



OCD-UK

Annual Report

for the year ended 31st December 2021.

OCD-UK
changing perceptions





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Front Cover Image: OCD-UK Fundraiser [Candice](#) leaping across the finish line of the 2021 Vitality London 10,000 in Hatfield Park in Hertfordshire. **Left Image:** OCD-UK trustee [Kylie Cloke](#) with Chief Executive [Ashley Fulwood](#) at the 2019 OCD-UK conference in Northampton. The 2021 conference was again held online due to the ongoing pandemic.

We are



Purpose, Vision and Values

Our Purpose

Is to make a positive and meaningful difference in the everyday lives of children and adults affected by **Obsessive-Compulsive Disorder (OCD)**.

Our Vision

Is of a world where the devastating impact of **Obsessive-Compulsive Disorder (OCD)** is reduced through effective and safe treatment.

Our Values

We are **supportive** and **innovative**.

We are **caring** and **compassionate**.

We have **lived experience** and real **understanding**.

We deliver **hope** and **inspiration**.

We are **inclusive**.

We are OCD-UK, and we are here for you!

Supportive and Innovative

We support all children and adults affected by Obsessive-Compulsive Disorder through the difficult times, right through to recovery and everything in between.

We are forward thinking, always seeking ways to improve and innovate in everything that we deliver to ensure we reach all those affected by OCD.

Caring and Compassionate

We provide emotional and practical advice or support in a non-judgemental way and will always demonstrate empathy, respect and dignity to the person we are working with.

We don't just listen, we hear, we understand and we see the individual not just the OCD.

Lived Experience and Understanding

Everything we do is based on the experiences of the people we serve, people affected by Obsessive-Compulsive Disorder.

We reach out to everybody within the OCD community, regardless of where they are in their own recovery journey.

Hope and Inspiration

Our passion and determination inspire those around us, we provide help and bring hope to people when they need it most.

We work together as one organisation, united behind one shared vision.

Inclusive

Irrespective of disability, gender, country of origin, race, religion or sexual orientation, everybody is welcomed and respected equally when using, attending and contributing to any of the OCD-UK services.

Charity annual report

Year ended 31st December 2021

The trustees of OCD-UK are pleased to present their annual report together with the financial statements of the charity for the year ended **31st December 2021**.

The financial statements have been prepared independently in accordance with the Charities Act 2011 by Eric O'Connor from Nicholson Tax & Accounts, Derbyshire, who found the accounts in good order.

A snapshot of our finances can be found on page 18, with further details on page 38.

PROVIDING



CREATING



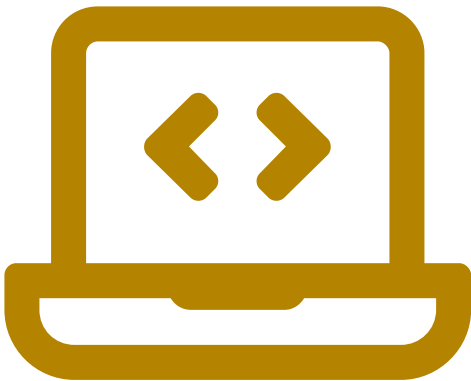
In 2021 we generated £229k to keep our services running, with £133k raised through the fundraising efforts and donations of our supporters.



71p in every
£1 spent

went towards charitable activities from raising awareness to supporting children and adults affected by OCD.

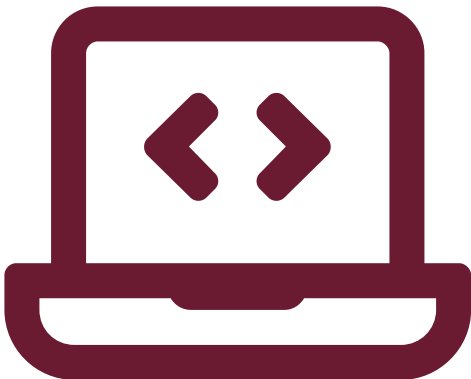
The charity reported a surplus of £60k in 2021, this money is due to be spent during 2022 on planned project work.



Our website had
2.2m page views by
918k users from across the globe.



£252
Could pay for our advice line to be staffed for 8-hours a day.



Our support forums had
1.1m page views by
39,811 users from across the globe.



One or Two
of us in every one hundred people in the UK will be living with Obsessive-Compulsive Disorder.



