



GENE PEOPLE Leadership Symposium 2022



New: Genetic conditions in a (hopefully) post-pandemic world



Delegate brochure

4 and 10 November 2022, 13:30 – 16:30. Virtual event



GENE PEOPLE

Leadership Symposium

2022

Welcome!

Welcome to the Gene People Leadership Symposium 2022! I am delighted that you are joining us for two afternoons of stimulating and informative speakers. They will cover a wide range of topics, some focused on genomics, treatments and data, others considering topics about the wellbeing of our teams and ourselves, legislation affecting our organisations and communities, and more.

I will be indulgent, if I may, and take this opportunity to acknowledge some people and organisations.

Gene People is a small organisation with large ambition to match the scale of needs and aspirations of the genetic conditions community. Thanks are due to the Gene People team, and our Board of Trustees who have been generous with their time and connections. From me to you, thank you!

Thank you to all the speakers and facilitators taking part in this event. Without you and your enthusiasm there simply would be no event.

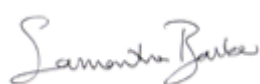
The Symposium has been supported by The Adelphi Genetics Forum and the Association of the British Pharmaceutical Industry. In addition, Rare Revolution Magazine has been a generous media partner for the event.

We are grateful to PTC Therapeutics for their support of the Best Research Partnership award category in the first ever Gene People Awards.

The scale of effort taken to produce the Symposium reflects the vast ecosystem that works with, and for, people living with genetic conditions. That, to me, seems appropriate.

Enjoy the Symposium. We do hope you will find it beneficial.

Many thanks.



Samantha Barber MA MSc FRSA



[Samantha Barber](#)
Chief Executive, Gene People

Why our event is different

The Gene People Leadership Symposium has always had a blend of celebration, science and practicality. This has been appreciated by the organisations and individuals that have attended in previous years, and this year's event will retain that unique mix.

Charity and not-for-profit speakers, big and small, have been approached to talk about topics relating to the operational side of running patient organisations. Industry and regulators have also been invited to talk about what is new in their work, such as the Innovative Medicines Fund, changes to NHS genetics services, and the advances made in diagnosing, treating and managing genetic conditions.

The genetic condition professional community will be celebrated during the Gene People Leadership Symposium 2022, in the inaugural Gene People Awards. Gene People is delighted to celebrate and acknowledge incredible work in the genetic condition sphere through the Gene People Awards.

As well as the usual speaker and panel sessions, there are genuine opportunities for delegates to network, through sessions focused on different, important industry topics. These sessions will give delegates the chance to meet people interested in that topic and forge new connections. This is complemented by three 'thinking sessions', where delegates will come together between events to contribute to the post-event report.

The Gene People Leadership Symposium 2022 post-event report will outline the key messages and themes from sessions. This will create a lasting legacy for the event.



Programme

Gene People Leadership Symposium 2022: Day One (4 November 2022)

Time	Event
13:30 – 13:40	Welcome and housekeeping Prof Bill Newman (Conference Chair) will introduce the first session of the Gene People Leadership Symposium Day One and will give the housekeeping notes for the day.
13:40 – 14:10	Keynote speaker: Dolores Cvitičanin (Public Affairs Manager, Rare Diseases International) <i>The #Act4Rare Toolkit: Implementing the UN Resolution on “Addressing the challenges of persons living with a rare disease and their families”</i> Genomic medicine has the potential to achieve faster, more accurate diagnoses and drive better, more targeted treatments for patients. To do this, scientists and clinicians need access to vast amounts of clinical and genomic data. In this keynote, Maria will talk about how Lifebit’s Platform is enabling secure, rapid sharing of this data, working with organisations like Genomics England and Boehringer Ingelheim to accelerate scientific discoveries and ultimately improve patient outcomes.
14:10 – 14:15	Coffee break Recharge your cup and to find out some of the nominees for the Gene People Awards 2022.
14:15 – 14:20	Welcome back and instructions for breakouts All delegates will return to the main session to hear the instructions for the breakout sessions.
14:20 – 14:45	Breakout events Breakout A: Sanford CoRDS Registry and NCBRS Worldwide Foundation: A case study Sanford CoRDS Registry is a global registry for all rare diseases/conditions. This session will provide more insight into the Registry and how NCBRS Worldwide Foundation is working with them to stimulate research into this ultra-rare condition. Speakers: Alyssa Mendel, Sanford Health, and Nuala Ryan, NCBRS Worldwide Foundation Breakout B: Preparing for Rare Disease Day 2023 Rare Disease Day on 28 February each year is a great opportunity for charities to work together and raise awareness of the challenges facing people living with rare, genetic and undiagnosed conditions and their families. Next year’s campaign will focus on the need for better coordination of care, and this session will help you to make the most of awareness-raising opportunities for your community before, during and after the big day. Speaker: Louise Fish, Genetic Alliance UK
14:45 – 15:15	Panel discussion. The IMF: An Opportunity for Patients The Innovative Medicines Fund (IMF) opened in June 2022. Amongst other things, it is a primarily a managed access scheme for non-cancer medicines that need additional data collection to inform decision makers on whether the medicine should be used routinely in the NHS. This session will set out the principles of the IMF and the respective roles and interaction of the organisations and sectors represented by the three speakers. Speakers: Nina Pinwill, NHSE, Thomas Strong, NICE, and Paul Catchpole, ABPI

