Eyes on the future: inspiring the new generation of cancer experts in Latin America

Dr. Márcio Debiasi shares his experience of the first Clinical Research Management Training for young oncologists.

Projeto CURA - when science and creativity unite to fight cancer

Engaging and educating all of society through art, music, design and sports to support cancer research.
On building bridges… not walls!

The moment seems to be quite appropriate for this discussion. We are living challenging times during which a significant number of people in the world seems to be favouring things that would keep us apart while challenging the concept of building what could bring us closer.

One of the most important paradigms of the Breast International Group (BIG), if not the most important, is that international collaboration is crucial to move breast cancer research forward. Globalisation is an arduous, convoluted and multifaceted concept. However, most of the scientific community agree that it is the best way to address the questions we face while dealing with patients with cancer. Cancer is a global problem and needs to be fought collectively.

And BIG is doing just that, looking for ways to increase international participation in breast cancer research by helping to address local challenges. This issue of BIG Research in Focus tells the story of a process that started with a visit by Martine Piccart, Fabrice André and representatives from BIG Headquarters to Porto Alegre a couple of years ago. There, they met with the six BIG member research groups working in Latin America. A careful analysis of the regional clinical research scenarios led to a few – but extremely important – conclusions. Some of the output of the discussion is presented here.

From a broader BIG perspective, one important point that cannot be stressed enough is that this process, and the way BIG leadership is dealing with challenges to international collaboration does not apply only to Latin America. Other regions of the world probably share the problems that were addressed and, while solutions should clearly be considered to be context dependent, there is obviously a broader applicability of the strategy to tackle these challenges.

Two issues are particularly important. The first is the need for professionalisation of research activities. This demands the development and continuous support of young dedicated talents as a key for the future expansion of research in our and other developing regions of the world. In his article, Dr. Debiasi addresses one recent attempt to address this problem which, we hope, will have positive consequences in the very near future. The other crucial and very practical aspect we identified in discussion with BIG leadership and staff was the vital need for financial support. While this is a problem everywhere, we agreed to consider the economic and cultural particularities of each region to develop a strategy with the highest chances of success. What works in Belgium or in the USA may not necessarily apply in Brazil or Peru. Fernanda Schwyter tells the story of an innovative and creative project aiming to change the local culture of patronage to support sustained research organisations in the Latin American region.

Remember this is a collective process, and we count on you to contribute!

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Breast cancer research in Latin America: challenges, progress and future possibilities

By 2030, it is predicted that there will be 1.7 million new cases of cancer diagnosed each year in Latin America, and over 1 million deaths from the disease. Yet, cancer research in the region has lagged well behind that in the USA and Europe. To address this problem, leading Latin American cancer experts from the BIG network met in Porto Alegre, Brazil, in 2014, to discuss perceived barriers to clinical research, particularly for breast cancer, and to draw up a plan of action. Two years on, Jenny Bryan spoke to some of the participants as well as to key opinion leaders in the field of academic cancer research. She discovered that considerable progress is being made in encouraging breast cancer research in Latin America.

A series of initiatives aimed at putting Latin America firmly on the map for breast cancer research is focused on reducing regulatory delays, training clinicians, improving infrastructure and boosting funding. Through a growing network of cancer organisations across the region, leading experts are steadily building a new culture of research which they predict will have a major impact in the years ahead.

"Breast cancer is a significant and growing problem in Latin America, and mortality is higher than in Western Europe and the USA. Results of clinical studies performed outside Latin America may not be applicable to women in our region, so it's important that we perform trials focusing on our particular problems," explains Professor Carlos Barrios, Executive Director of the Latin American Cooperative Oncology Group (LACOG) and Director of the Center for Research in Oncology at the São Lucas Hospital, Brazil. "We need to consider the important differences in subtypes of breast cancer, as well as stage at diagnosis and the available treatments, all while taking into account local ethnic and socioeconomic factors, and variations in access to treatment," he adds.
At present, Latin America takes part in only 5% of ongoing cancer trials, and 90% of the research studies that do take place in the region are funded by pharmaceutical companies. Professor Barrios points out that, while the level of pharmaceutical involvement confirms the expertise and the quality of research centres along with their staff, there is an urgent need for more independent academic research.

“We need to answer important questions about breast cancer in Latin America that pharmaceutical companies aren’t interested in. At the same time, research and innovation are integral parts of development in any society. We will only evolve if we can generate credible scientific information with high quality research,” he says.

Dr Raúl Sala, member of the Board of Directors of the Grupo Argentino de Investigación Clínica en Oncología (GAICO), agrees that Latin American participation in breast cancer research is important for generating results that are valid for the relevant populations. In addition, he highlights the need to understand the attitudes of Latin American patients towards their disease and its treatment and how these affect their adherence to medication.

