

LOST IN THE MAZE? NAVIGATING EVIDENCE AND ETHICS IN TRANSLATIONAL NEUROSCIENCE

February 14 - 16, 2018, Hanover, Germany
Herrenhausen Conference

PRELIMINARY PROGRAM (all academic titles have been omitted)

Wednesday, February 14th, 2018

11.30 a.m. **Registration, Coffee and Quick Lunch**

1.00 p.m. **Welcome Remarks:**
Wilhelm Krull, General Secretary, Volkswagen Foundation
Christopher Baum, Hannover Medical School, Germany

1.10 p.m. **Opening Session:**
A SERIES OF BRIEF TALKS TO ILLUSTRATE THE CONNECTIONS BETWEEN THE QUALITY OF PRE-CLINICAL RESEARCH AND THE ETHICS OF EARLY CLINICAL TRIALS
INTRODUCTION AND CHAIR: Ulrich Dirnagl, Charité-Universitätsmedizin Berlin and Berlin Institute of Health, Germany

MAPPING THE SCIENTIFICALLY AND ETHICALLY COMPLEX TERRAIN OF TRANSLATIONAL NEUROSCIENCE
Mark Yarborough, University of California Davis, USA

WHAT DO WE KNOW ABOUT SAFETY AND EFFICACY IN PHASE I NEUROLOGY CLINICAL RESEARCH?
Jonathan Kimmelman, McGill University, Canada

A QUESTION OF EVIDENCE: THE EXTENT AND DEPTH OF PROBLEMS IN PRE-CLINICAL RESEARCH
Emily Sena, University of Edinburgh, UK

HOW PROBLEMS IN PRE-CLINICAL RESEARCH AFFECT THE ETHICS OF CLINICAL RESEARCH
Daniel Strech, Hannover Medical School, Germany

PROPOSED SOLUTIONS TO IMPROVE THE QUALITY, RELIABILITY, AND PREDICTABILITY OF PRE-CLINICAL RESEARCH FOR NOVEL NEUROLOGICAL TREATMENTS: A REVIEW
Ulrich Dirnagl, Charité-Universitätsmedizin Berlin and Berlin Institute of Health, Germany

- 2:25 p.m. **Panel Discussion:**
CAUSES OF CURRENT PROBLEMS IN PRE-CLINICAL RESEARCH AND THE EXTENT OF THEIR ETHICAL IMPLICATIONS FOR EARLY TRIALS OF NOVEL INTERVENTIONS
MODERATOR:
Nanette Joyce, University of California Davis, USA
PANELISTS:
Ulrich Dirnagl, Charité-Universitätsmedizin Berlin and Berlin Institute of Health, Germany
Jonathan Kimmelman, McGill University, Canada
Jeffrey Mogil, McGill University, Canada
- 3.00 p.m. **Coffee Break**
- 3.30 p.m. **Small Group Sessions:**
CONFIRMING THE CHALLENGES IN TRANSLATIONAL NEUROSCIENCE
Pre-assigned groups will work with designated leaders to provide feedback about the opening afternoon session:
1. **Are there mitigating factors about the key points or challenges covered in the presentations that did not receive enough mention?**
 2. **Were any key points or challenges that need to be addressed not mentioned?**
 3. **Are there other improvement measures we should focus on, either in addition to or in place of, those mentioned by the presenters?**
- 4.30 p.m. **Keynote Address:**
EVIDENCE ABOUT EVIDENCE
John Ioannidis, Stanford University, USA
- 5.30 p.m. **Discussion of the Keynote Address and Small Group Sessions:**
MODERATOR: Alison Abbott, Nature Publishing Group, Munich, Germany
PANELISTS:
Annelien Bredenoord, Utrecht University, The Netherlands
Andreas Meyer-Lindenberg, Central Institute of Mental Health, Germany
Shai Silberberg, National Institutes of Health, USA
- 6.15 p.m. **Welcome Reception and Poster Session**
- 7.00 p.m. **Welcome Dinner**

Thursday, February 15th, 2018

- 9.00 a.m. **Session:**
INFORMED CONSENT: ITS ESSENTIAL ROLE AND SPECIFIC IMPLEMENTATION CHALLENGES FOR INDIVIDUALS CONFRONTED BY THE PROSPECT OF LIFE-LIMITING NEUROLOGICAL DISEASES AND DISORDERS
Jodi Halpern, University of California Berkeley, USA
- UNDERSTANDING AND WORKING WITH PATIENTS' THERAPEUTIC MOTIVATION FOR ENTERING CLINICAL TRIALS*
Scott Kim, National Institutes of Health, USA
- HOW PUBLIC REPRESENTATIONS OF SCIENCE AND HEALTH CAN IMPACT PUBLIC DEBATE AND PATIENT DECISION MAKING*
Timothy Caulfield, University of Alberta, Canada
- 10.00 a.m. **Panel Discussion:**
PUBLIC AND PATIENT PERCEPTIONS OF RESEARCH
MODERATOR: Paul Knoepfler, University of California Davis, USA
PANELISTS:
Virginie Bros-Facer, EURORDIS, France
Katherine Cowan, James Lind Alliance, UK
Scott Kim, National Institutes of Health, USA
- 10.45 a.m. **Coffee Break**
- 11.15 a.m. **Large Group Discussion among Panelists and Audience Members:**
THE INFORMED CONSENT PROCESS: HOW CAN WE IMPROVE IT?
MODERATOR: Alex Capron, University of Southern California, USA
PANELISTS:
Michael Rieder, Concerned parent, Germany
Sharon McClellan Thomason, Director of Education/Executive Secretary, Help 4 HD International, USA
Andreas Meisel, Charité-Universitätsmedizin Berlin, Germany
- 12.30 p.m. **Young Researchers Presentations (Travel grantees) - Part I**
- 1.00 p.m. **Lunch**

2.30 p.m.

