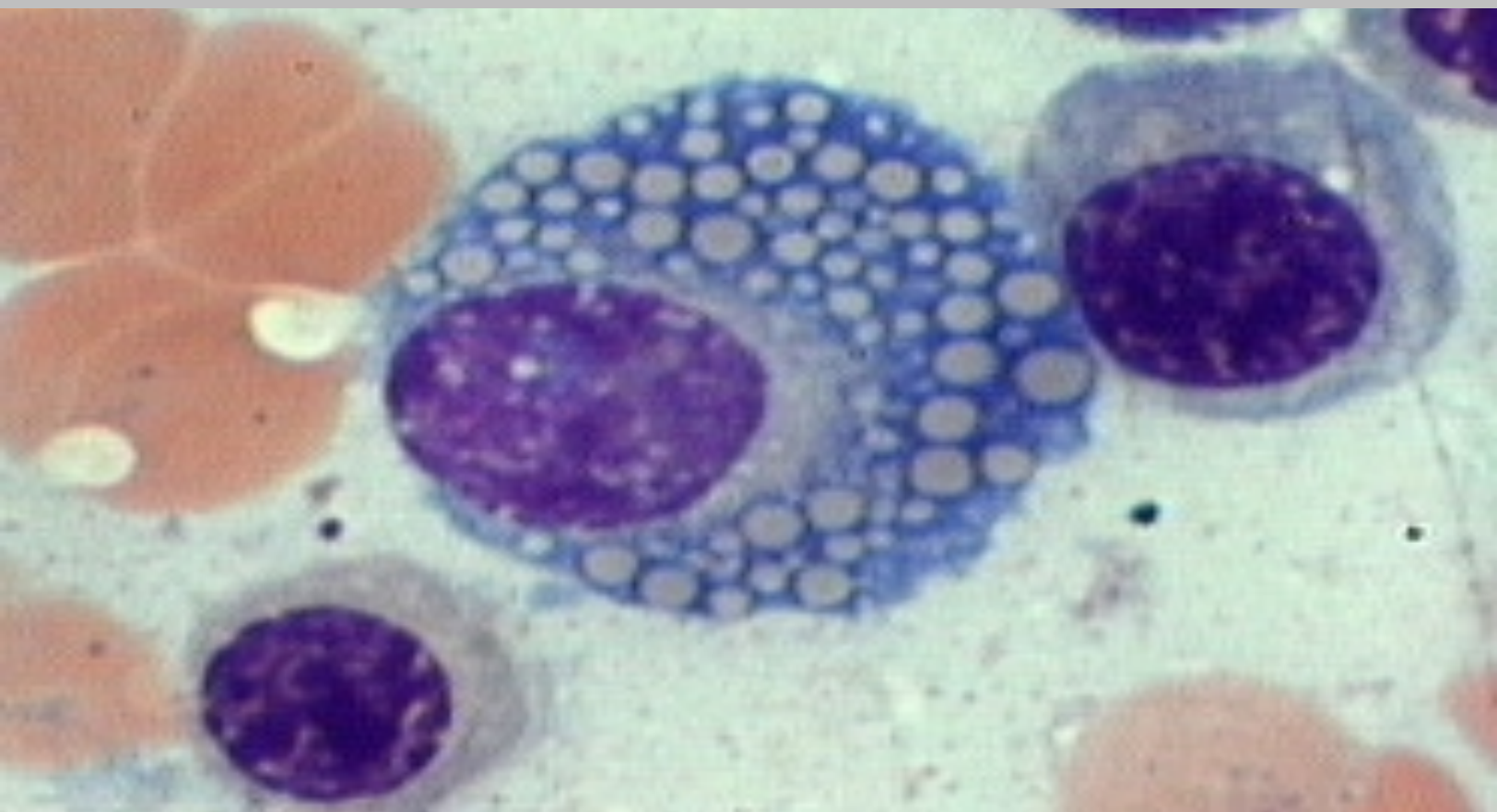


# THE EUROBIOBANK NETWORK

***[www.eurobiobank.org](http://www.eurobiobank.org)***



# The EuroBioBank Network

**EuroBioBank®** is the first operating network of biological banks in Europe providing human DNA cell and tissue samples for research on rare diseases.

The **Eurobiobank** network tackles two of the main problems facing European research on rare diseases:

- lack of human biological material
- quality of samples.

