



**FONDATION
BROCHER**

ABSTRACTS

(in alphabetical order)

Brocher Symposium:

**Between Policy and Practice:
Interdisciplinary Perspectives on Assisted Reproductive Technologies
and Equitable Access to Health Care**

July 6-7, 2015
Brocher Foundation
Hermance, Switzerland

Organized by:

Prof. Joanna Mishtal, Department of Anthropology, University of Central Florida (USA)

Prof. Magdalena Radkowska-Walkowicz, Institute of Ethnology and Cultural Anthropology, University of Warsaw (Poland)

Program

Day One: Monday, July 6, 2015

Part I – Morning Session (9.00-13.15):

Presentations by Invited Speakers

Disciplinary Area I: Bioethics & Law

Paweł Łuków, Ph.D., Institute of Philosophy, Ethics Department, University of Warsaw (Poland): *Assisted Reproductive Technologies. Regulation and Abstraction*

Guido Pennings, Ph.D., Bioethics Institute Ghent, Ghent University (Belgium): *Cross-border reproductive care and justice*

Karolina Więckiewicz, J.D., Polish Federation for Women and Family Planning; Warsaw (Poland): *European Court of Human Rights – developing the standards of art in the human rights dimension*

Disciplinary Area II: Sociology

Zeynep B. Gürtin, Ph.D., Department of Sociology, University of Cambridge (UK): *International Egg Exchanges: Beyond Exploitation and Consumerism*

Elżbieta Korolczuk, Ph.D., Department of Sociology and Work Science, University of Gothenburg, and Södertörn University (Sweden): *The Others, “fetal subjects” and “patients-citizens”. Reproductive technologies and citizenship in contemporary Poland*

Iva Šmídová, Ph.D., Department of Sociology, Masaryk University, Brno (Czech Republic): *Coping Strategies in Clinical Daily Chores: Gendered Provision of Health Care in the Czech Reproductive (Bio)Medicine*

11.15-11.45 Coffee / Tea Break

Disciplinary Area III: Anthropology & Gender Studies

Jill Allison, Ph.D., Faculty of Medicine, Memorial University of Newfoundland (Canada): *Enduring Politics: The culture of obstacles in legislating for ART in Ireland*

Charis Thompson, Ph.D., Department of Sociology, University of California, Berkeley (USA) and Department of Sociology, London School of Economics and Political Science (UK): *Transnational, Disability, and Reproductive Justice: Sociological Perspectives on ARTs and Equitable Access to Health Care*

Disciplinary Area IV: Health & Policy Advocacy

Anna Krawczak, M.A., President of the Society for Infertility Treatment and the Support of Adoption “Nasz Bocian” [“Our Stork”], Interdisciplinary Research Team for Childhood Studies, University of Warsaw (Poland): *Patient Monitoring in Polish Assisted Reproductive Technologies Centres: Patients' Perspectives*

Renate Kurszus, M.A., Ønskebarns. Norwegian Association for Fertility and Infertility, Oslo (Norway): *Conservative laws in a modern country*

13.15-14.15 Lunch Break

Part II – Afternoon Session: 14.15-18.00

Presentations by Symposium Participants

Bettina Bock von Wülfigen, Ph.D., Humboldt University (Germany): *Reconstructing the embryo: the new German PGD and in-vitro parenting*

Michelle Bayefsky, Pre-Doctoral Fellow, National Institutes of Health (USA): *Comparative PGD Policy in Europe and the United States and its Implications for Reproductive Tourism*

Antonietta Elia, Ph.D., University of Santiago de Compostela (Spain): *Balancing Ethics Values with Scientific Reasonableness: The Italian Law 40/2004 on the Access to Medical Assisted Reproduction in the Light of National and European Case-Law*

Mariella Hager, Ph.D., Erich Griessler, Ph.D., Institute for Advanced Studies, Vienna (Austria): *Changing direction. The Austrian struggle about how to regulate ART*

Debra Wilson, Ph.D., University of Canterbury (New Zealand): *Is A Ban On Commercial Surrogacy In The Best Interests Of The Child? Reflecting On Recently Proposed Irish Reforms*

Shirin Garmaroudi Naef, Ph.D. Candidate, University of Zurich (Switzerland): *Attitudes Towards Sex Selection: A Survey Among Iranian Medical, Legal, Philosophical and Religious Scholars*

Jenny Gunnarsson Payne, Ph.D., Södertörn University (Sweden): *Trans*forming the Fertility Patient. Egg Freezing and Transgendered Fertility Patients in Swedish Law and Policy*

Inmaculada de Melo-Martin, Ph.D., Cornell University (USA): *How Best to Protect the Interests of Donor-Conceived Individuals: Prohibiting or Mandating Anonymity in Gamete Donations?*

Atina Krajewska, Ph.D., Cardiff University (UK): *Legal issues concerning the access of single women to fertility treatment in England and Wales*

Poster Display:

Helen Allan, Ph.D., Middlesex University (UK): *The shaping of organisational routines and the distal patient in assisted reproductive technologies*

Esther Crespo, Ph.D. Candidate, University of Barcelona (Spain): *Women and partners experiences after successful Assisted Reproductive Techniques in Barcelona*

Dov Greenbaum, Ph.D., Interdisciplinary Center Herzliya (Israel): *A Novel Cause of Action to Discourage Detrimental Genetic Selection*

Sigurður Kristinsson, Ph.D., University of Akureyri (Iceland): *Surrogacy in Iceland: Legal developments and ethical issues*

Ginny Mounce, Ph.D. Candidate, University of Surrey (UK): *A longitudinal ethnographic study of couples' experiences of starting infertility treatments: early findings*

Maria Reimann, Ph.D. Candidate, University of Warsaw (Poland): *"I was with my wife all the time". Polish men's narratives of the IVF treatment*

Beatriz San Román, Ph.D., Autonomous University of Barcelona (Spain): *Assisted reproduction in Spain: between policies and practices*

Elissavet Symeonidou-Kastanidou, Ph.D., Aristotle University of Thessaloniki (Greece): *Medically Assisted Reproduction: Towards an integrated European legislation?*

Heleen Weyers, Ph.D., University of Groningen (Netherlands): *Mandatory sperm-donor registry: instrumental, symbolic or something in between?*

Tracie L. Wilson, Ph.D., Martin Luther University in Halle (Germany): *The Limits of Consensus: Ethics, Tolerance, and ART Practices in Germany and Poland*

