BIOBANCO -IMM

CENTRO ACADÉMICO DE MEDICINA DE LISBOA

2013 REPORT

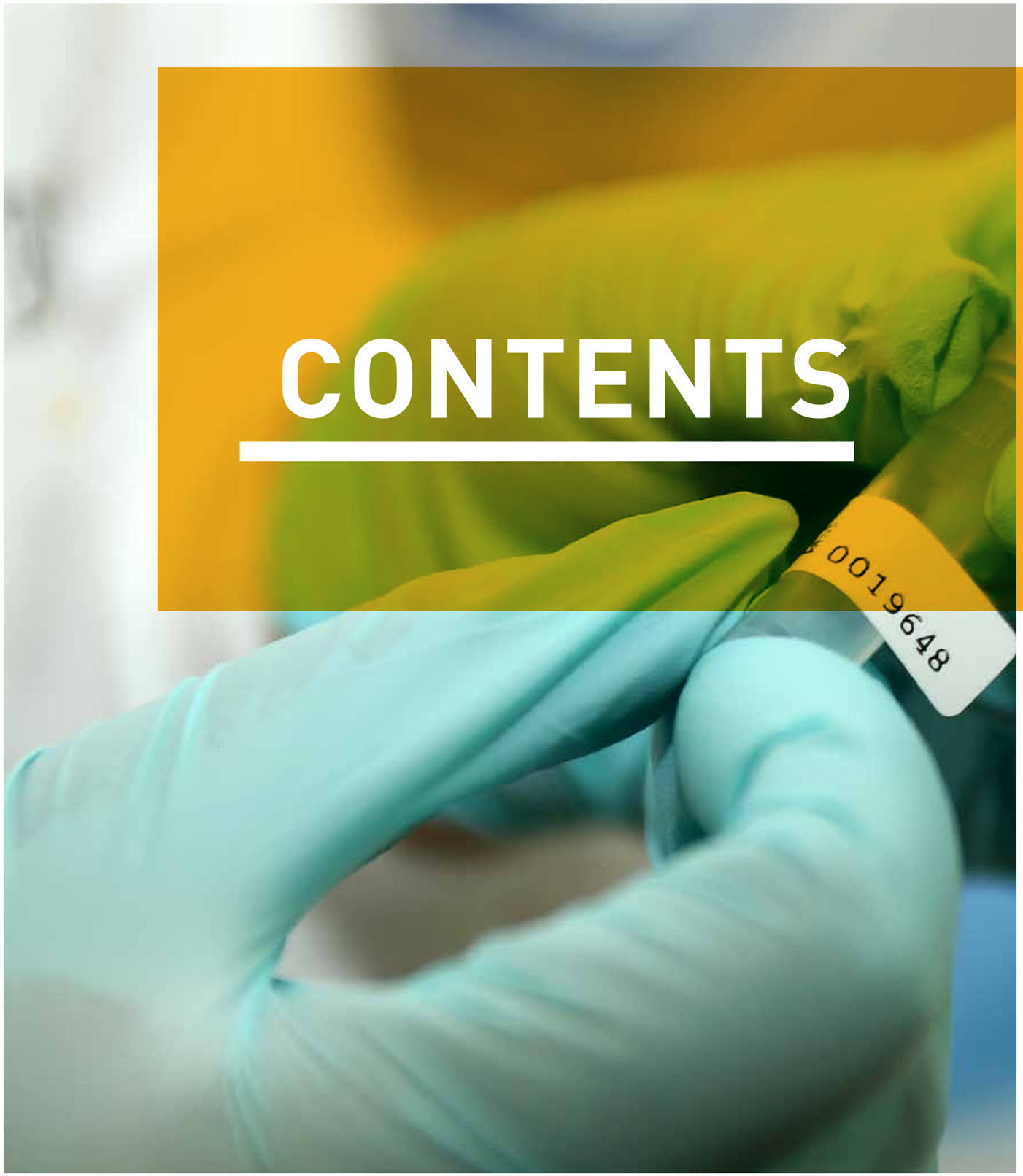
LISBON ACADEMIC MEDICAL CENTRE

CENTRO HOSPITALAR LISBOA NORTE, EPE

HOSPITAL DE SANTA MARIA

Hospital Pulido Valente

INSTITUTO DE MEDICINA MOLECULAR
FACULDADE DE MEDICINA DA UNIVERSIDADE DE LISBOA



CONTENTS

INTRODUCTION

The vision of the Biobanco-IMM CAML (Lisbon Academic Medical Centre) is to become as a major member of the European Network of Biobanks within the next 5 years, offering excellent opportunities for translational and clinical research. Our mission is to promote and facilitate biomedical research that will lead to the identification of new diagnostic and prognostic tests and new therapeutic targets. We have set as our goals to collect a wide variety of high quality human biological samples associated with detailed relevant clinical information and to promote its use for research purposes based on scientific and ethical criteria.

The 2 year operational phase of the Biobanco-IMM CAML development project started in May 2011, with a strategic plan that previewed the end of all the preparatory activities (including infrastructure, equipment, information system, training and legal / ethical authorizations) by February 2012. In fact, by January 2012 we were already able to start receiving samples and, as planned, in October 2012 we organized a formal opening event, which together with meetings in all medical departments of the Lisbon Academic Medical Centre, presentations in several other hospitals, meetings with scientific medical societies and patients associations, presentations in national medical congresses and involvement with the media gave the needed visibility for achieving by November 2013 almost 7 thousand donors and 60 thousand samples across 20 collections. We are now participating in several international networks and more than 1500 samples have been requested from this biobank. For the success of this strategy the funding partners had a crucial role by supporting key investments in the launching phase of the project, when the visible outcomes were still scarce. This was done with a generous attitude and with the strong belief that the creation of Biobanco-IMM CAML would lead to a global gain to the stakeholders of biomedical research. The strategy proved to be successful as the Biobanco-IMM CAML has its routine activities completely settled for 2 years, using standard operational procedures (SOPs) and being submitted to quality control. It continued to grow, establishing agreements with public and private institutions, always aiming at very concrete and tangible objectives. As can be read in this report effective use of the samples is ongoing, involving national and international institutions and this is the major guarantee of the success of any biobank. Moreover, publications have already resulted from these collaborations, which is absolutely exceptional, given the time frame of this project. We do believe that the moment has arrived for establishing a national network of biobanking infrastructures, sharing common SOPs and the same information system, which could give a major contribution for biomedical research in our country. Thus, we are now heading to a third phase of our development plan, aiming at promoting a functionally national biobank, based on local biobanking infrastructures that complement each other, optimizing resources and synergizing procedures. We will proceed in a parallel way with our own local sustainable growing process, by expanding collections (aiming at 10.000 donors by the end of 2014), improving infrastructures, optimizing operational procedures and enlarging partnerships. For achieving this during 2014 we will need again the trust and commitment of all the players in this project, including the staff members, the scientific and technical committees, the Lisbon Academic Medical Centre board of directors and the funding partners.

We know that we can improve and that motivates us.

TEAM

Biobanco-IMM CAML relies on a team of eight staff members, who contribute to the development of different areas. According to specific needs, however, we seek support from other professionals, including medical doctors, nurses and blood collection technicians.

In addition, Biobanco-IMM CAML is supported by both a Scientific and a Technical Committee, which account for the evaluation and authorization of the use of samples and the legal and technical assistance for biobanking activities.

