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THE TELETHON :
SHOWING THE BEST OF OURSELVES

by

Pierre BIRAMBEAU
Co-founder and director of the French Telethon (1987 – 2001)

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Overview

In 1977, Pierre Birambeau was an entrepreneur in charge of an industrial foundry when he discovered that one of this two sons had muscular dystrophy. He discovered the *Association française contre la myopathie* (AFM) founded by Bernard Barataud which escalated as a result of their joint efforts. Faced with the inertia of medical authorities who offered no hope of curing the disease, and motivated by a belief that there might be future genetic progress, he and his family left for New York in August 1986 to learn about the Telethon, in the country where Jerry Lewis' funny faces for charity had been transformed into millions of dollars. In 1987, he adapted and launched the US Telethon in France with instant, wide-ranging and growing success. Helped by donations resulting from the Telethon, the AFM was able to stimulate medical advances in deciphering the human genome. What was the original motivation for this extraordinary story ? What lessons can be drawn from it in the management of associations in general ?

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TALK : Pierre BIRAMBEAU

In 1978 my wife and I became aware of the diagnosis in our second son, Damien. We had been worried by his faltering walk and the fact that he could not climb stairs. The doctor said *« Your son has a genetic disorder which is progressive. At around the age of ten, he will not be able to walk any more. At eighteen, he will be bedridden. Don't grow too fond of him because he won't survive beyond the age of twenty. »* When we heard this prognosis, we felt utterly isolated. Despite having very supportive friends, we felt as if we had been rejected by the rest of the world.

Discovering the AFM

I was the Chairman and Managing director of a factory which produced aluminium and I knew nothing about the world of associations. As far as I was concerned, associations brought together people who talked a lot, were not very efficient, and were only good at crying together. However, a few weeks after our son's diagnosis had been made, I met several members of the *Association française contre la myopathie* (AFM : the French Myopathy Association), and in particular its founder Bernard Barataud. I met people who were dynamic, who already knew how to organise themselves, and who showed a potential which seemed to me remarkable by comparison with what I had experienced in my own company.

The association was the result of a separation from a larger association which was also called AFM and which was based in Angers. The two associations adopted very different attitudes. The Angers association accepted the disease and tried hard to improve the organisation of the patient's life as much as possible. By contrast, together with Bernard Barataud we were more proactive : we refused just to accept the disease and its inevitable outcome and believed that the only solution was to promote research.

Three months later, we had taken over the Angers association. The determination of a number of parents not to accept the disease had prevailed over the inertia of an association, which although it had good intentions did not know how to cope with the situation or to understand what needed to be done.

With the help of a consultant, we defined in three words the actions which we wanted to take : to refuse, to resist, and to cure. To refuse to accept the disease ; to resist it by taking certain procedures which can try to halt the disease (such as massages, moral support, and later on even surgery and tracheotomies) ; to cure it by rejecting acceptance of the disease which removes hope of recovery.

It did not take long to bear out Margaret Mead's saying *« Never doubt that a small group of thoughtful, committed citizens can change the world ; indeed, it is the only thing that ever has. »*

Obstacles to be overcome

The first obstacle which we had to overcome was cultural. In France, there is a great deal of respect for institutions. If we are horrified by a disease, each individual handles it differently and this is not always efficient, but nobody casts doubt on doctors, researchers, public health officials and even heads of pharmaceutical companies.

Obstacles are also material constraints. Looking after a child with muscular dystrophy demands a huge amount of energy and time and it is difficult to be militant at the same time. You are constantly subjected to minor incidents of everyday life such as a wheelchair tyre puncture, or to problems in the outside world. For example, in my son's school which has a reputation for its advanced teaching methods, even handicapped students were not allowed to use the lift. I remember writing an open letter to the head teacher : *« I hope that the use of the* *school lift which handicapped children are not allowed to use will give rise to fruitful exchanges with the teachers with regards to the innovative and social character of teaching at this school. »*

When you suffer from a less serious form of the disease than Damien has, and you reach the age of eighteen, you only have a very small State allowance. If you do not have the financial means necessary to pay for numerous pieces of equipment as well as paying for people whom you need for day-long help, then you have to be contented with living about half-an-hour per day.

