

## Short biographies of speakers and contributors (as available prior to the conference)

### **Athanasios Aessopos**

Associate Professor of Internal Medicine, Athens University. Member of Scientific Societies Medical Association of Athens. Hellenic Cardiology Society. Hellenic Study Society of Hypertension. Thalassaemia International Federation. Member of the European Cardiology Society. Active member of the St Luke's Hospital, Texas Heart Institute, Houston Texas USA. Honorary member of the New York Academy of Sciences

### **Edith Aimiuwu**

I joined the Whittington Hospital NHS Trust in 2006 as a Roald Dahl haemoglobinopathy clinical nurse specialist. I have also worked in various capacities as a registered general nurse, a registered midwife, a qualified paediatric nurse and as a sickle cell community nurse. Further qualifications were obtained in haemoglobinopathy and Pain management. My experience spans over 25 years both within the United Kingdom and Nigeria. As a Clinical Nurse Specialist in haemoglobinopathy, I provide and facilitate holistic care for patients and their families. The care provided goes well beyond the bedside and include aspects of culture, family dynamics, long-term needs, and life styles. As the lead nurse, I identify problems, facilitate interdisciplinary planning, promote development of improved care for patients to minimise disruption to both school and family life, develop patient education material, promote staff education, and monitor outcomes. I also work with schools and other organisations to create awareness as well as mediating on behalf of patients when required. Furthermore, I work closely with patients and their families to ensure treatment /drug compliance and adherence to their management plans. I ensure that the service is easily accessible to patients at all times by creating clear lines of communication.

### **Michael Angastiniotis**

Dr Michael Angastiniotis was Director of the Paediatric Department of the Archbishop Makarios III Hospital and the Cyprus Thalassaemia Centre from 1989 to 2001. Member of the Board of Directors, Cyprus Institute of Neurology and Genetics on Thalassaemia. Member of the implementation team of the Thalassaemia Control Programme from the outset (1972). Member of the WHO Advisory Panel on Human Genetics since 1990. Consultant assignments for the control of haemoglobinopathies to most countries of the Eastern Mediterranean region including the UNRWA fields. He has also been a member of the WHO ad hoc committee on hereditary anaemias established in 1983. This committee worked to establish standards of care and prevention of haemoglobinopathies to serve as a model for the control of other genetic disorders. These standards were published in various WHO working papers and distributed to all centres dealing with these disorders. In 1985 the Cyprus Thalassaemia Centre was declared a WHO Collaborating Centre and Dr Angastiniotis was appointed as a consultant for the organisation and member of the WHO Advisory Panel on Human Genetics.

### **Emanuele Angelucci**

Head, Struttura Complessa di Ematologia e Centro Trapianti. Presidio Ospedaliero "A. Businco", Centro di Riferimento Oncologico Regionale. ASL8 Cagliari. Head, Dipartimento di Oncologia Medica. Presidio Ospedaliero "A. Businco", Centro di Riferimento Oncologico Regionale. ASL8 Cagliari.

PUBLICATIONS: Original papers published on JCR listed International Journals. Source:

<http://www.ncbi.nlm.nih.gov/pubmed>

Papers: 140

Mean Impact Factor : 7,08

Total Impact Factor: 1025,93

Principal Papers ( source <http://www.ncbi.nlm.nih.gov/pubmed/>).

### **Dora Bachir**

Sickle Cell Centre (UMGGR, Henri Mondor Hospital , France. Clinical Haematologist, Henri Mondor hospital Sickle cell Center. Participation in clinical trials including: Iron chelation with oral chelator in  $\beta$  thalassemia and other anemias (ICL 670 107 and 108) as Investigator; Iron chelation with oral chelator ICL670 in SCD (ICL 109 and 2409) as Investigator

Pharmaco-kinetics analysis of hydroxyurea in SCD as Co-Investigator; Consultant for EMEA concerning iron chelation with deferiprone ( FERRIPROX) from 1996 to 2007.