Shawn Winsor, Ph.D. Candidate, McMaster University (Canada): *Medico-ethical Considerations Affecting Access to Assisted Reproductive Technologies (ART): Results from “The Gatekeepers’ Survey” of Canadian ART Professionals*

Auditors / Discussants:

Fabienne Imoberdorf, Ph.D. Candidate, University of Zürich

Ewa Maciejewska-Mroczek, Ph.D., University of Warsaw

Carolin Schurr, Ph.D., University of Zürich

16.15-16.45 Coffee / Tea Break & Poster Viewing

Plenary Discussion of Posters and Participants’ Papers

18.00 Dinner for all Symposium Participants and Auditors

Day Two: Tuesday, July 7, 2015 (09.00-13.00)

Brief summary by each of 10 invited speakers on the main issues that emerged from the first day and identification topics that require further discussion

11.00-11.30 Coffee / Tea Break

Plenary Discussions

13.00 Lunch

**Helen Allan, Ph.D., School of Health and Education, Middlesex
University (UK)**

*The shaping of organisational routines and the distal patient in assisted
reproductive technologies*

In this paper we comment on the changes in the provision of fertility care in Australia, New Zealand and the UK to illustrate how different funding arrangements of assisted reproductive technologies shape the delivery of patient care and the position of fertility nursing. We suggest that the routinisation of IVF technology has introduced a new way of managing the fertility patient at a distance, the distal fertility patient. This has resulted in new forms of organisational routines in assisted reproductive technologies which challenge both traditional forms of nursing and advanced nursing roles. We discuss the consequences of this increasingly globalised approach to infertility through the lens of three national contexts, Australia, New Zealand and the UK to unpack the position of nursing within the new forms of organisational routines.

**Jill Allison, Ph.D., Community Health and Humanities, Faculty of Medicine,
Memorial University of Newfoundland (Canada)**

Enduring Politics: The culture of obstacles in legislating for ART in Ireland

Assisted reproduction technologies (ART) have become a normalized part of reproductive medicine in many countries around the world. Access, however, is uneven and inconsistent, facilitated and restricted by such factors as affordability, social and moral acceptance or refusal, and local cultures of medical practice. In Ireland, ART has been available since 1978 but in spite of recommendations by a government commission and many examples where lack of clarity in the law have left families in limbo with regard to embryos, relational identities and even citizenship, ART remains unregulated by legislation. Physicians themselves have been obligated to carry the responsibility to self-regulate through their own professional licensing bodies. This creates an uncertain and untenable legal circumstance given the contested issues related to constitutional protection of the right to life of the unborn and the indeterminate legal status of embryos in vitro. This paper examines the impact of an enduring political impasse. I explore how clinical ART services in Ireland operate both inside and outside dominant institutional frameworks, meeting a pronatalist and pro-family social and political agenda while sometimes contradicting the pro-life politics that has continued to shape women's reproductive lives. The medical approaches to infertility thus intersect with the ongoing debates around abortion, the failure of the government to regulate assisted reproduction technologies, and notions of embodied motherhood and responsibility within changing meanings of family and kinship. At the same time women and their partners seek treatment with assisted reproduction technologies in other countries throughout the EU where laws differ and availability of services varies. A decade has passed since the Commission on Assisted Human Reproduction in Ireland released its recommendations; the enduring legislative vacuum leaves women and families and practitioners in potential legal limbo.

Antonietta Elia, Ph.D., University of Santiago de Compostela (Spain)
*Balancing Ethics Values with Scientific Reasonableness: The Italian Law 40/2004
on the Access to Medical Assisted Reproduction in the Light of National and
European Case-Law*

The Italian Law 40/2004 deals with the access to reproductive health care and technologies. It has been the result of a long and controversial political, social, ethical and also religious debate. Despite many voices from civil

society underlining the possible violation of access to reproductive health care and technologies, the legislative power estimated that the law was the only reasonable compromise between different and divergent interests.

However, the Italian Constitutional Court in a series of judgments had the opportunity to underline the incongruence of the law. In particular, in its judgment n. 162/2014 of June 2014, the Court, inter alia, examine if and how the contested law provided a reasonable balancing between opposite and different exigencies. One of the central point under scrutiny was the prohibition, under the law, to have access to “etero-technologies”, guarantying the reproductive health rights of parents, in cases of grave infertility of one of both of them. At the European level, the European Court of Human Rights (ECtHR) had the opportunity to deal with similar issues. The present proposal aims, inter alia, to: 1) present a general background of the Italian legal framework and its evolution in the light of Constitutional Court decisions; 2) pay attention to the Constitutional Court judgment declaring the unconstitutionality of the law 40/2004; 3) examining the contextual jurisprudential address of the ECtHR looking for similarity/divergences of view between national and European judges in relation to access to reproductive health care; 4) looking for possible modification of the national law in the light of Constitutional and International obligations of the State related to access to health care and reproductive technologies.

Michelle Bayefsky, Pre-Doctoral Fellow, Bioethics Department, National Institutes of Health (USA)
Comparative PGD Policy in Europe and the United States and its Implications for Reproductive Tourism

Unlike many European nations, the United States has no regulations for the use of preimplantation genetic diagnosis (PGD), the powerful technique employed during fertility treatment to select embryos based on their genes. As such, PGD can and is used for a variety of controversial purposes, including sex selection, selection for children with disabilities such as deafness, and selection for ‘savior siblings’ who can serve as tissue donors for sick relatives. The lack of regulation, which is due to particular features of the US political and economic landscape, has profound ethical and practical implications for patients seeking PGD around the world. This paper contrasts the absence of PGD oversight in the US with existing PGD policies in several European countries, specifically in the Switzerland, Italy, France and the United Kingdom. The primary reasons why PGD has not been regulated in the US are addressed, with consideration of factors such as varied funding schemes for ART, the proximity of PGD to the contentious issue of abortion, and the struggle of diverse, pluralistic democracies to develop just regulations on such a sensitive topic. The obstacles that would need to be overcome in the US for PGD to be regulated in the future are outlined. Then, the implications of the current divergence in PGD policy for patients around the world are discussed. Regulatory differences create opportunities for reproductive tourism, which result in legal, health and moral challenges. The paper concludes with comments on the need to balance respect for the characters and constitutions of individual countries with appreciation of the needs of infertile patients around the globe.

