



# Philanthropy in research and innovation in biosciences

Coordinators: Ricard Valls / Joan Bigorra

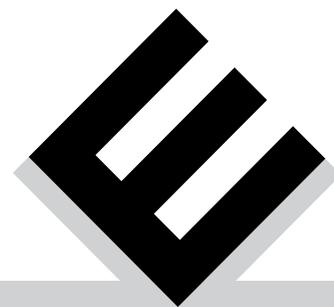


**ESTEVE**  
FOUNDATION



**"la Caixa" Foundation**

**41**



# Philanthropy in research and innovation in biosciences

Coordinators:  
Ricard Valls and Joan Bigorra



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of this book lies with the authors.

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The primary objective of the Esteve Foundation, established in 1983, is to stimulate the progress of pharmacotherapy through means of scientific communication and discussion.

The Foundation aims to promote international cooperation in pharmacotherapy research and, to achieve that end, organizes international multidisciplinary meetings where small groups of researchers discuss the results of their work. These discussions are set out in various published formats, such as the *Esteve Foundation Symposia* and the *Esteve Foundation Discussion Groups*.

Other activities of the Esteve Foundation include organizing meetings aimed at discussing more local issues, which are then published in the form of monographs, notebooks or journals. The Foundation also participates in conferences, seminars, courses and other forms of support to the medical sciences, both pharmaceutical and biological, which includes the granting of a Research Award on a biennial basis to the best paper published by a Spanish author in the area of pharmacotherapy.

The Esteve Foundation is involved in a number of publications, including the series *Pharmacotherapy Revisited*, which compiles, in a facsimile edition, the main articles that form the basis of a specific discipline.





# Contents

<b>Participants</b> .....	VII
<b>Introduction</b>	
<i>Fèlix Bosch, Ricard Valls and Enric Banda</i> .....	1
<b>Ten strategic principles for fundraising growth: lessons learned at Cancer Research UK</b>	
<i>Anthony Newman</i> .....	3
<b>Communication and fundraising strategies for public hospitals based on the Institut Curie's experience</b>	
<i>Hélène Bongrain</i> .....	7
<b>Breakthroughs for life: a fundraising campaign at the Karolinska Institutet (2005-2010)</b>	
<i>Philip von Segebaden</i> .....	11
<b>The experience of Josep Carreras Foundation in philanthropy and fundraising</b>	
<i>Antoni Garcia Prat</i> .....	15
<b>R&amp;I and philanthropy and fundraising in Spain: facts, figure and trends</b>	
<i>Ricard Valls</i> .....	19
<b>Consorti Hospitalari de Vic</b>	
<i>Núria Roger</i> .....	23
<b>Philanthropy, R&amp;I by the Research Foundation of Hospital Vall d'Hebron</b>	
<i>Alejandra Manau</i> .....	27
<b>Private fundraising for research: success stories. Hospital Sant Joan de Déu</b>	
<i>Mercè Tura Lladó</i> .....	31
<b>Role of philanthropy in biomedical research and innovation in Spain. A short review</b>	
<i>Fèlix Bosch, Joan Bigorra and Josep Esteve</i> .....	35
<b>Reflections on key factors in philanthropic fundraising</b>	
<i>Joan Bigorra and Antoni Plasencia</i> .....	43





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## Introduction\*

Fèlix Bosch, Ricard Valls and Enric Banda

In October 2013, the Esteve Foundation organized a one-day roundtable about “Philanthropy in biomedical research and development in Catalonia”. The idea was that, at that time of crisis, when public funding of research had decreased to the point where it was totally inadequate, philanthropy should take on a new dimension. Thus, the roundtable provided the opportunity to raise and discuss some questions related to this issue.<sup>1</sup>

On September 18, 2015, some of the same individuals who participated in that first meeting again contributed to the debate in a more international meeting jointly sponsored by the Esteve Foundation and Obra Social “La Caixa” that was held at CosmoCaixa Barcelona. During the morning, various exemplary experiences in philanthropy for research were presented. Anthony Newman of Cancer Research UK presented ten key principles underlying successful fundraising. Philip von Segebaden discussed why the Karolinska Institut’s “Breakthroughs for Life” campaign was so successful, and H el ene Bongrain of the Institut Curie shared her vision of communication and fundraising strategies for public hospitals. These views were complemented by singular views from a unique vantage point closer to home when Antoni Garcia Prat presented the experience of the Josep Carreres Foundation, where he is the general director, and Ricard Valls summarized the most noteworthy figures related to fundraising in Spain.

From this first part of the symposium, we learned that philanthropic contributions to research in Spain amount to about €130 million, representing only 6% of all charitable donations; by contrast, in other European countries such as France, Italy, and Great Britain, most charitable funds are allotted to research. Although various considerations help explain this disparity, the main factor seems to be that hospitals and research centers have not been very active in raising funds from private donors. The exception is contributions from companies and foundations, which have probably reached a ceiling. However, the proportional weight of individual donations and bequests, once an important source of hospital funding, is still negligible.

In the afternoon, Antoni Plasencia, the director of ISGlobal, moderated the second part of the symposium, a presentation of the particular experiences of three Catalan hospitals (Hospital General de Vic, presented by Nuria Roger; Institut de Recerca Vall d’Hebron, presented by Alejandra Manau; and Hospital Sant Joan de D eu, presented by Merc e Tura) and the Spanish ITEMAS network, presented by its coordinator, Manuel Desco. It is important to point out that in Catalonia and Spain the proportion of funding that comes from the government is higher than in the rest of Europe. This difference is due to the lower levels of private investment in research, development, and innovation and of philanthropic contributions to research at hospitals, universi-

\*Text adapted from “El potencial de la filantropia en la recerca i innovaci o en bioci encia” published in the CosmoCaixa blog 21/10/2015 and available in Spanish at <http://blog.cosmocaixa.com/ca/-/el-potencial-de-la-filantropia-en-la-investigacion-y-la-innovacion-en-biociencia>

ties, and research centers. Whereas funds from foundations, individual donors, and philanthropic investors account for about 4% of all funding for research in the European Union, these sources account for less than 1% of research funding in Spain.

There are various reasons for this deficit in private funding, such as inadequate or inexistent communication and underdeveloped strategies for capturing available funds. Scientists and research institutions have concentrated their efforts in communicating with the scientific community while neglecting to develop lines of communication with other key elements in society and the general public; consequently, philanthropy for research has barely been developed.

Nevertheless, it seems that things are changing very quickly. Society's view of science is improving, and this change is having an impact on health funding. The data from some foundations and hospitals show that people are more willing to help finance biomedical research. Now research foundations need to simplify the process to make it easier for individuals to contribute.

At the end of the day, Joan Bigorra reflected briefly on the proceedings, and Enric Banda brought the symposium to a close. We can draw

the conclusions that there is great potential for increasing philanthropic contributions for research and that efforts to boost fundraising will bear fruit. The examples presented at the symposium are proof in point, and it seems evident that research organizations' attitudes are changing. What is more, society can appreciate the impact of scientific research and wants to participate.

The active participation of the approximately 50 people that made up the audience also contributed to the debate. This Esteve Foundation notebook compiles the contents and main ideas of the presentations and discussions that took place at the symposium, with the hope that this valuable information can reach as many of the people interested as possible. We believe that this type of event and the publication of its contents can serve as an example for future undertakings to promote philanthropy for biomedical research and innovation.

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# Ten strategic principles for fundraising growth: lessons learned at Cancer Research UK

Anthony Newman

Cancer Research UK is the world's largest independent cancer research charity. It is the largest fundraising organization outside the USA — twice the size of its nearest competitor in the UK. Funding research into the prevention, diagnosis, treatment, and cures for all cancers, our work is implicated in over half of all lives saved from cancer in the UK and also has a dramatic impact in other countries. Cancer Research UK receives no financial support from the government, so its fight against cancer is totally dependent on fundraising. Over 4,000 scientists, doctors, and nurses depend on funds from our organization to carry out their research. To achieve our mission of defeating cancer, we need to continually increase income from fundraising. Between 2002 and 2014, net income from fundraising more than doubled, reaching a record-breaking £367M. Many factors have contributed to this success; what follows is a summary of 10 principles that have underpinned the growth we have achieved.

## Diversification

To protect the organization from key income streams wearing out, changes in consumer behavior, vagaries of the economy, and competition from other causes, it is essential to build up a broad portfolio of products, propositions, and approaches. Cancer Research UK initially depended almost entirely on legacy giving, in other words, on bequests in donors' wills. However, when property values went down in a real estate recession in the 1990s, legacy income decreased to the point where some research activities had to be shut down. Now the organization

uses a wide and ever-growing range of interrelated approaches to raise funds.

## Long-term propositions

Raising money for charity is a long-term project. We need to invest money today to ensure income in the future. It is essential to realize that you need to spend money to make money. Through the years, our expenditures have increased, but the income we derive from those expenditures has increased much more. We work hard to drive the cost-ratio down, but rather than limiting our expenditures to strategies that provide an immediate return on investment, we also try to develop long-term income streams by investing in propositions that will provide reliable income in the future. This approach allows us to plan for our research funding, because we know that even if the economy crashed or some other calamity interrupted our short-term income flow, funds will continue to arrive for a very long time. Examples of long-term propositions include soliciting commitments to give relatively small donations on a regular basis, for example, two to ten pounds a month, legacy giving, where the payoff might be 30 years down the road, or our long-term *Stand up to Cancer* partnership.

## Short-term propositions

We also need to find short-term income streams that provide good cash margins and cash-flow within a given year. Without these tactical measures, it would be difficult for our long-term investment strategy to thrive. One example of a

successful short-term fundraising project is our campaign to sell wrist bracelets in February 2015 for World Cancer Day. We always have a range of short-term return propositions underway to raise money in a given year.

### Capability

‘Capability’ means first and foremost, but not only, the capability of our staff. Unlike companies that own factories, equipment, patents, etc., a charity does not really own anything. Our people are our most important asset. Because the quality of our fundraising team is essential, we invest heavily in attracting, developing, and retaining the best talent in the UK sector. We have been able to create an “employer brand” — Cancer Research UK is actually an organization that people want to work for. Our strategy is to take in the people with the greatest potential and providing them with everything they need to flourish in our organization. We focus on recruiting the right people and inducting them very well through onboarding, making sure they acquire the necessary knowledge, skills, and behaviors to become effective members of our organization. We manage their performance very tightly —if they are not meeting our standards, we may exit them from the business; if they are meeting our standards and show potential, we develop them. We think carefully about insourcing, outsourcing, and skills transfer. We also strive to keep in touch with those who have worked with us and moved on to other organizations. Many of these people eventually come back, bringing with them valuable experience and skills they have acquired elsewhere.

Our concept of capability is much wider than people capability alone. We developed a target operating model to help us bear in mind where we are starting from and where we want to go, so we know where we are with respect to our goals. Using this strategy, we developed capability roadmaps to follow. By building deeper relationships to realize the full potential of our supporters, continuing to invest in proven winners, nurturing our “rising stars”, fostering innovation, and driving efficiencies to maximize contributions, we were able to transform the organization and ac-

complish what we had set out to do. Focusing on capabilities drives benefits.

### Culture

We have actively managed our culture to deliver our strategy. Although many organizations stress the importance of having core values, these tend to be generalities that do not really drive anything. Values are personal —they come from inside each individual. Obviously, an organization can define its values, make them explicit to individuals inside and outside the organization, conduct training courses to try to ensure that employees have acquired them, etc. But in the end, people’s values are those that have been instilled when they were growing up, and it is very difficult to change them. We have found it more useful to focus on brand beliefs, and it helps to keep these simple. Rather than lay out ten or more beliefs that cover everything, we chose to focus on just three beliefs that our staff need to share:

- 1) *Our stories change the world.* Our people need to believe that our work really makes a difference. We are saving lives, and we have masses of data to back up that claim.
- 2) *United we are stronger than cancer.* We are a really broad, diverse organization that includes thousands of people with different agendas. It is often difficult to get people to work together, but teamwork is essential. Cancer Research UK is not a democracy —each person has his or her role to play, and it is important that they understand their roles.
- 3) *Sharp minds and brave hearts win.* Our staff is made up of extremely intelligent, well-educated people —many people have a PhD, but being brave and doing something different can be much harder. We make sure that our employees understand that if they do not share these beliefs, they should not be in this organization.

### Brand

Our brand underpins everything we do both internally and externally, helping staff, supporters



and the public understand and believe in the organization. So we manage our brand very carefully. Brand management involves bringing together brand architecture, brand identity, and brand values so that no matter what we are doing at whatever level in our pyramid, the public understands that this is a singular organization doing the same thing in myriad ways. Each part of the organization reflects on the others, creating a “halo effect”. This effect means that when we do something good in one area, all the other areas benefit too. We were the first charity in the UK to start investing in our brand through advertising. A broadcast campaign to promote the brand can have amazing penetration. Commercials can be used with different purposes in mind or to target different groups, for example, wealthy middle-aged men. Some commercials are intended to drive mass fundraising; others might use a mass-market approach to driving high value giving.

