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FROM THE EDITORS

It is with great pleasure that we bring out the first issue of the Innovia Foundation Newsletter for 2008. It has been a long time coming! This short issue is packed with a punch, not least because we get to introduce the Newsletter's new co-editor, Zoe Goldstein. She takes over from our colleague and former co-editor Claire George. Zoe is originally from the UK, recently completed an MA in Medical Anthropology at the University of Amsterdam, and has interests in mental health, new medical technologies, and non-mainstream body modification. Welcome, Zoe, to the Newsletter, and thank you for putting your time and energy into it!

In this issue, the substance of our Newsletter revolves around three pieces.

To lead off, we get to the heart of what has been on a lot of people's minds lately: a timely follow-up to Innovia's first (and very successful) gathering in Bellagio, Italy. A few months ago, we began a process of thinking through and assessing where Innovia has been, and where it should be going. We received an assortment of thoughtful contributions, and we have listened. As Stuart Blume writes in the following pages, the time is now "ripe" to incorporate our collective learning and experiences of the last five years into modes of activity and inquiry that both take up but also build upon the problems that we – you! – initially formulated. As many of you know, we are currently putting together a proposal for another gathering at the Rockefeller Foundation's Bellagio Centre, and we ask you, the readership and membership and fellows of the Innovia Foundation, to stay tuned as we begin to polish the proposal and gear up the process.

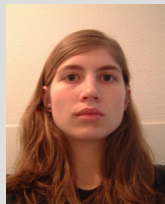
Finally, we continue our tradition of presenting to the Innovia community two of its members! Think of it as our perpetual "get-to-know-you" campaign, and a step toward accomplishing our goal of bridging the distance gap between scholars and activists around the world. Our colleagues

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Orla O'Donovan and Charles Weijer, from University College (Cork, Ireland) and the University of Western Ontario (London, Canada) respectively, are in the limelight ("spotlight" is too ominous) in this issue, and share with us their abridged professional biographies, including their involvement and interest with the Foundation and its mission. Thank you, Orla and Charles, for contributing.

You may notice a different format for the Newsletter, as well as a different file format. We are cognizant that many

Newsletter readers have had some difficulty receiving what in previous issues was becoming an increasingly large Newsletter file. Gone are the days of 8-10 megabyte files which some folks could download only with extraordinary difficulty! Back are eminently downloadable .pdf documents, which we hope you will continue to contribute to, reflect upon, and enjoy.

Thanks for your continued presence in the Innovia community, and Happy 2008!

Dale and Zoe

INNOVIA IS PLANNING A CONFERENCE

Stuart Blume

A little more than five years ago Innovia held an inaugural conference at the Rockefeller Foundation's Study and Conference Centre at Bellagio, Italy. Bringing together 23 participants from 15 countries, the conference had the overall theme of *Patient Experience and New Technologies in Health Care*. Its major purpose was to reflect on what Innovia, as a new player in the field, could and should do. Some basic principles had already been established. Innovia would aim to integrate insights and approaches from the various disciplines concerned with health and illness. It would look across the whole range of illnesses and illness-experiences. It would work cross-nationally, whilst emphasizing the dependence of illness-experiences and treatments on cultural, social, and economic conditions. Above all, and this is what made Innovia unique, was

its focus on the contribution research could make to the 'empowerment' of patients and to more equitable access to the fruits of medical advance. At the Bellagio conference we worked these principles out further. We agreed that Innovia's research should be of the highest possible scholarly standards; that it should be collaborative (across nations, or disciplines, or both); and that it would involve continuing collaboration with appropriate patient / consumer / community groups. (There is a report on the conference, written by Norma Morris and myself. It is to be found on the Innovia website, www.innoviafoundation.org).

Over the past five years we have learned a great deal about how, and on what, Innovia should work. None of it detracts in the slightest from the basic principles we established early on. We have learned, however, that our agenda has to reflect in some way the concerns of the patient movement, national and international. We have also learned that in approaching topics already attracting

substantial research attention we have to think carefully about what Innovia could add. In practical terms, we have learned that, important though research is, we need also to engage with making the fruits of research available and accessible to the patient movement and its allies around the world. This means that, in addition to research, we should engage in producing syntheses of research, and in trying to build bridges between patient/community groups and local research groups in regions where such bridges do not exist. Though hampered by a lack of financial resources we have begun to do these things.

Five years have passed, and the time seems ripe for a second conference. So we are working on a new proposal to the Rockefeller Foundation that we hope will again provide us with the opportunity of holding the conference at Bellagio. The overall theme this time will be *Prevention*. Preliminary discussion among the Innovia Fellows has identified a number of important and interesting questions that we would need to address.

There has been a shift, in the field of public health, from a 'classical' approach in which states assumed (or were expected to assume) responsibility for the health of their citizens, to an approach that stresses personal responsibility. In this new approach individuals are assumed, and expected, to 'act responsibly' in their health-related behaviour. Some commentators, in some places, argue that responsible behaviour (eating properly, exercising, not smoking, etc.) should be rewarded, deviance punished (for example by higher health insurance premiums). But how far can this go? What are the social, economic, and cultural factors that enable (or disable) 'acting responsibly' in this sense?

