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1. JEANS FOR GENES - AN INTRODUCTION

The annual Jeans for Genes fundraising event, encourages children and adults to wear their jeans to school or to work on a specific day in exchange for a small donation.

Monies raised by Jeans for Genes fundraisers are distributed by way of The Jeans for Genes Grant Programme.

Our extraordinary charity partners then put the money raised by Jeans for Genes fundraisers to work to change the lives of those across the UK with a genetic condition.

Visit our website to see <u>Jeans for Genes Funding in Action</u>

2. OUR FUNDING STRATEGY

In 2022, we launched a new funding strategy which focused Jeans for Genes' grant making on trying to achieve two ambitious impact goals:

- Organisations serving the genetic condition community become stronger, more resilient and sustainable improving their ability to meet need and provide appropriate support in the long term; and
- 2. Every individual in the UK living with a genetic condition and their family is able to access the appropriate support at the time they need it so that they feel supported, valued and included.

In order to work towards these impact goals, the Jeans for Genes Grant Programme is comprised of two strands of funding:

- Core cost funding we award small front line, genetic condition charities, who have previously been funded by Jeans for Genes, single year grants of up to £3,000 towards their organisation's core costs to enable them to be in a stronger, more resilient position to continue to provide vital support to their communities, in the long term; and
- Project funding we award single year project grants of up to £3,000 to front line, genetic condition charities so that individuals living with a genetic condition and their families can access the right support at the time they need it.



In March 2023, Jeans for Genes launched <u>The Listening Space</u>, making a commitment to continually challenge our thinking and adapt to what we hear from people with direct experience of living with and supporting people with a genetic condition. To ensure that we are funding what matters most to those living with a genetic condition.

Drawing on the insights contributed to the Listening Space so far, we have identified six funding priorities for each funding strand. These priorities address key issues that have to change in order for us to move closer to achieving our two impact goals.

3. HOW TO APPLY

We operate a simple one stage application process for both funding strands. Each strand has its own eligibility criteria, funding priorities, maximum grant size, application form and monitoring requirements. Please make sure you read through these documents carefully and use the correct application form.

Please note we can only accept one grant application per charity each year.

You cannot apply to both funding strands in the same year.

Completed applications in pdf format should be submitted by email between 2 October and 13 November 2023 to grants@jeansforgenes.org.

Please note that we cannot consider incomplete forms, unsigned forms or any additional attachments beyond those requested in the application form and applications received by email after midnight on 13 November 2023 will not be considered.

If you have any queries about the guidelines or you feel that you would benefit from additional support – for example, by completing this form in a different language or accessing the form in a different format, please get in touch with our Head of Community and Grants, Danielle Singleton who will be happy to help: grants@jeansforgenes.org



3.1 FUNDING STRAND 1: CORE COSTS GRANTS KEY INFORMATION

We know that the condition specific charities working within the genetic condition community are a lifeline to affected individuals and their families. They provide reliable information, understanding and support as well as tirelessly raising awareness, lobbying for change and raising funds for vital medical research.

If their services were lost, the impact on individuals living with a genetic condition and their families in the UK would be devastating.

This funding strand is designed to support the resilience of those small charities working closely with the genetic condition community.

We fund established organisations (by this we mean at least 18 months old and have published their first set of annual accounts), that have received Jeans for Genes funding in the past three years and have a track record of providing direct services and support to those with a genetic condition.

We use the term 'core costs' to describe funding that contributes towards the costs of running your organisation.

For example, these include support costs, management costs, communications, income generation, administration costs, governance activities, general overheads or other spending that is not project-specific.

The impact goal, funding priorities and eligibility criteria of this funding strand are set out below. Our application form asks you to identify which priority (or priorities) your work meets and if a grant towards your running costs was awarded, how it would contribute towards your organisation's resilience and sustainability.



Core Costs Grant - Impact Goal

Organisations serving the genetic condition community become stronger, more resilient and sustainable improving their ability to meet need and provide appropriate support in the long term.

Core Costs Grant - Funding Priorities

We want our funding to support frontline genetic condition organisations to:

- Be empowered, strong and sustainable
- Be flexible and responsive to changing circumstances
- Invest in organisational development, systems and processes
- Strengthen their governance
- Effectively demonstrate the impact that they make
- Collaborate, share expertise and resources

