GENETIC ALLIANCE UK

Report of the Board of Trustees and Accounts

2020-2021

GENETIC ALLIANCE UK

REPORT OF THE BOARD OF TRUSTEES

For the year ended 31 March 2021

The trustees who are also directors of the charity for the purposes of the Companies Act 2006, present their report with the financial statements of the charity for the year ended 31 March 2021. The trustees have adopted the provisions of the Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015) and the Companies Act 2016.

CONTENTS

Genetic Alliance UK
contactus@geneticalliance.org.uk
geneticalliance.org.uk

Registered charity numbers: 1114195 and SC039299
Registered company number: 05772999

WELCOME FROM THE CHAIR

If I may, I will begin by thanking everyone for their hard work in what has been a tumultuous year for everyone — in our case, for our members, our communities, our team and the Board of Genetic Alliance UK. Tumultuous yes, but also enlightening and, I'm particularly glad to say, successful. Covid-19 has undoubtedly severely impacted on all of us in one or more ways. At the same time, it has led us to look at new ways of working, both within the organisation and with our members and their families throughout the land. Our weekly Community check-ins have proven to be valuable to many in our community and such has been the success of their collaborative approach that we will continue with them, working with, and keeping in touch, with what matters to you – our families and carers.

It is unfortunate that some of our public affairs activities were necessarily truncated this year, largely due to most of our team being on furlough for several months. For those team members who remained, the road has been long and hard. That we have succeeded in so many areas is due to their unstinting efforts, for which I and the rest of the Board are enormously grateful.

There have also been challenges with fundraising and with the departure of our Chief Executive, Jayne Spink, at the end of March. To allow time for consolidation and stability in what was already a turbulent time, the board decided to appoint two joint interim chief executives, Nick Meade, Director of Policy and Lauren Roberts, Director of Engagement and Support, rather than proceed immediately to appoint a new CEO. This arrangement is ongoing and the Board will consider when and how best to fulfil the CEO role in the light of experience.

As far as fundraising is concerned, this continues to be a challenging area. Having succeeded in appointing a Director of Fundraising toward the end of the year, unfortunately personal circumstances meant that the postholder had to resign within a short time. It is to her credit however that in the few months she was with us, she undertook a robust review of fundraising and generated a new strategy which is now being pursued.

The Genetic Alliance UK Board has also taken the opportunity to look at how we work together and consider our governance responsibilities and arrangements to ensure we keep pace with, and meet, the expectations of the Charities Commissions in England and Wales and Scotland. This work is ongoing but has led to what we hope will be improved information and support for Trustees in the future. There is no doubt that remote working has brought with it some challenges and we are all looking forward to a time, hopefully soon, when we might be able to meet again in person.

It also gives me great pleasure to look forward to working with the four administrations across the UK as they work towards implementation of the new Rare Disease Strategy launched in February. This, and the launch of Genome UK, are particular highlights in what we hope will be new and exciting opportunities for everyone affected by rare, genetic and/or undiagnosed conditions to seek and see ongoing improvements in diagnosis, treatment and care.

As we look over the year it is with hopes of continued success in meeting the challenges faced not only by us, but most charities, as we all look to the future in a new light, living with and, hopefully, post Covid-19.

I commend this annual report to you, which is possible only through the work of the Genetic Alliance UK team and built on the experiences and hopes of families and carers throughout the UK.

Elizabeth Porterfield
Chair, Board of Trustees
Genetic Alliance UK

OBJECTIVES AND AIMS

Genetic Alliance UK is the national charity working to improve the lives of patients and families affected by genetic, rare and undiagnosed conditions. We are an alliance of over 200 patient organisations.

The objectives of the charity are to:

- Relieve persons affected by a genetic and/or rare and/or undiagnosed condition(s);
- Advance the education of the public concerning genetic and/or rare and/or undiagnosed conditions in such ways as the trustees of the charity think fit.

We advocate for fast and accurate diagnosis, good quality care and access to the best treatments. We actively support progress in research and engage with decision makers and the public about the challenges faced by our community.

Public benefit

The Board of Trustees confirm they have had regard to the Charity Commission's guidance on public benefit and have complied with their duty under section 4 of the Charities Act 2011 when reviewing the charity's aims and objectives; and in implementing current and planning future activities.

TERMINOLOGY WE USE

A word about our terminology:

Genetic, rare and undiagnosed

We support people with genetic, rare and undiagnosed conditions. Sometimes our work might focus particularly on a subset of these groups, such as with our SWAN UK (syndromes without a name) support network for families with children with undiagnosed conditions.

A genetic condition is one that is caused by a change in an individual's genome. (A genome is your complete set of genetic instructions. Each genome contains all of the information needed to build you and allow you to grow and develop.) The change might be a single letter of the DNA code added, deleted or rearranged, or a much bigger change with more of the genome added, deleted or rearranged.

A rare condition is one that affects fewer than 1 in 2,000 people in the UK. Almost all genetic conditions are rare. There are a handful of genetic conditions that are not rare, we support people with these conditions too. About 72% of rare conditions are genetic. We expect this proportion to grow with progress in genomic research. We support everyone living with a rare condition.

A syndrome without a name or undiagnosed genetic condition is a genetic condition that has not been diagnosed yet. This might be because the right test has not been carried out to make the diagnosis yet, or because the particular genetic cause of the condition has not been discovered yet. We support all families with children with undiagnosed genetic conditions.

Condition and disease

We prefer to use the term 'condition' as much as possible. This is because our members and the people they support prefer it. 'Disease' and 'condition' are technically interchangeable terms, but 'disease' has more negative connotations and for some implies that the condition might be contagious. We do have to use the term 'disease' sometimes, this is because the term 'rare disease' has a lot of traction at policy level. We named our campaign Rare Disease UK accordingly, and key UK policies such as the outgoing UK Strategy for Rare Diseases and the UK Rare Diseases Framework also use the term.

IMPACT OF COVID-19

COMMUNITY SUPPORT PROGRAMME

In response to the pandemic we quickly initiated new activities to support the whole genetic, rare and undiagnosed community. This included developing a **new information hub** that was updated regularly and signposted to condition specific information, and holding a weekly virtual Community check-in for organisations to work together to share information and ideas. As a result of these sessions we were able to quickly identify and proactively respond to a number of issues facing our community.

These included **alerting NICE to problems with the use of the clinical frailty score** for people with rare conditions, working with WellChild to resolve issues around getting children with rare conditions back to school due to the aerosol generating procedures guidance, and **successfully campaigning for people affected by rare conditions to be on the priority list for Covid-19 vaccinations**.

- **45 virtual community check-ins hosted**
- **Attended by 325 individuals**
- **150 organisations represented**
- **16K users visited our Covid-19 information hub**
- **Information hub pages viewed over 38K times**

THE RARE REALITY OF COVID-19

The pandemic caused sudden and, for many in our community, devastating changes to their lives.

Using UK specific data from the EURORDIS Rare Barometer Covid-19 Experience Survey, and findings from our weekly community check-ins during the months of April, May and June 2020, we produced a report, '**The Rare Reality of Covid-19**'. This highlighted how people living with rare conditions had been placed under immense pressure by the pandemic. Access to appropriate support, information, care and treatments had become more difficult and levels of social isolation had increased.

Key findings from the Rare Reality of Covid-19 report:

- **66% felt their healthcare disruptions were detrimental to their wellbeing**
- **40% reported closure of their hospital units**
- **20% of people had access to their medication disrupted**
- **40% feared Covid-19 posed a high threat to their health**

The report was shared with parliamentarians from the All Party Parliamentary Group (APPG) and Cross Party Groups (CPGs) on Rare, Genetic and Undiagnosed Conditions in Westminster, Wales and Scotland. On the same day, the report was attached to a letter to the Secretary of State for Health and Social Care and the minister responsible for rare diseases in England with two clear immediate asks: a risk assessment tool for Covid-19 and people with rare conditions to assist future shielding messaging; and an examination of telemedicine during the crisis period, to ensure best practice is maintained while services are restored.

The report was also promoted at the CPGs in Scotland and Wales and in the November **2020: APPG meeting on Covid-19** that focussed on the impact of Covid-19 on the rare, genetic and undiagnosed community. Over 80 people attended the meeting.

BUILDING RARE RESILIENCE

Identifying high levels of stress and signs of burn out in our community, we partnered with Rare Minds to offer group counselling to organisation leaders and SWAN UK parents. Over 50 people benefited from this pilot, and participants from Genetic Alliance UK organisations continue to meet.

DRIVING PROGRESS

POLICY AND PUBLIC AFFAIRS

Despite Covid-19, this has been a year of ongoing progress in key areas of work for Genetic Alliance UK and our members.

Genomics

In genomics, the NHS Genomic Medicine Service continued to build towards the roll out of the full service, and we were able to contribute through our connection to the UK National Genomics Board and NHS England's Genomics Board. We also welcomed the publication of the **UK's new genomic strategy, Genome UK**.

NICE methods and process review

The NICE methods and process review presents an opportunity to improve access to medicines for rare conditions. Our team had a position on the working group throughout the year, and we contributed to the methods review consultation and the consultation on topic selection.

UK Rare Diseases Framework

Most importantly the **UK Rare Diseases Framework** was published in January 2021, just in time to take over from the UK Strategy for Rare Diseases which ended in 2020. Members of our Rare Disease UK Patient Empowerment Group from across the UK played a key role in advising on the development of the Framework, and since publication we have switched our attention to supporting the development of action plans in the four nations. We were delighted when the chair of the All Party Parliamentary Group (APPG) on Rare, Genetic and Undiagnosed conditions secured a Westminster Hall debate on rare diseases.

In 2019, Genetic Alliance UK published two important reports, our **Patient Charter on newborn screening**, and our **Action for Access** report on access to medicines for rare conditions. Our original plan for 2020 was to promote the messages in these reports, and take forward these issues for our community. We had to shelve these plans, and intend to review these issues at the beginning of the next year to reframe them in the context of Covid-19, and take them forward in collaboration with our members.

Patient voice in policy development

We provided input to an Medicines and Healthcare products Regulatory Agency Patient Group Consultation Event on Regulatory Flexibilities during Covid-19 and a consultation event held by the Department of Health and Social Care (DHSC) regarding feedback on the initial draft of the new UK Framework for Rare Diseases.

We continue to input as a patient representative member to the Rare Disease Implementation Group (RDIG) which has oversight for the Welsh Action Plan and Genomics Partnership Wales Sounding Board. Throughout the last year, we fed in the experience of people living with rare conditions during the pandemic via the Rare Disease Implementation Group lead and lead commissioner for the Welsh Health Specialised Services Committee (WHSSC). We also fed in issues affecting the rare disease community via the Welsh Government Third Sector Stakeholder Forum.

Cell and gene therapy engagement workshops

We received over 100 applications to take part in a series of three virtual workshops on cell and gene therapy that took place in November and December 2020. We selected a small cohort of 20 candidates to take part with the recordings of the workshops sent to the remaining applicants alongside a survey.