What is the role of patient associations or support groups (for example in the field of HIV/AIDS) in propagating ways of 'healthy living' and de-stigmatization? How does de-stigmatization enable more responsible and healthier ways of living?

Prevention of what? Clearly prevention includes, but also goes beyond, infectious disease control. What shapes the 'prevention agenda'? For example, is obesity now becoming a topic for preventive action? If so why, and how are roles and responsibilities (e.g. of states and individuals) being conceived and assigned? Given the social and cultural differences in how body weight is perceived, how far can any preventive health-motivated campaign in this area justifiably go?

Tools of prevention. The traditional tools of preventive health have included both vaccines and coercions of various kinds (including most importantly restrictions on movement). Where vaccination is required by law the two come together. Where it is not, the assumption is that perceptions of the common good or of the interest of one's child will lead to voluntary vaccination. To what extent does appeal to the common good have moral force these days? And when, where, and how should it play a role? Prenatal genetic testing is a much more recent preventive health technology. What sort of a coercive element is involved here? What does the 'common good' mean when we think about the consequences attached to genetic testing?

These are difficult and complex questions, of great importance for the future of health and health care and for the work of NGOs, including patient organisations, concerned with health equity, access, and human rights. We hope they will provide

the agenda for Innovia's second conference. You will hear more about it as plans develop. Since it is likely to be an invitational conference (accommodation at Bellagio is limited) there won't be an open invitation to submit papers. However, if

anyone is interested in working with us on planning the conference I hope you will let Zoe Goldstein (whose address is to be found on page one of this Newsletter) or myself (s.s.blume@uva.nl) know.

BIOGRAPHY:
Orla O'Donovan

It was through my involvement as both an activist and academic in Irish government health policy consultations that I became intrigued by the politics and many paradoxes of patient and public participation in healthcare decision-making. Since the 1990s there has been a rash of state-led and intensely stage-managed public consultation processes in Ireland. Despite the widespread acclamation of the "social partnership" policy paradigm for its contributions to deepening democracy (not to mention enabling the transformation of the Irish economy), my direct experiences of healthcare public consultation processes led me to see them as fraught and frustrating. For example, in 2000 despite having made a written submission, the women's reproductive rights group of which I am an active member had to struggle for inclusion in public hearings about abortion. This and subsequent struggles entailed opposing official thinking about the "authentic voice" of women and the key participants in debates about reproductive health that privilege senior medical professionals. Another example is the consultation process for a policy on women's health that took place in the 1990s, which was the focus of ethnographic research that I conducted. Despite an ostensible rationale for granting

political presence to a major women's organisation that emphasised the need to move beyond the epistemic limitations of existing policy deliberations, at best this was an "excluded presence" that reaffirmed existing institutional thinking, not least because of the state sanctioned women's health representatives' efforts to appear reasonable.

More recently, I have become interested in one of the few policy domains in which the rhetoric of patient and public participation has yet to really take hold, pharmaceutical policy. A highly secretive and scientised policy domain in Ireland and elsewhere, my research has contributed to highlighting the ways in which public health and citizens' / patients' rights to access information are compromised by neo-liberal regulatory policies that place paramount importance on economic competitiveness [1]. There is a long history of denying access to information about pharmaceutical policy-making on the grounds that it is not in the public interest; prompted by persistent pestering from mental health activists it was only in 2006 that the first (highly constrained) public hearings on Irish pharmaceutical policy took place. Discussions at these public hearings, to which I contributed, were a reminder that not only are patients denied access to "vital" information, such as the clinical trial data submitted by pharmaceutical companies in support of

their applications for market authorisation for their products, but pharmaceutical regimes generally belittle patients' experiential knowledge of drugs. Pharmacovigilance systems that require patients' accounts of the adverse side effects of medicines to be mediated by health professionals are a clear illustration of this. However, while in principle I am committed to the inclusion of patients' experiential knowledge in pharmaceutical policy-making, I am also acutely aware of the many complexities and challenges it entails and that the character of this knowledge needs to be interrogated. Of particular interest to me is the influence that pharmaceutical corporations exert on the practices and sensibilities of patients' organisations, an influence that many commentators argue has intensified with the growing funding and founding of patients' organisations by pharmaceutical corporations, and is characterised more generally as the commodification and corporate colonisation of health activism.

In 2004 I began working on a study of Irish patients' and health advocacy organisations and their modes of engagement with pharmaceutical corporations. The empirical dimension of the research involved the development of a database of 112 organisations, a survey of them, and in-depth study of a small number of organisations that manifest diverse modes of engagement with the pharmaceutical industry. This research generated evidence of a strong and growing cultural tendency in Irish patients' organisations to frame pharmaceutical corporations as allies in their quests for better health. It also cautioned against an automatic assumption that industry funding increases corporations' influence on these organisations' "cultures of action"

(a term borrowed from Maren Klawiter).