Maximum grant size: £3,000

Core Costs Grant - Eligibility Criteria

- 1. Organisations must be registered with either the Charity Commission for England and Wales, The Charity Commission for Northern Ireland or The Scottish Charity Regulator (OSCR).
- 2. Organisations must be based and deliver their work in the UK.
- 3. Organisation's should be a genetic condition specific charity or a charity whose beneficiaries are solely those with genetic conditions and/or their families. Jeans for Genes defines a genetic condition as one that is caused by a gene or chromosome alteration. We recognise that there are genetic components to a number of complex health conditions but we do not consider these to be genetic conditions for the purposes of this grant programme.
- 4. The organisation must be at least 18 months old and have published their first set of annual accounts. If your organisation is less than 18 months old, you may apply for project funding under Strand 2 of The Jeans for Genes Grant Programme, but not for core costs under Strand 1.
- 5. Organisations should have an annual income of between £20,000 and £250,000 (as reported in their most recent set of accounts filed with The Charity Commission).
- 6. Organisations that hold more than one year's expenditure in unrestricted funds (or 'reserves') without a reason will be considered as a lower priority to be awarded a grant.
- 7. For charities that work with children and vulnerable adults, Jeans for Genes would expect that appropriate safeguarding policies are in place.
- 8. Organisations must have been in receipt of Jeans for Genes project grant within the past three years. If you have not received Jeans for Genes project funding within the last three years, you may apply for project funding under Strand 2 of The Jeans for Genes Grant Programme, but not for core costs under Strand 1).
- 9. End of Grant Report Forms for previously funded projects have been provided to Jeans for Genes. Please note that it is a condition of your grant that you send us an End of Grant Report Form. We cannot accept another application from you if a report on a previous award has not been received. If you currently have an active 2022 grant for which reporting is not yet due, please contact grants@jeansforgenes.org to arrange a short catch up telephone call before applying.



Core Cost Grant - Monitoring and Reporting Requirements

We ask that charities who receive a Jeans for Genes grant towards their core costs provide us with an End of Grant Report twelve months after receiving an award. We are keen to capture the quantitative as well as qualitative impact of your work but in order to reduce the administrative burden, we are happy to receive a copy of a report you are already producing if it contains this detail. For example, an impact report, a report for your trustee board or a progress report you have written for another funder.

We will also be in touch towards the end of the grant term to invite you to share your overall learning and experiences from the year with us. This can be by way of an email or a short telephone call.

3.2 FUNDING STRAND 2: PROJECT GRANTS KEY INFORMATION

We want to fund a wide range of innovative approaches to supporting the genetic condition community via this funding strand so that individuals living with a genetic condition can access the support they need, when they need it so that they feel supported, valued and included.

We use the term 'project' to describe funding restricted to the delivery of a defined set of activities and the costs involved in delivering those activities including staff costs and a percentage of overheads (up to 15%).

The project must be delivered by a genetic condition specific charity.

We will also accept applications under this funding strand from non registered patient groups that have a governing document and are run by at least two unrelated people, but the maximum grant available to these groups is £1,500 (the maximum project grant available to registered charities is £3,000).

The impact goal and funding priorities of this funding strand are set out below.

Our application form asks you to identify the difference your project will make by listing up to three intended outcomes you would like it to achieve. By 'outcomes' we mean the differences that will happen as a result of your project. It is important to make a distinction between the differences (outcomes) that a project is aiming to make and the activities and services it is providing.



For example,

- The project might be a new befriending service to help newly diagnosed individuals build peer support networks with volunteers that have more lived experience of the genetic condition. This will involve 1:1 befriending support and group events. These are the project's 'activities' or 'services.'
- The intended 'outcomes' of that project could be:
- 1) Newly diagnosed individuals feel more knowledgeable about their condition
- 2) Improved emotional wellbeing
- 3) Reduced social isolation

We will review your intended project outcomes to see how they align with our funding priorities and will contribute to Jeans for Genes overall goal for this funding strand that appropriate support should be available for all individuals living with a genetic condition and their families, when needed so that they feel supported, valued and included.

It is also important to think about how you intend to track the progress your project has made towards achieving the outcome(s) you have set because if a grant is awarded, then we will ask you to report back to us on this.

Project Grants Impact Goal:

Appropriate support is available for all individuals living with a genetic condition in the UK and their families, when needed so that they feel supported, valued and included.

Project Grants Funding Priorities

We want our funding to support projects that:

- Create new support networks or develop existing ones.
- Inform and empower individuals living with a genetic condition and their families and carers.
- Address a key transition point (e.g. point of diagnosis, transition to adult services or bereavement).
- Improve the physical, mental or emotional wellbeing of affected individuals, families and carers.
- Enable knowledge, awareness, skills or attitudes to be acquired that are then applied so that those with a genetic condition and their families are supported, valued and included.
- Engage with diverse and marginalised communities who are also living with a genetic condition to identify and challenge policies, practices and perceptions that contribute to health inequalities.

