







## Early Intervention and Diagnosis in Paediatric Neurodevelopment Defects

WORKSHOP I 29-30 NOVEMBER I RIO DE JANEIRO, BRAZIL



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- Independent, high quality medical science advice informs the decisions that affect society.
- More people have a say in the future of health and research. Our work focusses on four key objectives: promoting excellence, developing talented researchers, influencing research and policy, and engaging patients, the public and professionals.

The history of the **National Academy of Medicine** merges with the history of Brazil and is an integral and active part in the evolution of the practice of medicine in the country. The Academy also promotes national and international congresses, refresher courses and, annually distributes prizes to physicians and researchers not belonging to its staff.

Founded under the reign of Emperor D. Pedro I on June 30, 1829, the Academy has changed its name twice, but its purpose remains unchanged:

- Improve the dissemination of medical, pharmaceutical and related sciences ideas;
- Assemble professionals in periodic meetings with the purpose of discussing issues pertinent to national and international medicine;
- Respond, advise and assist, when requested, in Government matters related to public health and medical education;
- Promote and encourage postgraduate study, research and study of medicine in general, through the publication of scientific papers, promotion of courses, symposiums and awards for contributions that add value to the exercise of the profession.

The **Brazilian Academy of Sciences** (ABC), founded in 1916, is a non-profit, non-governmental, independent entity, which operates as an honorific scientific society and as a consultant for the government, when requested to do so, to perform technical studies and studies on scientific policies. Its focus is the scientific development of the Country, the interaction among Brazilian scientists and the interaction of these with researchers from other nations. The Institutional Missions of the Brazilian Academy of Sciences are:

- Recognize and stimulate the admittance to its staff of the most important Brazilian researchers who, due to the leadership they perform in the advance of scientific and technological activities of the Country, can be considered the most legitimate representatives of the national scientific community;
- Identify and stimulate young people with great potential for science, promoting the annual election of young researchers of notable talent to become Affiliated Members of the Academy for a limited period of time;
- Represent the Brazilian scientific community, nationally and internationally, aiming towards the implementation of a policy of Science, Technology and Innovation (ST&I) which promotes the development of Science to benefit the society;
- Promote the mobilization of the scientific community to act together with the constituted powers, aiming towards a national scientific and technological advance and the encouragement of innovation.

### Introduction

The trend in childhood disability has shifted over recent decades from physical and medical conditions to neurodevelopmental and behavioural disorders. Although long-term trends in paediatric neurodevelopmental disorders have been difficult to track, it is widely believed that the prevalence of children with neurodevelopmental disorders, particularly autism and ADHD, is increasing.

Neurodevelopment is a very complex process and disorders arise from a multitude of genetic, environmental and sociocultural factors. Thus, diagnostics and interventions are likely to vary between countries where demographics, health services and social culture all differ. The global burden of neurological disorders is underestimated and large numbers of children are now displaying neurodevelopmental disabilities.

However, research and medical progression in the field of paediatric disability is lagging and neurological services and resources are disproportionately scarce particularly in low- and middle-income countries.

The main objective of this workshop is to consider the burden of neurodevelopmental defects in children in Brazil, discuss strategies for early intervention programmes and to address the challenges facing the translation of research into paediatric healthcare.

The workshop will bring together experts across Brazil, the UK and other countries to better understand the epidemiology, genetics and nature of neurodevelopmental disorders in Brazil along with the latest evidence on brain neuroplasticity bringing together both human and animal models as well as basic and clinical science. The workshop will also investigate research and the future in the post-zika era in Brazil as well as current public health policies to cope with paediatric neurodevelopmental defects.

Following the workshop, a written report will be produced and disseminated to UK and Brazilian stakeholders with key recommendations of next steps in addressing the diagnosis and early intervention of paediatric neurodevelopmental disorders in Brazil.

### **Steering Committee Membership**

#### Co-Chairs:

- Professor Maria Elisabeth Lopes Moreira, Senior Paediatrics Researcher and Professor of Neonatal Growth and Nutrition, National Institute of Women's Health (Brazil)
- Professor David Edwards FMedSci, Chair in Paediatrics and Neonatal Medicine, Kings College London (UK)

#### Members:

- Dr Ana Maria Magalhães Costa, Medical Doctor, National Institute of Women, Children and Adolescents Health
- Dr Andrea Zin, Paediatric Ophthalmologist, Fernandes Figueira Institute
- Dr Fernanda Tovar Moll, Assistant Professor, Federal University of Rio de Janeiro and Vice-President, D'Or Research and Teaching Institute
- Dr Melissa Gladstone, Senior Lecturer in Paediatric Neurodisability, University of Liverpool

