

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 six consecutive terms (in office until 2018).

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

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.

Publications

2007 Loris Brunetta and Silvano Chidda 'Thalassaemia 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

- Memberships**
- Associazione Ligure Talassemici
 - Thalassaemia International Federation
 - Italian Foundation "L.Giambrone" for the cure of Thalassaemia
 - UNITED Italian Federation of the Associations for Thalassaemia, Sickle Cell Disease and Rare Anaemias
- 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-