Autistica fund research, shape policy and work with autistic people to make more of a difference

Annual report and accounts for the year ending 31 March 2020





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Autistica wants every autistic person to have a long, happy, healthy life. Our Trustees, honorary supporters and leaders help make that vision a reality by overseeing and managing all of the charity's life-saving and life-changing work.

## Honorary roles

Patron Professor Sir Michael Rutter

**President** Dame Stephanie Shirley CH

Vice Presidents Jane Asher Sir Christopher Ball Lady Christine Bett Hugh Merrill MVO

### Trustees

**Chair** Gill Ackers

Honorary Treasurer Matthew Harris

Dr Sarah Caddick PhD John Carey Matt Davis Michael Earl (retired October 2019) Professor Jonathan Green Professor Hilde Geurts (joined August 2019) Fraser Hardie (joined August 2019) Heather Kleeman Jeff Saul (retired August 2019) Vinny Smith (retired March 2020)

# Charity management

Chief Executive Jon Spiers

Director of Science Dr James Cusack

**Director of Fundraising** Jennie Chambers

# Auditors

Wilkins Kennedy Audit Services Greytown House 221-227 High Street Orpington Kent BR6 0NZ

# Bankers

Metro Bank One Southampton Row London WC1B 5HA

# **Registered** office

St Saviour's House 39-41 Union St London SE1 1SD

0203 857 4340 info@autistica.org.uk autistica.org.uk

**Charity registration no.** 1107350

**Company registration no.** 05184164

### **Chair and Chief Executive's Report**



Autistica's mission has never been more critical. The injustices and inequalities faced by autistic people of all ages are totally unacceptable and the gains we've made in recent years have been put at risk by the impact of the pandemic. Research is the critical catalyst to improve autistic lives. We don't do research for its own sake but always with the aim of providing the crucial data and evidence to shape services and society so everyone on the autism spectrum can live a long, happy, healthy life. That's needed now more than ever.





Gill Ackers Chair



Jon Spiers Chief Executive

We want to make sure every autistic person benefits from research and can achieve their full potential. That's why we invested in new highimpact science, including the next stage of our globally unique autistic healthchecks study to save lives and improve health, the second year of our DARE employment project with University College London to get more autistic people into work, developing a "research passport" to help more autistic people participate in research, and our flagship COMRAD study, developing new tools to ensure autistic people with complex needs are included in life-saving and life-changing science.

In 2019-20, we continued to grow Discover, the UK's national autism research network run by Autistica, bringing together families, autistic adults, researchers, clinicians and charities to accelerate autism science nationally. Over 16,000 people have now joined Discover and more than 20 universities are members. We held our second Discover research conference sharing the latest research with over 400 autistic people, parents and researchers. Discover's Autism Insight Group of 350 autistic people and parents helped develop a range of new research ideas, provided real-life insights and experiences and supported our policy work.

This year, our policy work went beyond campaigning for change into helping deliver it. Our influence can be seen throughout NHS England's and the Department of Health and Social Care's emerging work plans, both of which have adopted our "longer, healthier, happier lives" vision. We are now partnering with NHS England on over £2 million of transformative studies into health checks, diagnostic pathways and eating disorder care and have begun work on a National Research Strategy to cultivate more impactful science.

Despite a challenging final quarter when the coronavirus pandemic began in the UK, our fundraising performed well overall, including very generous support from the Maudsley Charity, Peter Sowerby Foundation and the Waterloo Foundation, successful corporate partnerships including Fujitsu and Jupiter Asset Management, and buoyant community, events and individual giving.

Our autistic Board Apprentices continued to observe and contribute to trustee meetings, gaining valuable board-level experience to become Trustees in the future at Autistica or elsewhere. We welcomed Professor Hilde Geurts and Fraser Hardie as new Trustees. We said fond farewells to Trustees Jeff Saul, Michael Earl and Vinny Smith, with Jeff subsequently joining our Finance Committee as a co-opted member. Their contribution has been immense and we wish them all the very best for the future. We're particularly proud to be recognised as the #5 Best Charity To Work For in the UK.

We know that autistic people have been particularly hard-hit by the pandemic and we are resolute in our determination to ensure they are not forgotten. In 2020-21, Autistica will continue working with all of our partners within autism and beyond to ensure every autistic person has the chance of a long, happy, healthy life by funding ground-breaking new science, expanding our reach and influence through Discover and international partnerships, and improving lives through our highly effective policy campaigns.

Our priorities include increasing further the impact of the research we fund, particularly through innovative collaborations; continuing to support and challenge policymakers to improve outcomes for all autistic people through the pandemic and beyond; widening our information and support resources; and creating opportunities to amplify a more diverse range of voices. We're tremendously excited to welcome Dr James Cusack, previously our Director of Science, as the new Chief Executive of Autistica in August 2020 who will lead us to even greater heights. We are very grateful to Jon Spiers, our outgoing CEO, for all he's done for the charity over the past five years.

# Autistica exists to offer autistic people and their families the chance of a long, happy, healthy life through funding and promoting ground-breaking research, improving understanding and advancing new therapies and interventions.

Despite scientific advances, too many autistic individuals and their families still tell us that they face a lifelong struggle to access appropriate support and services. Research can transform this experience, raise awareness, and ensure that services are based on the latest evidence. But autism research is poorly funded and if we want to overcome the stark inequalities faced by autistic people, a coordinated and focused effort is required to deliver change for the one in a hundred of us in the UK and around the world who are autistic.

Autistica works in partnership to achieve both a step change in the amount of resource focused on autism research and to ensure that research funding is directed to those areas of greatest need. Autistica is the UK's only national autism research charity and acts as the bridge between autistic people, the research community and other funders of autism science. This is an exciting time in autism research and significant advances have been made in the last decade, including a deeper understanding of autistic strengths, awareness of the tragic gap in life expectancy and a marked increase in the amount of autism science globally. Now, finally, we're starting to deliver hope through science — our healthchecks study at Newcastle University for example has the potential to be the most transformative change to NHS care for autistic people in decades.

Together we can and will make a real and lasting difference.

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our vision is That every autistic person has a long, happy, healthy life.

### $\bigcirc$

Our mission is

<u>To improve outcomes for autistic people</u> <u>of all ages</u> through world-class research.

<u>To grow autism research in the UK</u> through innovative collaborations with other funders, campaigning for increased state investment and developing capacity and infrastructure within the research community.

To be the bridge between researchers, policymakers and autistic people, ensuring that services are evidence-based and research responds to the autism community's needs and desires.

# Three values guide our work and help us ensure that our funds always have maximum impact

# 

### Our community is involved at all levels

Our research priorities are largely derived from the top ten questions for research identified by autistic people and their allies. We're leaders in involvement and our involvement strategy ensures autistic people are involved during the full research cycle through dialogue between researchers, autistic people and families. This means research has greater, faster impact for the people we serve.

# 20

# We are confident in our vision and in autism research's capacity to change lives

We don't accept the life chances that autistic people currently face. When that meant facing up to the early deaths of autistic people, we campaigned worldwide to make this a research priority and raised funds for vital studies to address this appalling inequality. We have clear ideas based on cutting-edge evidence and we fund innovative ideas and kick-start research in new areas. We make the right decisions, not the easy ones.

# 30

### We collaborate with others

Progress is best made together. We work in partnership and want everyone to win. Autistica works with international funders to develop autism research, including initiatives to understand global trends in funding for autism research. We proudly work with national and international research funders, and charities for autism, neurodevelopmental conditions and mental health. In line with our mission and in consultation with autistic people, parents and professionals, we continued to invest in new science following the priorities identified through our 2016 James Lind Alliance Priority Setting Partnership and our Research Strategy's key areas of focus.



### World class research

This year's competitive Call for Proposals led us to invest in a flagship new study at City University developing new ways to involve those with the most complex needs in research. We backed a team at University College London to create a new "research passport" to make it easier for autistic people and families to take part in autism studies. We invested further in two high-impact studies: SHAPe at Newcastle which is developing a GP healthcheck for autistic adults and DARE at UCL which is gathering data on autistic people's experiences in work.