Brand management at Cancer Research UK is complex. For example, we have a slightly different look and identity for our “scientific brand” and our “fundraising brand”, but it is still clearly recognizable and similar enough so that it still benefits from and contributes to the “halo effect”. In addition to our core brand, we have sub-brands, such as the *Race for Life*, that have been able to create strong identities of their own under the umbrella of the core brand. We also have stand-alone brands, such as *Stand up to Cancer*, which are different from sub-brands in that they represent partnerships that give money to us.

Brand growth needs to take place from the inside to the outside. Your brand comes from your organizational culture, from what you believe and what you do. Your brand beliefs permeate your culture and resonate throughout the organization. From there, your brand goes out into the external world through every touchpoint, where advertisements and logos are just the tip of the iceberg.

## Innovation

We have continued to innovate, coming up with new ways to raise funds. To foster innovation, you need to allow people to fail along the way. We have created a culture of innovation by investing

in innovation skills and capability. Innovation is so important to us that we have a dedicated innovation team. This works much better than asking busy people to innovate in addition to carrying out the other functions the organization has hired them to do. So we assign the task of innovating to a team of people that have the skills and capabilities necessary to innovate, and we encourage them to take risks. We know that many of the propositions they come up with will flop, but we also know that some of them will be truly successful and move the organization forward.

## Data

Carefully managing our data has been key to growth. Data management might seem dull, and it can be hard to motivate people on this subject. But data is crucial to everything we do. You need to invest huge amounts of money and energy into exploiting your data to the fullest. If you have done everything else right —diversified, innovated, and invested heavily in branding— but you have not taken care of your data, you are setting yourself up for failure. Years ago, we had several, separate legacy databases, so in a sense one hand did not know what the other was doing. If someone comes in to talk to you and you are unaware that they have already talked to somebody else, you might start thanking them for a donation when they have made a complaint or soliciting a donation from them when they have just recently made a very large contribution. This is a disaster, because your relationship with your donors is the backbone of fundraising. We merged all of those databases into an operational customer relationship management system with a single-customer view. Setting that up and migrating the data from the legacy bases required a large investment, but it has helped us sort out our relationships with our supporters, the heart of everything we do, and it has paid off.

## Portfolio management

If you have a diversified portfolio, you need to manage it carefully. While it is important to add new items and to grow your portfolio, the goal

is not to have more and more items on the list. The goal is to focus on the items that are going to raise the most money. This involves making difficult decisions all the time. Sometimes we need to discontinue an activity even when it is profitable. You need to really look closely at the markets that you are in and consider how you are serving those markets.

You have to manage your portfolio carefully to meet changing needs. There are many different ways to manage your portfolio. One way that we do it is to divide the different items into their stage of development, for example, pioneering, growth, mature, or declining, and then plot all of the income derived from a product versus the time it has been underway. Another approach is to divide items up according to their overall performance, for example, bronze, silver, gold, or platinum. Here you could plot the item's potential for growth against actual net income value or its cost ratio.

It does not matter what tools you use —the important thing is to actively examine your portfolio to understand how it is unfolding and how the different items are performing over time, so you can devise a plan to ensure that you maximize the potential of each item and of the portfolio as a whole. We have many different things in our portfolio, and they are all important, but managing them is also important.

## **Investment**

Last, but definitely not least, you need to continually invest in all the above to ensure growth.

Investing in growth can be difficult in charitable organizations. Unlike investors in commercial organizations, trustees in charities sometimes do not understand the need for investment; they can feel it is their duty to ensure that donors' contributions are spent toward helping the people they were intended to help. As a fundraiser, you need to help those who hold the purse strings to understand that you have to invest to grow. You need to make the case for investment. Everybody wants income, but you need to invest now so that you can spend later.

Sometimes we have overinvested. Sometimes we have invested badly. Sometimes we have failed at attempts to innovate. But, more often than not, we have gotten it right. Investing has enabled us to grow and to do many things to help many people. We could not have done any of that without investing.

## **Conclusion**

These principles are all interrelated. Building the capabilities and fostering a culture of innovation can help you create and manage a diverse portfolio including both short-term and long-term propositions. Paying attention to your data can help ensure you make the best choices to adapt your activities to the changing times and help you take care of your donors. All these aspects are essential in establishing a strong brand. Strategically applying these principles to any fundraising operation, whether large or small, will underpin income growth over the long term.



# Communication and fundraising strategies for public hospitals based on the Institut Curie's experience

Hélène Bongrain

Founded in 1909, Institut Curie is a private, non-profit organization comprising a hospital and a research center dedicated to the fight cancer. Since the end of World War II and the establishment of the French welfare state, the Institut Curie, like other hospitals in France, has been funded by the French government through ordinary taxes, while its research center was partly relying on private donations. However, the cost of healthcare increased faster than the amount of funds available for hospitals. In the 1980s, public funding started to decrease drastically, leading to a series of reforms to contain costs, such as pay-for-performance plans for hospitals and decreasing reimbursements for drugs and medical treatments, culminating in the implementation of activity-based funding for hospitals beginning in 2004 and completely in force in 2010. This meant that less funds were allocated for non-activity-based services such as emergency departments, organ harvesting and transplantation, training and innovation, to name just a few. Within this period, the worldwide financial crisis brought about a public finance crisis that necessitated further cutbacks. Cutbacks in public funding precipitated a hospital financing crisis that resulted in a deteriorating environment and consequent decrease in the quality of service, despite the efforts of excellent physicians and nursing staff. In this context where hospitals were struggling to reduce costs while increasing their activity, competition for grants from associations and foundations, always fierce, also increased dramatically. Thus, hospitals started their own fundraising activities.

Until 1950, the Institut Curie received donations and bequests for both the hospital and the research institute. However, from this time until

2010, most fundraising was done for its research institute, with the exception of two dedicated projects: building a new hospital in 1990 and opening a new proton therapy center in 2010. The fundraising culture was alive and well at the research center, but had largely disappeared from the hospital. When state funding for research decreased by two-thirds at the start of the new millennium, the research center initiated a structured fundraising effort, compiling lists of donors, dedicating some human and financial resources to fundraising, and setting up a back-office with the necessary resources to raise money and keep track of fundraising efforts.

By contrast, most people were totally unaware that the hospital was suffering from insufficient funding. In 2010, the hospital was in a very difficult financial situation, so the following year a fundraising effort was started to remedy this situation. This effort led to an increase in donations from about €1 million a year in 2009 to €15.7 million five years later.

Our first task was to explain that the hospital needed money because state funding had lowered drastically and that we now had to ask people to contribute. We had many factors in our favor, but we also faced considerable resistance from some sectors. One enormous advantage that hospitals have over other organizations for raising donations is that there is a constant flow of people through the hospital, and these people actually benefit from what the hospital offers them. In addition to the 14,000 patients treated at the Institut Curie every year, many friends and relatives of these patients pass through the hospital, providing us with the opportunity to ask

them directly for a contribution. However, persuading staff members to cooperate in this effort and convincing the general public that giving was necessary required a cultural change.

Hospital employees and many French citizens still believed that the state should take responsibility for funding the hospital and that they were already doing their part by paying their taxes. The trade unions considered that it was humiliating to have to ask patients and their families to contribute to the maintenance of the hospital. There was substantial resistance to even simple measures such as including questions about patients' willingness to receive information about the hospital on surgery satisfaction surveys and hospital admission forms or leaving copies of the institutional magazine in waiting rooms. So our first task was to raise awareness of the hospital's need for funding.

To this end, we held a series of conferences to discuss the hospital's need for money. We started selling daffodil brooches —not to raise money, but to raise awareness of the need to raise money. We were able to gain considerable internal support from the top management of the hospital, but top-down support was not enough. We seized the opportunity to build fundraising for specific projects by taking advantage of a brilliant physician who was good at communicating her projects to ordinary people. In turn, she brought in likeminded colleagues and we started to make a dent in this idea that only the government is responsible for funding the hospital. This illustrates how important it is to use available networks.

As we work toward this cultural change, it is important to focus on innovation and excellence. People do not want to give money for routine operations —they want to see the impact of their donations in things like cutting-edge equipment, new treatments, promising clinical studies, or a better environment for patients. So it is helpful to identify projects that can convey this sense of real progress. On the other hand, although there is nothing wrong with raising money for specific projects, ideally we would like to see people contributing funds that the hospital can use without restrictions. With the aim of capturing unrestricted funds, we emphasize our hospital's highly innova-

tive research. It is crucial to find some good ways of talking about research, for example, stressing how doctors and researchers work hand-in-hand to fight cancer and how clinical research done at the hospital ties in with basic research done at the research institute. The public really does not really know the difference between basic and clinical research, and the difference really does not matter to them. The important thing is to talk about research in a subtle way that taps people's feelings of caring and hope.

An experienced fundraising team or agency can help get things started. It is essential to let people know that the hospital needs donations, but it is equally important to contact the right people (i.e., the people who care) and to go about asking them for help in the right way. Potential donors for hospitals include patients and their families and friends, staff and their families and friends, neighbors, and suppliers. A hospital that treats 14,000 patients per year has the opportunity to tap these patients' networks, bringing the cause to 50,000 people per year —this adds up to half a million potential donors in a ten-year period! Hospitals are major employers; they give work to physicians, nurses, technicians, administrative staff, housekeeping personnel, and groundskeepers, amongst others. One of every ten employees is a potential donor, and each employee has his or her network of friends and family that also might want to help. Some staff members, especially nurses, are also very good at asking for donations. Suppliers and contractors will often contribute within the framework of the law. Local shops and local companies are often eager to show that they are good neighbors, and local clubs and associations will often volunteer to do some of the fundraising work for you.

Efforts to target people who do not care are usually a waste of time. In France, 50% of the people never give anything to anybody. This has remained unchanged over the past 20 years. However, the good news is 50% do donate! And generous people who donate to other causes might very well be happy to donate to your cause too. Read the annual reports of other foundations to get an idea of who is giving what. Although tax deductions are never the most important reason



for giving, the idea of being able to deduct contributions is attractive to corporations and individuals alike. Throughout the world, people hate to pay taxes —given a choice, they would gladly give their money to charity rather than to the government. You need to be optimistic —keep asking, because persistence pays off. An 8% response rate is very good and can make a real difference.

Some health problems inherently inspire more sympathy than others. People are more willing to give more for some health problems than for others. We know that there are good and bad issues for appealing to people; and there are other issues that are untested —we do not know whether they will be good or bad for appealing to people. That is why it is so important to test ideas to see what works and what does not, and to keep track of your results. The best issues for us have been cancer, pediatrics, cardiology, and technological innovation. Talk about a young mother 32 years old who just had a child and is now diagnosed with cancer. Children and youth are appealing. Even though most donors are over 60 years old, they want to give to causes that help young people. Other issues are more difficult to explain or less attractive. Talking about death and palliative care is likely to turn people off. Surgery conjures up images of blood and gore.

Be careful to frame your message in the right way. Find a way to state your case that potential donors can relate to. You need to engage people. Focus on the benefits to donors rather than on your needs. Think of things from their perspective, not yours —count the number of times you say “you” and contrast it to the number of times you say “we”. You have to be inspirational. You are selling hope —at the same time you have to give examples that show progress. You need to convey a sense of urgency or emergency. If there is no emergency, create one. On the other hand, frightening people is not a good way to persuade them to contribute —images of scary technology like radiotherapy, nuclear power plants, women who have lost their hair, children missing limbs, and so on induce aversion.

Timing can also work in your favor when appealing to people for money. Christmas is a great time to ask for money because people are in a

giving spirit; this is especially true when the beneficiaries of the donations are children. Taking advantage of special events and anniversaries is another way to increase funding. Contacting people a year after discharge from the hospital, whether face-to-face or by telephone or direct mailing, can be amazingly successful. For cancer patients, the one-year anniversary can be very important. Perhaps they already donated while they were being treated or maybe they were too caught up in their own ordeal to donate at time, but in either case they will be extremely grateful to be alive after their treatment, and there is a good chance that they will want to express that gratitude with a gift. An appeal at this time might even tip the scales toward a generous legacy.

Appeals to the general public greatly benefit from media coverage. Press releases and press conferences can be useful for launching and promoting campaigns. If you can persuade the right people that your cause is justified, the media are often willing to donate advertising time and space. It really helps to have famous people supporting your cause; their presence can attract free coverage and they have a wonderful capacity to engage people. Media campaigns can also help you create your own stars —doctors and researchers who are good at communicating the importance of their work can have a tremendous impact on donations. Take full advantage of everything the media has to offer and you will be generously rewarded.

