

**Patient organizations, health movements and medical research:  
varieties, effects and future of civil society engagement in science,  
technology development and research policies**

**Conference organized by Peter Wehling/Willy Viehöver (University of  
Augsburg), Augsburg, Conference Center Zeughaus, 10-12 May 2012**

**Thursday, 10.5.2012**

**10:30-11:00**      Welcome

**I. Introductory Session**

**11:00-11:30**      **Peter Wehling/Willy Viehöver** (University of Augsburg, Department of  
Sociology, Germany): Introduction to the workshop topics

**11:30-12:15**      **Massimiano Bucchi** (University of Trento, Italy): Democracy in the age  
of technoscience: the role of citizens' participation

**12:15-13:30**      **Lunch**

**II. Patient organizations' engagement with biomedical research and  
technology: conceptual models and empirical cases**

**13:30-14:15**      **Christel Nourissier** (EURORDIS, Rare Diseases Europe, Paris, France):  
Advocacy for research and empowerment of our 510 patient organisations membership:  
the role of EURORDIS, Rare Diseases Europe

**14:15-15:00**      **Frank Stehr** (NCL-Stiftung/NCL Foundation "National Contest for Life",  
Hamburg, Germany): Ten years of initiating and funding research into a rare and fatal  
children's disease: experiences of a German non-profit foundation. **(To be confirmed)**

**15:00-15:30**      **Coffee Break**

**15:30-16:15**      **Nadja Kanellopoulou** (University of Oxford, Centre for Health, Law and  
Emerging Technologies, UK): Patient advocacy groups as research organizations: legal  
instruments for group protection and empowerment

**16:15-17:00 Sharon Batt** (Dalhousie University, Halifax, Canada): "It takes two to PHANGO: Breast cancer activism, pharmaceutical industry and neoliberal policies in Canada"

**17:00-17.15 Short Coffee Break**

**17.15-18:00 Henriette Langstrup** (University of Copenhagen, Denmark): Patient organizations' reactions to being interpellated as future users of medical technologies

**19:30 Dinner**

**Friday, 11.5.2012**

**09:15-10:00 Stephen Zavestoski** (University of San Francisco, USA): Embodied Health Movements: contesting the Dominant Epidemiological Paradigm

**10:00-10:45 Peter Conrad** (Dept. of Sociology, Brandeis University, Waltham, MA, USA): Medicalization, the Internet and Patient Associations

**10:45-11:15 Coffee Break**

### **III. Success and failure of civil society engagement in knowledge production, technology development and research policies**

**11:15-12:00 Sabrina McCormick** (George Washington University, Research Faculty, School of Public Health and Health Services, Washington, DC, USA): The Environmental Breast Cancer Movement in the United States – a successful social health movement?

**12:00-12:45 Uta Wagenmann** (Gen-ethisches Netzwerk/Gene-ethical network, Berlin, Germany): Environmental links to breast cancer – a neglected issue in Germany?

**12:45-14:00 Lunch**

**14:00-14:45 Shobita Parthasarathy** (Gerald R. Ford School of Public Policy, University of Michigan, Ann Arbor, USA): Activist strategies in science and technology policy domains: conditions of success and failure?

**14:45-15:30 Kristin K. Barker** (Department of Sociology, Oregon State University, USA): Contested illnesses: success, failure and paradoxical effects of patient associations' struggles. The case of fibromyalgia syndrome

**15:30-16:00 Coffee Break**

**16:00-16:45 Orla O'Donovan** (University College Cork, Cork, Ireland): Europeanization of and by patients' organizations' evidence-based activism

#### **IV. Towards democratizing science and research politics through civil society engagement? Conceptual issues and future prospects**

**16:45-17:30**      **Silke Schicktanz** (University of Göttingen, Department of Ethics and History of Medicine, Germany): The troubles of representation: the legitimacy of patient organizations as political actors

**17:45-19:15**      Guided tour through to the historical center of Augsburg (optional)

**19:30**            **Dinner**

#### **Saturday, 12.5.2012**

**9:15-10:00**      **Thomas Lemke** (University of Frankfurt, Faculty of Social Sciences, Germany): Patient associations as biosocial communities? Conceptual clarifications and critical remarks

**10:00-10:45**      **Peter Wehling/Willy Viehöver** (University of Augsburg, Department of Sociology, Germany): Deliberative democracy and participatory governance of science – a challenging relation

**10:45-11:15**    **Coffee Break**

**11:15-12:00**      **David J. Hess** (Department of Sociology, Vanderbilt University, Nashville, USA): Beyond Scientific Consensus: Scientific Counterpublics, Countervailing Industries, and the Politics of Research Agenda Setting

**12:00-12:45**      **Madeleine Akrich** (Centre de sociologie de l'innovation, Mines-Paris Tech, Paris, France): Patient organizations' contribution to scientific and technological democracy

**13:00**            **Lunch (optional)**