Bettina Bock von Wülfingen, Ph.D., Humboldt University (Germany)
Reconstructing the embryo: the new German PGD and in-vitro parenting

Until recently, German laws protecting the human embryo from the moment of conception were some of the strictest internationally. These laws had previously prevented any manipulation of the embryo, such as in pre-implantation genetic diagnosis (PGD), and continue to affect stem cell research. In 2011, however, the German parliament voted in favour of allowing PGD in specific cases. This article analyses the arguments that led to the change: while the change in the law tends to be interpreted as being in keeping with the usual norms in Germany, this article argues instead that the reasoning behind the partial acceptance of PGD, rather than the legal change itself, is indicative of a fundamental cultural change that extends to the underlying civic epistemology (Jasanoff 2005). Not only has the identity of the embryo been reconstructed towards a pragmatic concept but the notions of parenting and pregnancy have also changed. The focus on the mother and the moment of birth has given way to a focus on conception. A new concept of ‘in-vitro pregnancy’ has been introduced in Germany in which the rights of the not-yet-implanted embryo are negotiated with those of the two parents-to-be.

Esther Crespo, Ph.D. Candidate, Joan Bestard, Ph.D, Department of
Cultural Anthropology, University of Barcelona (Spain)
*Women and partners experiences after successful Assisted Reproductive
Techniques in Barcelona*

Introduction: It's assumed that pregnancy and parenthood after suffering infertility is without problems and it's rewarding. However, the literature review highlights the complexity of the psychological and social consequences of pregnancy, childbirth and parenting after successful ART (Hammarberg K & Fisher JRW, 2008).

ART have created new forms on non-genetic and/or social parenthood. How do women and couples integrate its history of infertility to pregnancy and parenthood after successful ART?

Aim: To explore the psychosocial needs of women and partners following ART.

Methodology:

Site: Hospital Clinic of Barcelona and primary care in Barcelona.

Design: Ethnography.

Subjects: 30 pregnant women and 21 couples after ART from July 2010 to April 2014.

Technical data collection: participant observation, semi-structured individual interviews, self-administered questionnaire and documentary analysis.

Analysis: ATLAS.ti

Results: Ethnography.

Conclusions: Prior studies have found that couples that achieve pregnancy after infertility may experience higher levels of anxiety in relation to pregnancy. This anxiety can be linked with higher risk of complications during pregnancy after ART compared to spontaneous conception (Pinborg et al, 2013; Davies et al, 2012; Rimm et al, 2004; Wen et al, 2012). However, a number of issues were identified. The evidence about adjustment to pregnancy and parenthood is inconclusive.

It was also suggested that parents often express concerns about the possibility that their children may suffer negative health consequences arising from the techniques. However, according to most studies regarding assisted reproduction and neurodevelopment outcomes of the child, we know that there is no increased risk of mental disorders or cognitive, behavioural, socio-emotional deficits, and psychomotor development in children after ART (Bay, Mortensen & Kesmodel, 2013). There is a gap between the evidence available on studies around infertility and care focused on women and their partners during pregnancy after ART (Allan H, 2007).

Dov Greenbaum, Ph.D., Interdisciplinary Center Herzliya (Israel), Yale
University (USA)

A Novel Cause of Action to Discourage Detrimental Genetic Selection

Amit Shoval, Danielle Hornstein, Sara Weinberger, Sharon Nakar, Zvi Meiter Institute for Legal Implications of Emerging Technologies, Radzyner Law School, Interdisciplinary Center Herzliya (Israel),
Tzofia Cates & Dov Greenbaum, Ph.D., Zvi Meiter Institute for Legal Implications of Emerging Technologies, Radzyner Law School, Interdisciplinary Center Herzliya (Israel), Molecular Biophysics and Biochemistry, Yale University (USA)

With current technologies, putative parents have unprecedented opportunities to select one or more genetic characteristics for their next generation. But, as we continue to tease out genetic and/or epigenetic basis of more diseases, conditions and traits, we raise ever-more complicated ethically and morally questionable options in selecting against and/or for particular traits. In particular, what ought to be the litmus test, if any, in deciding which genetic disorders are "bad enough" to select against and what genetic conditions ought to be positively selected for? Particularly troubling are instances wherein parents might select a seemingly objectively disabling trait. For example, individuals from the deaf, high-functioning-autistic, dwarfism, and other non-typical communities, who might take particular pride in their condition, might employ ART to select for an embryo that will result in a child who is similarly disabled, an option still legal in most jurisdictions.

Currently, a child born from such a situation has little legal recourse: in many countries reproductive autonomy is a basic human right. However, parental rights vis-à-vis their children are not absolute and children ought to be

protected from the possibly misguided and potentially even capricious, whims of their parents. The wrongful life cause of action (available in very few jurisdictions) provides little deterrent for parents and their physicians to make very poor reproductive choices as the very philosophical and legal contortions necessary to effect this option limit its usefulness. In its stead, we argue for a “wrongful selection” cause of action. This cause of action would be useful for children whose parents egregiously, maliciously or perhaps even negligently selected for a trait that has a detrimental outcome for the child. We outline the legal ethical and social concerns that need to be addressed to create this possibility to protect future generations.

**Shirin Garmaroudi Naef, Ph.D. Candidate, University of Zurich
(Switzerland): *Attitudes Towards Sex Selection: A Survey Among Iranian
Medical, Legal, Philosophical and Religious Scholars***

This paper focuses on the recent debates over sex selection in Iran, where sex selection for both medical and non-medical reasons is allowed and is available in several leading infertility and IVF clinics under specific circumstances. Based on my extensive ethnographic research on assisted reproductive technologies in Iran which includes an examination of the normative arguments, I provide an overview of legal, ethical and religious arguments relating to the availability of sex selection methods, such as preimplantation genetic diagnosis (PGD) and sperm sorting, and their social implications. Although there are opposing arguments to the use of sex selection for non-medical reason, other arguments are in favour of permitting sex selection for a specific purpose, such as family balancing.