JOÃO EURICO FONSECA
MD PhD
DIRECTOR

IMM's Head of Unit, professor at the University of Lisbon Medical School and rheumatologist at Hospital de Santa Maria, Lisbon Academic Medical Centre. Supervises operations and coordinates the activities of the Scientific and Technical committees.
immbiobanco@fm.ul.pt

JOANA CAETANO-LOPES
Biologist PhD
PROJECT MANAGER

Improvement and quality counseling of Biobanco-IMM CAML projects.
jrlopes@fm.ul.pt

ÂNGELA AFONSO
Biochemistry BSc Hon
TECHNICAL SUPERVISOR

Preparation, storage, quality control of samples and database management.
angelaafonso@fm.ul.pt

RICARDO PIRES
Biologist BSc Hon
TUMOR COLLECTIONS MANAGER

Tumor collections management and liaison between the Biobanco-IMM CAML with the National network of tumor banks and the Oncology Register.
rpires@fm.ul.pt

JOAQUIM POLIDO PEREIRA
MD
CLINICAL CONSULTANT

Clinical support and medical communication.
joaquimpereira@fm.ul.pt

RITA CASCÃO
Biologist PhD

Development and maintenance of cell culture, quality control of samples and laboratory support.
ritacascao@fm.ul.pt

ANA SOFIA ZHAO
Biomedical scientist MSc

Blood collection technician, quality control of samples and laboratory support.
anazhao@fm.ul.pt

VANESSA SILVA
Biomedical scientist BSc Hon

Blood collection technician.
Master's student in molecular biology.
vanessasilva@fm.ul.pt

SCIENTIFIC COMMISSION

With the mission of evaluating research proposals and authorizing sample usage.
Alexandre Mendonça MD PhD; **Cristina Ferreira** MD; **Dulce Brito** MD PhD; **Gabriel Miltényi** MD PhD; **Joana Caetano-Lopes** PhD; **Joaquim Ferreira** MD PhD; **Luís Costa** MD PhD; **Madalena Martins** PhD; **Ruth Geraldes** MD; **Sandra Casimiro** PhD; **Sofia Oliveira** PhD; **Tiago Outeiro** PhD.

TECHNICAL COMMISSION

Ensures the legal, ethical and technical framework for adequate functioning.
Alexandra Maralhas BSc; **Liliana de Almeida** MSc; **Ana Panão** BSc; **Filipa Nunes** PhD; M**argarida Gago** BSc; **José Braga** PhD.

HALLMARKS OF BIOBANCO-IMM CAML HISTORY

The project of building a biobank at IMM started in 2008. During the first two years, three goals were achieved: attraction of funding from the High Commission for Health; approval from Hospital de Santa Maria's Ethics Committee and reception of the first samples on an experimental basis.

2011

MAY
Kick-off of the operational phase of the project

2012

JANUARY
Start of samples collection

MARCH
Joined the BBMRI network

SEPTEMBER
Beginning of outreach sessions to disseminate services

OCTOBER
Public presentation of Biobanco-IMM CAML

NOVEMBER
"Hospital do Futuro" award, biotechnology category (2nd prize)

DECEMBER
Presentation of the 2012 report to the partners

Start of control samples collection

2013

FEBRUARY
Meeting with the scientific medical societies

APRIL
Meeting with the patients societies

Visit of the Biobanco Nacional ADN to help us implement primary cell culture services

Partnership with the Joaquim Chaves laboratories for control samples collection

MAY
Partnership with the Germano de Sousa laboratories for control samples collection

JUNE
Refurbishment of the facilities to host cell culture facilities

Participation in the Visiogain's 4th Biobanking UK conference, London, UK

SEPTEMBER
Partnership with CUF hospitals

Participation in the 3rd Global Cancer Genomics Consortium meeting, Lisbon, Portugal

First masters students on Biobanco-IMM CAML

OCTOBER
Participation in the ESBB congress, Verona, Italy

NOVEMBER
Biobanco-IMM CAML public session: new opportunities to foster biomedical research

COLLECTIONS, DONORS AND SAMPLES

The Biobanco-IMM CAML principal commitment is to broaden the scope of its collections every year. Our major collaboration is with Santa Maria Hospital, which belongs to the Lisbon Academic Medical Centre. However, recently we started collaborations with other hospitals, not only in the Lisbon area, but also across the country.

COLLECTIONS

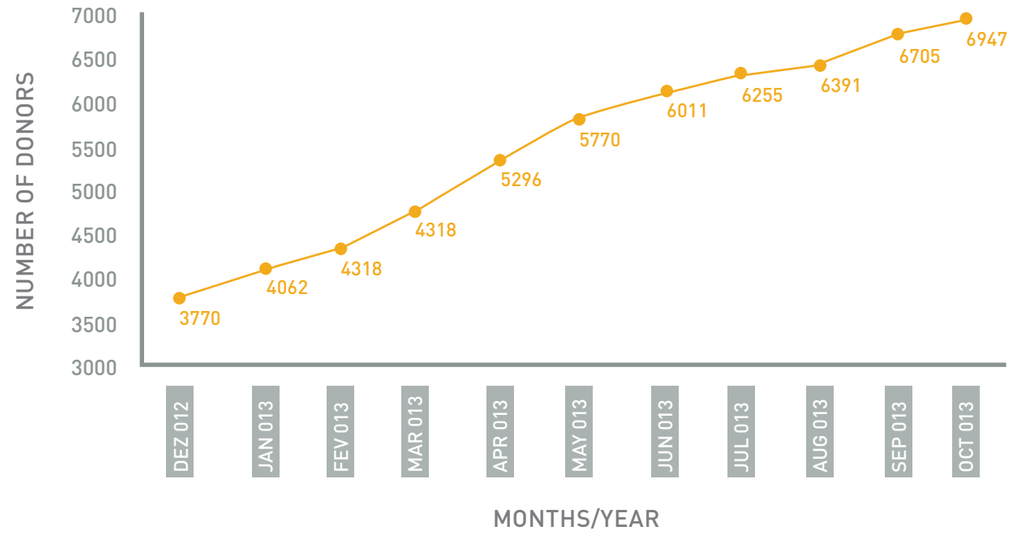
Biobanco-IMM CAML is organized in collections, under the responsibility of a principal investigator. At the moment, we have 20 active collections distributed as follows.