Fundraising is a formidable challenge, but one that is well worth the effort. Successful fundraising requires a team. Everybody needs to understand that it is essential to invest in fundraising —the old adage that you need to spend money to make money is true. It is not unusual for fundraising expenses to use up 20% to 30% of the funds that you raise, but you can expect to receive €3 to €10 in donations for every euro you spend. On the other hand, you should not expect to see a real return on your investment for at least two years. Sometimes you have to take risks, but doing so pays off in the long run. Fundraising efforts can help hospitals obtain 5% to 10% of their yearly budgets from philanthropy, and that goes a long way toward ensuring quality care.





# Breakthroughs for life: a fundraising campaign at the Karolinska Institutet (2005-2010)

Philip von Segebaden

The Karolinska Institutet, the largest center for medical education and research in Sweden, is one of the world's foremost medical universities and is responsible for selecting the Nobel laureates in physiology.

The establishment of the modern Swedish welfare state in the 1930s superseded an earlier tradition where local patrons and family foundations were the main sponsors of social welfare. In this new model, the so-called Nordic model, the people of Sweden paid very high taxes and thereby enjoyed access to services such as education and healthcare as well as the benefits of a tight-knit safety net such as poverty relief, unemployment compensation, and retirement pensions. Medical education and research, like other components of the welfare state, were funded almost in their entirety by the government with funds collected through taxation. Through the years, heavy state funding led to a declining sense of responsibility for all welfare and a sense of skepticism toward donations.

With time, however, demand started to outgrow supply. At the turn of the millennium, the cost of the welfare state surpassed the government's capacity to finance it. Taxes were already extremely high, so it was not feasible to raise them further. In parallel to this trend, some Swedes had managed to build up considerable wealth. Not only were many of these people content to remain in the country and pay a large percentage of their income in taxes, many of them were also interested in giving back to the nation that had helped them acquire their wealth and in actively participating in building a better society. This was accompanied by a cultural change in

which the media started to take a greater interest in donors and to give them the opportunity to tell others about the reasons for their philanthropy, with the result that these influential people end up inspiring others.

There is no tax deductibility for donations to charity in Sweden. Nevertheless, there were a few successful fundraising campaigns in other areas, and Swedes have always been generous to charities such as the Red Cross, cancer funds, and heart associations. On the other hand, higher education rarely benefited from charitable contributions, and all donations received had been unsolicited. There was no tradition of alumni giving, and there were no proactive efforts to raise funds for universities. Vice-chancellor Harriet Wallberg-Henriksson sought to change that with the *Breakthroughs for Life* campaign.

Before being elected Vice-chancellor, Dr. Wallberg-Henriksson had served as dean of research. Her experience in national research boards and meetings on a European level convinced her that Europe was lagging behind the United States because we were heavily dependent on state funding. Although the European Union's Lisbon Strategy in 2000 set a goal of all countries investing 3% in research and development by 2010, it seemed unlikely that that was going to happen (and in fact it did not). Therefore, if we wanted to keep up, we would have to change our funding models. To compete with universities in America, we would need access to different funds, and to more unrestricted funds, as well.

The upcoming bicentennial of the Karolinska Institutet's founding (2010) tied in nicely with the idea of a five-year initiative to raise one billion

Swedish crowns (slightly more than €100 million). In 2004, a UK fundraising consultant (Brakeley) did a pre-campaign SWOT analysis to see if this project would be viable. Among the noteworthy strengths, they identified were the Karolinska's highly renowned brand and its role in awarding the Nobel Prize for physiology, which was considered especially important if the campaign was to go international. The most important weakness identified was the university's lack of a clear mission. Universities are complex, multifarious institutions where a large set of diverse players with variegated wills and often disparate goals find it difficult to agree on what is best for the entire collective. Many top researchers were not really concerned about the collective. Nevertheless, the general conclusion of the analysis was that the campaign could be feasible.

The vice-chancellor set out to create internal awareness of the need for fundraising and to garner support for this initiative. She wisely insisted on a unanimous board decision as a precondition for undertaking the project, but she did not stop there. She met with each of the 22 heads of departments and demanded their full support. After all, the campaign was going to cost 40 million Swedish crowns, and investing this money in fundraising involved the risk of losing it all. To ensure success, the mission would require the concerted efforts of the board, deans, and heads of departments. Firmly anchoring the project within the institution proved to be one of the key factors in the project's eventual achievements.

A small back office was established to cover development, fundraising, and alumni relations. In retrospect, this three-person team was probably too small. Our team consisted of a campaign manager to hold things together, an administrative person capable of dealing with all sorts of things that come up, and a third person devoted mostly to prospect research, which involved analyzing the university's networks and how they linked to society. It was important to have a good understanding of what research areas were strong and what we could do with those areas. We needed to find champions who could attest to those strengths and translate them to

potential donors. Matching these strengths and people with targets and goals through our networks involved a great deal of desktop work and actually took several years to complete. With help from other resources in the university, this small team of full-time employees was able to make a tremendous difference because we were able to focus 100% on the campaign. We took the steps to set up a system that would last long after the original team members moved on, and the university continues to benefit from this system. Assigning the responsibility for fundraising to someone who is focused on other projects could never be as effective.

Fundraising is totally different from other activities that people at universities focus on, so when you start doing fundraising at a university, you need to address different sources of friction and deal with conflicts that will inevitably arise. Introducing fundraising represents a fundamental cultural change both inside and outside the institution. The success of the venture depends on your ability to forge long-term relationships. We had the privilege of working together with donors who not only sought to make an impact on our university, but also wanted to bring about a long-term cultural change in which philanthropy would spread throughout society.

It is crucial to define the role and goals of fundraising in the university. If you ask people within the organization about their ideas about what the project is and their expectations, you will receive a wide range of very different opinions. It can be very complex to arrive at common goals within diverse organizations like the university. Everyone agrees that they want more money, but you need to define the right cases for support. Dr. Wallberg-Henriksson realized that it would take over four years to achieve this through a bottom-up process, so she bravely decided to use a top-down approach where she designated focus areas (i.e., cases) that were being developed by people she believed in. It took great efforts to communicate this within the organization, so that people could understand why some areas were chosen and not others and therefore continue to support the project even though they would not immediately benefit.



The *Breakthroughs for Life* campaign selected areas that were already doing excellent work where the extra boost from donors' contributions could lead to a breakthrough. Obviously, the material had to be world-class research. Less obviously perhaps, the leaders of those research teams had to be willing to work with fundraising in the way that we wanted them to. We needed champions whose communication skills go beyond persuading other scientists in grant applications and scientific communications. We needed researchers who were also capable of repackaging their messages to engage private donors, people who could be visionary and straight to the point at the same time. Champions need to understand what appeals to donors. Leaders of research teams will tell you that they need better facilities and equipment, and more researchers. But donors are not very convinced by this approach. Donors want to know what the team will be able to accomplish with these tools in 15 years. Researchers are not accustomed to thinking along these lines.

From its conception, rather than appealing to the masses for many smaller donations the *Breakthroughs for Life* campaign sought to begin with very large gifts from a few wealthy individuals and then work our way down the pyramid to more and more modest contributions. Sweden is a small country where philanthropy is something new. We strived to bring on board very influential people who have private family foundations or large companies. We learned from the Americans that we needed a strong external advisory board (campaign committee), incorporating our top donors and friends —the idea was to bring them on the inside and make them part of the process. Princess Kristina, the king's sister, headed the board and she was extremely helpful and influential at bringing others to the project.

The external advisory board has several functions. The most important of these is not the large donations that its members normally make to the campaign. That is an important aspect, but what is even more important is the board members' networking capacity. These individuals can open doors because they are respected members of society who know your prospects. They are

good ambassadors, and when they deliver your message about the need for research, it is much more effective because it resonates with the target audience. When the famous chairman of one of the country's top brands tells the media that we are losing ground against the American institutions and that this situation can cast a shadow across the Nobel committee and indeed across the nation itself, the impact is far greater than if a representative of the university pushes the cause.

Another strategy used by most successful campaigns in the United States that we adopted was to start out with a silent phase in which we did not communicate our goals to the general public or to most potential donors. In this phase, we obtained very large donations from board members and from a very few prominent community members, so when we went public at the beginning of 2008, we had already reached 60% of our goal. When others saw, we had already raised 600 million crowns, many of the other people we were building relationships with also came forward and committed funds.

The *Breakthroughs for Life* campaign is the most successful campaign in Sweden to date. It is still one of the most successful academic campaigns in continental Europe. As far as fundraising goes, Europe as a whole is lagging behind the United Kingdom and is still light-years away from the United States, but we are learning.

It is very important to understand that fundraising is not about obtaining money. Money is the outcome of successful fundraising, but fundraising is really about building and strengthening relationships —friendraising rather than fundraising. Who would give money to someone they did not know and trust? Who would give money for a cause they did not understand? Use your networks to build central intelligence and bring in new potential donors. Networks grow new networks, and this ongoing prospecting never ends. Invite people in to learn about your organization and your projects. Share your vision and show them why you are unique. Understand how you link to specific donors and what could motivate them to support your research.

Even in countries where universities receive very strong funding from the government, uni-

versities are already becoming dependent on donations, especially for research. Every university needs to come up with a strategy to raise funds from other sources. State funding shifts over time, and it can be difficult to predict what areas will be prioritized. Yet the university needs to be able to set its own priorities and long-term goals. Increasing philanthropy has many positive effects. The United States leads the world in

philanthropy, and that is reflected in their results — the United States also leads the world in the number of Nobel Prizes. Philanthropists inspire others and more resources become available; more funding for one project does not have to mean less funding for another. As philanthropy grows, more funds become available across the board, fostering the diversity that makes university systems strong.



# The experience of Josep Carreras Foundation in philanthropy and fundraising

Antoni Garcia Prat

## About us

On July 14th, 1988, Josep Carreras created the International Leukaemia Foundation as a proof of his deep gratitude to both science and society for the care and affection he received during his illness.

The Josep Carreras Foundation is located in Barcelona but also have three other foundations in other part of the world:

- The US Friends of the José Carreras International Leukaemia Foundation funds a clinical research chair at the Fred Hutchinson Center. Mr. Josep Carreras and E. Donnall Thomas Chair for Cancer Research endowed with over US\$1,000,000.
- The Fondation José Carreras pour la lutte contre la leucémie, Genève in Switzerland maintains the high-resolution typing programme for the umbilical cord units in the Swiss Registry, which are available to any patient in the world.
- Deutsche José Carreras Leukämie Stiftung e.V. Thanks to donations of more than €200 million given over 21 editions of the television gala against leukaemia and the generosity of German donors, the Josep Carreras Foundation in Germany has funded 1030 projects, 595 of which were for research grants and funding, 59 created and renovated health care and research infrastructures and 376 were devoted to care for social matters and support for patient and family association.

All these organizations have in common:

- His founder and president, Mr. Josep Carreras.
- Mission.
- Legitimacy and credibility.
- Board members.
- Strong scientific boards and committees.
- Emphasis on research.
- Activities in health care, health care infrastructures development, social services.
- Consistency with founders' will.
- No public grants.
- Independence from political institutions.
- Cooperation and joint projects with public sector.
- Grant-giving for health-care and research infrastructures. Partners: hospitals, universities, public authorities, insurance companies. These partners fund operating costs and Foundation funds investment.
- Not a patients' association.
- Diversity of projects and of institutions.
- Fulfilling the mission take advantage of the artist's popularity in order to build a solid financial base (endowment).
- Running costs financed through financial revenue, donations and sponsorships.
- Charity performances by Mr. Carreras: minimum guaranteed donation, promotion of the event by third parties. Foundation controls production and publicity.

## Aggregated figures

### Josep Carreras Foundations Group

- More than €250 million in grants for research projects and infrastructure.
- More than 1500 research projects and grants.
- Five endowed research professorships.
- Funding for cord blood bank development: Düsseldorf, Barcelona and Geneva.
- Funding for seven bone marrow transplant units (Barcelona, Badalona, Munich, Jena, Hamburg, Berlin, Leipzig).
- Funding for ambulatory, day clinics, family and patients' summer camps.
- Six apartments for free use of low income patients and families.
- 7438 patients with a compatible donor.
- Consolidated net worth over €65 million, as of 31 December 2015.
- Mostly invested in financial assets, conservative profile.
- Annual consolidated turnover €40 million.
- Staff: 35 professionals (Barcelona, Munich), volunteers (Geneva, Seattle).

### Financial strategy 1988-2007 (Spain)

- Build endowment through charity concerts to guarantee long term survival:
  - More than 200 charity performances by Mr. Jose Carreras
  - €25 million raised through concerts and personal initiatives.
- No debt.
- High interest rates.
- Fund only what financial revenue could afford.
- Important risk: long payment terms Spanish public hospitals vs. short payment terms to international registries.

