



FIRST CONFERENCE ON



European Reference Networks

Brussels, June 23 2014

PROGRAMME

Share. Care. Cure.

TIME	ACTIVITY	SPEAKERS
08.00-09.00	Registration and welcome coffee	
09.00-09:15	Welcome address: European Reference Networks Dr Andrzej Rys - Director DG SANCO Health Systems	

9.15-10.05 MORNING PLENARY SESSION		
Keynote Speakers		
09.15-09.40	Only Connect: What ICT networks can do for society?	Mr Robert Madelin <i>Director-General for DG CONNECT: Communications Networks, Content and Technology</i>
09.40-10.05	Complex Systems and Networks	Professor Yamir Moreno <i>Institute for Biocomputation and Physics of Complex Systems (BIFI). University of Zaragoza</i>
10.10-12.20 ROUNDTABLE Highly specialised healthcare: framework for the establishment of ERN Dr Paolo G. Casali - Istituto Nazionale Tumori, Italy		
10.15-10.30	Past, present and future of centres of expertise and European reference Networks	Dr Till Voigtländer <i>Clinical Institute of Neurology, Medical University of Vienna, Austria</i>
10:30- 10.45	The importance of sharing expertise and the challenge to manage the exchange of knowledge in highly specialised healthcare.	Dr Josep Maria Borrás <i>Partnership for Action Against Cancer (EPAAC)</i>
10.45-11.00	Research priorities and Networks	Ms Irene Norstedt Philippe Cupers - DG RTD
11:00-11:25	The ERN model: Criteria and condi- tions for Networks and providers. Implementation of Networks: organi- sation framework	Dr Enrique Terol <i>DG SANCO</i>
11.25-12.00	Debate & Questions	Chair – all speakers
12.00-13.15 Lunch break		

13.15-16.30 AFTERNOON BREAK-OUT SESSIONS (Rooms A & B)		
Session A 13.15-16.30	Highly specialised healthcare for low prevalence, rare and complex diseases.	
Session A-1 13.15-14:15	The view of the stakeholders organisations Chair by Dr Andrzej Rys - Director Health Care Systems, DG SANCO	
13:20-13:35	The view of the professionals	Dr Edwin Borman <i>European Union of Medical Specialists</i>
13:35-13:50	The view of the managers	Ms Marianne Olsson <i>European Health Management Association</i>
13:50-14:05	The view of the patients	Ms Nicola Bedlington <i>European Patients Forum</i>
14:05-14:15	Debate & Questions	Chair – all speakers
14:15-14:30 Coffee break		
Session A-2 14:30-15:30	National models Chair: Dr Natasha Azzopardi Muscat - Public health practice and policy of EUPHA	
14:30-14:45	Specialised Commissioning Services in the NHS of England	Mr Edmund Jessop <i>Specialised Commissioning Team, NHS England UK</i>



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14:45-15:00	National Specialized Medical Care (NSMC) in Sweden	Mr Lennart Christiansson <i>National Board of Health and Welfare of Sweden</i>
15:00-15:15	The Portuguese model of Centres of Reference	Dr. Jorge Penedo <i>Ministry of Health of Portugal</i>
15:15-15:30	Debate & Questions	Chair – all speakers
Session A-3 15:30-16:30	Networking Experiences (Networks pilots funded by EC) Chair: Ms Annika Nowak - DG SANCO	
15:30-15:45	The Paediatric Cancer network-Expo-R-Net	Dr Ruth Ladenstein <i>Expo-R-Net.</i>
15:45-16:00	The refractory- epilepsy Network	Dr Professor Philippe Ryvlin <i>E-epilepsy Network</i>
16:00-16:15	European Network for Rare and Congenital Anaemias: ENERCA	Dr Joan Lluís Vives Corron <i>ENERCA</i>
16:15-16:30	Debate - Questions	Chair – all speakers

