



Advancing Research, Conducting Trials, Improving Care

Presentation of candidates for EC election

EHDN Election 2018

EC members standing for re-election

- Anne Rosser, current co-chair of EHDN EC
- Lesley Jones, current member of EHDN EC

New candidates

- Ahmad Aziz
- Flaviano Giorgini
- Jaime Kulisevsky
- Caterina Mariotti
- Catherine Martin
- Maria Judit Molnar
- Alzbeta Mühlbäck
- Christian Neri
- María Antonia Ramos-Arroyo
- Kathrin Reetz
- Hugh Rickards
- Carsten Saft
- Klaus Seppi

Anne Rosser



- **Professor of Clinical Neuroscience and Honorary Consultant Neurologist**
- Neuroscience and Mental Health Research Institute, School of Medicine, Cardiff University
- Brain Repair Group, School of Biosciences, Cardiff University

Anne Rosser



- 2004 **FRCP** - Royal College Physicians
- 1991 **MRCP** - Royal College Physicians
- 1987 **MB Bchir** - Cambridge University
- 1985 **PhD** - Cambridge University
- 1982 **BA (Hons) 1st class in Medical sciences with anatomy** - Cambridge University

Anne Rosser



Research interests:

- New therapies for Huntington's Disease
- Translational research for neurodegeneration
- Stem cell therapies for neurodegeneration

Anne Rosser



Visions:

- Contribution to EC
 - Current co-chair of EHDN EC
 - Ensure EHDN is representative of the HD community in Europe
- Contribution to EHDN
 - Promote collaboration between clinicians, scientists and the HD community
 - Encourage and foster next generation of clinicians, researchers and HD families
 - Facilitate the development of a wide range of therapies
 - Encourage Improvements in care across Europe

Lesley Jones



- **Professor of Neurogenetics**
- MRC Centre for Neuropsychiatric Genetics and Genomics; Div of Psychological Medicine and Clinical Neuroscience.
- School of Medicine, Cardiff University

Lesley Jones



- 1990 **PhD** - Cardiff University
- 1985 **B.Sc. (Hons) 1st class in Biochemistry** - Cardiff University

Lesley Jones



Research interests:

- Genetic modifiers in HD
- Aetiology and translational neuroscience in neurodegenerative diseases
- Dynamics of tandem repeats

Lesley Jones



Visions:

- Contribution to EC
 - Promote initiatives to improve HD research, therapeutic approaches and quality of life
 - Ensure current initiatives are productive
 - Promote multi-disciplinary research
 - Promote early career researchers to maintain EHDN in the future
- Contribution to EHDN
 - Promote research that helps HD treatments reach patients
 - Inspire other disease communities by example

Ahmad Aziz



- **Consultant Neurologist, Clinical Epidemiologist**
- Department of Population Health Sciences
- German Center for Neurodegenerative diseases (DZNE), Bonn

Ahmad Aziz



- **2017 Board certification Neurologist and Clinical Epidemiologist - Leiden University**
- **2011 MD (Hons) - Leiden University**
- **2009 PhD (Hons) - Leiden University**
- **2006 Master degree in Medicine (Hons) - Leiden University**

Ahmad Aziz

Research interests:

- Movement Disorders
- Neurogenetics
- Clinical aspects of HD



Ahmad Aziz



Visions:

- Contribution to EC
 - Experience with HD research and care in several European countries
 - Improve infrastructure needed to optimize clinical care
 - Facilitate implementation of novel therapies
- Contribution to EHDN
 - Facilitate access to optimal care
 - Increase training and support opportunities for the next generation of HD clinicians and researchers

Flaviano Giorgini



- **Professor of Neurogenetics**
- Department of Genetics and Genome Biology
- University of Leicester

Flaviano Giorgini



- **2002 PhD in Genetics/Genome Sciences** - University of Washington, Seattle (USA)
- **1996 MA in Molecular Genetics** - Washington University in Saint Louis (USA)
- **1992 BS in Biological Sciences (Genetics) (Highest Distinction)** - Purdue University (USA)

Flaviano Giorgini



Research interests:

- Molecular mechanisms underlying HD
- Translation of promising candidate drug targets to animal models
- Development of novel potential therapeutics

Flaviano Giorgini



Visions:

- Contribution to EC
 - Promote opportunities for young scientists and clinicians to gain experience and expertise in the HD community
 - Encourage the continued growth of EHDN across Europe, particularly in less represented regions
 - Previous chair of the EHDN SBAC
- Contribution to EHDN
 - Promote interactions between professionals and people affected by HD
 - Facilitate basic research and translation to the clinic

Jaime Kulisevsky



- **Director of the Movement Disorders Unit & Research Institute, Sant Pau Hospital**
- **Full Professor of Neurology, School of Medicine, Autonomous University of Barcelona**

Jaime Kulisevsky



- 2017 **Vice-Dean** Faculty of Medicine, Autonomous University of Barcelona
- 1992 **Ph.D. in Medicine** - Autonomous University of Barcelona
- 1986 **Board Certification in Neurology** -Hospital Sant Pau, Autonomous University of Barcelona
- 1981 **Medical degree** - University of Barcelona

Jaime Kulisevsky



Research interests:

- Translational and clinical research in HD and Movement Disorders
- Cognition/Behavior, Neuroimaging, New Therapies for HD and Movement Disorders

Jaime Kulisevsky



Visions:

- Contribution to EC
 - Experience in organizing and conducting research and clinical trials in movement disorders
- Contribution to EHDN
 - Promote collaboration between professionals with different backgrounds and the HD community to progress in awareness, care and research in HD
 - Inspire young clinicians in doing clinic research in HD
 - Encourage families with HD to participate in clinical trials as crucial way to advance development of new treatments

Caterina Mariotti



- **Permanent position as Neurologist**
- Unit of Genetics, Neurodegenerative and Metabolic Diseases
- Neurological Institute Carlo Besta, Milan

Caterina Mariotti



- **2000 Specialization in Medical Genetics - Milan University**
- **1992 Specialization in Neurology - Milan University**
- **1987 Medical degree - Milan University**

Caterina Mariotti



Research interests:

- Interventional and observational trials
- Studies evaluating different factors influencing clinical and preclinical disease progression
- Premanifest participants
- Biological markers

Caterina Mariotti



Visions:

- Contribution to EC
 - Possibility of sharing projects
 - Favor multidisciplinary expertise and collaboration within the network
- Contribution to EHDN
 - Support the efforts toward therapeutic advancements and promote clinical trials
 - Educational programs and continuous medical learning
 - Homogeneous clinical and diagnostic high-standard approaches across different European Centers

Catherine Martin



- **Global Executive Director**
- Huntington's Disease Youth Organization
- Children & Young People Services

Catherine Martin



- Current study **MSc Citizenship & Human Rights** - Glasgow Caledonian University
- 2006 **Foundation Degree Youth & Community Work** - Open University
- 2003 **NS Social Psychology** - Cumbernauld College
- 2001 **SQA Certificate in Event Management** - Glasgow College of Food Technology

Catherine Martin



Research interests:

- Experience of working with youth impacted by HD
- Engage families and youth in the importance of education and research

Catherine Martin



Visions:

- Contribution to EC
 - Engage the youth to bring new perspectives of an under represented population of the HD community
 - Experience and knowledge about the impact and day to day reality of living with and caring for someone with HD
- Contribution to EHDN
 - Link the research with the reality
 - Develop space for collaboration between clinical and social research
 - Improve clinical practice and treatment for JHD

Maria Judit Molnar



- **Professor of Neurology, Psychiatry, Clinical Genetics, and Clinico-pharmacology**
- Director of Institute of Genomic Medicine and Rare Disorders
- Semmelweis University, Budapest, Hungary

Maria Judit Molnar



- **2017 MBA in healthcare management** - Semmelweis University
- **2012 Doctor of the Hungarian Academy of Sciences** - Hungarian Academy of Sciences
- **1997 Ph.D. in Neurobiology** - University Medical School of Debrecen
- **1986 MD (summa cum laude)** - University Medical School of Debrecen

Maria Judit Molnar



Research interests:

- Basic and clinical studies on rare neurological disorders
- Research of the genomic background of rare neurodegenerative disorders (phenotype-genotype correlations using whole exome and genome analysis and deep phenotyping)
- Bioinformatics

Maria Judit Molnar



Visions:

- Contribution to EC
 - Commitment in the following fields: research and education management, congress preparation, regulatory affairs and international affairs
- Contribution to EHDN
 - Optimize the standard of care in HD in collaboration with ERN-RND and support of caregivers especially in Central-Eastern European countries
 - Develop new therapies and support the market access, support research in various fields of HD
 - Increase awareness about HD

Alzbeta Mühlbäck



- **Senior Consultant Neuropsychiatry**
- Huntington Center South at the kbo Isar-Amper-Klinikum Taufkirchen/Vils, Germany
- Charles University Prague, Department of Neurology and Centre of Clinical Neuroscience

Alzbeta Mühlbäck



- **2015 Board Certificate for Human Genetic Testing and Counselling in Neuropsychiatry** - Bavarian State Chamber of Medicine
- **2014 Board Examination in Psychiatry and Psychotherapy** - Bavarian State Chamber of Medicine
- **2004 Medical Degree** - University of Olomouc (Czech Rep.)

Alzbeta Mühlbäck



Research interests:

- How can we improve the everyday life for patients and families?
- How can we implement best counselling practice to all?
- How can we succeed in making treatment a collaboration between clinician/ patient and family?
- How can eHealth solutions provide expertise to patients and families in underserved regions?

Alzbeta Mühlbäck



Visions:

- Contribution to EC
 - Spread the EHDN expertise and spirit to underserved European regions, as she originates herself from East Europe and is fluent in Slavic languages
 - Enhance more active collaboration between EHDN, the HD associations and EHA, as already done in the projects “Ask the Doctor” or JPND-call
 - Increase patient and family involvement in continuous development of EHDN in the working groups and other activities/ projects.
- Contribution to EHDN
 - Advance the expertise about HD to underserved regions
 - Improve the awareness, understanding and respect for HD families
 - Improve the quality of life of HD patients through proactive support, strengthening an infrastructure for HD services in underserved countries and regions.

Christian Neri



- **Research Director at INSERM**
- Institute of Biology Paris-Seine
- Sorbonne University, Paris
- CNRS, Paris

Christian Neri



- 1997 **HDR** - University Pierre and Marie Curie
- 1990 **Ph.D. in Genetics and Microbiology** - University Aix-Marseille
- 1986 **M.Sc. in Immunology and Genetics** - University Aix-Marseille

Christian Neri



Research interests:

- Translational research on compensatory mechanisms in HD and other neurodegenerative diseases
- Computer models of molecular pathogenesis and disease progression
- Clinical innovation through target prioritization and biomarker detection

Christian Neri



Visions:

- Contribution to EC
 - Promote inclusive and innovative initiatives
 - Ensure translational research efficiency
 - Ensure EHDN is representative of the HD community in Europe
 - Promote early career clinicians and researchers
- Contribution to EHDN
 - Lead Facilitator of the EHDN's Working Group 'Systems Modeling'
 - Foster the integration of therapeutic discovery and biomarker discovery
 - Promote multi-disciplinary research on care, personalized medicine and early-stage intervention in HD

María Antonia Ramos-Arroyo



- **Director of Medical Genetics**
- Complejo Hospitalario de Navarra, Osasunbidea
- Pamplona, Spain

María Antonia Ramos-Arroyo



- **1987 PhD in Medical Genetics** - Universidad del País Vasco, Bilbao
- **1985 MS in Medical Genetics** - Indiana University, Indianapolis
- **1978 Medical degree** - Universidad del País Vasco

María Antonia Ramos-Arroyo



Research interests:

- Genetics of neurodevelopment
- Genetics of neurodegeneration
- Epidemiological, phenotypic and molecular characterization of the HD gene mutation and the intermediate alleles
- Role of modifying factors

María Antonia Ramos-Arroyo



Visions:

- Contribution to EC
 - Set up the first HD Consulting Medical Genetics Clinic and became one of the founders of the Spanish HD Association
 - Experience as a member of the Registry steering committee and Registry PI
- Contribution to EHDN
 - Key infrastructure for high-quality, definitive clinical trials of potential therapeutics, with robust research teams and working groups able to address the emerging scientific enigmas, as well as the medical and social needs of HD families