The last obstacle to be overcome is the ignorance regarding the subject. When we started out, we knew nothing about the kind of research which was being carried out in this disorder or whether any new drugs were being developed. We were overjoyed whenever a new drug appeared. In the beginning, each one of us was seduced by complementary medicine, and we were strung along by the promises of doctors who genuinely thought they had found a miracle solution.

Looking for allies

In the face of with these obstacles, we looked for supporters. Bernard Barataud turned to Simone Veil, the Health Minister at that time, who advised us to talk to François Gros, the director of the Institut Pasteur. I met Jean Frezal, the director of genetics at the *Hôpital Necker des enfants malades* ; Jérôme Lejeune, in charge of Down's Syndrome research ; and André Hennequé, in charge of Cystic Fibrosis research . We also contacted Michel Fardeau who was the only person who had carried out significant research into muscular dystrophy at that time and who told us : *« Of course I would be delighted to find a cure, but before getting there, we have to start by classifying the disorders because there are dozens of them. »*

Gradually we were able to build up a scientific board which included some of these specialists. Initially, they encouraged us out of sympathy, since we had no means whatsoever – and perhaps also because they understood that to make progress in research into these diseases, they needed to be able to turn to a patient association which had some sort of structure and which brought together the 'raw materials', in other words, a group of patients who have the same pathology.

Today, all decisions taken by the AFM have been discussed beforehand by this scientific board. In particular, no financial programme has been launched without the guarantee of the board first.

Adopting a role

As time went by we acquired more knowledge and defined our field of work. We are interested in muscular dystrophy disorders ranging from Duchenne's muscular dystrophy (the disease which Damien has), to motor neurone diseases affecting the spinal cord, for example spinal muscular atrophy. Between these two diseases, there are all the diseases concerned with the neuromuscular junction.

We could have limited ourselves to just one disease, such as Duchenne's muscular dystrophy, as is usually the case in other countries, we decided to deal with several disorders in order to reach a sufficient critical mass and also to benefit from connections which may exist between them.

In our capacity as an association for the handicapped, we were also involved with WHO (World Health Organisation) programmes. An individual may be handicapped either as a result of a genetic disorder or because of a quadriplegia following an accident. The genetic disorder may result in a protein deficiency causing malfunction of the muscles with a resultant disability such as loss of mobility or sight. This disability may result in a problem if society does not meet its needs. Each stage corresponds to a certain form of action : fundamental research into the disorders ; medical care for disabilities ; compensation of functions for inability ; social integration for the handicapped.

We decided that one of our priorities was fundamental research, but this had its difficulties because the existence and the role of genes was not very well known at that time. When articles were to be published, the media systematically refused the term ‘gene’ in the title because they thought the publication would not sell.

Learning

When one wants to develop this type of project, one has a great deal to learn. For example, one might think that there is nothing simpler than recruiting volunteers. In fact, it is quite complicated…. recruiting an employee, when one has very few resources, is also taking a risk.

It is very difficult to raise funds. It is a job which most people do not want to do. Attempting to establish partnerships with companies is also relatively difficult. The world of associations is afraid of being judged by the business world which is supposed to function according to stricter rules – and vice versa. In addition, associations are frequently obsessed by fund-raising rather than strategy.

The last crucial thing that has to be learned is communication. Most associations do not try to communicate, either because the idea has not crossed their minds, or because they think that what they have to say is not very interesting, or because they do not know how to do so. When we got an article published in the *Figaro Magazine* or were given two minutes' airtime on France 2 television news, we were delighted until we realised that such publicity did not amount to very much apart from pleasing our members, without running a complementary campaign.

Birth of the Telethon

We had heard about the Telethon, an unusual event organised very year in the United States. It was televised and during it one could see Jerry Lewis’ funny faces, Liz Taylor’s charm, an accumulator board, and commentators who kept repeating *« another record, the best ever. »* We managed to persuade Jerry Lewis to come to France to explain what it was all about but we still needed something to launch it in France.

