

WELCOME

# from Gene People's Chair of Trustees

Dear Colleagues,

Innovative research is delivering more opportunities to create disease modifying interventions for increasing numbers of patients

living with serious, chronic and often progressive rare genetic conditions. Yet it is by no means a foregone conclusion that these interventions will reach those who need them. The NHS, alongside every other health service across the globe, is struggling to create a framework for the allocation of constrained resources where demand far outstrips capacity and opportunity.

Against this background the voices of patients and families are increasingly influential in informing health care decisions. While the rise of an independent patient voice is welcome, decisions are informed by evidence and an understanding of how innovative ideas become health gain. Equally, innovators must appreciate the importance of patients' experiences, insights, and priorities for their ideas to truly address the unmet health need of patients and families and be commissioned.

Nowhere is this more important than in the case of rare genetic and life limiting conditions.

Gene People has created a forum where representatives from the corporate sector and the rare genetic disease community can meet regularly to share ideas, explore possibilities, and inform actions through the creation of mutual understanding and the building of trust.

I invite you to join us and play a part in creating a vibrant community of ideas and action which will help ensure that those living with rare genetic conditions can benefit from the speedy access to innovations in the NHS and elsewhere.

Alastair Kent OBE FRSA
Chair of Trustees

Gene People

### VISION FOR THE CONNECTION

The world is changing. The health and social care system, processes and institutions are changing. The emphasis on genomics is increasing. The need to engage with patient organisations is increasing. The need for the health industry, its supporting service companies, regulators and condition-specific support groups to work together to tackle the big issues facing the genetic conditions' community is vital. Otherwise, the momentum created by all these various changes, innovations and improvements will be lost to the detriment of this often-overlooked community.

This is where the Gene People Corporate Connection comes in.

The Gene People Corporate Connection cements our emphasis on improving the lives of those affected by genetic conditions. There is simply too much to be done alone so we are inviting likeminded, action focussed organisations to band together in our Corporate Connection.

### WHY JOIN US?

Gene People has a well-established Partnership Network of patient groups and organisations, ranging from household name charities to volunteer-only groups. All are expert in the conditions experienced by their communities. Our Partnership Network Advisory Panel informs and shapes the work of Gene People. We will facilitate exchanges of views on key issues that impact both patient organisations and industry.

There are so many opportunities for our community amongst this operating environment that is flexing and morphing at speed. For us, the time to achieve real change is now.

Whilst your company as a partner in the Corporate Connection will receive several advantages, the Gene People Corporate Connection is a movement for change. You will make a true difference to the lives of those affected by genetic conditions and benefit from:

- Collaborating to improving the lives of those affected by genetic conditions
- Access to a wide variety of condition-specific support groups in a Code compliant way
- Brand awareness for your company
- Discounts on and early access to other opporunities.

### PARTNERSHIP BENEFITS

### Working with Gene People

- Gain insights from our community on a regular basis through meetings with Gene People's CEO
- Explore opportunities to work together on white papers, consultation responses and other projects

### General public awareness

- New Corporate Connection partners welcomed on public-facing social media channels including relevant company handles and logo
- Partnership Network made aware of new Corporate Connection partners through the Partnership Network Newsletter and private social channels
- Logo featured on Gene People website in a dedicated Corporate Connection section
- Items of interest to the public to be shared on Gene People's public-facing social media channels

### Early access to sponsorship opportunities

 Corporate Connection partners receive early notification of sponsorship opportunities at least 21 days prior to non-partners

### Sharing Patient-focused news

 Links to online web items will be shared to the Gene People Partnership Network through the Partnership Network Newsletter and private social channels

Recognition in Gene People's annual report and accounts



# PARTNERSHIP CONTRIBUTIONS

Organisation sector	Organisation size	Partnership contribution
Biotech and Pharmaceutical Companies	Start-up OR Basic research OR 1-250 staff	£5,000
	Clinical research & development OR 251-1000 staff	£10,000
	Licensed therapies OR 1001+ staff	£15,000
Service Providers	1-250 staff	£5,000
	251-1000 staff	£10,000
	1001+ staff	£15,000
Trade organisations	N/A	£5,000

Please note that at the time of writing Gene People is not registered for VAT.