'I felt all areas were well covered and especially appreciate the fact that they were moderately geared to the understanding of those of us who had little prior knowledge. The extra reading resources and videos contributed to such a lovely comprehensive seminar.'

The purpose of these workshops was to follow up on the previous work with Progress Educational Trust on Understanding Genome Editing with the aim of educating people with experience of living with a genetic or rare condition about cell and gene therapy. It was also to prepare a report which describes the priorities of our community in learning about cell and gene therapy.

The project is ongoing and will be completed in the autumn of 2021.

WALES

Genomics Partnership Wales Patient and Public Sounding Board consultations

We worked with Genomics Partnership Wales to recruit the second cohort of 11 new members to the Patient and Public Sounding Board which provides patient and public advice and input to the work of the Genomics of Precision Medicine Strategy and its programme of work.

We held three meetings of the Board in the reporting period for 2020 and two in the reporting period for 2021 (28 April 2020, 14 July 2020, 8 October 2020, 19 January 2021, 15 April 2021).

Topics included: input to the design and development of a new estates building bringing together genomic testing, clinical facilities and genomic research in Wales and feedback on patient and public involvement in other programmes including pathology, imaging and advanced therapies.

Coproduced with members, **an impact video** has been created to showcase the impact members have made through being involved with the Board.

Cross Party Group meetings

The Welsh Cross Party Group (CPG) for Rare, Genetic and Undiagnosed Conditions held its inaugural meeting in the Senedd in September 2019. Since then, the group, chaired by Angela Burns MS and administered by Genetic Alliance UK, has heard a broad range of people's experiences. Over the last 12 months, meetings have moved to a virtual platform and we have been able to feed back experiences directly to Welsh Government through the third sector stakeholder forum.

September 2020: The first virtual meeting of the CPG since the start of the pandemic focused on the immense pressure Covid-19 was putting on people living with rare conditions. Reports highlighted difficulties gaining access to appropriate support, information, care and treatment and an increased level of social isolation had a detrimental impact on mental health.

January 2021: The final meeting of the CPG ahead of the Senedd elections in 2021 examined the future for individuals and families affected by rare conditions in Wales. Key findings from Genetic Alliance UK's Rare Experience Report 2020 were presented and alignment to the priorities in the new UK Rare Diseases Framework were highlighted. Discussion focused on priorities for the implementation of a Welsh Action Plan.

February 2021: Angela Burns MS, Chair of the Welsh Cross Party Group **launched the final report** of the Cross Party Group for Rare, Genetic and Undiagnosed Conditions. Chair of the Rare Disease Implementation Group, Dr Graham Shortland spoke about Wales' plans for implementing the Framework and two guest speakers highlighted their experiences of life with Turner Syndrome.

Bringing together people affected by rare conditions, patient group representatives, health care professionals and researchers, the report identifies a series of recommendations which would improve the lives of people affected by rare conditions across four broad themes:

- The effect of rare conditions on mental health
- Access to orphan medicines
- The impact of Covid-19 on those affected by rare conditions
- A future Welsh Action Plan to implement the UK Rare Diseases Framework

CROSS PARTY GROUP ON RARE, GENETIC & UNDIAGNOSED CONDITIONS

Final Report 2021

GENETIC ALLIANCE UK

SCOTLAND

Cross Party Group meetings

The Cross Party Group (CPG) on Rare, Genetic and Undiagnosed Conditions adopted virtual meeting practices from March 2020 and continued to provide a forum for people living with rare, genetic and undiagnosed conditions to come together to discuss and debate key issues. Since March 2020 the CPG has held five meetings.

May 2020: The first virtual meeting of the CPG was an opportunity to address the significant challenges affecting the community in the first months of the Covid-19 pandemic. Professor Jason Lietch, National Clinical Director for NHS Scotland, attended the meeting to provide an in depth question and answer session and to hear the experiences directly from group members.

October 2020: The impact of Covid-19 was addressed again with a presentation of Genetic Alliance UK's 'The Rare Reality of Covid-19 Report'.

January 2021: The CPG held a meeting focused on the vaccination programme.

November 2020: The CPG meeting was attended by the CoOrdiNated Care Of Rare Diseases (CONCORD) study team who provided an overview of their findings on the principles of care coordination. This session informed the development of the CPG's report, 'Improving Care for Rare Conditions in Scotland', which was agreed at the final meeting of the CPG in March 2021.

June 2021: Due to the 2021 Scottish Parliament election, the current CPG ceased to exist on 26 March 2021. Following the election, work has been undertaken to re-establish the CPG, and a first meeting of the new CPG will be held in June 2021.

Scotland policy – 'Improving Care for Rare Conditions in Scotland' report

On 23 March 2021, the Cross Party Group published the **'Improving Care for Rare Conditions in Scotland' report**.

The report provides a narrative of experiences raised with the Cross Party Group in the 2016-2021 parliamentary session and outlines what is needed to increase awareness of rare conditions among healthcare professionals and to improve coordinated care in Scotland.

'Improving Care for Rare Conditions in Scotland' calls for the development of a funded Rare Conditions Coordination Service for Scotland.

The report is intended to inform implementation of the UK Rare Diseases Framework and the development of the new Scottish Action Plan for Rare Diseases.

Engagement networks

In Scotland, work is underway to formalise the way in which we engage and involve people in our work. Through the development of engagement and involvement networks, we will seek to build a strong multi-stakeholder community.

We have developed the **Scottish Virtual Involvement Panel** for people living with, or caring for someone living with, a rare, genetic or undiagnosed condition in Scotland. Our Virtual Involvement Panel will be at the heart of our work in Scotland and will provide our 'VIPs' (Virtual Involvement Panelists) an opportunity to contribute to our work and wider policy and service development decisions.

Virtual Involvement Panellists receive regular, information e-newsletters with news about developments in health and social care services. They will also be invited to attend a programme of digital events, contribute their experience for media work and be invited to take part in surveys and consultation events to shape policy and services in Scotland.

The Virtual Involvement Panel will play an important role in the development of the Scottish Rare Diseases Action Plan, as Genetic Alliance UK will be working closely with the Scottish Government to ensure people living with rare conditions are actively involved in the development and implementation of the plan.

Work is also underway to develop a Policy Involvement Network to bring together patient organisations in Scotland to have their say on genomic, rare disease and other relevant policy being developed by the Scottish Government and NHS Scotland. We are also growing our Professional Engagement Network, bringing together professionals working in health and social care in Scotland with an interest in rare, genetic and undiagnosed conditions to provide them with relevant information, training opportunities and the option to share their views on our policy work.

IMPROVING CARE FOR RARE CONDITIONS IN SCOTLAND

A report by the Cross Party Group of Rare, Genetic and Undiagnosed Conditions

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RESEARCH

We were fortunate that the impact of the Covid-19 pandemic on our two major research projects was minimal. Data collection for the CONCORD study on care coordination was largely complete before the first wave. We switched the face-to-face CONCORD workshops planned for summer 2020 to online events, which had the positive effect of allowing more geographically diverse groups to attend. The 2020 Rare Experience survey was always going to be an online activity, and again we were able to hold online workshops to test the findings in lieu of face-to-face meetings. The pressures facing our community meant that activities aimed at upskilling our members in research techniques were deprioritised but we hope to revitalise them in the forthcoming year.

The number of external researchers seeking our support for their studies increased as many Covid-19-specific projects were launched. We promoted good quality studies that were relevant to people with rare conditions to our networks, including bringing academic speakers into our community check-ins, and we have developed new ongoing relationships with researchers as a result. We also supported our member Ataxia UK to design their own survey and analyse the results, and co-presented findings at Ataxia UK events.

CoOrdinated Care of Rare Diseases (CONCORD)

We have now finished the data collection and analysis for the CONCORD project which were presented at a **virtual meeting** attended by 170 people and **published on our website**. The results were also presented as a poster at the European Conference on Rare Diseases (ECRD). See page 13).

Collaboration with external researchers has led to publication of the following peer-reviewed papers co-authored by members of our research team:

- **Simpson A**, Bloom L, Fulop NJ, Hudson E, Leeson-Beevers K, Morris S, Ramsay AIG, Sutcliffe AG, Walton H, **Hunter A**. How are patients with rare diseases and their carers in the UK impacted by the way care is coordinated? An exploratory qualitative interview study. Orphanet Journal of Rare Diseases 2021; 16: 76.

- Hammond J, Garner I, Hill M, Patch C, **Hunter A**, Searle B, Sanderson SC, Lewis. Animation or leaflet: Does it make a difference when educating young people about genome sequencing? Patient Education and Counseling, 2021. In press.

Rare Experience 2020 report

Over 1,000 people responded to our five-yearly survey and 11 attended our follow up workshops. **The Rare Experience 2020 report** was launched in December 2020 with over 80 people in attendance.

This was the third comprehensive survey Genetic Alliance UK has undertaken to capture the experiences of people affected by rare conditions. It is seven years since the publication of the UK Strategy for Rare Diseases and a decade since we published the report of our first comprehensive survey - a decade in which we have seen significant progress in science, medicine and in terms of awareness of rare conditions.

Our 2020 survey provided a measure of the extent to which these advances have filtered through to impact on the lives of those affected by rare conditions, how their experiences have changed across the last decade, and a baseline against which we might judge future progress.

Whilst satisfaction remains high amongst those who have access to specialist care and treatment for their condition, we see few improvements for the majority of those who do not. The diagnostic odyssey remains a major challenge and new genomic services have yet to deliver on the promise of early and accurate diagnoses. The scale and frequency at which patients and families experience challenges relating to coordination of care seems to have been unaltered by the passage of time. Despite the commitments made in the UK Strategy, which came without specific financial resources dedicated to its implementation, there remains much to be delivered.

Messages from the Rare Experience 2020 report included:

- **People with rare conditions are insufficiently served by the system**
- **Diagnosis is crucial**
- **Awareness of rare conditions among professionals is valuable and needs improving**
- **Professional care coordination is rare but necessary**
- **Pockets of excellence can demonstrate how the system can deliver**

RARE EXPERIENCE 2020

The lived experiences of people affected by genetic, rare and undiagnosed conditions

GENETIC ALLIANCE UK

HOW ARE PATIENTS WITH RARE DISEASES AND THEIR CARERS IMPACTED BY THE WAY THEIR CARE IS COORDINATED IN THE UK? An exploratory qualitative interview study

Amy Simpson*[1], Naomi Fulop[2], Emma Hudson[3], Stephen Morris[3], Angus Ramsay[2], Holly Walton[2] & Amy Hunter[1] (on behalf of the CONCORD study team)

[1] Genetic Alliance UK; [2] University College London; [3] University of Cambridge

Contact: amy.simpson@geneticalliance.org.uk / +44(0)20 7704 3141 / www.geneticalliance.org.uk

Background

UK policy frameworks highlight the importance of care coordination for rare conditions. Yet, there is a lack of evidence exploring if and how patients and carers are impacted by the way in which their care is coordinated. We aimed to explore how care coordination (or lack of) impacts on patients and carers.