### **Innovative involvement**

In 2019-20, we invested further in our globally leading community involvement, including supporting our new autistic academics, widening our Discover Insight Group, working with our Autism Study Groups who focus on major challenges in autism science, and continuing to lead on autistic and family involvement in the world's largest autism research grant.



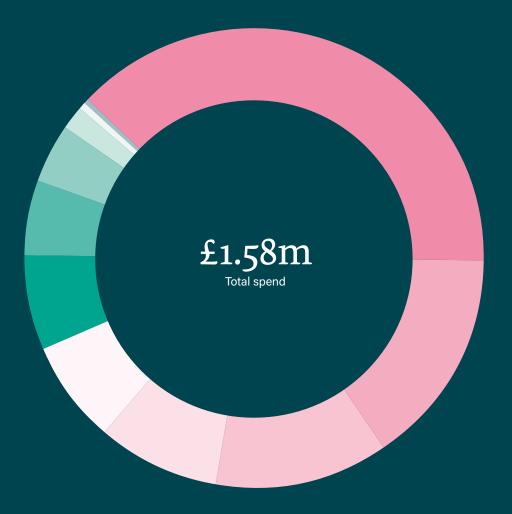
### **Outstanding environment**

We continued to expand Discover, the UK's autism research network we created in 2017. Discover is a strategic initiative which accelerates autism research by fostering new collaborations between the people we serve, academics and professionals. Through Discover, autistic people and their loved ones can find out about the latest research findings, join new studies and even help design and deliver research themselves. We now have around 17,000 members of Discover, which includes almost 1000 researchers, as well as community members and professionals.



### **Clear focus**

We're proud that our research priorities are set by our community, tackling the outcomes that matter most to you. This year, these were complex needs, physical health, employment and epilepsy. On top of our existing studies looking at critical autism issues across the lifespan, we spent £1.5 million on our scientific work.



£642,194 Scientific staff and research governance

£259,469

Health checks

£208,507 Communicating research

£141,531 Discover national research network

£125,743 Complex needs

£109,998 Grant administration

£91,246 <sub>Dare</sub>

£66,320 Embracing Complexity

£28,654 Research passport

£7,186 Autistic-led grants

£6,000 ARFID and autism

# Making a difference today

"Thank you so much for this information, it has been incredibly useful and helped me to understand what my daughter is experiencing."

Coronavirus webinar attendee

# Making sure employment works for autistic people

Having a job is often key to a person's health and wellbeing, but for decades we've known that autistic people are less likely to be in employment than most other disabled groups and markedly less than the typical population. New research from DARE (Discover Autism Research and Employment, our research partnership with University College London) confirmed this year that when autistic people do secure a job, they are less likely to be appropriately compensated relative to the skills they have. We also found that autistic people have significant concerns about disclosing their diagnosis in the workplace and so frequently choose not to do so.

Clearly the status quo is unacceptable. Through DARE, we're developing evidence-based solutions that ensure autistic people can find and remain in fulfilling and well-rewarded employment. This year, we will be working to consider how disclosure can be discussed and sharing our new guides on making reasonable adjustments for autistic people based on the evidence collected through DARE.

### **Changing public policy**

Last year, pressure from Autistica and our partners prompted the NHS to make autism a top policy priority for the first time. This year, we helped the NHS take strides towards dismantling the health inequalities facing autistic people and their families, working with them to recognise the gaps in support for autistic people at different stages of their lives and build evidence-based solutions. In 2019-20, we and NHS England partnered on over £2 million of scientific studies to test autistic health checks, explore better diagnostic pathways for children and inform services about the latest evidence on eating disorders and autism.

NHS England agreed to work with us to develop a national research strategy for autism and learning disability. Throughout 2020-21, we will be working with autistic people, people with learning disabilities, families, professionals and researchers to co-create this strategy, so that together we can support more transformational science and equip services with well-evidenced tools for supporting our neurodiverse communities.

### A new strategic focus on information

In the past, we've always communicated the research that we fund, but as the UK's leading autism charity, we see that we have a unique ability to go further. We can identify, translate and apply research findings for a range of audiences so everyone has access to solutions based on the best evidence. While we lack the capacity to become a comprehensive knowledge hub, we are best placed to create resources on the most vital issues in autism and its co-occurring conditions.

'Empowering people with the knowledge and tools to change lives' became one of our core strategic objectives and we began to develop a strategy for this early in 2020.

### **Responding to coronavirus**

With the urgent information needs arising from the pandemic in March, we started testing our new strategic approach, focusing on a topic each week relating to the pandemic. Topics were first identified by a consultation with the Autistica Insight Group and included 'uncertainty', 'relationships' and 'structure and routine'. We then reached out to academics and clinicians in a variety of fields to contribute to written resources for our website, webinars broadcast live on our Facebook channel, and podcasts. Our coronavirus-themed webinar series has had over 3,000 views and our web resources are among our most visited on the site.

We're now developing blog content to provide human experiences alongside evidence and practical advice. These materials combined will also help drive integrated fundraising campaigns.

Partnerships are proving increasingly important for



"Having Autistica there, being understanding and supportive and facilitating research that might help others just understand what autism is and how it impacts an autistic person's life is absolutely lifesaving. I can't stress that enough."

Discover member

"I thought the content was marvellous. The key notes and the various streams that I attended were jam packed with cutting edge science! The autistic representation, as always with Autistica, was second to none."

Conference delegate

disseminating information and gathering a wide range of experts to feed into our communications in future. We will be working on developing these networks over the coming year.

### Influencing the media

We continue to work closely with the Science Media Centre (who compile expert comments on emerging science for the media) and national health journalists to provide scientific comment on autism-related news pieces. We aim to tackle myths and fake treatments and increase the accuracy of media coverage on not just science, but also the representation of autism in the media.

### **Communicating the Autistica brand**

Autistica has changed a lot since we first launched in 2001, and as a charity, we need to stand out and clearly communicate what we do in order to make more of a difference. We've been working on a refreshed brand identity which aligns with our new strategy, due to be launched later this year. Staff, Trustees, donors and Autistica Insight Group members were all involved in the process to develop a new logo, tagline, colour palette and photography. With these new elements in place, we can appeal to a wider audience and grow our supporter base.

### Finding the right people for research

In the last year, more than 3,000 new members have signed up to our Discover network to hear about opportunities to take part in research, bringing our total membership to over 16,000.

This year, Discover supported 23 research studies to hit their recruitment targets. Support from Discover allows researchers to recruit people into their studies much faster than they typically can without our help - sometimes as many as 200 people take part in just a couple of days. This means progress is accelerated and researchers can spend time improving other aspects of their research. For members of the community, finding out that so much research is happening and being invited to take part gives them hope.

### Sharing the latest science

Our 2019 Discover Conference was held at the University of Reading and chaired by researchers Dr Teresa Tavassoli and Prof Bhismadev Chakrabarti. We had almost 100 researchers speak across our different panels, workshops and poster sessions, all showcasing innovative and thought inspiring autism research. Over 300 people attended in person with many more attending virtually via live streams or recordings of the sessions, kindly supported by Fujitsu. Delegate feedback strongly rated the programme and speakers, the accessibility of the event and the autistic representation at the event.

### Involving you in our work

Our Insight Group has continued to grow, with a strong focus on Equality, Diversity and Inclusion. Our Diversity workshops in May saw staff work with existing members of the Insight Group to look at how we can better support and include people whose demographics were currently underrepresented. The knowledge and insights gained in these workshops were reflected when we were recruiting for new members as well as our day to day running of Discover.

This year, we've had over 35 Insight Opportunities, where members of the Insight Group have been consulted on an area of research or strategy and have given insight into the autistic community's perspectives. One of the most common activities has been to look at surveys and tools to ensure questions are phrased in a way that participants will be confident to answer, but we also have members of the Insight Group sitting on steering committees, co-contributors to research projects and working as Research Assistants. We now have 350 members of our Insight Group, covering all ages and with a strong mix of backgrounds, co-occurring conditions and experiences. In 2020, a major focus will be upskilling members of the Insight Group through training and building a sense of community and support via events, a blog and a monthly newsletter.

# Making a difference tomorrow

This year, NHS England committed to implementing the health check in GP practices and have extended our clinical trial with over £770,000 of additional funding.