Last year the time given by our amazing volunteers contributed the equivalent of
£36k

Welcome to the OCD-UK Annual Report for 2021

by **Ashley Fulwood** *Chief Executive* and **Catherine Mills** *Chair of OCD-UK*

As a charity, OCD-UK has always embodied openness, so we want to share with you our little glimpses into our OCD this year, the challenges, the lessons learned and our successes against it.

CATHERINE - Chair

In January 2021 I started working with a Therapist, Anne, to help me deal with some of the consequences I was experiencing as a result of my OCD. To explain briefly, I have found some of my intrusive thoughts to be quite traumatic and Anne suggested we try a technique called EMDR to help process these thoughts and reduce some of the distress I was experiencing from having them. I have found this therapy very helpful and it has helped me reduce the amount of 'neutralising' I do from having the thoughts.

Another approach we took was to help me develop a more compassionate response to these thoughts. Like many people with OCD, I have a tendency to 'beat myself up' because I have these distressing and repugnant thoughts. For me, this often takes the form of denying myself food and this can be a very slippery slope. So we have been engaging in Compassion Focussed Therapy and trying to reduce my tendency to punish myself.

Having also experienced CBT for my OCD, I see the above therapies as complementing the evidence-based approach of CBT. They are not a replacement for CBT but rather have helped me manage some of the secondary difficulties that can arise from having OCD. CBT remains the first line therapeutic approach for OCD but I have also found it helpful to explore other, complementary models too.

ASHLEY - Chief Executive

Not that I needed a wake-up call for where we are in terms of people accessing NHS treatment for OCD, but I am going to be honest and say I had a stark realisation in 2021 when I reached out to my local Derbyshire 'Improving Access to Psychological Therapies' service.

Despite frequently being debilitated by the ravages of OCD forcing me to spend two to three hours cleaning when triggered, sometimes with pure bleach, I was told I did not meet clinical criteria for treatment (Cognitive Behavioural Therapy). I was shocked and bewildered. It was only when I put in a formal complaint that the service admitted they had got their decision wrong and relented, finally offering me treatment.

But it should not take a formal complaint to get me the treatment I so desperately needed when I reached out for help. If this has happened to me when I know the system so well, then it can happen to anybody. It also shows how much more work the charity has to do and the importance of independent charities like OCD-UK in providing those needing help with information about their rights in accessing OCD treatment.



OCD-UK

In reflecting on the work of the charity in the past year it would be impossible to do so without reflecting on the continuing global impact the COVID-19 pandemic caused during 2021. Increased wait times for NHS treatment led to more demand on our services. More lockdown fears meant we remained largely delivering online during the year, typified by our online support groups which have flourished under Kirstie and Gemma's guidance. It allowed us to offer everyone the chance to feel they have a platform through OCD-UK to create powerful supportive connections that help them communicate and help each other.

Lifting of lockdown restrictions then generated more fears for many with OCD, where the pandemic caused their usual fears and worries to morph into all new terrifying intrusive thoughts aligned to the virus and spreading it to loved ones.

So the COVID-19 pandemic continued to play a significant impact on what we could deliver and what we needed to deliver during 2021.

The dedication and commitment of our staff during the year was exemplary with Gemma, Kirstie and Zoe working all year round to deliver vital services for children and adults affected by OCD. We also welcomed new volunteers like Evelyn and Bismah to the team.

Despite everything that was going on last year, the support of our supporters never waned. So, to each and every person who has given their support and donated their time or money to OCD-UK, may we offer our heartfelt thanks. The successes we've seen this year as a charity would not have been possible without your drive, passion and generous support during such a difficult time for the nation – so on behalf of the people we support, thank you to all of you who supported OCD-UK in some capacity.

We wrote last year that our aspiration is for the UK to be a place where everyone has access to the best possible treatment, ensuring that the devastating impact of OCD is reduced significantly. Right now, that is still not happening in many areas, as Ashley found out, so we're not going to stop until our vision has become a reality.

OCD-UK still has much work to do; we hope that our passion and determination inspires those around us and creates hope for those who need it most. With your help we can work as one, united behind our shared vision of life without the impact of Obsessive-Compulsive Disorder.

Wishing you all good mental health.

Ashley Fulwood
Chief Executive of OCD-UK

Catherine Mills
Chair of OCD-UK

Both Ashley and Catherine have lived experience of OCD.

