

news release

For Immediate Release: 18/04/07

Rapporteur abuses power whilst patients are left without treatments.

EGAN and its members are increasingly concerned with the way the rapporteur entrusted with the Proposed EU Advanced Therapies Regulation (COD/2005/0227), Miroslav Mikolášik, has been carrying out his duties. The progress of a triologue between the rapporteur and shadow rapporteurs, the European Commission and the European Council was halted on 29th March at an extremely late stage due to a sudden decision by Mr Mikolášik. This triologue was designed to engineer a package of technical amendments to the regulation, to be voted on “on block” at the plenary stage. Acceptance of this package by MEPs at the plenary stage would have resulted in a first reading adoption for this regulation, leading eventually to the earlier delivery of novel, much needed treatments. The decision by the rapporteur to insist on including extremely controversial ethical amendments in the compromise package amounts to sabotage of the possibility of a first reading adoption.

In justifying his obstructive position, the rapporteur describes his actions as “defending human dignity”. EGAN represents millions of European citizens with incurable and/or untreatable conditions who look toward treatments that would be facilitated by this regulation with hope and expectation. Any delay in the introduction of this regulation leads to delays in the delivery of treatments. The dignity of the millions of patients that EGAN represents is being compromised further with every delay.

If all of the amendments supported by the rapporteur are adopted, the eventual result would be a *de facto* ban of many treatments that currently hold the greatest potential. This ban would be effected by contradictions between the rapporteurs amendments, (which would prevent the central licensing of therapies derived from embryonic stem cells, amongst others), and other regulations, (already ratified), that do require central licensing of drugs for the treatment of HIV and cancer, such as the Tissue and Cells Directive 2004/23/EC. This potential outcome is an extremely distressing prospect for the millions of patients that EGAN represents.

“This move by the rapporteur, cynically delaying the possible adoption of this amendment is the latest of many Machiavellian moves by Mikolášik. The fact that he describes his actions as in the interest of preserving human dignity is laughable. He can’t have considered the lives of the patients we support.”
Alastair Kent, President of EGAN.

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Notes to Editors

- EGAN is the European Genetic Alliances' Network, an alliance of national genetic alliances and European disease specific patient groups with a special interest in genetics, genomics and biotechnology. EGAN works for a voice in research and health policy and seeks a world in which genetic diseases are understood, effectively treated, prevented and the people affected supported.