### Addressing health inequalities

In 2016, we revealed the unacceptable health inequalities and tragically low life expectancy that autistic people face in our report Personal Tragedies, Public Crisis. Since then, we have campaigned and developed research solutions to address these unacceptable outcomes. In our original report, we proposed that an annual personalised health check could be key for meeting the health needs of autistic people. We convened autistic people, family members, world-leading researchers, policymakers and clinicians to co-design a health check. Thanks to the generosity of the Peter Sowerby Foundation, we have now funded this health check study at Newcastle University and are working with policymakers to ensure its implementation. This year, NHS England committed to implementing the health check in GP practices and have extended our clinical trial with over £770.000 of additional funding. This health check will represent the biggest ever health intervention for autistic adults and we hope that it can be part of the solution towards ensuring that autistic people live healthier lives.

### Building better social care for autistic people

Autistic people have told us that research into adult social care is their third highest priority, but a scoping report funded by Autistica found that almost no research is funded in this area despite the appalling failures we have seen in our social care system, the high costs associated with providing such provision and the knowledge that, for many autistic people, high-quality social care is key to alleviating these inequalities.

Research clearly has a major opportunity to provide solutions to improve social care for autistic adults. That's why we hosted a 2019 summit at the University of Kent on research on adult social care and autism with autistic people, family members, care providers, researchers, commissioners and funders. They came up with a range of research ideas on areas such as housing, peer mentoring, measuring quality of care, low-level support, staff training and self-generated outcome measures that could act as a catalyst for research in this area. We're now working with the National Institute of Health Research to explore how we could fund research together in social care and autism to kickstart research in this crucial field.

### Developing new scientific ideas

Our four Autism Study Groups within the Discover network have each made substantial progress this year. The Complex Needs Study Group was awarded a grant by Autistica to fund the COMRAD study mentioned above. The Physical Health and Ageing Study Group co-wrote an open letter in the new AMRC Open Research publication platform about the provision of social prescribing for autistic people and have written to funders backing research into physical health conditions to seek more collaborative action to understand how to treat physical health issues in autistic people. The Language and Communication Study Group developed an idea to support researchers interested in language and communication to collaborate more, share resources and crosscheck each other's work to improve the accuracy and pace of evidence being developed. The Mental Health Study Group are undertaking a systematic review of the evidence on the experiences of professionals providing mental health support to autistic people. They are also designing a study to better understand how a neurobiological process called emotion regulation might relate to mental health difficulties among autistic people.

### Databases

Since 2010, Autistica has funded and worked in partnership with a team of researchers based at Newcastle University to develop and run two family research databases, one UK-wide and one specific to the North-East of England. These databases have been critically important assets to the autism research community, supporting the recruitment of participants into hundreds of clinical research studies, collecting nationally representative data about autism and pioneering the inclusion of members of the autism community within the committees that govern the databases. After 10 years of working together, this year marked the final instalment of Autistica funding for the Newcastle databases. We want to extend our thanks to all of the researchers, and, most importantly, community members and families who volunteered their time to take part in cutting-edge autism research.

# Making a difference for everyone

We funded a team at UCL to develop the first research passport for autism science, which will make it easier and more comfortable for everyone to take part in new studies.

### Including those with complex needs in research

In a 2018 report, we revealed that people with complex needs are frequently excluded from autism research. Our report found that despite as many as half of autistic people having a learning disability, only 6% of participants involved in autism research have a learning disability.

To address this, we made funding available this year for research with groups who are frequently underrepresented in autism research and set up a complex needs study group to develop research solutions. We have now funded a project by this group to create a Complex Needs Research and Development Hub (COMRAD) at City University in London.

Through a literature review, co-designing new solutions and testing new research tools, the research team will produce:

- Comprehensive best-practice guidelines on how to include autistic people with complex needs in research
- A toolbox of research methods that help researchers conduct robust research with people who are minimally verbal, who have profound intellectual disabilities or who experience difficulties participating in daily activities due to severe sensory processing differences and distress.
- A forum where researchers can exchange resources and ideas and foster new collaborations.

### Helping more people take part in research

Participating in autism research isn't always easy, from needing to take the same tests repeatedly for different studies to communicating your personal needs and reasonable adjustments. We funded a team at UCL to develop the first research passport for autism science, which will make it easier and more comfortable for everyone to take part in new studies.

### **Embracing Complexity**

In May 2019, we launched Embracing Complexity, a coalition of organisations working together to improve the lives of the 10% of the population who have one or more neurodevelopmental conditions. The coalition has now tripled in size to include over 50 leading charities and professional bodies and we are delighted to have the kind support of the Waterloo Foundation. Our first report into the often difficult experiences of people with neurodevelopmental conditions prompted the Secretary of State to establish a Neurodiversity Team in the Department of Health and Social Care. Embracing Complexity's second report, highlighting emerging models for diagnosing multiple neurodevelopmental conditions simultaneously, stimulated interest across the NHS and has already led some services to re-examine their diagnosis pathways.



# 2019–20 was another hugely challenging year for many charities but despite this Autistica continued to adapt and innovate and we were proud of a number of major fundraising achievements and exciting 'firsts'.

Our Trusts & Foundations team secured the most income they have ever raised in Autistica's history. Notable successes including securing a new partnership with the Maudsley Charity who generously provided over £270,000 to support the next development phase of Molehill Mountain, our research-led app helping autistic people understand more about anxiety. We were delighted to continue our successful partnerships with the Peter Sowerby Foundation and Waterloo Foundation.

The Corporate & Games Partnerships team completed the first year of our two-year Charity of the Year partnership with Fujitsu and welcomed them as the first Official Sponsor of our Discover Conference. We launched Discover Autism Research & Employment (DARE) partnerships with a number of companies, using data and insights to underpin neurodiversity strategies which maximise both business and employee needs. We also launched our first set of online games streaming events and benefited from the continued support of GamesAid.

f1,725,219 Total income Autistica was also generously supported with in-kind advice, venues and consultancy from organisations including JPA, BRE Trust and JP Morgan.

We continued to benefit from the loyal support of our Major Donors who help us deliver on our unique commitment to tackling the challenges that matter most to autistic people and their families. Their significant gifts have ensured we can continue investing in ground-breaking areas of research and growing our pioneering Discover Network. To widen our major donor supporter base, we rolled out a new special events programme, including an exclusive evening at the Cavalry & Guards Club for friends new and old.

We expanded our digital fundraising work this year, utilising platforms and tools such as Facebook, Twitch and Mobilise which helped to ensure we had our most successful ever fundraising campaign during World Autism Awareness Month. Throughout the year, we benefitted from the generosity and energy of supporters who took part in sponsored events or organised their own fundraising in their communities.

We receive no government funding so we want to thank everyone who has given such invaluable support this year — we couldn't deliver our vital work without you.

£279,526 Corporate

£599,442 Trusts and foundations

## **£518,662** Major donors



£121,757 Gifts in kind

£14,802

One-off events

£52,904 Other

£12,144



"I hope that autism in girls and women and people of colour is researched further, as we can fall through the system." It's inevitable that the coronavirus crisis will have a significant impact on Autistica and our work in 2020–21. Our work is needed now more than ever: autistic people faced unacceptable inequalities before the pandemic, emerging data is showing that they have been particularly hard-hit by the virus, and we risk seeing inequalities widen further unless we have the right data and evidence to support better diagnosis, care and outcomes. Thanks to the amazing support of our donors, researchers and community, we're in a strong position and remain resolutely focused on improving the lives of all autistic people and their families through world-class research, information and campaigning.

Although we are likely to have reduced funds for research compared to previous years, we want to carry on investing in high-impact science, working in partnership with others across the NHS, academia, the corporate world and wider society to protect and grow autism research in the UK.

