

« Philanthropic Foundations and Medical Research in France » by Nicolas Truffinet

This paper is the presentation of an ongoing PhD in Economic History (Paris I - Pantheon Sorbonne University, IDHES). It is a work in progress and should be considered as such. It is not for publication at this stage (rather for internal use, for the listeners at the conference), but a final version will be elaborated eventually.

Introduction

American philanthropic foundations are starting to get a well-deserved attention in France, in the academic world: Pr Olivier Zunz published *Philanthropy in America: A History* (2011) and the author of this paper dedicated his Master's degree to this question. French organizations did not raise the same interest so far. Indeed their economic weight is not the same, which makes them less impressive at first glance. It is often said that France remains less incitative to non-profits than most of its neighbours, because of a conception of general interest that excludes private actors and a lack of trust for anything that looks closely or remotely similar to a corporation.

Though a bit unfair to all the associations who work in the territory, this statement highlights the traditional weakness of the foundations. Important legislative acts were adopted though, which significantly helped them to grow, particularly in the health sector where the needs are important in matter of care, but also research.

What is, what can be the place of the non-profits compared to the public sector on the one side, the for-profit private sector on the other side ? In the field of medical research: what role do the philanthropic foundations play, next to public bodies (Inserm, teaching hospitals, centers of research against cancer) and pharmaceutical companies, and how have they evolved for the past 20 or 30 years ?

First, we will observe that an important legislative activity took place in the last 20 years, creating new incentives, new instruments, that undeniably helped the sector to grow (I). Secondly, we will describe the philanthropic organizations: foundations and funds active in the field of medical research: how many they are, how much they spend, how they work (II). Thirdly we will present one organization in particular: La Fondation Motrice, dedicated to Cerebral Palsy, as a case study (III). Finally we will ask how internationalised, how worldwide the sector is today (IV).

I-

Philanthropic foundations find their roots in the medieval congregations that developed for charitable purposes (helping the poor and the sick), then the religious and secular charities of the Renaissance. The movement was interrupted during the Revolution by the Le Chapelier Law (1791), which stated the monopoly of the State on all general interest activities and dissolved other charitable institutions. A new dynamic started at the end of the 19th century, when the Pasteur Institute was created (1887), followed by others (Fondation Thiers, 1893, Rothschild, 1904...). To a large extent, they remained isolated initiatives though. Only at the end of the 1960s, when President De Gaulle and his secretary André Malraux decided the creation of the Fondation de France to bring together and promote philanthropic organizations, did we observe the emergence of consistent policies in their favor.

Things accelerate at the end of the 1980s with the Léotard Law (1987), which clarifies the foundations' status and starts raising tax deductions for the donators. The Aillagon Law on

patronage, associations and foundations, voted in 2003, increases the advantages for individuals as well as businesses. Its main features are as follows:

- for businesses (Art. 238 bis, FTC): corporate income tax reduction equal to 60% of the amount of gifts (in cash or in kind) made to “general interest” bodies or charities, subject to an annual giving limit of 0.5% of the company’s turnover. If the limit is surpassed, the business has five fiscal years in which to use its tax reduction.
- for individuals (Art. 200, FTC): individual income tax reduction at the rate of 66% of the amount of any gifts made to general interest bodies or charities, subject to the limit of 20% of the donor’s taxable income, with a 5-year carry-forward possibility if the limit is surpassed.

In 2007, the TEPA Law allows individuals liable to the wealth tax ISF to deduct up to 75% of their donations to foundations.

At the same time, the number of statuses for foundations increased. Aside from the foundations recognized of public utility, the company foundations, the sheltered foundation: foundations of scientific cooperation, partenarial foundations, university foundations, endowment funds, who offer more choices to future funders. The endowment fund, in particular, is a flexible instrument, easier to create (one month, while it usually takes between one and two years for a foundation to be approved) and to handle.

Today, in matter of tax deductions, France caught up with its neighbors. For those who support philanthropy, the next goal is to reform inheritance law. Indeed for now, the rule is that most of the estate is necessarily reserved to the heir, which makes difficult for an individual with children to bequeath a significant part of his wealth to a cause. A bill was proposed to this aim in 2011, with no result so far.

