

2020/2021 REFLECTION

# GRANT FUNDING



**WRITTEN BY**

Danielle Singleton  
Community & Grants Officer

# IMPACT OF OUR COVID-19 RESPONSE AND FINDING A WAY FORWARD

## Introduction

In March 2020, the outbreak of the global Covid-19 pandemic catalysed grant-makers across the UK to think differently about how, what and why they funded. Jeans for Genes were no different.

As the country moves forward into 'recovery', we are reflecting on the impact of Jeans for Genes' funding response during this period and what we can learn about how we approach our grant making in the future.

## Covid: impact on the genetic condition community

The pandemic had an immediate and profound impact on the genetic condition community.

The many challenges faced by those living with a genetic condition, their families and carers on a daily basis including social isolation, diagnostic delay, and fragmented coordination of care to name but a few, were exacerbated by Covid-19 and the measures taken by the government to contain its transmission.

Research undertaken by concerned advocates within the genetic condition community, (in particular, a report produced by ARDEnt '***Making the Unseen Seen - Rare disease and lessons learned from the Covid-19 pandemic***') shed a light on some of the common experiences faced by individuals with a genetic condition, their families and carers during the pandemic:



**Lily, aged 18, has a rare chromosome disorder called 16p11.2 microdeletion.**

**For Lily, the condition means she finds it a challenge to communicate and express herself. She finds it very difficult to make friends and socialise like other young adults which can be isolating for her, a problem which has really been compounded by the pandemic.**

**Lily is looking forward to returning to college as the lockdown restrictions ease.**



- Heightened anxiety and stress as a result of trying to navigate government and NHS advice on shielding for those in the 'extremely clinically vulnerable' category, and the knowledge that those in this category were at higher risk of becoming seriously ill.

- Disruption or suspension of clinical trials.
- Negative impact on mental health and emotional wellbeing caused by isolation from family, friends and the wider community whilst shielding.
- Challenges maintaining medical care due to availability of PPE, closure of clinics and cancellations of treatments.
- Reduced access to therapies essential to slow disease progression and enhance quality of life.
- The closure of day centres, respite services and special schools saw carers providing 24-hour, seven days a week care with very little support.

## Covid: impact on charities and our initial response

Charities of all sizes working to mitigate the impact of Covid on those with a genetic condition were severely impacted financially as mass fundraising and supporter events were cancelled.

The survival of the vital, often lived experience, volunteer run, condition specific charities and patient groups in this space was of particular concern. Their sustainability was already precarious prior to the pandemic, but the surge in demand for their services and advocacy, at a time when their volunteers were now juggling home schooling, working and care responsibilities, meant their ability to adapt their services quickly and stay afloat was at risk.

Despite having the odds stacked against them, these small charities pivoted quickly, moving services online and working tirelessly to support clinically vulnerable and isolated communities.

Wanting to stand by their side and offer what support we could, Jeans for Genes responded by converting all our restricted grant pledges to unrestricted grants.

Feedback received from our charity partners told us that giving them the freedom to use their knowledge and expertise of how best to repurpose the Jeans for Genes grant to support their communities through the pandemic, significantly helped them adapt their services quickly and effectively.



**5 year old Jack has a genetic condition called Kleefstra Syndrome. Jack's mum Lindsay says:**

**"it was initially nice to have a break from appointments and therapies which up until the pandemic had felt relentless at times but we are still catching up on missed appointments. The biggest hit was on his therapies, for example, speech and language therapy and physio".**



**"The Jeans for Genes unrestricted grant enabled the Muscle Help Foundation charity to push on during the COVID-19 pandemic.**

**Thanks to this grant, the charity was able to pivot and deliver a number of virtual Muscle Dream activities, allowing us to bring some of the joy and magic that we strive hard to bring to some incredibly vulnerable, shielding families."**

**Michael McGrath, CEO – The Muscle Help Foundation**

**'The AKU Society used its Jeans for Genes grant to provide virtual counselling to AKU patients. One AKU patient's husband passed away during the pandemic and she said this about the service:**

**"The counselling is being a great help, thank you. They have made a huge difference and helped me through a difficult time. He (the counsellor) asks how I'm feeling with my AKU and even helps me through the frustrations."**

**Juliet Rowe, AKU Society**



Our funding partner, The Marfan Trust moved their annual Information Day online during the pandemic. The rights to this image are owned by The Marfan Trust.

**Throughout 2020 and 2021 we distributed £283,863.84 of unrestricted funding to 43 charities providing vital support within the genetic condition community to help them adapt, respond and recover from the Coronavirus pandemic. Learn more about our funding partners and the support they provide: <https://www.jeansforgenes.org/funding-in-action>**

## Listening

**83%**

of charities told us that funding was their biggest concern, particularly the lack of unrestricted funds to cover core costs

**50%**

of charities told us that they were struggling with the capacity to meet the demand for their services

**35%**

of charities were worried about the long-term sustainability of their organisation

Taken from Jeans for Genes Funding Strategy Consultation 2021

It soon became clear that this was not going to be a short-lived crisis. Our funding partners were going to have to grapple with supporting their communities through the everchanging nature of the pandemic for some time; blending remote and face to face services and trying to mitigate the longer-term effects of the disruption felt by the people they worked with.

