



ESHRE Patient Leader Forum



International Consumer Support for Infertility

## **Global principles for assisted conception and infertility: A patients' rights charter**

The ESHRE Patient Leader Forum (EPLF) links patient leaders and health professionals around the world to discuss patient and consumer needs. The EPLF aims to provide opportunities for patient leaders and health care professionals to work in partnership to address government policy barriers to accessing affordable, safe health care.

The vision for the International Consumer Support for Infertility (iCSi), a network of patient leaders from 39 countries, is to empower patients to become full partners in ART healthcare and public policy by building effective relationships with providers, governments and media world-wide.

The EPLF/iCSi coalition acts as a global voice to government as well as medical, mental health authorities, industry and the media. iCSi coalition members act as a national voice in their respective countries to bring the needs of people who benefit from ART to public awareness.

### **The EPLF/iCSi coalition:**

- Remains committed to assisting all men and women experiencing infertility, including those in lesser developed countries and those living in poorer socio-economic conditions in developed countries, in their quest to fulfil their family building dreams;
- Respects not only the importance of their commitment to their own countries but also contributes to international cooperation and collaboration to advance infertility understanding, options and compassionate support globally;
- Encourages heightened investment in research into infertility causes including environmental factors and the disease burden in developing countries due to poor obstetric care;
- Provides compassionate support to men and women experiencing infertility as they deal with not only the physical aspects of their journey but also the serious emotional and financial impacts;
- Respects religious and cultural diversity;
- Is a signatory to the Patient Centred Healthcare Declaration of the International Alliance of Patients' Organisations (IAPO);
- Is represented on the United Nations NGO Health Committee.

### **The EPLF/iCSi coalition holds the following principles and practices as essential to the rights of all experiencing infertility:**

1. As infertility has been recognised by the World Health Organisation (WHO) as a public health issue, affecting tens of millions of people worldwide, it should be universally recognised as a medical condition or disease, which causes suffering.
2. Assisted Reproductive Technologies (ART) are standard, proven treatments for infertility and should be reimbursed in each country's national health scheme.
3. People experiencing infertility should have equity of access to high quality health care services, focusing on the best and most recent scientifically and clinically approved guidelines.

## **Global principles for assisted conception and infertility: A patients' rights charter (cont.)**

4. People experiencing infertility should expect to receive open and honest communications from professionals who, through their own continuing education, maintain their knowledge of the most scientifically advanced and proven medical and emotional care available and in the instance of adoption professionals, the latest and most accurate information on laws and rules governing adoptions.
5. People experiencing infertility must have access to practical information about all their family building options, including clinical alternatives, domestic and foreign adoptions and approaching life without children.
6. People experiencing infertility must have access to comprehensive and understandable information about all aspects of diagnostic tests and treatments, together with their relative risks. They should also have access to their personal medical records: their confidentiality must be protected and their distribution must be guided with patient consent.
7. Infertility does not discriminate by race, gender, culture, faith or ability to pay and our health care systems must not discriminate against those with the condition by denying them access to appropriate and necessary high quality care.
8. Infertility remains a highly stigmatised medical condition that can lead to depressive illnesses. Therefore, the physical treatment of the patient must be accompanied by the availability of counselling and support services to help address the psychosocial impacts of the medical condition/disease.

People experiencing infertility should be encouraged and supported to take advantage of professional and peer-led support groups as research has demonstrated these outlets contribute measurably to wellbeing.

9. Decisions to use donor gametes, donor embryos or surrogacy, where permitted, are multi-faceted; incorporating medical, legal, ethical, social, emotional and psychological aspects. Clinics should not only inform couples of the medical diagnosis and treatment but also provide through counselling the opportunity to explore in detail with the couples and the donors, all the issues that the use of donated material and surrogacy necessarily raises. Donors should be open about their medical and genetic history and be tested for transmissible diseases.

Where donor gametes, donor embryos or surrogacy are used, the resulting children's interests must be acknowledged and the basic principles of openness and honesty should apply; that the donor-conceived individuals and those born through a surrogacy arrangement have a right to information about their biological origins. While it is acknowledged that not all individuals will be made aware of their donor conception (for religious, cultural, social and/or psychological reasons), parents should be provided with information and guidance with regard to informing their children about the use of donor gametes in their conception.

Where surrogacy arrangements are permitted, to provide certainty for the child as to his or her parentage and remove the need for the intended parents to adopt their child, a mechanism should exist for the intended parents and the surrogate to apply to the Courts for a parenting order to recognise the intended parents as the legal parents.

Whilst acknowledging the donor-conceived individual's right to have access to and knowledge of their donor, legislation in some countries does not provide for this. Thus in the event that the identity of the donor is requested, that donor should have an opportunity to explore the implications of revealing his identity. Where donors have donated on the understanding that they would remain anonymous, their consent should be required to provide identifying information to offspring. Preferably, donors should donate in the knowledge that identifying information about them will be available to the child when he or she reaches 18 years.

10. The physical and emotional health and well being of all children conceived via assisted reproductive technologies (ART) or acquired through adoption is of paramount importance and should be assessed via government-supported longitudinal research to confirm the continuing efficacy and effectiveness of assisted therapies.
11. The quality of care provided by those offering assisted reproductive technologies and associated counselling services should be monitored by nationally recognized accrediting agencies, which should include patient representatives, under established, evidence-based guidelines and where an appropriate accrediting body exists, with the direct participation of consumers.
12. Meaningful nationwide and practice-based clinical statistics regarding infertility treatment outcomes must be disclosed to the public in an understandable, transparent and comparable manner for inter and intra country comparisons.
13. Infertility can be influenced by a variety of known risk factors such as smoking, alcohol and substance abuse, obesity, age and sexually transmitted diseases. Public preventative education must be supported to help preserve fertility and reduce the impacts of unhealthy lifestyle behaviours and decisions.