### **Soroya Beacher**

I am a fully trained intensive care nurse I came into contact with other patients because they were admitted to the ward I was working on. I realised that there was not much knowledge about the problems these patients had. In the 1970s the easiest method to “stop the pain” was to give large doses of Pethidine or Morfine. Sickle cell patients were seen as having a drug problem. It took many years for knowledge about the disorder to improve. In the 1980s I moved to the Netherlands, where I was even more shocked to find a lack of knowledge about sickle cell and thalassaemia. I decided to work with the UK, realising that the UK Thalassaemia Society had a lot to offer, they too were fighting for patients and encountering many problems, but they never gave up. The decision to set up Oscar Netherlands was not only out of need, but also out of necessity, as we needed a voice. Multidiplinary care was non existent, patients were not receiving the best management, and we saw clearly that the management of thalassaemia was on a very basic level. 20 years on, we are still fighting. My one conclusion is that just because our patients live in western Europe, most people expect that the care and management of sickle cell and thalassaemia should be optimal. All patients are insured for basic care, we do not have long waiting lists, we have “state-of-the-art” equipment. And yet, it is clear that there may be money and a healthcare programme, but if there is no knowledge then our patients will continue to get second-best care.

### **Antonio Cao**

Antonio Cao was born in Cagliari, Italy in 1929. In 1954, he got a first-class honours degree in Medicine and Surgery. In 1962 he became First Assistant Professor at the Paediatrics Clinic of the University of Cagliari, and in 1968 First Assistant Professor at the Paediatrics Clinic of the University of Perugia. In 1974 Antonio Cao became Full Professor of Paediatrics and Chair of the Paediatric Department of the University of Cagliari, and in 1992 he was nominated Director of the National Council of Research Institute for Research on the Thalassemias and Mediterranean Anemias (IRTAM) – Cagliari. Presently Prof. Cao is Director of the Istituto di Neurogenetica e Neurofarmacologia – CNR Cagliari, President of Scientific Committee for Orphan Diseases of the Ospedale Regionale per le Microcitemie, and Consultant on the same topic for the Italian Department of Public Health.

### **Maria Domenica Cappellini**

Prof. Maria Domenica Cappellini. Born in Milan at June, 1949. Graduated in Medicine, at Milan in 1974. Specialized in Gastroenterology in 1978. Specialized in Hematology in 1981. Stage at the Pasteur Institut in Paris in 1975. Stage at Instituut vor Anthropogenetica "Dept of Human Genetics" University of Leiden in 1976. From September 1981 to December 1982 Research Fellow at MRC, Molecular Hematology Unit, John Radcliffe Hospital, Oxford University. Visiting Scientist of the same Unit for short period in 1983, 1984, 1985, 1987 for cooperative project. Associate Professor and since March 2002 full Professor of Internal Medicine at the University of Milan. Member of Italian Society of Hematology. Member of Italian Society of Internal Medicine. Member of the Editorial Board of Haematologica. She performed researchs on hereditary disorders of Red Blood Cells with particular interest for Thalassaemia, RBC enzyme deficiency and Porphyrias. She developed long term erythroid tissue culture techniques to study the hemoglobin switching and the induction of HbF by different compounds. She published more than 100 peer reviewed papers, invited speaker to several national and international meetings.

### **Holger Cario**

Member of the European Haematology Association, the German Society of Pediatric Oncology and Hematology, the German Society of Pediatrics, the German Society of Pediatric Infectiology, the ‘Red Cell and Iron Club’ of the French Society of Hematology

### **George Constantinou**

George Constantinou, is a patient with thalassaemia major born in Nicosia, Cyprus. He is by profession involved in travel and tourism. George has been a founding member of the Cyprus Thalassaemia Association and later of Thalassaemia International Federation (TIF). His contribution at the national level in Cuprus and later in UK Thalassaemia Society, is invaluable. His international contribution through TIF’s activities is considered exemplary and he is recognised by all involved in this field as a patient expert. George has devoted is whole life on sprading awareness and securing the rights of patients for quality healthcare in every corner of

the world. He has participated in over 40 delegation visits in over 30 countries and in numerous workshops, seminars, conferences at national regional and international level as a speaker and a member of the faculty.

### **Mariane De Montalembert**

Mariane de Montalembert is a pediatrician, responsible for the Centre for Hemoglobinopathies in the Hopital Necker in Paris. She has developed a network in France for the follow-up of SCD children treated with hydroxyurea. She is also doctor in Ethics.