“It’s also important for oncologists to know how to set up the technologies for different treatments and to deal with toxicities, and they can do this by participating in clinical trials. Without this, we risk new drugs being introduced into our countries without oncologists having any experience of using them and managing their toxicities,” he says.

International research organisations, such as the Breast International Group (BIG) and the European Organisation for Research and Treatment of Cancer (EORTC), recognise the importance of including Latin America in major breast and other cancer trials and support training for the next generation of oncology researchers (see also pages 11-12). However, they find that the cumbersome regulatory systems for approving clinical trial protocols and the lack of infrastructure to support clinicians during studies are a significant handicap.

“We want trials run under the BIG umbrella to reflect real life as widely as possible, and we know that researchers in Latin America are incredibly motivated and enthusiastic to participate. But we have encountered regulatory barriers, especially in Brazil, which has meant that potential investigators were unable to participate or only started to recruit a few patients at the end of a study, which is a great pity,” says BIG Chair, Professor Martine Piccart.

Dr Denis Lacombe, Director General of the EORTC and member of LACOG’s Advisory Board, explains that the organisation is eager to look beyond its European borders for collaborators. The increasing complexity of today’s cancer trials of biomarker-guided treatments means that international recruitment across large populations is essential for finding sufficient patients with appropriate tumour mutations, but the EORTC has also encountered regulatory and infrastructural barriers.

“Clinicians may be well trained and experienced but if they don’t have the facilities for clinical trial coordination and data management it’s very difficult to do the important public health type studies that are needed,” he says.

While countries such as Brazil and Argentina may be large enough to participate at a national level, the EORTC would need to partner with smaller countries through a regional organisation.

“Nothing is black and white but, while there may be very enthusiastic researchers in countries such
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as Bolivia or Uruguay, it’s much more efficient for us to work with a single coordinated ‘one-stop-shop’ platform for the whole of Latin America rather than to try and work with the smaller, individual countries,” says Dr Lacombe.

Even so, he and Professor Piccart remain optimistic that the barriers to breast cancer research in Latin America can be broken down and that these countries can make a valuable contribution to the understanding of breast cancer and its treatment.

Speeding up regulatory approval for clinical trials

Recruiting over 8300 patients with early-stage breast cancer to the ALTTO study of adjuvant lapatinib and/or trastuzumab was a major undertaking for BIG groups and their centres between 2007 and 2011. A subsequent analysis showed significant differences in regulatory approval time across the 44 countries that took part in the study.

While it took a median 26 days in North America, 52 in Europe and 62 in Asia Pacific countries, it was a median 236 days before South American centres received the regulatory approval they needed to participate. Even this was quite fast compared with the 18 months it has frequently taken to get clinical trial approval for other studies in Brazil.

Professor Barrios explains that improving regulatory timelines has been a high priority because of the effect of delays on clinical research in Brazil. “Patient recruitment is a competitive business, he says, and Brazilian as well as other Latin American oncologists have consistently found themselves so late to the starting line that recruitment to many trials is almost over by the time they are ready.” In Brazil, legislation forbidding the export of biopsy samples has made life even more difficult for researchers, given the growing use of tumour biomarkers to identify patients eligible for different treatment options.

“It’s not just legislation that has held us up, it’s government ideology about research. We are spending a lot of time on educating the authorities to show that everyone can benefit from clinical research – clinicians, patients, research sites and institutions, sponsors and countries,” says Professor Barrios.

In the case of biopsy material, it was important to correct misinformation about the potential for inappropriate use of genetic information derived from sample analysis.

“We have made great strides in the last 18 months in Brazil, and I’m very optimistic that new legislation will soon be passed that will speed up regulatory processes. We are also educating people around the problem of biopsy samples and I don’t envisage this being a problem for much longer,” predicts Professor Barrios. As a result of the collective efforts and a lot of pressure from many investigators and patient organisations over the last few months, recent trials have received full regulatory approval in Brazil in less than five months, a record time!

In Argentina, progress is also being made in speeding up regulatory processes, thanks to a three-way alliance between oncologists and key government bodies involved in cancer policy and drug regulation. The collaboration, which includes GAICO, the National Cancer Institute of Argentina, and the Administración Nacional de Medicamentos, Alimentos y Tecnología Médica (ANMAT), has the potential to expand the country’s cancer research base and speed up approval of clinical trial protocols.
Dr Sala explains that, since it was first created by the Ministry of Health in 2010, the National Cancer Institute has recognised the importance of research in Argentina and understands the issues that need to be addressed. ANMAT, one of the first national regulatory agencies to be set up in South America, already audits and inspects sites to ensure the quality of clinical research. So Dr Sala is confident that, by working with these organisations, GAICO can achieve the desired effect on clinical trial regulation.

“In recent years – particularly in the last year – we have seen an improvement in the regulatory process and a better understanding of the need for a faster and simpler regulation of clinical trials,” he says.