### Day 1: Epidemiology, genetics and brain neuroplasticity

08:30-09:00	Registration	
09:00-09:15	Chairs' welcome and introductions  Meeting co-chairs: Professor Maria Elisabeth Lopes Moreira and Professor  David Edwards FMedSci	
09:15-11:10	<ul> <li>Session 1: Understanding the epidemiology, genetics and nature of neurodevelopmental disorders         Chair: Dr Juan Llerena         This session will aim to gain an understanding of the epidemiology, genetics and nature of the problem within the context of neurodevelopmental disorders in Brazil and South America more broadly. It will also provide context for the following sessions over the course of the workshop.     </li> <li>Speakers:         <ul> <li>Burden estimation and life course epidemiology</li></ul></li></ul>	
11:10-11:25	Break	
11:25-12:25	Breakout Session 1 Chair: Professor Neil Marlow FMedSci Group Facilitators: Professor Hannah Kuper, Professor Stevens Rehen and Dr Alex Paciorkowski This session will give participants the opportunity to further discuss some of the issues raised in the opening session, focusing on identifying the nature of the problem, the size of the problem and what is known and unknown. Using this as the basis, through small group work, participants will develop research solutions to address these issues.	



# Day 1: Epidemiology, genetics and brain neuroplasticity Breakout group information

Understanding the epidemiology, genetics and nature of neurodevelopmental disorders

(Session 1; 11:25-12:25)

Chair: Professor Neil Marlow FMedSci

#### **Group One**

Facilitator: Professor Hannah Kuper

Dr Adriana Suely de Oliveira Melo, Professor Solange Salomão, Professor Karin Nielsen-Saines, Dr Thereza de Lamare Franco Netto, Professor Rubens Belfort Jr., Dr Larissa Queiroga, Professor Iscia Lopes-Cendes, Dr Eduardo de Sá Campello Faveret, Dr Lynn K. Paul, Dr Fernando Kok, Dr Myriam Calheiros

#### **Group Two**

Facilitator: Professor Stevens Rehen

Dr Tania Saad Salles, Dr Andrea Zin, Dr Bernardo Horta, Dr Albert Ko, Professor David Edwards, Dr Patrícia da Silva Sousa, Dr Ana Maria Magalhães Costa, Dr Fernanda Tovar Moll, Dr Renan Junior, Dr Gilca Maria Soares Gonzaga, Dr Marcio Vasconcelos, Professor Marcello André Barcinski, Professor Paulo Niemeyer Filho, Dr Fernanda Fialho

#### **Group Three**

**Facilitator:** Dr Alex Paciorkowski

Dr Patricia Silva, Dr Patricia Garcez, Dr Fernando Bozza, Dr Melissa Gladstone, Professor Neil Marlow, Dr. Marília Rosa Abtibol Bernardino, Professor Maria Elisabeth Lopes Moreira, Dr Cally Tann, Professor Jerson Lima, Dr Juan Llerena, Dr Leila Chimelli, Dr Nisia Trindade Lima, Professor Amilcar Tanuri

#### Focus questions:

- What are the main difficulties in defining the epidemiology of neurodevelopmental defects, and how can this be improved?
- What are the most common neurodevelopmental disorders observed in clinical practice? How can diagnosis and interventions for these be improved?
- What are the main genetic forms of neurodevelopmental defects and what can be done to address these?



### Day 1: Epidemiology, genetics and brain neuroplasticity

12:25-13:10	Feedback from breakout groups Each breakout group lead will report back to the rest of the participants on the responses to these questions in 10 minutes. This will be followed by 15 minutes of discussions and responses from the rest of the participants and the panel of speakers.		
13:10-14:10	Lunch		
14:10-15:55	<ul> <li>Session 2: Brain neuroplasticity and next steps         Chair: Professor Paulo Niemeyer         This session will focus on brain neuroplasticity and aim to bring together both human and animal models as well as basic and clinical science. Speakers will cover the importance of early intervention in perinatal and childhood brain disorders and strategies for early intervention programmes for neurostimulation.     </li> <li>Speakers:         <ul> <li>Development and plasticity of early brain circuits</li></ul></li></ul>		
15:55-16:10	Break		
16:10-17:10	Breakout Session 2 Chair: Dr Fernando Kok Facilitators: Professor Neil Marlow FMedSci, Dr Melissa Gladstone and Dr Cally Tan This session will aim to give all participants the opportunity to discuss the evidence base in brain neuroplasticity in more detail and what lessons might be learned in the area.		



# Day 1: Epidemiology, genetics and brain neuroplasticity Breakout group information

Brain neuroplasticity and next steps

(Session 2; 16:10-17:10) Chair: Dr Fernando Kok

#### **Group One**

Facilitator: Professor Neil Marlow FMedSci

Dr Juan Llerena, Dr Patrícia da Silva Sousa, Dr Stevens Rehen, Dr Patricia Garcez, Professor Marcello André Barcinski, Professor Jerson Lima, Dr Bernardo Horta, Professor Paulo Niemeyer Filho, Dr Eduardo de Sá Campello Faveret, Dr Fernando Bozza, Dr Marcio Vasconcelos, Dr Fernanda Fialho

#### **Group Two**

Facilitator: Dr Melissa Gladstone

Dr Albert Ko, Dr Tania Saad Salles, Dr Nisia Trindade Lima, Dr Adriana Suely de Oliveira Melo, Professor Hannah Kuper, Professor Karin Nielsen-Saines, Dr. Marília Rosa Abtibol Bernardino, Professor David Edwards, Dr Gilca Maria Soares Gonzaga