THROUGHOUT 2021 THE OCD-UK TEAM DELIVERED THE FOLLOWING

Our online support groups were hosted and attended by participants



2,291
times



Your fabulous support, through membership donations and fundraising, has helped our small team of staff and volunteers to continue to work hard for people affected by **Obsessive-Compulsive Disorder**.

This is just some of what we provided during 2021.



We started delivering interactive face-to-face workshops across the East Midlands for parents of children and young people with OCD.

1,492

SUPPORT EMAILS ANSWERED,
OFFERING PERSONALISED
ADVICE AND SUPPORT



20,169

Community support forum posts
made by **2,948** different forum
users.



895
OCD-UK
members



235

SUPPORT CALLS OFFERING
PERSONALISED ADVICE
AND SUPPORT



13.9K
FOLLOWERS



6,423
FOLLOWERS



12.9K
FOLLOWERS



15 interactive
online webinars
delivered to **127**
parents of children
and young people
with OCD.

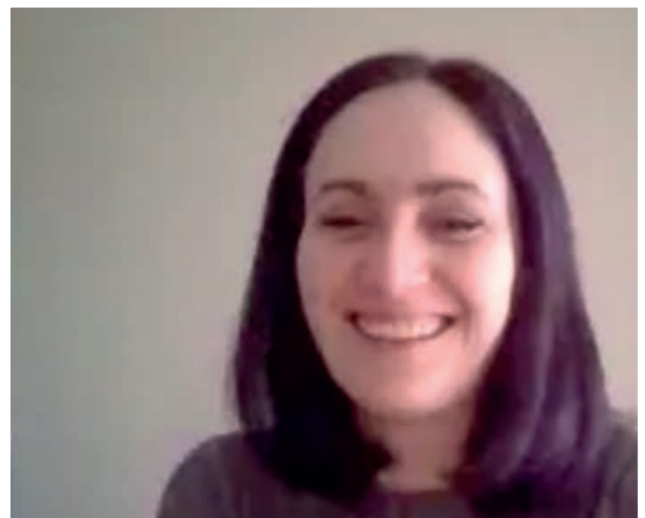
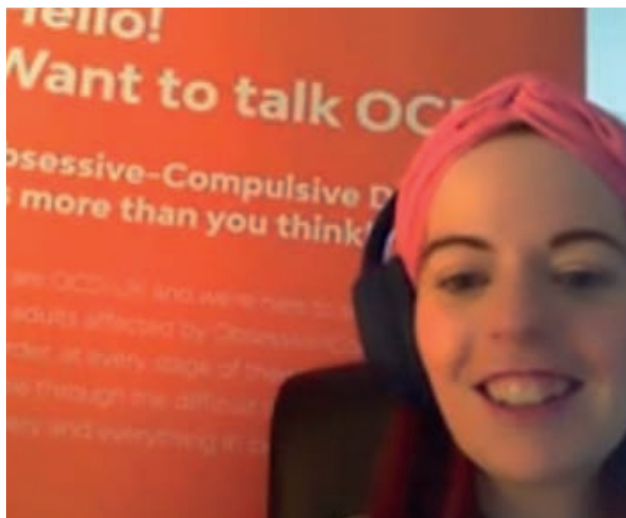
What else we have been doing...

- ✓ Delivering themed support groups for under 18s
- ✓ Delivering themed support groups for over 50s
- ✓ Delivering themed support groups for family and friends
- ✓ Planning ahead for our 2022 conference
- ✓ Providing training and supervision to OCD-UK volunteers
- ✓ Delivering OCD training workshops for teachers
- ✓ Creating new advice guides for parents of young people with OCD
- ✓ Creating social media advice posts
- ✓ Working with the media to ensure positive & accurate OCD coverage
- ✓ Responding to inaccurate OCD articles across a variety of platforms
- ✓ Working with retailers to remove products that contain inaccurate or stigmatic representations of OCD
- ✓ Attending NHS stakeholder meetings to represent our community

We deliver all of this work with the policy that irrespective of disability, gender, country of origin, race, religion or sexual orientation, everybody is welcomed and respected equally when using, attending and contributing to any of our services.

Meet the team

OCD-UK, a charity run by and for people with lived experience of Obsessive-Compulsive Disorder. We are here for you!



Zoë • Ashley • Kirstie • Gemma

If you have used any of our services during 2021 or attended our online conference then you will undoubtedly have already met some or all of Team OCD-UK, which remained at four people during 2021. So meet Zoë Wilson, Ashley Fulwood, Kirstie McBryan and Gemma Blueitt.