What triggered the launch was the discovery of the Duchenne dystrophy gene by Louis Kunkel’s team in Boston in September 1986. This discovery was the result of the work of about twenty teams throughout the world, including three French teams whom we supported. The method could be used for other genetic diseases. Bernard Barataud had a premonition that we were going to need a great deal of money and that our charity sales, our postcards, and the generosity of our friends was not going to be enough. We would have to have a budget totalling several hundred million Euros.

I took my family to the United States to meet the American association which explained to us how the Telethon worked. It was not very complicated. The most important thing was to catch the American bug, in other words, to see things on a large, or even very large scale straightaway : not to think twice about innumerable press releases, huge quantities of targeted mail, important partnerships, in other words, not to have any inhibitions.

To establish the French Telethon, the board of directors agreed to take a big risk which was to free Bernard Barataud and myself from our professional obligations for a year so that we could devote ourselves entirely to this task. It was fundamental : numerous projects of associations never see the light of day simply because those involved are not readily available.

Then a sort of initiation course began : we contacted Antenne 2 and we were sent from one person to another without ever seeing the people in charge. Sometimes, the door was closed in our faces but we found a way in through the window. What was essential was that they got used to seeing us, and that we made our presence felt. At the same time, we met our sponsors. We pulled a fast one on both sides, by telling Antenne 2 that we had sponsors, and telling our sponsors that we had Antenne 2. This is how we got both of them.

Negotiations with Antenne 2 were long and complex. The media has a ‘scoop’ culture and our only scoop was that our children were going to die. They deal with subjects very quickly and superficially, whereas our disorders and the research carried out are extremely complex. Antenne 2 wanted to use its own hosts while we wanted hosts capable of explaining the problems. The station refused to change its programme layout because it was worried about losing its audience accustomed to the usual programme planning. By contrast, we wanted the Telethon to disrupt the whole of the normal programming. We dealt with this situation by convincing the station programmers that it was their idea to stage the Telethon and not ours, and they were happy because they had the last say.

From the very beginning, the results were spectacular : one million donations worth one hundred and eighty million Francs, and the approval of almost all the media… but there was also a lot of criticism. We were always aware of an extremely deep conviction which most of us held, that it is normal and acceptable to fail, and not to succeed. This criticism took various forms : *« Why are you asking the French people for money, when they already have to pay so many taxes ? Why so much money for such a rare disorder ? With your kids in wheelchairs, it is easy for you to gather lots of money ; it is more difficult when the patients are old or when they have Aids. »* We were also blamed for disrupting the strategy of the State’s research, which presupposed that there already was a strategy…

Patient power

We were greatly inspired by Michel Callon’s book *Le pouvoir des malades* (The power of patients). We learnt how to make our presence felt in scientific board meetings. Our presence significantly changed the ways problems were approached because even if doctors have unimpeachable values, they have their own network of friends and rivals just like any other profession. We explained to them that it was not a case of favouring such-and-such a person but identifying the research areas which were most important in advancing our project. In the same way, we organised conferences which brought together a mixture of research workers, doctors and patients which was quite innovative at that time.

We also had to be very firm with the State because public authorities are tempted to recover the money when an association succeeds in its objectives. Finally, we also had to be very firm with our industrial partners : other associations had been careless enough to have made themselves too dependent on pharmaceutical laboratories.

The results

As a result of the Telethon’s success, we came into contact with Nobel Prize winners Jean Dausset and Daniel Cohen who had launched the idea of mapping the human genome. We had realised that five years was necessary to isolate the gene from Duchenne’s muscular dystrophy and that in view of the existence of dozens of different neuromuscular disorders, many years would be necessary to get a result. It seemed more logical to proceed in a systematic way by identifying the genome. Therefore, we decided to invest enormous sums of money in creating the Genethon, the AFM’s laboratory.

The human genome map

The result lived up to our expectations : we published the genome map five years ahead of schedule. By gathering DNA samples from our members who had been classified according to their clinical signs, we were able to identify more than six hundred genes responsible for genetic disorders as a result of this map. We used this for a new form of research called inverse genetics, which depends on original causes and not consequences, and is based on automation.

