
NEWS RELEASE

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NHS reform; will it deliver equity and excellence for families with genetic conditions?

The Department of Health [White Paper, Equity and Excellence: Liberating the NHS](#) was released on Monday 12th July. The White Paper proposes one of the most radical restructures of the NHS in its history.

Alastair Kent, Director says, “We will be keeping a close eye on the policy detail which will be released over the coming months. Many of the principles outlined are vague. The genuineness of the principles will need to be demonstrated in practice if patients and citizens are to trust that the changes are to be real and paramount, and move the NHS in the direction stated as desirable”.

Genetic Alliance UK has some concerns, including how the GP commissioning consortia will link with other levels of commissioning and also the linkages between the new consortia and the devolved nations. We would also like further detail on how providers of care on different levels, from those working locally to specialists, will be empowered to work in a coordinated way to provide integrated, multidisciplinary care. There was, however, much to welcome in the White Paper as long as the principles outlined are backed up by detailed plans which are implemented effectively to make real improvements for patients affected by genetic disorders. Some of the points we welcome include:

- The retention of national and regional commissioning, which will come under the remit of a new NHS Commissioning Board. We would like more detail on these arrangements and await the further publication due to be launched this month
- The commitment to shared decision making and the recognition that it results in a better quality of care
- Reductions in inequalities in care
- Increased patient access to information, including increased control over their records and more information on research
- Integration of health and social care and creating a system that works more effectively across boundaries
- The recognition that research is vital in order to identify new ways of preventing, diagnosing and treating disease.

We will be scrutinising the papers outlining the restructure in more detail and we will be responding to the relevant consultations.

The White Paper is available at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353



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Notes to Editors

About Genetic Alliance UK

Genetic Alliance UK is the national charity of over 130 patient organisations, supporting all those affected by genetic conditions.

Supporting

We seek to raise awareness of genetic conditions and improve the quality of services and information available to patients and families.

Campaigning

We actively campaign on issues of policy and practice to influence governments, policy makers, industry and care providers such as the National Health Service.

Uniting

We provide a united voice for all those affected by genetic conditions, enabling us to work together towards a common goal of making life better for patients and families at risk.

As an organisation focusing on issues of policy and practice Genetic Alliance UK keeps an active watch on developments in the UK and Europe that will influence the effective transfer of knowledge and understanding into products and services for families that are supported by our member groups.

In a potentially controversial field like genetics Genetic Alliance UK provides a strong voice advocating the benefits of scientific progress in understanding the contribution being made now and that will be made in the years to come for improving health and combating many currently incurable diseases.

For more information please go to www.geneticalliance.org.uk

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Genetic Alliance UK
Supporting. Campaigning. Uniting.

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