Rare diseases are defined as affecting less than one citizen in 2,000.

30 million people in the 25 EU member states are affected.

Due to their rarity and the consequent lack of relevant information, patients affected by rare diseases do not benefit from appropriate medical resources and care.



## ACTIVITIES OF THE NETWORK

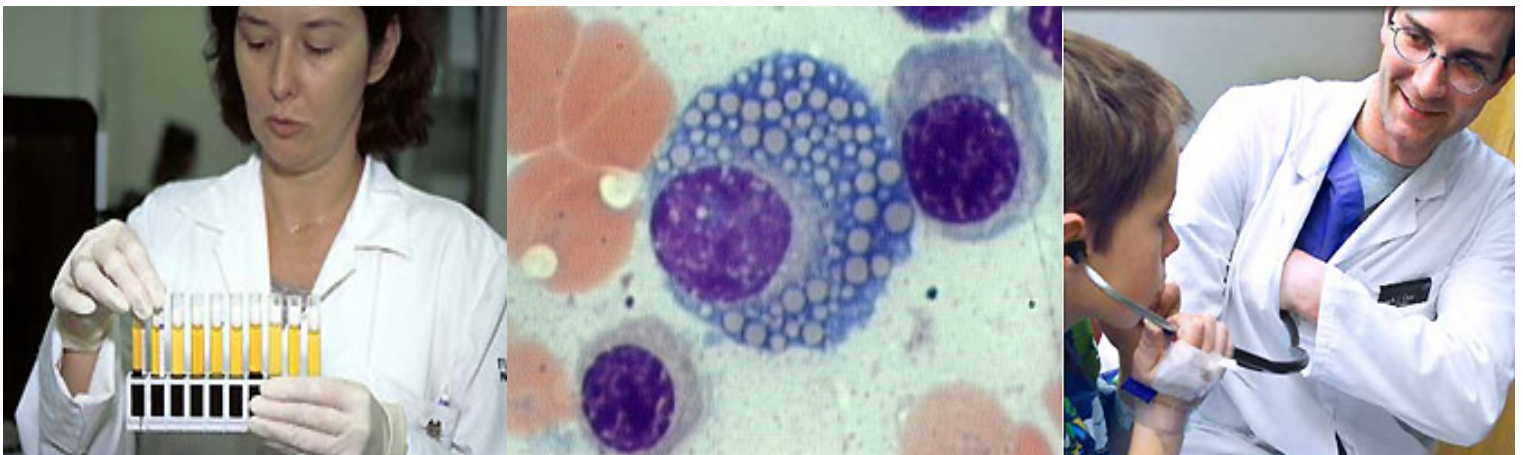
- Identify and localise rare disease biological material of interest to researchers
- Process and store a critical mass of rare disease sample collections
- Maintain a centralised website with an online catalogue offering an easy access to the referenced samples available
- Distribute high quality material and associated data to users
- Promote quality biobanking practices (collection, transport, storage and exchange of biological material) adapted to each type of material (DNA, tissue, cell)
- Map ethical issues related to the use of biomaterial samples
- Disseminate knowledge and know-how to the scientific community
- Identify collaboration with the medical and scientific community in the field of rare diseases

## The role of EURORDIS in the EuroBioBank network:

- Coordinate the network administratively
- Apply for grants and find corporate sponsors to ensure long term sustainability of the network
- Maintain the EuroBioBank website ([www.eurobiobank.org](http://www.eurobiobank.org))
- Serve as the main contact point for the network

# Key features

- A web-based catalogue displaying 1241 sample collections
- More than 170,000 samples available
- Thousands of samples collected each year (e.g. 64,000 in 2005)
- Thousands of samples distributed each year
- 30 Standard Operating Procedures developed by the network
- 14 members from 7 EU countries including 11 biobanks
- 47 publications acknowledging EuroBioBank
- A book published on “Outstanding Legal and Ethical Issues on Biobanks”



# Ethics

- **Respect of anonymity** in the sample collection
- Respect of the **patient's autonomy** by using the Informed Consent Form, for collection and use of the biological material for research
- Access to sample: ad-hoc **board approval of the projects for which the biological samples are requested, no distribution of samples for cloning projects** (Respect of the Oviedo Convention on Human Rights and Biomedicine and Additional Protocols, 4<sup>th</sup> April 1994; and International declaration on human genetic information, UNESCO general conference, 32<sup>nd</sup> session, Paris, October 8<sup>th</sup> 2003)
- **Confidentiality** of the data associated with the samples
- **Information** to the patients on the use of collections and the outcomes of the research projects.
- **A book was published:** "Outstanding Legal and Ethical Issues on BioBanks- An Overview on the regulations of member states of the EuroBioBank project"