Year of start	Name	Description	Parties Involved	Principal Investigator
2013	Auto-inflammatory Diseases	Collection of samples from young patients with auto-inflammatory diseases	Pediatrics and Rheumatology and Bone Metabolic diseases Departments, Hospital Santa Maria	Filipa Ramos
2013	Inflamassome	Collection of samples from patients with early arthritis.	Rheumatology Research Unit (IMM), Rheumatology and Bone Metabolic Diseases Department, Hospital Santa Maria	Rita Cascão
2013	Bipolar Disorders	Collection of samples from patients with Bipolar Disorders	Psychiatry Department, Hospital Santa Maria	Maria Luisa Figueira
2013	Cystic Fibrosis	Collection of samples from patients with Cystic Fibrosis.	Pulmonary Department, Hospital Santa Maria	Carlos Lopes
2013	Hematology	Collection of samples from transplanted patients.	Hematology Department of Hospital Santa Maria	João Lacerda
2013	Rheumatic BioMarkers	Collection of samples from rheumatic diseases patients.	Faculdade de Medicina da Universidade Nova de Lisboa	Jaime Branco
2012	Bone	Collection of femoral epiphysis, including bone and cartilage, from hip replacement surgery patients.	Rheumatology Research Unit (IMM), Orthopedics Department, Hospital Santa Maria	Helena Canhão
2012	Controls	Collection of samples from controls, based on a questionnaire and interviewed by a physician.	Biobanco-IMM CAML	Biobanco-IMM CAML
2012	Endocrinology	Collection of samples from patients with endocrinology disorders.	Endocrinology Department, Hospital Santa Maria	Sónia do Vale
2012	Epireuma.pt	Collection of samples from a national epidemiological study on rheumatic diseases. A prospective follow-up is ongoing.	Sociedade Portuguesa de Reumatologia	Jaime Branco
2012	Heart Failure	Collection of samples from patients with heart failure.	Cardiology Department, Hospital Santa Maria	Dulce Brito
2012	Brain Metastasis	Collection of samples from patients with brain metastasis.	Neurosurgery Department, Hospital Santa Maria	Cláudia Faria
2012	Movement Disorders	Collection of samples from patients with neurological movement disorders, including Parkinson's disease.	Neurology Department, Hospital Santa Maria	Joaquim Ferreira
2012	Neurotumors	Collection of samples from patients with brain tumors.	Neurosurgery Department, Hospital Santa Maria	Cláudia Faria
2012	Rheumatoid Arthritis	Collection of samples from patients with rheumatoid arthritis. Link with detailed clinical data on Reuma.pt.	Rheumatology Research Unit (IMM), Rheumatology and Bone Metabolic Diseases Department, Hospital Santa Maria	Helena Canhão
2012	Spondyloarthritis	Collection of samples from patients with Spondyloarthritis. Link with detailed clinical data on Reuma.pt.	Rheumatology Research Unit (IMM), Rheumatology and Bone Metabolic Diseases Department, Hospital Santa Maria	Elsa Sousa
2012	Stroke	Collection of samples from patients with stroke, and controls.	Neurology Department, Hospital Santa Maria	Ruth Geraldes, Sofia Oliveira
2012	Synovial Fluid	Collection of samples from patients with rheumatic diseases.	Biobanco-IMM CAML Rheumatology and Bone Metabolic Diseases Department, Hospital Santa Maria	Helena Canhão
2012	Synovial Membrane	Collection of samples from patients with rheumatic diseases.	Rheumatology Research Unit (IMM), Rheumatology and Bone Metabolic Diseases Department, Hospital Santa Maria	Elsa Sousa
2012	Tumors	Collection of samples from gastrointestinal tract cancer and breast cancers.	Clinical and Translational Oncology Research Unit (IMM), Oncology and Pathology Departments, Hospital Santa Maria, National Tumor Bank Network and Hospital CUF	Luis Costa

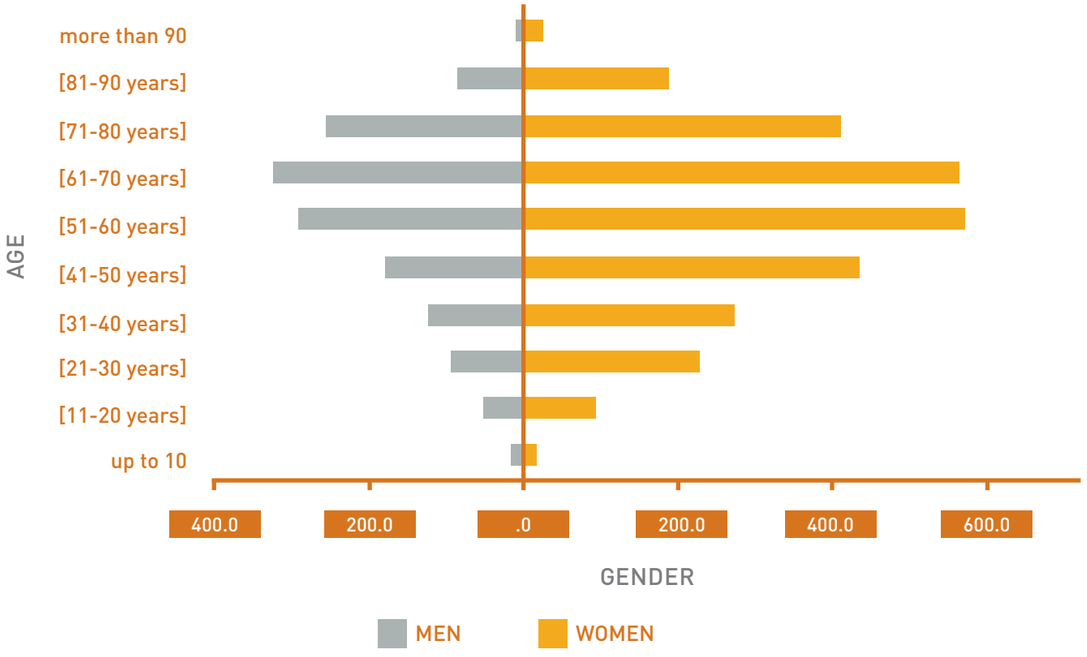
Six new collections started in the beginning of 2013 and three more are waiting for ethics committee approval to start.

DONORS

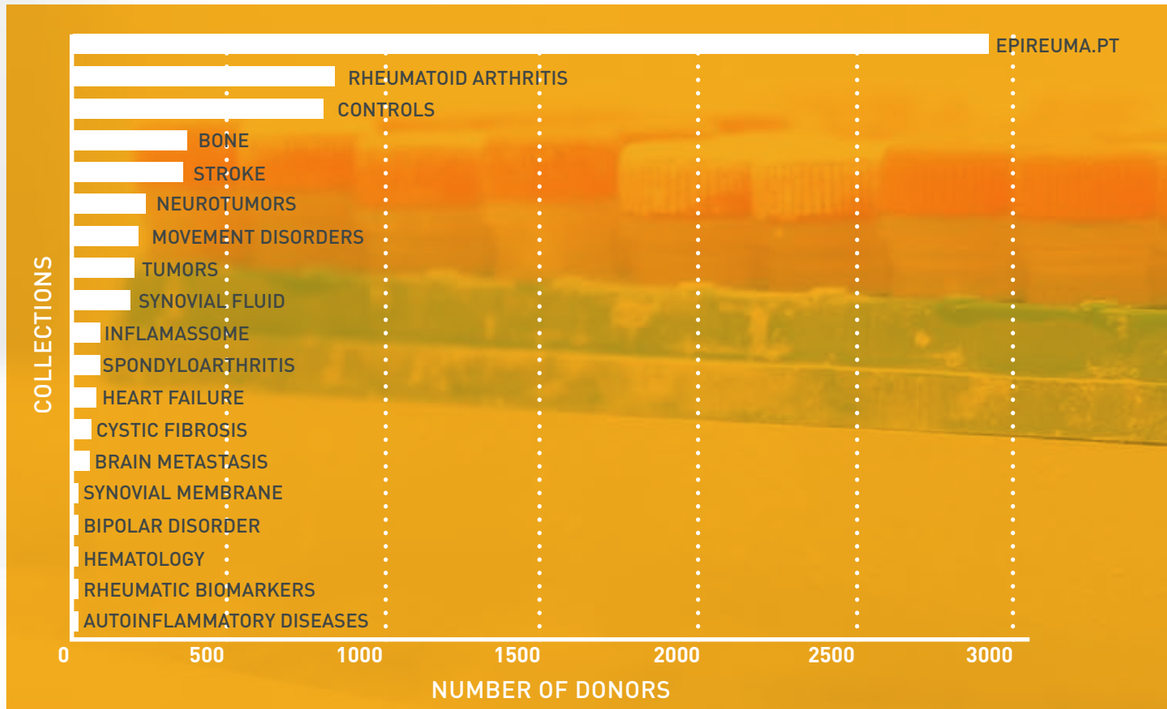
Since the end of 2012 and until October 2013, the number of individuals who donated samples to the Biobanco-IMM CAML increased 84% from 3770 to 6947 donors, with an average of 318 donors per month.



