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Writing on Gene Therapy for the lay reader
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First of all the word « media » encompass a whole range of type of news vehicles of very different quality standards. I will refer to the stadards that Le Monde promotes and by which I abide.

Gene therapy is a more than 15 years old story. Talking about story this is definitely a geaat one from a media point of view. With its very simple and logical basis that one could sum up in one sentence the concept is brilliant, smart, looking towards the future and potentially a breakthrough in therapeutics for life threatening diseases. This is amjor reason why medias were at once utmostly keen to write and talk about it.

From its first steps gene therapy was seen as a would be peak in the revolution that molecular biology has launched and the highest achievement of the period opened with the uncovering of DNA structure and the discovery of the genetic code. This could be as great a milestone as antibiotics were the highest peak of the Pasteurian revolution and heart transplantation was in the history of surgery.

On the eve of the first gene therapy performed by French Anderson and Michael Blaese on Friday 14 septembrer 1990, three days after FDA gave a green light, Le Monde published and article focussed on Franch Anderson. The article mentionned his « visionary paper entitled “Modifying gene defects” [*translated from the french*] proposed 22 years ago to the prestigious New England Journal of Medicine » and stressed that « if he succeeds » this would be « a new chapter in the history of medicine ». As the numerous following papers in Le Monde, even with a caveat and the conditional tense, the tone was rather enthusiastic. For instance in the 19 february 1993 edition of Le Monde one could read : « It seems that with a prodigious quickness, thanks to the help of the techniques of molecular biology and the concepts of gene therapy, we are getting close to the time when we can hope curing so far uncurable hereditary diseases. »

Looking back we can understand this enthusiasm and assume that we would have been on the same wavelength. A lot is at stake. Gene therapy combines the most advanced scientific researches, very serious diseases belonging to a wide range (enzymatic defects, myopathy, cancer, aids, cardiovascular diseases, a.o.), human dramas, major economic decisions.

However we would all agree in saying that of all the promises made by gene therapy pioneers very few were fulfilled. A great disappointment after those great expectations both on a scientific and on a social levels, promoted in France by associations like the French Association against Myopathies (AFM) and amplified by the medias.

We can see how gene therapy is a perfect example of thrilling but also hard to cope with topics.

A journalist writing on this kind of issues has to combine scientific requisites of rigour (from peer-reviewed publications basis to including ethical issues) and resisting the tide of pressure both from his hierarchy and from himself or herself (publishing a scoop or at least not being late in coverage). Notwithstanding writing with pedagogy in mind.

Ethical issues have been raised very early about gene therapy. Not only germinal gene therapy has been rejected from the inception but the issue of access to treatment and the geographical distribution of the people affected by the diseases gene therapy could cure were featured in Le Monde columns.

Gene therapy raise the issue of the obvious responsibility and duties of the medias by their readers and listeners. There is a whole ring of actors in that field including researchers and their institutions, affected individuals and their caregivers, associations, medias, a.o. So no one is innocent or the only one to blame for what goes wrong.

I have to say that journalists are often their own best enemy for several reasons. One is the issue of competence. Neither journalists nor researchers are able to encompass the whole spectrum of medical and scientific knowledge. But competence is also a matter of keeping up to date and not to rely on one source of information only. Keeping a critical mind may be hard but that is the only way to keep up with the standards.

Obviously and gene therapy is by no way an exception what is needed is the greatest possible transparency about what is the present stage what has been done and what is left to discover, the importance and the limits of an experimental gene therapy. I have to underline the remarkable way Pr Alain Fischer and Pr Marina Cavazzana-Calvo behaved when their so far successful treatment of ten children suffering from a complete immune deficiency was darkened by serious side effects in two children.

This transparency is needed because a lot is at stake including financial interests and we know that stock exchanges and investors are very media sensitive.

Lastly - and once again gene therapy is no exception - all the issues raised can also be found in other topics. We can already see it with stem cells. Even if the balance sheet of gene therapy is still weak one of its greatest contributions are the lessons medias can draw from it : a critical enthusiasm is needed and we must put all stakes in the open light. Our readers and listeners deserve it.