For example, while regulatory delays meant that only a few centres were able to contribute to BIG’s APHINITTY study of single-versus-dual anti-HER2 therapy in women with human epidermal growth factor receptor 2 positive (HER2+) breast cancer, the situation was very different with the recent OlympiA study of olaparib in women with BRCA-mutated, high risk HER2- breast cancer.

“We achieved rapid regulatory approval, which meant that we started with seven sites involved in the trial, and that has now increased to 11. It’s a very important study for us, not only because of the funding, but because of the responsibility and the fact that we are able to turn many clinical trial processes from theory into practice,” concludes Dr Sala.

Improving infrastructure

Lack of infrastructure is one of the most commonly cited reasons for the limited amount of breast cancer research being carried out in Latin America where there are just two research sites per million population, compared to the 10 to 12 per million present in Western Europe and 80 per million in the USA.

To address this problem, LACOG was established in 2008 to build a network of investigators in oncology in order to develop, conduct and coordinate academic research and clinical trials in the region, in addition to educating and
encouraging clinicians to become involved in research.

Starting with a core team of a research physician, a statistician and an executive secretary, LACOG built key research coordination and data monitoring and management services that formed the basis for subsequent developments. LACOG now has 147 investigator members from 70 institutions in Argentina, Bolivia, Brazil, Chile, Colombia, Cuba, Ecuador, El Salvador, Guatemala, México, Nicaragua, Panama, Peru, Venezuela and Uruguay.

“We created the basic infrastructure at a central office so we could coordinate the efforts of all the good quality research centres in the region. We are now increasing the number of trials that we are conducting, including a significant number of epidemiological studies, for which there is a great need. We now have a total of around 7000 Latin American patients in these studies,” says Professor Barrios.

Within this research there are a number of breast cancer studies that are shining new light on the nature of the disease in Latin America and its management. These include a recently published phase II trial of anti-HER2 therapy with lapatinib in combination with capecitabine, vinorelbine or gemcitabine in women with breast cancer progressing after taxane therapy. The study was coordinated by LACOG across 16 centres in Brazil, Argentina and Peru.

Other ongoing breast cancer studies in which LACOG researchers are participating include:

- **PENEOLEPE-B** (LACOG0313 / BIG 1-13): A phase III study evaluating palbociclib in patients with hormone receptor positive (HR+), HER2-normal primary breast cancer with high relapse risk after neoadjuvant chemotherapy. This study is sponsored and conducted by the German Breast Group (GBG) under the BIG umbrella.

- **The International Programme of Breast Cancer in Men** (LACOG0413 / BIG 2-07): An international study of the clinical and biological characterisation of male breast cancer. This study is coordinated by the EORTC (sponsor outside the USA), the North American Breast Cancer Group (NABCG), and the Translational Breast Cancer Research Consortium (TBCRC) (USA) and involves 8 research groups from the BIG network.

- **AMAZONA III** (GBECAM0115): A prospective evaluation of breast cancer at Brazilian institutions, sponsored by Grupo Brasileiro de Estudos de Câncer de Mama (GBECAM).

- **PALLAS** (LACOG0715 / BIG14-03): A randomised phase III trial of palbociclib with standard adjuvant endocrine therapy versus standard endocrine therapy alone for HR+/HER2- early breast cancer. This study is led by the Alliance Foundation Trials, LLC (AFT) (sponsor in USA), and Austrian Breast & Colorectal Cancer Study Group (ABCSG) (sponsor in the rest of the world), in collaboration with BIG.

While LACOG acts as an umbrella group for cancer research in Latin America, a number of national organisations are also forging strong links between oncologists interested in clinical research. In Brazil Grupo Brasileiro de Estudos do Câncer de Mama (GBECAM), which has been temporarily integrated into LACOG’s infrastructure, develops, implements and facilitates multi-institutional clinical studies in breast cancer and supports educational programmes about the disease. It has members in 17 major cancer centres and aims to extend its membership to all of Brazil’s cancer centres over the next few years.

Ongoing breast cancer studies in which GBECAM members are taking part include:

- **ALITTO** (BIG 2-06): A phase III study of lapatinib and trastuzumab as adjuvant treatment for patients with HER2+ primary breast cancer. The study is sponsored by Novartis and conducted by BIG, Institut Jules Bordet’s Clinical Trials Support Unit (IJB CTSU; formerly BrEAST Data Centre), Frontier Science Foundation and Alliance (former NCCTG, sponsor for the USA).

- **Neo-ALITTO** (BIG 1-06): A phase III study of neoadjuvant lapatinib, trastuzumab and their combination plus paclitaxel in women with HER2+ primary breast cancer. The study is conducted by SOLTI, BIG, IJB CTSU, Frontier Science Foundation.

- **CIBOMA**: A phase III study of capecitabine and adjuvant treatment in triple negative breast cancer, run in collaboration with the Ibero-American Breast Cancer Research Coalition.