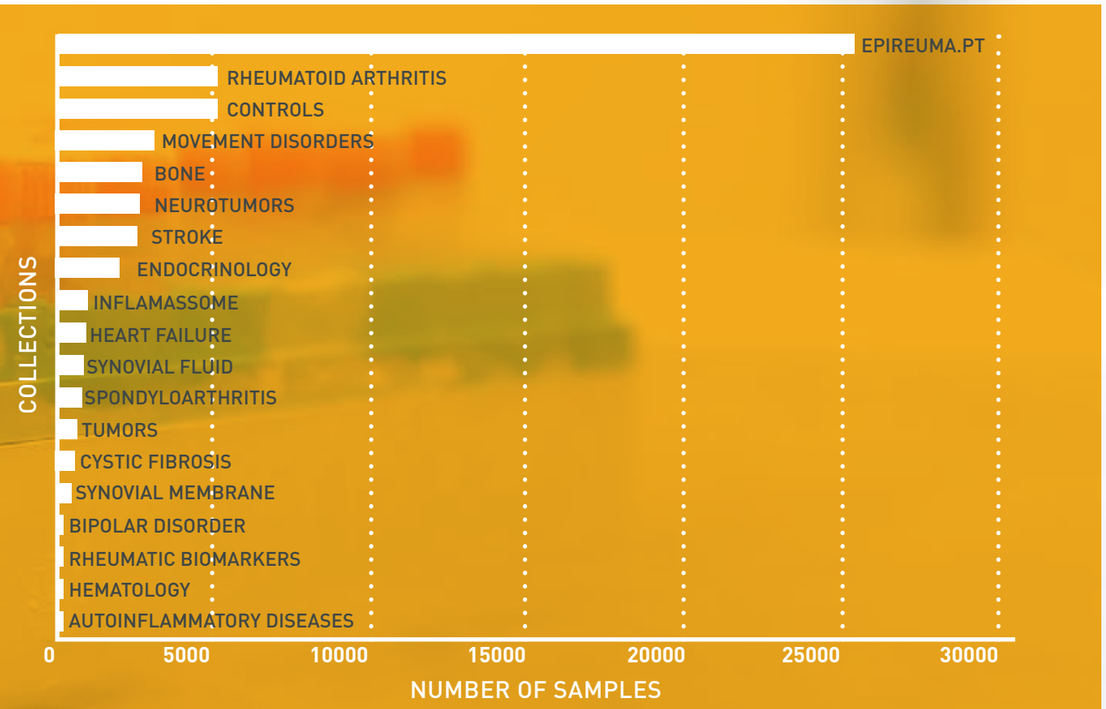
In the donors population we found a predominance of the female gender, mostly in the 50-70 years age range.



These donors are distributed by the 20 collections, as shown below:

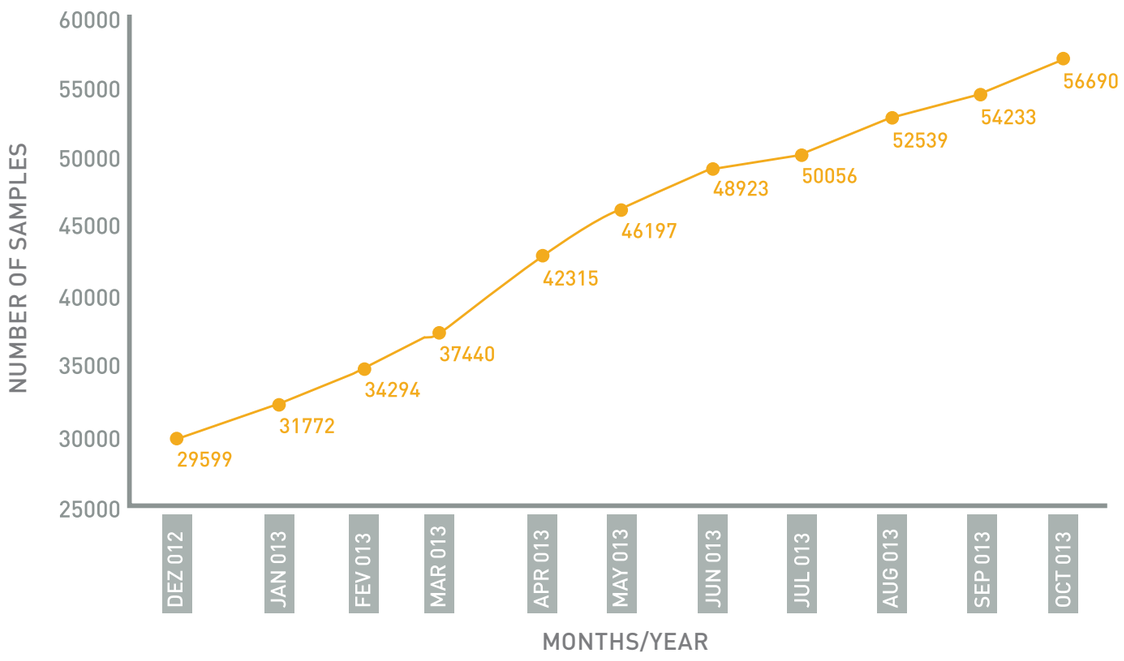


These samples are distributed by the collections, as depicted below, with predominance of Epireuma.pt collection (47%), followed by Rheumatoid Arthritis (11%) and controls (11%) collections.

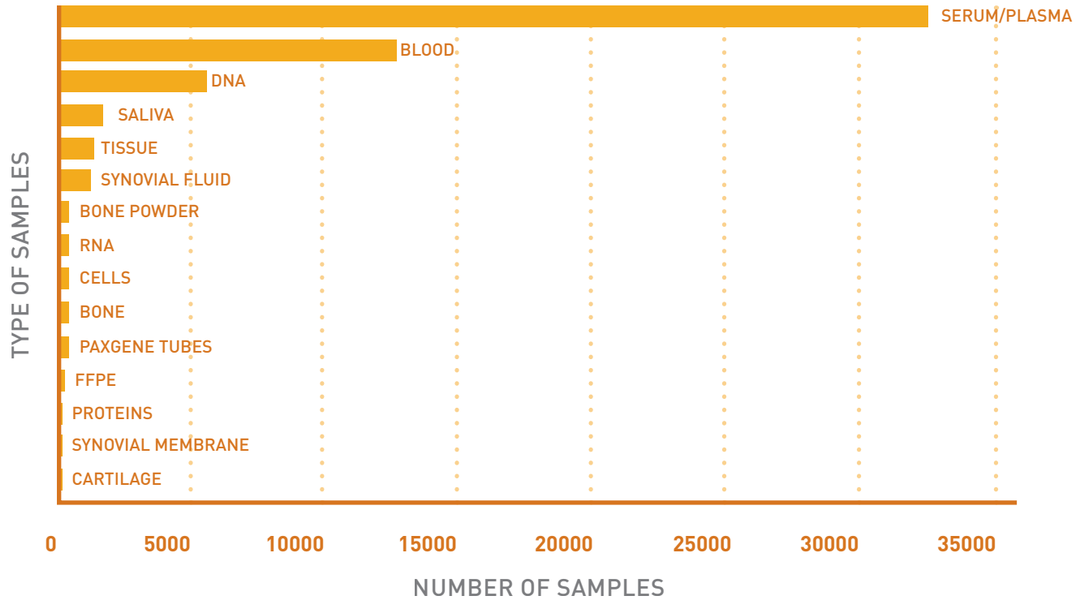


SAMPLES

Since the end of 2012 and until October 2013, the number of samples in Biobanco-IMM CAML increased 92% from 29559 to 56690 at a rate of 2709 aliquots per month.