Dr Larissa Queiroga, Dr Fernanda Tovar Moll Dr Ana Maria Magalhães Costa, Dr Fernando Kok, Dr Alexander Paciorkowski

#### **Group Three**

Facilitator: Dr Cally Tan

Dr Thereza de Lamare Franco Netto, Dr Andrea Zin, Dr Patricia Silva, Professor Rubens Belfort Jr., Dr Myriam Calheiros, Professor Solange Salomão, Professor Amilcar Tanuri, Dr Leila Chimelli, Professor Maria Elisabeth Lopes Moreira, Professor Iscia Lopes-Cendes, Dr Renan Junior, Dr Lynn K. Paul

#### **Focus questions:**

- How has poor brain development led to neurodevelopmental defects?
- How can imaging be better used to define neurodevelopmental defects?
- Are there alternative models for the study of brain plasticity and development?
- What are the genetic and environmental effects on the genesis of autism and other neurocognitive disorders?



### Day 1: Epidemiology, genetics and brain neuroplasticity

17:10-17:55	Feedback from breakout groups  Each breakout group lead will report back to the rest of the participants on the responses to these questions in 10 minutes. This will be followed by 15 minutes of discussions and responses from the rest of the participants and the panel of speakers.
17:55-18:10	Daily Wrap Up Meeting co-chairs: Professor Maria Elisabeth Lopes Moreira and Professor David Edwards FMedSci
18:10-19:10	Break before dinner
19:10	DINNER



### Day 2: Paediatric research post-zika

09:00-09:05	<b>Welcome</b> Meeting co-chairs: Professor Maria Elisabeth Lopes Moreira and Professor David Edwards FMedSci	
09:05-10:40	<ul> <li>Session 3: Research and the future in the post-zika era         Chair: Professor Maria Elisabeth Lopes Moreira         This session will look at what the research landscape looks like post-zika, with a focus on the challenges for the production of knowledge in translational research in paediatrics, the lessons we can learn from the zika outbreak and ethical issues in paediatric research.     </li> <li>Speakers:         <ul> <li>Infectious diseases impairing neurodevelopment Professor Karin Nielsen-Saines</li> <li>Zika and microcephaly Dr Patricia da Silva Souza</li> <li>Impact of in utero Zika Virus infection on vision development Dr Andrea Zin</li> <li>Autism and Neurocognitive Disorders Dr Lynn K. Paul</li> <li>Q&amp;A (20 mins)</li> </ul> </li> </ul>	
10:40-11:00	Break	
11:00-12:00	Breakout Session 3 Chair: Professor Jerson Lima Facilitators: Dr Albert Ko, Dr Fernando Bozza and Professor Rubens Belfort Jr. This session will aim to give all participants the opportunity to discuss the future of research in Brazil in more detail post-zika and what lessons might be learned.	
12:00-12:45	Feedback from breakout groups  Each breakout group lead will report back to the rest of the participants on the responses to these questions in 10 minutes. This will be followed by 15 minutes of discussions and responses from the rest of the participants.	



# Day 2: Paediatric research post-zika Breakout group information

Research and the future in the post-zika era

(Session 3; 11:00-12:00) Chair: Professor Jerson Lima

**Group One** 

Facilitator: Dr Albert Ko

Professor Amilcar Tanuri, Dr Eduardo de Sá Campello Faveret, Dr Stevens Rehen, Dr Gilca Maria Soares Gonzaga, Dr Patrícia da Silva Sousa, Dr Fernanda Fialho, Dr Larissa Queiroga, Dr Thereza de Lamare Franco Netto, Professor Solange Salomão, Dr Nisia Trindade Lima, Dr

Bernardo Horta, Professor Neil Marlow

**Group Two** 

Facilitator: Dr Fernando Bozza

Professor Jerson Lima, Professor Maria Elisabeth Lopes Moreira, Dr Melissa Gladstone, Dr Adriana Suely de Oliveira Melo, Dr Fernando Kok, Professor Iscia Lopes-Cendes, Dr Juan Llerena, Dr Leila Chimelli, Professor Hannah Kuper, Professor Marcello André Barcinski, Dr Ana Maria Magalhães Costa, Professor Karin Nielsen-Saines, Dr Tania Saad Salles

#### **Group Three**

**Facilitator:** Professor Rubens Belfort Jr.

Dr Fernanda Tovar Moll, Dr Andrea Zin, Dr. Marília Rosa Abtibol Bernardino, Dr Lynn K. Paul, Dr Patricia Silva, Dr Patricia Garcez, Dr Cally Tann, Dr Renan Junior, Dr Alexander Paciorkowski, Dr Marcio Vasconcelos, Professor David Edwards, Dr Myriam Calheiros, Professor Paulo Niemeyer Filho

#### Focus questions:

- How can new protocols and diagnostic tools be developed for newborns at the post-zika era?
- What improvements can be made to ophthalmological interventions in newborns with neurodevelopmental defects?
- What are important considerations in designing national and international programmes for surveillance of emerging and re-emerging diseases leading to neurodevelopmental defects?