Method

We conducted semi-structured interviews with 15 UK-based patients and carers/parents with lived experience of a range of rare and undiagnosed conditions. Transcript data were grouped into themes and sub-themes.

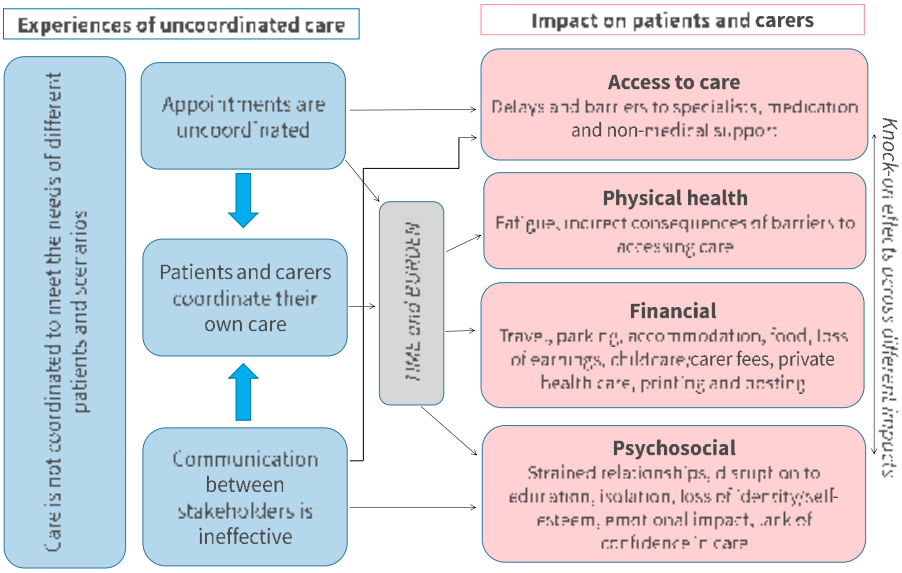
Findings

- Participants reported that their care was uncoordinated in four key ways (see 'experiences of uncoordinated care' in figure 1)
- Patients and carers were negatively impacted in terms of their finances, psychosocial and physical wellbeing, and access to care (see figure 1).
- Many of the impacts were attributed to the time and burden felt by the individual(s) who attended appointments and took on the key role of coordinating care.

Negative impacts could be reduced by:

1. Having the support of a professional to coordinate care
2. Changing the approach of clinics and appointments (eg where they take place, which professionals/services are available and how they are scheduled)
3. Improving communication between professionals, services and patients (eg by using technology)

Figure 1: Patient and carer experiences of uncoordinated care and their impact



'I think anybody that's in a position like I am should have an appointed care coordinator, an appointed person to go to that pulls everything together, that looks at [the] whole person' **[patient and carer, diagnosed rare condition]**

'...there are instances where it has been coordinated well by being able to condense all my appointments into one day, which is obviously much kinder on the bank balance... Obviously, it's got a financial cost, but there's a physical cost there, you know, having to go to extra appointments when I needn't have to'. **[patient, diagnosed rare condition]**

'I would like there to be one central website where I could log in... I could see when he's due to see them next, I could message Consultants... and I could book appointments; maybe I could see his test results and stuff too... to actually access these digitally and online would be fantastic.' **[carer, undiagnosed rare condition]**

Conclusions

Our findings suggest that uncoordinated care has a negative impact on patients, and their families, in many different ways. Models of care coordination which lessen the time and burden placed on families may be particularly beneficial in reducing these impacts. Findings should influence future service developments (and the evaluation of such developments). In the first instance, findings will inform the COordiNated Care of Rare Diseases (CONCORD) Study.

GENETIC ALLIANCE UK

CONCORD STUDY Coordinated Care of Rare Diseases

FUNDED BY NIHR | National Institute for Health Research

Genetic Alliance UK is an alliance of over 190 patient organisations and the national charity working to improve the lives of patients and families affected by genetic conditions

The CONCORD project is funded by the National Institute for Health Research (NIHR) Health Services and Delivery Research Programme (project number 16/7/04). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care

MAKING THE VOICE OF OUR COMMUNITY HEARD

Our team sat on various committees, steering groups and attended numerous meetings during the year to represent the views of our community:

- Advanced Therapy Medicinal Products – The Landscape, Challenges & Opportunities in Wales
- Presented findings of mitochondrial research priority setting project to the Great Ormond Street Hospital metabolic clinical team
- Association for Responsible Research and Innovation in Genome Editing conference on genome editing
- BIO-Europe
- Breaking Down Barriers Advisory Board
- Congenital Anomalies and Rare Diseases Registration and Information Service for Scotland Expert Advisory Panel (Scotland)
- Co-applicant Delivering Genomic Sequencing In Clinical Practice: A Patient-centred Evaluation Of The New NHS Genomic Medicine Service
- CRISPR Ideas Symposium
- EURORDIS Round Table of Companies Summit on Newborn Screening
- EXPRESS study patient and public involvement group
- Genetic Counsellor Registration Board
- Genetics Evaluation Panel (Scotland)
- Genetics Laboratory Management Meeting (Scotland)
- Genomics Leadership Group (Scotland)
- Medicines Healthcare Regulatory Authority / Office of Life Sciences innovative regulation project interview
- National Genomics Board
- National Institute Health Research Bioresource Steering Committee
- National Patient, Public and Professional Involvement Group (Scotland)
- NHS England - Genomics People and Communities Forum
- NHS England - Genomics Programme Board
- NHS England - Patient and Public Voice Assurance Group
- NHS England - Specialised Commissioning Stakeholder Forum
- NHS England - Women and Children's Programme of Care Board Meeting
- NICE Guideline Committee - Children and young people with disabilities and severe complex needs
- NICE Methods review - working group and task and finish groups
- Office for Rare Conditions (Glasgow) Steering Group
- Office of Health Economics Expert Roundtable: Reform options for the next Voluntary Pricing and Access Scheme
- Preimplantation Genetic Testing Expert Panel (Scotland)
- Public Involvement Network Advisory Group Meeting (Scottish Medicines Consortium)
- Rare Disease Strategic Oversight Group Meeting
- Responding to genetic risk associated with customary consanguineous marriage
- Scotland Rare Disease Strategic Oversight Group
- Scottish Medicines Consortium Patient Involvement Network (Scotland)
- Solve RD Community Engagement Task Force
- Steering Group Meeting
- Wales Rare Disease Oversight and Implementation Group
- Welsh Conservatives 2021 Manifesto Roundtable

BUILDING GREATER AWARENESS

Social media

We continue to have a strong social media presence with varied audiences on our different channels. This year the combined reach of our channels grew to 21,000 on Facebook and 41,000 on Twitter and we saw a combined growth of 2,657 new followers on Instagram, and 541 new followers on Linked In. Press included articles in the media planet rare diseases supplement, the New Scientist, Pharma Times, The Sun and Sky News.

Genomics cafés

Public Genomics Cafés, delivered by Genetic Alliance UK and Wales Gene Park form part of the Genomics Partnership Wales engagement programme. These are free and open to all events which include short, relaxed talks about genomics relating to health and medicine, with guest slots from health professionals, researchers, and those affected by genetic and rare conditions who share personal experiences.

Since May 2020 events have been virtual with themed cafés, online engagement and e-networking. Translation to a virtual platform has been successful, with a positive effect on attendee numbers and broader audiences from across Wales and beyond. Six virtual Genomics Cafés have been held, reaching over 420 people from the public and rare disease community.

In October 2020, a Young People's Genomics Café – primarily aimed at the 16 to 25 age group – was launched. Two events have been held to date, attracting over 225 attendees.

Annual Rare Disease Patient Network meeting (Wales)

The annual Rare Disease Patient Network meeting was held virtually in December 2020 and was attended by 71 people affected by rare and genetic conditions. The meeting included the launch of Rare Experience 2020 report in Wales.

UNDIAGNOSED CHILDREN'S DAY

Undiagnosed Children's Day takes place every year on the last Friday of April. Falling this year in the first national lockdown our plans were drastically impacted by the pandemic. We had to cancel our planned events and activities and move everything online at the last minute. Unsure how much engagement we would get as everyone was struggling to adjust to lockdown and shielding, the day ended up providing much needed light relief for the SWAN UK community.

Adapting the hashtag #PaintLockdownPink people took to social media to join in the fun in various ways including dying their hair and beards pink, baking pink cakes and having pink makeovers!

SWAN UK Twitter channel was taken over by our Parent Reps and bloggers who shared their experiences on the day.

RARE DISEASE DAY 2021

Rare Disease Day takes place at the end of February each year. In 2021, it took place on Sunday 28 February and was celebrated in more than 85 countries around the world. Through our campaign Rare Disease UK, we are the official organiser of the day in the UK.

This year our activities were planned around three aims:

- Utilise the unique opportunity provided by the Covid-19 pandemic to build greater understanding of what it is like to live with a rare disease, and the importance of research to provide answers.
- Unite the UK's rare community to have a strong, amplified voice with which to share their stories and experiences.
- Show our solidarity with the rare disease community in other European countries in light of Brexit.

For the first time, we decided to use the international EURORDIS branding for the day. We ran a six month programme of activities leading up to the day, starting with stakeholder planning events in the Autumn.

The official video,generated from user footage, was reviewed over 5,000 times and accompanied by a story a day published on our website (see pages 19 and 20). We also launched a new TikTok channel and Instagram filter.

TWITTER
February - 641K impressions
28 February - 124,173 impressions
#RareDiseaseDay 2021 trending

FACEBOOK
344 new likes on day
#RareDiseaseDay2021 used in 31k posts

INSTAGRAM
New followers up 82% from January
Content interactions up by 972.5%
Instagram filter used by 1.1k people, 43.7 impressions

TIKTOK
100 followers in first week.
#ShowMeYourRare challenge video viewed almost 3K times

Virtual parliamentary event

In February we hosted the **first ever UK-wide parliamentary event** bringing together Health Ministers, parliamentarians, and health officials from all four nations. The meeting focussed on the implementation of the new UK Rare Diseases Framework in each UK nation. Over 230 people attended the event and Ministers from England, Scotland and Northern Ireland were able to contribute to the meeting. The video of the event of the meeting has since been viewed over 170 times.

'It's a great conference. Very touching stories.'
Lord Bethell

'I think the event went beautifully. There were some really amazing speakers and I look forward to checking out some of the sections again.'
Rhoda Walker, Chair, NIRDP

'It was a great event. Everyone seemed very engaged and to get the sort of line up you did from all four nations was really very impressive and hopefully reflects the level of interest and focus on the subject.' Sarah Walker, Senior Consultant Policy and Public Affairs, MAP BIO PHARMA

'I wanted to say thanks for a really excellent and engaging event this morning. I was genuinely gripped throughout and took lots of notes.'
Jessica March, Associate Director for Public Policy & Government Affairs, UK & Ireland

Rare Disease Day video and stories

The **UK's official video** was produced using footage supplied from the community, with a daily blog post published throughout February to accompany it.