It was a major advance in establishing the diagnosis. Before that time, families sometimes had to consult a dozen or more specialists before a diagnosis was made and even then it was often wrong and labelled as a mental disorder whereas it was actually a physical problem.

From 1992 onwards, this research also resulted in thousands of pregnancies going to full term because antenatal diagnosis was accurately established, and consequently unnecessary abortions were avoided.

The Genethon

The Genethon was able to adapt itself to various kinds of research. Having started out as a means of mapping the genome, it became a way of identifying genes and subsequently a method of finding the carriers of the genes to enable gene therapy to take place.

In the last few weeks, the Genethon team has carried out trials in mice with Duchenne’s muscular dystrophy called 'exon skipping'. Throughout our involvement, we had a great number of disappointments but this time, it would appear that we have come across something which is extremely promising.

We have also created a unique study of muscle problems. Muscles of patients are compared to sportsmen’s and old people’s muscles in order to complete a genetic method using a pathological study of muscles.

The Genopole®

The Telethon has enabled us to finance the creation of the Evry Genopole® which includes both public and private laboratories, a business ‘incubator’ park, about sixty biotech companies, etc.. This initiative has undoubtedly contributed to keeping France in the biotechnology race, even if the United States, the United Kingdom and Germany are still clearly in the lead.

Medical and social results

In all our departments, we have set up regional help and information services permitting an interface between patients and medicine and also between patients, society, work and leisure. These services help patients achieve their objectives and allow them to express their aims, which hitherto they had suppressed subconsciously. This part of AFM’s activity is much less spectacular than the Genethon, but plays a key role : many other patient associations today would like to create these sorts of networks.

There has been huge progress in patient life expectancy and quality of life. Today, Damien, who was forecast not to survive beyond the age of twenty, is thirty-two years old and is in remarkably good health. He is trained in computer graphics, has created a multimedia association and is developing a wide range of activities and a long list of social contacts. He has managed to reverse a fatalistic viewpoint expressed in the following sentence : *« With muscular dystrophy, nothing good can happen to you : each day is worse than the day before, and tomorrow is worse than the previous day. »* Of course, Damien continues to get weaker and he can only just about move two fingers. He is fed through a gastrostomy, he has a tracheostomy which allows him to breathe, and he had an operation on his spine to prevent him having a scoliosis. However, each day he continues to make progress in his activities and I am not sure that there are many men over thirty who manage to achieve as much as he does.

Effects on other diseases

Neuromuscular disorders are a mere drop in the ocean compared with the other six thousand genetically identified disorders – and each day more disorders are discovered. Over the years, we have adopted a strategy of supporting research into rare diseases. We did not aim to cure them all, because we would have been unable to do so, but we have identified those disorders which had the greatest chances of developing rapid treatment. This is how, in 2000, we were able to treat about fifteen "bubble-babies" (immunodeficient babies kept in sterile environments) who were terminally ill and were saved. For three of them, genetic therapy caused a cancer which killed one of them. This first implementation of treatment however showed the feasibility of genetic therapy.

We also went further afield in Europe, by creating an association, the European rare disorders organisation devoted to orphan drugs in partnership with Aides, the Cancer League and the Association for Cystic Fibrosis. In combining our efforts, we managed to manufacture several dozen drugs for a number of rare diseases.

Spreading good practices

Today the AFM serves forty thousand patients. It employs five hundred people and has two thousand volunteers. Having seen it in action, as well as other associations for rare diseases, both French and American, I have come to the same conclusion as Michel Callon, namely that associations are called on to play an increasingly fundamental role. This role depends in particular on the efforts of the volunteers. If one puts the activities of volunteers in France into numbers, it represents seven times the sum of two-and-a-half billion Euros which the French give each year to all charities combined. However, the real role of associations is the quality of their organisation : if the organisation is inefficient, the power which patients can exercise is quite simply reduced to nothing.