### Day 2: Paediatric research post-zika

12:45-13:45	Lunch
13:45-15:30	Session 4: Public Health Policies to cope with paediatric neurodevelopmental defects Chair: Dr Paulo Buss  This session will aim to discuss key conclusions and the implications for policy in Brazil. It will include reflections from the Brazilian Ministry of Health and other participants.  Speakers:  Effects of Breast feeding on the Building of Human Capital Dr Bernardo Horta  Strengthing public health interventions Professor Hannah Kuper  The social impact of the post Zika syndrome Dr Nisia Trindade Lima, President, Institute Oswaldo Cruz  Problems and perspectives: the role of the Ministry of Health Dr Thereza de Lamare Franco Netto, Brazilian Ministry of Health Q&A (30 mins)
15:30-16:00	Closing Lecture Giving Visibility To Invisible Children Chair: Professor Rubens Belfort Jr.  Speaker: Professor Maria Elisabeth Lopes Moreira
16:00	End



# **Speaker biographies Meeting Co-Chairs**

Professor Maria Elisabeth Lopes Moreira Senior Paediatrics Researcher and Professor of Neonatal Growth and Nutrition, National Institute of Women's Health (Brazil)

I am in my 19th year as a growth development and nutrition professor and in my 30th year as a clinical neonatologist. My primary focus is growth and nutrition and perinatal health and I and my institution are members of the Brazilian Neonatal Research Network. I am directing my own laboratory of growth and body composition and I am doing research on neonatal growth and human milk. My laboratory works with Luminex platform for hormones and equipments as BOD POD and PEA Pod to perform measurements of body composition and Deltatrac and perform measurements of metabolic rest in neonates. I participated in a large survey in Brazil called Birth in Brazil that including 24,000 births in every state, capitals and in the interior of Brazil, in order to study the unnecessary performance of C-sections, a major problem in the field of perinatal health in Brazil. Currently, I participate in a study in partnership with the Albert Einstein College of Medicine and funded by the Bill and Melinda Gates Foundation in order to reduce prematurity rates through interventions in prenatal care. I am a PI in our cohort of Pregnant with rash RT-PCR for Zika Woman and positive virus in Rio InstitutoFernandesFigueira/Fiocruz/ UCLA and I will be a PI in a Cohort of pregnant woman to study the incidence of neurological and clinical problems in newborns from woman exposed a Zika Virus in utero (Rio de Janeiro site) in a partnership between NIH and Fiocruz.

### Professor David Edwards FMedSci King's College London

David Edwards is Professor of Paediatrics and Neonatal Medicine, Kings College London, Head of the Department of Perinatal Imaging and Health, and Director of the Kings College Centre for the Developing Brain. He was previously the Weston Professor of Neonatal Medicine, Head in the Neonatal Medicine Group at the Medical Research Council Clinical Sciences Centre, and Chairman and Head of the Division of Paediatrics, Obstetrics and Gynaecology at Imperial College London.

After graduating from Oxford, he spent a year as a Kennedy Scholar at Harvard University and the Massachusetts Institute of Technology. He trained at the Medical School at Guys Hospital and studied neonatology at University College London before moving to the Hammersmith Hospital and Imperial College.

He became a Member of the Royal College of Physicians in 1986 and a Fellow in 1993, a Fellow of the Royal College of Paediatrics and Child Health in 1998, a Fellow of the Academy of Medical Sciences in 2002, and a Fellow of the Royal College of Radiologists in 2016.

In 2007 he was awarded the Arvo Yllpo Quinquennial Gold Medal and Prize for Research in Neonatal Medicine and appointed Senior Investigator in the National Institute of Health Research.

He holds current grant funding from the MRC, EPSRC, Wellcome Trust and other bodies. He leads the Developing Human Connectome Project, a €15 million programme funded by the European Research Council to map the development of structural and functional connectivity in the fetal and newborn brain. His published work is extensive, including papers in the New England Journal of Medicine, Lancet, and the Proceedings of the National Academy of Science, USA.

## Dr Cally Tan University College London Hospital, the London School of Hygiene & Tropical Medicine

Cally Tann is an Associate Professor in Child Health & Development working at the MARCH Centre at the London School of Hygiene & Tropical Medicine and a Consultant Neonatologist at University College London Hospitals. Her research interests focus on global newborn health and early childhood outcomes and interventions in low and mid-resource settings. She is the Chief Investigator on the ABAaNA studies, which focus on risk factors for, and early outcomes from neonatal encephalopathy in Uganda and also on early identification and intervention for children with developmental disability. Working with Prof Joy Lawn and colleagues at the MARCH Centre, Cally has led on aspects of the recent global landscaping of maternal and newborn Group B Streptococcal infection and an impact analysis of the Saving Brains portfolio of Early Child Development interventions. She is the co-Chief Investigator on an RCT examining the feasibility and impact of an early intervention programme for young children with developmental disability in Africa in collaboration with the International Centre for Evidence in Disability (ICED) and the MRC/UVRI Uganda Research Unit. She is collaboratively working with ICED in the development of an early intervention programme to support children with Congenital Zika Syndrome and their families in Brazil.