This year we wanted to do something different that highlighted the highs and lows of having a rare condition. We also wanted to have the wider community more involved in the official video for the day so invited people to submit their footage to be included. Over 100 people sent up clips and 28 people also volunteered to share their stories to accompany it - you can read these by clicking on the image below and on pages 19 and 20.

RARE DISEASE DAY 2021 VIDEO

Rare Disease Day stories

Click on the images below to read the stories

LAUREN'S STORY

LUCY'S STORY

ABIGAIL'S STORY

WILL'S STORY

KIRSTY'S STORY

GAIL'S STORY

SALLY'S STORY

PAM'S STORY

MEGAN'S STORY

MARY'S STORY

CHRISTINE'S STORY

MYA'S STORY

NUALA'S STORY

RAJ'S STORY

PHIL'S STORY

CHARLOTTE'S STORY

LEANNE'S STORY

CORRINNE'S STORY

DOTTIE'S STORY

SARAH'S STORY

JESSICA'S STORY

JEMMA'S STORY

KAT'S STORY

FRANCESCA'S STORY

SUZANNE'S STORY

KAREN'S STORY

RACHEL'S STORY

RARE REACH FESTIVAL

Launched on Rare Disease Day, the Rare Reach Festival social media awards were a celebration of storytelling in the rare community. Over 100 entries were shortlisted by our judges: Lara Bloom from Ehlers Danlos Society, paralympian Natasha Coates, Cardigan Hughes from Same but Different, Rachel Farrow from Route 73 Consulting and Gavin Jones from Open Health. Click on the images to view the entries.

PEOPLE'S CHOICE AWARD
@jessicamayhall

BEST STORYTELLING BY A SMALL CHARITY
THE APLASTIC ANAEMIA TRUST

BEST IN SHOW
LUKE PEMBROKE'S 'A HAEMOPHILIA GENE THERAPY JOURNEY' (IN THE INDIVIDUAL CAT)

BEST STORYTELLING BY A VOLUNTARY GROUP
TIMOTHY SYNDROME ALLIANCE

BEST STORYTELLING BY A FAMILY MEMBER
ZAINAB @ADNANTHEKALEJU

BEST STORYTELLING BY A YOUNG PERSON
ROBBIE @MEMYSELFANDBEHCETS

BEST STORYTELLING BY A LARGE CHARITY OR INDUSTRY
NERVE TUMOURS UK

BEST STORYTELLING BY AN INDIVIDUAL
LUKE PEMBROKE

BUILDING OUR COMMUNITY

WORKING WITH OUR MEMBERS

We are proud to be the UK's largest alliance of organisations supporting the genetic, rare and undiagnosed community. Made up of over 200 members ranging from the large to the tiny, we welcomed 12 new members this year (see page 23). Over 50% of our members are small charities or voluntary led and represent a range of conditions from the rare to the ultra rare. We also have a number of umbrella organisations or those working within our community to support or upskill others.

Covid-19 and the move to virtual working and events has had a positive impact on our relationship with our member organisations encouraging a more interactive and dynamic interaction. This has given us a greater understanding of the issues many of our members, especially the smaller ones, are facing and how we can support them. Using the weekly community check-in we have hosted discussions on diverse topics to aid sharing tips and good practice including running virtual meetings, collaborating with industry, pairing with MSC student for research and supporting mental wellbeing. We also hosted sessions on the NICE methods review, the new genomic medicine service and the new Medics for Rare Diseases Rare Diseases 101 platform.

Our closer relationship with our members has been mirrored in taking a more proactive approach to engaging with them on our social media channels to help amplify their voice and showcase their work. We helped promote numerous awareness campaigns and during the run-up to Rare Disease Day we provided branded assets for 25 organisations. In partnerships with Findacure, we also ran three social media workshops to support organisations to produce their own graphics.

Despite the pandemic we have continued to offer information and support to individual members on a range of topics including access to medicine and new born screening. We also responded to over 1,000 emails and phone calls asking for information on a topics including insurance, access to genetic testing, PGD and vaccines and rare conditions.

NEW MEMBERS

Genetic Alliance UK is the largest alliance of organisations supporting people with genetic, rare and undiagnosed conditions in the UK. Our members and the people they support are at the heart of everything we do. We were delighted to welcome 12 new members this year.

Syngap Research Fund

Neuroendocrine Cancer UK

Cure Myotonic Dystrophy UK

The Schinzel-Giedion Syndrome Foundation

Cystinosis Foundation UK

NF2 Biosolutions

Hadiza foundation

Northern Ireland Rare Disease Partnership

PIP-UK

SarcoidosisUK

Medics for Rare Diseases

Hope for Hasti

RARE RESOURCES – SCOTLAND

Rare Resources (Scotland) is a project designed to address the gaps in information and support provided to people living with, or caring for a person living with, a rare condition in Scotland.

Through co-production with our community we have developed the **Rare Resources Toolkit** - a downloadable, toolkit of information for families in Scotland who have recently received a diagnosis of a genetic or rare condition.

The toolkit contains a wide range of general information on genetic, rare and undiagnosed conditions as well as information on how to access reliable information, care and support in Scotland.

In 2021, we have expanded the toolkit to include a **short leaflet for adults** receiving a diagnosis of a rare condition. We have also developed a **helpful leaflet for health professionals**, designed by people living with a rare condition, which explains how they wish to be treated and where health professionals can access further information and training.

Due to the Covid-19 pandemic, plans to deliver a Rare Resources Roadshow in Scotland were postponed. The Roadshow was intended to feature a series of informal information sessions for people living with a rare, genetic condition, delivered in collaboration with local support, and healthcare services in six locations across Scotland.

Whilst the Roadshow could not take place, as part of the project, to we delivered a series of online events, activities to offer families support during the lockdown periods.

Events included:

- A virtual mental health support session delivered by Breathing Space
- Brew and Blether sessions (six informal coffee-morning sessions for people to share their experiences of lockdown - attendees were offered a mug, biscuit and tea bags to be posted to them)
- A Q and A session with Scottish Government's Vaccination Team

Over 40 people attended these events and we also offered 30 'boredom packs' for children living with rare, genetic and undiagnosed conditions during lockdown. The boredom packs contained fun craft activities for children.

3.2 What does NHS Scotland provide for children?

NHS Scotland is responsible for providing care for children with genetic, rare or undiagnosed conditions in Scotland.

This includes GP appointments, appointments with specialist clinicians, visits to NHS regional genetic centres and a wide variety of other services.

NHS Scotland also commissions specialist services for rare conditions, including services for genetic and undiagnosed conditions.

The services available for genetic, rare or undiagnosed conditions are varied and wide ranging.

The National Services Division (NSD) is responsible for the national commissioning for very specialist services that cannot be provided at a local or regional level.

These services are generally concerned with the diagnosis and/or treatment of rare conditions.

The diversity of rare conditions and the specialist knowledge required to diagnose and treat them mean that it is not always possible to have a service for a rare condition available near to home.

Sometimes a specialist can't be found in Scotland and a child will have to travel to another part of the UK to access specialist care.

National Service Division is responsible for the commissioning of specialist services from elsewhere in the UK and ensuring that Scottish patients are able to access them.

There are also National Managed Clinical Networks (NMCNs) that link together health professionals, patients, third sector organisations and other partners to improve access to services for patients who often have complex or rare conditions.

For example, the Children with Exceptional Healthcare Needs NMCN exists to strengthen specialist services for children in Scotland with complex and exceptional healthcare needs.

PAGE FROM THE RARE RESOURCES SECTION: NAVIGATING THE NHS IN SCOTLAND

RARE resources SCOTLAND

1 Genetic, rare and undiagnosed conditions explained

FRONT PAGE OF RARE RESOURCES: GENETIC, RARE AND UNDIAGNOSED CONDITIONS EXPLAINED

SWAN UK

It was a difficult year for our SWAN UK families as they struggled to cope with the pandemic, shielding and lack of clear information about the risk of Covid-19 for their families.

Welcoming 195 members, this was a drop compared to previous years, and caused by the impact of Covid-19 on our usual outreach channels. We now support 3,476 members across the UK.

Family events

With all of our usual regional events cancelled, we quickly put a new programme of support in place including virtual drop ins, kids quizzes and discos and a Christmas sing and sign event. We also ran targeted outreach and support to SWAN UK dads including sending out care packages and running a comedy night.

'Guy's, for those who joined the Comedy Night and those who stayed on afterwards, what a great night and a BIG SHOUT OUT to the organisers, thank you.' SWAN UK dad

'Nice surprise with the bag of tricks, thank you. The chocolate was lovely and my youngest loved the Whoopi cushion….They've been in stitches with it before bath time...been the best fun all lockdown.' SWAN UK dad

Emotional support

Recognising the additional emotional stress of Covid-19, we also piloted running weekly group counselling sessions for 23 parents.

'I found it really helpful to connect with others who I could speak with freely without judgement. I felt able to talk about things that I hadn't had the opportunity to 'offload' in a safe and supportive space.' SWAN UK member

Parent Reps and the SWAN UK Council

Our usual volunteering programme has been paused during the pandemic but we have continued to meet virtually with our Parent Reps and SWAN UK Council members. They have helped us to continue to monitor the impact of Covid-19 on the undiagnosed community and how we can respond.

SWAN UK - Cymru

We were delighted this year to successfully be awarded a three year grant from the National Lottery in Wales to expand our SWAN UK support network in Wales. Our new bi-lingual outreach worker joined us in January and we officially launched the project on St David's Day with our first ever bi-lingual newsletter. We also have new bi-lingual social media channels and are working on a Rare Resources: Cymru toolkit.

LOUISE JAMES, CHAIR, SWAN UK COUNCIL

GWANWYN 2021
Cylchlythyr Chwarterol

SPRING 2021
Quarterly Newsletter

SWAN UK
syndromes without a name

FRONT COVER OF THE BI-LINGIAL SWAN UK CYMRU NEWSLETTER

BUILDING OUR ORGANISATION

As for many charities, the pandemic was a disruptive event that forced us to respond quickly and proactively to ensure our future. The financial situation at the end of the previous year meant that the team was primed to react quickly to the financial risks that the pandemic brought. We moved quickly to virtual working and made the difficult decision to furlough the majority of our staff team over the summer. The majority of our funders also reacted quickly to the urgent need to deliver a service to our community. The combination of our quick reaction and the support of our funders has allowed us to build back our organisational reserves despite the challenging circumstances.

Our organisation has now embraced the opportunities of virtual working and working from home. Those few team members for whom home working is not possible have had necessary adjustments made, with desk space rented as needed.