**Jenny Gunnarsson Payne, Ph.D., School of Historical and Contemporary
Studies, Södertörn University (Sweden)
*Trans*forming the Fertility Patient.
Egg Freezing and Transgendered Fertility Patients in Swedish Law and Policy***

In October 2012, *the American Society for Reproductive Medicine* (ASRM) published a report saying that technologies of egg freezing should no longer be considered experimental. In the literature, “social egg freezing” refers to the phenomenon whereby women freeze their eggs for other reasons than purely medical (i.e. to delay reproduction). This is contrasted to “medical egg freezing”, that is, fertility preservation that is practiced, for example, as a preventive measure before a woman is undergoing cancer treatment. Less visible in the public domain is the specific form of medical egg freezing that concerns people undergoing gender transition. In the Swedish context, a recent law change removing a previous demand for sterilization as a compulsory part of gender corrective surgery, however, has meant that Swedish fertility clinics have faced a new patient group – the transgender fertility patient.

Building on policy documents and interviews with medical doctors, this paper seeks to shed light on the very process by which claims for reproductive rights through access to reproductive technologies, and new laws and policies that are formed as a result of such right claims become ‘translated’ in the constitution of a new patient category, and a new care chain to suit these specific needs. In addition to the empirical aim of this paper – which is to document the constitution of this new category of fertility patients which is made possible because of the recent developments in egg freezing, as well as processes of social and political change – this paper seeks to raise more general questions pertaining to issues concerning the relationship between reproductive rights, reproductive technologies, law and policy.

Zeynep B. Gürtin, Ph.D., Department of Sociology, University
of Cambridge (UK)
International Egg Exchanges: Beyond Exploitation and Consumerism

This talk seeks to map the contemporary social and ethical implications of international egg exchanges. Drawing on existing empirical data by a range of researchers, particularly from the UK and the US, and engaging with ethical analysis, particularly as promoted by Professor Stephen Wilkinson in his book *Bodies for Sale*, the paper tried to elucidate the aspects of egg exchanges that require our urgent and rigorous attention. By identifying and categorizing different kinds of practices that currently exist within a broad and largely undifferentiated international market, and briefly considering the different opportunities and challenges generated by each, the paper argues that the current vernaculars around egg exchanges often obfuscate rather than illuminate the issue. The goal is not to offer a simplistic prescription for best practice, but rather to illuminate the proliferating means by which eggs are acquired and exchanged, and to enable reflection on the potential consequences of these for global inequalities and policy making.

Mariella Hager, Ph.D., Erich Griessler, Ph.D., Institute for Advanced
Studies, Vienna (Austria)
Changing direction. The Austrian struggle about how to regulate ART

Austria from 1992 until 2015 had a very restrictive Reproductive Medicine Law that prohibited a number of ART treatments such as, e.g., egg donation, PGD, heterologous sperm donation for IVF/ICSI as well as general access to ART for same sex couples. As a consequence of this rather prohibitive law, Austrian physicians active in the area of ART cooperated with or had daughter institutes in countries with less restricting legal regulations such as the Czech Republic and Slovakia, which are only a few hours' drive away. A more liberal reform of the Reproductive Medicine Law was for a long time blocked by the fierce and seemingly unresolvable struggle between permissive social democrats and restrictive conservatives, a division which also mirrored in the respective recommendations of the Austrian Bioethics Commission to the Federal Chancellor. Only this year the gridlock, which lasted over decades, was dissolved in favor of a more liberal Reproductive Medicine Law that permits egg donation, PGD in some cases and heterologous sperm donation also for IVF/ICSI and lesbian couples. ART treatments for single women and surrogate motherhood are still prohibited. The new Reproductive Medicine Law is heavily criticized by the Catholic Church, by some conservatives as well as by disability associations. The paper will present the political positions taken before and after the reform and will outline the effects of the former restrictive law, which resulted in open medical tourism. The paper is based on an extensive empirical study on the use of ART in Austria "Genetic Testing and Changing Images of Human Life" funded by the Austrian Genome Research Program GEN-AU).

Elżbieta Korolczuk, Ph.D., Department of Sociology and Work Science,
University of Gothenburg, and Södertörn University (Sweden)
*The Others, "fetal subjects" and "patients-citizens". Reproductive technologies
and citizenship in contemporary Poland*

Our reproductive experiences are shaped by and are reflective of ideological, sociopolitical and economic trends. Contradictory views on human reproduction which circulate in society, influence political debates and regulations as they become part of "emergent national styles of reproductive governance" (Knecht, Klotz and Beck, 2012: 12). These debates involve the negotiations of right claims and terms of belonging, as well as the formation of new political subjects. Thus, there is a need to examine the field of assisted reproduction through the lens of the contemporary scholarship on citizenship, which has been rarely done so far.

In my presentation I will discuss the ways in which citizenship identities are discursively constructed in the debate on infertility and in vitro fertilization (IVF) in Poland. I analyze the rhetoric strategies of the main social actors: the representatives of the Catholic Church, conservative politicians, and the people experiencing infertility. The specific questions to be answered concern how institutional actors construct discourses on citizenship in relation to infertility and IVF and how people active in the Association for Medical Treatment of Infertility and Supporting Adoptions "Our Stork" construct and negotiate their citizenship status from below. The analysis draws on a variety of texts published in print and electronic media between 2007 and 2014. These include articles on infertility and ARTs published in main Polish dailies and weeklies, online resources such as "Our Stork" web page, forum and facebook page as well as documents issued by the representatives of the Church, e.g. open letters, commentaries, information for the media, and interviews. Additionally, individual interviews with "Our Stork" activists were conducted.

Atina Krajewska, Ph.D., Cardiff Law School, Cardiff University (UK)
Legal issues concerning the access of single women to fertility treatment in England and Wales

The purpose of this article is to evaluate the extent to which single women (SW) gained and secured access to fertility treatment after the amendments introduced by the HFE Act 2008. It claims that despite the fact that great progress has been made in removing gender inequalities in the area of assisted reproduction in England and Wales in recent years there are points in the regulatory framework that still allow for discrimination against SW. Contrary to many commentaries, the paper argues that it is not the interpretation or the implementation of s 13(5) HFE Act per se that has the potential to hinder access to fertility treatment for SW. Rather it is the tension between different levels and aspects of governance: a) the HFE Authority's code of practice (COP), b) NICE clinical guidelines, and c) CCGs and Health Boards' resource allocation policies that should be seen as the primary reason for any remaining inequalities. The paper argues that current regulation does not go far enough in acknowledging SW's impossibility to conceive naturally, but at the same time that it struggles to address the fluidity of contemporary familial relationships. The paper provides a detailed analysis of the problematic areas in the regulatory framework of fertility treatment, focusing on NICE guidelines and rationing decisions of individual CCGs and health boards. The analysis presents an opportunity to contribute to debates about the role of law in shaping the scope of reproductive autonomy, gender equality, and social justice.