In the United States, from local school level right up to Harvard, there is teaching on philanthropy, in other words non-profit making activities. A great number of consultants, either volunteers or not, help associations, their volunteers and their employees to be trained to know how to choose an administrator, how to choose a president, how to make a board of directors work efficiently, etc.

In France, none of this exists. There are books on how to create an association, the financial considerations and legal aspects, but nothing about the management of an association, whether it be in terms of developing a strategy, the management of volunteers, communication skills or raising funds. This is why, in partnership with the École des mines which provides links between companies and associations (health, ecology, social issues), we created a training unit concerned with the management of associations this year, for an audience made up of employees and volunteers working for associations, and even students and executives in companies who want to move towards non-profit making activities.

DISCUSSION

Therapy or prevention ?

Question : *Given that your work extends over a protracted timescale, do not the results from genetic therapy come too late, because meanwhile it should have been possible to prevent the births of children affected by this disorder ?*

Pierre Birambeau : It is true that genetic advice means avoiding a number of pregnancies but in Duchenne muscular dystrophy for example, the spontaneous mutation rate is 30 % ; and in these cases the disease is totally unpredictable. Developing treatment consequently remains essential. In addition there are all the children who remain alive and whom we want to cure !

Q. : *How long before you hope to have the first real cures ?*

P. B. : The axon skipping method is extremely encouraging even if it is just a case of repairing, but not healing the disease process. As a result of the progress which we have made, we acquire information which expands our database, and are better prepared for the next phase. Therefore, there should be progress towards a definitive result. The knowledge we acquire augments the scientific experiments on all genetic disorders.

Relations with the medical world

Q. : *How did you manage to make doctors and research workers accept the fact that you were interfering in their work ?*

P. B. : Initially we were appalled by the lack of enthusiasm from doctors and research workers who did not want to join us. Then we realised that despite such opposition there were some positive elements and that arrogance was not always the best solution. Gradually we learned to co-operate without losing sight of our objective of highlighting patients' needs. It was a question of human relationships which called for both humility and strength. Our progress depended on the personality of the person who was chosen to take part in scientific meetings…

Q. : *Your approach is revolutionary. You have put the patient back at the centre of medical affairs. Compare it with putting a child into the centre of the educational system, as is frequently talked about, but which has never happened…*

Q. : *As a research worker, I can confirm that initially research workers who worked for you were afraid that that you were going to make them concentrate on a specific disorder whereas this was not the most efficient approach. In fact, as you described, one had to begin by deciphering the human genome. Later on, the margin of freedom which you left them was greatly appreciated.*

P. B. : We quickly realised that if we did not protect their freedom of action, they would not be efficient. We are always looking for a compromise between taking into account the subjects which interest us, and respecting this freedom. For example, the establishment of the genome made research workers agree to take part in "*bio-medical research*", in other words, processes which are extremely automated as in industry and the opposite of "traditional" methods of research. The same is true of the manufacture of new vectors: the industrial aspect takes up more and more space.

Q. : *But in order to develop axon skipping, you resorted to "traditional" methods !*

P. B. : Of course, but this discovery was only possible because we invested a huge amount of money in vector research contrary to the advice of many experts. Some of them, even a few weeks ago, thought that it was a bad investment.

Settling for the long term

Q. : *How did you manage to persuade your members to undertake fundamental research rather than to concentrate on a specific disorder ?*

P. B. : Of every one hundred Euros collected as a result of the Telethon, eighty Euros goes towards projects and twenty to bureaucratic costs. Of the amount which goes into projects, 60 % goes towards research and 40 % is invested towards improving people's lives and medical practice. Something which has always surprised me is that of one thousand two hundred voters, there have always been 90 % who approve of action on a long term basis. This outcome was supported by the "hard core, founding members" from the beginning and is ongoing. One should also mention that long-term action allows us to keep our hopes alive and gives patients hope too, something which they really need. On the other hand, since they are very anxious to receive treatment and since we handle one hundred and twenty different disorders, there is a sort of rivalry between their different representatives who would like to see their disorder being treated first.