In the year ahead, we will:

- Invest at least £1m in autism research and involvement, including further investments in epilepsy, employment, mental health and GP healthchecks
- Further develop our Discover network, including delivering a Discover autism science festival
- Create a more sophisticated version of our popular Molehill Mountain app for managing anxiety

- Continue building the evidence base for recruiting and retaining autistic people in employment through our unique DARE partnership with UCL
- Carry on our leadership of the Embracing Complexity coalition, bringing together over 50 charities and organisations supporting people with neurodevelopmental conditions
- Work with NHS England and many others to create the UK's first national strategy for autism and learning disability research
- Push for the Government to release the revised national autism strategy for England, with appropriate funding to make its ambitions a reality
- Continue campaigning to change the appalling rates of premature death among autistic people

# In January 2020, our CEO Jon Spiers notified the Trustees of his intention to seek a new challenge after five rewarding and successful years at Autistica.

"To overcome the unacceptable inequalities that autistic people face, we must ensure we listen to the experiences of all autistic people and deliver transformative change based on the best evidence. I look forward to working with our supporters and partners to make more of a difference."

James Cusack New Autistica CEO The Nominations Committee selected experienced non-profit recruiters Gatenby Sanderson to support their search. Following the outbreak of the Covid-19 pandemic, the Committee considered a variety of options, but unanimously agreed that the appointment of a new CEO was a critical task for Autistica and our long term strategy, and therefore agreed to continue the search as planned, with modifications to conduct interviews remotely. Having considered a wide range of potential candidates, a shortlist of three were interviewed by the Committee. The Committee unanimously agreed to recommend the appointment of Dr James Cusack as new CEO, effective from 7 August 2020. The Board endorsed this recommendation at their meeting in July 2020.

As Director of Science at Autistica since 2015, James has been integral to the charity's growth and success, not only in terms of driving an ambitious and impactful scientific agenda, but contributing to all of the charity's activities from fundraising and communications to policy and strategy. Diagnosed as autistic in childhood, he has worked with families and autistic people from a young age and before joining the charity, was a post-doctoral autism researcher at the University of Aberdeen.

The Board are grateful to Jon for his tremendous contribution to Autistica over the last five years, we wish him well in his future endeavours, and we know that he will always be an advocate for the autistic community. The appointment of James is a very exciting development for us. We look forward to continued success for those we represent under his leadership.



The Trustees have referred to the Charity Commission's guidance on public benefit in relation to the charity's aims and objectives. The Trustees consider it important to demonstrate to supporters and others interested in our work that the research we have funded will support medical progress and enhance understanding.

'Most parents fear for what happens to our children when we're gone." Lisa Autistic people and their families are at the heart of our Research Strategy, our national Discover research network and embedded within our wider governance processes. Our overarching aim by doing so is to improve outcomes, giving longer, healthier and happier lives to all autistic people.

Autistic people and family members play an active role on our Scientific Review Panel and the many advisory structures which oversee our work. Both our Ageing with Autism programme and our Mental Health in Autism programme are supported by the National Institute of Health Research (NIHR), building on their investment in the Biomedical Research Centres for Ageing and Mental Health. Through Discover, our autism research network, we provide mechanisms to involve autistic people and families in research as participants, advisers, co-designers and researchers.

We know how important it is that scarce resources are deployed on research that is not just important to families, but is also of the highest quality, internationally competitive and does not inappropriately duplicate investment made elsewhere. As a member of the Association of Medical Research Charities, we are committed to the highest possible standards of research governance and independent peer review underscores all the research that we fund.

In addition to the Scientific Review Panel which scores and deliberates on all research proposals, we are fortunate to benefit from independent strategic advice from world-leading experts in neurodevelopmental conditions, including autism. Autistica is regulated by the Fundraising Regulator and a proud member of the Fundraising Standards Board. We are committed to best practice in fundraising and customer service. Through our Privacy Policies, we promise to keep our supporters informed about our work and to treat their information with respect.

tica Annual Report and Accounts 2020

#### How we are governed

Autistica was registered as a charity in December 2004 and its governing document is its Memorandum and Articles of Association, which were adopted on 20 July 2004. Autistica is incorporated under the Companies Act 2006 as a company limited by guarantee having no share capital. For the purposes of this Act, the Chair and other Trustees (none of whom receives any remuneration) are the directors of the company. A full list of Trustees, together with other legal and administrative information, can be found at the front of this report.

The Board of Trustees meets formally four times a year and additionally relies on a number of Board sub-committees to provide further oversight of the work of the charity (see inside back cover), which are each chaired by a Trustee. All key decisions, including the allocation of funds for research, are taken at full meetings of the Trustee Board.

On 31 March 2020, there were nine members of our Trustee Board. Trustees may serve for up to two terms of three years and are appointed in accordance with the Memorandum and Articles of Association. The Board approved the appointment of Professor Hilde Geurts and Fraser Hardie in August 2019. Jeff Saul stepped down in August 2019, Michael Earl stepped down in October 2019 and Vinny Smith stepped down in March 2020 following their terms on the Board.

The following issues are addressed by the Trustees during the year:

- reviewing progress against our business plan and research strategy
- agreeing and monitoring an annual business and financial plan
- the award of all grants for research
- the risks the charity is facing in delivering its plans
- the impact of the charity's work.

Each year the skills and expertise required within the Trustee Board are reviewed to help the charity deliver its objectives. If gaps are identified or a vacancy occurs, new Trustees with the appropriate skills and experience are identified. All Trustees are offered a full induction when they join and Trustee training is available to keep Trustees up to date with the environment in which the charity operates.

#### How we are managed

The Chief Executive is responsible to the Board of Trustees for the management of the charity. The Director of Science and Director of Fundraising report to the Chief Executive. Remuneration for senior staff is set at market rates and reviewed annually by the Remuneration Committee.

The administrative offices of the charity are in Southwark.

#### **Risk management**

The Trustees formally consider the major risks faced by the charity as part of a risk management strategy that comprises:

- an annual review of the risks faced by the charity in delivering its plans
- the establishment of systems and procedures to manage those risks identified in the review
- the implementation of procedures designed to minimise any potential negative impact on the charity should those risks materialise.

The charity has identified a number of key risks this year, including the short term impact of Covid-19 on research, fundraising, policy influencing, communications and staff, the medium-term impact of a potential recession on our income, and the medium-term effect of Brexit on income, income diversification and improving national and international collaborations in autism research. Our loyal donor base and strong external relationships put us in a strong position to maintain income and influence and continue supporting UK autism research. We continue to actively seek new partnerships within and beyond autism science and build pro bono support to increase capacity.

### Reserves

The Trustees review the reserve policy annually and consider the charity should hold free reserves of approximately £550,000 (2018–19 – £550,000) to cover six months' operating costs with a contingency of £50,000 in the event of a significant reduction in planned income. At 31 March 2020, the charity had free reserves excluding designated funds of £732,807 (2018–19 – £534,120). We would traditionally designate the surplus above the free reserve threshold towards future research spend but in light of the coronavirus pandemic, we agreed to keep the excess in the free reserve until the economic and research impacts were clearer.

At 31 March 2020, the charity had restricted reserves of £472,272 (2018–19 — £509,345).





"I hope that problems of getting jobs and staying in jobs will one day be a thing of the past."

### Investments

Free reserves and other surplus cash are held in interest bearing deposit accounts with authorised UK deposit takers or in regulated money market funds, with a maximum of four to six months' operating costs (c.£400,000– £550,000) held in the current account.

Cash outside of the current account should be held in individual interest bearing deposit accounts with authorised UK deposit takers which benefit from the government FSCS guarantee scheme (currently up to £85,000), using the Insignis cash management platform. The maximum amount per deposit account should not exceed £100,000. These can be a mix of instant or close to instant access and longer-term access accounts.

A maximum of 50% of total cash or £1,100,000, whichever is lower, can be held in regulated money market funds with an AAA rating from Fitch and/or Standard & Poor's, provided that the funds offer instant, or close to instant, access.

A maximum of 25% of total cash or £750,000, whichever is the lower, can be held in equities or funds in line with the asset investment policy. These should be managed by a regulated asset manager.

Investments are reviewed by the Finance Committee, which meets four times a year, and Trustees are advised of any recommended changes at full meetings of the Trustee Board.

### **Statement on Covid-19**

The Trustees judge that the coronavirus pandemic was an event that occurred during the financial year ending 31 March 2020. As such, the financial statements reflect the impact of the pandemic as at 31 March 2020. The Trustees are aware that they must continue to monitor events and evaluate their impact on Autistica.