In her clinical work she is a Consultant on the tertiary Neonatal Intensive Care Unit at UCLH, specialising in neonatal neurology and neurodevelopmental follow-up. She is the Neonatal Unit Training Director and is a College Tutor at the RCPCH. She teaches on clinical newborn care in low resource settings across the UK and East Africa.

## Professor Iscia Lopes-Cendes Universidade Estadual de Campinas

I am a physician scientist, professor of Medical Genetics and head of the laboratory of Molecular Genetics at the University of Campinas (UNICAMP), BRAZIL. I obtained my M.D. degree at UNICAMP, followed by a medical specialty training in pediatrics and a Ph.D. degree in Neuroscience at McGill University, Canada.

I work in the field of neurogenetics, focusing on the study of genetic and phenotypic markers in neurologic disorders. Currently, I am particularly interested in studying the underlying molecular mechanisms leading to disease, aiming to finding better treatment options and prevention. In recent years, my laboratory has focused on the use of new genomic techniques to answer some of these biological and clinical questions. My laboratory is a reference in Latin America for next generation sequencing technologies, bioinformatics analysis of complex genomic data and the study of non-coding RNAs. I have received several honors and awards for my scientific contributions, including the election as member of the Brazilian Academy of Sciences, the highest award for scientists in Brazil.

I am the head of the neurogenetics outpatient clinic at UNICAMP University hospital, and I was responsible for introducing the first presymptomatic testing clinic for late onset neurodegenerative disorders in Brazil.

### Professor Neil Marlow FMedSci Professor of Neonatal Medicine, University College London

Neil Marlow is Professor of Neonatal Medicine at University College London and current Chair of the NHS England Neonatal Critical Care Clinical Reference Group. He took up this appointment following 11 years as Professor of Neonatal Medicine at Nottingham and 7 years as Senior Lecturer in Bristol. He is an Honorary Consultant in the University College Hospital Neonatal Service. His major academic interests have been in long-term outcomes following prematurity and he is the Director of the MRC-funded EPICure studies (<a href="www.epicure.ac.uk">www.epicure.ac.uk</a>). He runs a series of local studies into brain and cognitive development following very preterm birth and is a coinvestigator on a range of mainly UK based cohort and randomised studies. Neil has been President of the British Association for Perinatal Medicine, Director of the UCL Institute for Women's Health, President of the European Society for Paediatric Research and Chair of two European Academy of Paediatric Societies Meetings. He was elected a Fellow of the Academy of Medical Sciences and is an Honorary Life Friend of Bliss, the UK-based charity for premature babies. He has recently been appointed to the executive of the European Foundation for the Care of Newborn Infants.

### Dr Melissa Gladstone University of Liverpool

Dr Melissa Gladstone is a Senior Clinical Lecturer in Neurodevelopmental Paediatrics and International Child Health at the University of Liverpool. Her main research interest is in the assessment of neurodevelopmental and neurobehavioural outcomes in children in low income and cross cultural settings globally. She has underaken and is presently undertaking large field studies in a number of African and Asian settings and is interested to pursue the linkages between assessment of children's development and interventions which can be provided in community settings.

She created a neurodevelopmental assessment tool, the MDAT, which is being utlised in over 10 countries in Africa for research and programmatic work – much of this linking early interventions in nutrition, WASH and early stimulation programmes with later outcomes in children.

She is particularly interested in the creation of culturally relevant outcome tools which can measure both behaviour and child development across settings and which can demonstrate good predictive validity for later neuropsychiatric outcomes in children.

Dr Gladstone works closely with the WHO and has served as an expert in the creation of the recent WHO toolkit for the care and support of people affected by complications associated with Zika virus. She is presently working on creating a CORE outcome set through consensus Delphi processes for measuring outcomes in trials of children affected by Zika and other congenital infections. This includes working with families and children to understand what outcomes researchers should consider as being most important and relevant to them. Dr. Gladstone supported the development of the CRFs recommended by the International Severe Acute Respiratory and Emerging Infection Consortium.

### Dr Patricia Garcez Universidade Federal do Rio de Janeiro

Patricia Garcez graduated in Biomedical Sciences from the Federal University of Rio de Janeiro (UFRJ) in 2003 and received a Master degree in Morphological Science from the same University (2004). During the academic year of 2004-2005, she was a doctoral fellow at the Anatomy and Physiology Department at the Friederich-Schiller University of Jena, Germany. In 2008 she received a Ph.D. degree with a thesis about the cellular and molecular mechanisms of corpus callosum development. From 2009 until 2014, she was a MRC postdoctoral fellow at the National Institute for Medical Research in London, at the Department of Molecular Neurobiology led by Dr. François Guillemot. Patricia is currently Assistant Professor of Anatomy at the Biomedical Institute at the Federal University of Rio de Janeiro, Brazil. Her research is about the mechanisms of brain development formation and malformation such as Zika virus congenital syndrome.