From each donor different samples can be collected, according to the need of each collection. We store predominantly serum samples (57%), followed by blood (22%) and DNA (10%) samples.



The table below indicates the type of sample in each collection.

Collection name	Type of Sample	DNA	PAXgene tubes	RNA	Protein	Cells	Snap Frozen	OCT Frozen	FFPE
Autoinflammatory Diseases	Blood	√					√		
	Serum						√		
Bipolar Disorders	Blood	√				√	√		
	Serum						√		
Bone	Blood	√					√		
	Serum						√		
	Bone Powder			√			√		
	Femoral Epiphysis*	√		√	√		√	√	
	Cartilage								
Controls	Blood	√					√		
	Serum						√		
Cystic Fibrosis	Blood	√					√		
	Serum						√		
Endocrinology	Saliva						√		
Epireuma.PT	Blood	√					√		
	Serum						√		
Heart Failure	Blood	√					√		
	Serum						√		
Hematology	Blood	√				√	√		
	Serum						√		
Inflamassome	Blood	√					√		
	Serum						√		
	RNA								
	Cells	√		√			√		
Metastasis	Blood	√					√		
	Serum						√		
	Brain Metastasis						√		
Movement Disorders	Blood	√	√				√		
	Serum						√		
Neurotumours	Blood	√					√		
	Serum						√		
	Brain Tumour					√	√		
Rheumatoid Arthritis	Blood	√					√		
	Serum						√		
Rheumatic Diseases BioMarkers	Blood	√					√		
	Serum						√		
Spondyloarthritis	Blood	√	√				√		
	Serum						√		
	Synovial Fluid						√		
Stroke	Blood	√					√		
	Serum						√		
Synovial Fluid	Blood	√					√		
	Serum						√		
	Synovial Fluid						√		
Synovial Membrane	Blood	√	√				√		
	Serum						√		
	Synovial Fluid						√		
	Synovial Membrane							√	
Solid Tumors	Breast Tumor							√	√
	Esophagus Tumor							√	√
	Gastric Tumor							√	√
	Colorectal Tumor							√	√
	Paired Healthy Tissue							√	

*Sample available for structural and mechanical tests.

THE TUMORS COLLECTIONS

The tumours collections were originally created to support translational research projects in Lisbon Academic Medical Centre. In March 2012 we started collecting colorectal cancer samples and in July 2012 we added samples of breast cancer and all digestive cancers, including pancreas. From each tumour we collect a fragment of the tumour and a paired fragment of healthy tissue. Paired samples of primary tumours and metastasis are also collected, representing an important asset of this biobank. All samples undergo two quality control levels. In the first, a pathologist identifies the tumor tissue in the sample and the absence of tumor cells in the healthy paired sample. Biobanco-IMM CAML's team is responsible by the second quality control level by performing DNA, RNA and Imunohistochemical tests.

Biobanco-IMM CAML holds about 700 samples of tumors and in order to improve our input of samples we set up a partnership with CUF Hospitals specifically to collect colorectal cancer samples.

Active participation in biomedical research for the prevention, diagnosis and treatment of diseases is to hospitalcuf descobertas a priority intrinsic to their culture as a private institution with high health responsibility to their patients and professionals.

The adherence to a biobank, allowing for the preservation and availability of biological samples for scientific research and associated clinical information was a key player in the process of affirmation of our commitment in this area.

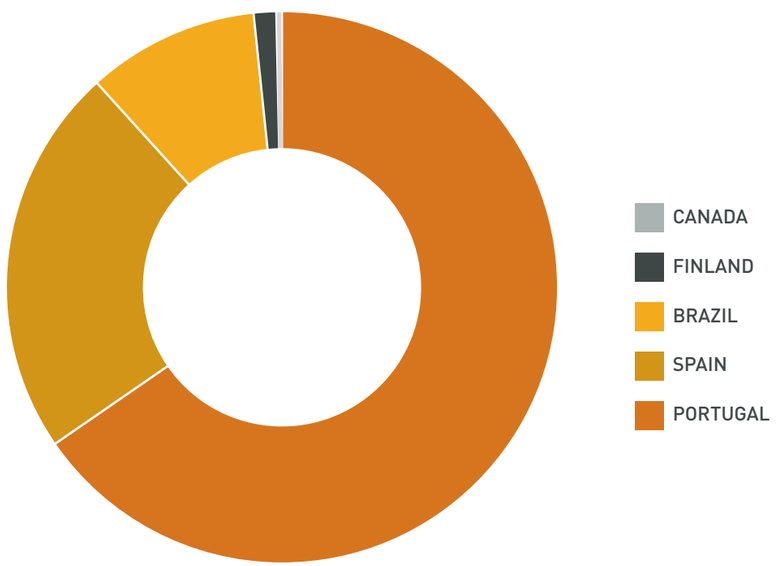
The Biobanco-IMM CAML – for their experience, quality and reputation – emerges as the natural and unquestionable partner for preservation and management of biological samples.

The formation of a collection in the area of colon cancer in 2013 followed by gathering biological samples from the orthopedic surgery for the bone and cartilage collection, are the first steps implemented with success, resulting from a true team effort between the two institutions.

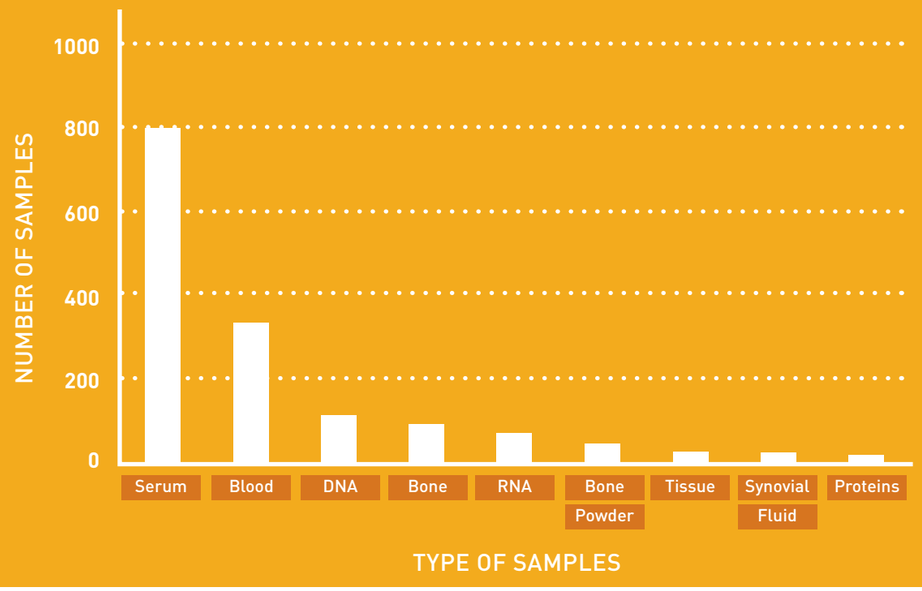
Jorge Mineiro
Clinical Director, hospitalcuf descobertas

SAMPLE REQUESTS

We are now participating in several international networks and samples from the Biobanco-IMM CAML have started to be requested for research projects. Up until now, 1520 samples have left the Biobanco-IMM CAML mostly through collaboration with research institutions in Portugal (65.4%), Spain (22.9%), Brazil (10.1%), Finland (1.3%) and Canada (0.3%).