### **Vincenzo De Sanctis**

Vincenzo De Sanctis obtained his medical degree at the University of Bologna, Italy, in 1970 and specialized later in paediatrics and endocrinology. He was Assistant Professor of the Division of Paediatrics at the Arcispedale S. Anna, Ferrara, Italy, from 1972 to 1994, and has been Director of the Division of Paediatrics and Adolescentology there since 1995. In 1984, he was a research fellow at the Department of Haematology, Whittington Hospital, and the Department of Reproductive Endocrinology-Pathophysiology, University College Hospital, both in London, UK. His experience in the field of paediatrics and endocrinology is also based on the research he conducted at the Paediatric Clinic of Padua, Italy, the Department of Haematology of Whittington Hospital, the Department of Andrology of the Karolinska Hospital, Stockholm, Sweden, and the Department of Adolescentology of University College Hospital. His research interests include diagnosis and treatment of thalassaemias and haemoglobinopathies, endocrinology and diabetes, adolescent medicine. Dr De Sanctis is member of the Società Italiana di Endocrinologia e Diabetologia Pediatrica (SIEDP). Since 2001, he has had teaching responsibilities in the post-graduate medical school programmes of evolutionary endocrinology and adolescentology at the University of Ferrara. As a director and a trainer, Dr De Sanctis organized advanced training courses in adolescent medicine – accredited by the regional health organization – in 2001, 2002, and 2003. He has been Editor-in-Chief of *Rivista Italiana di Medicina della Adolescenza* since 2003, of *Emothal* since 2005, and of *PER Crescere* since 2007, a member of the editorial boards of *Minerva Pediatrica* and *Pediatric Endocrinology in Review* since 2001, and a member of the scientific committee of *Rivista Italiana di Emergenza-Urgenza Pediatrica* from 2005 to 2009. He has been President of the Mediterranean and Middle East Action Group for Adolescent Medicine (M.A.G.A.M.) and since 2006, President of the Italian Society of Pediatrics (SIP), Section Emilia e Romagna Region. Dr De Sanctis has published circa 350 scientific papers published in national and international journals and is author of numerous medical textbooks and book chapters in the fields of paediatrics, adolescentology, haematology, and endocrinology.

### **Vito Di Marco**

Lecturer of Internal Medicine and of Gastroenterology, University of Palermo. More than 100 full papers in international journals, and over 100 presentations to international and national meetings.

Recent papers on thalassaemia patients:

- Di Marco V, Bronte F, Cabibi D, Calvaruso V, Alaimo G, Borsellino Z, Gagliardotto F, Almasio PL, Capra M, Craxì A. Noninvasive assessment of liver fibrosis in thalassaemia major patients by transient elastography (TE) - lack of interference by iron deposition. *Br J Haematol*. 2010
- Di Marco V, Capra M, Gagliardotto F, Borsellino Z, Cabibi D, Barbaria F, Ferraro D, Cuccia L, Ruffo GB, Bronte F, Di Stefano R, Almasio PL, Craxì A. Liver disease in chelated transfusion-dependent thalasseemics: the role of iron overload and chronic hepatitis C. *Haematologica*. 2008
- Di Marco V, Bronte F; Sicily Group for the Study of Thalassaemia, Capra M, Gerardi C, Maggio A, Malizia R, Rizzo M. HCV clearance among hemophiliacs and beta-thalasseemics. *Gastroenterology*. 2007

### **Roswitha Dickerhoff**

Paediatrician, Head of Hematologie / Oncologie Department Johanniter Kinderklinik (now Asklepios-Klinik) St. Augustin. Counseling for patients and families with rare anemias at Children's Hospital St. Augustin. Foundation of Sick cell and Thalassaemia patient/parent group „Interessengemeinschaft Sichelzellerkrankheit und Thalassämie e.V.“ Hematology Clinic at University Children's Hospital Düsseldorf.

### **Androulla Eleftheriou**

Dr Eleftheriou obtained her graduate and postgraduate degrees (BSc Hons, MSc, PhD) from the University of London, in the fields of Biochemistry, Microbiology and Virology. She has been awarded a number of scholarships by the World Health Organisation and the Fulbright Commission. Her postdoctoral fellowship was completed at the Centre for Disease Control in Atlanta, GA, USA. Dr Eleftheriou has also recently obtained a Diploma in Business Management from the University of Leicester - UK. Since 1990 and until August 2006, Dr Eleftheriou had been the head of the Virus Reference Centre of the Cyprus Ministry of Health – a centre she was closely involved in establishing. She is now the Executive Director of the Thalassaemia International Federation (TIF) Headquarter Offices, based in Nicosia, Cyprus, and the Coordinator of its educational programme. In addition, Dr. Eleftheriou regularly acts as a World Health Organization (WHO) consultant on issues related to her field of expertise. Through her work with TIF, Dr Eleftheriou has carried out numerous projects of local, national, regional and international scope, working closely with international experts, local physicians and thalassaemia associations worldwide. She is the author of several works published by TIF, as well as a number written in collaboration with the W.H.O. and other international bodies on a wide range of scientific topics. Dr Eleftheriou is the Chief Editor of TIF Magazine, issued quarterly and which is distributed to 3,500 subscribers, in more than 40 countries worldwide.