- **CAP NEO**: A phase II study of neoadjuvant treatment of patients with locally advanced triple negative breast cancer with cyclophosphamide, Adriamycin and cisplatin, sponsored by GBECAM.

There are a number of breast cancer studies that are shining new light on the nature of the disease in Latin America and its management.
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• AMAZONA 2: An update of a large retrospective survey of breast cancer patients treated in Brazil to get data on numbers of patients, care offered and survival.

In Argentina, where about 10% of oncologists are involved in research, GAICO members are also initiating their own studies and participating in international breast cancer trials, such as APHINITY (BIG 4-11) and OlympiA (BIG 6-13).

Another priority is to build stronger links between basic research scientists and clinicians.

“We have high quality basic researchers in Argentina, but they don’t always speak the same research language as clinical researchers. So we need to gain a better understanding of the needs and challenges of basic scientists so we can take the results of their studies forward into clinical research,” says Dr Sala.

He believes it will also be important to extend the remit of GAICO beyond its current membership of oncologists so that it includes surgeons and radiotherapists, and there is potential for subgroups specialising in specific tumours, such as breast cancer.

Enhancing access to cancer care

All initiatives to increase breast cancer research in Latin America must be seen within the context of the variability of healthcare provision and limited funding in the region. Approximately half of the 600 million people living in Latin America are not covered by health insurance and very few countries have universal health insurance for patients.

Professor Barrios explains that access to modern cancer treatment is one of the main challenges that requires particular attention. This problem is not exclusive to Latin America. A significant and impressive discrepancy illustrates this point: 88% of the new drugs released by pharmaceutical companies over the last five years are consumed exclusively in the USA (55%), Western Europe (23%) and Japan (10%). The rest of the world uses only 12% of the total amount of new drugs. Opening clinical trials with new drugs in the countries with limited access may offer an invaluable opportunity to provide treatments that would otherwise not be available for a significant number of patients in Latin America and other regions of the world.

Professor Carlos Barrios

Breast cancer in Latin America

With at least 115 000 women diagnosed with the disease each year, breast cancer is as common in parts of Latin America as in many other parts of the world. The incidence is lower in northern countries of Latin America, such as Mexico, Panama, Colombia and Ecuador, and more common in Argentina, Uruguay and Chile, where the incidence is comparable with that of Europe and the US. In recent decades the incidence of breast cancer has increased by 30% in Latin American countries with national or regional registries, though the incidence in Brazil appears to have peaked and started to decline. The general rise is attributed to changing reproductive, dietary and hormonal risk factors associated with socioeconomic development. Improvements in screening and diagnostic services are also thought to play a role in some countries.

Each year, over 37 000 women die from breast cancer, though mortality rates vary across the region. Mortality rates are declining in Argentina and Chile, in line with those in Europe and the US, while levels are stable in Mexico and Colombia, and rising in Brazil and Cuba. In Chile, the improved mortality has been related to the introduction of a primary care mammography screening programme in 2001, leading to a rise in early stage diagnosis from 43% in 1999 to 70% in 2003. In contrast, in some other Latin American countries, including Peru, Colombia and Mexico, about half of cases of breast cancer are diagnosed at an advanced stage.
“This is another important reason for clinicians to become more involved in clinical trials in cancer, especially as we see more drugs emerging with potentially curative effects”, says Professor Barrios.

Although patients may be wary of trials at first, he adds, they are eager to take part once the purpose is explained.

“In Brazil, the refusal rate is very low – less than 5% – but we need to educate not only the patients about the opportunities to take part in clinical trials, but also the physicians,” he says. “In many cases, doctors are unaware of clinical trials available at cancer centres and patients often have to travel long distances to take part. This is another reason why we need more clinical research sites to bring optimal cancer care nearer to patients’ homes.”

Despite progress in overcoming many of the barriers to cancer research in Latin America, funding remains a major issue. In 2011, Latin America spent 0.65% of its GDP on research and development, 3.4 times less than in developed countries, and Brazil was the only country to spend more than 1%.  

The economic downturn is thought to result in further reduction in public funding for research.

In Brazil, a new initiative, Projeto CURA (the CURE Project), is aiming to encourage philanthropic sponsorship of cancer research through the arts, sports and social events (see pages 13-14).

“We hope that Projeto CURA will spread to other countries of Latin America and help to develop a culture of giving similar to that which is already present in the USA and Europe,” explains Professor Barrios.

A brighter future

As the barriers that have held back breast cancer research in Latin America are gradually broken down, clinicians in the region will be able to make a much larger contribution to the global understanding of the disease.

“Latin America is a large territory and, with some investment, it has the potential to build a very significant platform for clinical research and this, in turn, will help improve patient access to better treatment,” says Dr Lacombe.