Session B 13:15-16:15	Quality, clinical criteria and performance assessment	
Session B-1 13:15-14:15	Clinical and professional criteria Chair: Ms Flaminia Macchia - Director for European Public Affairs, EURORDIS	
13:20-13:35	Enhancing medical professionalism, interdisciplinarity and quality of health care through clinical practice guideline development	Dr Ina Kopp <i>German Association of the Scientific Medical Societies 'Institute of Medical Knowledge -Management (AWMF-IMWi) at Philipps-University, Marburg. Germany.</i>
13:35-13:50	Establishment of clinical criteria: Best Practices, clinical guidelines and patient pathways	Dr Judith Richardson <i>Clinical Pathways NICE. United Kingdom</i>
13:50-14:05	Assessment of the use of EU clinical guidelines in a Network environment (experiences)	Dr Marco Pierotti <i>The Lombardy Cancer Network (ROL). Italy</i>
14:05-14:20	Debate & Questions	Chair – all speakers
14:20-14:35	Coffee break	

Session B-2 14:35-16:15	Accreditation, certification and evaluation Chair: Nathalie Chaze - DG SANCO	
14:40-14:55	Recognition and approval of highly specialised hospital services in Denmark	Ms Stine Jønson <i>Danish Health and Medicines Authority. Denmark</i>
14:55-15:10	The healthcare accreditation model of France	Ms Fabienne Menot <i>HAS, France</i>
15:10-15:25	Accreditation of Hospitals in Poland	Dr Barbara Kutryba <i>National Centre for Quality Assessment in Health Care (NCQA) Poland</i>
15:25-15:40	Independent assessment/ accreditation models	Mr Sébastien Audette <i>Accreditation Canada International</i>
15:40-16:15	Debate & Questions	Chair – all speakers
16:30-17:00	Closing remarks, Conclusions and call for action Dr Andrzej Rys - Director Health Care Systems, DG SANCO	

SPEAKERS



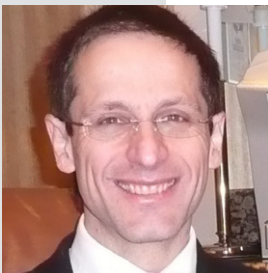
Sébastien Audette

Sébastien Audette holds a bachelor's degree in Business Administration from HEC Montreal, and a graduate degree in Public Administration from l'École Nationale d'Administration Publique. His career in healthcare started in 1994, with the Canadian Forces (CF) Health Services, as a part time medical technician, serving as an officer in Bosnia-Herzegovina. Mr. Audette joined Accreditation Canada in 2008 and was appointed as inaugural Chief Executive Officer of Accreditation Canada International in January 2011.



Nicola Bedlington

Nicola Bedlington is the Executive Director of the European Patients' Forum. She studied business and human resource management. She was founding Director of the European Disability Forum, and she worked as an external expert for the European Commission, heading the NGO unit within the HELIOS Programme. Additionally, she worked for the Swiss Government, leading ENSI, an international government-based network set up by OECD. Furthermore, she worked as an independent consultant/evaluator, specialising in European social and development policy and health advocacy.. In this capacity, she is the Co-ordinator of the EUPATI.



Edwin Borman

Edwin Borman serves as the Secretary General for the UEMS, the organisation that represents medical specialists throughout Europe. The UEMS has 35 member states, representatives of more than 50 medical specialities, and is active in lobbying, training standards, accreditation, and clinical safety. He is also the Medical Director for the Shrewsbury and Telford Hospital NHS Trust, a group of acute hospitals in Shropshire, England.