The principal impact on the reported figures is on the fair value of investments held for future use by the charity. The Trustees had decided to sell approximately one third of the holdings prior to the pandemic being declared, but the residual declined by approximately 8% in the fourth quarter. This has been reflected at the balance sheet date.

The precise impact on the charity's future income is unclear but the charity is predicting its 2020–21 income to be 20–25% lower than the original forecast from January 2020, with donations from challenge events, community fundraising, corporate fundraising and individual giving most likely to be affected. The charity has spoken to its most significant donors, most of whom have already indicated their willingness to make funds available to support the charity's ongoing work.

The charity has taken steps to mitigate the impact of lower income, including reducing discretionary spending on future grants, cutting staff costs, cutting administration and fundraising costs, and renegotiating our office lease. We have not, however, made any use of the furlough scheme introduced by the UK Government, notwithstanding the outlook on our income, as our staff have been working to support the autistic community. Overall, expenditure is expected to be 25–30% lower than previously forecast in January 2020.

A number of donors who have given restricted gifts have signalled their willingness to be flexible in how these gifts are subsequently deployed by the charity, potentially resulting in transfers between restricted and unrestricted funds.

All grants that the charity commits to are supported by reserves held in cash. Therefore, we remain able to complete all previously committed grants in full, subject to the recipient(s) meeting the defined criteria for their studies.

### **Going concern statement**

The financial statements have been prepared on a going concern basis, but the Trustees recognise that the economic impact of coronavirus in the medium term remains unclear. The Trustees have carefully considered the level of funds held and the expected level of income and expenditure for 12 months from the approval of these financial statements. The Trustees have concluded that the budgeted income and expenditure is sufficient with the level of reserves for the charity to be able to continue as a going concern.

### Approval

The report has been prepared in accordance with the Statement of Recommended Practice: 'Accounting and Reporting by Charities' and in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to smaller entities.

The Trustees' Report and Financial Statements were approved by the Board of Trustees on 30 July 2020.

On behalf of the Board

Matthew Harris Honorary Treasurer 30 July 2020

### **Statement of Trustees' responsibilities**

### Statement of disclosure to auditors

The Trustees (who are also directors of Autistica for the purposes of company law) are responsible for preparing the Trustees' Annual Report (including the Strategic Report) 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 these financial statements, the Trustees are required to:

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charities SORP 2015 (FRS 102);
- make judgements and estimates that are reasonable and prudent;
- state whether applicable UK Accounting Standards have been followed, subject to any material departures disclosed and explained in the financial statements;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in operation.

The Trustees are responsible for keeping adequate accounting records that disclose with reasonable accuracy at any time the financial position of the charitable company and 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 auditor is unaware; and
- 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 auditor is aware of that information.

Gill Ackers Chair of Trustees 30 July 2020

"It would be really helpful if people had a better understanding of neurodiversity." Alex



"I consider it as a superpower, something that makes me unique."

0

George

### Opinion

We have audited the financial statements of Autistica for the year ended 31 March 2020 which comprise the Statement of Financial Activities, Balance Sheet, Cash Flow Statement and notes to the financial statements, 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 (United Kingdom Generally Accepted Accounting Practice).

In our opinion the financial statements:

- give a true and fair view of the state of the group's and parent charitable company's affairs as at 31 March 2019, and of the group's 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 and the Charities Act 2011.

### **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 group and parent 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

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the Trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the Trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the group's or parent charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

### 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 (incorporating the strategic report and the Trustees' report) for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the strategic report and the Trustees' report have 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 group and parent charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the strategic report and the Trustees' report.

We have nothing to report in respect of the following matters in relation to which the Companies Act 2006 and the Charities Act 2011 requires us to report to you if, in our opinion:

- adequate and sufficient accounting records have not been kept by the parent charitable company, or returns adequate for our audit have not been received from branches not visited by us; or
- the parent charitable company's 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.

### **Responsibilities of Trustees**

As explained more fully in the Trustees' responsibilities statement set out on page 20, 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 group's and parent 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 group or the parent 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

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.

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.

We communicate with those charged with governance regarding, among other matters, the planned scope and timing of the audit and significant audit findings, including any significant deficiencies in internal control that we identify during our audit.

### 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. 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 group, for our audit work, for this report, or for the opinions we have formed.

Michelle Wilkes FCA for and on behalf of Wilkins Kennedy Audit Services

Senior Statutory Auditor Chartered Accountants Greytown House 221–227 High Street Orpington Kent BR6 0NZ

13 August 2020

# Statement of Financial Activities, including Income and Expenditure

for the year ending 31 March 2020

### Year ending Year ending 31 March 2020 31 March 2019

Income from	Notes	Unrestricted	Restricted	<b>Total Funds</b>	Total Funds
		£	£	£	£
Donations	2	777,821	935,254	1,713,075	1,171,127
Shirley Foundation	2	-	-	-	540,991
Investment Income		12,144	-	12,144	29,865
Total Income		789,965	935,254	1,725,219	1,741,983
Expenditure on					
Costs of Raising Funds					
Costs of generating donations	3	372,224	29,221	401,445	428,915
Cost of events	3	12,988	-	12,988	56,408
		385,212	29,221	414,433	485,323
Expenditure on Charitable Activities					
Grants for medical research	4	485,432	564,735	1,050,167	1,496,995
Medical research dissemination	4	456,537	73,067	529,604	496,804
		941,969	637,802	1,579,771	1,993,799
Total Expenditure		1,327,181	667,023	1,994,204	2,479,122
Net income					
(expenditure) before gains and losses on					
investments and transfers		(537,216)	268,231	(268,985)	(737,139)
Net gains on investments		15,599	-	15,599	32,536
Transfer between funds	15	305,304	(305,304)	-	-
Net Movement In Funds		(216,313)	(37,073)	(253,386)	(704,603)
Total funds brought forward		1,031,120	509,345	1,540,465	2,245,068
Total funds carried forward		814,807	472,272	1,287,079	1,540,465

The statement of financial activities includes all gains and losses recognised in the year. All income and expenditure is derived from continuing operations.

### **Balance Sheet**

as at 31 March 2020

	Notes	£	2020 £	£	2019 £
Fixed assets					
Tangible assets	8		161		942
Investments	9		382,393		573,527
			382,554		574,469
Current assets					
Debtors - amounts falling due within one year	10	432,318		245,854	
Current asset investment	11	-		90,088	
Cash at bank		1,326,534		2,177,063	
	_	1,758,852		2,513,005	
Creditors					
Creditors: amounts falling due within one year	12 _	(649,786)		(1,353,256)	
Net current assets			1,109,066		1,159,749
Total Assets Less Current Liabilities			1,491,620		1,734,218
Creditors					
Creditors: amounts falling due after one year	13		(204,541)		(193,753)
Net assets			1,287,079		1,540,465
Reserves					
Unrestricted funds - general	14		732,807		534,120
Designated funds	14		82,000		497,000
Restricted funds	15		472,272		509,345
Total funds	16		1,287,079		1,540,465

Approved by the Board of Trustees on on 30 July 2020 and signed on behalf of the Board

Matthew Harris Honorary Treasurer Company Registration Number: 05184164

### **Statement of Cash Flows**

for the year ending 31 March 2020

	Notes	2020 £	2019 £
Net cash (outflow)/inflow from operating activities	17	(1,159,494)	(613,445)
Cash flow from investing activities			
Bank interest		12,144	29,865
Purchase of fixed asset investment		(212)	-
Proceed from disposal of fixed asset investment		206,946	-
Net cash from investing activities		218,878	29,865
Net (decrease)/increase in cash and cash equivalents		(940,616)	(583,580)
Cash and cash equivalents at beginning of year		2,267,151	2,850,731
Cash and cash equivalents at the end of the year		1,326,535	2,267,151

for the year ending 31 March 2020

### **1. ACCOUNTING POLICIES**

### a. Basis of preparation

Autistica is a company limited by guarantee in the United Kingdom. In the event of the charity being wound up, the liability in respect of the guarantee is limited to £1 per member of the charity. The address of the registered office is given in the charity information on page 4 of these financial statements. The nature of the charity's operations and principal activities are set out on page 6.