Across Latin America, other national organisations are building infrastructures and networks for clinical cancer research including:

GOCCHI (Grupo Oncológico Cooperativo Chileno de Investigación), which plans, promotes and develops cancer research in Chile, and encourages collaboration between healthcare providers, universities and the Ministry of Health.

FICMAC (Fundación para la Investigación Clínica y Molecular Aplicada del Cáncer), which was created to develop new models of personalised cancer diagnosis and treatment in Colombia, through molecular and clinical research.

GECOPERU (Grupo de Estudios Clínicos Oncológicos Peruano), which focuses on epidemiological and basic sciences research and clinical trials in cancer.

GOCUR (Grupo Oncológico Cooperativo Uruguayo), which includes a breast cancer working group, promotes and develops clinical or basic-clinical studies in Uruguay related to the prevention, diagnosis and treatment of cancer, through cooperative and multidisciplinary research with national and international projects.

GOCCHI, GECOPERU, and GOCUR are also members of the BIG network.
Meet the experts

Carlos H. Barrios, MD
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- Co-founder and Director, Latin American Cooperative Oncology Group (LACOG)

Denis Lacombe, MD, MS
- Director General, European Organisation for Research and Treatment of Cancer (EORTC), Brussels, Belgium

Martine Piccart, MD, PhD
- Head of Medicine Department, Institut Jules Bordet, Brussels, Belgium
- Chair, Breast International Group (BIG)

Raúl Sala, MD
- Instituto de Oncología de Rosario
- Member of the Board of Directors, Grupo Argentino de Investigación Clínica en Oncología (GAICO), Argentina

Although the EORTC is not a funding body, Dr Lacombe believes there are opportunities for joint projects with Latin American researchers.

“The best scenario would be to identify a key question around which we could build a strong clinical trial together, which could be carried out in Europe and Latin America, and for which we could get joint funding. This would be great and, having achieved one success, we could move on to achieve even more,” he says.

While acknowledging the continuing need to build infrastructure to support such a study in Latin America, Dr Lacombe believes that this should not be a cause for delay:

“If we wait for the perfect infrastructure, it will never happen. LACOG already has the basis for the necessary infrastructure and, to make progress, I think we now need to ‘fly the plane and build the plane at the same time’.”

Professor Piccart also believes that it is time to for a more positive outlook:

“I’m very optimistic for a number of reasons. Research organisations in Latin America are recognising the value of joining forces, they are educating their young doctors about the importance of clinical research, and they are sending them abroad for training. They are also building the infrastructure in their own countries that will attract their young doctors back home to do their research. I just wish it could all happen even faster!”

Others are also optimistic about the future role of Latin American research. Dr Sala believes that collaborations between organisations such as GAICO in Argentina and BIG are the way forward, not least because of the value of lessons already learned by more established organisations. Professor Barrios is confident that improvement in regulatory processes in Brazil will rapidly impact on the country’s ability to participate in clinical trials, so that researchers can make a major contribution with significant levels of patient recruitment.

References

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11. http://www.sompu.org.uy/content/grupo-oncol%c3%b3gico-cooperativo-uruguayo Grupo Oncológico Cooperativo Uruguayo (GOCUR)
Eyes on the future: inspiring the new generation of cancer experts in Latin America

Cancer is a global epidemic. Indeed, there were an estimated 17.5 million new cases and 8.7 million deaths worldwide in 2015 (GBDCC, 2016). As populations get older, these numbers tend to rise. In Latin America for instance, the cancer incidence is expected to increase from about 1.1 million new cases in 2012 to 1.8 million in 2030, while mortality will grow from 0.6 million in 2012 to approximately 1.1 million in 2030 (GLOBOCAN, 2012).

Clinical research is the weapon that enabled mankind to declare war against cancer. Science has empowered us to fight this face-shifting enemy using creative and elegant ways of tackling our common headsman. Nowadays we have at our disposal targeted therapies, antibody-drug conjugates, immunotherapies and more accurate and effective ways of delivering radiotherapy thanks to the advances brought on by cancer research.

Unfortunately, despite representing a global health challenge, the "cancer problem" has particularities and specific challenges in each region and in each country, and clinical research does not yet equally benefit all patients in the world.

Collaborative cancer research groups in Latin America

Research centres and investigators in Latin America have already developed expertise in conducting clinical trials by successfully accruing patients into some of the most important pivotal studies in oncology, such as the HERA trial (BIG 1-01). The conduct of these trials took the leading oncologists from Latin America out of inertia, and led to the creation of pioneering, country-level cancer research groups, such as GAICO (Grupo Argentino de Investigación Clínica en Oncología), GBECAM (Grupo Brasileiro de Estudos do Câncer de Mama), GECOPERU (Grupo de Estudios Clínicos Oncológicos Peruano), GOCCHI (Grupo Oncológico Cooperativo Chileno de Investigación) and GOCUR (Grupo Oncológico Cooperativo Uruguayo), which paved the way for the foundation of the Latin America Cooperative Oncology Group (LACOG). LACOG was created to catalyse the development of independent research oriented towards regional needs as well as collaborative clinical research with overseas partners in order to make Latin America part of the vanguard of cancer research. It is within this collaborative context that the BIG Latina Retreat took place two years ago.