### **Panos Englezos**

He is a graduate of London University in Economics and Accounting and Chairman and Chief Executive of a group of companies which he established in 1961. In 1969, he promoted the establishment of the Cyprus Thalassaemia Association and was elected its first president, a post he held to June 1995. In 1986 TIF was established and he was elected chairman and has also been regarded as a 'founding Father'. He has travelled extensively promoting TIF's objectives, mainly establishing Thalassaemia associations, promoting improved medical care, international research and prevention programmes. He has received several awards and has held important public offices, including the chair of the Cyprus Telecommunications Authority and the currently the Cyprus Tourism Organisation.

### **Giuliana Ferrari**

Associate Professor of Molecular Biology, HSR Medical School, University Vita-Salute, Milan, Italy. Research Coordinator, HSR-TIGET, Scientific Institute H.S.Raffaele, Milan, Italy Editorial Activities. Human gene Therapy: Associate European Editor (1995-1997); The Journal of Gene Medicine: Editorial Board (1999-present); Scientific Associations: European Society of Gene Therapy (ESGCT), American Society of Gene Therapy (ASGCT).

### **Gerhard Gaedicke**

Professor and Director Dept. of Pediatrics, Charité, Medical Faculty, Humboldt University, Berlin Memberships; President of the North German Society of Pediatrics and Adolescent Medicine (1996 – 2007); Executive Board of the German Society of Pediatrics and Adolescent Medicine (1999 - 2001, Member since 1973); Executive Board of the German Society for Pediatric Oncology and Hematology (1991 - 1995, Member since 1975); Executive Board Member of the European Paediatric Association( EPA / UNEPSA); (2003 -) Member of the European Society for Bone Marrow Transplantation (EBMT) (1983 -) Member of the European Society for Pediatric Infectious Diseases (ESPID) (1999 -)International Member of the American Society of Hematology (ASH).

### **Frédéric Galacteros**

Professional position: Director of Creteil's Henri Mondor Hospital Sickle Cell Center

### **Renzo Galanello**

Professor Renzo Galanello is Professor of Paediatrics at University of Cagliari and Director of the 2nd Paediatric Clinic and the Thalassaemia Unit at Ospedale Regionale per le Microcitemie in Cagliari. He graduated and completed his paediatric residency at the School of Medicine of the University of Perugia, and has been a senior fellow at the Department of Medical Genetics at University of Washington, Seattle. His main research interests are in the molecular genetics of thalassaemias and other haemoglobinopathies, glucose-6-phosphate dehydrogenase deficiency, and Gilbert syndrome. In the last 10 years he has been the principal investigator of several clinical trials of new oral iron chelators. Besides haemoglobinopathies, the clinical department directed by Prof. Galanello deals with genetic diseases, including rare diseases, and other aspects of paediatric haematology. He has teaching responsibilities at the School of Medicine

and the Postgraduate Medical School in Paediatrics at University of Cagliari. He is scientific advisor of Thalassaemia International Federation and member of the Human Genetics Programme at the WHO Committee on Epidemiology and Care of Haemoglobin Disorders. His is author of over 150 peer-reviewed publications and co-author of Prevention of Thalassaemias and Other Haemoglobin Disorders, Vol. 1&2 edited by TIF and of chapter "The thalassaemias" in Wintrobe's Clinical Haematology (11th edition).

