Italian Twin Registry
Biobank

Maria Antonietta Stazi

National Center for Epidemiology, Surveillance and Health Promotion (CNESPS)
Italian Twin Registry, 2000-ongoing

Supported by the Italian Ministry of Health and coordinated by the Italian Institute of Health (ISS)

Aims

1. To estimate the genetic and environmental component of various health related traits

2. To establish a biobank through the collection of biological material and phenotypic information of twin donors

3. To act as scientific tool in genetic epidemiology for the Italian and international research community
ITALIAN TWIN REGISTRY

TWIN ENROLLMENT:

FROM GENERAL POPULATION
- Local Population Registries
- At birth, in selected hospitals (MUBICOS study)
- Volunteers (WEB - http://www.iss.it/gemelli/)
- Twin days in several Italian cities

FROM PATHOLOGY REGISTRIES
- Matching population registries with pathology registries (celiac disease, multiple sclerosis, type 1 diabetes).
Up to now:

24,800 twins enrolled
10% with biological samples
ITALIAN TWIN REGISTRY

SAMPLE COLLECTION
Cardiovascular and cognitive traits
Serum, plasma, buffy coat
450 twins

Psychological and behavioural traits
DNA extracted from saliva
1300 twins

Reproductive history
DNA extracted from saliva
400 young twin mothers

Newborn twin cohort (MUBICOS)
DNA extracted from saliva
350 twin pairs with their parents
Ethical and legal procedures for the Biobank for biological material collection, storage and use (present and future)

- Analysis of each specific study
- Adoption of the best format of Informed Consent (IC)
- Procedures for sensitive and in particular genetic data treatment according to the Italian legal requirements
- Analysis and adoption of level of anonymization of data (retrievable) according to the specific cohort, size, variables collected etc.
- Definition of specific policies for vulnerable individuals
- Updating of the IC format towards a “partially restricted consent” model for most of the cohorts of donors in order to make both the collection usable also in future studies as well as to respect individual autonomy and choice.
Research understanding, attitude and awareness towards biobanking: a survey among Italian twin participants to a genetic epidemiological study

Virgilia Toccaceli, Corrado Fagnani, Lorenza Nisticò, Cristina D'Ippolito, Lorenzo Giannantoni, Sonia Brescianini and Maria Antonietta Stazi

Published: 16 June 2009
Received: 26 November 2008
Accepted: 16 June 2009

Pediatric Biobanking: A Pilot Qualitative Survey of Practices, Rules, and Researcher Opinions in 10 European Countries

Elena Salvaterra, Roberto Giorda, Maria Teresa Bassi, Renato Borgatti, Lisbeth E. Knudsen, Andrea Martinuzzi, Maria Nobile, Uberto Pozzoli, Gian Paolo Ramelli, Gian Luigi Reni, Damiano Rivolta, Maria Antonia Stazi, Sandra Strizzer, Carel Thijs, Virgilia Toccaceli, Antonio Trabacca, Anna Carla Turconi, Sergio Zanini, Claudio Zucca, Nereo Bresolin, and Leonardo Lenzi on behalf of the Pediatric Biobank ELSI Working Group†
Technical aims
• Build an international twin registry and biorepository;
• Obtain and synchronize informative variables from twin registries in 3 continents by adapting standard informatics tools from the Public Population Project in Genomics (P3G, http://www.p3g.org).
• Establish and link geocoding databases that will allow evaluation of the effects of the built environment on obesity and other health conditions;
• Identify, enroll, and collect data and biological samples from 500 MZ twin pairs discordant for obesity.

Scientific aims
• Conduct co-twin control twin study of obesity.
• Examine 500 pairs of obesity MZ discordant pairs from a multitude of cultures, racial/ethnic groups and genetic backgrounds.
Sabrina Alviti
Antonio Arnofi
Sonia Brescianini
Rodolfo Cotichini
Davide Delfino
Cristina D’Ippolito
Corrado Fagnani
Maurizio Ferri
Simona Giampaoli
Cinzia Lo Noce
Emanuela Medda
Lorenza Nisticò
Luana Penna
Miriam Salemi
Virgilia Toccaceli

GRAZIE!!!!!