We undertook a full organisational and fundraising review exploring where we could make savings, work more effectively and how to maximise our fundraising capacity. As a result of the restructure we merged all our membership support activities with our work with the SWAN UK community into a new Engagement and Support department. This resulted in three new hybrid roles and some empty posts being made redundant. This allowed us to streamline our staff team to ensure we are working in the most cost effective way.

Our work with an external fundraising consultant identified areas of strength and areas of potential growth but the full execution of these plans were disrupted by the pandemic. The strength and dedication of our team however ensured that despite having very limited team fundraising capacity, we successfully gained funding for our Covid-19 relief programme, and a new grant from the National Lottery to develop a SWAN UK network in Wales. At the end of 2020-21 we recruited a new Director of Fundraising who developed a new three year fundraising strategy.

At the time of writing we are pleased to note that the average length of service of the current team is more than five years, and that eight out of the eighteen of the team have been with us longer than this time. The commitment of our staff, combined with their high levels of expertise, fosters a strong institutional memory - the latter of which we are also continuing to embed in new processes to reduce the potential risk associated with any future staff departures. The stability of the team, and strong working relationships between team members, allowed a smooth transition to virtual working and maintaining our team culture. It is also thanks to their dedication and hard work that we are ending this year in a much stronger financial position than the previous year.

MEMBERS OF THE GENETIC ALLIANCE UK TEAM

THE COMING YEAR

This has been a transitional year for Genetic Alliance UK in many ways. As we move forward into 2021/22 and beyond our focus will be on developing a sustainable and responsive organisation. Responsive to the changing national context as we move beyond the pandemic, responsive to a post Brexit world and most importantly, responsive to the needs of the community we serve - everyone affected by a genetic, rare or undiagnosed condition.

With our mid-point strategy review due in the Autumn, we will take this opportunity to reflect on our many successes over the last few years, but also be open and honest about the areas where we will have more work to do. As the UK's largest alliance of rare genetic organisations, we have a responsibility to ensure that all voices are heard. So with a spirit of collaboration at the heart of everything we do, we will focus on strengthening existing relationships with our members and key stakeholders whilst also forging new, and repairing lapsed ones. We will strive to give our members the best possible platform to achieve their aims, including by introducing new member benefits to amplify their voice.

As we continue to welcome new members we will particularly focus on ensuring the voice of people living with rare conditions is as diverse as possible. During 2021/22 we will undertake a full diversity and inclusion review of our internal and external working practices and commit to taking action to make our organisation fully representative of the community we serve.

Following the publication of the UK Rare Diseases Framework at the beginning of 2021, this year will be crucial to maximising the potential of this policy opportunity. We will put significant resources into ensuring that there are as many voices of people living with genetic, rare and undiagnosed conditions feeding into the development of the four nations' action plans as possible. This will be done by empowering our membership to take up formal representative roles and ensuring our team members are connected to these roles, and also by empowering our broadest networks to feed into the process. We will support all these representatives and provide a forum for them to exchange information and support each other. It is crucial that we carry the thread of inclusion through to this element of our work so that the voice of our community in this process is diverse and representative.

The Framework has the potential to bring together many of our policy priorities including diagnosis, screening and access to medicines for rare conditions. We will continue to engage closely with the development of genomic medicine across the UK, and in the myriad expected opportunities to improve access to medicines for rare conditions that will arise from the Innovative Licensing and Access Pathway, the Innovative Medicines Fund and the NICE Methods and Process Review.

To an extent our strong performance in fundraising in the previous year was related to a quick reaction to the Covid-19 need, and the novelty of the situations charities in our sector faced. The funding environment is still constrained by the impacts of the pandemic, and the challenges our community faces continue to be considerable. This means income generation may be more difficult in this year than the previous. We intend to broaden our income streams as much as possible, broadening our relationships with corporate funders while maintaining our independence, expanding our approach with trusts and foundations, while maintaining the growth of our community fundraising activities. We will also explore and encourage collaborative and partnership funding to ensure the sustainability of the whole community.

We have no immediate plans to return to a fully staffed office in the near future and instead will utilise a hybrid approach with some staff members co-located in shared workspace, while the majority of the team work from home. Once the team is fully-vaccinated, we will consider how we can regularly bring the team together to foster and maintain the sense of team spirit that was a key element of our previous office-based environment.

Having had a transitional year, our focus is now on laying the groundwork for a sustainable future, which we will set out in detail in our upcoming strategy review.

TREASURER'S LETTER AND FINANCIAL REVIEW

31 March 2021

Thank you to all our members and funders. You have ensured that the work outlined in this report could continue at such a challenging time for the people we support.

REVIEW OF THE FINANCIAL POSITION

INCOME

The results for the year are set out in the statement of financial activities on page 37. The total income for year was £939,440 (£804,434 in 2020).

The increase in income is a significant achievement in a challenging fundraising environment. It was driven principally by a greater level of funding from our supporters as shown in Note 2 of the Financial Statements. We were also able to access support from the Government's Job Retention Scheme as the pandemic continued to disrupt our operations.

Expenditure

Total expenditure for the year was £808,907 (£1,005,274 in 2020).

The decrease in the spending is principally due to a marked fall in the funding secured for specific projects in support of our charitable activities and the disruption caused by the Covid-19 crisis.

The organisation also took a series of cost control measures during the year as part of the plan to ensure a more resilient financial position.

Surplus/Deficit

Our final financial position for the year across all funds is a surplus of £130,533 (deficit of £200,840 in 2020). The majority of the surplus is driven by a surplus on our unrestricted funds of £115,952 (compared to a deficit of £142,731 in 2020).

This reflects the changed income mix during the period and reduction in restricted project funding received.

Reserves Policy

Total reserves at the end of the financial year are £199,864 (£69,331 in 2020).

This is made up of restricted reserves of £39,134 (£24,513 in 2020) and unrestricted reserves of £160,730 (£44,778 in 2020).

The small increase in restricted reserves is due to slightly higher income then spending on specific projects as detailed in Note 18.

The increase in unrestricted reserves is due to the success of income raising efforts in the period, a reduction in spending as noted above and thoughtful cost control measures.

The Trustees have set a target in the medium term to hold unrestricted reserves that equate to approximately six months of unrestricted expenditure. Our current level of reserves has significantly increased over the year and is now approximately four months by this measure. This is a positive development, however, the Board and Executive Team are clear that income generation and cost control measures need to continue to ensure that we can maintain and maximise our impact in the years ahead.

Conclusion

The financial year ended 31 March 2021 was a challenging one for Genetic Alliance UK from an operational and financial perspective. However, at the year end the financial position shows a notable improvement from that seen 12 months prior.

At the time of writing, Covid-19 remains the dominant issue likely to impact during the current financial year, however, the Executive Team have demonstrated their ability to lead and manage in a challenging environment.

In this uncertain time, financial risk still remains and the year ahead will require a renewed focus on fundraising and continued cost consciousness. Genetic Alliance UK starts the period with stronger financial foundations and we are pleased that the Auditors have endorsed the view that Genetic Alliance UK remains a going concern and we will work to ensure that it continues to be there for all those who need.

D A Ramsden
Treasurer, Board of Trustees

REFERENCE AND ADMINISTRATIVE DETAIL

Governing document
The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

Registered company number
05772999

Registered charity numbers
1114195 & SC039299

Registered office
During the period of this report: Third Floor, 86-90 Paul Street London, EC24 4NE
Currently: Creative Works, 7 Blackhorse Lane, London, E17 6DS

Trustees
Ms S Butterworth
Ms G J Clark
Ms P A Farrant
Ms S J Hunt
Dr C Lewis
Mr N McClements
Ms S J Millman
Mrs E Porterfield
Mr D A Ramsden
Ms S Walsh
Mrs J S Wootton
Dr S Wynn

Board observer
Robin Nott

Chief Executive Officer
Dr Jayne Spink (until 31 March 2021)
Lauren Roberts and Nick Meade (appointed as Joint Interim Chief Executives 1 April 2021)

Management team
Dr Amy Hunter, Nick Meade, Lauren Roberts

Auditors
Nyman Libson Paul Chartered Accountants, Regina House, 124 Finchley Road, London, NW3 5JS

Management accountant
Fiona Bevan Financial Management

Bankers
CAF Bank Ltd, 25 Kings Hill Avenue, Kings Hill, West Mailing, Kent, ME19 4JQ
HSBC, Lion House, 25 Islington High Street, London, N1 9LJ
Virgin Money Saving, Jubilee House, Gosforth, Newcastle upon Tyne, NE3 4PL

Website
geneticalliance.org.uk

Facebook
GeneticAllianceUK

Twitter
GeneticAll_UK

Instagram
GeneticAllianceUK

LinkedIn
Genetic Alliance UK

STRUCTURE, GOVERNANCE AND MANAGEMENT

Constitution

Genetic Alliance UK is the trading name for Genetic Alliance UK Ltd, a registered charity and a company limited by guarantee, incorporated on 6 April 2006 and governed by its Memorandum and Articles of Association.

Appointment and training of Trustees

Trustees are elected by the membership. Members co-opted in year and new nominees must be proposed and seconded by a member. Trustee appointments are for three years, after which trustees retire but are eligible for re-election for a further term of three years. New trustees must undertake an induction and are provided with an information pack detailing the charity's work, governance, management policies and procedures, and potential conflicts of interest that may arise.

Governance and organisational management

Trustees met five times in the year ending 31 March 2021, where they reviewed the charity's performance and determined and approved operating plans and budget. Trustees delegate certain powers in connection with the charity's management, remuneration (related to responsibility and market comparisons) and administration to the Finance and Governance (F&G) committee, which met four times in the year. The Finance and Governance Committee provides detailed oversight and advice to the Board of Trustees in relation to financial management, financial viability, risk management and governance. The Finance and Governance committee has a minimum of three Trustee members, appointed from and by the Board of Trustees that includes the Treasurer (Chair of the Committee), Chair of Genetic Alliance UK and the Deputy Chair. The Chief Executive Officer and Directors of Genetic Alliance UK are ex officio.

Risk management

Trustees have considered the major risks to which the charity is exposed and have established procedures including a risk register to identify and manage those risks. A new Covid-19 risk register has also been produced. All risks are reviewed at each meeting of the Board of Trustees and by the Finance and Governance Committee.

Fundraising

Genetic Alliance UK undertakes most of its fundraising activities in-house but used a consultant solely for the purposes of large grant applications. Genetic Alliance UK is registered with the Fundraising Regulator and have adhered to the codes of ethics laid out by the Fundraising Regulator and The Code of Fundraising Practice in relation to all fundraising activities. The charity received no complaints about its fundraising practice in this financial year.

Governing document

The charity is controlled by its governing document, a deed of trust, and constitutes a limited company, limited by guarantee, as defined by the Companies Act 2006.