Global Clinical Research Management

In November 2014, leading Latin American experts from the BIG network met in Brazil to address the current clinical research situation in Latin America, the perceived barriers, the challenges and opportunities. From this meeting, it was decided that the training of early-career investigators should be part of a global plan of action to enhance clinical research in the region. With the mutual commitment from BIG, the European Organisation for Research and Treatment of Cancer (EORTC) and LACOG leadership, this idea turned into reality on October 13, 2016, with the launch of the first Training Programme on Global Clinical Research Management in Brussels, Belgium. I had the opportunity to attend this in-depth programme, together with Dr. María Clara Rodríguez Palleiro (GOCUR, Uruguay), Dr. Javier Retamales (GOCCHI, Chile) and Dr. Zaida Denisse Morante Cruz (GECO-PERU, Peru).

Clinical research is the weapon that enabled mankind to declare war against cancer. Science has empowered us to fight this face-shifting enemy using creative and elegant ways of tackling our common headsman. Nowadays we have at our disposal targeted therapies, antibody-drug conjugates, immunotherapies and more accurate and effective ways of delivering radiotherapy thanks to the advances brought on by cancer research. It is within this collaborative context that the BIG Latina Retreat took place two years ago.

By Dr Márcio Debiasi

Dr. Márcio Debiasi
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During the four weeks of intense training, we attended workshops daily from 8 a.m. to 5 p.m., and became immersed in the field of clinical research management. With classes and presentations given at different places and by different experts, the EORTC focused on statistics as well as operational and technical issues in clinical research, while BIG focused on networking between collaborative research groups, communications and fundraising activities. At the European Centre for Clinical Research Training (ECCRT) we learned about legal basics and team leadership. As our last activity, we visited the Clinical Trials Support Unit (CTSU, formerly known as BrEAST) and the Breast Translational Research Laboratory (BCTL), both located at Institut Jules Bordet.

One remarkable aspect of this training is that it was focused on stimulating us to put into a pragmatic perspective the healthcare problems of our countries, asking us how we could fit the development of research into our realities and improve not only the science itself, but also the healthcare assistance for our populations.

The Latin American reality

The most comprehensive description of the Latin American reality has been reported by the Commission for Planning Cancer Control in Latin America and the Caribbean. It highlighted fragmented health infrastructures, restricted healthcare coverage, insufficient implementation of cancer registries and lack of funding, as well as heterogeneity in the distribution of resources, as the main issues that should be urgently addressed in Latin American countries in order to better assist the growing contingent of cancer patients. (Goss, 2013)

It is well known that the great accomplishments brought by science into medicine usually come with high market prices and thus only benefit wealthy populations. Throughout the world, clinical research plays an important role in making new technologies available to populations in low and middle-income countries. Developing research in this context will help to build a sustainable structure to facilitate access to high-cost technologies in Latin America. Additionally, a frequently overlooked indirect benefit of conducting research in a country is the qualification it brings to all the health professionals that take care of patients in the involved institutions. The standardisation and the quality control that these professionals are required to implement to comply with the Good Clinical Practice Guidelines create a virtuous cycle culminating in better health care assistance to all patients. Unfortunately, the development of clinical research throughout Latin America is jeopardised by the way policymakers currently address it in our countries, including long regulatory times and heavy financial costs for investigators. The countries’ laws must be urgently revised in order to stimulate academic research in our region.

Not only us, the four early-career Latin American investigators trained at BIG/EORTC, but all professionals involved in research in Latin America have tremendous challenges to overcome: (1) improving the structure of national organisations dedicated to cancer research; (2) training qualified and specialised staff (project managers, statisticians, etc); (3) improving communication with public audiences to make clinical research become considered a regional priority; and (4) increasing fundraising from donations to sustain independent research focused on the local needs.

BIG and the EORTC are recognised as solid institutions, which represent examples of successful academic research endeavours. With the training and the support we have been offered, BIG and EORTC became much more than a model to be followed, but examples of commitment within the development of science throughout the world.

References

Science and creativity unite to fight cancer

We met with Fernanda Schwyter, Fundraising Coordinator for the Latin American Cooperative Oncology Group (LACOG). In the interview hereunder she lifts the veil on an innovative and creative project that aims to raise awareness and support cancer research in the Latin American region.