### **Roberto Gambari**

Roberto Gambari is full Professor of Biochemistry (Degree in Chemical and Pharmaceutical Technologies, CTF, Ferrara University, Faculty of Pharmacy) since 2001. He has been chairman of the PhD course in Biotechnology and Director of the Biotechnology Center of Ferrara University. Director of the Laboratory for the Development of Gene and Pharmacogenomic Therapy of Thalassaemia ([www.talassemiaricerca.it](http://www.talassemiaricerca.it)). In September 1991 he was elected as member of the Council of European Tissue Culture Society (ETCS). Prof. Gambari is member of the Scientific Committee of the Interuniversity Consortium for Biotechnologies (C.I.B., Italy). Chief-Editor of the Journal *Minerva Biotechnologica*. Member of the Editorial Board of the *American Journal of Pharmacogenomics*, *Technology in Cancer Research and Treatment*, *International Journal of Oncology*, *Drugs Design Reviews*, *Molecular Diagnosis and Therapy*, *Medicinal Chemistry*. Referee of the following Journals: *FASEB J.*, *Biochemical Pharmacology*, *Human Gene Therapy*, *BioTechniques*, *Biological Chemistry*, *J. of Clinical Investigations*, *Nucleic Acids Research*, *J. Agricultural and Food Chemistry*. Chairman of Workshops on Synthetic Oligonucleotides in Biotechnology and Molecular Biology, Ferrara 1992-1995. Coordinator of several Research Projects, including Target Project Genetic Engineering (1992-1995), ISS-AIDS (1992-1993), Telethon, Target Project ACRO (1992-1995), Fondazione Italiana per la Guarigione dalla Thalassaemia, AIRC (1992-1994; 2003). Coordinator of the Network "Use of PNA, ribozymes and peptides for the study of gene functions and possible diagnostic and therapeutic applications" (COFIN-1998). Coordinator of the Network "Applications of a dielectrophoresis-based Lab-on-a-chip to diagnosis and drug research and development" (COFIN-2002). Coordinator of the Telethon Project "Modifiers of globin gene expression for therapy of beta-thalassaemia". Coordinator of the Project "New Frontiers in Molecular Diagnosis and Experimental Therapy of Beta-Thalassaemia", funded by Fondazione CARIPARO (Italy). More than 280 papers, published by Roberto Gambari, are present in Medline. Co-author of more than 12 patents.

### **Béatrice Gulbis**

Béatrice Gulbis, MD, PhD, is head of the Department of Clinical Chemistry since November 2006 (47 staff members) which includes a specific laboratory for prevention and diagnosis of hereditary red blood cell disorders. She is the President of a subgroup dedicated to the red blood cell disorders within the Belgian Hematological Society. She is responsible for the neonatal screening in Brussels since 1994.

### **Michele Lipucci di Paola**

Michele Lipucci di Paola is a parent of a young adult living with thalassaemia. He was a Eurordis Board Member from 1997 to 2006 and its Vice President. Michele is a researcher in biological sciences at the University of Pisa.

### **Aurelio Maggio**

Director of Haematology II Division with Thalassaemia at Ospedali Riuniti Villa Sofia-Cervello, Palermo-Italy. RESEARCH AREAS AND PUBLICATIONS:

Mathematical studies on iron kinetics at Pavia University. Prenatal diagnosis of haemoglobinopathy since 1982. Collaboration with Dr. H.H. Kazazian at the John Hopkins Hospital in Baltimore on the spectrum of  $\beta$  thalassaemia mutations in Sicily. Collaboration with Columbia University in New York, on the globin gene regulation of  $\beta$  and  $\delta$  genes and on retroviral vectors. Set-up of Reverse Dot-Blot Analysis for thalassaemia in collaboration with Y.W. Kan, Howard Hughes Medical Institute in San Francisco; "In utero" transplantation for thalassaemia in collaboration with Karolinska Institute (Stockholm). Collaboration with Introgen Company in Leyden (The Netherlands) on gene therapy of haemoglobinopathy using AAV vectors; Collaboration with Dr. M. Sadelain, MSKCC of New York on thalassaemia gene therapy. PEER REVIEWED PUBLICATIONS: 118 publications, overall Impact Factor (IF): 383.185

MEMBERSHIPS: Member of the Regional League for the Fight Against Thalassaemia and Cancer in Children; Scientific Committee of the Health Minister; Regional Board for Thalassaemia (LR/20); Scientific Committee of Iron Club for Oral Chelation; National Register of Researchers

(Art. 7, comma I, DL 27/7/1999, n°297); Scientific Committee of The Journal of Transfusion Medicine.