### Financial strategy 2008-2017 (Spain)

- Companies devote less resources to sponsoring concerts.

- Strong endowment but Interest rates decrease diminishes financial revenue.
- Expected artist's stage life: 10-15 years.
- Challenge: develop a large social base to fund running costs. As in 2016, our donor base is made of well over 70,000 regular donors, with very high loyalty indicators.
- Program Expenses are now mainly funded by donations.

### Financial strategy 1995-2012.

#### Spectacular growth in Germany

- Great opportunity: ARD-MDR Christmas Gala.
- 18 editions.
- Prime-time ARD-1, week before Christmas.
- Over 15% audience share.
- Peaks over 5,000,000 viewers.
- Database over 1,000,000 donors.
- Every year, more than €5,000,000 collected during program, from 20:15h to 22:45h.
- Simultaneous development of donor base.
- Grant giving.

### Financial strategy 2013-2015 (Germany)

- Great risk: ARD-MDR Christmas Gala, discontinued!
  - New cooperation with private channels.
  - Christmas Gala as promotional event (break-even).
  - Decreased collection of funds but very successful donor base loyalty.
  - Extreme generosity in legacies.
- More favorable endowment building legislation.
- Continuity.

### Other considerations

- The largest part of running costs of REDMO are held by the Foundation. Fees only cover some direct costs.



- Meanwhile we have a new project to develop in research field...
- Next steps...
  - We needed to get finance of REDMO.
  - We proposed a new line of communication through mass media.

### Lines of work

The Josep Carreras Foundation concentrate their efforts in different areas:

- Improve patient's quality of life: the Foundation offers a free medical advice service and also offers six apartments for patients with limited economic resources who have to travel far from home to receive prolonged treatment (Program "Apartments for patients who stay for a long period of time"). Patients must often undergo a bone marrow or umbilical cord blood transplant. Because of this, they will be required to spend large amounts of time in hospital and, in many cases, far from their homes. In such cases, it is extremely important that they are able to count on the help and company of their family. These six apartments are available to meet the requirements of patients and families with limited financial resources or that must move away from their normal place of residence (conditional on reports from the social workers at the hospitals in which they are receiving treatment). The apartments are located near the main transplant centres in Barcelona: Hospital Clínic, Hospital de Sant Pau, Hospital Vall d'Hebron, Hospital de Bellvitge and Hospital Germans Trias i Pujol, the final being located in Badalona. Since July 2012, our entity has another accommodation available for patients and their families thanks to a collaboration agreement signed by Hospital Infantil Sant Joan de Déu de Barcelona and NH Hoteles. As part of the social program of the company, the hotel chain facilitates a room at the NH Porta de Barcelona hotel to patients and their families, who are being treated at the nearby Hospital Sant Joan, who have to travel far from their home to receive treatment.

- REDMO: since 1991 we manage the official bone marrow donor's registry in Spain, REDMO. A transplant from an unrelated donor is the only curative treatment for a large percentage of leukaemia patients, as only one in every four patients have a compatible family member. More than 7000 patients around the world have been able to undergo a bone marrow transplant thanks to the searches we perform every day.
- Scientific research: in 2010 we created the Josep Carreras Leukaemia Research Institute (IJC), one of the few centres in the world devoted entirely and monographically to leukaemia and other haematological malignancies. The IJC wants to promote the development of research in the field of oncohaematology, accelerate the implementation of new treatments, improve care and patient survival, contribute to the training of new researchers and establish synergies with other national and international research groups. The IJC has three independent yet coordinated scientific campuses: the Clinic-UB Campus, located in the research facilities at the UB's Faculty of Medicine and Barcelona's Hospital Clinic; the ICO-Germans Trias i Pujol Campus in Badalona, located in the environs of the Germans Trias i Pujol University Hospital, the Germans Trias i Pujol Teaching Unit at the UAB and the Institute of Predictive and Personalised Cancer Medicine (IMPPC); and the Sant Pau Campus, located in the healthcare complex.

### Lines of research and the different scientific campuses

The opportunities presented by research into leukaemia and other haematological malignancies are evident. The strategies for responding to these opportunities must use a methodology and technologies which match the challenges of battling to cure these diseases. As such, the IJC is following these lines of research:

- Acute leukaemias.
- Chronic lymphoproliferative syndromes.
- Chronic myeloproliferative neoplasms.

- Monoclonal gammopathies.
- Myelodysplastic syndromes.
- Haematological malignancies and coagulation.
- Complications associated with therapeutic procedures.
- Haematopoietic progenitor transplants and cell therapy.
- Epidemiological research.
- Clinical research.

### **Our line of communication**

We have moved towards a new communication line. At the beginning, our focus was on REDMO, our main program at the time. After the creation of the Josep Carreras Leukaemia Research Institute (IJC) we decided to stress our communication on RESEARCH program. Our aim is to make leukaemia 100% curable. To achieve it we need to work on research. To sensitize society, we must communicate the impact of our work.



# R&I and philanthropy and fundraising in Spain: facts, figure and trends

Ricard Valls

## Facts and figures

In Spain, there is a lack of information available about philanthropy, that is even greater when it comes to see the impact of philanthropy in R&I in biomedicine, but we will try to go through all these difficulties in the present article.

The first “official” data is the one from Eurostat and other national statistics about funding of R&I in each country. In this statistics the EU identifies the three main sources of income: public funding, private funding and philanthropy.

The comparative results with other countries shows the following in table 1.

**Table 1.** Philanthropy as a percentage of R&I funding.

Country	Philanthropy as % of R&I funding	Millions of euros
Spain	0.6	85
Italy	3	600
France	2	8930
UK	5	1560
USA	4	15147

Zohar from Eurostat 2015 and national statistics.

The differences between Spain and Anglo-Saxon cultures, where philanthropy has an important role in society, is enormous but differences are also significant if we compare it with Italy or France, two countries with a philanthropy culture quite closer to the Spanish one. Anyway the differences are clear not only in percentage but also in absolute numbers.

But the question remains: why there is such a difference? Is a question of the dimensions of philanthropy market in Spain? Is a question related to the actors in the field? Is question of the social perception of R&I?

Let's focus in the first possible answer: philanthropy market in Spain goes to a total of €2313M, with a strong concentration of the resources from individual donors and foundations, 81% of the total (Table 2).

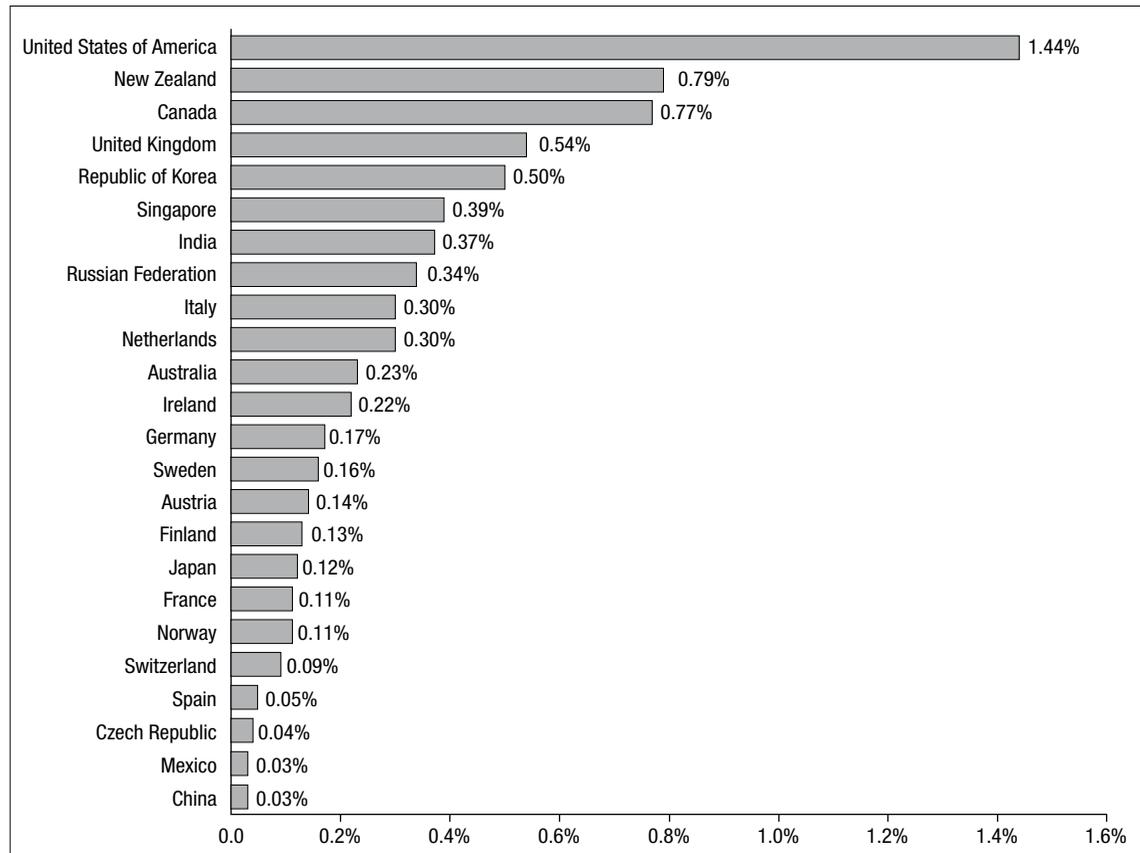
This is a first important difference with the rest of the countries compared, as philanthropy market represents in Spain only a 0.05% of the GDP, compared with the 1.4% of the USA, the 0.5% of UK, the 0.3% of Italy or the 0,11% of France (Figure 1). But it doesn't look like the only reason for the gap of philanthropy in R&I.

**Table 2.** Dimension of the philanthropy market in Spain by sources of donors, 2015.

Donors	Nº of donors	Total amount 2013 (€)	%	Media/donor (€)
Individual donors	2,609,621	469,731,780	34.41	180
Legacies	900	132,000,000	9.67	146,667
Crowdfunding	130,000	7,800,000	0.57	60
Foundations	140	680,000,000	49.81	4,857,143
Companies and company foundations	6,915	75,648,239	5.54	10,940
Total	2,747,576	1,365,180,019	100	497

Resource: information based on Spanish Tax Agency and analysis on foundation annual reports.

© Zohar 2014



**Figure 1.** Philanthropy as percentage of GDP.

Gross Domestic Philanthropy, Charity Foundation 2016, <https://www.cafonline.org/docs/default-source/about-us-publications/caf-gdp-report-v89c47ac334cae616587eff3200698116.pdf?sfvrsn=2>

The second answer is how the total amount of giving in Spain is distributed between different causes and which is the share of R&I in biomedicine (Table 3); meanwhile most the countries we are comparing with (USA, UK, Italy and France), giving to research in health and biomedicine is the first cause, in Spain is only the fifth.

Why philanthropy in R&I is in such position? Are we still a different country from the rest? The answer is close to the role of the different actors in the field, not only donors, but also to the existing funding foundations, companies and research institutions centres/hospitals or universities.

### The actors

The first reason for people to give to any cause is because they are asked for, and this is probably the main reasons for the weak role that phi-

**Table 3.** Philanthropy by cause in Spain, 2015.

Philanthropy by cause	%
Social	43
International development	3
Children	7
Environment	6
Research	6
Total	100

Zohar, based on the analysis of foundations and NGO's annual reports 2015.

lanthropy has in biomedicine. Until the deepest moment of the financial crisis the resources for research had increased continuously for years, and in the sector there was not a perception of need that drive them to focus in fundraising.



For years, research centres, hospitals and universities, from which they depend, had focused their fundraising strategies only in the institutional market: that is to say government sector, companies and foundations. Those three sectors have been strongly shocked by the financial crisis and reduced their budgets from the beginning in 2008.

Compared with other countries in Spain the number of existing giving foundations that invest in R&I is weak, with some exceptions to be mentioned like la Caixa Foundation, Fundació Cellex or Fundació Ramón Areces. The Spanish government has stand up a programme, *Fundaciones por la Ciencia*, to raise the number and percentage of the budget that giving foundations focus on R&I.

It has been only after the financial crisis that R&I centres and hospitals have been more active in fundraising from individual donors at the same time that emerge the social perception of the importance of investing in the knowledge economy.

In Spain, there are a number of fundraising foundations, like Fundació Carreras, Asociación Española Contra el Cáncer, Sant Joan de Déu or Hospital Universitari Vall d'Hebron-Institut de Recerca, but they are not the leading foundations by resources and budgets. That's an important difference when we compare them with Cancer UK with an annual budget of €500M. Although the success of la *Marató* de TV3, we just do not have nationwide telethons with such and impact as the ones in Italy or France.