Anna Krawczak, M.A., Director of Patients Association for Infertility Treatment and Adoption Support Our Stork; Interdisciplinary Research Team for Childhood Studies, University of Warsaw (Poland)
Patient Monitoring in Polish Assisted Reproductive Technologies Centres: Patients' Perspectives

Currently there is no legislation regarding ART procedure in Poland and no system of accreditation or control over ART centres is installed. Therefore, patients undergoing ART procedures act on the basis of civil contracts signed with ART centres. Since 2006, Polish state's actions have remained on the level of political discourse and lack real action. In 2013, the National Health Programme of IVF Reimbursement was accepted and installed by the Ministry of Health, which slightly normalised IVF treatment socially. Nevertheless, patients remain unprotected in terms of safety of treatment, even though some of them get a chance of free therapy. Therefore, Patient Association for Infertility Treatment and Adoption Support *Our Stork* introduced in 2014 the project called „patient monitoring of Polish ART centres” to check and describe how the situation of infertile people looks in a lawless environment. The project started with a general questionnaire among patients aimed to understand patient's expectations, opinions and experiences. Based on 722 questionnaires and the *Guidelines for counselling in infertility - ESHRE 2001* as well as other documents, a document titled „Patients recommendation in infertility treatment” was prepared. 37 Polish ART centres adopted the „Patients recommendations” into their

practice. Then, in the second part of our project we sent seven well-trained teams, consisting of one former patient and one non-patient, to ART centres to analyse civil contracts and their correctness in the context of patients' rights, as well as to interview doctors, midwives and patients to get the objective picture of infertile patients' care. Consequently, we observe and describe the infrastructure of ART centres, including arrangement of examine rooms, psychological care, and the semen examination procedures. The goal of the project is to empower patients' voice through the central monitoring report, which will be presented in the Polish Parliament in autumn 2015. Our initial conclusion is that even though Polish ART market has existed since 1987 and achieved a reasonable quality in terms of pregnancy rates and medical standards, there is still a lack of patient-oriented approach among doctors and medical staff in Poland.

**Sigurður Kristinnsson, Ph.D., School of Humanities and Social Sciences,
University of Akureyri (Iceland)**
Surrogacy in Iceland: Legal developments and ethical issues

ART-surrogacy is currently prohibited by Icelandic law. In recent years, however, surrogate motherhood has received increased discussion and debate in Iceland. Infertile couples have sought transnational surrogacy in India and the United States, despite uncertainties about legal parental status as they return to Iceland with infants born to surrogate mothers abroad. In some such cases, the Icelandic parliament has granted these infants citizenship. At least one court case has been announced, demanding recognition of parental status based on the child's rights and interests.

In January 2012, the Icelandic Parliament passed a multi-partisan resolution to the effect that the Ministry of Welfare should appoint a working group to prepare legislation that would make altruistic ART-surrogacy legal in Iceland, subject to strict regulation and oversight. One of the stated aims of this initiative was that clear regulation of surrogacy in Iceland would reduce evasive travel. In February 2015, the working group submitted a complete proposal for a new law on altruistic surrogacy, which may now be presented in Parliament.

This paper will describe the main features of this new legislative proposal, including definitions, the rights and interests of the child, surrogate mother, and intended parents, process and oversight, conditions to be fulfilled by applicants and how they are assessed, counselling requirements, transfer of parentage, and procedures for preventing, handling and settling disputes. Key ethical issues will be discussed, including the distinction between altruistic and commercial surrogacy and the distinction between gestational (full) and traditional (partial) surrogacy. Special attention will be paid to the question whether and how this legislation is likely to affect evasive surrogacy travel.

**Renate Kurszus, M.A., Ønskebarns. Norwegian Association for Fertility
and Infertility, Oslo (Norway)**
Conservative laws in a modern country

The Norwegian law is strict. Treatment abroad is common. Travelers circumvent the Norwegian legislation, thereby providing Norway several challenges the current legislation has neither taken account of, or has practice dealing with.

It is a paradox that treatments considered medically and ethically responsible in a number of our neighboring countries do not meet the same acceptance here. I argue that the knowledge in Parliament when it comes to infertility and egg-donation is poor. I experience that the common politician is not particularly keen to acquire knowledge on the topic, and instead of seeking advice from patient organizations they keep arguing against, bringing their personal religious beliefs to the debate. Some of the representatives do represent a conservative Christian belief, stating the mother can only be the person carrying the child. That person must have biological strings to the child.

When I point out that a law against egg donation will not stop people wanting a child, but rather seek abroad for treatment I rarely get answers. The response is that Norway can't allow egg donation only because the alternative is going abroad. It leaves me to believe that politicians think it is not their problem. It leaves people struggling with infertility to feel quite discriminated.

The debate about egg-donation has been going on for years, but we have failed to conclude. It seems impossible to take the debate from a yes or no debate, to the next step; investigating how it could be implemented in the current treatment. Debates tends to focus on the welfare of the child, as if the welfare of children conceived with this treatment abroad is worse than a biological born child. This depicts childless people as a group that does not have the welfare of the child in mind.

Paweł Łuków, Ph.D., Institute of Philosophy, Ethics Department,
University of Warsaw (Poland)

Assisted Reproductive Technologies. Regulation and Abstraction (draft)

There are two types of argument appealed to in most ethical and legal debates about regulation of ARTs. One, usually offered in support of ARTs, is based on individual rights. It assumes that individuals have a right to shape their future according to their beliefs. Accordingly, if a person believes that having children is an essential part of her or his life projects, she or he should have access to technologies which can help her or him to achieve her or his goals. The other type of argument, usually critical of ARTs, discusses the moral status of the human embryo or fetus and appeals to the principle of life protection. On this argument, since the fetus is a (potential) human being, it must be protected in the way in which born humans are protected, and so ARTs are permissible only if they do not endanger the life of the embryo or fetus.

