

PERSONAL INFORMATION

Angelo Loris Brunetta

WORK EXPERIENCE

October 1988–June 2012

Responsible of Secretary

Comune di Genova (Italy)

Chief of Director's Secretary, responsible of personnel of General Affairs a sector of Comune di Genova, computer management

September 1986–August 1988

Responsible of computer sector and stock management

Executive Global Courier (Italy)

EDUCATION AND TRAINING

September 2006–November
2009**Graduate**

University of Genoa (Italy)

Graduation in Social and Institutional Communication. The title of the final examination for achieving his graduation degree was: "Disease and discrimination: paths to communicate disability".

September 2012–Present

Graduation

University of Genoa (Italy)

Ongoing Course for getting the graduation in History and Philosophy

ADDITIONAL INFORMATION

Expertise

I am a Patient Representative.

Founding member of Comitato Ligure Giovani Talassemici, created in 1983 that since June 2000 has been renamed as Associazione Ligure Talassemici.

Founding member of Thalassaemia International Federation (TIF) in 1987.

Founding member of UNITED (Italian Federation of the Thalassaemia Associations) in 2012.

Since 2000 I have led the activities of the volunteer organization the Associazione Ligure Talassemici, from the position of the president, having being elected to this office for seven consecutive terms (in office until 2021).

Their activities include membership organization of workshops and seminars on blood diseases, participation in congresses, conferences and workshops, creation of projects for fundraising for scientific research and projects to support families and patients suffering from thalassaemia, sickle cell disease and rare anaemias.

In this field, on behalf of the Italian Foundation 'L. Giambrone' I am responsible, since 2011, for relations with the Thalassaemia International Federation (TIF). He has also been a collaborator of Italian Foundation's magazine "Progetto Guarigione", and the spokesperson of Italian Associations of thalassaemia in relations with Italian Ministry of Health for the claiming of the patients' rights for the damages due to the infected blood transfusions.

Since 2017, coordinator of the Italian Association Advocacy Council (IAAC) at Italian Foundation 'L. Giambrone' for the cure of Thalassaemia.

Since 2011 I am a Board Member of Thalassaemia International Federation (TIF) and member of IEPCG (International Expert Patients' Core Group) of TIF.

Serving as TIF's Board member he is a collaborator for many international projects, for the organization of educational events for patients. Attended several TIF's delegation visits, in many countries of the world as Cina, Morocco, Algeria, Albania and at UN, representing the Board of Directors.

In 2018, he has been appointed by the Board of Directors for the European Affairs.

Since 2004 I have been committed in dissemination activities for disability issues by participating in conferences, debates, television appearances on major national and local levels, publishing articles on the general daily newspapers and specific press.

Since May 2016, I've been elected by Eurordis (European Rare Disease Organization) as ePAG (European Patients Advisory Group) in the context of ERNs (European Reference Networks) project. He's official member of the Strategic and Scientific Board of the European network for rare hematological diseases called "EuroBloodNet", coordinator of the TFA on Research and Clinical Trials at EuroBloodNet.

Also, appointed or the ePAGs Steering Committee at Eurordis and Eurordis representative.

EUPATI Training Course Cohort 3 on Medicine Research and Development has been successfully completed in december 2018. EUPATI is the European Patients' Academy for Therapeutic Innovation.

- Publications**
- 2007 Loris Brunetta and Silvano Chidda 'Thalassemia e dintorni' published by Liberodiscrivere (2007) Genoa
 - 2009 Reviewer, to the Guidelines for Sickle Cell in Pediatrics with AIEOP (Italian Society of Pediatric Hematology and Oncology).
 - 2011 Loris Brunetta "In-sha-Allah – A true story between desperation and hope" published by De Ferrari Editore (2011) – Genoa.
- Projects**
- from 2006 to 2012 'A bridge between Genoa and Rabat' for supporting thalassaemia-affected children in Rabat - Morocco managed in collaboration with Rotary Foundation and Associazione Ligure Talassemici
 - from 2011 IEPCG (International Expert Patients' Core Group) of TIF (Thalassaemia International Federation) for defining international programs for patients' empowerment
 - from 2014 Generic Drugs Internation Project of TIF
 - DEEP Project (Deferiprone Evaluation in Paediatrics) WP7 Framework supported by EC
- Memberships**
- Associazione Ligure Talassemici
 - Thalassaemia International Federation
 - Italian Foundation "L. Giambone" for the cure of Thalassaemia
 - Eurordis (European Organization for Rare Diseases)
 - In 2008 I've received the Paul Harris Fellow Award from Rotary Club Genova-Nord for the project "A bridge between Genoa and Rabat" for supporting thalassaemia-affected children in Rabat - Morocco
- Other Relevant Information**
- Since 2012 close collaborator and editorialist of "EX", a monthly Italian magazine issued for thalassaemia and hemophilia patients, edited in Ravenna -Italy-