### Philanthropy trends and R&I

As we have already seen the relationship between philanthropy and R&I is not stable and a lot of changes are already going on:

- The stagnation in institutional funding, governments, foundations and companies will be

kept for years and there is a need to diversify fundraising to other donors.

- When doing fundraising from companies and foundations we are all knocking always the same doors.
- There is need to communicate better the results and impact of R&I to society.
- Social perception of R&I has changed in recent years: the importance of R&I as part of the knowledge economy is already in the minds of people.
- New attitude of celebrity patients and the value of: the cases of Oliver Sacks in NYT or Pau Donés video at Vall d'Hebron Hospital, are critical to change perceptions in a society of digital communication and social media.
- We need more successful stories: from TV3 Telethon to new approaches to fundraising and philanthropy at hospital foundations and research centres, for example face to face in Hospital Vall d'Hebron.
- Although limited, hospital foundations and research centres are already receiving donations and legacies.
- At hospital foundations, donors are already inside just created the tools to let people give.
- There will be a need to look for private co-funding of EU funds, and there is no other public money for it.
- Research centres, hospitals and universities need to understand that fundraising is and investment and needs resources and time to be developed.

We are all in a moment of change but it is sure that philanthropy will have a greater role in biomedicine R&I in short term but research centres have to invest and fight for the resources.





# ConSORCI Hospitalari de Vic

Núria Roger

I would like to introduce you to the events that we have experienced in Osona that have taken more than twenty years, and which have involved lots of people.

Osona is a county of Catalonia situated approximately 70 Km to the North of Barcelona. It's a semirural county with an area of 1260 Km<sup>2</sup> that means 3.6% of Catalonia. It's formed by 51 villages. It has a population of 155,000 inhabitants, which means 2% of the Catalan population. There are two main cities Vic and Manlleu that includes 45% of the population. The population density is about 124 inhabitants/m<sup>2</sup>. So, it's a low population with a high dispersion.

Health system is distributed between different providers. Consorci Hospitalari de Vic that is the main hospital, Hospital de Santa Creu and Hospital de Manlleu that are two intermediate care hospitals and eleven clinics that provides the primary care assistance, that are distributed in several points of primary care attention.

The average income per capita of Osona is €15,462/hab (Catalonia is €16,000/hab) and the unemployment rate of 14.6% (the same as Catalonia).

The county of Osona has been characterized for years by a conscientious society that have been involved in different projects that have had as a main topic health. Most of the times this social movement has been conducted by different associations.

In 1995 the first marathon promoted by *Osona against cancer* took place. This association is widely extended in the county and it's a grass roots organization. Their members are ordinary people belonging to all the social classes with the

objective of improving the care of patients who have been diagnosed with cancer. The objective of this marathon was to raise money in order to buy different specific equipment to improve the diagnostic and treatment of oncologic illness. Rotary club Vic-Osona was in charge of the organization and direction of the campaign. The collections were taken from individuals and companies. Companies and unions were involved. In different factories, workers could fill in a donation form that authorized the giving of some quantity of money from their salary for the objective proposed.

This collection has initially the objective of raising money for a mammograph, but after analyzing the situation of different oncologic illnesses in the county the purpose was widened. The initial objective was extended to the purchase of an echograph for urology and a videolaringoscopy. The design of the campaign was based on different premises: each citizen of Osona should be involved, from the youngest to the oldest; it should have a secondary objective that would be the diffusion of the importance of the preventive campaigns against cancer. A communication strategy was designed to give answers to frequent questions of people. Another important key was to achieve the involvement of the Hospital and the Health Department. Finally, when the involvement of all the stake holder was achieved the campaign began.

The final result was a higher quantity of money than expected. Equipment could be bought and it was donated to the Consortium Hospitalari of Vic the acute hospital so it could improve the care to patient suffering from oncologic illnesses.

The remaining amount was used to create a Research Foundation FORES, which is the acronym for the Fundació d'Osona per la Recerca i Educació Sanitàries. The quantity that have been raised was €280,000 (in that moment in pesetas), and it was a great quantity for the period when the campaign took place.

The second big campaign that took place in Osona was the marathon under the topic of mental health. It was detected the necessity of a new model of organization of the attention to mental health in Osona. The objective was to raise funds to build a facility that allowed to unify and expand the care of mental health in the county in order to give a quality care appropriate to the demand of the population. Secondary objectives of the campaign were to change the paradigm about mental health illness and to achieve that mental illness could be considered as a normal illness not being a discriminative tag. It was also important to involve politicians of our county with the idea of making facilities and services closest to the citizen.

The campaign began as if an Olympic Games were with the ignition of torches. Every village has a torch that should remain alight during all the campaign in a representative place of the village. So, these torches remind people the slogan of the campaign.

Different activities took place in all the villages. The campaign raised €375,671 (62,640,070 ptas).

This marathon was the beginning of a new model of working with mental health and it has been exported to other hospitals.

At this moment, I would like to explain another two examples of raising money for health bases objectives. The campaign organized for the same association *Osona against cancer* in order to collect money for the purchase of a digital mammogram. The slogan of the campaign was "*Estimo la mama*" (I love mama). This campaign managed to raise €330,000 that were invested in the purchase of a digital mammograph that allowed to improve the diagnosis of breast cancer. The way in which money was collected was similar to the previous experience that I have explained. The donation was also given to the CHV the acute hospital.

An agreement between *Osona against cancer*, the Department of Health of the Catalan Government and the hospital was needed in order that the equipment could be donated to the hospital.

The campaign was based on different activities done in all the county with and involvement of all the councils and the different villages. Activities included collecting money in the street or school festivals, theater, sportive competition, etc. Once again, the grass roots organization started the movement of the collection of the money. Other activities were a draw for a patchwork bed cover handmade by ladies, scratch card to collect money or a fashion show.

One of the last contributions done to the health care in Osona was the new building of the oncology ward. Since the beginning of the operation of the hospital, the activity referred to oncology illnesses had increased a lot and the complexity of the treatments had also increased. Room designated to these patients had been insufficient and they received treatments in uncomfortable conditions. Also, the incorporation of other professionals to the oncologist field of knowledge, as pharmacist has showed the need to increase the space designated to oncology. A new campaign promoted by the society and conducted by the association *Osona against cancer* was designed. This was a new marathon that had also the contribution of all the villages of the county and all of the population. The new ward could be inaugurated in July 2014. It cost approximately one million euros and 70% of this amount was financed by this extensive and charitable campaign.

And finally, one of the latest contributions of the social involvement in improving population health has been the support than Rotary Club of Vic-Osona, and *Osona against cancer* have given to the project that campaigns for the screening of colon cancer. The economical support of these entities achieved by the donations of society has allowed the health service to initiate this screening program earlier than it was expected.

Finally, as a reflection of all these examples that have taken place in Osona the important points to highlight:



## Philanthropy in research and innovation in biosciences

- These projects have been possible initially by the promotion and direction of civil society that has managed to connect all the stakeholders: patients and associations, philanthropic entities, entities that provides health care such as hospitals and politicians.
- Without this cooperation, it wouldn't be possible to do this job.
- A trusting climate has been created between all the institutions and entities in the way that new projects are now easier to develop.
- The civil society of the county is able to be involved in collecting campaigns when there has been a tangible objective to fight for.
- Objective about education of the population regarding some illnesses were always included in the campaigns.





# Philanthropy, R&I by the Research Foundation of Hospital Vall d'Hebron

Alejandra Manau

## Vall d'Hebron Research Institute

Vall d'Hebron Research Institute (VHIR) is a public sector institution which promotes and develops biomedical research and innovation at the University Hospital Vall d'Hebron (HUVH). Since its foundation in 1994, VHIR is oriented towards finding solutions to the health problems of the citizens and has the will to contribute to the scientific, educational, social and economic development within its area of competence.

In our institute are working more than 1300 people, of which over 1200 doing research and others, around 100, help to do it or transfer it to the society once made, whether in the form of projects, technology transfer and innovation, communication or fundraising, among others. Our research groups have been recently redistributed from 10 to 8 research areas, hosting 56 research groups of practically every medical specialty: oncology, neurosciences, infectious diseases, cardiovascular diseases, gynecology, pediatric diseases and experimental surgery, endocrinology and nephrology, digestive and liver diseases, respiratory and systemic diseases. VHIR also count with two transversal areas, who gives support to the other 8 longitudinal areas: epidemiology, pharmacology, new therapies and clinical research, and nanomedicine.

VHIR is located in Barcelona urban area, inside the Vall d'Hebron Barcelona Hospital Campus. VHIR has two main lab buildings: the Mediterrània building (4600 m<sup>2</sup>), located by the General Area of the Hospital, and the Collserola building (2100 m<sup>2</sup>),

in the highest point of the campus (Figure 1). In July 2013 opened a new space dedicated to clinical research, placed in the 13th floor of the Mother and Child Area, inside the Hospital. A few months later, was put into operation a new module focused on Bioinformatics (340 m<sup>2</sup>), to evidence the importance of this transversal discipline in our research.

This physical proximity between clinical, teaching and researching centers facilitates the translation from the hospital to laboratory research and clinical practice. Two main factors are key in VHIR's translational medicine:

- Most of VHIR's researchers and principal investigators are at the same time leaders in the clinical practice at the hospital.
- VHIR have the beds of the hospital separated in less than 50 meters of laboratories, and the patients and the society will benefit directly from its research.

## Board of trustees

The members of our Board of Trustees are the Catalan Ministry of Health, the Catalan Ministry of Economy and Knowledge (we are a CERCA center), HUVH, Bank of blood and tissues, the Autonomous University of Barcelona (UAB), of which we are an accredited research institute, and the Vall d'Hebron Institute of Oncology (VHIO), which together with VHIR is part of Accredited Institute of Campus Vall d'Hebron Institute by the Institute of Health Carlos III (ISCIII).

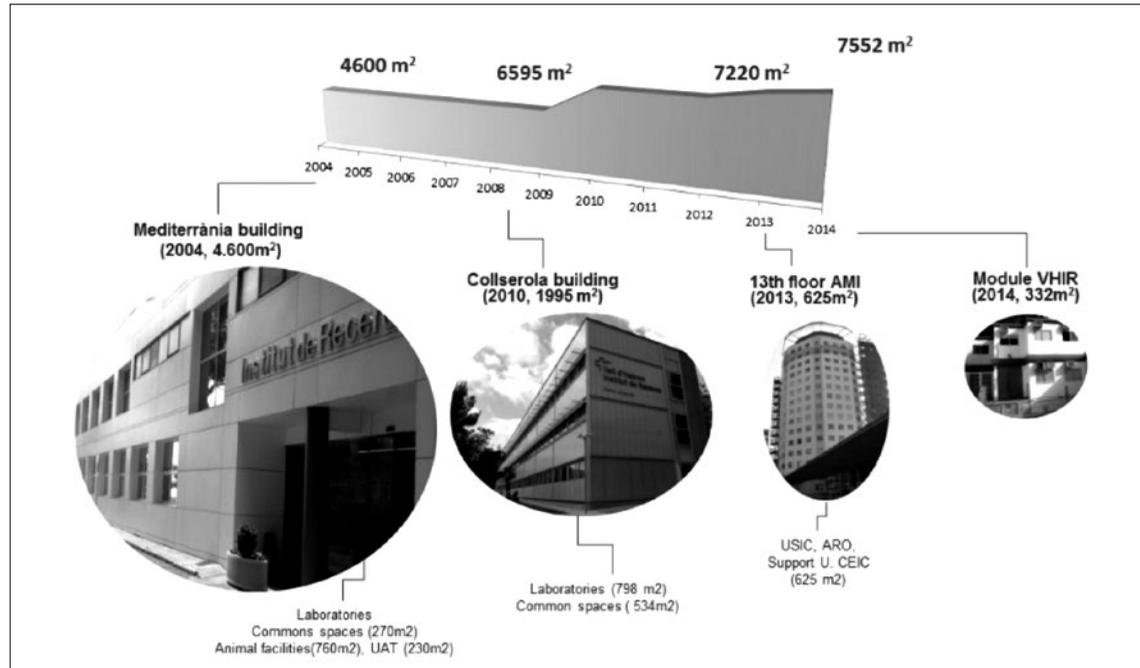


Figure 1. Distribution of Vall d'Hebrón Research Institute buildings.

## Research areas

### Longitudinal areas

- Digestive and liver diseases.
- Endocrinology and nephrology.
- Gynecology, pediatric diseases and experimental surgery.
- Cardiovascular diseases.
- Infectious diseases.
- Neurosciences.
- Oncology.
- Respiratory and systemic diseases.

### Transversal areas

- Epidemiology, pharmacology, new therapies and clinical research.
- CIBBIM – Nanomedicine.

## VHIR in numbers 2015

### Research activity

- Publications: 844 number of publications.