These are very abstract approaches. They seem to assume that consideration of rights or the value of human life can help us decide how the use of ARTs should be regulated. I will argue that in a pluralistic society these approaches must be inconclusive because they tend to neglect central aspects of human life and parental aspirations. Although the law must be abstract, and so regulation of ARTs cannot directly address substantive views of a good life, the debate on ARTs must give up abstraction. One of the key features of abstraction in moral and legal discourse is that it makes human aspirations, interests, needs, and values invisible. I am going to argue that public debates which are to result in regulation of ARTs must address human lives in their concreteness and, in particular, they must articulate those moral goods which are at stake for particular people, embedded in their narrative concreteness, who consider the use of ARTs. I will offer an argument in favor of ARTs which relies on an analysis of the worth of parenthood. On the basis of these conclusions I will also delineate some elements of the boundaries, which need to be included in any plausible regulation of ARTs.

Inmaculada de Melo-Martin, Ph.D., Weill Cornell Medical College,
Cornell University (USA)

How Best to Protect the Interests of Donor-Conceived Individuals: Prohibiting or Mandating Anonymity in Gamete Donations?

Anonymous gamete donation continues to be practiced in most jurisdictions around the world. Indeed, in some countries such as Spain, France, and Denmark, the anonymity of donors is explicitly protected by legislation. This practice, however, has come under increased scrutiny. Thus, several countries including Sweden, Austria, Switzerland, the Netherlands, Norway, the United Kingdom, New Zealand, and Finland, as well as the Australian states of Victoria and New South Wales now mandate that donors be identifiable to their genetic offspring. A significant reason for the current trend towards legislation prohibiting anonymous gamete donations is the belief that donor-conceived individuals have a fundamental moral right to know their genetic origins and that such moral right should be legally protected by policies that prohibit anonymous donations. Proponents of a right to know one's genetic parentage usually argue that such a right protects at least three vital interests of donor-conceived individuals: their interest in having strong family relationships, their health interests, and their interest in forming a healthy identity. These vital interests are presumably respectively protected by different aspect of the right to know: knowing one's mode of conception, accessing medically relevant information, and accessing identifying information about one's genetic parents. In this presentation I first discuss each of these interests, examine what they amount to, and explore whether and how they might be set back by an individual's lack of access to information about his or her genetic parentage. I then evaluate legislation in countries that

prohibit anonymous gamete donations and in those that mandate anonymous donation so as to assess the ways in which these different legislations might or might not protect these vital interests.

Ginny Mounce, Ph.D. Candidate, School of Health Sciences, University of Surrey (UK)

A longitudinal ethnographic study of couples' experiences of starting infertility treatments: early findings

Ginny Mounce*, Helen Allan[#] and Nicola Carey*.

(*School of Health Sciences, University of Surrey, UK; [#]School of Health and Education, Middlesex University, UK)

This study investigates the experiences of couples seeking medical assistance in their desire for biological children. Infertility is a complex social experience for couples, which evolves over time and with differing circumstances. Unlike previous research around this topic, this study utilises a longitudinal ethnographic design with a prolonged data collection period of 18 months (March 2013 to September 2014).

Fourteen (14) couples took part in the study. Data were collected at the first medical encounter and then after any subsequent consultations. Therefore data collection involved repeated rounds of observation (22) and interviews (22) with the same participants, facilitating an iterative process to inform and refine analytic ideas as they emerged. The researcher, as participant observer, attributes cultural meaning to the couples' experiences and uses field notes to reflect on other senses, to fully embody inquiry in the field. The philosophy of interpretative phenomenology informs the analysis of interview data; with the aim of uncovering subjective lived experience at each point.

Initial thematic analysis of the interview transcripts was undertaken. Expressions of infertility 'as a journey' were common, and the initial medical consultation can be considered like a 'junction box' on this journey. The junction box offers several alternative possibilities but is not always helpfully configured and may in fact sometimes be the cause of unexpected delays. Significantly the junction is situated in a wide social and political landscape, which is a prism through which couples' perceive the relevance of this junction – and medicalisation - in their own journey.

Guido Pennings, Ph.D., Bioethics Institute Ghent, Ghent University (Belgium)

Cross-border reproductive care and justice

Cross-border reproductive care (CBRC) is a large phenomenon in Europe and worldwide with thousands of patients moving to other countries to obtain infertility treatment. These movements raise several aspects related to justice and policy.

The presentation will focus on two aspects. Firstly, it is well-known that one of the main reasons for cross-border movements is law evasion. People are leaving their home country because they are denied access to treatment. These groups are very diverse and so are the reasons for excluding them. We will scrutinize the criteria for access to medically assisted reproduction and the exclusion of certain groups such as lesbian couples and older women. The important question here is how we are supposed to decide whether certain restrictions are justified. The second issue is the matter of financial access and costs of medically assisted reproduction in different countries. There are huge differences between countries regarding reimbursement of ART treatment. Many people seem to assume that this diversity violates the principle of equitable access to reproductive care. However, this depends on the status of infertility within the taxonomy of diseases. Is infertility a disease and, if so, should it be included in the package of decent health care? The principle of justice only applies when infertility treatment is part of decent health care.

CBRC can only exist when there is diversity in legislation and practice across countries and regions. The question is whether harmonization of legislation and practice is a desirable evolution or not. Several reasons for maintaining diversity are discussed. Related to this last aspect, some discussion on the position of the European Court of Human Rights will be included.

Maria Reimann, Ph.D. Candidate, Institute of Ethnology and Cultural Anthropology, University of Warsaw (Poland)

“I was with my wife all the time”. Polish men’s narratives of the IVF treatment

In vitro fertilization technology has been in use in Poland for almost 30 years, but until today the law does not regulate all its aspects. Even though public support for the method is rather high, the public debate on in vitro fertilization is extremely heated and the arguments are very often of non-substantive nature. The omnipresent right-wing discourse not only stigmatizes the practice of in vitro fertilization as “murdering embryos”, but also stigmatizes the children who were born with the use of the method as “monsters”. The discourse is disseminated to the public not only through the media, but also through the Sunday masses and religion classes in schools. In this atmosphere, Polish infertile couples still decide to pursue the desire to become parents with the use of IVF technology, and Polish infertility clinics have high rates of success in treatment.

This article is an analysis of in-depth interviews with 12 men whose partners underwent the IVF treatment. Men are not subjects of the public debate, which focuses on the embryos and the female bodies. Their role in the IVF treatment seems axillary. The aim of the article is to shed light on the male experience and understanding of infertility and its treatment.

