

# THE SPEAKERS IN ALPHABETICAL ORDER

### **Christiane Denzel**

Head of Country Operations, Alexion Pharma, Germany

Christiane Denzel has been working in management roles in the field of rare diseases since 2004. After graduating as a medical documentation specialist (Clinical Studies Expert) from the University of Ulm in 1996, she first worked in clinical research as a (principal) clinical research associate, first at Bencard Allergie GmbH and then at ICON Clinical Research. From 2004 to 2020, she worked at the Sanofi subsidiary Genzyme, most recently in the role of Senior Director and Global Head of Registries.

### Prof. Dr. Ralf-Dieter Hilgers

Managing Director of the Institute for Medical Statistics at the RWTH Aachen University

Since 2000, he has worked as Professor of Biometry at the Medical Faculty of RWTH Aachen University. From 2013 to 2017, he coordinated the project "Integrated Design and Analysis of Small Population Clinical Trials (IDeAI)", which was part of the European Union's Seventh Framework Programme for Research and Technological Development. He graduated in mathematics with a minor in physics from RWTH Aachen University in 1986, received his doctorate in statistics from the Technical University of Dortmund in 1991 and his Venia Legendi in medical statistics from the University of Cologne in 2000.

### Prof. Dr. Martin C. Hirsch

Head of the Institute for Artificial Intelligence in Medicine at the Philipps University of Marburg

Martin Hirsch studied human biology at the Philipps University of Marburg and received his doctorate in neurosciences. He founded several companies at the border of biomedicine and information technology. His special area of interest is the linking of cognitive neuroscience, knowledge transfer through visual models (images) and technologies to support human decision-making. In 2010, he co-founded a health and technology company where he continues to work in an advisory capacity.

### Prof. Dr. Martin J. Hug

Director of the Pharmacy of the University Hospital Freiburg

Martin Hug studied pharmacy in his hometown of Freiburg and obtained his doctorate from the Physiological Institute of the Albert Ludwig University. After working as a scientist in the USA, Münster and Frankfurt am Main, Hug moved to Freiburg University Hospital in 2003, where he took over the management of the pharmacy in 2011. In 2013, he completed his habilitation in clinical pharmacy. He has been a professor at the Institute of Pharmaceutical Sciences since 2018. Martin Hug was a member of the Board of the Federal Association of German Hospital Pharmacists from 2008 to 2012 and has been on the Scientific Advisory Board of the Federal Chamber of Pharmacists since 2015. Since 2020, he has also been chairman of the new "Pharmaceutical Logistics" committee of the Federal Association of German Hospital Pharmacists.



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### Prof. Dr. Wolf-Dieter Ludwig

Chairman of the Drug Commission of the German Medical Profession (AkdÄ), the scientific expert committee of the German Medical Association

Since obtaining his doctorate at the Free University of Berlin, Wolf-Dieter Ludwig has worked in various medical management positions in the field of haematology, oncology and tumour immunology at various Berlin hospitals. In 1994, he was appointed to a professorship in internal medicine with a focus on haematology, oncology and applied molecular biology at the Rudolf Virchow University Hospital in Berlin. Since 2017, he has been working as an outpatient haematologist, currently in an oncology practice in Berlin-Mitte. His scientific work includes the characterization of cell biological features of acute leukaemia as a basis for risk-adapted treatment decisions. Furthermore, his research interests include drug safety and the handling of conflicts of interest in medicine. In 2022, he received the Ernst von Bergmann Medal, an award of the German Medical Association for services to continuing medical education. He is a member of numerous national and international professional societies and expert groups.

### **Prof. Thomas Klopstock**

Senior Physician at the Friedrich Baur Institute at the Neurological Clinic of the LMU University Hospital in Munich; Study Director at the German Centre for Neurodegenerative Diseases (DZNE) in Munich

Thomas Klopstock completed his medical studies at Ludwig-Maximilians-Universität (LMU) Munich and Harvard Medical School in Boston. At the DZNE Munich, he leads studies on hereditary spastic spinal paralysis (HSP) and hereditary ataxia. In addition, his clinical and scientific interests include mitochondrial diseases, the disease group "Neurodegeneration with Brain Iron Accumulation" (NBIA) and other neurogenetic diseases. With his research group, he pursues a translational research approach. The focus is on the identification of new disease genes, the understanding of pathomechanisms, the investigation of patient cohorts in cross-sectional studies (registries) and in longitudinal studies ("natural history") as well as treatment studies.

### Mirjam Mann, LL.M.

Managing Director at the Alliance of Chronic Rare Diseases (ACHSE e.V.), which is based at the DRK Hospitals Berlin Mitte

Mirjam Mann, a native of the Netherlands, studied law at Amsterdam University and Columbia University, School of Law, New York. She has worked for more than ten years in commercial law firms and as an in-house counsel. Since 2004, she has worked as the Executive Director of the ACHSE Alliance. She has helped to establish the umbrella organization of and for people with rare diseases from the very beginning. For almost 20 years, ACHSE has been pooling expertise and knowledge in the field of rare diseases and representing the interests of all those affected in politics and society, in medicine, science and research. ACHSE now has 130 member organizations, 18 employees and a large national and international network. Political advocacy and networking are particularly close to Mirjam Mann's heart.