- Research projects and networks:
  - 86 research projects granted on 2015.
  - 290 ongoing research projects.
  - 884 ongoing clinical trials.
- Clinical trials: 351 clinical trials submitted to CREC in 2015 (325 approved).
- Events and seminars: 220 in total (2 extraordinary conferences, 62 courses, 156 seminars).
- 48 enrolled students at the second editions of the master's degree in Translational Biomedical Research.
- 36 doctoral thesis read.

### Economic summary

- Total income in millions of euros: €39.28M
  - €16.85M public.
  - €22.43M private.
- €4.37M in donations and €2.10M public funding.
- Innovation: 177 innovation requests, 88 patents, 37 cooperative projects.



### Human resources

- 1,411 staff in total:
  - 941 research staff: 613 researchers, 225 predocs, 103 postdocs.
  - 470 supporting research staff: 115 laboratories, 60 administrative, 210 graduates, 68 nurses, 17 others.

### Media and social media

- 544,984 visits at [www.vhir.org](http://www.vhir.org).
- 3445 page likes at Facebook, 4498 followers at Twitter, 3545 followers at LinkedIn, 150,936 accumulated views at YouTube.

### Raising philanthropic funds

The VHIR strategic plan 2011-2015 included in its strategic lines the “Delivering the results to society”, which means, the enhancement and the transfer of outcomes of the clinical practice research so the quality of life of patients will be improved. In order to comply with this plan, a patronage system has been established for the last years at VHIR as one of the channels to raise funds and to bring research closer to society and make people part of this progress.

The patronage strategy at VHIR mainly involves Friends of the Vall d’Hebron Research which includes people who kindly cooperate every month and every year for the research funding; it also involves companies and foundations which support all the grant programs from VHIR in order to attract and to keep the best talent with them.

Furthermore, VHIR can count on many people’s generosity who wants to spread their solidarity with future generations and channel their wish by adding in their will a solidarity legacy for progress in research and the cure of diseases.

Other ways to raise philanthropic funds are, firstly, by organizing supportive events (Vall d’Hebron Research Party, concerts, races...) and campaigns (*#GivingTuesday*, *World Ovarian Cancer Day*...) which make possible to raise awareness about the importance and need of clinical research and, at the same time, to raise funds (Figure 2 and Table 1). Secondly, we use



Figure 2. Image of the #Giving Tuesday campaign.

Table 1. #Giving Tuesday campaign information.

- #GivingTuesday is a global movement that wants to promote and multiply good deeds of people.
- #GivingTuesday first came to Spain in 2015, achieving a total of 405,000 € for the more than 260 social projects that participated.
- VHIR is one of the promoting entities from the beginning.

the crowdfunding system, allowing to collect funds through specific portals such as *Mi Grano de Arena* or SMS.

### #GivingTuesday activities

VHIR also counts with the commitment of their ambassadors, renowned professionals of different sectors who give support to the Institut by spreading our work and activity to society and media.

To conclude, special reference should be made to all the people and families that are cooperating personally or through patient’s associations to raise funds thanks to the multiple support activities that have been kindly carried out.

### Friends of Vall d’Hebron Research Institute

The Friends of Vall d’Hebron Research Institute are people committed with the advancement of our research, with the aim to find the cure of today’s illnesses. Our Friends support economically

our Institute every month and every year to promote the program Friends of Vall d'Hebron Predoctoral Scholarship.

The objective of this program is to train future researchers for three years in basic and clinical research, ending in the presentation of their doctoral thesis and becoming doctors. This program is a call for aid open and competitive to all of our 56 research groups, and aimed at graduates from any discipline of life sciences. The selection and evaluation of candidates is done by an external scientific committee to VHIR.

Since 2014, our Friends have been funding the training of 11 young researchers at our institute, doing research, for instance, in oncology, neuroscience or infectious diseases (Table 2).

They are the future of our research, and it wouldn't be possible without the support of our Friends. That's why we organize visits to the laboratories where they are developing their research projects, so our Friends can learn and enjoy from these young talented researchers.

**Table 2.** Information about the initiative Friends of VHIR (2015 data).

- 
- 1405 friends and particular donors.
  - 11 predoc –3 years scholarship– thanks to friends.
  - 4.37M€ of funds raised.
- 

### 2015, the strategic year

2015 has been a turning point year. It marked the end of the 2011-15 and the beginning of the 2016-20 Strategic Plan.

During the last five years VHIR has reached a leadership position in the biomedical research centers of Spain, especially in clinical research and specifically in clinical trials. The next five years must serve to establish this position and to be recognized as a leading, excellent and competitive research center in Europe, linked to a university hospital in clinical and translational research. Internationalization and precision medicine will be some of the keys to take the research of today to the medicine of tomorrow.



## Private fundraising for research: success stories. Hospital Sant Joan de Déu

Mercè Tura Lladó

Barcelona's Sant Joan de Déu Hospital for Women and Children is nearly 150 years old; it belongs to the Hospitaller Order of Saint John of God, which has 300 healthcare centers around the world. The hospital is a privately owned non-profit institution that has been affiliated with the Catalan Health Service since the 1970s.

Sant Joan de Déu has always had close ties with the city of Barcelona through the involvement and commitment of civil society. The institution's mission to humanize healthcare depends on the contributions, great and small, of individuals, social entities, and businesses, and these contributions have enabled the high levels of specialization and technology that have made this center an international reference in pediatrics, obstetrics, and gynecology.

Our overall mission to improve and humanize healthcare also implies the goal of reconciling the purely humane aspects of care with the development of new scientific advances. We want to promote initiatives that make it possible to reduce the negative impact of hospitalization on children and their families. We want to promote research to improve the treatment of diseases and find new treatments for patients with diseases that cannot be presently cured.

Our pediatric patients, their families, patients' associations, institutions, companies, foundations, and volunteers take the initiative in obtaining the resources necessary for each project. We are privileged to be able depend on a network of collaborators who show their solidarity in everything that they do.

Experience has shown us that defeating severe diseases is a long-distance race in which

research is the path toward the finish line. In pediatric diseases, this path is full of obstacles. One of the main obstacles to progress is the lack of funds for research into rare pediatric diseases.

In 2015, a total of 190 research projects were carried out at the hospital by 180 investigators, with the aim of improving patients' quality of life; these projects also generate knowledge that benefits society overall. These projects were funded through competitive grants from Spanish and European institutions (40%) and through private contributions (60%). In 2015, funds dedicated to research totaled €7.3 million derived from donations received over different years (Fig. 1).

Private donations for research have increased every year; in 2015 we received a total of €3,308,000, €1,785,000 (53%) of which was earmarked for research into cancer in children (Fig. 2). These private donations came from various sources, although most came from patients' families, who are our most active donors. By way of contrast, contributions from companies accounted for only 10% of our resources. It is important to point out that most funds are donated for specific research lines with concrete goals. This makes sense, given that the donors are family and friends of patients or associations that provide support for specific diseases.

Our experience in recent years has enabled us to grow and to develop a fundraising team. This team has led several projects, and we are happy to share our experience so that others can learn from our success.

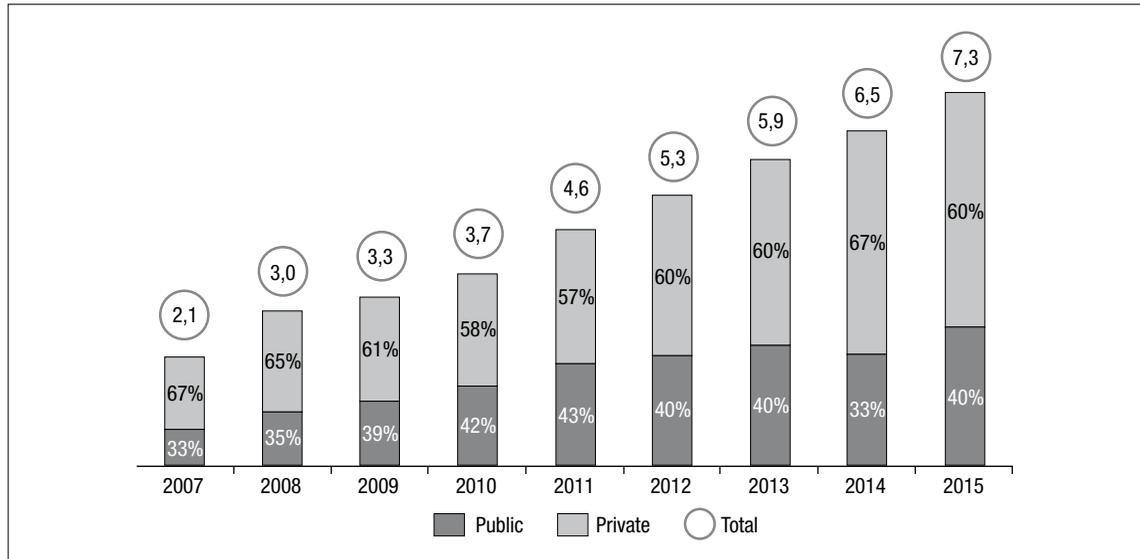


Figure 1. Total income 2015 (millions of euros)

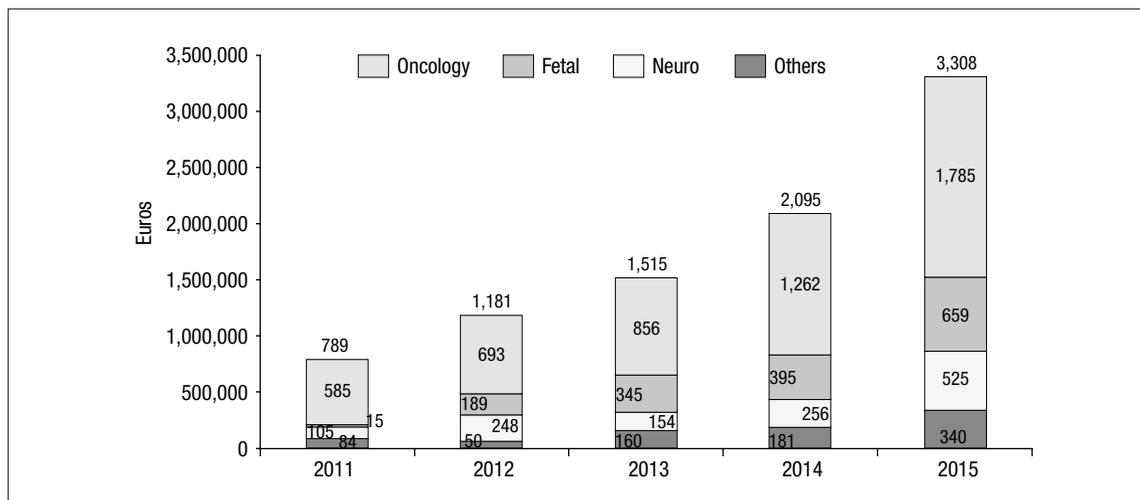


Figure 2. Total private funds obtained (thousands of euros).

### The hospital's Pediatric Oncology Laboratory is an accomplishment of civil society

Created in 2003, the hospital's Pediatric Oncology Laboratory, under the leadership of Dr. Jaume Mora, researches cancers that affect children and adolescents. Three-quarters of its budget comes from initiatives by the family entities that are interwoven into Sant Joan de Déu's research activities.

Over 10 years' experience in this project have taught us that the most important aspects of fund-

raising are increasing awareness of the disease and building hope for improved treatment.

To this end:

- We have consolidated a trend toward continuous income growth, with €1,785,000 in non-competitive private funding received in 2015.
- We have benefited from the growing involvement of patients' families and friends —every event, action, and proposal expands our network of collaborators.
- We rely on a self-sufficient management team that includes volunteers who participate in



fundraising proposals and activities. A wide variety of events have become established in our annual calendar. Especially noteworthy are the institutional oncology supper, sales of fair-trade products, and many sporting events, ranging from basketball or hockey tournaments to running the Barcelona Marathon for the Hospital Sant Joan de Déu. Society's involvement goes well beyond patients' families to include elements such as schools, parent associations, foundations, civic centers, town councils, cultural associations, and companies.

- This great movement to support research into pediatric cancer is a reference for the third sector.

Reviewing our experience, we conclude that the keys to our success are:

- The individuals that support us form part of and actively participate in the projects.
- The close working relationship among volunteers, donors, and the hospital's fundraising team leads to great ideas —taking into account a wide variety of points of view helps us to get it right.
- The multidisciplinary team guarantees effectiveness and reinforces the commitment and motivation of everyone involved.
- Everyone involved in the project —donors, volunteers, physicians, researchers, and fundraisers— benefit in a win-win situation, resulting in tangible gains, with transparency adding value to solidarity.