Q. : *How do you cope with the anxiety and frustration of people who have to miss their turn ?*

P. B. : One of the secrets which Michel Callon talks about is standardising procedures, starting with writing up the minutes of board meetings which are proof that decisions have been taken. It seems hard to believe but nine out of ten associations do not hold board meetings and those which do, dash off the minutes in no time or do not take minutes at all.

Technical assistance

Q. : *Why do you not try to breathe new life into other sectors of research which might benefit other patients ? Your son has a tracheostomy and undoubtedly needs very powerful batteries. If work had been carried out to make progress in this field, as with other electrical devices, this might bring huge additional comfort immediately to quadriplegics. It is often these little improvements to daily life which are most important for handicapped people. Why not develop, next to your company incubator in the Genethon, a breeding ground for companies to develop technologies for handicaps in general ?*

P. B. : According to our statutes, we are responsible for our children and for them alone. If we tackle other diseases, this is only possible if the approach is part of a research logic similar to that of our own disorders. It is always much more efficient to concentrate one's energy rather than to dilute it. The right degree of concentration or dilution is debatable but in any case one should avoid finding oneself in the situation in which the French state finds itself when it is faced with six thousand genetically different disorders, and is forced to adopt an egalitarian policy, and consequently cannot do very much.

On the other hand, some of the progress we have made for our patients benefit everyone. For example, when one of our regional centres is allowed to build a lift in a public establishment, all the handicapped people can benefit from it.

In fact, we have already considered the idea of creating a business breeding ground for developing technical assistance. It is a very difficult industrial sector because there is a large number of small manufacturers who do not possess the capability for mass production. Our strategy consists of playing our associative role as a consumer : we let the manufacturers know what works and what does not, what is desirable, and what is not etc. From time to time, we finance a prototype, without going any further. But it is an excellent idea which might one day be developed by us or by someone else. We remain very keen on the idea of giving priority to research : if we were to abandon the hope which research give us, patients would lose heart, doctors and paramedics would give up, and even in daily life things would not work nearly so well.

The transfer of power in the association

Q. : *How will the transfer of power take place ?*

P. B. : We have one sacrosanct rule : the AFM board of directors is made up exclusively of parents of children with muscular dystrophies or of affected adults who normally make sure that the spirit and principles of the AFM are respected. However, the board of directors is elected at the general meeting by people from very diverse backgrounds, and two years ago, the board lost its majority.

Bernard Barataud created a strict democracy which was very efficient – it was he who devised the project of establishing the genome map – but his succession posed a problem. We found a young woman who embodies our values and today things are going very well. Having said that, it is normal for there to be ups and downs. In truth, it will always be very difficult to ensure the survival of a non-profit making company whose aim is to cure incurable diseases.

Recruiting senior executives is a tricky problem, and this is still carried out mostly externally. We would like to recruit internally, but clearly we have not managed to train people adequately within the association. Some jobs are particularly difficult to fill, for example that of scientific director which involves liaising with university research workers, biotechnological companies and patients. Being in charge of medical and social affairs is another job which is very delicate : the candidate should understand the nature of our disorders and he should know how to lobby. With regards to my own job, one should know how to negotiate with France 2 (national television channel), find sponsors, and manage about thirty people while at the same time preserving the values of the association.

However, I am confident : despite all the difficulties, that everything has worked out amazingly well, most likely because we devised a very sound strategy.

Will the Telethon's fundraising be able to last ?

Q. : *Over the past fifteen years, apart from one or two years, the Telethon has collected more money each year than the year before. This is far from the case with other organisations which take part in fund raising. To what do you attribute this continuing success ? Do you think it will last ?*

P. B. : When one sees what has happened to other Telethons abroad, one may well start worrying. In the US, the Telethon is no more than a vehicle to publicise its sponsors and to collect money, perhaps because Jerry Lewis is increasingly handicapped and it is not easy to replace him. In Canada, where there have been as many as ten or fifteen different telethons at one time, there now is only one and it is not very important. What enabled the French telethons to keep going are undoubtedly the results we obtained during favourable years in the past and again this year with the axon skipping. However, people have to understand that research makes advances every year. Research is based on laborious, difficult and unrewarding work. We try to give research workers a voice so that they can explain how they work, but France 2 is worried that people will change channels if the Telethon takes a scientific turn. Therefore, we also have to use other forms of the media…