Josep M Borrás

Josep M Borrás is Professor of public health at Department of Clinical Sciences from the University of Barcelona. Further, he is advisor to the cancer strategy of the Department of Health of the Region of Catalonia as well as to the Ministry of Health. He is MD and PhD in public health. He has worked for the Department of Health in cancer control and technology assessment in cancer and was director of the Catalan Institute of Oncology. His main research interests include the analysis of trends in cancer incidence and mortality and health services research in determinants of utilization of cancer prevention and care. He has been Work Package leader (Health care) in the European Partnership Action Against Cancer and is presently involved in the joint action on Cancer Control (CANCON)



Paolo G. Casali

Paolo G. Casali, medical doctor and medical oncologist, is Head of the Adult Mesenchymal Tumour Medical Oncology Unit at Istituto Nazionale Tumori, Milan, where he also serves as Secretary of the Ethics Committee. Further, he is a member of the Executive Board of ESMO, a Chair of the Public Policy Committee, and a member of the Board of Directors of ECCO. His clinical and research activities focus on sarcomas, mainly adult soft tissue sarcomas and gastrointestinal stromal tumors (GIST). He is Secretary of the Italian Sarcoma Group and a member of the EORTC Soft Tissue & Bone Sarcoma Group and is an Editor in Chief of Clinical Sarcoma Research and a member of the ESMO Sarcoma Faculty. In the area of rare cancers, he founded and chairs the Italian Rare Cancer Network. Finally, he coordinates Rare Cancers Europe, teaches at the Milan University Postgraduate School in Oncology and is (co)author of more than 170 publications in peer-reviewed journals.



Nathalie Chaze

Nathalie Chaze is the Head of Unit of Healthcare Systems at DG Sanco from the European Commission, with responsibilities including patient safety, quality of care, health workforce and health systems financial sustainability. From origin she is a lawyer, with a specialisation in EU law. She worked 15 years in DG Trade (European Commission) on several issues (services, WTO, IPR). In 2008 she began at DG Sanco, more particularly looking after the directive on application of patients' rights in cross border healthcare.



Dr Lennart Christiansson

Dr Lennart Christiansson is Senior Advisor for Medical Affairs of the Unit for Highly Specialised Care at the National Board of Health in Stockholm. Previously he worked at the Department of Surgical Sciences of the University Hospital in Uppsala. Further, he is also involved in two ongoing National Reviews on Trauma Care Systems and Development of Highly Specialised Care. Moreover, he is the President of the European Board of Anaesthesiology of the UEMS. Finally, he has background in accreditation starting with a national reviewer's programme, from where he moved to European accreditation as he became chairperson of the joint committee organising the EBA/ESA Hospital Visiting and Training Accreditation Programme.



Philippe Cupers

Philippe Cupers has a PhD in cell biology and biochemistry from the University of Louvain and has worked at Harvard University, at the Flemish Institute for Biotechnology and at GlaxoSmithKline. He moved in 2001 to the Directorate General for Research and Innovation (DG RTD) of the European Commission. He first worked as scientific officer for brain research and then for setting up the Innovative Medicines Initiative (IMI). In 2011, he moved back to brain research as Head of Sector before becoming since 1 January 2014 Deputy Head of the Unit 'Strategy' within the Health Directorate of DG RTD. His responsibilities include the development of strategies for the implementation of the European Research Area concept in human health-related research, and the coordination and policy input into the health research activities.



Edmund Jessop

Edmund Jessop works for the National Health Service in England. He is part of a team which funds all specialised healthcare in the English NHS, including care for patients with rare disease. The team plans, funds and monitors services with a total budget of £12bn per annum.



Stine Jønson

Stine Jønson, MSc. is Public Health Head of section at Hospitals and Emergency Services, Danish Health and Medicines Authority and is working with Planning of Specialized Hospital Care in Denmark



Ina Kopp

Ina Kopp is Director of the German Association of the Scientific Medical Societies' Institute of Medical Knowledge-Management (AWMF-IMWi) at Philipps-University, Marburg. She serves as coordinator and consultant for CPG development of the 168 specialty societies organised under the umbrella of AWMF and oversees the internet distribution of CPGs, related information and tools for guideline developers via the AWMF-website. Ina Kopp is involved in several quality initiatives on the national level in Germany and Vice Chair of the Guidelines International Network.