Programme

Gene People Leadership Symposium 2022: Day One (4 November 2022)

Time	Event
15:15 – 15:25	Coffee break More nominees for the Gene People Awards will be announced, and you can grab a tea or coffee.
15:25 – 15:30	Welcome back and instructions for breakouts All delegates will return to the main session to hear the instructions for the breakout sessions.
15:30 – 15:50	Breakout events Breakout C: Wellbeing and Values-based Work When we work or volunteer in an organisation that aligns with our values, the work we do can become part of our identity, sometimes leading to overwork and, ultimately, burnout. Find out more and how to avoid this with Dr Esther Murray. Speaker: Dr Esther Murray CPsychol, Reader in Health Psychology Breakout D: Three treatments, one disease This breakout session will focus on how three revolutionary treatments have changed the disease landscape for Spinal Muscular Atrophy (SMA) over just six years, and what the impact of this has been on the wide and varied SMA community. Speaker: Portia Thorman, Spinal Muscular Atrophy UK
15:50 – 16:20	Keynote speaker: Prof. Jackie Hunter Naylor (Benevolent AI) In this talk Prof. Jackie Hunter will explore how artificial intelligence and machine learning technologies are empowering scientists to identify novel drug candidates that are anticipated to have a higher probability of clinical success than those discovered using traditional methods. She will also provide an overview of BenevolentAI's transformative drug discovery platform which consists of products and tools that allow scientists to ask and answer complex biomedical questions, run insilico experiments and advance hypotheses in real time.
16:20 – 16:30	Thank you and close Led by Prof Bill Newman will wrap-up today's session and outline the Thinking and Networking Sessions taking place before the Day Two of the symposium

Programme

Gene People Leadership Symposium 2022: Day Two (10 November 2022)

Time	Event
13:30 – 13:40	Welcome and housekeeping Prof Bill Newman (Conference Chair) will introduce the first session of the Gene People Leadership Symposium Day Two and will give the housekeeping notes for the day.
13:40 – 14:10	Keynote speaker: Dr Maria Chatzou Dunford (Founder, LifeBit) <i>Using data to help people with genetic conditions</i> Genomic medicine has the potential to achieve faster, more accurate diagnoses and drive better, more targeted treatments for patients. To do this, scientists and clinicians need access to vast amounts of clinical and genomic data. In this keynote, Maria will talk about how Lifebit's Platform is enabling secure, rapid sharing of this data, working with organisations like Genomics England and Boehringer Ingelheim to accelerate scientific discoveries and ultimately improve patient outcomes.
14:10 – 14:15	Coffee break Recharge your cup and find out some of the winners of the Gene People Awards 2022.
14:15 – 14:20	Welcome back and instructions for breakouts All delegates will return to the main session to hear the instructions for the breakout sessions.
14:20 – 14:45	Breakout events Breakout A: Pharma insight research The results of the Pharma Insight Research project are rich and point the way for shaping how condition-specific support groups can work with industry. Samantha will take you through the headlines ahead of the publication of the report. Speaker: Samantha Barber, Gene People Breakout B: Charity law update including the Charities Act 2022 Join Hannah Kubie, Head of Charity & Social Enterprise Team at Stone King, for an overview of the new Charities Act 2022, the current regulatory priorities for the Charity Commission and more to help you stay on top of the latest developments and keep compliant. Speaker: Hannah Kubie, Stone King LLP Breakout C: The importance of videos, and the right videos This session focuses on the importance of using videos in getting your messages across, and why video is becoming increasingly important. Chris will cover what they are for, how we might use them, the types we might make, how we might make them, and the need to be relatable, correct and supported. Speaker: Chris Chinn, Bioscientifica
14:45 – 15:15	Panel discussion. To be confirmed ... Speakers: To be confirmed

Programme

Gene People Leadership Symposium 2022: Day Two (10 November 2022)