### **APPLICATION FORM**

All partners in the Gene People Corporate Connection agree to support the Gene People aims and objectives and the terms of reference for the Corporate Connection shown in the following section. Please select the sector and size that best represents your organisation.

Organisation sector	Organisation size	Partnership Contribution	Please select
Biotech and Pharmaceutical Companies	Start up OR Basic research OR 1-250 staff	£5,000	
	Clinical research & development OR 251-1000 staff	£10,000	
	Commercially approved therapies OR 1001+ staff	£15,000	
Service Providers	1-250 staff	£5,000	
	251-1000 staff	£10,000	
	1001+ staff	£15,000	
Trade organisations	N/A	£5,000	

Authorised by:
Job title:
Organisation:
Email:
Date:
I understand that by ticking this box I am consenting to my information being stored and used by Gene People for the purposes of the Gene People Corporate Connection.

## GENE PEOPLE CORPORATE CONNECTION TERMS OF REFERENCE

The Gene People Corporate Connection has been created to form and develop a positive collaborative relationship between leaders in the healthcare industry and their support organisations, health and social care system, and patient advocates. The Corporate Connection seeks to contribute to a work programme that will improve the lives of those affected by genetic conditions.

The ABPI Code of Practice rules will apply. The Connection will operate under the Chatham House Rule unless explicitly decided otherwise on a case-by-case basis.

### BECOMING A CORPORATE CONNECTION PARTNER

To become a partner in the Gene People Corporate Connection, organisations should complete the form in this brochure. The Gene People Team will review the application and may contact you for additional information. You will be asked to supply your logo, if you have one, when your application is approved. Payment of the annual partnership contribution is required before participation in the Corporate Connection can begin.

### **OBLIGATIONS**

The Corporate Connection is formed to advance the work of Gene People to improve the lives of those living with genetic conditions. The following obligations form the expectations on participating companies.

- Corporate Connection partners should endorse the aims and objectives of Gene People
- Corporate Connection partners should not bring any party in the Corporate Connection into disrepute
- Corporate Connection partners should provide details at least one contact and preferably two and commit to informing Gene People of changes in a timely manner to facilitate the smooth running of the Corporate Connection
- Corporate Connection partners commit to actively participating in and contributing to the Corporate Connection.

Please note that nothing in these Terms of Reference is intended to, or shall be deemed to, establish any legal partnership between the parties or legal membership of the charity. Gene People remains wholly independent with the Board of Trustees being the legal members of the charity.

#### CONFIDENTIALITY

The programme of work conducted by the Gene People Corporate Connection should be treated as confidential. Meetings are conducted under Chatham House rules unless agreed in advance with attendees. Where public communication forms part of an activity the communication will not make any one contributor identifiable without their express permission. Anything that is shared within the conduct of the Gene People Corporate Connection should be treated as confidential.

#### DATA PROTECTION

Individuals give their consent to Gene People using and storing their data when they complete the application form. All data will be processed in line with Gene People's Privacy Policy available on our website: www.genepeople.org.uk.

### **CONFLICTS OF INTEREST**

Gene People protects its reputation and only works with organisations that do not expose it to disrepute or reputational risk. Any organisation that exposes Gene People to such risks will be removed from the Corporate Connection.

### SOLICITATION

The Corporate Connection will enable collaboration and deepening of working relationships. However, Corporate Connection partners from service companies should not use their participation in the Corporate Connection to directly approach other partners. If such solicitation takes place please refer to Gene People for investigation.

### TERMINATION OF PARTICIPATION

Please note that participation in the Gene People Corporate Connection is at the discretion of Gene People and can be withdrawn at any time. Similarly, partner organisations can terminate their participation in the Corporate Connection at any time or may decide not to renew their participation. Refunds will not be given on partnership contributions already paid. Gene People reserves the right to terminate the Gene People Corporate Connection. In all circumstances, early communication is requested.

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