Grant size: up to £3,000



Project Grants - Eligibility Criteria

- 1. Organisations must be registered with either the Charity Commission for England and Wales, The Charity Commission for Northern Ireland or The Scottish Charity Regulator (OSCR). We recognise that it is not always possible for patient groups who are supporting those living with a genetic condition to have established a charity. We will accept applications from unregistered patient groups who have a signed governing document and are run by at least two people who are not related but the maximum grant available to these groups is £1,500.
- 2. Organisations must be based and deliver their work in the UK.
- 3. Organisations should be a genetic condition specific charity. Organisations supporting a range of beneficiaries that include those with genetic conditions among them (for example, hospices and special needs schools) are NOT eligible to apply for this funding. Jeans for Genes defines a genetic condition as one that is caused by a single gene or chromosome alteration. We recognise that there are genetic components to a number of complex health conditions but we do not consider these to be genetic conditions for the purposes of this grant programme.
- 4. The organisation should have an annual income of less than £1 million (as reported in their most recent set of accounts filed with The Charity Commission).
- 5. Organisations that hold more than one year's expenditure in unrestricted funds (or 'reserves') without a reason will be considered as a lower priority to be awarded a grant.
- 6. For charities that work with children and vulnerable adults, Jeans for Genes would expect that appropriate safeguarding policies are in place.
- 7. If you have received Jeans for Genes funding before, then the reporting for the previously funded projects must be up to date. We cannot accept another application from you if an End of Grant report for a previous award has not been received. If you have currently have an active 2022 grant for which reporting is not yet due, please contact us at grants@jeansforgenes.org to arrange a short catch up telephone call before applying.

Project Grants - Monitoring and Reporting Requirements

We ask charities who receive a Jeans for Genes project grant to provide us with an End of Grant Report twelve months after receiving an award. In your application we asked you to tell us the difference you hope your project will make by listing up to three intended outcomes you would like it to achieve and how you will measure this.

In your report we would like to know to what extent you have achieved these outcomes and any learning or challenges you have faced along the way.



4. APPLICATION TIMETABLE

Application window opens	2 October 2023
Closing date for applications	13 November 2023 (Applications received by email after midnight on 13 November 2023 will not be considered)
Notifications to applicants not shortlisted	By 1 December 2023
Call to discuss application further (if we have any questions about your application, then we will contact you to arrange a mutually convenient time for a telephone call)	Early December 2023
Applications will be considered by an independent grant panel	Late January 2024
Jeans for Genes trustees to review and approve decisions of grant panel	Late March 2024
Payments will be made by BACS to successful applicants	Late March 2024

5. CAPACITY BUILDING COLLABORATION WITH BEACON FOR RARE DISEASES

<u>Beacon</u> (formerly known as Findacure) is a UK-based charity that upskills rare disease patient groups through trainings, guided programmes, community projects and research initiatives. Beacon helps rare disease patient groups maximise their impact and deliver change for rare disease patients.

As 80% of rare disease has a genetic component, Jeans for Genes is partnering with Beacon and committing to funding a number of places for genetic condition charities on one of their training programmes (depending on the subject, this may be a masterclass, workshop or webinar).



All of Beacon's trainings are delivered by experts in a small group setting to ensure all attendees have the opportunity to receive direct support and feedback from the trainer. They are intended to be hands-on training where participants leave with something tangible they can put into practice for their organisation.

We would envisage that this training would be most suited to the small and emergent charities with an income under £250,000 applying to our core cost funding stream, but any charity applying to our grant programme are welcome to also apply for a space.

The subject of the training is yet to be finalised but will be on a subject identified via our Listening Space enquiry as being relevant to small genetic condition charities, for example:

- Being financially and operationally fit
- Employing staff
- Measuring Impact
- Strategic planning
- Succession planning

The application form asks you to indicate if you would like to apply for a space on the Beacon training and if so, what would be your preferred subject.

5. RAISING AWARENESS IN PARTNERSHIP

We regard our grant programme as an opportunity to create a learning partnership with the charities that receive Jeans for Genes funding.

Jeans for Genes shines a spotlight on the experiences of families in the UK living with a genetic condition, and the wonderful work of our charity partners and ask that our charity partners help us raise awareness of the Jeans for Genes campaign and it's impact. Although it is not a formal condition of a grant award that your organisation takes part in these awareness raising activities, it would be helpful to know at the application stage if you envisage any issues with the following:

- Promoting your Jeans for Genes Day grant in your organisation's communications, including in newsletters and social media and the difference it will make to your organisation's services.
- Displaying the Jeans for Genes' partnership logo on your organisation's website for a duration of one year following the awarding of a grant.
- Providing us with quotes, photos, case studies and/or videos demonstrating your charity's work
 in action to use on the Jeans for Genes website, social media platforms and fundraising materials
 to help us communicate to the public why signing up to hold a Jeans for Genes Day is so
 important.



6. ONCE A DECISION HAS BEEN MADE

If your application is successful, we will email you with an offer letter outlining the terms and conditions of your grant and the next steps.

If you have had an application for funding declined by us then we will indicate in your rejection letter when/if you are eligible to apply for funding again. Please note that all decisions are final and we cannot revisit any decision.

We are a very small team but will try to offer verbal feedback to unsuccessful applicants if requested. If you would like feedback please email us at <u>grants@jeansforgenes.org</u>

7. QUESTIONS AND FEEDBACK

The <u>Frequently Asked Questions</u> page on our website provides answers to some common questions about our application process.

We hope this Guidance for Applicants explains the application process for the 2023 Jeans for Genes Grant Programme in a clear and transparent way.

If you have a question that is not answered in this document or you have any feedback/ suggestions regarding the grant programme and/or the application process, please email us at grants@jeansforgenes.org.

www.jeansforgenes.org