Reading the transcripts of the parliamentary debates (I studied the Leotard and the Aillagon Laws in particular), a few things can be said :

- those who support these reforms are mostly centre and right-wing. They insist that general interest can express itself through private actors, and that in mater of philanthropy, France should catch up with the anglo-saxons. The left-wing socialist party recognizes that civil society should be favored, but not necessarily through tax deductions that benefit only to the wealthy. Especially in a context of budgetary discipline where a number of associations, because of decreased public subventions, are put in a difficult position.
- The debates are generally very theoretical, about principles rather than fieldwork. Many representants have a vague knowledge of philanthropy, that they confuse with patronage. They sometimes seem to believe that it is exclusively about culture and arts, with no regard for the foundations' role in other fields, like research.
- Comparing the debates in 1987 and 2003, one cannot help but noticing that a consensus is building nonetheless. In 1987, the left-wing was afraid that favoring philanthropic institutions might lead to public disengagement. In 2003, it agrees that non-profits have a role to play. At the same time, the anti-statist speeches of the right under the influence of Thatcher or Reagan disappeared and Jean-Jacques Aillagon, a centrist, repeatedly re-affirmed that he didn't want less state. The discussion was mostly about the budgetary context.

II-

In 2015, there exist around 4000 funds and foundations. They were only 1100 in 2000 and 2200 in 2010. The creation of the endowment fund in 2008 explains that in part. Looking at the number of foundations only, we still find that the number doubled in 15 years.

In medical research, after an investigation of my own, I found 141 foundations (almost half being sheltered foundations) and 85 funds.

I started investigating the foundations recognized of public utility (fondations reconnues d'utilité publique, or FRUP), excluding the institutes, the Pasteur Institute in particular, who does have the juridical status of a FRUP, but shows many specificities. Its research budget: 160 million euros, is more important than all the others combined. It has important links with the state and almost functions like a public institution in many regards, for instance by taking part in public service missions like disease detection or vaccination. It also contributes to the production of vaccines, in relation with private for-profit companies. Including the institute in our sample would generate a bias, leading to non-representative results. The same is true, to a lesser extent, of the Curie Institute, the Brain and Spinal Chord Institute...

Thus the following results will be on 35 organizations. The list below, by reverse chronological order:

Fondation ophtalmologique Adolphe de Rothschild (1909)
Fondation pour la recherche médicale (1965)
Fondation nationale de gérontologie (1967)
Fondation Josette Day Solvay (1973)
Fondation Mérieux (1976)
Fondation Bettencourt Schueller (1987)
Fondation de l'avenir pour la recherche médicale appliquée (1988)
Fondation Lucien Dreyfuss (1989)
Fondation Fourmentin Guilbert (1990)
Fondation française pour la recherche sur l'épilepsie (1991)
Fondation Martine Midy (1991)
Fondation René Touraine pour la recherche en dermatologie (1991)
Fondation Jean Dausset CEPH (1993)
Fondation Jérôme Lejeune (1996)
Fondation Leducq (1996)
Fondation Renaud Febvre (1999)
Fondation Apicil (2004)
Fondation ELA (2004)
Fondation cœur et artères (2005)
Fondation Thérèse et René Planiol pour l'étude du cerveau (2005)
Fondation ARCAD (2006)
Fondation Arthritis (2006)
Fondation motrice (2006)
Fondation de recherche sur l'hypertension artérielle (2006)
Fondation Toulouse Cancer Santé (2006)
Fondation Pierre Deniker pour la santé mentale (2007)
Fondation Digest Science (2008)
Fondation ARSEP (2010)
Fondation cœur et recherche (2010)
Fondation Raymond Tourre pour la recherche fondamentale contre le cancer (2010)
Fondation internationale de la recherche appliquée sur le handicap (2011)

Fondation du souffle (2011)
Fondation Arc pour la recherche sur le cancer (2012)
Fondation AVEC (2013)
Fondation francophone pour la recherche sur le diabète (2013)

The first thing to notice is the sector's youth. On the 35, 5 were created after 2011, 10 between 2006 and 2010, 4 between 2001 and 2005. So more than half are less than 15 years old.

Regarding their economic weight, one thing I wanted to find was their research budget. For the year 2013 (for a start). Looking at their annual reports, I was able to find the numbers for 28 (on 35) organizations. In euros:

Fondation ophtalmologique Adolphe de Rothschild: ?
Fondation pour la recherche médicale (1965): 37 368 389
Fondation nationale de gérontologie: ?
Fondation Josette Day Solvay: ?
Fondation Mérieux: 5 713 000
Fondation Bettencourt Schueller: 9 600 000
Fondation de l'avenir pour la recherche médicale appliquée: 1 475 000
Fondation Lucien Dreyfuss: ?
Fondation Fourmentin Guilbert: 100 000
Fondation française pour la recherche sur l'épilepsie: 195 249
Fondation Martine Midy: ?
Fondation René Touraine pour la recherche en dermatologie: 45 000 (2012)*
Fondation Jean Dausset CEPH: 4 683 903
Fondation Jérôme Lejeune : 3 832 000 (2012) *
Fondation Leducq : 16 503 890
Fondation Renaud Febvre: ?
Fondation Apicil: 891 665 (2012) *
Fondation ELA: 1 727 729 (2012) *
Fondation cœur et artères: 448 363 (2012) *
Fondation Thérèse et René Planiol pour l'étude du cerveau: 60 000
Fondation ARCAD: 630 800
Fondation Arthritis: 507 621
Fondation motrice: 216 000
Fondation de recherche sur l'hypertension artérielle: 317 177
Fondation Toulouse Cancer Santé: 875 000
Fondation Pierre Deniker pour la santé mentale: 113 428
Fondation Digest Science: ?
Fondation ARSEP: 1 570 282
Fondation cœur et recherche: 300 000
Fondation Raymond Tourre pour la recherche fondamentale contre le cancer: 50 000
Fondation internationale de la recherche appliquée sur le handicap: 250 000
Fondation du souffle: 111 786
Fondation Arc pour la recherche sur le cancer: 29 902 556
Fondation AVEC: 108 533
Fondation francophone pour la recherche sur le diabète: 248 000

* in a few cases, the numbers were accessible for 2012, not (yet) 2013. When there wasn't any reason to think it would be significantly different, I chose to use this number – while indicating the year of course. The purpose here (again, a work in progress) is not to be perfectly accurate, but to

give an order of magnitude.

[for 7 foundations, the number remains unknown. That can be because the foundation did not declare its budget as it should have ; is under the threshold and thus not in the obligation to declare it ; has many activities, making it difficult to isolate what goes to medical research per se. The Foundation Adolphe de Rothschild finds itself in this last situation, while the foundations Josette Day Solvay, Lucien Dreyfuss, Martine Midy are more than likely to be in the second situation... if they're not extinct, which is the case of the Fondation nationale de gérontologie (since 2013) and probably the Renaud Febvre Foundation (no website, no information).]

Overall, the 35 FRUP active in the field of medical research, not counting the institutes, had a research budget of around 115/120 millions euros for 2013. The same work must be achieved for the foundations of scientific cooperation, the company foundations, the sheltered foundations... and so on, in order to give the best possible estimate of the sector's economic weight.

As one can see, the research budgets vary significantly one foundation from another. The Foundation for Medical Research and the ARC Foundation against cancer count for more than half the total. With the Leducq, Bettencourt and Mérieux Foundations, these five represent more than three quarters.

In comparison, the Inserm itself has a research budget of about 650 million euros (and the Inserm is far from being the only public body on the field). The pharmaceutical industry spent 4.6 billion euros in 2010, 10,2% of the sales (half of that by the company Sanofi-Aventis). Indeed the order of magnitude is not the same.

Asides from the numbers, how do these foundations work ? For the most part, they are non-operative. They make do rather than do – the institutes being, here again, the exception. They have a few employees, a scientific council that launches calls for projects, reads the proposals and awards grants.

Except for a few ones, for instance the Bettencourt Foundation, they are dedicated to one disease or kind of disease in particular : Alzheimer, diabetes etc (see the list above).

III-

This third part is a case study. It describes La Fondation Motrice, created in 2006, dedicated to Cerebral Palsy. The author of this paper has a personal link, both familial and friendly, with the foundation. The aim is to give a concrete and lively picture of one organization in particular, thus giving a fair idea of many others.

Usually one creates a non-profit out of personal concern. For instance, the foundation Thierry Latran, sheltered by the Fondation de France, was created by an individual just diagnosed with Amyotrophic Lateral Sclerosis. Sometimes the disease hits a member of the family: the funder and president of La Fondation Motrice has a son suffering from Cerebral Palsy. A medicine doctor who also worked for the pharmaceutical industry, he thought that a FRUP was a good tool to raise funds and redistribute them in the form of grants to projects that tackle this issue.

For its launching, the foundation benefited from a very incentive mechanism decided by Mr François Goulard (centre-right), then secretary of research, known to be particularly in favor of private non-profit actors: for every euro brought by the funder, as start-up capital, the state would add one. Around twenty new organizations benefited from this program. That, plus all the legislation previously described (new juridical statuses, tax deductions), shows the State's new

commitment towards philanthropy.