Beatriz San Román, Ph.D., AFIN Research Group – Universitat Autònoma de Barcelona (Spain)

Assisted reproduction in Spain: between policies and practices

Diana Marre, Ph.D., Beatriz San Román, Ph.D., Bruna Alvarez, AFIN Research Group – Universitat Autònoma de Barcelona (Spain)

At the beginning of 2015, one of Spain’s most important newspapers referred to the Spanish “fecundity toboggan”(Ansede 2015). Spain’s total fertility rate has declined since 2,8 children per woman in the mid 70s, when Spain was a place where foreign people adopted children, to 1,14 in 1995 and 1,32 in 2012. While Spain has been classified as a country with a *lowest-low fertility rate* (that is, TFR at or below 1.3; Kholer et al. 2002: 643), since the mid-90s a large number of people have had children through some kind of assisted reproductive technologies, including transnational adoption and commercial surrogacy. This apparent contradiction between low fertility rates and the increasing number of families formed or enlarged by adoption, surrogacy and other NRTs can only be understood in the context of an “structural infertility” (Marre 2009). On the other hand, these new reproductive strategies raise questions about what can and cannot be considered work and the risks and rights for those involved.

Elissavet Symeonidou-Kastanidou, Ph.D., Faculty of Law – School of Medicine, Aristotle University of Thessaloniki (Greece)

Medically Assisted Reproduction: Towards an integrated European legislation?

Despite the common European values, each European country has not adopted a common and binding position on the matter. Notwithstanding these different approaches, convergences can be found, so that the impact of the problems that have arisen can be kept to a minimum.

Our research includes:

- The identification of the key points of current legislature regarding methods of assisted reproduction and protection of the genetic material in specific European countries (Sweden, Germany, France, England, Ireland, Italy and Greece).
- The recording of case law, which has been created during the past 15 years.
- The recording of the opinions on the matter of the Heads of the Bioethics Committees of these countries, of the Heads of National Agencies of MAR, of scientific societies or groups of citizens and of the Heads of Centers of Assisted Reproduction.
- The collection and study of the relative bibliography, all associated decisions and reports, by the Bioethics Committees or the National Agencies of MAR.

Our research deals with issues, which affect directly the life and health of individuals, as well as the social cohesion and national economy, matters for which the search for convergences seems to a much greater degree attainable.

The Proceedings of the Congresses organized by our research team and the research team's final proposals are going to be delivered to the Council of Europe, to the European Commissioner of Justice, Fundamental Rights and Citizenship, to the President of the European Parliament, to the National Agencies of Medically Assisted Reproduction as well as to the President of the Greek Parliament.

Iva Šmídová, Ph.D., Department of Sociology, Masaryk University, Brno
(Czech Republic)

Coping Strategies in Clinical Daily Chores: Gendered Provision of Health Care in the Czech Reproductive (Bio)Medicine

There is an ambivalence among Czech medical professionals to changes in the provision of health care in the field of reproductive medicine. Access to health care as well as its provision is strongly gendered and influenced by a lengthy transformation process from state paternalistic to a consumer based one. The focus of the paper is on the question of what kinds of influence the position of doctors and their hierarchy of rule have on patient care. The paper thematises the level of professionalism of the care provided and/or available, relations among the key stakeholders and the national systems of health care provision influencing the specific status quo. It explores limits and challenges of the individual representatives of the powerful medical profession, based on their position in the hospital hierarchy, clinical seniority, location and size of their hospital, and gender. A debate on particular policies, initiatives and their effects needs to be framed and contextualised by the conditions for structural changes of existing practices in the respective cultural and organisational contexts, and the specific forms of resistance to them deserve a closer analytical attention, too, as they affect the care provided. Empirical evidence from the Czech context indicates that coping strategies of the involved actors are sometimes not more than a call of a drowning clinical person catching at a straw.

Charis Thompson, Ph.D., Department of Gender and Women's Studies,
University of California, Berkeley (USA) and Department of Sociology,
London School of Economics and Political Science (UK)

Transnational, Disability, and Reproductive Justice: Perspectives on ARTs and Equitable Access to Health Care

ARTs are often thought about from three perspectives that make it hard to integrate them into scholarship on health equity: from an experimental biomedical point of view, in terms of breakthroughs in the treatment of

infertility or any of IVF's biomedical spin-offs, including stem cell research; in terms of individual narratives of infertility, especially in an era of postponed childbearing and single and LGBTQI parenting in the West, and lack of access and affordability in less well resourced countries where childlessness may be both common and highly stigmatizing; from a highly critical point of view, focused on ethical evils such as the exploitation of the women (and some men) who are third parties to ARTs through providing gametes and wombs for the reproductive projects of others, and eugenics. These perspectives on ARTs—biomedical, individual, ethical—are vitally important but they don't fit easily with health equity agendas, such as how to prevent infertility, how to make treatments accessible to all, and how to monitor for and be proactive regarding long-term health effects and eugenic trends. In this paper, I draw on scholarship and activism to bring together four approaches to ARTs that, if they were developed together, could begin to bridge the gap between ARTs and health equity. They are: the continued development and deployment of low cost ARTs; adopting a post-Cairo version of global reproductive rights; insisting on a reproductive justice framing; and insisting on a disability justice framing. With these perspectives in place, it is possible to argue for developing an intra- and inter-country tracking registry that would collect data on access and affordability and roles in ART as they co-vary with poverty, ethnoracial identity, sexual orientation, employment, citizenship status, disability, gender, nation, and trait selection. Such ARTs health equity data could inform policy needs.

Heleen Weyers, Ph.D., Department of Legal Theory, University of Groningen (Netherlands)
Mandatory sperm-donor registry: instrumental, symbolic or something in between? A comparison of laws

Since the eighties, several European countries have adopted the position that anonymous sperm donation in clinics should be illegal. The aim of these laws is to meet the right of the child to know ones genetic origins. In my paper I will compare some of these countries (at least Sweden, Austria – the countries which first made donor registry obligatory – and the Netherlands – the country I am most familiar with). My research questions regard the black letter laws and the effectiveness of the law. For example with respect to the first: What is the goal of the law? Which interventions are used to achieve these objectives? How can children obtain donor information? And regarding the latter: Do parents inform their children on their conception? How many children feel the need to know something about the donor? Do they get what they are looking for? My provisional conclusion is that the laws are quite similar in goals and chosen interventions but nevertheless differ considerably in nature. And although the laws penetrate deeply in the private life of parents and donors, there is little interest for the effectiveness of the laws. Furthermore, more research into the ultimate goal of the laws (right of the child/best interest of the child) is needed to know in which way the laws should be improved.