### **Anna Meo**

Professor of Medicine (Professore Aggregato) since 2006 at the University of Messina, Italy, Paediatrics Department - Policlinico "G. Martino". MD researcher since 1980 at the University of Messina, Italy. Full time physician at Policlinico "G. Martino" Paediatrics Department since 1977 and at Paediatrics Department – Thalassaemia Ward since 1987. Certified specialist cum laude in Paediatrics (1979) and Haematology (1984). Degree in Medicine summa cum laude awarded in 29/10/1975. Teacher at the Medical School, Faculty of Medicine and at post graduate School of Paediatrics and School of Paediatric Surgery at the University of Messina, Italy. Teacher at School for Nurses – Faculty of Medicine, University of Messina, Italy. Teacher at "Master of Bioetica" – Theological Institute of Messina, Italy. Master in Bioethics at Catholic University of Rome in 2002. Training at the Whittington Hospital in London, Department of Hematology - Thalassaemia Ward in 2000. Her clinical research activities are mainly in the area of the haemoglobin disorder's prevention, prenatal diagnosis, management and organ failure surveillance in thalassaemia major and thalassaemia intermedia patients. Involved in monitoring and clinical follow up of thalassaemia patients after stem cells transplantation. Clinical trial participation: Principal investigator of "Deferiprone versus DFO: Italian randomised clinical trial"(2001-2006) and ICL670/EXIADE Prot n.CICL670A2203 (2006-2007) Novartis Farma. Member of the European Hematology Association (EHA), Società Italiana di Pediatria (SIP) Associazione Italiana di Oncoematologia Pediatrica (AIEOP), Società Italiana di Talassemia ed Emoglobinopatie (SITE). Medical scientific collaborator of the Thalassaemia International Federation (TIF) since 2007.

Author of international publications mainly on the aspects of biology of iron overload and long term complications of thalassaemia and management. Responsible for the Italian editions of Beta-Thalassaemia educational booklet, Alpha-Thalassaemia educational booklet, Sickle Cell Disorders educational booklet (2007), About Thalassaemia and of the Guidelines for the Clinical Management of Thalassaemia published by TIF.

### **Loizos Pericleous**

Loizos Pericleous was born in Nicosia, Cyprus in 1966. He is the only son of Andreas and Avghi and younger brother of Maria. Educated to degree level in Business Studies in London, he married Despina shortly after his graduation in 1989, and they became a foster family to baby Anastasia in 1996. He has been involved with the family business of wholesales of healthcare products since 1990, and he is currently running the business. Loizos served on the Board of Directors of the Cyprus Thalassaemia Association in the 1990s and was the patient representative of the Association on the Board of Directors of the Thalassaemia International Federation from 1998 to 2004, where he served as its Secretary. He rejoined the Board of TIF in 2008 as a Member of the Board. He is currently serving as the President of the Cyprus Thalassaemia Association until the end of his term in May 2010.

### **Antonio Piga**

Antonio Piga obtained his Degree in Medicine in 1975 from the University of Turin and went on to gain a specialisation in Paediatrics in 1978 (University of Turin) and in Haematology in 1982 (University of Milan). He is a Researcher Professor of Paediatrics, University of Turin from 1980 and Professor of Paediatrics at the University of Turin since 2006. He is the Chief in charge of the Thalassaemia Centre of the Department of Biological and Clinical Sciences at the University of Turin since 1987. He is President of the Medical Libraries of University of Turin since 2006. He is a reviewer for several international journals on haematology and paediatrics, a scientific advisor of the Italian Thalassaemia Foundation since 1996, and a scientific advisor of the Thalassaemia International Federation since 1997.

### **John Porter**

John Porter, MD, FRCP, FRCPath is Professor and Consultant in Haematology at UCL School of Medicine since 1999. He graduated from the University of Cambridge (BA Hons 1974, MB B Chir 1977, MD 1999). He has very long experience in Clinical Haematology and has been active in the field of iron metabolism and iron chelation for many years. Professor Porter is a member of the British Society of Haematology and active on its Scientific Advisory Committee. He is a scientific advisor of the Thalassaemia International Federation. Professor Porter is the author of a large number of peer-reviewed original articles and books in the field of thalassaemia. He is a regular contributor and invited speaker at national and international meetings.

### **Stefano Rivella**

Associate Professor in Genetic Medicine, Weill Cornell Medical College, New York. International Biolron Society (IBIS). American Society of Hematology (ASH). Member of the Committee on Hemoglobin and Red Cells (4 year period). International Society of Experimental Hematology (ISEH). The American Society of Gene Therapy (ASGT). 5 Travel Grant Awards. First Prize for New Investigator Award – International Society of Experimental Hematology (ISEH). Doctoral Award – Department of Genetics, University of Pavia, Italy. Prize for the best poster – International Symposium on Genomic Imprinting and New Approaches in the Identification and Mapping of Genetic Syndromes, Florence, Italy. Prize for Italy's Best University Thesis – Italian Genetics Institute (AGI)