### Dr Fernanda Tovar Moll Vice-Presidente Instituto D'Or Pesquisa e Ensino

Fernanda Tovar-Moll earned her MD degree from the Federal University of Rio de Janeiro (1999, UFRJ), Brazil. She completed a Medical Residency program in Radiology (2003), with an emphasis in Neuroradiology, and obtained a PhD in Morphological Sciences at UFRJ (2007). Her PhD thesis explored the use of advanced neuroimaging techniques in assessing neuroplasticity in children with brain malformation (callosal diysgenesis). She was a postdoctoral Fellow at the National Institute of Neurological Diseases and Stroke, National Institutes of Health (USA), from 2004-2007.

Dr. Tovar-Moll is currently an adjunct professor at the Institute of Biomedical Sciences and the vice-director of the National Center of Structural Biology and Bioimaging (CENABIO), at UFRJ. In addition, she also holds a position as the vice-president of the D'Or Institute for Research and Education (IDOR), a private not-for-profit research institute, which she co-founded in 2009. She is affiliated member of the Brazilian Academy of Sciences (2016-2020) and has been working in projects related to basic, clinical and translational research in neurodegenerative and neurodevelopmental conditions. Her main research interest is to employ novel in vivo imaging techniques in human and rodents to map brain circuits in order to improve the understanding of pathophysiological mechanisms related to functional and structural brain connectivity and brain plasticity, in normal and pathological conditions. Another focus of interest is to employ neuromodulatory techniques, such as tDCS, TMS and MRI neurofeedback to induce changes in brain circuits to improve neurological function in stroke and other abnormal conditions.

### Dr Alexander Paciorkowski University of Rochester Medical Center

Dr. Alex Paciorkowski is Assistant Professor of Neurology, Pediatrics, Neuroscience, and Biomedical Genetics at the University of Rochester Medical Center. My overall career goal is to help improve the care of children with neurologic disability. Early in my training I decided to focus on neurogenetics, as many causes of neurologic disorders in childhood have a genetic basis. After completion of my pediatrics and medical genetics training at the University of Connecticut, I then moved to St. Louis for child neurology training at Washington University. In Rochester, NY I see patients as part of the Neurogenetics Consultation Service and the Hereditary Ataxia Program. I direct a research program focused on the discovery of genes involved in childhood neurologic disorders, and how those genes affect brain development. Currently, our lab uses massively-parallel sequencing approaches to gene discovery in severe pediatric epilepsies such as infantile spasms. We are also studying complex developmental disorders where autistic features, intellectual disability, epilepsy, and movement disorders overlap. A key part of our research program is the creation of new bioinformatics tools to analyze and integrate data. As my undergraduate university area of concentration was Latin American Studies, I also maintain a strong interest in collaborations with Latin American colleagues, and currently participate in neurology patient care and education projects in Ecuador as well as congenital Zika syndrome related projects in Brazil.

### Professor Karin Nielsen-Saines University of California (UCLA)

Dr. Karin Nielsen is Professor of Clinical Pediatrics in the Division of Infectious Diseases at UCLA Children's Hospital and a member of the UCLA faculty since 1996. She is also an attending physician for Pediatric Infectious Diseases at Mattel Children's Hospital and co-director of the Care4Families HIV clinic at UCLA. Dr. Nielsen was born in Rio de Janeiro where she obtained medical training from the University of Rio de Janeiro and completed a pediatric residency at the Hospital dos Servidores do Estado, also in Rio. She obtained further training at UCLA where she completed both clinical and research postdoctoral fellowships in pediatric infectious diseases and obtained a master's degree in Public Health/ Epidemiology. Dr. Nielsen's main area of research has been perinatal/ pediatric infections particularly in the area of HIV and congenital infections. She has worked extensively in collaborative clinical studies in the United States, Brazil, Argentina, and in sub-Saharan Africa, particularly in Mozambique, Malawi and South Africa, focused on prevention of mother to child transmission of HIV and HIV transmission between couples, as well as treatment of this disease in children, adolescents and adults. Dr. Nielsen has a very active collaboration at present in Brazil with the Fiocruz Institute, Arboviral Division and the Instituto Fernandes Figueira focusing on ZIKA virus transmission during pregnancy and infant outcomes. She also has ongoing studies in HIV prevention and treatment in adolescents, acute infections during pregnancy, adherence studies in HIV sero-discordant couples and studies of sexually transmitted diseases in pregnancy, and congenital infections with institutions in Rio de Janeiro and Porto Alegre, Brazil. She also collaborates with colleagues from the University of the Philippines on a large study of TB in children, and with investigators from the University of Graz in Austria in studies of neurodevelopment following infections. She is Principal Investigator of a large study of acute HIV infection in at risk youth in Los Angeles and New Orleans. Dr. Nielsen directs the Center for Brazilian Studies at UCLA and has mentored multiple medical students, residents, graduate students and post-doctoral fellows from North, Central and South America, Europe, Africa and Asia.

