

# The Cooksey Review



## A response from the Genetic Interest Group

---

The Genetic Interest Group (GIG) is a UK-wide alliance of organisations with a membership of over 130 charities which support children, families and individuals affected by genetic disorders. Its 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 the only UK organisation of its kind.

The Genetic Interest Group welcomes this consultation and we are pleased to give our views.

In contributing to this consultation from the perspective of the patients and families that make up our member groups, we have no authority to comment on either technical aspects of this consultation or the infrastructure of agencies delivering the new funding. We have not answered the consultation questions, instead we present our favoured scientific and health objectives that we believe can be delivered by this funding opportunity.

### **Basic Scientific Research**

In representing patients and families affected by incurable or intractable rare conditions, our organisation is well aware of the value of basic science research. This is often the only avenue of hope available for patients with conditions that are currently poorly understood. Basic research that can benefit under-researched conditions, especially those that are complex and/or rare, should be enabled and allowed to thrive.

This work should be supported by a well structured mechanism for the transformation of success in the research arena into innovative products; and their subsequent safe, appropriate, and expeditious delivery to patients.

The UK is currently a world leader in the field of biomedical research, we should endeavour to maintain this position; particularly in the exciting fields of genetic research and stem cell research, in which the UK holds a competitive advantage over many countries.

### **Orphan Medicinal Products**

We note that the BioIndustry Association (BIA), in their response to this consultation, have emphasised the importance of research and development in relation to rare disorders, and highlighted the success of orphan medicinal product legislation implemented by the European Commission five years ago.

We believe the UK has the potential to build on its academic, clinical and commercial expertise in this area; and as such consolidate its position as a world leader in genetic and biotech research with the aim of producing applications to meet serious unmet medical needs.

The Genetic Interest Group commends and supports the BIA's submission in this respect.

### **Conclusion**

The Genetic Interest Group would urge that the needs of patients with rare diseases that are serious, chronic, or life-limiting, be given a higher priority than currently appears to be the case.

The UK has a long tradition of undertaking high-quality biomedical research; but it is perceived to be poor at translating this into products to serve those that need them. If the new single fund for

health research is to deliver sustainable benefit to the UK, a mechanism for ensuring new knowledge can be efficiently converted into clinical service delivery in the NHS, needs to be addressed.

We would be happy to expand further on any of the issues discussed above.

A handwritten signature in black ink that reads "Alastair Kent." The signature is written in a cursive, slightly slanted style.

**Alastair Kent**  
**Director**

Tel: 020 7704 3141  
Fax: 020 7359 1447

Genetic Interest Group  
Unit 4D, Leroy House  
436 Essex Road  
London N1 3QP  
Registered Charity Number 803424