The charity constitutes a public benefit entity as defined by FRS 102. The financial statements have been prepared in accordance with 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 (FRS 102) issued on 16 July 2017, the Charities Act 2011 and UK Generally Accepted Practice as it applies from 31 March 2018

The financial statements are prepared on a going concern basis under the historical cost convention, modified to include certain items at fair value. The financial statements are prepared in sterling which is the functional currency of the charity.

The significant accounting policies applied in the preparation of these financial statements are set out below. These policies have been consistently applied to all years presented unless otherwise stated.

### b. Income

All income is included in the Statement of Financial Activities (SoFA) when the charity is legally entitled to the income after any performance conditions have been met, the amount can be measured reliably and it is probable that the income will be received.

For donations and grants receivable are included in full in the Statement of Financial Activities when receivable.

Investment income is accounted for when received. Tax recoverable on investment income is accounted for on a receivable basis.

Other income is included in full in the Statement of Financial Activities when receivable.

Gifts in kind and donated services are included at the open market value of the goods or services provided.

### c. Expenditure

All expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all costs related to the category. Expenditure is recognised where there is a legal or constructive obligation to make payments to third parties, it is probable that the settlement will be required and the amount of the obligation can be measured reliably.

It is categorised under the following headings:

- Raising funds are those costs incurred in attracting voluntary income.
- Expenditure on charitable activities includes expenditure associated with grants for medical research and medical research dissemination. Grants payable are accounted for at the point that either conditions for receipt have been satisfied or the post being funded is filled.

### d. Fund accounting

Unrestricted funds are available for use at the discretion of the trustees in furtherance of the general objectives of the charity and which have not been designated for other purposes.

Restricted funds are funds which are to be used in accordance with specific restrictions imposed by donors or which have been raised by the charity for particular purposes. The cost of raising and administering such funds are charged against the specific fund. The aim and use of each restricted fund is set out in the notes to the financial statements.

The designated fund balance has been represented to ensure that fund balance stated accurately reflects the designation policy adopted by the trustees.

### e. Tangible fixed asset

All assets costing over £5,000 are capitalised. Tangible fixed assets are stated at cost less depreciation. Depreciation is provided at rates calculated to write off the cost or valuation of fixed assets, less their estimated residual value, over their expected useful lives as follows:

- Computer equipment 33% straight line
- Other equipment and fittings 25% straight line
- f. Debtors and creditors receivable / payable within one year Debtors and creditors with no stated interest rate and receivable or payable within one year are recorded at transaction price. Any losses arising from impairment are recognised in expenditure

### g. Leasing commitments

Assets acquired under finance leases are capitalised and depreciated over the shorter of the lease term and the expected useful life of the asset. Minimum lease payments are apportioned between the finance charge and the reduction of the outstanding lease liability using the effective interest method. The related obligations, net of future finance charges, are included in creditors.

Rentals payable and receivable under operating leases are charged to the SoFA on a straight line basis over the period of the lease.

for the year ending 31 March 2020

### h. Going concern

The financial statements have been prepared on a going concern basis as the trustees believe that no material uncertainties exist. The trustees have considered the level of funds held and the expected level of income and expenditure for 12 months from authorising these financial statements. The budgeted income and expenditure is sufficient with the level of reserves for the charity to be able to continue as a going concern. This included consideration of the effect of the coronavirus on the Charity's operations.

i. Judgements and key sources of estimation uncertainty "The following judgements (apart from those involving estimates) have been made in the process of applying the above accounting policies that have had the most significant effect on amounts recognised in the financial statements:

### Useful economic lives of tangible assets

The annual depreciation charge for tangible assets is sensitive to changes in the estimated useful economic lives and residual values of the assets. The useful economic lives and residual values are re-assessed annually. They are amended when necessary to reflect current estimates, based on technological advancement, future investments, economic utilisation and the physical condition of the assets. See note 8 for the carrying amount of the tangible fixed assets, and note 1(e) for the useful economic lives for each class of assets.

### Bad debts

Debtors are regularly reviewed for recoverability. Any debts which in the opinion of trustees are not recoverable are provided for as a specific bad debt.

The are no key assumptions concerning the future and other key sources of estimation uncertainty at the reporting date that have a significant risk of causing a material adjustment to the carrying amounts of assets and liabilities within the next financial year.

### j. Fixed Asset Investments

"Investments are recognised initially at fair value which is normally the transaction price excluding transaction costs. Subsequently, they are measured at fair value with changes recognised in 'net gains / (losses) on investments' in the SoFA if the shares are publicly traded or their fair value can otherwise be measured reliably. Other investments are measured at cost less impairment"

### 2. Income

	2020	2019
	£	£
Donations	670,679	578,116
Shirley Foundation	-	540,991
Gifts in kind	57,395	78,292
Challenge events	49,747	37,666
Unrestricted income	777,821	1,235,065
Restricted donations	870,892	477,053
Restricted gift in kind	64,362	-
Restricted income	935,254	477,053
Total Income	1,713,075	1,712,118
	2020	2019
Gifts in Kind	£	£
Costs of activities for generating funds, challenge events	1,500	-
Charitable activities, disseminating information on autism and autism research - Unrestricted	55,895	70,792
Charitable activities, disseminating information on autism and autism research - Restricted	64,362	-
Governance costs and consultancy	-	7,500
	121,757	78,292

The above activities were organised by the charity. Income from activities organised by individuals and donated to the charity are included in voluntary income.

for the year ending 31 March 2020

### 3. Cost of raising funds

	2020	2019
Costs of Generating Donations	£	£
Website, database, literature and PR costs	8,909	23,199
Other fundraising expenses	66,596	51,648
Allocation of administrative support costs (Note 6)	46,911	73,142
Staff costs (note 7)	279,029	280,926
	401,445	428,915
	2020	2019
Cost of Events	£	£
Challenge events costs	3,715	31,085
Other event costs	6,038	6,075
Allocation of administrative support costs (Note 6)	3,235	19,248
	12,988	56,408

### 4. Expenditure on charitable activities

	Unrestricted	Restricted	2020	2019
Grants for medical research	£	£	£	£
The Institute of Psychiatry, Psychology & Neuroscience				
Mental Health - Anxiety Toolkit"	-	258	258	72,969
The Autism Spectrum Database – UK	(513)	-	(513)	-
Discover Network	-	141,531	141,531	102,171
ESRC Studentship – multi-lingualism and autism	-	-	-	15,000
Research Databases	(106,824)	-	(106,824)	214,007
SHAPe, The Sowerby Health intervention for Autistic People	-	259,469	259,469	30,000
Social Care Scoping	-	-	-	9,355
Residential Care	-	-	-	19,998
Research Passport	28,654	-	28,654	5,099
Home based PECs	-	-	-	197,104
DARE	80,221	11,025	91,246	82,470
Impact of AEDs	-	-	-	20,000
Future Leaders Award - Becky Lawson	-	-	-	99,836
Future Leaders Award - Jane Waite	-	-	-	99,086
Turing Citizen Science	-	-	-	150,000
Autistic-Led Grants – Kabie Brook	-	1,797	1,797	12,400
Autistic-Led Grants – Royal Holloway, University of London	-	1,797	1,797	12,495
Autistic-Led Grants – Sara King	-	1,797	1,797	12,330
Autistic-Led Grants – Joseph Scanlon	-	1,797	1,797	9,468
Embracing Complexity	-	66,320	66,320	-
City University – COMRAD				
(Complex needs underrepresented populations)	125,743	-	125,743	-
University College – ARFID – Eating disorders & autism	-	6,000	6,000	-
Governance costs (Note 5)	15,307	-	15,307	25,564
Grant Administration costs (Note 6)	109,998	-	109,998	80,842
Staff costs (Note 7)	232,846	72,944	305,790	226,801
Total Grant Expenditure	485,432	564,735	1,050,167	1,496,995
Research Dissemination	208,384	123	208,507	244,440
Governance costs (note 5)	15,307	-	15,307	25,563
Staff costs (note 7)	232,846	72,944	305,790	226,801
	941,969	637,802	1,579,771	1,993,799

for the year ending 31 March 2020

### **5. GOVERNANCE COSTS**

	2020	2019
	£	£
External audit	9,280	8,700
Trustees' liability insurance	3,259	2,837
Consultancy & recruitment costs	-	2,694
Other governance costs	6,440	7,994
Allocation of administrative support costs (Note 6)	1,618	19,248
Staff costs (Note 7)	10,017	9,654
	30,614	51,127

No Trustees were paid during this period. Two trustees received reimbursements for travel expenses amounting to £947. Governance costs were allocated equally against Grants and Dissemination expenditure in Charitable Activities.