### **Chris Sotirelis**

Dr Chris Sotirelis is a 45-year old qualified aeronautical engineer with a doctorate in Air Transport Engineering. He is also a licensed private pilot and a patient with beta-thalassaemia major. He works as an air transport consultant on projects involving economics, management and planning issues for airlines, airports and associated organisations. He speaks another 3 languages. His interests outside aviation include music, history and travelling around the world. Chris has served on the Board of Trustees of the UK Thalassaemia Society for several terms. He has represented the UKTS and the Thalassaemia International Federation at many national and international conferences, functions, workshops and delegate visits. His areas of interest include thalassaemia awareness, patient advocacy and the improvement of thalassaemia treatment in developing countries. His aim is to contribute towards further improving the situation and condition of people living with thalassaemia in the UK and around the world, so that they are better able to live a normal life and fulfil their personal potential.

### **Allison Streetly**

Dr Allison Streetly is a Consultant in Public Health based at Greenwich PCT in London. Since 2001 she has been seconded to the NHS Sickle Cell & Thalassaemia Screening Programme Centre and takes the lead in the implementation of the national haemoglobinopathy screening programmes. She is also responsible for the development of the specialist centres for paediatric care of children with sickle cell disorders. Dr Streetly studied medicine and social and political sciences at Cambridge University and completed her clinical training at St Thomas' Hospital. She trained in Public Health at the London School of Hygiene and Tropical Medicine and SE London, Kent and East Sussex. In 1994–1998 she co-ordinated a national audit of the newborn bloodspot screening programmes in England (1994–1998), which led to the establishment of the Newborn Bloodspot Screening Programme Centre. She is a Fellow of the Faculty of Public Health, a member of the Fetal, Maternal & Child Health sub-group of the National Screening Committee of the UK, and a member of the NCEPOD expert advisory group on audit of sickle and thalassaemia deaths.

### **Ali Taher**

Ali Taher is Professor of Medicine, Division of Hematology & Oncology, and Assistant to Chair for undergraduate education at the Department of Internal Medicine, the American University of Beirut Medical Center, Lebanon. He is also Consultant Hematologist at the Chronic Care Center (Thalassaemia Center). Dr Taher's research focuses on haemoglobinopathies, notably thalassaemia and sickle cell disease, as well as thrombosis & haemostasis. Within thalassaemia, his research interest lies in the detection of iron overload and the efficacy and safety of novel oral iron chelators. Moreover, he investigates the pathophysiology and clinical implications of thalassaemia intermedia, mainly the associated hypercoagulable state. In thrombosis & haemostasis, he investigates inherited thrombophilia and bleeding disorders, as well the incidence and prophylaxis of venous thromboembolism across several medical and surgical settings. Dr Taher has published more than 200 peer-reviewed original articles in international high-impact journals and three textbook chapters in the area, as well as being a regular contributor and invited speaker at national and international meetings. He is the Principal Investigator (PI) on several clinical trials studying the novel oral iron chelator deferasirox. He is also the PI of the Thalassaemia Intermedia Registry series of studies on thalassaemia intermedia, and lead investigator on the AVAIL|ME study on thromboprophylaxis. He is also one of the PIs on the National Institutes of Health-funded TCRN trials. He is a member of the American Society of Hematology, the International Society on Thrombosis and Hemostasis, the Mediterranean League against Thromboembolic Diseases, and Alpha Omega Alpha.

### **Paul Telfer**

Paul Telfer is a Consultant in Paediatric Haematology at St Bartholomew's and The Royal London NHS Trust, and a Senior Lecturer in Haematology at Queen Mary, University of London. He obtained his medical degree at Oxford University School of Medicine, and trained in Haematology at The Royal Free, Whittington, University College Hospital, Great Ormond Street Hospital for Sick Children and North London Blood Transfusion Centre, Colindale. He is the Clinical Lead for Adult and Paediatric Haemoglobinopathy Services at The Royal London Hospital. He also leads the East London and Essex Clinical Haemoglobinopathy Network. He is currently serving as Vice Chairman of the Steering Committee for The English National Haemoglobinopathy Screening Programme, and is a Committee Member of The UK Forum for Haemoglobin Disorders. He has also served on the Writing Committee for UK National Standards of Care for Thalassaemia and for Sickle Cell Disease. He is an advisor to The UK Thalassaemia Society, the Thalassaemia International Federation, and to the Ministry of Health of Cyprus, and served for two years in Cyprus to assist with thalassaemia and transfusion services. He is involved in several international multi-centre clinical trials in Thalassaemia and Sickle Cell Disease, and has published articles on management of haemoglobin disorders and blood transfusion. His current interests are in developing new therapies for Sickle Cell Disease, neurological complications of Sickle Cell Disease, and optimizing clinical outcomes with iron chelation therapy.