It is a fact that currently the donations given by telephone are levelling off and conversely there is an increase in the amount of money collected in person, via the twenty thousand events organised on the same day throughout France. I think that what is important is not only to collect money like the Americans, but to collect money giving it added meaning by going to talk to people, explaining to them what we do, and also organising this collection around a festive theme. The biggest change in the Telethon by comparison with how we started is our organisation in the field. In the early days, volunteers who organised the events in each *département* worked alone despite a huge workload. Today, they work in teams, they are trained, and gradually we have welcomed volunteers who were formerly sales managers, for example, and are fully able to do this type of work.

Q. : *Do you not think that with this festive dimension you are losing the meaning of the work which you do ?*

Q. : *In an previous session of the* École de Paris*, one of the founders of the association* Restos du cœur *explained why the festive dimension was very important : when one is involved in charity appeals, one humiliates the person to whom one donates the money. In order to give without humiliating someone, one has to use an event which creates a certain symmetry between people.*

Q. : *The Telethon may appear to be a big piggy-bank, but in reality, it is something which makes sense because it develops a link between all those who take part ; the patients, the donors, the organisers, and the people who surpass themselves in the field to achieve exceptional results. Imagine what is going through the head of a fireman who is climbing his ladder very quickly or the artist who is tightrope walking between two buildings for charity : they are giving something of themselves to the patient who is seen live in the television studio. It is this self-sacrifice which for me is characteristic of the Telethon and explains its success.*

P. B. : This is undoubtedly the main reason but it is not the only one. The quality of the organisation has a great deal of importance as well. Additionally, it is much easier to get sponsors to support a festive event than simply collecting money.

Dealing with important topics

Q. : *One day Pierre Birambeau told me about his son and assured me that his son was happy. I thought this could not possibly be true in view of the disease he had. Later on, I was lucky enough to meet Damien and I can say that when I saw this boy's beauty and the light in his eyes, I instantly realised that it was true, that he was really happy. As far as I can see, this is the most extraordinary success that you and your wife have achieved.*

Q. : *Your experience reminds me of Saint-Exupéry's* Le Petit Prince*. The pilot is busy repairing his aeroplane and sent the Petit Prince, worried about whether the sheep will eat the rose, packing :* « You can see that I am busy with important things ! – But what is more important than my rose ? »*, replies the Petit Prince. You devote your time and your energy to a field – voluntary work or more broadly speaking non-economic activities – which generally speaking are regarded as secondary and yet take up a much greater part of our lives than 'true' economic activities. Therefore, you are a pioneer of the moment identified by Keynes, when we will have developed the economy to such an extent that it will become trivial and will be no more than the handmaid of what really has some meaning.*

Q. : *Despite it all, you have indicated that the creation of the Genethon and the Genopole® enabled France to stay in the biotechnology race. Can you assess the economic consequences of your work ?Is there not a risk that these consequences interfere with your work ?*

P. B. : In the beginning, one of Bernard Barataud's key phrases was *« If things continue like this, we will end up paying for our medicine in dollars in order to care for the French unemployed. »* It is a fact that we have made an important economic contribution, not least the two thousand jobs created by the Genopole®, which should soon increase. My belief is that any strategy involving quality should have economic consequences. However, economic development should only be a by-product of our strategy. If we become merely administrators of these jobs, we run the risk of forgetting our original mission which is to save the lives of our patients.

Presentation of the speaker :

Pierre Birambeau : graduate of the École supérieure de commerce de Paris (ESCP). Today, he develops, in partnership with the École des mines, the *Unités de formation au management des associations* (UMA : Training units for managing associations) which are aimed at people in charge of companies and associations. He was Chairman and Managing Director of an aluminium foundry and then co-founder and director of the French Telethon from 1987 to 2001. He is the author of *Téléthon, le meilleur de nous-mêmes* (published by Balland, 2003).

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