I am a woman, a psychologist, a Brazilian citizen and a Latin American. I have lived in five cities in different Latin American countries and I now reside in the USA. In 2009 I got sick, not with cancer, but I felt the fear of death and the consequences of not being able to care for my family. As I recovered, I met a 38 year old Brazilian woman with three children and a stage four breast cancer diagnosis. It was through helping her that I met her doctor, Dr. Orlando Silva, who introduced me to the complexity of cancer as a global problem, and on this path I met Dr. Martine Piccart, Chair of the Breast International Group (BIG), who put me in contact with LACOG’s president, Dr. Carlos Barrios. All of this motivated me to engage in the fight against cancer and led to the creation of Projeto CURA (the CURE Project) for Latin America.

I really believe that research saves lives!

What does Projeto CURA mean?

Projeto CURA’s objectives are to use different methods and activities such as music, art, design, sports and other events to educate and connect people as a source to raise funds for scientific research to fight cancer in Latin America.

The project’s main challenge is to make society aware of the fact that cancer is our biggest global enemy today. We want people to identify with the cause and consequently engage with it.

Projeto CURA invites everyone to unite in the search of a cure for cancer, since research saves lives.

What makes Projeto CURA stand out when compared to other organisations in the region?

What makes us stand out is that until today there has not been, in Latin America, a non-profit organisation raising money for research with an impact on society as a whole. There have only been organisations providing assistance to victims. So that makes us a pioneer in the region. It is important to clarify and educate people about the fact that the only way to increase awareness about and cure our common enemy, cancer, is through further and thorough research.

What kinds of research does Projeto CURA expect to support?

Latin Americans cannot sit and cross their arms waiting for developed countries to find a path to cure cancer. We urgently need to know our own genetics, and our eating and cultural habits, which are different from other regions.

We need to do epidemiological research and, as a consequence, develop treatments that are better adapted to our people’s needs. We need to understand the Latin American population and know how many cancer cases exist, and which are the most common, since some cases are more common in our region than in more developed regions, such as uterine cancer. Developed countries are more efficient regarding uterine cancer prevention thanks to the human papillomavirus (HPV) vaccine. Here, prevention is not as efficient, and as a result, we still have a lot of fatalities. We need to continue understanding, investigating and developing specific drugs for other types of cancer as well, such as prostate and breast cancer.

Furthermore, academic research carried out with funds raised by Projeto CURA will contribute to investigations developed in the USA and Europe, as they will be able to involve more patients with more diversity of tumours, and with that, build a better and faster understanding of cancer development. Ultimately we want to create more efficient medicines, and offer people less traumatic treatment options with fewer side effects.

What will supporters of Projeto CURA receive in return?

From a commercial point of view, the larger companies that support Projeto CURA will have their brands recognised and linked to an important cause. From a human point of view, each donor will have the satisfaction of knowing they helped finance a cause with universal impact.
Why did LACOG think it was important to create Projeto CURA?

There were several contributing factors to the creation of Projeto CURA.

From a scientific and academic point of view, the project would allow us to develop research independently from the pharmaceutical industry.

Furthermore, Projeto CURA is a LACOG initiative, working with about 150 scientists in 15 countries throughout Latin America, meaning we will be able to map the entire Latin American population.

The situation is serious and there is no time to wait for governmental support. It is a race against time. Each year there are more and more cases, so the need to be creative in order to raise funds has never been more crucial.

From an educational perspective, we need to explain to society, using less scientific and formal vocabulary, what research is, and how beneficial it is. Sadly, people still believe in the taboo that research is all about taking placebos or being research “guinea pigs”, even if they are being treated for a serious disease.

Indeed, we cannot lose patients because without them we cannot run clinical trials.

We want patients to know that beyond getting the standard treatment they need, participating in research opens the door to receiving the most innovative therapeutic options for their specific form of cancer. Herein lies the importance of engaging the society in its entirety.

Donations that come from companies and people, not from the pharmaceutical industry, are the result of a society that believes in research.

Why is it critical nowadays to develop and support cancer research in Latin America?

Supporting and developing research in Latin America is crucial because we still lack resources and a culture of donating to research. It is estimated that millions of people will die of cancer in the years to come.

As cancer kills regardless of race, gender, religion or status, the only way to beat it is through a joint effort, of governments, companies and people in general, working together – exactly like in the USA 100 years ago when the American Cancer Society was founded. There has to be an understanding that the investment in research is really costly and we need legislation that gives incentives to the private sector for such investment.

There is a tremendous lack of public policies and social conscience in terms of health in Latin America. We must all understand how cancer has an impact on the individual, the family and society from an emotional, social and economic perspective.

Do you think that people in Latin America are aware of the importance of cancer research in their region and the importance of supporting it?

Absolutely not. Latin America has several urgent needs such as infrastructure, public policies, education, fighting corruption, etc.

Due to these serious problems, people believe that supporting research should only be a concern in developed countries, where these other basic issues are already being addressed. There is a denial of the need to unify ourselves to beat this evil. We must overcome these problems and also bring research to our lives, explaining to society how research is just as important as the chickenpox vaccine. We need people to understand that research can be like bringing cell phones to places that never even had a home phone: revolutionary.