Basia Kutryba

Basia Kutryba is a fellow and board member of the European Society for Quality in Healthcare. She is co-founder of the first quality institute in CEE and Senior Adviser at the National Centre for Quality Assessment in Health Care in Krakow. She is the Chair of the EU Working Group on Patient Safety and Quality of Care and she worked as Head of the WHO Collaborating Centre for Developing Quality and Safety in Health Systems. She is founder and Vice-president of the Polish Society for Quality Promotion in Health Care. Finally, she was president till 2010 of the ESQH, of which she is currently fellow and board member.



Prof. Ruth Ladenstein

Prof. Ruth Ladenstein, is Coordinator of the ExPO-r-NeT European Expert Paediatric Oncology Research Network for Diagnostics and Treatment recently granted by the European Union. She is MD, MBA, cPM Head of S2IRP Studies and Statistics on Integrated Research and Projects of the Clinical Trial Unit of the Children's Cancer Research Institute (CCRI) of the St. Kinderkrebsforschung e.V., Vienna. Since 1996 Head of the department for paediatric solid tumours St. Anna Children's Hospital, Vienna.

Since 1998 Prof. Ladenstein, has been involved in several research projects and areas related with cancer in children: Project coordinator of the EU FP7 funded Network of Excellence: "EUROPEAN NETWORK for CANCER research in CHILDREN and ADOLESCENCE" (ENCCA); former President and current board member of SIOPEUROPE. Chair of the ECRC and advisory board member of SIOPEUROPE (SIOPEUROPE Neuroblastoma Group) of which formerly president; Coordinator of the SIOPEUROPE Neuroblastoma Research Network (SIOPEUROPE-R-NET) involving more than 200 clinics in 25 countries.

Flaminia Macchia



Flaminia Macchia is EU Public Affairs Director at EURORDIS, which she joined in 2004 as European Public Affairs Officer after having worked for EURORDIS as consultant. Previously Flaminia worked in EU affairs at the European Commission (Euro-Mediterranean partnership), in the European Parliament, and in the health team of a EU policy consultancy firm. As a patient with the rare disease Colitis Ulcerosa, she has been active in the European rare disease community, more specifically in public health issues. Further, Flaminia holds an honours degree from the Université Libre de Bruxelles in Political Science, and a Master of Arts in International Relations.

Robert Madelin



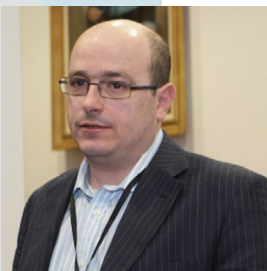
Robert Madelin is the Director-General responsible for the Digital Agenda for Europe. Mr Madelin was educated in England at the Royal Grammar School, High Wycombe and at Magdalen College, Oxford. He has also studied at the Ecole Nationale d'Administration in Paris. Born in 1957, a British civil servant since 1979. Robert has served in the Commission since 1993, in his current post since 2010 and as Director General for Health and Consumer Policies from 2004 to 2010, and previously on trade and investment policy.

Fabienne Menot



Fabienne Menot is a Technical Advisor to the Director for the Improvement of Quality and Safety of Healthcare and she joined HAS in 2005. Her business portfolio covers numerous aspects of improving the quality of healthcare in France; these include helping to develop the strategy and reference standards for certification in France, international cooperation outside Europe, and the certification of health websites. Fabienne is also in charge of the certification aspects of HAS' accreditation by ISQUA.

Yamir Moreno



Yamir Moreno has a PhD in Physics and is a Research Professor, Scientific Secretary and Head of the Complex Systems and Networks Lab at the Institute for Biocomputation and Physics of Complex Systems, Professor of Physics at the Department of Theoretical Physics at the University of Zaragoza, and Fellow of the ISI Foundation at Turin. His main research lines include the study of nonlinear dynamical systems coupled to complex structures, mathematical biology with special focus on the development of more realistic scenarios for the modeling of infectious diseases, the emergence of collective behavior in socio-technical systems and the structure and dynamics of complex networks.

