**Written contribution to the draft General Comment on Science and economic, social and cultural right on *the right to enjoy the benefits of scientific progress and its applications***

**(Art. 15: 15.1.b, 15.2, 15.3 and 15.4 of the ICESCR)**

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**Science and Right to Health**

**Introduction**

The criteria for regulating and funding biomedical scientific experimentations and applications must consider all those researches and results that can protect and promote scientific progress in the treatment of serious diseases in order to guarantee the primary interest of patients and future generations of Mankind.

**Embryonic stem cells**

Scientific evidences show that the research on embryonic stem cells is among the most promising frontiers to find cures for several types of severe diseases through regenerative therapies.

So States should not forbid but encourage also the research on embryonic stem cells.

**The threat of heritable diseases**

About 8000 monogenic diseases are known and each individual, often without knowing it, is a carrier of various mutations that can cause a genetic disease and to date some hundreds of millions of people worldwide are affected by heritable genetic diseases, perhaps more than one person on twenty.

Today, fortunately, the new medical advances sometimes allow people affected by a hereditary disease which reveals itself (or which anyway revealed itself) at young age to live (longer) and have a healthier life and this often allows them also to get to have children. Thank to research, in the future, this will be even more true, and for an increasingly number of hereditary diseases. Obviously all that is a good news but this also means that harmful genetic variants are and will be always passed to children and therefore (also) to future generations.

So, due to medicine, natural selection is and will be missing in human species. This will have serious consequences, especially in the long term. Indeed the harmful genetic mutations inevitably accumulate in the absence of the natural selection, because harmful mutagenic events occur more frequently than beneficial ones. So, considering all that, about those (many) hereditary diseases whose onset occurs (or may also occur) before or during the usual reproductive period of the individual's life, it is more than predictable that, moreover, their incidence in the human population over the generations will tend to increase so that more and more people will need important therapies. Also the birth rate of very unfortunate children who will experience multiple hereditary diseases and the necessary related multiple therapies in their life is very likely to increase. The incidence of heritable diseases could even up to a "point of unsustainability" for human species.

This principle apply to heritable genetic diseases and, in a similar way, to some chromosomal diseases.

**Pre-implantation genetic analysis and “mitochondrial donation”**

Nuclear genetic and chromosomal diseases can be prevented respectively with pre-implantation genetic diagnosis and screening whereas mitochondrial DNA related diseases can be prevented through mitochondrial replacement techniques (MRTs), better known to public like “mitochondrial donation”. MRTs are the only concrete possibility available to date able to prevent the transmission of mitochondrial DNA related diseases from mother to her children and from her daughters to future generations. MRTs have already successfully passed both basic and preclinical trials. Not only. Some of them have already been tested in the clinic leading to the birth of children. Although there are very few cases, these children are all healthy.

So States should not forbid but encourage both the pre-implantation genetic analysis and the mitochondrial replacement techniques in order to prevent inheritable diseases.

**Germ-line genetic modification through genome editing**

Unfortunately, about nuclear DNA, pre-implantation genetic analysis of embryos (on its own) has limits that do not always make it sufficient or useful to deliver a "healthy" child and, in any case, a child not carrier of a dangerous genetic or chromosomal variant inherited from her\his parents and, in turn, transmissible to her\his future children.

However, if appropriate basic research were carried out on human “fertilized oocytes”, zygotes, very early embryos and precursor stem cells of the gametes one day predictably it may become possible to modify the human genome sequence in hereditary way with safety and efficacy.

These inheritable genetic treatments for hereditary diseases would prevent the disease for all the descendants. That would avoid having to cure and heal people for each generation, something of which, moreover, there would be need more and more.

So States should not forbid but encourage such research.

However this must be confined in the laboratory for now. Indeed both a long phase of improvement with basic and preclinical experimentations and a social and ethical deep debate will be needed before these inheritable treatments can be implemented in clinic.

Only after that society could decide to apply the results of such research in the clinic to reduce the incidence of hereditary diseases.

A strong regulation will be also required both to avoid abuse on human person, who must always be protected, and discrimination between riches and poor and people from different countries. In particular three things will be very important. First, there will have to be no coercion in these techniques but future parents should be able to freely choose them. Second, no ethnic purpose will have to be permitted. Third, the results of all these researches will have to be shared among the people and to benefit the entire world population.

**The need**

For all the reasons said above, to introduce a new paragraph in the section V. of the General Comment on the “Human Right to Science” is necessary:

**Science and Right to Health**

***In the field of biomedicine, States must allow and promote all scientific research and relative results applications which, performed with respect for dignity, freedom and safety of the human person, have as their ultimate purpose the health of human individual and species, aiming to cure, heal, prevent and eradicate any disease, pathology or disability that afflicts Mankind, both as regards present and future generations.***