While working on this study of Irish patients' organisations during a sabbatical, part of which was spent in the Amsterdam School for Social Science Research (ASSR) in the University of Amsterdam, I had the good fortune to meet Stuart Blume and learn about the exciting works and networks of the Innovia Foundation. I chose the ASSR because of contact I had had with Anita Hardon through our membership of the NGO Health Action International, and her academic and activist interest in interrogating and promoting equitable access to and rational use of medicines. The brief few months that I spent in Amsterdam that year provided me with an opportunity to immerse myself in the writings of these and associated scholars (many of whom I subsequently came to see are involved with Innovia), writings that have helped me think in different ways about health activism and that I have incorporated into my teaching in the Department of Applied Social Studies in University College Cork.

Staying with questions about the dynamics and implications of patients' organisations' alliances with private corporations, my most recent research focuses on Alzheimer's disease organisations' (national and "Europeanised" ones) campaigns for greater access to controversial antidementia medications. It considers the tendency to understand these patient organisations' struggles for access to what are widely deemed to be "irrational" medicines by recourse to false consciousness type explanations. Not only do these explanations reflect antidemocratic sentiments, they frame the drug dispute as a battle between science and ideology, and between reason and emotion. Patient activists' knowledge and hopes about

antidementia drugs are frequently represented as having been distorted both by deceptive pharmaceutical industry drug promotion strategies, and also by the fear and distress associated with diagnosis of this much-dreaded and bewildering disease. In this work, which acknowledges the many forces that drive the assimilation of Alzheimer's disease and other forms of health activism into contemporary consumer capitalism, I am interested in exploring possibilities for respectful dialogue between actors with radically different clinical and moral assessments of particular medical technologies, and patients' rights to access them. As noted already, the work of many people associated with Innovia has been a considerable resource to me in my research.

BIOGRAPHY: **Charles Weijer**

I am a philosopher and physician with a long-standing interest in the ethics of clinical research. My first encounter with the Innovia Foundation was memorable indeed. I had written a series of articles on the ethics of the inclusion of communities in research and, as a result, Stuart Blume generously invited me to Innovia's inaugural meeting in September 2002. The Bellagio Study and Conference Centre offered an attractive setting in which to speak with and learn from the remarkable group of social scientists assembled for the meeting.

My work at the time was critical of the undue focus in the bioethics literature on individual rights, and the general failure to take account of the moral status of



I look forward to more direct communication with those who share an interest in the topics mentioned here, be it virtual or real.

Orla O'Donovan is a lecturer in the Department of Applied Social Studies, University College Cork, Ireland.

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[1] O'Donovan, O. & K. Glavanis-Grantham (2008) *Power, Politics and Pharmaceuticals. Drug Regulation in Ireland in the Global Context*. Cork: Cork University Press.

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communities [1]. As genetic research focused primarily on communities with high prevalence rates for common diseases, it became clear that this could have a substantial impact on communal social structures. If communities in research were to be protected, a novel ethical principle of 'respect for communities' was required. Ideally, researchers would enter into a partnership with the community being studied, and the community would participate in the design, conduct, analysis, and reporting of the study. While the idea met resistance initially, international codes of ethics now recognize the need to protect and empower communities in research.

More recent work has focussed on obligations owed to participants in research in developing countries. The pressing nature of the issue was brought to the fore

by the closure of a series of international studies examining use of an antiretroviral drug, Tenofovir, for the prevention of HIV in high-risk populations [2]. While participants would be provided with condoms, behavioural counselling, and treatment for other sexually transmitted diseases, advocacy groups claimed that researchers had a moral obligation to provide treatment to participants who became infected during the study. However, it is far from clear just where such an obligation might come from. In this case, HIV infection is not a research-related injury as it would not be caused by study participation. While the provision of treatment to research subjects with HIV is a worthy goal, I argue that calling it a moral obligation is not the right approach. Viewing it as a matter for negotiation between researcher and community, however, allows the community to identify its own health priorities and permits different solutions in diverse settings.

Much of my time and energy of late has been devoted to a new project that aims to broaden our understanding of medical science. For the last three decades, the engagement of bioethics with medical science has occurred along a narrow front of issues. With an exclusive focus on ethics, scholarship has left unexplored the contribution of epistemology and scientific practice to contentious issues in medical science. Funding from the Canada Foundation for Innovation allowed us to build a Science, Epistemology and Ethics Research (SEER) Lab at the University of

Western Ontario that aims to explore the interface between ethics and epistemology in science (www.seer.uwo.ca). The lab is an open-concept collaborative research space that houses two faculty, two post-doctoral fellows, and seven doctoral students with backgrounds in philosophy of science and in ethics. Though it is yet early days for the SEER Lab, through collaborative projects, reading groups, and conversations over coffee, we are beginning to map out a novel scholarly terrain.

In an important sense, my latest ventures are an attempt to recapture the intellectual excitement from discussions across disciplinary boundaries that I first encountered in Bellagio with the Innovia Foundation. I look forward to rekindling my relationship with Innovia to continue exploring the ways in which ethics and social science might show us how to better meet the ends of social justice.

Charles Weijer (pronounced VI-er) is Professor of Philosophy and Medicine, and Canada Research Chair in Bioethics at the University of Western Ontario in London, Canada.

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