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### Dr. med. Christine Mundlos

Deputy Managing Director at the Alliance of Chronic Rare Diseases (ACHSE e.V.), which is based at the DRK Hospitals Berlin Mitte. She is also a guide for doctors and therapists and Head of the ACHSE Knowledge Network and Counselling

After studying medicine in Mainz in the early 1990s, Christine Mundlos first worked in cytogenetics (laboratory diagnostics) and later in molecular genetics (research). During this period, she spent several years abroad in Australia and the USA. She has been working in Berlin since 2000 and, as a project staff member of a consulting company there, accompanied the introduction of Diagnosis Related Groups (DRGs) at the Charité University Hospital. From 2005 to 2007 she completed the Master's programme "Science Marketing and Science Communication" at the Technical University (TU) Berlin. At the end of 2008, she began her work as an "ACHSE guide" for ACHSE and has since been working at the interface between medicine, research and patient self-help groups.

#### Prof. Dr. med. Lutz Nährlich

Managing Senior Physician in the Department of General Paediatrics, Paediatric Allergology, Paediatric Pneumology and Cystic Fibrosis at the University Hospital Giessen and Marburg; Medical Director of the German Cystic Fibrosis Registry

Lutz Nährlich is a specialist in paediatric and adolescent medicine and habilitated in 2016 in paediatric and adolescent medicine at Justus Liebig University Giessen, where he was awarded an extraordinary professorship this year. His research focuses on the diagnosis and epidemiology of cystic fibrosis. He has been the Medical Director of the German Cystic Fibrosis Registry since 2014 and has been the Pharmacovigilance Study Manager of the European Cystic Fibrosis Society Patient Registry since 2020. He is also involved in the European Cystic Fibrosis Society Patient Registry, contributing his expertise there as Medical Director from 2017 to 2020. In parallel, he has been working as a Senior Physician in the Department of General Paediatrics and Neonatology at Justus Liebig University Giessen since 2010.

### Michael Scholz

Board Member of the self-help association ELA Deutschland e.V. (European Association against Leukodystrophies)

As a social insurance and health insurance specialist, Michael Scholz worked in management positions in various organizational units of the statutory health insurance from 1993 to 2017. During this time, he also worked part-time as a lecturer in adult education and completed further education studies in labour sciences at Leibniz University in Hanover from 2002 to 2009. In 2017, his then six-year-old daughter required long-term care and he gave up his active professional activity. Since 2019, he has been active at ELA at board level. In 2020, he was nominated as a topic-related patient representative to the Federal Joint Committee (G-BA), and since 2021 he has been active in the European Reference Network Neurological Diseases (ERN-RND) in the same capacity.



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### Dr. med. Martina Schüßler-Lenz

Specialist for Internal Medicine, Department of Haematology, Cell and Gene Therapy at the Paul Ehrlich Institute, the Federal Institute for Vaccines and Biomedical Products

After clinical and scientific work with placements in Berlin, New York and Barcelona, Martina Schüßler-Lenz completed her specialist training in internal medicine at the University Hospital in Mainz. From 1992 to 2005, she worked in the pharmaceutical industry, where she supervised and managed the clinical development of drugs in haemato-oncological therapeutic indications. Since 2005, she has been working as a clinical expert at the Paul Ehrlich Institute. Her tasks in the Department of Haematology, Cell and Gene Therapy include the evaluation of clinical trials, approvals and scientific advice to developers of gene and cell therapeutics. As coordinator of the research programme of the Paul Ehrlich Institute and the German Consortium for Translational Cancer Research (DKTK), regulatory support for academic developers is a particular concern for her. From 2017 to 2023, she chaired the Committee for Advanced Therapies (CAT) of the European Medicines Agency.

### Dr. Julian Witte

Managing Director of Vandage GmbH

Julian Witte is the founder and managing director of Vandage GmbH, a boutique consultancy specializing in health economic evaluation, economic modelling and data-based storytelling. Previously, he was a research associate and doctoral student at the Chair of Health Economics and Health Management at Bielefeld University.

### Chair:

### Prof. Holger Wormer

Professor of Science Journalism at TU Dortmund University

Since 2004, Holger Wormer has worked as a freelance author and professor of science journalism at the Technical University of Dortmund. He is a member of the jury for the Communicator Prize of the German Research Foundation. He has worked as a freelance journalist since 1986 for various media such as Rheinische Post, dpa, P.M.-Magazin and WDR. From 1996 to 2004 he was science and medicine editor at the Süddeutsche Zeitung, specializing in medicine, genetic engineering as well as quality, ethics and fraud in research. Holger Wormer is the author of several books. He studied chemistry with a minor in philosophy in Heidelberg, Ulm and Lyon. He has received several awards, including a nomination of his project medien-doktor.de for the Grimme Online Award 2011.