We launched a survey of our funding partners, past, present and future, to ask what was needed from us as a funder to support them to meet this challenge, and to gain a deeper insight into emerging needs of the genetic condition community following the pandemic.

Through this feedback, and by having conversations with our grantees, it became clear that due to the increased demands for their services since the onset of the pandemic, many were working beyond capacity, risking the burn out of key members of staff and volunteers.

Concerns about loss of unrestricted funding streams, capacity to meet emerging needs and long term sustainability were also repeatedly raised.

In response to this listening exercise, we took the decision that our 2021 grant programme would again provide unrestricted funding. This time to assist our partner organisation's to recover from the impact of the pandemic financially and to support their communities as we emerged from the crisis.

**Our support and advice services are at risk of becoming overwhelmed as the support our members need grows exponentially in response to local authority cuts and difficulties accessing medical care since the pandemic.**

**Charity CEO**

We refocused our grant making on smaller, condition specific charities with annual incomes of less than £200,000 as these were the charities that felt the impact the most and found it more difficult to access Covid response funding from other sources. We also made our grant process more streamlined and straightforward, so as not to further stretch the limited resources of those applying. This resulted in 82% of those that applied for a grant being successful.

For some organisations the unrestricted grant allowed them to plug their funding gap, and others reported that the grant gave them the freedom to respond quickly and flexibly to changing priorities and needs of their beneficiaries during this period.

**The unrestricted funding has been of huge benefit to our organisation. It has supported our agility of service delivery, giving us far greater freedom to spend the money where we think we can make the biggest impact for our families in that particular moment**

**Helen Hargrave, The Smith-Magenis Syndrome (SMS) Foundation UK**

**Jeans for Genes unrestricted funding has been really helpful in resourcing the changing needs of our families.**

**Since Covid, we have had to be increasingly adaptive with how we support families. This would have been difficult if we were confined by the terms of a detailed bid.**

**Jan Fowler, Chair of Trustees - SOFT UK**



**Ten-year-old Florence has a number of eye conditions, the result of a rare genetic condition. She has limited vision and is registered blind. Thanks to Newlife – a Jeans for Genes funding partner for the last 12 years – Florence has her own BrailleNote tablet to use at home to help with her schoolwork. It was essential during the Coronavirus lockdown and home learning. Mum Pip described it as "liberating for Florence, life changing."**





This image shows families at Zellweger UK's last face-to-face family conference in 2019 which was supported by Jeans for Genes funding. The rights to this image are owned by Zellweger UK.

## Finding a new way forward

In the aftermath of the pandemic, many in the funding sector feel that we should not return to pre-Covid funding practices and this is now the moment for transformative change in UK grant-making.

Funders are being called upon by grant recipients and more forward thinking grant makers to continue to take an open, trust-based approach to their funding and award unrestricted funds where appropriate. This means trusting charities to use their expertise and experience to make the decisions about where the grant funds should be applied.

At Jeans for Genes, we have always considered our funding partners who work within the community to be the experts. Whilst this mindset exists, it does not mean that we should be complacent and we are committed to continually challenging our thinking and adapting to what we hear from the communities we serve.

However, unlike independently endowed foundations, we are a grant maker whose main income stream is generated from a national public fundraising campaign. Prior to the Covid pandemic, our grant programme was project based as we believed this made it easier to demonstrate the difference being made with the public's donated funds. Our Covid response has demonstrated that impact goes beyond project based quantitative metrics and that investing in organisational infrastructure, capacity and core costs where appropriate, has a much deeper impact for those we work alongside.

We have been reflecting on what we have learned from our response during the pandemic, thinking carefully about the role of Jeans for Genes in the genetic condition community and the contribution we want to make in the future.

What is clear is that unrestricted, flexible funding can't just be a crisis response. It is what genetic condition charities need to sustainably thrive and Jeans for Genes needs to work harder to articulate to our fundraisers why supporting the resilience and sustainability of our funded charities is so important.

As an organisation, we are now feeding what we have learned into a new funding strategy and grant programme. The key features of which are:

- Building upon the strong relationships that we already have with our funding partners by taking a more trust-based, flexible approach to funding these organisations.
- Providing a blend of unrestricted and project funding and responding to what charities know will have the most impact.
- Aiming to leverage additional support for our grantees from other funders and organisations.
- Developing our listening practices so that we can be more responsive as a funder and work alongside our funded charities to address emerging needs in the genetic condition community.

Deeper listening, meaningful collaboration and the continual challenge of our practices will underpin our approach as we move forward towards our aim of being a year round, trust-based, impactful and responsive grant giver.

“

**To have been awarded an unrestricted grant that we can use towards core costs is such a breath of fresh air!**

**The last two years have been difficult due to reduced fundraising but every year we have the worry of are we going to receive enough donations to cover our core costs - a worry I carry every day. Having spent the last 25 years building the ED Society my biggest fear is for it to close due to lack of funding, leaving all our families to swim in the dark.**

**Diana Perry, CEO, The ED Society**

”



This image shows a research project taking place involving boys with XLHED, a form of Ectodermal Dysplasia. The rights to this image are owned by The ED Society.