### Dr Patricia da Silva Souza CDNeuro Neurological Diagnostic Center

My medical degree from the Federal University of Maranhão (1993) and a PhD in Sciences from the Paulista School of Medicine, Neurology - Epilepsy (2006). I have experience in the area of Neurology (Specialist title by the Brazilian Academy of Clinical Neurology-ABN), Child Neurology (medical residency at the Hospital das Clinicas UNICAMP) and Neurophysiology (Specialist title by the Brazilian Society of Clinical Neurophysiology- SBNC, electroencephalography), with emphasis and acting mainly on the following topics: Epilepsy, Neuropsychomotor Development (preterm and full term infants) and Neurophysiology (EEG and Video - EEG). I am the author and currently general director of the Project Casa de Apoio NINAR in São Luis - MA for Families of Children with neuropsychomotor developmental disturbances.

### Dr Andrea Zin Instituto Brasileiro de Oftalmologia

Dr Zin is a pediatric ophthalmologist working at the Neonatology Department and Clinical Research Unit, Instituto Fernandes Figueira (IFF), FIOCRUZ, Brazil

Her research focuses on prevention of childhood visual impairment and blindness due to retinopathy of prematurity and infantile cataract, as well as health care personnel education strategies. Since January 2016, Dr Zin and her team prospectively follow-up 300 infants with known or suspected exposure to ZIKV in Rio de Janeiro.

## Dr Lynn K. Paul California Institue of Technology (Caltech)

Lynn K. Paul, Ph.D. is a Senior Research Scientist at California Institute of Technology, where she is directing a research program studying brain-structure, cognition and social processing in Dysgenesis of the Corpus Callosum (DCC). Dr. Paul received a Ph.D. in Clinical Psychology from Fuller Graduate School of Psychology and completed a post-doctoral fellowship in clinical neuropsychology from the Department of Neurology, UCLA. Since graduate school, Dr. Paul has collaborated with Dr. Warren Brown to describe the cognitive and behavioral profile of individuals with agenesis of the corpus callosum. In addition to ongoing studies of adolescents and adults with DCC, she is also conducting a longitudinal study of infants with DCC which involves comparison to early development in a large cohort at risk for developing autism (in collaboration with the Infant Brain Imaging Study - Autism Center of Excellence)

In 2002, Dr. Paul collaborated with other professionals and family members to found the National Organization for Disorders of the Corpus Callosum (NODCC). The NODCC is a 501c3 not-for-profit that brings families, clinicians, and scientists together in the effort to improve quality of life for people with callosal disorders. During her tenure as NODCC president, she co-authored « ACC and Me,» a children's book about a boy with callosal agenesis. She is currently the founding president of the International Research Consortium for the Corpus Callosum and Cerebral Connectivity (IRC5).

### Dr Bernardo Horta Universidade Federal de Pelotas

I have a PhD in Epidemiology at McGill University. I am an associate professor in the Postgraduate Program in Epidemiology, Universidade Federal de Pelotas. I am the principal investigator of the 1982 Pelotas Birth Cohort Study. I have conducted extensive research on the long-term consequences of infant feeding and nutrition.

### Professor Hannah Kuper London School of Hygiene and Tropical Medicine

I am the Director of the International Centre for Evidence in Disability, a research group at the London School of Hygiene & Tropical Medicine (LSHTM). We work to strengthen the work at LSHTM in the field of global disability, through research and teaching. My main research interest is on disability in low and middle income countries, with a particular focus on investigating the health and rehabilitation needs of people with disabilities, and how these can be met. I am collaborating on four research projects related to Congenital Zika Syndrome in Brazil.

I have an undergraduate degree from Oxford University in Human Sciences and a doctorate from Harvard University in epidemiology. I have worked at LSHTM since 2002.

### Dr Nisia Trindade Lima President, Institute Oswaldo Cruz

She joined the institution in 1987 as a researcher at the Casa de Oswaldo Cruz (COC / Fiocruz), assuming the direction of the unit from 1999 to 2005. Already in the first decade of the new millennium, Nísia also served as a member of the editorial board of Editora Fiocruz, scientific and executive committee of the 4th World Congress of Science Centers and the organizing committee of events to commemorate the centenary of the discovery of Chagas Disease. She participated in the creation of the specialization course in health history in Amazonia, in partnership with the Instituto Leônidas and Maria Deane (Fiocruz Amazonas), and the Graduate Program in History of Science and Health of COC.

She was also responsible for starting the partnership with the federal government to increase policies for the preservation of the cultural heritage of health, concentrated to a large extent in Fiocruz's own buildings. In this decade, Nísia was nominated as a finalist of the Jabuti Prize with the work "Louis Pasteur and Oswaldo Cruz: tradition and innovation in health" and received the medals of the centennial of the Oswaldo Cruz Foundation, Euclides da Cunha and in commemoration of the 110 years of foundation of the Brazilian Academy of Letters. She was also awarded the "Highlight of the Year in Guidance for Scientific Initiation" award from CNPq. In 2016, in the context of confronting the global sanitary emergency due to the zika virus, and with the objective of centrally placing the human dimension in the search for solutions to this problem, Nísia created, within the scope of the Vice Presidency of Education, Information and

Communication, the integrated research program Social Sciences Network and Zika of Fiocruz.