### **Isabelle Thuret**

Dr Isabelle Thuret is a pediatrician working in the Pediatric Haematology department of Marseille, South of France. She is in charge of the Center for Rare Disease dedicated to Thalassaemia, which was created in 2006. She coordinated the establishment of the French register for Thalassaemia and the elaboration of the national guidelines for treating patients with severe forms of thalassaemia.

### **Joan Lluís Vives Corrons**

Professor of Medicine and Head of the Haematology Laboratory Department of the Hospital Clinic i Provincial (University of Barcelona) since 1976, with a high input on Haematology Research, Education and Diagnosis. Main activity has been focused on the development of new procedures for the diagnosis of anaemias and haematological malignancies (acute and chronic leukaemias and lymphomas) as well as in the standardization and quality assessment of haematology laboratory practice. Research has mainly related with physiopathology, molecular mechanisms and epidemiology of red blood cell (RBC) disorders due to hereditary enzymopathies (G6PD, PK and others), haemoglobinopathies (Sickle-cell anaemia and thalassaemias) and membrane defects (hereditary spherocytosis elliptocytosis and stomatocytosis). This has given to the creation of the Red Cell Pathology Unit a recognized Expert Centre for the diagnosis of RBC defects and in the identification of low prevalence anaemias, also known as "rare anaemias". Scientific Trajectory is guaranteed by over 400 publications in scientific journals, the participation (as editor or collaborator) in about 20 books of haematology, and by the accomplishment of 28 research projects, which have been partially funded by different public health organizations from Spanish (Ministry of Health and Education and Science) and Catalan Governments. Since 2002. Leader of a Public Health Project of the European Commission for the development of a European Reference Network (ERN) of Expert Centres in Rare Anaemias (RA). This Project called ENERCA ([www.enerca.org](http://www.enerca.org)), is intended to contribute to the better knowledge of rare anaemias in Europe, its faster detection, diagnosis, treatment and epidemiological surveillance.

### **Ersi Voskaridou**

Dr Ersi Voskaridou-Dimoula obtained her MD at the University of Athens School of Medicine in 1979, and her PhD at the University of Athens School of Medicine in 1991. She then gained specialisations in Internal Medicine (1986) and in Haematology (1990). Since 1987 she is Associate Director of the Thalassaemia Centre at the Laikon General Hospital, Athens, Greece. Her previous positions include: Registrar in Internal Medicine, "Red Cross" Hospital, Athens, Greece (1981–1986); Registrar in Haematology, Laikon General Hospital, Athens, Greece (1988–1990); Consultant Haematologist, Thalassaemia Centre, Laikon General Hospital, Athens, Greece (1990–2006); Director of the Thalassaemia Centre (2006 to date). Her clinical research experience and main research interests include the pathophysiology and management of bone disorders and renal impairment in haemoglobinopathies, iron chelation, and hydroxyurea treatment in sickle-cell syndromes.

**Malcolm J Walker**

Consultant Cardiologist University College & the Heart Hospital, London. Clinical Director Hatter Cardiovascular Institute UCLH London. Appointed as Consultant Cardiologist to University College and the Middlesex Hospitals in 1987. Established in 1990, the Hatter Institute of Cardiovascular Studies at UCH, with Derek Yellon as the chief Scientist. Basic research has focused on the heart's adaptation to ischaemia and other stresses. In 1997 a satellite research institute was developed in co-operation with the University of Cape Town, RSA. Clinical expertise encompasses cardiology from intervention by PCI to the development of a successful exercise based cardiac rehabilitation program, now in its 19th year. An interest in heart muscle diseases associated with iron overload led to the establishment of the a unique cardiac service dedicated to patients with thalassaemia, The Haemoglobinopathy Cardiac Clinic at UCLH. Over 200 thalassaemia patients are seen per year for cardiovascular screening and treatment. Collaborative projects with the Cardiac MRI centre at the Brompton Hospital have led to the development of the T2\* tool, enabling the quantification of tissue iron load. Author of more than 60 scientific papers and book contributions.