Karolina Więckiewicz, J.D., Polish Federation for Women and Family Planning; Warsaw (Poland)
European Court of Human Rights – developing the standards of art in the human rights dimension

There have been several judgments and decisions regarding IVF ruled by the European Court of Human Rights (hereinafter: the Court).

They come from different countries (United Kingdom, Austria, Italy, Romania) and deal with a number of issues regarding infertility treatment.

Most of the cases fall within the scope of article 8 of the Convention on the Protection of Human Rights and Fundamental Freedoms (hereinafter: the Convention). Majority of alleged violations in the plaintiffs' individual cases were claimed on the ground of the restrictions in respecting their family and private life. It was seen from different perspectives – in terms of making decisions about becoming or not becoming parents (Dickson vs.

United Kingdom), possibility to use donated eggs or sperm (S.H. and others vs. Austria), possibility for pre-implantation diagnosis of embryos (Costa and Pavan vs. Italy) or the way clinics secure patients' interests (Knecht vs. Romania). In some cases the Court had to deal with the allegation of violations of article 14 which prohibits discrimination (S.H. and others vs. Austria), in some also an alleged violation of the right to life (article 2 of the Convention) was discussed (Evans vs. United Kingdom). The Court therefore needed to decide about the wide range of issues that are connected with infertility treatment.

Although some findings of the Court may be in a way disappointing, in some cases the Court found violations of article 8 (or ruled why there were no violations) and by this set up some standards regarding legislation and practice that is in accordance with the Convention. It is especially important for countries that still have not adopted any laws or want to make them up to the highest human rights standards.

Most cases ruled by the Court refer to the restrictions in domestic regulations regarding entitlement and possibilities to use IVF in certain situations, some of the also are a chance to look at the IVF laws and practices from the point of view of protection of patients' interests as well as the legal 'status' of an embryo.

**Debra Wilson, Ph.D., School of Law, University of Canterbury
(New Zealand)**

***Is A Ban On Commercial Surrogacy In The Best Interests Of The Child?
Reflecting On Recently Proposed Irish Reforms***

In February 2015 the Irish Health Minister announced that new legislation would soon be introduced in order to ban commercial surrogacy. The main justification for this reform was to ensure that "the welfare of the child is paramount". Such a prohibition on commercial surrogacy can also be found in other jurisdictions, with similar justifications given.

Using the recent Irish announcement as a catalyst for discussion, this paper will consider and evaluate justifications for banning commercial surrogacy, and ask whether such a prohibition could actually achieve the objective of holding the welfare of the child paramount. It will begin by considering cases in which the increasingly blurred distinction between commercial and altruistic surrogacy has become apparent, before addressing the obvious practical consequence to such a prohibition under domestic law: international surrogacy tourism. This paper will argue that a desire to cling to traditional distinctions like 'commercial' and 'altruistic' surrogacy not only fails to recognise that these terms have become nearly indistinguishable in practice, but also that the distinction in itself is arguably inconsistent with an approach claiming to be focussed on the best interests of the child. The best interests of the child are more appropriately served by ensuring that the legal and ethical issues resulting from international surrogacy arrangements are addressed. If these issues are the logical result of a prohibition on commercial surrogacy, then the distinction between commercial and altruistic surrogacy should be abandoned.

Surrogacy reform can only truly be useful and fulfil its stated objectives if the practical realities and consequences of surrogacy are understood and accepted.

Tracie L. Wilson, Ph.D., Martin Luther University in Halle (Germany)
***The Limits of Consensus: Ethics, Tolerance, and ART Practices in Germany and
Poland***

This paper examines ethical and legal aspects of assisted reproduction policy and practices in Germany and Poland. Germany is among the most restrictive countries in the European Union with regard to ART. In Poland, in contrast, despite vocal opposition to IVF from conservative Roman Catholic activists, most practices are unrestricted. In this case, it is rather a lack of clear laws addressing ART that shapes practices. Germany and Poland differ significantly regarding cultural narratives and historical experience that impact attitudes toward

reproduction. In Germany, discussions on assisted reproduction often invoke concerns about medical intervention in ethically complex matters due, in part, to the country's Nazi past. In addition, the widespread practice of cross border reproductive care (CBRC) demonstrates that there are extensive transnational connections and that policies in one country may impact practices and CBRC trends found in other accessible, but less restrictive countries.

Shawn Winsor, Ph.D. Candidate, Department of Clinical Epidemiology and Biostatistics, McMaster University (Canada)

Medico-ethical Considerations Affecting Access to Assisted Reproductive Technologies (ART): Results from “The Gatekeepers’ Survey” of Canadian ART Professionals

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Objective: To identify the degree of consensus on medico-ethical issues among professional staff and students at Canadian fertility clinics.

Design: The Gatekeepers’ Survey included 14 patient scenarios involving assisted reproductive technology (ART). ART professionals were asked to indicate for each scenario if they would allow or refuse treatment, or provide conditional access to treatment. Scenarios included medical, social and legal issues. All responses were anonymous although some demographic information was requested (but not required).

Setting: The survey was distributed to ART professionals and students attending the Gatekeepers’ Dilemma Symposium (Toronto, May 2013), as well as being sent by email to members of the Canadian Fertility and Andrology Society (CFAS) (December 2013).

Main Outcome Measures: Responses were collated and analysed by profession, gender, age, and survey source using SigmaPlot 12.5.

Results: There were 134 completed surveys from (among others) 39 physicians, 27 embryologists, 20 fertility counselors, and 19 fertility clinic nurses. Almost 90% of all respondents indicated they would provide unconditional access to ART to lesbian or gay couples or to individuals (either sex). Over 80% had some reservations or would refuse access to a patient with an addiction to prescription drugs or alcohol; 50% would refuse access to patients who regularly use marijuana. The suggested maximum age for female patients (own eggs or egg donors) ranged from < 40 to 56 years. The most frequently cited upper limit for body mass index was 35 (range: < 30 - 40). Fifteen percent of respondents indicated that if it were legal, they would enable sex selection of embryos.

Discussion: There was near consensus among our sample of respondents regarding unconditional access to treatment for gay, lesbian and single patients. All other scenarios elicited a range of responses, even those that are currently illegal in Canada or that have acknowledged increased obstetric risk. Our findings indicate that patients’ access to ART in Canada may be influenced by the prevailing norms of professional staff at the fertility clinic they choose to attend.