He has published more than 130 scientific papers in peer-reviewed journals and is co-editor of the book "Handbook on Biological Networks", 2009. He is an Editorial Board Member of Scientific Reports, PLoS ONE and Journal of Complex Networks. Prof. Moreno is the elected Vice-President Secretary of the Complex Systems Society (CSS) and belongs to the Future and Emerging Technology (FET) Advisory Group for the H2020 Research Program of the European Commission, to the Board of the Network Science Society and to the Advisory Board of the WHO Collaborative Center "Complexity Sciences for Health Systems" (CS4HS).



Dr Natasha Azzopardi Muscat

Dr Natasha Azzopardi Muscat is President of the Section for Public Health Policy and Practice from EUPHA and a member of the Editorial Board of the European Journal of Public Health. She has occupied various positions within the Ministry for Health in Malta including Director for European Union Affairs, Director General for Strategy and Chief Medical Officer.

She was President of the Malta Association of Public Health Medicine. She is currently a Consultant in Public Health Medicine at the Directorate for Health Information and Research in Malta, a Lecturer in Health Policy and Management at the University of Malta and affiliated with the Department of International Health at Maastricht University. Her main research interest includes Europeanization of health systems with a particular focus on small Member States.



Annika Nowak

Annika Nowak is currently team Leader at DG Sanco unit D2 from the European Commission. After obtaining her law degree at the Humboldt-University in Berlin, she completed a legal Clerkship at Appellate Court Berlin. Before joining the European Commission, she worked as an Assistant to a Member of the European Parliament, specialising in food safety, public health and environment policy. From 2004 to 2009 she was the DG Sanco Co-ordinator for relations with the European Parliament, before joining the Health Directorate to work on cross-border healthcare.



Marianne Olsson

Marianne Olsson is currently managing a quality improvement project covering the entire county council of Sörmland in Sweden. She also runs a consulting firm, Mofirm. She has been the leader of the project building a new hospital in a multi-cultural setting in Göteborg. She formerly worked as Director of Quality Improvement at Sahlgrenska University Hospital and she worked for the Federation of Swedish County Councils. Furthermore, she has held senior leader and expert positions in the social welfare and healthcare sector in Sweden, was the president of the Swedish Society for Quality in Health Care, and was a board member. She is also a member of the board of the Swedish Standards Institute and has been a member of the board of the EHMA, of which she is president since 2012.



Jorge Penedo

Jorge Penedo is Senior Assistant of the Portuguese Minister of Health. Consultant of General Surgery at the Centro Hospitalar de Lisboa. Central Assistant Clinical Director at the Centro Hospitalar de Lisboa. Central Senior Lecture in General Surgery at the Nova Medical School. Coordinator of the study "Health Reference Centers in Portugal". Member of Portuguese Team for National Hospital Reform.



Marco A. Pierotti

Marco A. Pierotti is Scientific Director at the Fondazione IRCCS Istituto Nazionale dei Tumori of Milan since 2006. He has been president of the Italian Society of Oncology, EACR, OECl, and scientific secretary of ACC. He is currently scientific director of the Lombardy Oncology Network. He has been a member of the Executive Committee of the AACR Clinical and Translational Research Committee and is in the Advisory Board of the AIRC.

He contributed to various international review committees and collaborated, among others, with the Institute National du Cancer, the Research Council of Norway, the Swedish Research Council and the Canadian Institutes of Health Research. Dr Pierotti has published more than 480 papers in international peer-reviewed journals. His main research interest is the molecular biology of carcinogenesis.



Judith Richardson

Judith Richardson is an Associate Director within the Health and Social Care team at the National Institute for Health and Care Excellence (NICE). She is responsible for the delivery of the NICE Pathways project. Judith has worked at NICE for 6 years and was previously a Consultant Clinical Advisor in Implementation and then an Associate Director with the Clinical Guideline team. Judith worked in public health for 15 years before joining NICE, holding a range of positions at local, regional and national levels. She has also trained in general practice.