Serum was the sample type that received more requests; almost 800 aliquots of serum (53%) have left the Biobanco-IMM CAML.



These samples were used in several research projects. Some of them were already published in international peer-reviewed journals:

- Northcott, P. A., Shih, D. J. H., Peacock, J., Garzia, L., Morrissy, A. S., Zichner, T., Stütz, A. M., et al. Subgroup-specific structural variation across 1,000 medulloblastoma genomes. Nature 2012, 488(7409), 49–56.
- Ramaswamy, V., Remke, M., Bouffet, E., Faria, C. C., Perreault, S., Cho, Y.-J., Shih, D. J., et al. Recurrence patterns across medulloblastoma subgroups: an integrated clinical and molecular analysis. The lancet oncology 2013, Oct 16 [Epub ahead of print]
- Caetano-Lopes J*, Rodrigues A*, Lopes A, Vale AC, Pitts-Kiefer MA, Vidal B, Perpétuo IP, Monteiro J, Konttinen YT, Vaz MF, Nazarian A, Canhão H*, Fonseca JE*. Rheumatoid Arthritis bone fragility is associated with upregulation of IL17 and DKK1 gene expression. Clinical Reviews in Allergy & Immunology 2013 Apr 2 [Epub ahead of print].
- Cáliz R, Canet LM, Lupiañez CB, Canhão H, Escudero A, Filipescu I, Segura-Catena J, Soto-Pino MJ, Expósito-Ruiz M, Ferrer MÁ, García A, Romani L, González-Utrilla A, Vallejo T, Pérez-Pampin E, Hemminki K, Försti A, Collantes E, Fonseca JE, Sainz J. Gender-Specific Effects of Genetic Variants within Th1 and Th17 Cell-Mediated Immune Response Genes on the Risk of Developing Rheumatoid Arthritis. PLoS One 2013 Aug 30;8(8):e72732. doi: 10.1371/journal.pone.0072732.
- Madruga Dias JA, Rosa RS, Perpétuo I, Rodrigues AM, Janeiro A, Costa MM, Gaião L, Pereira da Silva JA, Fonseca JE, Miltenberger-Miltenyi G. Pachydermoperiostosis in an African patient caused by Chinese/Japanese SLCO2A1 mutation – case report and review of literature. Semin Arthritis Rheum. 2013 Sep 5. [Epub ahead of print]
- Vale AC, Aleixo IP, Lúcio M, Saraiva A, Caetano-Lopes J, Rodrigues A, Amaral PM, Rosa LG, Monteiro J, Fonseca JE, Vaz MF, Canhão H. At the moment of occurrence of a fragility hip fracture, men have higher mechanical properties values in comparison with women. BMC Musculoskelet Disord. 2013 Oct 16;14(1):295.
- Bettencourt BF, Rocha FL, Alves H, Amorim R, Caetano-Lopes J, Vieira-Sousa E, Pimentel-Santos F, Lima M, Porto G, Branco JC, Fonseca JE, Bruges-Armas J. Protective effect of ERAP1 haplotype in ankylosing spondylitis: investigating non-MHC genes in HLA-B27-positive individuals. Rheumatology (Oxford). 2013 Sep 17 [Epub ahead of print]
- Vale AC, Faustino J, Reis L, Lopes A, Vidal B, Monteiro J, Fonseca JE, Canhão H, Vaz MF. Effect of the strain rate on the twisting of trabecular bone from women with hip fracture. J Biomech Eng. 2013 Dec 1;135(12):121005-9

"At the Institute of Clinical Medicine at the University of Helsinki and Helsinki University Central Hospital we are actively doing musculoskeletal research. In this endeavor we have established international connections. One of the most positive and productive contact has been with Instituto de Medicina Molecular in Lisbon. This has lately been further facilitated by the excellent Biobanco-IMM CAML action taken in Lisbon. We have received synovial fluid to a joint project on IL-17 family cytokines and their heterodimeric receptors in Rheumatoid Arthritis. These samples were exemplary labeled with anonymous codes, the clinical information was perfect, sampling and transfer were really professionally handled, as was the communication necessary to this complex international biobanking transfer action. It is strongly recommended and also foreseen that the Biobanco-IMM CAML will become a significant factor in various EU-supported large projects due to the excellent value it has in this field of study as a really solid resource and well organized records, combined with secure data handling and superb communication."

Yrjo T. Konttinen
Tules Research Laboratory, Institute of Clinical Medicine, Department of Medicine, Biomedicum Helsinki, Helsinki, Finland

"Rheumatoid arthritis (RA) is a common and complex autoimmune disease characterized by a systemic inflammatory disorder that mainly affects joints but that can eventually spread to other organs leading to severe disability and premature mortality. Although many aspects of RA pathogenesis remain unknown, it is commonly accepted that RA onset is determined by the interaction between genetic variations and environmental factors.
In close collaboration with the Biobanco-IMM CAML we have conducted large international population-based case-control studies to assess whether genetic variations within immunoregulatory and estrogen-related genes influence on the risk of developing RA. Our studies have confirmed that genetic variants in C-type lectins (*Dectin-2, MCP-1 and DC-SIGN*), cytokines (*IL4, IL13*) and their receptors (*IL8RB*) as well as hormone metabolism-related genes (*SULT1A1*) may play a role in determining the risk of developing RA. Given the adequate population size of our study (2.243 individuals), we could also identify genetic variants in these genes as contributing to gender-specific risk for RA.
The main goal of our research project would have been impossible without the participation of the Biobanco-IMM CAML as this institution was critical for an effective recruitment of DNA samples from both RA patients and controls. The scientific value of our collaboration with the Biobanco-IMM CAML was determined not only by the high number of biological specimens provided (773 RA patients and 201 healthy controls) but also by the technical homogeneity of biological specimens and by the immediate availability of relevant clinical information. All samples provided by Biobanco-IMM CAML were appropriately anonymized and annotated and had high quality. In summary, our experience working in collaboration with Biobanco-IMM CAML was excellent and we hope to continue working with this institution in future research projects."

Juan Sainz Pérez
Genomic Oncology department, Parque Tecnológico de Ciencias de la Salud and Unit of Clinical and Laboratory of Hematology and Transfusion, Unidad de Gestión Clínica de Hematología y Hemoterapia, Granada, Spain

"Starting in late August 2012, 286 patients were included in the stroke collection.
Samples were collected in the cerebrovascular accidents unit of the Hospital de Santa Maria, with the collaboration of the nursing team, during the routine first blood collection. The samples were processed by the Biobanco-IMM CAML team soon after collection, in accordance with the standards of the Biobanco-IMM CAML. The clinical information associated with each sample included the etiologic diagnosis at 3 months, in addition to vascular risk factors, disability scale and clinical characteristics at the time of collection. Despite the difficulties of collecting informed consent in acute cerebrovascular disease there was high acceptance both by donors and their families, who considered this an important initiative to encourage research in stroke. During this year, samples were requested for a study to assess whether NT-proBNP can be used as a marker of paroxysmal atrial fibrillation in acute ischemic stroke. The samples requested left the Biobanco-IMM CAML, after approval by its Scientific Committee, appropriately."