The foundation has three, now two employees, a scientific council in charge of the calls for projects. It awards a few grants every year. Besides these annual calls, the foundation developed two important projects over time: the Pain Project, and the Pace for CP Program. Description below:

PACE FOR CP PROGRAM

PERCEPTION, ACTION, COGNITION, ENVIRONMENT FOR CEREBRAL PALSY

Considering the person as a whole to better understand Cerebral Palsy

Children development requires learning and adapting to the outside world, through the following functions:

- Perception (how they perceive their environment)
- Action (their capacities to act on it)
- Cognition (the way they treat information)

These three functions interact with each other, thus determining children psychomotor development.

Cerebral Palsy following a brain damage in the fetus, the new-born or the infant can affect each of these functions, directly or indirectly, separately, or the way they articulate one with the others, to allow everyday life gestures.

The complexity of this pathology results from the number of possible combinations between these symptoms, and their degree of severity.

A better understanding of CP mechanisms would allow significant progress in the handling of the patients and in their quality of life. To make this understanding progress, it appears more and more important to consider the patient as a whole, and to develop a global approach of Cerebral Palsy, including for instance the study of the integration phenomena between the different functions altered by the pathology: perception, action and cognition, as well as the patient relation with the outside world, made possible by these three functions.

That's why, in 2010, with the support of its partner Sodiaal, La Fondation Motrice launched the Pace for CP Program (Perception, Action, Cognition, Environment for Cerebral Palsy), which started with the constitution of an expert network and has developed a number of complementary projects for three years:

- An international scientific prize (2011)
- A big scale study associating a number of units and experts through Europe, from different and complementary disciplines (2011-2012)
- A call for projects (2012)
- The organization of an international scientific meeting day (November 29, 2013)

The PACE Network

This network teams together many internationally recognized experts, in different disciplines: neurology, physiology, psychology, epidemiology, medical imaging, physical and rehabilitation medicine, philosophy, architecture and so on

Its mission is to develop this research path, on the one hand through multidisciplinary thinking, aiming at proposing a scientific strategy, on the other hand through collaborations on the field, between research units from all Europe working on these questions.

In order to achieve this goal, the PACE network chose a project manager from La Fondation Motrice: Emilie Gaillard. Her role is to facilitate these projects coordination, as well as their overall consistency.

She plays an important role in animating the network, supporting its multidisciplinary approach (through seminars, etc), as well as providing the research teams with the necessary means:

- Either through direct funding from La Fondation Motrice (covering the whole project or a part of it)
- Either by helping them to find other sources of funding

The Pace for CP Program big steps:

2010: launching, constitution of the expert network

2011: identification of the priority research areas by the Pace network

- Launching of a pilot study

The foundation supported a big scale study aiming at developing new tests allowing to study the coordination Perception-Action-Cognition-Environment in children (in particular children with CP, from a very early age), as well as its evolution during their development : elaborating accurate tests for research and diagnosis was finally considered a top priority in order to address this complex issue.

This study considers itself a first step toward a bigger research program, to be developed in the long run. Based on the collaboration of different partners through all Europe, it is coordinated by Pr A. Berthoz and Pr G. Cioni. It ended in November 2012, and should lead to the publication of at least five articles in peer-reviewed scientific journals.

- Creation of the international scientific prize La Fondation Motrice-Sodiaal to reward innovative works on “the role of the mouth on early cerebral development through the interaction with the environment”, with a 30000 Euros endowment.

It was attributed to Dr Guislaine Dehaene-Lambertz for her work on “the role of the mouth and joint movements in maternal language acquisition”.

2012: launching of a call for projects: “from the PACE approach to therapeutic interventions in Cerebral Palsy”, for the attribution of a two-year post-doctoral grant (100000 Euros maximum), to a high-level team, for an innovative and promising project in terms of applications.

Based on the scientific jury's recommendations, La Fondation Motrice Administrative Board selected the following project: “Through the mirror system: observing and hearing the actions: a new tool for motor restoration of the upper limb.” Michela Bassolino (Dir Pr Giulio Sandini; coll Pr Thierry Pozzo; at the Istituto Italiano di Tecnologia (ITT), Genoa, Italy).

This project aims at improving motor restoration by combining the use of stimuli associated with multimodal actions for persons suffering from hemiplegic Cerebral Palsy.

Given the great success met by this call for projects, and the high quality of the received applications, La Fondation Motrice is considering the possibility of reiterating this call in 2014.

Summary of the awarded project:

“Through the mirror system: observing and hearing the actions: a new tool for motor restoration of the upper limb.”