TRUSTEE RESPONSIBILITY

The trustees (who are also the directors of Genetic Alliance UK Ltd for the purposes of company law) are responsible for preparing the Report of the Trustees and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice).

Company law requires the Trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period.

In preparing those financial statements, the trustees are required to:

- Select suitable accounting policies and then apply them consistently.
- Observe the methods and principles in the Charity SORP.
- Make judgements and estimates that are reasonable and prudent.
- Prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The Trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006.

They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- There is no relevant audit information of which the charitable company's auditors are unaware.
- The Trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

Auditors

The auditors, Nyman Libson Paul Chartered Accountants, will be proposed for re-appointment at the forthcoming Annual General Meeting.

Report of the trustees, incorporating a strategic report, approved by order of the board of trustees, as the company directors, on 11 August 2021 and signed on the Board's behalf by:

Elizabeth Porterfield,
Chair, Board of Trustees

INDEPENDENT AUDITOR'S REPORT TO THE MEMBERS OF GENETIC ALLIANCE UK

Opinion

We have audited the financial statements of Genetic Alliance UK Ltd for the year ended 31 March 2021 set out on pages 37 to 53 which comprise the statement of financial activities, the balance sheet, the cash flow statement and the related notes, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards, including Financial Reporting Standard 102 The Financial Reporting Standard applicable in the UK and Republic of Ireland (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- Give a true and fair view of the state of the charitable company's affairs as at 31 March 2021, and of its incoming resources and application of resources, including its income and expenditure, for the year then ended;
- Have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice; and
- Have been prepared in accordance with the requirements of the Companies Act 2006, the Charities and Trustees' Investment (Scotland) Act 2005 and regulations 6 and 8 of the Charities Accounts (Scotland) Regulations 2006 (amended).

Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditor's responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

Conclusions relating to going concern

In auditing the financial statements, we have concluded that the directors' use of the going concern basis of accounting in the preparation of the financial statements is appropriate.

Based on the work we have performed, we have not identified any material uncertainties relating to events or conditions that, individually or collectively, may cast significant doubt on the company's ability to continue as a going concern for a period of at least twelve months from when the financial statements are authorised for issue.

Our responsibilities and the responsibilities of the directors with respect to going concern are described in the relevant sections of this report.

Other information

The Trustees are responsible for the other information. The other information comprises the information included in the Trustees' annual report, other than the financial statements and our auditor's report thereon. Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to

be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact.

We have nothing to report in this regard.

Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- The information given in the trustees' report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- The directors' report has been prepared in accordance with applicable legal requirements.

Matters on which we are required to report by exception

In the light of our knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Report of the Board of Trustees and Accounts.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Accounts (Scotland) Regulations 2006 require us to report to you if, in our opinion:

- Adequate accounting records have not been kept, or returns adequate for our audit have not been received from branches not visited by us; or
- The financial statements are not in agreement with the accounting records and returns; or
- Certain disclosures of directors' remuneration specified by law are not made; or
- We have not received all the information and explanations we require for our audit; or
- The Trustees were not entitled to prepare the financial statements in accordance with the small companies' regime and take advantage of the small companies' exemption in preparing the Report of the Board of Trustees and Accounts.

Responsibilities of trustees

As explained more fully in the Trustees' responsibilities statement set out on page 33 the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the Trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

Auditor's responsibilities for the audit of the financial statements

We have been appointed auditor under section 44(1)(c) of the Charities and Trustees Investment (Scotland) Act 2005 and under the Companies Act 2006 and report in accordance with regulations made under those Acts.

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue an auditor's report that includes our opinion. Reasonable assurance is a high level of assurance but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

Irregularities, including fraud, are instances of non-compliance with laws and regulations. We design procedures in line with our responsibilities, outlined above, to detect material misstatements in respect of irregularities, including fraud. The extent to which our procedures are capable of detecting irregularities, including fraud is detailed below:

We gained an understanding of the legal and regulatory framework applicable to the company and the industry in which it operates and considered the risk of acts by the charity that were contrary to applicable laws and regulations, including fraud. We designed audit procedures to respond to the risk, recognising that the risk of not detecting a material misstatement due to fraud is higher than the risk of not detecting one resulting from error, as fraud may involve deliberate concealment by, for example, forgery or intentional misrepresentations, or through collusion.

We focussed on laws and regulations which could give rise to a material misstatement in the financial statements, including, but not limited to, the Companies Act 2006.

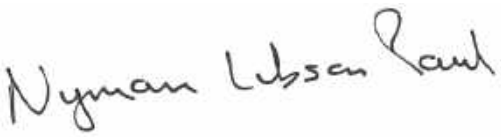
Our tests included agreeing the financial statement disclosures to underlying supporting documentation and enquiries with management. There are inherent limitations in the audit procedures described above and, the further removed non-compliance with laws and regulations is from the events and transactions reflected in the financial statements, the less likely we would become aware of it. We did not identify any key audit matters relating to irregularities, including fraud. As in all our audits, we also addressed the risk of management override of internal controls, including testing journals and evaluating whether there was evidence of bias by the trustees that represented a risk of material misstatement due to fraud.

We also communicated relevant identified laws and regulations and potential fraud risks to all engagement team members and remained alert to any indications of fraud or noncompliance with laws and regulations throughout the audit.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at: www.frc.org.uk/auditorsresponsibilities. This description forms part of our auditor's report.

Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006 and to the charity's trustees, as a body, in accordance with Regulation 10 of the Charities Accounts (Scotland) Regulations 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditor's report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.



Jennifer Pope (senior statutory auditor)
for and on behalf of
Nyman Libson Paul LLP
Chartered Accountants
Registered Auditors
124 Finchley Road
London
NW3 5JS
Date: 11 August 2021

STATEMENT OF FINANCIAL ACTIVITIES INCLUDING INCOME AND EXPENDITURE ACCOUNT

Year ended 31 March 2021

	Note	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £	Total Funds 2020 £ (Restated)
Income from:					
Donations and legacies	**2**	584,410	349,473	933,883	761,400
Charitable activities	**3**	5,557	-	5,557	42,134
Investments			-	-	900
Total income		589,967	349,473	939,440	804,434
Expenditure on:					
Raising funds	**4**	105,444	-	105,444	117,812
Charitable activities	**5**	368,613	334,850	703,463	887,462
Total expenditure		474,057	334,850	808,907	1,005,274
Net income/(expenditure)	**8**	115,910	14,623	130,533	(200,840)
Transfers between funds	**18**	42	(42)	-	-
Net movement in funds		115,952	14,581	130,533	(200,840)
Total funds at start of year	**18**	44,778	24,553	69,331	270,171
Total funds at end of year	**18**	160,730	39,134	199,864	69,331

The Charity has no recognised gains or losses other than the results for the year as set out above.

All of the activities of the charity are classed as continuing.

The notes on pages 40 to 53 form part of the these financial statements
See note 11 for fund-accounting comparative figures

BALANCE SHEET
Year ended 31 March 2021

Company number: 05772999

	Note	2021 £	2020 £
Current assets			
Debtors	**12**	126,373	146,855
Cash at bank and in hand		239,896	112,055
		366,269	258,910
Liabilities			
Creditors : amounts falling due within one year	**13**	(166,405)	(189,579)
Net current assets		199,864	69,331
Total assets less current liabilities		199,864	69,331
Net assets		199,864	69,331
FUNDS			
Unrestricted funds			
General funds	**19**	62,409	44,778
Designated funds	**19**	98,321	-
Restricted funds	**19**	39,134	24,553
Total funds		199,864	69,331

These financial statements have been prepared in accordance with the special provisions for small companies under Part 15 of the Companies Act 2006.

These financial statements were approved by the Trustees on 11 August 2021 and are signed on their behalf by:

Liz Porterfield
Chair of Trustees

The notes on pages 40 to 53 form part of the these financial statements

CASH FLOW STATEMENT
Year ended 31 March 2021

	Note	2021 £	2020 £
Net cash inflow from operating activities	**15**	127,841	(183,259)
Non-operational cash flows:			
Investing activities			
Investment income		-	900
		-	900
Net cash inflow/(outflow) for the year	**16**	127,841	(182,359)

Cashflow Restrictions

Charity law prohibits the use of net cash inflows on any endowed or other restricted fund to offset net cash outflows on any fund outside its own objects, except on special authority. In practice, this restriction has not had

The notes on pages 40 to 53 form part of the these financial statements

NOTES TO THE FINANCIAL STATEMENTS
Year ended 31 March 2021

1 Accounting policies

Accounting convention
The financial statements have been prepared under the historical cost convention, and in accordance with the companies Act 2006, the Charities Act 2011, the Financial Reporting Standard 102 (FRS102) and the requirements of the Charities Statement of Recommended Practice based thereon.

The charity is a public benefit entity as defined under FRS102.

Going concern
Following significant forward planning, fundraising efforts and other initiatives undertaken in early 2020, when the Charity was facing a challenging future, the Trustees and Executive have been able to reverse the financial decline and are able to report an unrestricted fund surplus for the year ended 31 March 2021 of £115,952, compared to a deficit for the previous year of £144,667. As a result of this outturn the Charity's unrestricted free reserves (general and designated funds) stand at £160,730 as at 31 March 2021, providing a solid base from which to continue to build reserves.

The charity did face additional challenges in the year arising from the economic and other consequences of the Covid-19 pandemic but any adverse effects were countered by the careful planning and budgeting undertaken.

The Trustees have now reviewed the current circumstances of the Charity and updated budgets, forecasts and projections for the next 12 months have been prepared. Prudent assumptions indicate that the Charity will earn a small surplus for the year ending 31 March 2022 and that adequate liquid resources will continue to be available to fund the activities of the charity for the forseeable future.

Accordingly, the Trustees consider it appropriate for the Charity to continue to adopt the going concern basis in preparing its financial statements.

Income
Income from donations is included in income when these are receivable, except as follows:

I. When donors specify that donations given to the charity must be used in future accounting periods, the income is deferred until those periods;
II. When donors impose conditions which have to be fulfilled before the charity becomes entitled to use such income, the income is deferred until the pre-conditions have been met.

Grants, including government grants are accounted for as receivable and are allocated to Income from Donations and Legacies. Other grants which are received subject to the charity providing a specific level of service are included within Income from Charitable Activities.

Membership income is accounted for as receivable.

Investment income is included on a receivable basis.

Donations in kind comprise donated services where the costs are measurable and the services would otherwise have to be paid for to maintain operational effectiveness.

1 Accounting policies *(continued)*

Expenditure

Expenditure is recognised in the period in which it is incurred. Expenditure includes attributable VAT which cannot be recovered.

Raising funds

Raising funds expenditure include those costs incurred in seeking voluntary contributions and other costs which include the costs of running and participating in fundraising events and collections.

Charitable Activities

Grants awarded are allocated to charitable activities.