## History of the network

- Initiated in 2001 by the European Organisation for Rare Diseases (Eurordis) and the French Muscular Dystrophy Association (AFM)
- Financed by the European Commission between 2003-2006
- 16 founding partners in 8 countries (Belgium, France, Germany, Hungary, Italy, Malta, Slovenia and Spain)
- EurobioBank was awarded the Newropeans Grand Prix 2004 for Research and Technology
- In 2006, the EuroBioBank network was cited by the IPTS/ESTO work group as a European model of coordination and of integration of Biological Resources Centers\_for the optimisation and improvement of the use of human biomaterial at European level
- Since January 2007, EuroBioBank is partner of the TREAT-NMD network of excellence in charge of the workpackage "Develop and Manage Supernational BioBanks"

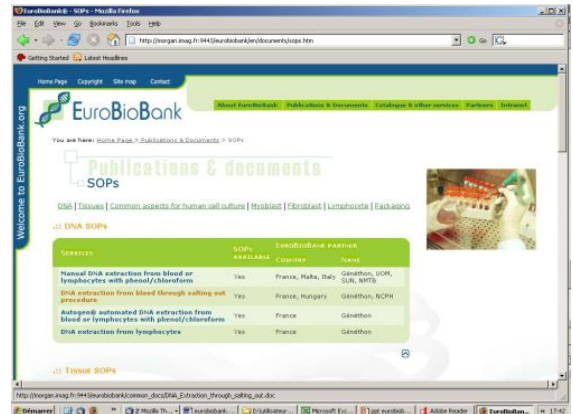


# Standard Operating Procedures

The Eurobiobank partners worked in common to develop **harmonised Standard Operating Procedures** that comply with the OECD's recommendations for Biological Resource Centres.

## Examples of services for which Standard Operating Procedures are available:

- Purification of lymphocytes from peripheral blood
- DNA extraction from lymphocytes
- Primary myoblast culture from fresh human muscle biopsy
- Detection of contaminants in human cell culture
- Freezing and thawing of vital muscle biopsy for culture
- Protocol for conditioning and transport of DNA



*The Standard Operating Procedures are available on the EuroBioBank website*

## Network actions for 2007

- Optimise current collections of samples and create new ones
- Search for new partners to join the network
- Service Biobanks in Europe to benefit rare disease research projects
- Participate in the TREAT-NMD network of excellence funded by the European Union, (2007-2012)
- Apply for grants and find corporate sponsors to ensure long term sustainability of the network

### For further information

**[www.eurobiobank.org](http://www.eurobiobank.org)**  
**[contact@eurobiobank.org](mailto:contact@eurobiobank.org)**

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102 rue Didot – Paris 75014 – France  
Tel + 33 1 56 53 52 10 Fax + 33 1 56 53 52 15 Brussels office: Tel/fax + 32 2 733 81 10

## EuroBioBank's current partners



- EURORDIS (European Organisation for Rare Diseases), Paris, France
- AIM (Association Institut de Myologie), Paris, France (biobank)
- Fondazione IRCCS Istituto Nazionale Carlo Besta, Milan, Italy (biobank)
- Fondazione Ospedale Maggiore Policlinico Mangiagalli e Regina Elena, IRCCS, Università Studi Milano, UOS Malattie Neuromuscolari, Milan, Italy (biobank)
- Fundación CSAI Carlos III, Madrid, Spain (biobank)
- GENETHON, Evry, France (biobank)
- MTCC (Muscle Tissue Culture Collection), Munich, Germany (biobank)
- National Institute of Environmental Health (NIEH), Budapest, Hungary (biobank)
- NMTB (University of Padova), Padova, Italy (biobank)
- UNIVERSITY OF LJUBLJANA, Ljubljana, Slovenia (biobank)
- UOM (University of Malta), Malta (biobank)
- SUN (Second University of Naples), Caserta, Italy (biobank)
- TEAMLOG SA, Montbonnot, France
- 3 C-R Consulting, Castelginest, France

## EuroBiobank's current sponsors