Time	Event
15:15 – 15:25	Coffee break More winners for the Gene People Awards will be announced, while you can grab a tea or coffee.
15:25 – 15:30	Welcome back and instructions for breakouts All delegates will return to the main session to hear the instructions for the breakout sessions.
15:30 – 15:50	Breakout events Breakout D: What's new for disabled people - welfare benefits, financial help, community care and employment The team at Disability Law Service look at recent developments in welfare benefits, financial help, community care and employment. Speaker: Disability Law Service Breakout E: Ethical Issues in prenatal genetic diagnosis: New guidance The Joint Committee on Genomics in Medicine has recently produced guidance considering the ethical issues that can arise in prenatal genetic testing. The guidance incorporates relevant legal principles, existing professional guidelines and practical sources of support, with the aim of facilitating the decision-making processes for both professionals and patients. Speaker: Gemma Chandratillake, British Society for Genetic Medicine
15:50 – 16:20	Keynote speaker: Patrick Short (Sano Genetics) <i>Accelerating precision medicine by putting patients and families at the center of development</i> 'Patient-centricity' is a common theme, but what does it really mean? How do we go from focus groups and surveys to a true re-design of the system? In this presentation, we'll cover some of the technological and social drivers that are changing drug development, and what it means for patients, families, and pharma.
16:20 – 16:30	Thank you and close Led by Prof Bill Newman will wrap-up today's session and the symposium.

Thinking and networking sessions

The Gene People community requested specific opportunities to network with colleagues in a way that allowed them to also contribute to an important piece of work. This resulted in the Gene People team developing the Thinking and Networking Sessions.

Taking place between the two main days of the Symposium, the Thinking and Networking Sessions will involve delegates discussing and considering the UK Government's Rare Disease Framework, which sets out a coherent, national vision on how the UK will improve the lives of those living with rare diseases.

The resulting deliberations from all three Thinking and Networking sessions will be gathered and developed into a standalone document that reflects the views of leaders within the genetic condition community on the framework. This will be included in the post-Symposium report.

Delegates can choose from three different dates to be involved in the Thinking and Networking Sessions. Choose your preferred date and time below to register.

Once you have registered, you will receive the link for the session you have selected. Meetings will take place on Zoom, led by Samantha Barber (Chief Executive, Gene People).

These sessions are for Symposium delegates only.

- **7 Nov 2022 12:30** ([click here to register](#))
- **8 Nov 2022 12:30** ([click here to register](#))
- **9 Nov 2022 12:30** ([click here to register](#))

GENE PEOPLE Awards 2022

Celebrating **excellence** in the genetic conditions community



The Gene People Leadership Symposium 2022 is delighted to host the very first Gene People Awards 2022 – an opportunity to highlight the incredible efforts of individuals and organisations in improving the lives of people affected by a genetic condition.

The Gene People Awards celebrates the huge positive impact that the genetic condition community has on the 2.4 million people in the UK living with a genetic condition.

Nominees for the four categories in the Gene People Awards 2022 are as follows. Thank you PTC Therapeutics for sponsoring the Best Research Partnership category.

Best Campaign

- Huntington's Disease Alliance UK & Ireland
- Pulse Inframe & BHD Foundation/Myrovlytis Trust

Best Volunteer

- Lee Reavey, NCBRS Worldwide Foundation
- Clare Stacey, Annabelle's Challenge

Best Research Partnership (kindly sponsored by PTC Therapeutics)

- The AKU Society, National Alkaptonuria Centre, and the University of Liverpool
- Timothy Syndrome Alliance and The Neuroscience and Mental Health Research Institute, Cardiff University



Lifetime Achievement

- Patricia Durao Lewi, The CATS Foundation
- Louise Fish, TSA/Genetic Alliance UK
- Dr Michael McGrath, Muscle Help Foundation
- Prof Lakshminarayan Ranganath, AKU Society



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Thank you to our sponsors



The AGF promotes and supports the scientific exploration of all aspects of human heredity through:

- Education and communication with all interested individuals and groups
- Stimulating and informing public debate on the social and ethical implications and relevance to human well-being.
- The study and understanding of the historical origins and development

For further information see www.adelphigenetics.org.



The Association of British Pharmaceutical Industry (ABPI) is the trade association for over 120 companies in the UK producing prescription medicines for humans, founded in 1891.

With Gene People's sincere thanks, the ABPI has kindly provided the charity with the gift of the event platform and technology to make the Gene People Leadership Symposium 2022 possible. Thank you to everyone at the ABPI.

Sponsor of the Gene People Awards 2022 category 'Best Research Partnership'





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Get in contact

We hope that the Gene People Leadership Symposium and Gene People Awards have inspired, educated and pushed you to attain even greater things with your organisation.

Gene People is proud to stand with everyone in the genetics condition community. If we can help you to achieve your aims and goals, don't hesitate to get in touch to discuss anything related to your work, Gene People or progressing the genetic conditions agenda.

Samantha.Barber@genepeople.org.uk

Chief Executive, Gene People





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See you next year!

Call for abstracts and sponsors for the
Gene People Leadership Symposium 2023
to begin very soon