Grants awarded are treated as expenditure and a liability in the accounts as soon as they become legal or constructive obligations. In the case of multi-year grant awards, the funding for all years is immediately recognised unless there are conditions which need to be met by the recipient to enable the release of subsequent years' funding.

Governance costs

Governance costs include those costs associated with meeting the constitutional and statutory requirements of the charity and include the audit fees and costs linked to the strategic management of the charity. Governance costs are included within support costs.

Allocation and apportionment costs

Certain expenditure is directly attributable to specific activities and this has been included in those cost categories. Other costs, which are attributable to more than one category, are apportioned across cost categories on the basis of an assessment of workload carried out from time to time.

Overhead support costs have been allocated between fundraising and charitable activities. The apportionment has been allocated on the basis of usage and is analysed in note 6.

Pension costs and other post-retirement benefits

The charity contributes to defined contribution pension schemes. Contributions payable to the charity's pension schemes are charged to the Statement of Financial Activities in the period to which they relate.

Fixed assets

Fixed assets are held at cost less accumulated depreciation. Assets costing less than £500 are not capitalised.

Debtors

Debtors are initially measured at the setlement amount after any trade discounts. Subsequently they are measured at the value of the consideration expected to be received.

Cash

Cash balances represent cash and cash equivalents held with a maturity date of less than one year and are included at fair value.

1 Accounting policies *(continued)*

Creditors

Creditors are measured at the settlement amount less any trade discounts.

Fund accounting

Unrestricted funds can be used in accordance with the charitable objects at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Designated funds form part of unrestricted funds and have been identified as being for particular purposes by the Trustees. They are not restricted and can be transferred to general funds at any time at the discretion of the Trustees.

Further explanation of the nature and purpose of each fund is included in note 18 to the financial statements.

2 Income from donations and legacies

	Unrestricted Funds	Restricted Funds	Total Funds 2021
	£	£	£
Donations from supporters	397,745	185,235	582,980
Wellcome Trust	50,590	-	50,590
University College London	-	44,841	44,841
The Corra Foundation	-	36,805	36,805
National Lottery funding	-	25,907	25,907
City Bridge Trust	-	25,700	25,700
Edward Gostling	4,994	-	4,994
Grants from Government			
National Lottery funding	-	20,026	20,026
Scottish Government	-	9,821	9,821
Covid Job Retention Scheme fund	67,202	-	67,202
Other grants received	1,000	-	1,000
Donations through fundraising:			
Community fundraising	7,552	-	7,552
Online donations	55,327	1,138	56,465
	584,410	349,473	933,883

2 Income from donations and legacies *(continued)*

Prior year

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
			(Restated)
Donations from supporters	58,564	241,450	300,014
Wellcome Foundation	95,000	-	95,000
University College London	-	64,563	64,563
Sheffield Hallam University	-	9,907	9,907
Other grants	-	85,000	85,000
Smaller grants	18,941	81,932	100,873
Grants from Government			
Department of Health and Social Care	20,000	-	20,000
Public Health England	25,000	-	25,000
Donations through fundraising:			
Community fundraising	13,039	-	13,039
Online donations	48,004	-	48,004
	278,548	482,852	761,400

3 Income from: Charitable activities

	Unrestricted Funds £	Restricted Funds £	Total Funds 2021 £
Consultancy work	5,557	-	5,557
	5,557	-	5,557

Prior year

	Unrestricted Funds £	Restricted Funds £	Total Funds 2020 £
			(Restated)
HFEA work	12,519	-	12,519
Conference receipts	8,890	-	8,890
Industry supporters	20,725	-	20,725
	42,134	-	42,134

4 Expenditure on: Raising funds

		Total Funds 2021 £	Total Funds 2020 £ (Restated)
Staff costs, including consultancy work		62,938	34,373
Fees		2,990	-
Other direct costs		44	5,403
Support costs	(Note 6)	39,472	78,036
		105,444	117,812

5 Expenditure on Charitable activities

	Direct Costs £	Support Costs (Note 6) £	Total Funds 2021 £
Membership and Engagement	110,002	114,597	224,599
Policy work	122,778	194,119	316,897
Research	71,233	90,734	161,967
	304,013	399,450	703,463

Prior year	Direct Costs £	Support Costs (Note 6) £	Total Funds 2020 £ (Restated)
Membership and Engagement	274,218	78,522	352,740
Policy work	257,935	127,362	385,297
Research	85,474	63,951	149,425
	617,627	269,835	887,462

£244,779 of the above support costs in notes 4 and 5 and £229,278 of direct costs relate to unrestricted funds spent during the year. £194,143 of support costs and £140,707 of direct costs relate to restricted funds spent during the year.
£254,271 of the above support costs in notes 4 and 5 and £209,313 of direct costs relate to unrestricted funds spent during the prior year. £93,600 of support costs and £448,090 of direct costs relates to restricted funds spent during the prior year.

6 Support costs

Support costs are allocated between raising funds and charitable activities on the basis of usage.
Support costs, included in notes 4 & 5, are as follows:

		Raising Funds	Charitable Activities	Total 2021
		£	£	£
Staff costs		32,455	271,435	303,890
Communications		1,637	13,691	15,328
Office and admin costs		5,380	44,999	50,379
Travel		-	231	231
Finance costs		-	889	889
Professional fees		-	58,005	58,005
Governance costs	(Note 7)	-	10,200	10,200
		39,472	399,450	438,922

Prior year		Raising Funds	Charitable Activities	Total 2020
		£	£	£
				(Restated)
Staff costs		34,154	127,983	162,137
Office and admin costs		43,882	97,203	141,085
Travel		-	28	28
Finance costs		-	971	971
Professional fees		-	36,407	36,407
Governance costs	(Note 7)	-	7,243	7,243
		78,036	269,835	347,871

7 Governance costs

		Total Funds 2021	Total Funds 2020
		£	£
Auditor's fees	- for audit services	7,200	7,200
Accounts review		3,000	-
Trustee expenses		-	43
		10,200	7,243

8 Net income/(expenditure) for the year

This is stated after charging:

		2021	2020
		£	£
Auditor's remuneration	- for audit services	7,200	7,200
Trustees' travel, meeting and training expenses		-	43

No Trustee received any remuneration during the year.

9 Staff costs and numbers

The aggregate payroll costs were:

	2021	2020
	£	£
Wages & salaries	483,459	528,270
Social security costs	47,496	49,269
Pension contributions	33,650	37,209
Redundancy costs	33,901	-
	598,506	614,748

The number of employees whose employee benefits exceeded £60,000 during the year were:

	2021	2020
Between £60,001 and £70,000	-	1
Between £70,001 and £80,000	1	-

The average weekly number of employees during the year was 17 (2020: 22), calculated on the basis of average headcount. The total employment benefits received by key management personnel including employer's national insurance and employer's pension contributions were £234,821 (2020: £246,460).

10 Taxation

The charity is exempt from corporation tax on its charitable activities.

11 Statement of Financial Activities comparative figures

For the year ended 31 March 2020	Unrestricted Funds £ (Restated)	Restricted Funds £ (Restated)	Total Funds 2020 £ (Restated)
Income from:			
Donations and legacies	278,548	482,852	761,400
Charitable activities	42,134	-	42,134
Investments	900	-	900
Total income	321,582	482,852	804,434
Expenditure on:			
Raising funds	116,888	924	117,812
Charitable activities	346,696	540,766	887,462
Total expenditure	463,584	541,690	1,005,274
Net income/(expenditure)	(142,002)	(58,838)	(200,840)
Transfers between funds	(2,665)	2,665	-
Net movement in funds	(144,667)	(56,173)	(200,840)
Total funds at start of year	189,445	80,726	270,171
Total funds at end of year	44,778	24,553	69,331

During the current year, the trustees reviewed the classification of income and expenditure, and reallocated the total amounts to better reflect the nature of the transactions in the light of the requirements of the Statement of Recommended Practice.

12 Debtors

	2021 £	2020 £
Due in less than one year:		
Trade debtors	125,729	66,665
Prepayments and accrued income	-	62,390
Other debtors	644	17,800
	126,373	146,855

13 Creditors: amounts falling due within one year

	2021	2020
	£	£
Trade creditors	7,551	87,442
Social security and other taxes	11,248	27,054
Other creditors	3,446	4,851
Accruals and deferred income	144,160	70,232
	166,405	189,579

14 Operating lease commitments

At 31 March 2021, the charity had future minimum lease payments under non-cancellable operating leases as follows:

	2021	2020
	Equipment	
	£	£
Expiry Date:		
Not later than one year:	5,171	5,839
Later than one year, and not later than 5 years:	-	6,464
	5,171	12,303

15 Reconciliation of net movement in funds to net cash inflow from operating activities

	2021	2020
	£	£
Statement of Financial Activities: Net movement in funds	130,533	(200,840)
Investment income	-	(900)
(Decrease)/increase in creditors: current liabilities	(23,174)	86,235
Decrease / (increase) in debtors	20,482	(67,754)
Net cash inflow/(outflow) from operating activities	127,841	(183,259)

16 Analysis of changes in cash during the year

	Note	2021 £	2020 £	Change £
Cash at bank and in hand		239,896	112,055	127,841

	2020 £	2019 £	Change £
Cash at bank and in hand	112,055	294,414	(182,359)

17 Analysis of changes in net debt

	1 April 2020 £	Cashflow Movements £	31 March 2021 £
Cash at bank and in hand	112,055	127,841	239,896
	112,055	127,841	239,896

Prior year	1 April 2019 £	Cashflow Movements £	31 March 2020 £
Cash at bank and in hand	294,414	(182,359)	112,055
	294,414	(182,359)	112,055

18 Movement in Funds

For the year ended 31 March 2021

	At 1 April 2020 £	Income £	Expenditure £	Transfers £	At 31 March 2021 £
Restricted funds					
Rare Disease Day 2018	28	-	(28)	-	-
Scotland Boost	-	9,821	(8,512)	-	1,309
Action for Access	13,047	10,000	(4,646)	-	18,401
Concord	1,061	44,841	(45,902)	-	-
RD PSPs	6,881	-	(1,439)	-	5,442
SWAN UK: Dads' Summit	-	6,364	(6,364)	-	-
SWAN UK Wales	-	25,907	(15,979)	-	9,928
Genomic Data	42	-	-	(42)	-
Building Rare Resilience	-	20,026	(20,026)	-	-
Talking about Gene Therapy	3,494	10,000	(9,440)	-	4,054
Patient survey	-	38,600	(38,600)	-	-
Rare Resources	-	2,846	(2,846)	-	-
Covid-19	-	158,505	(158,505)	-	-
Rare Disease Day	-	22,563	(22,563)		-
	24,553	349,473	(334,850)	(42)	39,134
Unrestricted funds					
General funds	44,778	182,069	(162,607)	(1,831)	62,409
Designated funds					
Rare Disease Day	-	60,000	(25,133)	-	34,867
Rare Disease UK General Donations	-	290,748	(227,294)	-	63,454
SWAN UK: General Donations	-	57,150	(59,023)	1,873	-
	44,778	589,967	(474,057)	42	160,730
Total funds	69,331	939,440	(808,907)	-	199,864

Fund descriptions

Restricted funds

Rare Disease Day - funds received to help with the costs of putting on our annual Rare Disease Day

Scotland Boost - funds received for the dissemination of a toolkit for families affected by genetic, rare and undiagnosed conditions.