Team OCD-UK are here for you!





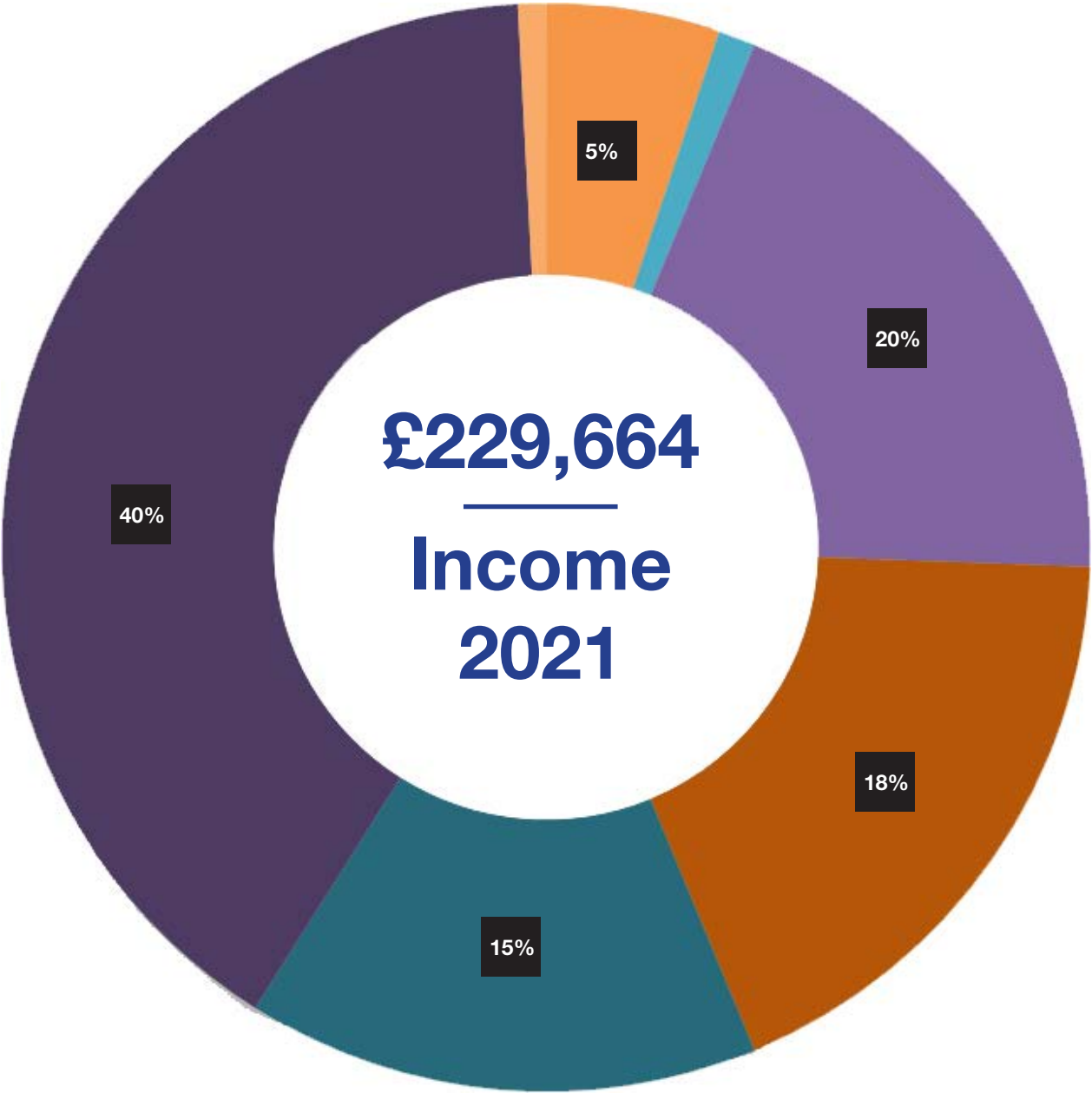
OUR BRANCHES OF SUPPORT

OCD-UK, a charity run by and for people with lived experience of Obsessive-Compulsive Disorder

