

# 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 14<sup>th</sup>, 2018

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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 15<sup>th</sup>, 2018

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- 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  
**Vicki Wheelock**, University of California Davis, USA
- 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 16<sup>th</sup>, 2018

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- 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:** Vicki Wheelock, 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**