### Firefighters light the fuse for solidarity

The calendar *Bombers amb causa* ('Firefighters with a Cause') finances a grant dedicated to funding three-year projects. In five years, thousands of people have bought this photo calendar for €10, and this means:

- €260,000 has been collected in five years.
- The calendar is present in 7000 homes in Catalonia.

- Sales have increased every year, and the project continues to grow and to incorporate new initiatives.
- It has had a good impact in the mass media and brought recognition to our institution.
- This initiative came from a group of firefighters who wanted to volunteer to help a good cause promoting research.
- The project currently enjoys the support of the firefighters of the Government of Catalonia, of Andorra, and of the city of Barcelona.
- Patients, their families, volunteers, researchers, active photographers and photojournalists, illustrators, and various shops and stores collaborate in the project.

### Keys to success

- We promote solidarity as a collective good that adds value to the entire process of making and distributing the calendar: a product resulting from a multidisciplinary team.
- All participants share the stardom.
- We focus on transparency and creating win-win situations: everyone who participates in the project discovers positive aspects and identifies with the action.
- We maintain coherency with the final aim, ensuring maximum efficiency in management and production.

### Crowdfunding, an endless sea of actions that can be used for fundraising

Our platform *Implica-t.org* ('Get-involved.org') and other online initiatives are also examples of successful cases that provide us with a measure of power with respect to the position of the institution and add value to our brand, a reference for both healthcare and charity.

These initiatives are focused toward fundraising for research projects in various fields such as oncology, neurology, rare diseases, and diabetes. Promoters tend to be patients' families, who

are keenly aware of the diseases that their sons or daughters, nieces or nephews, or grandchildren suffer from and are highly motivated to fight against them.

Our success lies in the emotions that are implicit in the message —these are real stories, life experiences that result in a nearly immediate emotional response. Empathy is the key, because everybody knows that something similar could happen to anyone, and everyone would want to be able to count on help from others in that situation.

Our fundraising team focuses on advising families, enriching proposals, setting reasonable and feasible financial goals, and building our hospital's brand.

### *Keys to success*

- The emotion in the message is what moves society to show solidarity.
- This social impulse leads to a community that is involved and spreads its solidarity.
- We grow our circle of collaborators, and these people make others aware of our cause and bring others on board.
- The success of an action depends in large part on getting the promoters involved and ensuring they are proactive.

- Crowdfunding initiatives for the hospital add up, involving more and more people and multiplying the intake: some projects have brought in more than €30,000.

These examples of fundraising initiatives for research projects at the Sant Joan de Déu Hospital for Women and Children are only a small sample of the more than one hundred diverse activities that we carry out every year in Catalonia and in the rest of Spain.

The people who deserve the credit for these results, successes, and donations that are transformed into opportunities are first and foremost our patients, their families, and friends, followed by the team of professionals who care for them and anyone else that believes in our work and shares our vision of humane care.

It is truly gratifying to find donors committed to the Hospital Sant Joan de Déu's work, because every message, photo, idea, and campaign comes from the sincerest motivation and because it is exciting to grow our resources when we know that they will lead to better care and scientific discoveries that can lead to better treatments. And maybe someday we will find the keys to treating these diseases for which no cure is yet available.



# Role of philanthropy in biomedical research and innovation in Spain. A short review\*

Fèlix Bosch, Joan Bigorra and Josep Esteve

## Introduction

A country's standard of living and future are directly related with its basic and applied scientific research. However, it is not always easy to convince the general public that this is so. Biomedical research is probably the area where the benefits are most easily appreciated, because its accomplishments have increased life expectancy and quality of life. These advances warrant placing a much higher priority on research, development, and innovation (RDI) than we have to date. To ensure that biomedical research advances knowledge and technology, adequate funding is essential not only to undertake new projects but also to maintain them once they are underway.

Currently, however, government support for research is foundering, thus threatening the country's scientific development. This situation represents a significant step backward from what had been achieved through great efforts in the recent past. The political and economic environment is suffocating scientific and technical research in our country, and this is one of the most complex problems we face today. Moreover, unfortunately, civil society generally believes that the state should be responsible for funding all research. Society is neither sufficiently involved nor sufficiently aware to participate in RDI. This situation is paradoxical, given that Spain in general and Catalonia in particular should be proud to have generated internationally renowned research scientists, some of whom are working here and others who are working abroad. Both our society

and our political leaders should be much more aware of our country's potential in science.

The substantial cutbacks in public funding make it essential to foster private initiatives. Private initiatives can take on various forms, for example, patronage, and this is where foundations and other nonprofit organizations can play a fundamental role.

In Spain, the tradition and importance of private funding of public RDI projects cannot compare with those in the rest of Europe and the United States. Therefore, we need to analyze the situation in our environment and try to promote measures that incentivize patronage and that enable new funding strategies. Here below we will comment on venture philanthropy (philanthropic risk-involving investments) and different varieties of micropatronage such as crowdfunding. We also need to continue to emphasize efforts to increase society's awareness of the benefits of science and technology through better communication to the general public, because this is another means of boosting patronage. The future patronage law should favor this kind of initiatives considerably.

## Low funding for research

After nearly five years of progressive growth (2006-2011), all regions of Spain saw a significant reduction in funding for science, technological development, and innovation, three elements that are essential in modern economies. Cut-

\* Chapter modified from Bosch et al. (2014) and translated by John Giba.

backs hit RDI especially hard, and the decrease in the funds earmarked for RDI in the national budget in 2012 was one of the largest in history.

The State's contribution to research in 2012 was under €6.4 billion, 26% less than in 2011, when it was €8.6 billion. If we consider both the public and private sectors, the amount spent on RDI in 2012 was about €13.4 billion, which is similar to the amount spent in 2007. Moreover, in 2013, government spending on RDI fell to €5.9 billion —8% less than the year before.

On the other hand, the percentage of RDI investment in Spain is much lower than in other developed countries. To make matters worse, there is little tradition of cooperation between the public and private sectors in RDI. This is the wrong approach for a country striving for economic and industrial recovery —Spain should be trying to boost its human research potential.

Unfortunately, the situation in Catalonia is no different from the overall situation in Spain. Catalonia's expenditure on research peaked in 2008 at €3.2 billion, dropping 6% to €3.1 billion in 2011. Nearly half of this amount came from the private sector; in the public sector, 24% came from the universities, 20% from public administrations, and 6.7% from the European Union. Government funding for research in Catalonia is being cut by the central government of Spain on the one hand and by the regional government of Catalonia on the other. In 2013, funding from the central government of Spain had decreased by 40% in comparison with 2009 and by 30% in comparison with 2012. Between the start of cutbacks in 2010 and 2014, funding from the regional government of Catalonia dropped 27% (€166 million), from €608 million to €442 million.

However, apart from funding from the central government of Spain and the regional government of Catalonia, research teams in Catalonia also receive support from the European Union and private sources. The overall data show that the current political and economic decline is having direct repercussions in two pillars of biomedical and healthcare research. On the one hand, the cutbacks are affecting the institutions that participate in research, such as hospitals, universities, foundations, and public and private re-

search centers. On the other hand, they are also directly affecting the investigators, including physicians, nurses, pharmacists, biologists, and others. The financial situation not only prohibits our country from attracting talent from abroad, but also forces our most highly trained and capable investigators to emigrate and carry out their projects abroad. Finally, it is important to remember that, apart from conferring direct benefits on the institutions and individuals who carry it out, RDI also generates benefits for businesses in the sector, with all the economic and social consequences that this implies.

### Patronage in research

Before the financial crisis, one could optimistically think that research funding was changing for the better both in Catalonia and in the rest of Spain. The commitment to promoting biomedical research was very strong. Large research centers and renowned investigators, enticed from abroad or trained here at home, had helped establish quality biomedical research in our country. With this background, philanthropy for research was strengthened and inspired by the recognition of the need to create wealth that could transform the country into one of the most active focal points of biomedical research in the world. Now, however, the years of financial crisis have left their mark not only by thwarting efforts to establish this research hub, but also by weakening philanthropy and private support for research.

As long as the funding from public administrations continues to diminish, patronage will be fundamental to reverse the financial crisis in research. To discuss this aspect, we need to review the available data about patronage. These data, although not totally precise, can at least provide useful information that will allow us to analyze trends.

Donations to nonprofit organizations have decreased significantly, hurting their ability to carry out their programs. In 2011, donations in Spain reached €1180 billion, 62% of which came from partners and individual donors. However, within Europe, Spain was at the bottom of the list if we consider the number of donors as a percent-



age of the population. The second major source of philanthropic funding came from bequests, which accounted for 10% of the total. In Catalonia, donations in 2011 reached 349 million euros, in other words, 30% of the total in all of Spain. The distribution by donors varied slightly from that of the rest of Spain, with only 45% coming from partners and individual donors.

The amount donated specifically for RDI in 2011 in Spain is estimated at 160 million euros, representing 14% of all donations to charitable causes and about 1% of the total expenditure in RDI. In Catalonia, it was about €48 million (30% of the €160 million), representing 14% (as in Spain) of all donations and about 1.5% of the total expenditure in RDI. In Catalonia, most of this money came from partners and individual donors (44%), collaborative social programs (29%), and personal- and family-based foundations (12%).

### Patronage in other countries

Examples of the philanthropic vocation of American fortunes include Muriel Block, Michael Bloomberg, the Lauder family, and the Bill and Melinda Gates Foundation. The significant tax benefits of philanthropic donations in the United States can only explain a small part of the success story that many try to emulate, especially in situations of crisis and cutbacks in public funding for social services, healthcare, education, and scientific research.

Although tax breaks for charitable donations are an important incentive, cultural, historical, and religious factors are also important. American children learn about philanthropy from a very young age, and Calvinism almost obliges the wealthy to seek ways to return a part of their gains to society. Americans get personal satisfaction and social status from donating large amounts of money. Curiously, the wealthy often prefer to bequeath part of their fortunes to charity rather than to pass on the entire sum to their heirs and family. Another figure that shows the cultural differences among countries is the percentage of the adult population that donates to charity: in Europe, the mean is 50%, whereas in Spain it is only 18%.

In some countries, private foundations have been important sponsors of scientific research since the nineteenth century. Until the National Institutes of Health started to fund external research in the 1940s, more than a quarter of all medical research in the United States was funded by charitable organizations. More recently, support for nonprofit organizations in the United States has turned to other countries. In Europe, philanthropic sources currently provide 6.5% of the funds for competitive research, compared to nearly 10% in the United States.

In countries closer to Spain, some research centers are taking serious initiatives to raise private funds and strengthen their RDI. For years, the Institute Pasteur in France has been financed fundamentally by private firms and foundations without the need for any special efforts to raise funds through donations. Recently, however, this institution started a much more aggressive communication and fundraising campaign with the slogan "*Vaccinate our researchers against a lack of funds*". For institutions like this prestigious research institute, these actions are justified, because fundraising and bequests made up 25% of the resources in their last budget, with about 54 million euros coming from these sources.

In Spain, most research centers have yet to resolve the issue of fundraising if we compare their efforts with those of centers in countries with stronger traditions in this area.

### Science foundations in Spain

As mentioned above, science foundations have played a key role in general patronage of scientific research, whether as benefactors or beneficiaries. Within the so-called third sector, foundations often meet the needs of the general public efficiently and have actively contributed to our country's socioeconomic development.

No data are available about the total number of foundations in Spain or about their contribution to funding biomedical RDI. The Spanish Association of Foundations currently lists 14,011 foundations, although only about 9000 are probably active; 1849 (13%) foundations are dedicated to health research. A total of 3051 foundations

are registered in Catalonia, representing 22% of all foundations in Spain, and 324 (11%) of these work in research or health.

One of the most noteworthy philanthropic foundations working in science in Spain is the Ramón Areces Foundation, created in 1976 by the founder of El Corte Inglés, a chain of department stores. This endeavor has many points in common with those initiated by wealthy Americans. This foundation is dedicated to promoting scientific research, contributing to the development of human capital and to the dissemination of knowledge and of academic and scientific advances. Another effort worthy of special mention is the Juan March Foundation, which played an extraordinary role in the world of biology for many years.

In Catalonia, many noteworthy contributions to research have come from foundations, including international foundations like the Bill and Melinda Gates Foundation, Spanish ones like the Esther Koplowitz Foundation, and Catalan ones like the Cellex Foundation or “la Caixa” Foundation. There are also institutions in Catalonia that receive funds and directly promote research, such as the Hospital Clínic de Barcelona, the Vall d’Hebron Institute of Oncology, the Josep Carreras Leukemia Foundation, the Hospital Germans Trias i Pujol Health Sciences Research Institute, the Hospital Sant Joan de Déu Research Foundation, the Pasqual Maragall Foundation for Research into Alzheimer’s Disease, the IrsiCaixa AIDS Research Institute, the Barcelona Global Health Institute (ISGlobal), or the Institute of Photonic Sciences, among many others.