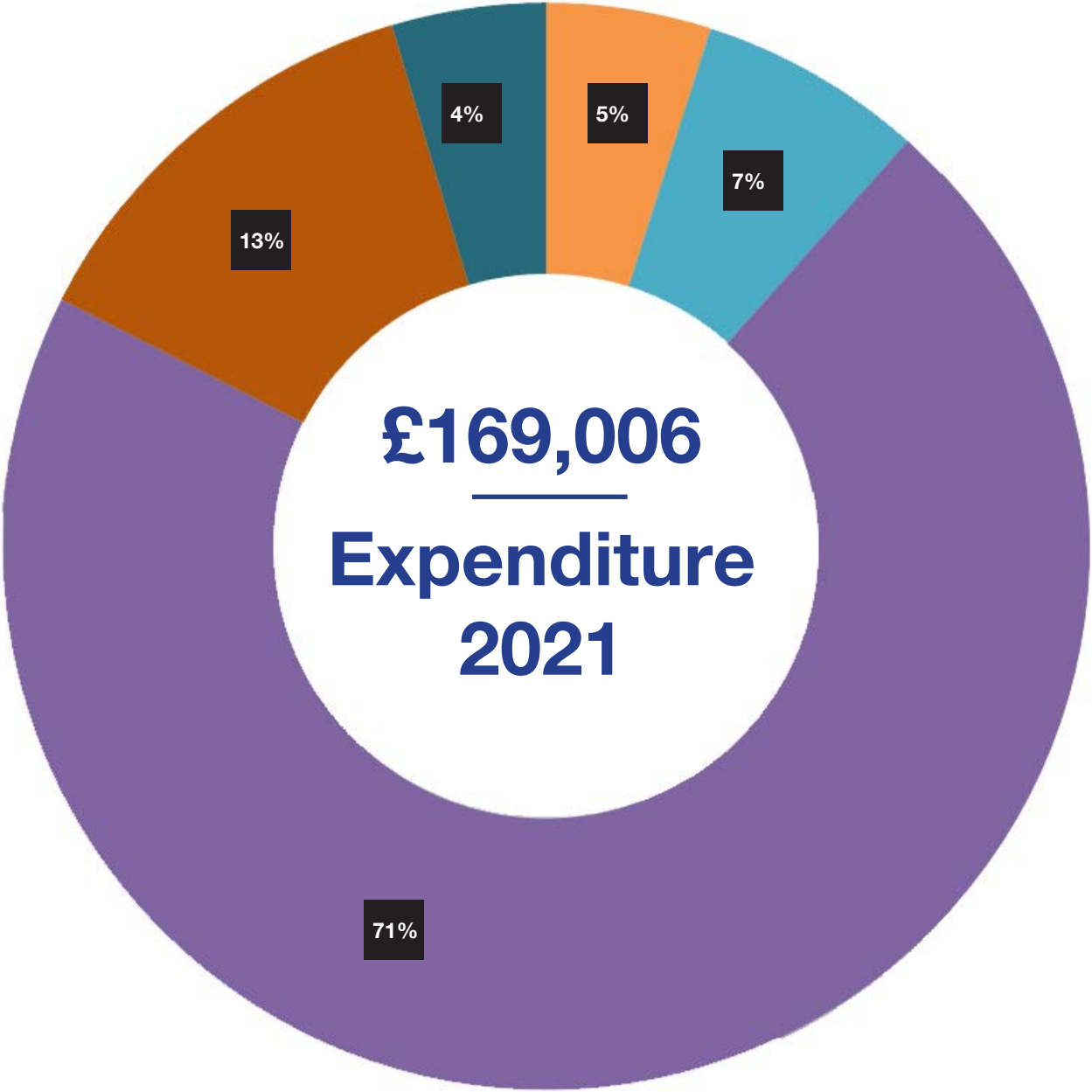


In 2021 we generated £229k to keep our services running, with £133k raised through the fundraising efforts and donations of our supporters.

For every £1 we spent in 2021, 71p was spent on delivering charitable activities across the OCD community.



- Grants - £92,316 (40%)
- Fundraising - £44,352 (20%)
- Donations - £41,758 (18%)
- Membership - £34,962 (15%)
- Trading (Books, Greetings Cards, Gifts) - £11,846 (5%)
- Consultancy - £2,520 (1%)
- Misc Income - £1,910 (1%)



- Charitable Activities - £119,821 (71%)
- Governance and Administration - £21,844 (13%)
- Trading - £11,320 (7%)
- Costs of generating voluntary income - £8,284 (5%)
- Rent and electricity - £7,737 (4%)

Our financial snapshot shows our expenditure split into the charity's key operating areas. Salaries are split within each relevant area.
[Turn to page 38 for our financial summary explained.](#)

OCD-UK providing help and creating hope

About OCD-UK

OCD-UK has been working for children and adults affected by Obsessive-Compulsive Disorder since 2004.