Ruth Geraldes
Neurology Department, Hospital de Santa Maria, Lisbon, Portugal

"This testimonial has the purpose of portray our experience with the use of samples requested to the Biobanco-IMM CAML.
The research project entitled *Investigation of possible associations with the HPA-1, -3 and -5 systems and rheumatoid arthritis*, is being developed as a collaboration between the Laboratório de Biologia Molecular do Hemocentro, Faculdade de Medicina de Botucatu, UNESP, SP, Brazil and the Instituto de Medicina Molecular of University of Lisbon Medical School, Portugal. The study was approved by the local Ethics Committee at the meeting on 6/12/2012.
The project envisaged the use of DNA samples from peripheral blood of 200 patients with rheumatoid arthritis. We have received aliquots of 30 µl containing the number ID of the patients having, thus, maintained full confidence. The samples were sent by the company FEDEX, on the date agreed, in a proper package, accompanied by a datasheet containing information on the DNA concentration, ratio A260/A280, status of the gel run, collection date, and some epidemiological data such as gender, race and date of birth.
At the Brazilian airport Congonhas customs, there was a long delay in the release of the samples due to bureaucratic obstacles. Even having strongly requested, we have no real knowledge if the samples were kept in ice during the delay.
At this moment, the samples have already been used and the laboratorial part of the project was successfully completed. The data are currently under analysis.
We would like to congratulate the Institution's biobank initiative for the responsiveness and quality of samples sent. Initiatives like this should serve as an example for other institutions that want to be competitive on the world of research, assisting the collection of biological samples for the execution of relevant research projects. We are grateful for the opportunity to work with this honorable institution."

Maria Inês Pardini
Responsible for the Laboratório de Biologia Molecular do Hemocentro de Botucatu, Faculdade de Medicina, UNESP, São Paulo, Brazil

"The Labatt Brain Tumour Research Centre, at the Hospital for Sick Children in Toronto, Canada, is leading major discoveries in the molecular biology and the genomics of pediatric brain tumors. Medulloblastoma is the most common malignant brain tumor in childhood and one of the leading causes of pediatric cancer deaths. Through MAGIC (Medulloblastoma Advanced Genomics International Consortium), Dr. Michael Taylor was able to gather an unprecedented number of tissue samples of medulloblastoma from several centers around the world. In this project, the mRNA expression profile of more than 1,000 medulloblastoma tumor specimens was studied to identify novel genes and pathways involved in medulloblastoma formation and progression. The novel insights from this study were recently published in *Nature 2012*. Some of the tumor samples included in this project were sent from the Biobanco-IMM CAML, which provides an excellent service. The specimens were well preserved and shipped in a careful manner. The sample quality was excellent as determined by the high yield and quality of the DNA and RNA extracted. Furthermore, the clinical information provided was detailed and timely. Through its collaborative efforts and high quality services, the Biobanco-IMM CAML is undoubtedly promoting worldwide biomedical research."

James Rutka
Director of the Labatt Brain Tumour Research Centre, The Hospital for Sick Children, Toronto and RS McLaughlin Professor and Chair of the Department of Surgery, University of Toronto, Canada

PARTNERSHIPS

Biobanco-IMM CAML works with several public and private partners. It is our belief that the consortium of Biobanco-IMM CAML partners is motivated to support the activities that will foster the development of biomedical research in Portugal. We further believe that partnership ought to be flexible in order to meet the motivations of each potential partner. Biobanco-IMM CAML collaborates with scientific societies, biotechnology and pharmaceutical companies, banks, as well as communication and design companies. The consortium has supported equipment, software, consumables and human resources allowing the full operational potential of Biobanco-IMM CAML since January 2013. The total funding obtained reached 67.500€.

The members of this consortium are:

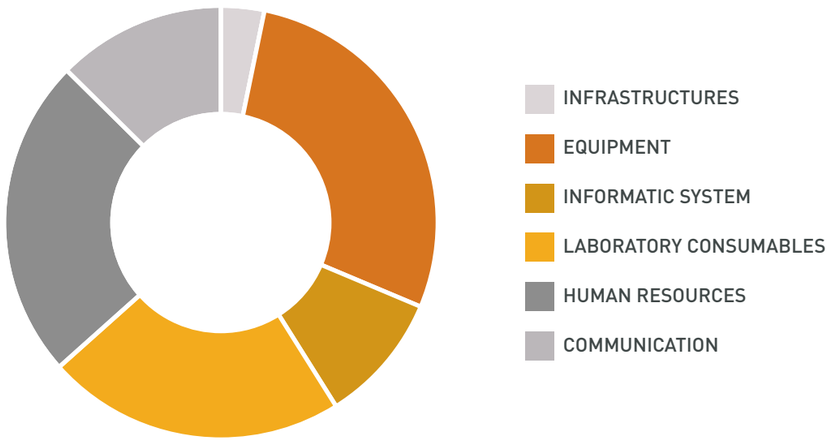
Fundação Calouste Gulbenkian has specifically supported the synovial tissue collection and Fundação Millennium has specifically supported the neurotumors collection.

FINANCIAL ANALYSIS

With the support of our partners we have made the following investments since January 2013.

AREA OF SUPPORT	INVESTMENT	AMOUNT
Equipment & Infrastructure	Infrastructure	4.500,00€
	Storage Equipment	12.325,00€
	Laboratory Equipment	22.570,17€
	Equipment Maintenance	4.177,76€
Software	LIMS Licenses	12.281,55€
	Consulting Activities	1.260,62€
Laboratory Consumables		31.033,97€
Communication	Events and Visibility	17.516,08€
Human Resources	Biobanco-IMM CAML Team	28.741,36€
	Training	4.633,30€
TOTAL		139.039,81€

Biobanco-IMM CAML funding investment



SCIENTIFIC ACTIVITIES

POSTER PRESENTATIONS

- 3º Encontro de Biologia Molecular em Saúde, Escola Superior de Saúde Egas Moniz, Caparica, Portugal. March 15-16, 2013
- Visiongain's 4th Biobanking UK conference, London, England. June 20-21, 2013
- 3rd Global Cancer Genome Consortium symposium, Lisbon, Portugal. September 18-20, 2013
- ESBB congress, Verona, Italy. October 9-11, 2013

SEMINARS

- Outreach sessions across all Hospital de Santa Maria departments, University of Lisbon Medical School, institutes and IMM Units.
- Caetano-Lopes J. "Biobanco-IMM CAML: the first steps". 3º Encontro de Biologia Molecular em Saúde, Escola Superior de Saúde Egas Moniz, Caparica, Portugal. March 16, 2013
- Seminar "The experience of the National DNA Bank Carlos III" by Dr. F Javier Garcia, hosted by Biobanco-IMM CAML. April 16, 2013
- Afonso A. "Biobanco-IMM CAML, os primeiros passos". Associação Portuguesa de Doentes com Immunodeficiências Primárias meeting, Belém, Portugal. May 18, 2013
- Fonseca JE. "O Biobanco-IMM CAML como fulcro do desenvolvimento da investigação médica na pediatria". Congresso Nacional de Pediatria. October 4, 2013
- Fonseca JE. "Biobanco-IMM CAML: uma oportunidade para todos?". XIII Congresso Nacional da Sociedade Portuguesa de Menopausa. October 17, 2013.