Andrzej Ryś

Andrzej Ryś is currently the Health Systems and Products Director at DG Sanco from the European Commission. He is originally a medical doctor specialized in radiology and public health from Jagiellonian University, here he established and was director of the School of Public Health. Further, he was director of Krakow's city health department and deputy Minister of Health in Poland. In addition, he established and was director of the Centre for Innovation and Technology Transfer at Jagiellonian University. In 2006, he became Director for Public Health and Risk Assessment at DG Sanco (European Commission). Finally, he entered in 2011 his current director position at DG Sanco.



Philippe Ryvlin

Philippe Ryvlin is Coordinator of the European pilot network of reference centres in refractory epilepsy and epilepsy surgery recently granted by the European Union. He is Professor of Neurology, Chair of the Department of Functional Neurology and Epileptology at Hospices Civils de Lyon, Director of the TIGER, at Lyon's Neuroscience Research Centre, and co-Founder of the Epilepsy Institute, IDEE.

He is also President of the European Epilepsy Monitoring Association, co-Chair of the Epilepsy Advocacy Europe Joint Task Force of the ILAE and IBE, founder of the European Network for Epilepsy Research. He has published over 165 PubMed referenced papers on topics primarily related to epilepsy surgery, anti-epileptic treatments and Sudden Unexpected Death in Epilepsy.



Enrique Terol

Enrique Terol Works as National Expert in DG Sanco unit D2 from the European Commission and is in charge of the implementation of the European Reference Networks under the framework of the Directive of Cross-border Health care. He is MD, specialized in Family and Community Medicine, MSc and PhD in Public Health.

His professional experience includes the clinical practice, Health Care Management in Primary and Specialised Healthcare. He was Deputy General Director of Quality and Health Planning of the Ministry of Health of Spain and Health attaché in the Spanish Permanent Representation and coordinator of the area of Health in the Spanish Presidency of the EU in 2010.



Prof. J.L. Vives Corrons

Prof. J.L. Vives Corrons is head of the European Network for Rare and Congenital Anaemias (ENERCA). He is Professor of Medicine and Head of the Haematology Laboratory department and Head of the Red Cell Pathology Unit of the Hospital Clinic i Provincial, with main activity focused on the diagnosis of anaemias and haematological malignancies as well as in the standardization and quality assessment of haematology laboratory practice.