We provide advice, information and support services for those affected by OCD. We also campaign to end the trivialisation and stigma of OCD.

Our team are passionate about creating a world in which people with Obsessive-Compulsive Disorder are able to lead the life they want, without the impact of OCD.

Uniquely, the charity is completely service-user led, and everybody involved in the organisation has personal experience of OCD, either directly or indirectly through a loved one.

For our team, because of their own experiences, this is not just a job. For us, this is a passion, this is a commitment... because we ARE OCD-UK!



Strategic Objectives for OCD-UK

✓ SUPPORT

We provide support services for all those affected by the devastating impact of Obsessive-Compulsive Disorder.

✓ AWARENESS

We promote better understanding and education about Obsessive-Compulsive Disorder.

✓ TREATMENT

We campaign for improved access to effective and quality treatment for Obsessive-Compulsive Disorder.

✓ RECOVERY & MENTAL WELL-BEING

We promote mental well-being and recovery to offer hope for a life unhindered by Obsessive-Compulsive Disorder.

✓ YOUNG PEOPLE

We offer young people with Obsessive-Compulsive Disorder a platform to share their story and connect with others.

Trustees



L-R – OCD-UK trustees: Charlotte Rowe, Joanne Griffiths with former trustee Yolanda Jerrard.

OCD-UK is a membership-based charity, managed by a team of dedicated trustees which make up our executive membership committee.

These are endorsed and elected by our members at our Annual General Meeting. They are all members who have volunteered for the charity for a period of time before being approached to become a trustee. They receive no remuneration, other than essential working costs approved by the charity.

Uniquely, OCD-UK is completely service-user led; all of our trustees have suffered or have a close family member suffering with OCD.

The trustees listed below were all re-appointed by our members at our last AGM held online on Saturday 6th March 2021:

Catherine Mills
Chair, Merseyside

Claire Gellard
Trustee, Essex

Claire Goldenberg
Trustee, Sussex

Thorrún Govind
Trustee, Manchester

Nick Marlow
Trustee, Nottingham

Sandy Nisbet
Trustee, Glasgow

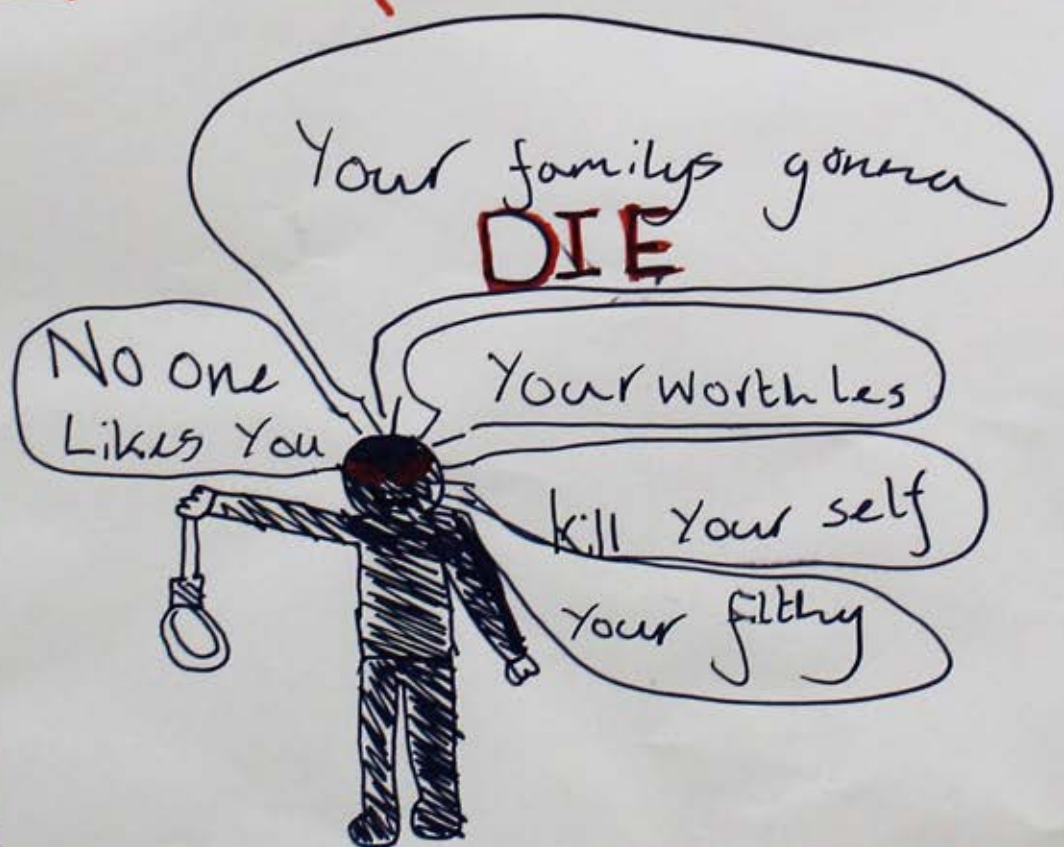
Charlotte Rowe