Action for Access - funds received to help with the dissemination of the messages in the Action for Access report.

Concord - funds received for research on coordination of care in the UK and dissemination of findings.

RD PSPs - funds received for establishing, and dissemination of, research priorities for mitochondrial disease.

18 Movement in funds *(continued)*

SWAN UK: Dads' Summit - funds received for outreach for dads of children affected by undiagnosed genetic conditions
SWAN UK Wales - funds received for the development of a support network in Wales for families with children affected by undiagnosed genetic conditions
Genomic Data - funds were received to complete work to understand the attitudes of people living with genetic, rare and undiagnosed conditions and storage of their data.
Building Rare Resilience - funds are restricted to supporting our members with the challenges associated with Covid-19
Talking about Gene Therapy - funds are restricted to fund workshops with people living with rare and genetic conditions and report on the outcomes.
Patient survey - funds are restricted to implementing and analysing a survey on individuals' experiences of living with rare and genetic condition and disseminating the findings
Rare Resources - funds are restricted to the development and dissemination of a toolkit for families affected by genetic, rare and undiagnosed conditions

Designated funds

Rare Disease Day - funds were set aside by the trustees to support awareness of rare conditions. They will be spent on awareness raising activities.
SWAN UK General Donations - the trustees have set aside these funds received as general donations to SWAN UK, to ensure they are spent on activities within the SWAN UK community.

18 Movement in funds *(continued)*

For the year ended 31 March 2020

	At 1 April 2019 £	Income £	Expenditure £	Transfers £	At 31 March 2020 £
Restricted funds					
SWAN UK: BLF England	21,141	21,141	(42,282)	-	-
Rare Disease UK	-	224,950	(224,950)	-	-
Rare Disease Day 2018	20,000	73,750	(93,722)	-	28
Scotland Boost	-	-	(117)	117	-
Action for Access	10,000	54,000	(50,953)	-	13,047
Solve-RD	3,350	9,906	(15,192)	1,936	-
Concord	-	64,563	(63,502)	-	1,061
RD PSPs	26,235	5,000	(24,354)	-	6,881
SWAN UK: Dads' Summit	-	-	(612)	612	-
Genomic Data	-	3,042	(3,000)	-	42
Talking about Gene Therapy	-	26,500	(23,006)	-	3,494
	80,726	482,852	(541,690)	2,665	24,553
Unrestricted funds					
General funds	90,312	222,524	(266,121)	(1,937)	44,778
Rare Disease Day	-	16,630	(16,630)	-	-
Rare Disease UK General Donations	18,072	16,761	(34,716)	(117)	-
SWAN UK: General Donations	81,061	65,667	(146,117)	(611)	-
	189,445	321,582	(463,584)	(2,665)	44,778
Total funds	270,171	804,434	(1,005,274)	-	69,331

19 Analysis of net assets between funds

As at 31 March 2021	Restricted Funds £	Unrestricted Designated Funds £	Unrestricted General Funds £	Total £
Bank and cash	39,134	98,321	102,441	239,896
Other net assets	-	-	(40,032)	(40,032)
	39,134	98,321	62,409	199,864

19 Analysis of net assets between funds *(continued)*

As at 31 March 2020	Restricted Funds	Unrestricted Designated Funds	Unrestricted General Funds	Total
	£	£	£	£
Bank and cash	24,553	-	87,502	112,055
Other net assets	-	-	(42,724)	(42,724)
	24,553	-	44,778	69,331

20 Related party transactions

There are no transactions with trustees or other related parties other than those disclosed as required by the SORP elsewhere in the financial statements.

ACKNOWLEDGEMENTS

Thank you to all the individuals and organisations who have supported our work during this difficult year. We are so grateful to everyone who has worked with us, volunteered or fundraised for us, or supported our work in other ways. We would also like to thank all our funders who have given grants, sponsorship or donations to support our work this year.

Akcea Therapeutics
Albireo
Alexion
Amicus Therapeutics
BioCryst
Biogen
Bluebird Bio
Bond and Coyne
Chiesi
City Bridge Trust through London Community Response
CORRA Foundation
Covid-19 government emergency funding through National Lottery
Gilead
Illumina
Incyte
Janssen
Kyowa Kirin
Lupin Pharmaceuticals
Medpace
Novartis Gene Therapies
Novartis Pharmaceuticals
Orchard Therapeutics
Pfizer
PTC Therapeutics
Rhythm
Roche
Sanofi
Santhera
Sarepta
Sobi
Spark Therapeutics
Takeda
The Catherine Cookson Foundation
The Edward Gostling Foundation
The National Lottery Wales
UCB Celltech
Vertex
Vertex, Albireo
Wellbeing Fund in Scotland
Wellcome Trust

OUR MEMBERS

The Aarskog Foundation

Action Duchenne

Action FCS

Action on Gilbert's Syndrome

Addison's Disease Self-Help Group

Adrenal Hyperplasia Network

Advocacy for Neuroacanthocytosis Patients

Albinism Fellowship UK Ireland

Alex, The Leukodystrophy Charity

ALK Positive Lung Cancer (UK)

Alkaptonuria Society

Alpha-1 Awareness UK

Alpha-1 UK Support Group

Alport UK

Alström Syndrome UK

Amy and Friends

ANE International

Angelman UK

Aniridia Network

Annabelle's Challenge

Anorchidism Support Group

Antenatal Results and Choices

Archangel Mld Trust

Association For Glycogen Storage Diseases UK

Ataxia UK

Ataxia-Telangiectasia Society

Bardet-Biedl Syndrome UK

Barth Syndrome UK

Batten Disease Family Association

Beat SCAD

Beckwith-Wiedemann Support Group UK

Behçet's UK

BRCA Umbrella

British Heart Foundation

Cadasil Support UK

Cambridge Rare Disease Network

Cardiomyopathy UK

Cavernoma Alliance UK

CdLS Foundation UK and Ireland

CGD Society

CHAMP1 Patient Support Group

Charcot-Marie-Tooth UK

Childhood Eye Cancer Trust

Childhood Tumour Trust

Children's Liver Disease Foundation

Children's Mitochondrial Disease Network

Children's Health Scotland

CML Support Group

Congenital Adrenal Hyperplasia Support Group

Costello Support Group International

Cri Du Chat Syndrome Support Group

Cure and Action for Tay-Sachs Foundation

Cystic Fibrosis Trust

DC Action

DDDC3G Renal Support Group UK

Dercums Disease and Rare Disease Foundation UK

Diamond Blackfan Anaemia Support Group UK

Dravet Syndrome UK

Duchenne Family Support Group

East Lancashire Community Genetics Service

East London Branch Sickle Cell Society

Ehlers-Danlos Society

EHLERS-DANLOS SUPPORT UK

ELIJAH'S HOPE

FANCONI HOPE CHARITABLE TRUST

Fap Gene Support Group

Fibromuscular Dysplasia Society

Fibrous Dysplasia Support Society UK

Fight for Sight

Findacure

FND Hope UK

FSH Muscular Dystrophy Support Group

Fuchsfriends UK

Funny Lumps

GATA2 Deficiency Support Group

GENE People UK

George Pantziarka TP53 Trust

GIST Support UK

Gorlin Syndrome Group

HAE UK

Haemochromatosis UK

Haemophilia Society

Headlines Craniofacial Support

Hereditary Spastic Paraplegia Group

HPS Network UK

Huntington's Disease Association UK

Hypermobility Syndromes Association

Ichthyosis Support Group

IIH UK

Inherited Prion Disease Support Group

Jeune Syndrome Foundation

Jnetics

KIF1A.ORG

Kleefstra Syndrome

Krabbe UK

Leber's Hereditary Optic Neuropathy Society

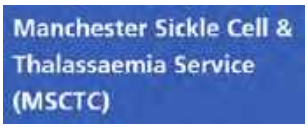
Lipodystrophy UK

Local Families With Bleeding Disorders

Lynch Syndrome UK

Macular Society

Making It Better - The Daniel Courtney Trust



Manchester Sickle Cell and Thalassaemia Centre

Marfan Trust

Mast Cell Action

Max Appeal

MEBO Research

Metabolic Support UK

Moebius Research Trust

Motor Neurone Disease Association

Mowat-Wilson Syndrome Support Group

MPGN/DDD Support Group

Muscle Help Foundation

Muscular Dystrophy UK

Myotubular Trust

Naitbabies

Narcolepsy UK

National Deaf Children's Society

NCBRS Worldwide Foundation

Nemaline Myopathy Support Group

Nerve Tumours UK

Niemann-Pick UK

NLRP12.COM

Noonan Syndrome Association

Ocumel UK

Osteopetrosis Support Trust

Pans Pandas UK

Parathyroid UK

Pemphigus Vulgaris Network

Pitt Hopkins UK

PNH Support Group

Prader-Willi Syndrome Association UK

Primary Ciliary Dyskinesia Family Support Group

Primary Immunodeficiency UK

PSC Support Group

Pseudoxanthoma Elasticum Support Group

PTEN UK and Ireland Patient Group

Rare Autoinflammatory Conditions Community - UK

Rare Dementia Support

RETT UK

Reverse RETT

RING20 Research and Support UK

SADS UK

Salivary Gland Cancer UK

Scleroderma And Raynaud's UK

Sense Usher Service

Shwachman-Diamond Support UK

SOFT UK

Special Needs Jungle

Spinal Muscular Atrophy UK

Spotlight YOPD

Stargardt's Connected

Stickler Syndrome UK

Stiff Person Syndrome

Thalidomide Society

The Aortic Dissection Charitable Trust

The Aplastic Anaemia Trust

The British Porphyria Association

The Children's Hyperinsulinism Charity

The Fragile X Society

The Gauchers Association

The Lily Foundation

The Maddi Foundation

The MPS Society

The Smith-Magenis Syndrome Foundation UK

The UK Mastocytosis Support Group

Thyroid UK

Timothy Syndrome Alliance

TreatSMA

TRPS Support Group UK

Tuberous Sclerosis Association

Turner Syndrome Support Society UK

UK LGLL

UK Thalassaemia Society

UKPIPS

Unique – Understanding Chromosome Disorders

Urddad Foundation

Vasculitis UK

VHL UK/Ireland

Williams Syndrome Foundation Limited

Wilson's Disease Support Group UK

Wolfram Syndrome UK

Womb Cancer Support UK

Worster-Drought Syndrome Support Group

XLP Research Trust

XP Support Group

Yellow Brick Road Project Inc