How is Projeto CURA adapted to the specificities of each region in Latin America?

One of Projeto CURA’s goals is to invite influencers such as athletes, artists and businesspeople to be our ambassadors. Each Latin American country will have its local icons as spokespeople for the cause. Another goal is to engage local non-profit organisations that provide assistance to communities to be our partners and help to introduce and implement the project in their area, in order to adapt the approach to the local culture in each country.

How can people or companies contribute to Projeto CURA?

Anyone can help support Projeto CURA. Donations can be made online through our website and other digital platforms. Other ways to help are by sponsoring events, promoting political changes that support research, sharing on social media, and volunteering. Actually, volunteering is very important in giving assistance and it is just as important as raising funds for research. So far, almost everything done for Projeto CURA has been done on a volunteer basis. Our logo and platform were created by a Brazilian agency called Blackninja and the same goes for translations and events.

I have also been a volunteer until now!

www.projetocura.org
www.facebook.com/projetocura.org
The Breast International Group (BIG) is a not-for-profit organisation for academic breast cancer research groups from around the world.

Founded by leading European breast cancer experts in 1999, BIG now constitutes a network of 56 groups and data centres based in Europe, Canada, Latin America, the Middle East, Asia and Australasia. These entities are tied to several thousand specialised hospitals and research centres worldwide. About 30 clinical trials and several research programmes are run or are under development under the BIG umbrella at any one time. BIG also works closely with the US National Cancer Institute and the North American Breast Cancer Group, so that together they act as a strong interacting force in the breast cancer research arena.

www.BIGagainstbreastcancer.org

The 56 breast cancer research groups of the BIG network

ABC(G Austrian Breast & Colorectal Cancer Study Group
AGO-B Arbeitsgemeinschaft Gynäkologische Onkologie Breast Study Group
ANZBCTG Australia & New Zealand Breast Cancer Trials Group
ARCHY-DINECO Association de Recherche dans les Cancers dont Gynécologiques – Groupe d’Investigateurs Nationaux pour l’Etude des Cancers Ovariens et du sein
BGICS Breast-Gynecological International Cancer Society
BIEI Breast Intergroup of Eastern India
BODG Borkranker Onderzoek Groep
BREAST Breast European Adjuvant Study Team
CCTG Canadian Cancer Trials Group
CEEOG Central and East European Oncology Group
CT-IRE Cancer Trials Ireland
CTRG Cancer Therapeutics Research Group
DBCG Danish Breast Cancer Cooperative Group
EORTC BCG European Organisation for Research and Treatment of Cancer, Breast Cancer Group
FBCG Finnish Breast Cancer Group / Suomen Rintasyöpäpäättyymä
FBI Francisco Breast Intergroup
GAICO Grupo Argentino de Investigación Clinica en Oncologia
GBCAM Grupo Brasileiro de Estudos do Câncer de Mama
GBG German Breast Group
GECO PERU Grupo de Estudios Clinicos Oncologicos Peruano
GECAM Grupo Español de Investigacion en Cancer de Mama
GOCHI Chilean Cooperative Group for Oncologic Research
GOCOR Grupo Oncologico Cooperativo Uruguayo
GOIRC Italian Oncology Group for Clinical Research
GONO Grupo Oncologico Nord-Ovest
HBSS Hellenic Breast Surgical Society
HeCOG Hellenic Cooperative Oncology Group
HKBOG Hong Kong Breast Oncology Group
HORG Hellenic Oncology Research Group
IBCG Icelandic Breast Cancer Group
IBCSG International Breast Cancer Study Group
IBG Israeli Breast Group
IBIS International Breast Cancer Intervention Studies
ICCG International Collaborative Cancer Group
ICON ARO Indian Co-Operative Oncology Network
ICRC Iranian Cancer Research Center
ICR-CTSU Institute of Cancer Research – Clinical Trials & Statistics Unit
IOMG Indian Oncology Study Group
ITCMO Italian Trials in Medical Oncology
JBCRG Japan Breast Cancer Research Group
LACOG Latin American Cooperative Oncology Group
MICHELANGELO Fondazione Michelangelo
NBOG Norwegian Breast Cancer Group
NCRI-BCSG National Cancer Research Institute - Breast Cancer Clinical Studies Group
SABO Swedish Association of Breast Oncologists
SACK Swiss Group for Clinical Cancer Research
SBCG Sheba Breast Collaborative Group
SweBCG Swedish Breast Cancer Group
SKMCH & RC Shaukat Khanum Memorial Cancer Hospital & Research Centre
SLO Societé Luxembourgoise d’Oncologie
SOLI SUCCESS Study Group
TCOG Taiwan Cooperative Oncology Group
TROG Trans Tasman Radiation Oncology Group
UCBG Unicancer Breast Group
WSS Westliche Studiengruppe
BRUSSELS BELGIUM

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