### 6. Administrative support costs

The following administrative support costs are allocated between other categories of resources expended as detailed below. Costs are attributed directly where possible and the balance is allocated based on time spent by trustees, staff and consultants.

	2020	2019
	£	£
Telephone	6,852	7,797
IT Expenditure	21,733	40,659
Stationery, copying, postage and other office expenses	6,531	5,507
Staff recruitment and professional development	35,698	46,148
Rent and rates	43,517	30,155
Depreciation	781	2,152
Other	13,107	28,710
Staff costs (note 7)	33,543	31,352
Total support costs	161,762	192,480

These are divided:

Generating donations 29% (Note 3) (2019: 38%)	46,911	73,142
Events 2% (Note 3) (2019: 10%)	3,235	19,248
Charitable activities 68% (Note 4) (2019: 42%)	109,998	80,842
Corporate governance 1% (Note 5) (2019: 10%)	1,618	19,248
	161,762	192,480

for the year ending 31 March 2020

### 7. Staff costs

	2020	2019
	£	£
Salaries	824,638	673,225
Social security costs	86,482	84,223
Pension costs	23,049	18,086
	934,169	775,534
These are allocated:		
Generating donations (Note 3)	279,029	280,926
Charitable activities (£145,888 is restricted expenditure (2019 £70,042) (Note 4))	611,580	453,602
Corporate governance (Note 5)	10,017	9,654
Administration - support costs (Note 6)	33,543	31,352
	934,169	775,534

The charity employed 20 full-time and 6 part-time staff members during the year to 31 March 2020 (2019: 27 full-time and 1 part-time). Staff costs are allocated between the various activities according to time spent.

	2020	2019
The amounts disclosed above include the following number of highly paid employees:	no.	no.
£60,000-£70,000	-	1
£70,000-£80,000	2	2
£90,000-£100,000	-	1
£100,000-£110,000	1	-

The total amount of employee benefits received by key management personnel is £286,479 (2019 – £269,304). The charity considers its key management personnel to comprise those individuals listed on page 3.

### 8. TANGIBLE FIXED ASSETS

	Computer Equipment	Other equipment and fittings	Total
Cost	£	£	£
At 1 April 2019	2,760	1,285	4,045
Additions	-	-	-
Disposals	-	-	-
As at 31 March 2020	2,760	1,285	4,045
Depreciation			
At 1 April 2019	2,300	803	3,103
Depreciation on disposals	-	-	-
Charge for the year	460	321	781
As at 31 March 2020	2,760	1,124	3,884
Net book value at 31 March 2020	0	161	161
Net book value at 31 March 2019	460	482	942

for the year ending 31 March 2020

### 9. Investments

	2020	2019
Market Value	£	£
As at 1 April 2019	573,527	-
Additions	580,765	540,991
Disposals	(787,498)	-
Unrealised gains/loss	15,599	32,536
As at 31 March 2020	382,393	573,527
Historical cost	386,995	540,991
Investments at fair value comprise		
Fixed Income	87,038	73,653
Equities	218,672	443,313
Alternatives	54,902	30,176
Cash	21,781	26,385
	382,393	573,527

All investments are carried at their fair value. Investments in equities are all traded in quoted public markets, primarily the London Stock Exchange. Holdings in common investment funds, unit trusts and open-ended investment companies are at the bid price. The basis of fair value for quoted investments is equivalent to the market value, using the bid price. Asset sales and purchases are recognised at the date of trade at cost (that is their transaction value).

	2020	2019
Investments individually representing greater than 5% of the portfolio held are:	£	£
Waverton Global Strategic Bond Fund 'A'	-	20,185
UK Treasury 2% 22/07/2020	23,858	-
Waverton Sterling Bond Fund 'A' Inc	29,852	-

### 10. Debtors: amounts falling due within one year

	2020	2019
	£	£
Other debtors	370,895	206,105
Prepayments and accrued income	61,423	39,749
	432,318	245,854

Other debtors includes £32,314 receivable within more than one year

### **11. CURRENT ASSET INVESTMENTS**

	2020	2019
	£	£
Short term deposits	-	90,088
	-	90,088

for the year ending 31 March 2020

### 12. Creditors: amounts falling due within one year

	2020	2019
	£	£
Trade creditors	24,342	287,080
Other creditors	1,441	-
Grant commitments (see Note 13 below)	581,754	1,028,157
Accruals and deferred income	42,249	38,019
	649,786	1,353,256

### 13. Creditors: amounts falling due after more than one year

2020	2019
£	£
Grant commitments (see table below) 204,541	193,753

	Less than 1 yr	More than 1 yr	Total	
	£	£	£	
At 1 April 2019	1,028,157	193,753	1,221,910	
Transfers	25,008	(25,008)	-	
Grant commitments	437,769	35,796	473,565	
Paid in year	(909,180)	-	(909,180)	
As at 31 March 2020	581,754	204,541	786,295	

### 14. UNRESTRICTED FUNDS 2020

	Balances	Income	Expenditure	Transfers	Balances c/f
	£	£	£	£	£
Unrestricted funds - general	534,120	789,965	(1,327,181)	735,903	732,807
Designated funds	497,000	-	-	(415,000)	82,000
	1,031,120	789,965	(1,327,181)	320,903	814,807

### Designated funds

£82,000 2020 Future Leader Awards in Epilepsy

### **UNRESTRICTED FUNDS 2019**

	Balances	Income	Expenditure	Transfers	Balances c/f
	£	£	£	£	£
Unrestricted funds - general	557,354	1,264,930	(2,186,882)	898,718	534,120
Designated funds	814,000	-	(814,000)	497,000	497,000
	1,371,354	1,264,930	(3,000,882)	1,395,718	1,031,120

### Designated funds

£300,000 Underserved Populations Call for Proposals £107,000 Newcastle Cohort Database Costs

£90,000 2020 Future Leader Awards in Epilepsy

for the year ending 31 March 2020

### 15. Restricted funds 2020

University of Newcastle	Balances b/f	Income	Expenditure ح	Transfers	/Balances c
University of Newcastle ASD-UK Research Database	£	<b>£</b> 12,713	£	(12,713)	1
Autistica Centre for Ageing with Autism Project 2	-	-	-	- (12,713)	
The Institute of Psychiatry, Psychology & Neuro	oscience				
Mental Health - Anxiety Toolkit	-	270,365	(259)	-	270,100
Bangor University					
Early intervention - Incredible Years	-	-	-	-	
The University of Bedfordshire					
Early intervention - Stigma prevention	-	-	-	-	
Discover Network	307,905	-	(204,303)	(28,653)	74,949
Epilepsy summit	-	-	-	-	
Impact Reporting	-	-	-	-	
Local Engagement	14,553	30,000	(36,526)	-	8,027
Epilepsy	-	23,000	-	(5,000)	18,000
Language and Communication Call	-	-	-	-	
Intolerance of Uncertainty	-	3,000	-	(3,000)	
Anxiety and Depression in					
Minimally Verbal Individuals	-	8,500	-	(8,500)	
University College					
Anorexia Nervosa in Autistic Women	-	1,000	-	(1,000)	•
DB Intern Scheme (Phase 2 - UK only)	-	-	-	-	
SHAPe, the Sowerby Health					
Health intervention for Autistic People	147,628	104,200	(283,740)	(2,400)	(34,312
Autistic-led Grants	15,807	100,000	(7,186)	(58,621)	50,000
Alan Turing Institute					
Turing citizen science fellow	-	50,000	-	(50,000)	
Residential Care	-	1,000	-	(1,000)	
DARE	3,452	61,550	(20,052)	(47,018)	(2,068
Home Based PECs	-	63,214	-	(63,214)	
Podcast	10,000	-	(9,104)	-	896
Embracing Complexity	10,000	114,087	(85,263)	-	38,824
Al Summit	-	36,625	(15,440)	(19,185)	2,000
City University - COMRAD					
(Complex needs underrepresented populations)	-	5,000	-	(5,000)	-
Social Care Scoping	-	25,000	-	-	25,000
University College - ARFID					
Eating disorders & autism	-	6,000	(5,150)	-	850
Ambitious about Autism	-	20,000	-	-	20,000
Total restricted funds	509,345	935,254	(667,023)	(305,304)	472,272

