



*Making life better for people
affected by genetic disorders*

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news release

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**HFE Bill needs to be fair to all patients. MPs must not create inequalities
for families most in need.**

The Genetic Interest Group, the UK patient organisation for all those affected by genetic disorders, urges MPs not to go back on the decisions already made in the HFE Bill. The Bill which is entering the report stage in the Houses of Parliament on 22nd October, must reflect the views and opinions of patients and families affected by inherited disorders.

Alastair Kent, Director stated, "*Hundreds of hours of consultation have gone into the HFE Bill and many patients affected by genetic conditions have expressed their views and opinions. These have been listened to and are reflected in the current draft of the Bill. There is however a real danger that last minute amendments to the HFE Bill will limit its ability to help patients and families, limiting treatments and research possibilities into lethal conditions. Research for those with children whose lives will be drastically shortened, some not living beyond 5 years, is the only hope of helping so that others in years to come may not have to face such an untimely death*".

The current bill enables new and evolving areas of research to be carried out. MPs should not be distracted, or waver from their commitment to support patients and families with life limiting diseases as the Bill nears the end of its time in the House of Commons.

Progress is threatened by amendments put forward by those opposed to this developing field of research which promises hope of many life saving therapies

The current bill has support from medical research charities and patients support groups as well as medical researchers and clinicians and a substantial majority of the general public.

- Ends -

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Notes to Editors

- The Genetic Interest Group (GIG) is a UK national alliance of organisations with a membership of over 130 charities that support children, families and individuals affected by genetic disorders.
- GIG's primary goal is to promote awareness and understanding of genetic disorders so that high quality services for people affected by genetic conditions are developed and made available to all who need them.
- GIG is asking MPs to **oppose amendments that will harm child health, No 36** which bans bone marrow transplants from “saviour siblings” and to **oppose amendment Nos 56 – 66** which will prevent parents from consenting for their children to donate genetic material for embryonic research into their condition.
- GIG is also asking MPs to **oppose amendment 74** which will damage research into serious disease.

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