Kathrin Reetz



- **Consultant Neurologist and Professor of Imaging in Neurodegenerative Disorders**
- Euregional Huntington Center Aachen (EHZA), Department for Neurology at the RWTH Aachen University
- Head of Clinical Research in Neurology

Kathrin Reetz



- 2011 **Habilitation thesis** - RWTH Aachen University
- 2011 **Board Certification in Neurology** - RWTH Aachen University
- 2004 **Medical degree** - University of Cologne (summa cum laude)

Kathrin Reetz



Research interests:

- Neurodegenerative diseases
- Clinical trials
- Identification of clinical and neuroimaging biomarkers
- Clinical innovation through target prioritization and biomarker detection

Kathrin Reetz



Visions:

- Contribution to EC
 - Expertise in clinical and research studies in HD
 - Improving clinical care in HD
- Contribution to EHDN
 - Consolidate existing large databases and ascertain best possible use of these to answer specific clinical and research questions
 - Identify suitable markers to monitor disease progression and interventional effects
 - Enable well designed clinical trials
 - Inspire and support young clinicians and researchers for HD

Hugh Rickards



- **Honorary Professor in Neuropsychiatry,
Consultant in Neuropsychiatry**
- University of Birmingham

Hugh Rickards



- 2004 **Fellow of Royal College of Psychiatrists**
- 2001 **MD** - University of Birmingham
- 1993 **MMedSci** - University of Birmingham
- 1988 **Medical degree (MBChB)** - University of Birmingham

Hugh Rickards

Research interests:

- Changes in social cognition
- Clinical trials
- Drug affordability



Hugh Rickards



Visions:

- Contribution to EC
 - Psychiatric expertise to the work of EHDN
 - Represent the experiences of patients with HD and their families, as clinician Trustee of the UK HD Association
- Contribution to EHDN
 - Maintain a European identity to HD research
 - Highlight the affordability of any emerging disease modifying therapies
 - Develop the capacity to deliver clinical trials and encouragement of a greater range of clinic-based research projects

Carsten Saft



- **Professor of Neurology**
- Research department “Neurodegeneration”,
Huntington Center North Rhine Westphalia (HZ-
NRW)
- St. Josef- und St. Elisabeth- Hospital, Ruhr-
University, Bochum

Carsten Saft



- **2013 Professor of Neurology** - Ruhr-University Bochum
- **2013 Genetic Counseling for Neurology**
- **2007 Habilitation thesis in Neurology** - Ruhr-University
- **2004 Board Certification in Neurology** - Ruhr-University
- **1996 Medical degree** - University Mainz, Münster, Philadelphia

Carsten Saft



Research interests:

- Huntington's disease
- Lead author of the Guidelines Committee “Huntington's Disease / Chorea” of the German Society of Neurology
- Peripheral pathology in HD
- Biomarkers and modifier genes in HD (Habilitation thesis: “Biomarkers in HD”)
- Clinical Trials in HD including Antisense

Carsten Saft



Visions:

- Contribution to EC
 - Optimize clinical care
 - Hold close contact to the SBAC
 - Current chair of the EHDN SBAC
- Contribution to EHDN
 - Initiate some more topic-specific smaller meetings for e.g. peripheral pathology in HD, cannabinoids in HD, situation of care and treatment for more severe affected in Europe
 - Drive the focus of plenary meetings to more smaller groups, more short presentations of elected posters, or develop an “out-of-the-box” corner

Klaus Seppi



- **Professor of Neurology**
- Department of Neurology
- Innsbruck Medical University

Klaus Seppi



- **2016 Secondary certification in Intensive care medicine**
- **2012 Secondary certification in Geriatrics**
- **2012 Additional certification in Palliative care medicine**
- **2006 Board certification in Neurology**
- **1999 Medical degree - University of Innsbruck**

Klaus Seppi



Research interests:

- Neuroimaging in Movement disorders
- Epidemiology of Movement disorders
- Clinical trials, evidence-based medicine and rating scales

Klaus Seppi



Visions:

- Contribution to EC
 - Exchange between European research groups and with industry
 - Increase public awareness of HD and spread knowledge on best practice in treatment and care of HD in Austria
- Contribution to EHDN
 - Shape the future of research and management of HD in a global way
 - Develop clinical training curricula for use in Europe