PUBLICATIONS

- Fonseca JE. Biobanco-IMM CAML: a case study. Acta Med Port 2013 Jul-Aug; 26(4): 312-314.

TRAINING

- Biobanco-IMM CAML has collaborated in a master course on oncobiology (June-July 2013) by contributing with technical skills on molecular biology.
- For the period of 2013/2014 Biobanco-IMM CAML has two masters students that will contribute to the development of improved methods for sample quality control.

"Biobanco-IMM CAML is the starting point of many important scientific projects with possible impact on the diagnosis and therapeutic of several diseases. The sample workflow, from information to collecting, processing, storage and quality control of each sample stored in the Biobanco-IMM CAML requires extreme care by a team trained to work with daily rigor. To study in Biobanco-IMM CAML implies the same rigor, becoming challenging to understand which techniques can be applied to improve the work of this structure, as well as adjust the protocols, materials and methods that allow accuracy in processing and quality control of the samples stored. These studies can be important because they contribute to the effectiveness and efficiency of the objectives of Biobanco-IMM CAML ensuring that the samples and associated information are available to the scientific community in the best possible conditions."

Vanessa Silva,
MSc student at Biobanco-IMM CAML

OTHER ACTIVITIES

OPEN DAYS

SportExpo (feira do desporto e lazer), Belém

XIII Jornadas da ANDAR, Lisbon

Parkinson open day, IMM, Lisbon

Escola Superior de Saúde Egas Moniz open day, Caparica

Hospital de Santa Maria open day, Lisbon

Encontro Nacional de Doentes com Lúpus, Belém

II Encontro de Familiares com Imunodeficiências Primárias, Lisbon

Open day at Faculdade de Ciências da Universidade de Lisboa, Lisbon

Open day at Faculdade de Farmácia da Universidade de Lisboa, Lisbon

Open day at students association of Faculdade de Medicina da Universidade de Lisboa, Lisbon

XVI Fórum de Apoio ao Doente Reumático

The richness and usefulness of structures such as Biobanco-IMM CAML depends on the quality and diversity of biological samples. Samples from donors representing the population are central for every biobank. The effectiveness of a biobank depends almost equally from samples representing diseases as well as those that belong to the general population. These samples can be used as controls, that may be age and sex matched, if needed. These donors do not need to be entirely healthy. They are selected for studies because they don't carry the specific disease on study.

One of the central aspects in selecting volunteers is the questionnaire. It should be easy to fill by most of the population. Biobanco-IMM CAML has created a simplified questionnaire that is monitored by a medical doctor when collecting samples from volunteers. Our questionnaire is shorter than most of other biobank questionnaires, but as the information is checked by a medical doctor it allows us to validate the data properly and ensure that no vital information is missed.

Only volunteers able to give informed consent may contribute with samples and clinical information to Biobanco-IMM CAML.Despite legal complexities that are inherent to a biobank informed consent, Biobanco-IMM CAML personnel makes an effort to thoroughly and clearly explain its content to every volunteer, and any doubt is clarified as simply as possible.

To be able to collect a diverse collection of volunteers, Biobanco-IMM CAML engages closely with several organizations that facilitate the contact with the population such as private laboratories, students and patients associations. Other collaborations are under way.

During 2013 several actions of clinical data and blood sample collection were performed and allowed Biobanco-IMM CAML to achieve more than 800 control samples by October 2013.

The *open days* allowed us to enlarge not only our controls collection but also to enrich other collections. Soon we realized about the importance of the control samples for researchers and, in order to raise public awareness of the importance of their contribution to science and to promote Biobanco-IMM CAML we settled a collaboration with 2 private laboratories: Joaquim Chaves and Germano de Sousa. Both readily collaborated with our blood collection initiatives and two members of our staff are present at the laboratories at least once a month.

"Dr. Joaquim Chaves, Clinical Laboratory has dedicated 54 years to Health and Laboratory Diagnosis, assisting doctors helping people. Throughout these years we have provided innovative methods and executed blood tests for the majority of the country's private and hospital laboratories. As a result of constant evolution and innovation we have participated in numerous clinical trials, Masters and Doctoral thesis and research projects coordinated by universities and national and International research institutions. We assume our social responsibility by training specialists and blood collection technicians. In this context, when we were challenged by Biobanco-IMM CAML to collect biological samples with relevant clinical information, we envisage this request as an extension of our duties of social responsibility and as a contribution for the society. We, therefore, joined the project without hesitation. Contributing, modestly and selflessly, to quality clinical education and research in Portugal is for our Laboratory a source of pride and joy. We found a complete identity between the culture of the Laboratory and the objectives of the Biobanco-IMM CAML. Both intend to contribute indelibly to the Health of our fellow citizens. The institutional collaboration could not be more natural."

Dr. Joaquim Chaves laboratory

"The Center for Laboratory Medicine Germano de Sousa (CML GS) considers of extremely importance the existence of a well organized bank of sera and tissues, accessible to all who are engaged in clinical, basic and applied research, particularly in the area of autoimmune diseases. Hence, we considered as an ethical duty to collaborate with the Biobanco-IMM CAML in collecting blood samples to supplement its collection. Thus, with the appropriate free and informed consent from each donor we reserve a small portion of their blood for sending to the Biobanco-IMM CAML. It is worth to highlight the willingness that almost all of the patients showed by positive responding to our consent request to the keep some of their blood for scientific purposes. The CML GS is pleased to participate in this initiative of the Instituto de Medicina Molecular and is available for future partnerships."

Center for Laboratory Medicine Germano de Sousa

PLANNED ACTIVITIES FOR 2014

Promote the creation of a national network of biobanking facilities, sharing common standard operating procedures and using the same information system.

Scientific Development areas

- Implementation of induced pluripotent stem cells (iPS) culture;
- Leukocyte Immortalization;
- Quality control protocols for all types of samples;
- Rare diseases collection;
- Collaboration with Instituto de Medicina Legal for cadaveric samples.

Expansion of the collections

- Increase the number of donors aiming at 10,000;
- Increase the number of samples aiming at 80,000;
- Increase the number of control donors to up 2,000;
- Increase the range of collections.

Improvement of infrastructure

- Increase laboratory and storage space.

Improvement of operational activities

- Strengthen the administrative support.

Consolidate visibility

- Disseminate Biobanco-IMM CAML among research institutes and researchers as a key resource for biomedical research;
- Continue to bring Biobanco-IMM CAML closer to the public.

Enlarge partnerships

- Increase partnerships with research institutes and biotechnology companies;
- Establish an institutional partnership with the Portuguese Institute of Blood and Transplantation;
- Establish institutional partnerships with health units.

CONTACTS

Biobanco-IMM CAML is located at the Edifíco Egas Moniz, on the campus of the Lisbon Academic Medical Centre, that hosts the University of Lisbon Medical School as well as the Hospital de Santa Maria and the Instituto de Medicina Molecular (IMM).

ADDRESS

Biobanco-IMM CAML
Edifício Egas Moniz
Av. Prof Egas Moniz
1649-028 Lisbon
Portugal

TLF

(+351) 217 999 437
(+351) 965 152 588

WEB

www.biobanco.pt
www.facebook.com/BiobancoIMM

EMAIL

immbiobanco@fm.ul.pt