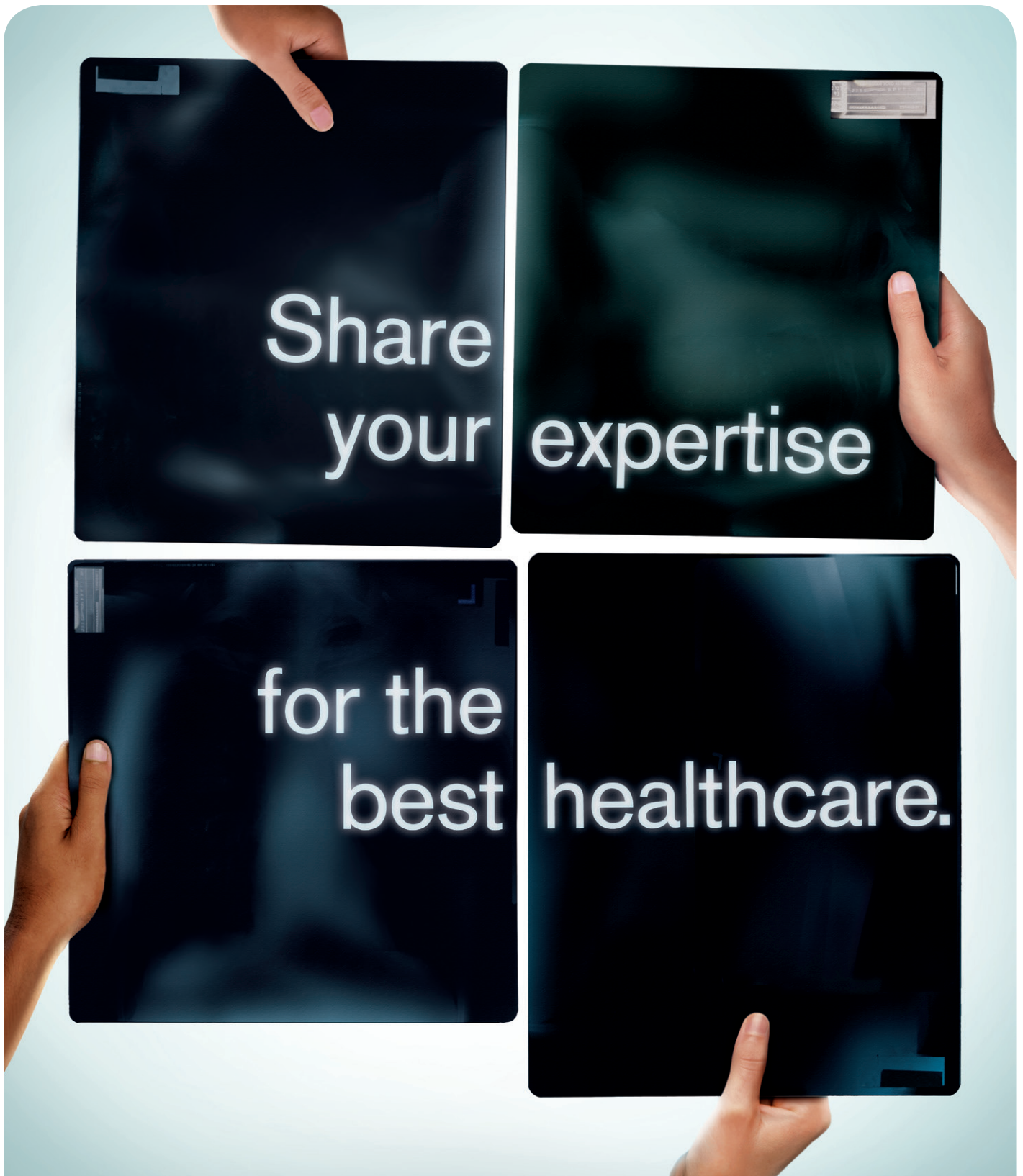
Research has mainly based on physiopathology, molecular mechanisms and epidemiology of rare red blood cell (RBC) disorders (enzymopathies, haemoglobinopathies and membrane defects). He has published over 400 publications in scientific journals and has been editor or collaborator in about 20 books of haematology. He has participated in 28 research projects, some of them founded by different public health organizations from Spain and the European Union.



Till Voigtländer

Till Voigtländer is a medical doctor working as assistant professor of neurobiology and university lecturer of neurosciences at the Clinical Institute of Neurology, Medical University of Vienna. Inside the institute, he leads a clinical laboratory that is focussed on the diagnosis of selected rare neurometabolic, neuroimmunological and neurodegenerative diseases.

On the national level, he is, amongst others, the head of the National Coordination Centre for Rare Diseases at the Austrian Health Institute, established at the request of the Austrian Health Ministry in 2011, and country coordinator of Orphanet since 2004. He was and is the official representative of the Austrian Health Ministry in several European expert groups and committees including the European Commission Cross-Border Healthcare Expert Group and the current Commission Expert Group on Rare Diseases.



Imagine if the **best specialists** from across Europe could join their efforts to tackle **complex or rare medical conditions** that require **highly specialised healthcare** and a concentration of knowledge and resources.

That's the purpose of **the European Reference Networks** and it's becoming a reality.

Share and enhance your expertise. Talk with your colleagues. **Be ready to prepare a proposal and join a network.** The European Commission will launch a **call for Networks in 2015.**

More information at ec.europa.eu/join-ern



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