### **Restricted funds 2019**

University of Neurosette	Balances b/f	Income	Expenditure	Transfers	Balances c/f
University of Newcastle	£	<b>£</b>	£	£	£
ASD-UK Research Database	-	26,308	-	(26,308)	-
Autistica Centre for Ageing with Autism Project 2	-	1,250	-	(1,250)	-
The Institute of Psychiatry, Psychology & Neur	oscience				
Mental Health - Anxiety Toolkit	44,893	24,100	(72,567)	3,574	-
Bangor University					
Early intervention - Incredible Years	-	2,500	-	(2,500)	-
The University of Bedfordshire					
Early intervention - Stigma prevention	-	1,000	-	(1,000)	-
Autism Clinical Research Network	594,776	-	(160,445)	(126,426)	307,905
Epilepsy summit	28,425	-	(10,558)	(17,867)	
Impact Reporting	28,000	_	(_0,000)	(28,000)	-
Local Engagement	16,482	30,000	(31,929)	(20,000)	14,553
Epilepsy	15,000	-	(01,020)	(15,000)	1,000
Language and Communication Call	25,000	_	(75)	(24,925)	_
Intolerance of Uncertainty	12,500	1,400	(73)	(13,900)	_
Anxiety and Depression in	12,500	1,400	-	(13,900)	-
Minimally Verbal Individuals		500		(500)	
	-		-	(500)	-
DB Intern Scheme (Phase 2 - UK only)	(33,862)	33,862	-	-	-
SHAPe, the Sowerby Health	00.000	1 50 000	(0,005)	(00.000)	4 47 000
Health intervention for Autistic People	30,000	152,893	(2,265)	(33,000)	147,628
Autistic-led Grants	62,500	-	-	(46,693)	15,807
Alan Turing Institute					
Turing citizen science fellow	50,000	50,000	(51)	(99,949)	-
Residential Care	-	6,000	-	(6,000)	-
DARE	-	47,240	(14,350)	(29,438)	3,452
Home Based PECs	-	80,000	-	(80,000)	-
Podcast	-	10,000	-	-	10,000
Embracing Complexity	-	10,000	-	-	10,000
Al Summit	-	-	-	-	-
City University - COMRAD					
(Complex needs underrepresented populations)	-	-	-	-	-
Social Care Scoping	-	-	-	-	-
University College - ARFID					
Eating disorders & autism	-	-	-	-	-
Ambitious about Autism	-	-	-	-	-
Total restricted funds	873,714	477,053	(292,240)	(549,182)	509,345

Restricted funds are funds where the donor has specified the funds must be spent on a particular project as listed above. All of these grants represent either programme grants for autism research at a particular institution, specific Autistica-led projects or where specified fellowships are awarded for the purposes of supporting individuals engaged in autism research.

Transfers out of restricted funds were restricted donations received after funding was committed to specific projects.

Transfers into restricted funds were donations received as unrestricted and subsequently restricted by request of the donor.

for the year ending 31 March 2020

16. Analysis of net funds 2020	General	Restricted	Total
	£	£	£
Fixed assets	161	-	161
Investments	382,393	-	382,393
Debtors	61,423	370,895	432,318
Cash and cash equivalents	438,862	887,672	1,326,534
Liabilities	(68,032)	(786,295)	(854,327)
	814,807	472,272	1,287,079

### Analysis of net funds 2019

	General	Restricted	Total
	£	£	£
Fixed assets	942	-	942
Investments	573,527	-	573,527
Debtors	39,749	206,105	245,854
Cash and cash equivalents	742,001	1,525,150	2,267,151
Liabilities	(325,099)	(1,221,910)	(1,547,009)
	1,031,120	509,345	1,540,465

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### 17. Reconciliation of net expenditure to net cash flow from operating activities

	<b>£</b>	£
Nist an average the funds	(050.006)	
Net movement in funds	(253,386)	(704,603)
Bank interest	(12,144)	(29,865)
Non-cash donations (see note 9)	-	(540,991)
Net gains on investments (see note 9)	(15,599)	(32,536)
Depreciation charges	781	2,152
(Increase)/decrease in debtors	(186,464)	47,843
Increase/(decrease) in creditors	(692,682)	644,555
Net cash flow from operating activities	(1,159,494)	(72,454)

### **18. Related Party Transactions**

Related party transactions during the period to 31 March 2020 - £947 (2019: £25,200). The related party transactions are in relation to travel expenses incurred by Trustees in attending meetings, and have been claimed in accordance with our guidelines.

### 19. GUARANTEE

Autistica is a company limited by guarantee. Its Memorandum of Association prohibits any income or property of the company being paid or transferred to the members. Members of the company undertake to contribute a maximum of £1 to cover its liabilities.

### 20. Lease commitments

	2020	2019
The charity had the following commitments under operating leases at the year end	£	£
Due within one year	31,050	27,000
Due in 2-5 years	-	20,250
	31,050	47,250

### 21. COVID-19

Subject to the financial impact of Covid-19 that has arisen in March 2020, the Trustees have assessed the operational and financial impact on the charity in the Trustees' Report on pages 10, 18 and 19 and in the going concern statement at note 1h.

### Board of Trustees Committees and Advisory Committees

# **Board Committees**

**Finance Committee** Chair: Matthew Harris

Gill Ackers

Matt Davis (joined March 2020)

Jeff Saul (retired August 2019, co-opted as non-Trustee member August 2019)

Vinny Smith (retired March 2020)

Nominations Committee Chair: Gill Ackers

John Carey

Matthew Harris

Heather Kleeman

# Advisory Committees

### Scientific Review Panel

Chair: Professor Terry Brugha MD (NUI), FRCPsych

Vice Chair: Professor Christopher Oliver BSc, MPhil, PhD, CPsychol.

Professor Dermot Bowler, PhD Leneh Buckle

Professor Mark Brosnan, PhD, CPsychol

Professor Lucy Henry, DPhil, DClinPsych

Dr Catherine Jones, PhD

Claudia Klaver

Professor Jonathan Mill, PhD

Professor Courtenay Norbury, PhD

Dr Richard Rowe, MSc, PhD

# We were very grateful for significant support in 2019–20 from the following:

Adrian Binks and Lisa Wood Alison Hillman Charitable Trust Allergan International Foundation Argus Media Ltd **BRE Trust** Brunswick Professor Bhismadev Chakrabarti **Charles Sharland** Sir Christopher and Lady Wendy Ball DARE Advisory Board Members Edith Murphy Foundation The Edward Cadbury Charitable Trust Fujitsu GamesAid The Gerald Palmer Eling Trust Invesco Perpetual Jeff Saul John and Margaret Skerritt JPA JP Morgan Jupiter Asset Management King's College London London Stock Exchange Group Foundation Masonic Charitable Foundation

Maudsley Charity Members of the One in a Hundred Club Meryl Wakefield-Caio Next Plc Paperchase The Paul Foundation Peter Sowerby Foundation Red Brick Road **Rick Medlock Robert Luff Foundation Limited Roche Products Limited** Dr Seb Gaigg The Stanley Grundy Foundation Students and staff at Stanley House, Wellington College The Swire Charitable Trust Dr Teresa Tavassoli University of Newcastle Ukie The Waterloo Foundation The employees of Wellington Management Company Worshipful Company of Management Consultants

Thank you to the autism community and to all the supporters that make the work that we do possible.



# Making more of a difference

Autistica St Saviour's House 39-41 Union Street London SE1 1SD T 020 3857 4340 info@autistica.org.uk

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