Without doubt, the main sponsor of science in Catalonia has been the Cellex Foundation, founded by the Catalan industrialist Pere Mir. It has contributed in three main ways: 1) providing state-of-the art equipment for clinical practice and scientific research; 2) remodeling and constructing research buildings for the Institute of Photonic Sciences, the Hospital Clínic de Barcelona, and the Vall d’Hebron Institute of Oncology; and 3) funding research programs in regenerative medicine, malaria, epigenetics, and cancer, among others. The Institute of Photonic Sciences is considered one of the world’s best centers in

both basic and applied research in photonics. This prestigious center emphasizes the cross-cutting nature of photonics and its possible applications in medicine, energy, telecommunications, and nanotechnology. A recent example of its application in medicine from research at the center is a diagnostic instrument based on the noninvasive monitoring of blood flow as an approach to cardiovascular disease.

The “la Caixa” Foundation is the greatest supporter of biomedical research projects, bestowing various kinds of scholarships and grants. Although it is true that the Foundation’s investment in research has grown in recent years, this investment still represents only a small proportion of the funds it allocates for other charitable initiatives. The “la Caixa” Foundation has participated in research projects at hospitals and reference centers in Catalonia in such diverse areas as AIDS, vaccines, oncology, aging, cardiology, digestive disease, endocrinology, and multiple sclerosis.

The Fundació La Marató de TV3, with 20 years’ experience, has become a reference point not only in Catalonia but also in the rest of Spain and abroad. This foundation raises significant amounts of money, helps disseminate biomedical science, and boosts crowdfunding; moreover, it is characterized by exemplary organization in the awarding and follow-up of all of the grants it allots.

On the other hand, the Autonomous Government of Catalonia fosters private investment through the Catalan Foundation for Research and Innovation. This foundation’s goal is to facilitate the connection between public-sector and private-sector research and to increase patronage for science. The Catalan Foundation for Research and Innovation has undertaken diverse initiatives to modify the fiscal framework for philanthropy and to improve the social perception of patronage in our country.

Finally, it is also worth mentioning the considerable contributions to research of much more modest, but no less important, foundations. The Fundació Vila Casas, apart from promoting contemporary Catalan art, also sponsors activities to disseminate medical knowledge through meetings and publications in collaboration with the



Science Communication Observatory of Pompeu Fabra University. Other examples include the Víctor Grífols i Lucas Foundation, which focuses above all on activities and publications related with bioethics, and the Uriach Foundation. The contribution of the Esteve Foundation also deserves to be pointed out. Oriented toward favoring scientific discussion and communication in pharmacotherapy, this foundation organizes a wide variety of national and international meetings, awards research prizes, and is firmly committed to the training of biomedical and healthcare professionals. The Esteve Foundation also publishes a wide range of scientific materials and distributes them free of charge.

### Healthcare professionals and philanthropy

Most of the above-mentioned philanthropic institutions primarily favor investments in facilities and cutting-edge research projects. However, as is also mentioned above, some orient their patronage toward the actual people who carry out biomedical and healthcare research, in other words, toward healthcare professionals and researchers. Some philanthropic institutions provide support in attracting talent or training biomedical and healthcare students by awarding grants, clinical or research prizes, and courses. It is just as important to develop talent through training as it is to attract and retain talent. For this reason, the new patronage law should make it easier to attract talented individuals who, for diverse reasons, have to go abroad to develop their professional careers.

Many internationally renowned investigators have settled here or combine their activity here and abroad to promote high-level scientific research. All these prestigious investigators could potentially benefit from philanthropic contributions to research. Society should be made much more aware of the important role of world class investigators and pay more attention to them.

### The legal framework

At present, our country suffers because of insufficient legal support and scant fiscal incentives

for donations. This represents a serious obstacle to funding nonprofit organizations that generates great difficulties in the execution of the programs they develop for the benefit of all.

The current law for a special tax regimen for nonprofit organizations needs to be improved to adapt it to the current circumstances so that it can foster more and new philanthropic initiatives. The law needs to be changed to boost donations for social action, cooperation, research, education, and culture. It should foster the general public's participation in activities for the public good by increasing the percentage that can be deducted for donations to nonprofit organizations. It would be beneficial to achieve higher deductions for corporations and individuals. For example, in some European countries like Austria, or in the United States, 100% of the amount donated can be deducted. To foster patronage in RDI, the law should make it easier to donate to hospitals and research centers, without the need for them to set up foundations. It should also take into account philanthropic risk-involving investments, in other words, investments with clear social objectives that aim for modest returns. Apart from boosting philanthropy, our society should also seek ways to increase public recognition for the role of philanthropists. Finally, the new law should consider crowdfunding as way to support science with or without the possibility of financial returns for donors.

### Some proposals and recommendations

The following list summarizes some proposals and recommendations that could help boost philanthropy for biomedical and healthcare research and innovation in Spain (Bigorra y Bosch, 2014):

- Bring science and technology closer to society through the collaboration of scientists, institutions, and the media.
- Foster a culture of science and patronage among the general public, making people aware of the importance of research in general and of biomedical research in particular.
- Increase our political representatives' awareness of the importance of research and of the

need to encourage patronage, learning from successful social and scientific experiences in other environments.

- Work to increase public recognition for researchers and philanthropists. Increased awareness of the general public and political representatives could lead to better recognition for researchers and philanthropists. Healthcare and teaching are as essential as research itself.
- Involve universities in philanthropy. Universities have the mission to educate and train, so ensuring long-term research, especially basic research, is partly their responsibility. There are already philanthropic initiatives and collaborations with universities in our environment, but these must be strengthened.
- Motivate and involve the members of research centers and hospitals in philanthropic actions. Successful fundraising depends on involving the members of research institutions in actions to promote philanthropy. These people should act as ambassadors for their hospital, foundation, or research group, establishing relationships and contacts to capture funds.
- Strengthen the role of the institutions and ensure the professionalization of their chiefs in obtaining resources through foundations and research centers. This professionalization should be combined with the incorporation of young people into research management.
- Appeal to possible donors. Some of these recommendations can be oriented toward increasing both crowdfunding and patronage from the very wealthy. As a general rule, to persuade potential donors, messages must be motivating, clear, and understandable, through a convincing story about the research being promoted and information about the benefits that can be expected. Technology and social networks are key tools for strengthening communication from institutions that benefit from patronage. Finally, it would also be advisable to seek different ways to reward donors.
- Establish simple and fast channels to process donations. Individuals and corporations need simple and fast ways to send donations to the institutions that benefit from them. It is surprising that the process of donating to a research or care facility is often so complicated.
- Establish lines of cooperation among different entities. In addition to individual efforts, collaborative and shared fundraising initiatives will become more and more common. Cooperation among institutions is the key to social innovation and one of the aspects that make nonprofit and charitable organizations different from other organizations.
- Ensure more transparent philanthropic relations. Transparency is a hot topic even in countries with much stronger philanthropic traditions than ours.
- Strengthen communication from the institutions that benefit from patronage. Appropriate communication is fundamental for transparency. This communication should also involve the scientists themselves.
- Seek out applications of the projects funded that can lead to greater social impact. The priority for allocating the funds raised should be for projects that have the greatest social impact as a return on investment.
- To strengthen basic research projects, it would be a good idea to change more long-term fundraising strategies.
- Explore new models of patronage and sponsorship: move toward a new philanthropy. Most philanthropists are not making the necessary changes required to adapt to the current situation. There is talk of a “new philanthropy” in which philanthropists are more demanding when they choose benefactors to administrate their donations; they ask for more explanations about results and require greater competence and transparency. In this way, they can exercise greater control over their donations.
- Strengthen micropatronage as a new alternative. The new patronage law should foster



crowdfunding and encourage individual donors and bequests. Crowdfunding is growing considerably, although its use for biomedical research is merely anecdotal.

- Stimulate initiatives to increase awareness of the need for a new patronage law. Avoid delays in approving the new law and make sure that it takes into account the needs outlined above, such as better fiscal incentives, increased social recognition, and the development of new patronage solutions. And most importantly, develop a legal and fiscal framework that stimulates and rewards philanthropy in science and medicine.

## Conclusions

We need to continue to have confidence in our institutions' capacity to research and innovate, and at the same time we need to work to increase their ability to compete. At the institutional level, we cannot continue to decrease investments in RDI because doing so would leave us without a sufficient scientific and technological base from which to grow once the current economic downturn has been overcome. Improving philanthropy for research and innovation in Spain would involve cultural change, legal and fiscal changes, greater social awareness, more activism in patronage, increased professionalization, and mechanisms to facilitate donations in a new philanthropic environment. In the end, the beneficiaries of biomedical and healthcare research are the members of society themselves, who would enjoy better treatments and much better understanding of the many diseases that we suffer. In this sense, it should be clear that we can all help to improve the current situation.

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# Reflections on key factors in philanthropic fundraising

Joan Bigorra and Antoni Plasencia

After the outstanding symposium on *Philanthropy in Research and Innovation in Biosciences* held by “Obra Social de la Fundació la Caixa” and Esteve Foundation in September 2015, it seemed appropriate to capture the flow of fresh and innovative thoughts and proposals to elaborate on what are the hints and the key success factors in fundraising through philanthropy in biomedical research and innovation.

## A short introduction

In the 20th century, philanthropy has long followed and contributed to the steady increase in public funding to support academic science, particularly in the United States due to a number of factors that include social recognition and fiscal policies, which are, for the time being, far from applicable to Europe. Regrettably this public funding is turning stagnant across the world in the beginning of the 21st century, while Government's support to higher education institutions and research centers has fallen significantly. To solve some of our greatest societal problems, we not only need to focus on basic science research, we also need sufficient resources and new approaches. Without adequate resources, great visions cannot be fulfilled. Although private funding cannot match the scale of Government funding, it can help to fill the gaps. And, most importantly, it can initiate thrusts into unproven directions, which generally do not draw government funding.

Philanthropic investment in biomedical research is ideally positioned to make relatively high risk investments that could significantly move a

field of research forward and increase the likelihood that other parties will also invest.

Considering the wider experience in certain countries (i.e., USA) it can be said that although private philanthropy is only a small share of overall spending, its flexibility and focus on outcomes have an outsized impact on the biomedical research enterprise.

Thus, it seems clear that fundraising through philanthropy is no longer an option, but a need to sustain impactful medical research in the current global scenario.

## Some general hints

Through the Symposium there were a number of general statements or soft hints from experts and innovators, from speakers, panelist and participants on how to raise the chances of success, that we believe are worth outlining:

- Do friend-raising before fundraising.
- Make it easier to donors.
- “Touch” people.
- Choose the medical topic well.
- Keep an attitude of readiness.
- Jump over emerging opportunities.
- Assume that there is no interest for “collective best” among top researchers and cope with it.
- Anchor the campaign internally.
- And just a reminder: “be hard on issues and soft on people”.

### A reflection on key success factors

Besides some external factors, such as appropriate fiscal incentives, political support and social recognition, that are widely accepted as highly positive influencers of philanthropy, one has to consider also the internal managerial aspects that can make a difference in fundraising.

Most nonprofits with a long track record of tangible results have inspirational, often visionary leaders. But visionary leadership should not be confused with visionary management. Effectively resetting aspirations and strategy, institutionalizing sound management processes, improving systems to work at scale –progress on any of these aspects requires managerial ability, as well as good leadership.

There were a number of highly stimulating presentations and discussions addressing the “harder” managerial aspects of fostering and fundraising initiatives and projects, which we shall summarize in 10 key success factors:

- Having a strong organizational vision which can be communicated through a short sentence by all members of senior management.
- Remarking the unique aspects of your work and facts and figures about its impact.
- Telling a compelling story about why are you asking for funds.
- Being credible and knowledgeable and allow for measuring and tracking your notoriety.
- Being a leader ready to commit a substantial proportion of your time to the job of finding and engaging donors.

- Providing inspiring explanations of the difference that will be achieved with a donation.
- Having a clear fundraising strategy: taking into account internal and external factors (competition, changes in the environment, most likely sources of financial support), amount invested, a consideration of all fundraising aspects and sources.
- Analyzing the “market” carefully and identifying future prospects.
- Gathering a professional and committed fundraising team and promoting people’s capabilities.
- Getting the commitment of all the concerned departments and teams.

### Some final considerations

Unlike governmental or industry players, private foundations and individual donors are free from obligations to political constraints or shareholders, so they can direct their donations to the projects or organizations they choose. Philanthropy can serve as a reliable source of funds for innovative research that might not be able to compete effectively for public or industry funds.

However, developing and executing a sound strategy of fundraising through philanthropy requires not only a strong institutional leadership, as an absolute must be, but also a dedicated professional team, a clear and focused strategy and strong quality assessment systems and processes.

On top of that, please apply the “hints” that the experts in this symposium openly and generously disclosed to us all.

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