#### Dr Thereza de Lamare Franco Netto

#### **Brazilian Ministry of Health**

Thereza De Lamare Franco Netto holds a Bachelor Degree in Social Communication from the Catholic University of Minas Gerais (UCMG, 1990) and received a Master degree in Social Policies from the University of Brasília (UNB, 2007). She is the director of the Programmatic and Strategic Actions Department of the Secretariat of Health Care, Brazilian Ministry of Health. This department is responsible for the implementation of health policies for children, teenagers, women, men and elderly. In addition, the department addresses mental health, disabled people and abuse of alcohol and other drugs. She has been working over 12 years in public service, especially in the health field and in policies related to strategic and vulnerable populations.

Thereza was responsible for the implementation of the Fast Strategy of Action for diagnose and confirmation of the Zika virus in children on 2016. As coordinator of teenagers health area, she stablished the guidelines of attention to the problems related to this category, such as the sexual and reproductive issues.

She also implemented the health's booklet for youngsters on the Brazilian Unified System of Health and a guide for actions that merge education and health care together by creating the program Health at the School. Additionally, she coordinated the implementation of the Stork Net, from 2011 to 2013, and was the secretary of the State of Work, Social Assistance, Children and Teenagers of Minas Gerais state from 2002 to 2003.





### **Attendees**

Name	Organisation
Professor Marcello André Barcinski	Academia Brasileira de Ciências Academia Nacional de Medicina
Professor Rubens Belfort Jr.	Universidade Federal de São Paulo
Dr. Marília Rosa Abtibol Bernardino	Universidade de São Paulo
Ms Elizabeth Bohm	Academy of Medical Sciences
Dr Fernando Bozza	Instituto Nacional de Infectologia Evandro Chagas
Dr Myriam Calheiros	Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira, Fundação Oswaldo Cruz
Dr Leila Chimelli	Universidade Federal do Rio de Janeiro
Dr Ana Maria Magalhães Costa	Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira, Fundação Oswaldo Cruz
Professor David Edwards FMedSci	King's College London
Dr Fernanda Fialho	Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira, Fundação Oswaldo Cruz
Dr Katharine Fox	Academy of Medical Sciences
Dr Patricia Garcez	Universidade Federal do Rio de Janeiro
Dr Melissa Gladstone	University of Liverpool
Dr Gilca Maria Soares Gonzaga	Universidade Federal do Rio de Janeiro
Dr Bernardo Horta	Universidade Federal de Pelotas
Mr Alex Hulme	Academy of Medical Sciences
Dr Renan Junior	Instituto Professor Joaquim Amorim Neto
Dr Albert Ko	Yale School of Public Health
Dr Fernando Kok	Mendelics Genomic Analysis and University of Sao Paulo
Professor Hannah Kuper	London School of Hygiene and Tropical Medicine
Dr Thereza de Lamare Franco Netto	Brazilian Ministry of Health



### **Attendees**

Name	Organisation
Professor Jerson Lima	Universidade Federal do Rio de Janeiro, Foundation Carlos Chagas Filho Research Support of the State of Rio de Janeiro
Dr Nisia Trindade Lima	President, Institute Oswaldo Cruz
Dr Juan Llerena	Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira, Fundação Oswaldo Cruz
Professor Iscia Lopes-Cendes	Universidade Estadual de Campinas
Professor Maria Elisabeth Lopes Moreira	Oswaldo Cruz Foundation
Professor Neil Marlow FMedSci	University College London
Professor Karin Nielsen-Saines	University of California (UCLA)
Professor Paulo Niemeyer Filho	Medical Director, Paulo Niemeyer State Brain Institute
Dr Adriana Suely de Oliveira Melo	Instituto Professor Joaquim Amorim Neto
Dr Alexander Paciorkowski	University of Rochester Medical Center
Dr Lynn K. Paul	California Institute of Technology (Caltech)
Dr Larissa Queiroga	Instituto Professor Joaquim Amorim Neto
Dr Stevens Rehen	Universidade Federal do Rio de Janeiro
Dr Eduardo de Sá Campello Faveret	Instituto Estadual do Cerébro Paulo Niemeyer
Dr Tania Saad Salles	Instituto Nacional de Saúde da Mulher, da Criança e do Adolescente Fernandes Figueira, Fundação Oswaldo Cruz
Professor Solange Salomão	Universidade Federal de São Paulo
Dr Patricia Silva	Instituto Professor Joaquim Amorim Neto
Dr Patrícia da Silva Sousa	CDNeuro Neurological Diagnostic Center
Dr Cally Tann	University College London Hospital, London School of Hygiene & Tropical Medicine
Professor Amilcar Tanuri	Universidade Federal do Rio de Janeiro
Dr Fernanda Tovar Moll	Vice-Presidente Instituto D'Or Pesquisa e Ensino
Dr Marcio Vasconcelos	Universidade Federal Fluminense
Dr Andrea Zin	Instituto Brasileiro de Oftalmologia

### **Notes**

