CD4 (Cluster of Differentiation 4) receptor. T lymphocytes are the maestros of cellular immune response (cells capable of killing foreign agents directly), while antibodies are produced by B lymphocytes. To date, due to the extreme genetic variability of HIV (the virus mutates with great ease), no antibody capable of neutralizing all HIV variants has been identified.

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But let's get back to our Parisian team and their conundrum. As we said above, AIDS was a source of fear at the time, and few doctors were willing to deal with it. However, in 1982, Professor Willy Rozenbaum, Clinic Director at the Hôpital Bichat Claude Bernard in Paris, suggested that the pathology observed was

secondary to a retroviral infection. He was so convinced that he performed a biopsy on a lymph node of one of his patients and took it to the Pasteur Institute, where it was cultured by Professor Luc Montagnier's team, who detected "Reverse Transcriptase-type activity". The results just needed to be confirmed by America's master of the art, Professor Gallo. Samples were sent from Paris to Bethesda, giving rise to one of the 20th century's most unbelievable scientific disputes: due to a probable cross-contamination of the cultures, Professor Gallo's team isolated the agent responsible for AIDS, baptized HTLV-III, while Professor Montagnier's team named it LAV. But when the 2 viruses were compared, it turned out they were from the same patient in Paris. The controversy continued until 1987 – with rights to the HIV blood test at stake – when France and the United States finally signed a political agreement. On the scientific front, it is now recognised that Luc Montagnier's team discovered HIV and Robert Gallo's team discovered how to detect it, also demonstrating that HIV was the causative agent of AIDS.

At the time, there were no reliable markers capable of distinguishing the functions of the various immune cells. In short, we knew of the existence of T lymphocytes in charge of cellular response to a foreign agent and B lymphocytes in charge of antibody response to a foreign agent. It has to be said that the HIV pandemic was a

driving force for the fast-track development of many immunological and genetic engineering tools, not only for research laboratories but also, very rapidly, for diagnosis labs.

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To date, around 35 million people are HIV-positive throughout the globe and over 25 million people are known to have died as a result.

In France, it is estimated that around 140,000 people live with diagnosed HIV and 30,000 are unknowingly infected. The number of new contaminations has been stable in France for several years, at around 6,000. Since the outbreak of the epidemic in France, 40,000 people are thought to have died of AIDS. Despite major leaps in antiretroviral therapy ("triple therapies"), people in France are still dying of AIDS (650 cases in 2010 according to the French National Institute for Health Surveillance). "The War Is Not Over" was the title I chose for the convention I organized in Toulon a few years before the arrival of triple therapies… And that still remains true nearly 20 years on.

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The years of fire