Cerebral palsy (CP) is a complicated pathological condition, encompassing various symptoms and degrees of severity. The most frequent limitation affecting children with CP concerns the motor difficulties related to the upper limb. Traditionally, physical trainings stress the re-use of the damaged body part. However, in daily life activities this could be problematic because it induces fatigue, pain or frustration. In this context, scientific knowledge about healthy brain can suggest new therapeutic interventions aiming to activate the motor system also in alternative, less demanding way. One possibility may rely on action observation. Indeed, when we carefully watch an action performed by another individual (e.g. on television), our brain is activated as we are really executing that particular movement. This mechanism is already used for therapeutic purpose with adults after stroke. However, typically the actions are simply observed. Here we propose a new intervention in which during action observation, other sensory stimuli are provided. This is in order to re-create a very natural condition similar to everyday action execution and provide a “complete” stimulation. Specifically, we will deliver the sounds characteristically produced by an action (e.g. crushing a bottle) and the hand sensation related to that movement (e.g. the bottle in the hand). This method will have the advantage of involving not only one specific competence, but the integration between different functions: the possibility of perceiving the surrounding environment and the ability to act on it. Moreover, the employed tasks will be very simple and the training could be performed also in non-clinical structures (as at home). Given all these characteristics, the proposed methodology is expected to produce beneficial effects on children everyday life skills and development.

2013 :Organisation of an international scientific meeting day dedicated to the Pace for CP Program achievements , November 29, 2013, in Paris

Modest by its scale, the foundation does not want its action to be just « powdering ». It has an agenda and is willing to exert an impact on research on Cerebral Palsy as a whole. In particular: by putting forward Pain. When asked what they consider the worst in their situation, patients with Cerebral Palsy frequently answer that, more than motor troubles, continual pain is the issue. Muscles and joints are especially hit. La Fondation Motrice's grants reflect this priority.

Reading the board meeting and the scientific council's 2013 reports, one gets a good idea of the daily life of the foundation:

- organization of fundraising events: runs (« Course des Héros »), dinners... one in the company of Andréa de Monaco, the foundation's sponsor
- ISF (wealth tax) fundraising campaign: the most important period of the year for donations
- 2013 call for projects: launching, reception of the research projects and grants award
- organization of conferences, in particular the Day on Pain at the Pasteur Institute
- replacement of A., the secretary, departure of E., in charge of the Pace for CP Program

IV-

How internationalised, how worldwide are philanthropic foundations ? Looking at La Fondation Motrice, one can say that:

- there is a willingness to exchange with international foundations that work on the same field, on the occasion of conferences for instance. Sometimes to build partnerships, even if they often proved difficult to keep alive.
- the researchers awarded come from different countries. Whoever works on Cerebral Palsy, whether in France, Germany, Italy... is likely to hear of the foundation and can apply. Research projects must be written in english and there is no nationality condition.

That being said, all foundations cannot be described as 'global'. How to explain these differences ? My impression (that still has to be confirmed by datas) is that they mostly depend on the foundations' size. Big ones are prone to seek international partnerships: having a worldwide activity is valued. Little ones have trouble enough surviving, in a more and more competitive environment (everyone has to put forward their disease), in a context of economic crisis where donors are sometimes hard to reach.

In terms of 'influence' and 'models', philanthropy appears to be very internationalised though. The anglo-saxon model remains a reference. At conferences or colloquiums, it is rare that no one thought of inviting an american philanthropist to present their action and give a few advises. Every law on the topic starts by presenting the anglo-saxon achievements, before stating that France has to catch up with them. Sometimes to the annoyance of the left : « please, enough with the american model, it cannot be compared, public bodies do not play the same role there... ».

In the UK, the existence of the Wellcome Trust must be mentionned. Dedicated to medical research, this is the second biggest foundation in the world, behind the Gates Foundation.

Germany also hosts a number of diverse and interesting non-profits: more than 10000 foundations, between two and three times more than in France, twice if we consider the number of inhabitants.

This comparison with philanthropic foundations active in medical research in the rest of the world will be the center of my investigations in the following months.

Conclusion

What place for the non-profits ? Looking at the numbers, one can only observe that the foundations' research budgets do not come close to what private companies on the one hand, public bodies on the other hand are spending. Which does not mean that their actions can't exert an impact on certain issues, certain diseases.

The subsidiarity principle may come in handy. Each category of actors must find the problems it can handle the best at its level. Indeed no foundation, except for the Pasteur Institute, could drugs the way the pharmaceutical industry does. It should be reminded that conceiving a drug is an extremely costly operation that takes many years, during which most candidates are eliminated. And even among the successes, it usually takes a long time for a new drug to be made profitable. For now only private companies with a big start-up capital can handle these costs, and these risks.

The same way, foundations must find the activities in which they have a comparative advantage: for instance research projects that do not necessitate important fundings, but can nonetheless exert an impact, by highlighting certain topics, certain issues that other actors could put in their agendas too.