Session:

ETHICALLY RESPONSIBLE SCIENCE COMMUNICATION

Ubaka Ogbogu, University of Alberta, Canada

HOW COMMUNICATION FRAMING INFLUENCES PUBLIC PERCEPTIONS

Dominique Brossard, University of Wisconsin-Madison, USA

THE ROLE OF SOCIAL MEDIA IN PUBLIC UNDERSTANDING OF BIOMEDICAL RESEARCH

Julia Belluz, Vox.com, USA

Speaker Discussion and open to the Auditorium:

MODERATOR: Sarah Perrault, University of California Davis, USA

3.30 p.m.

Small Group Exercises:

RESEARCHER RESPONSIBILITIES FOR IMPROVING SCIENCE COMMUNICATION

Pre-assigned groups will work with designated leaders to:

1. Discuss the relative weight of science communication responsibilities of researchers compared to their other professional responsibilities
2. Explore strategies to improve science communication

4.30 p.m.

Coffee Break

5.00 p.m.

Young Researchers Presentations (Travel grantees) - Part II

5.30 p.m.

Large Group Discussion to hear and discuss Small Group Findings:

RECOMMENDATIONS FOR IMPROVING SCIENCE COMMUNICATION

MODERATOR: Timothy Caulfield, University of Alberta, Canada

6.00 p.m.

Reception and Poster Session

7.00 p.m.

Conference Dinner and Social Event

Friday, February 16th, 2018

- 9.00 a.m. **Panel 1:**
THE ROLE OF UNIVERSITIES IN IMPLEMENTING BEST PRACTICES FOR IMPROVING TRANSLATIONAL NEUROSCIENCES
Moderator: Alex Kolodkin, Johns Hopkins School of Medicine, USA
PANELISTS:
Frank Miedema, University Medical Center Utrecht, The Netherlands
Cornelius Frömmel, Charité-Universitätsmedizin Berlin, Germany
- 9.30 a.m. **Panel 2:**
THE ROLE OF DRUG AND DEVICE REGULATORY AGENCIES IN IMPLEMENTING BEST PRACTICES FOR IMPROVING TRANSLATIONAL NEUROSCIENCES
MODERATOR: Iain Chalmers, James Lind Initiative, UK
PANELISTS:
Enrica Alteri, European Medicines Agency, UK
Laurent Pradier, SANOFI R&D, France
Thomas Steckler, Janssen Pharmaceuticals, Belgium
- 10:00 a.m. **Panel 3:**
THE ROLE OF FUNDERS IN IMPLEMENTING BEST PRACTICES FOR IMPROVING TRANSLATIONAL NEUROSCIENCES
MODERATOR: Oliver Grewe, Volkswagen Foundation, Germany
PANELISTS:
Leena Kaarina Bruckner-Tuderman, Albert-Ludwigs-University of Freiburg and Deutsche Forschungsgemeinschaft, Germany
Shai Silberberg, National Institute of Health, USA
- 10.30 a.m. **Coffee Break**
- 11.00 a.m. **Panel and Audience Discussion:**
MOVING FORWARD TO STRENGTHEN THE QUALITY AND PREDICTIVE VALUE OF PRE-CLINICAL RESEARCH
MODERATOR: Ulrich Dirnagl, Charité-Universitätsmedizin Berlin and Berlin Institute of Health, Germany
PANELISTS:
Jeffrey Mogil, McGill University, Canada
Hanno Würbel, University of Bern, Switzerland

- 11.30 a.m. **Panel and Audience Discussion:**
MOVING FORWARD TO STRENGTHEN THE OVERSIGHT OF CLINICAL RESEARCH ON NOVEL INTERVENTIONS FOR NEUROLOGICAL DISEASES AND DISORDERS
MODERATOR: Nanette Joyce, University of California Davis, USA
PANELISTS:
Insoo Hyun, Case Western Reserve University
Bernard Ravina, Voyager Therapeutics, USA
- 12.00 p.m. **Panel and Audience Discussion:**
MOVING FORWARD TO STRENGTHEN THE ETHICS OF CLINICAL RESEARCH ON NOVEL INTERVENTIONS FOR NEUROLOGICAL DISEASES AND DISORDERS
MODERATOR: Mark Yarborough, University of California Davis
PANELISTS:
Annelien Bredenoord, Utrecht University, The Netherlands
Jodi Halpern, University of California Berkeley, USA
- 12.30 p.m. **Announcement of Best Poster and Best Talk Prize Winners, Closing Remarks & Adjourn Conference:**
Ulrich Dirnagl and Mark Yarborough
- 12.45 p.m. **Lunch**
- 1.30 p.m. **End of event**