Trustee, France

Joanne Griffiths
Trustee, Cornwall

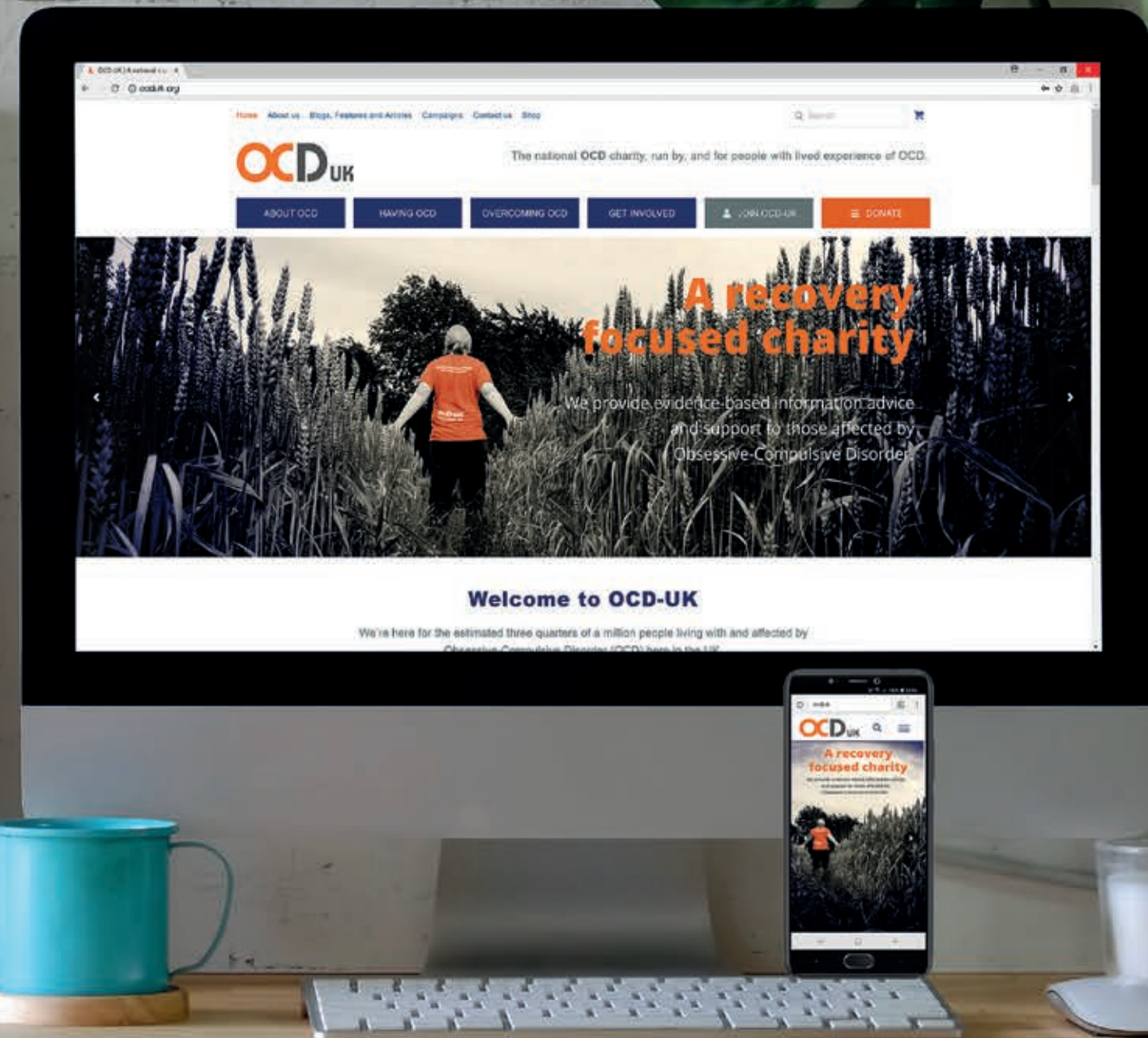
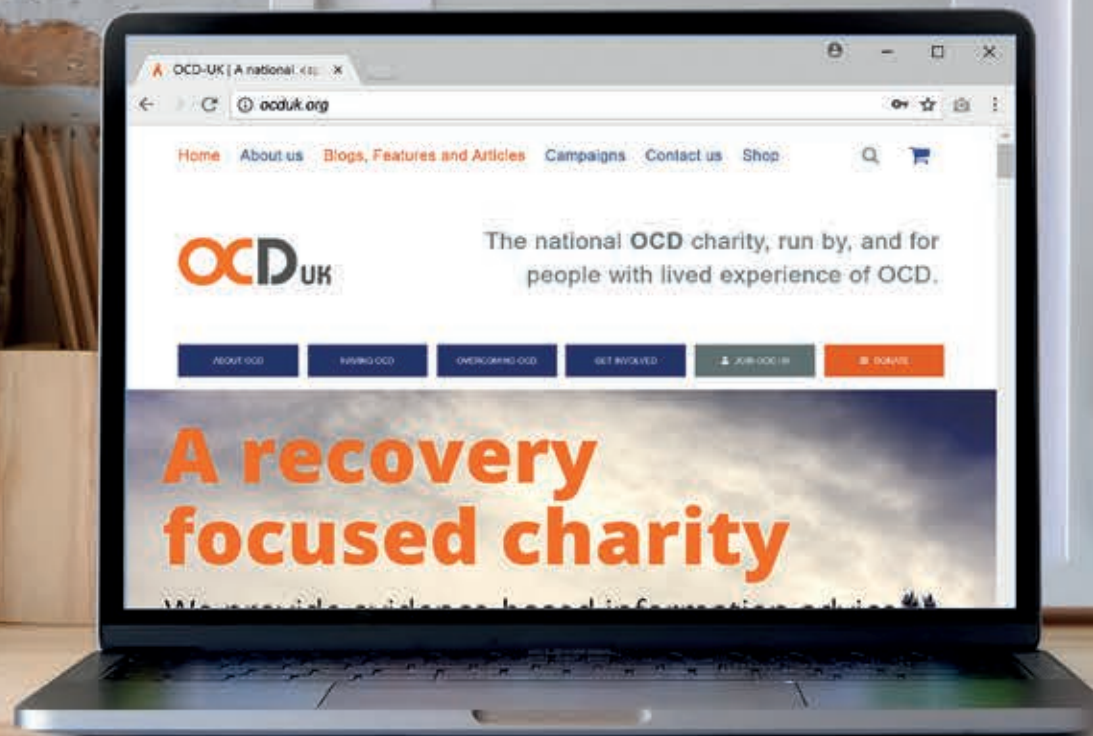
Kylie Cloke
Trustee, Gloucestershire

OCD MONSTER

HELP



www.ocduk.org



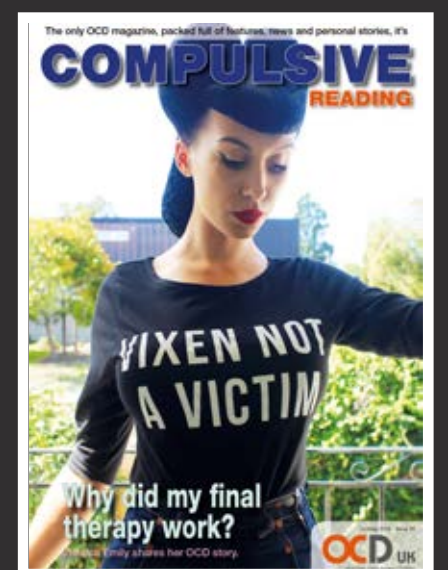
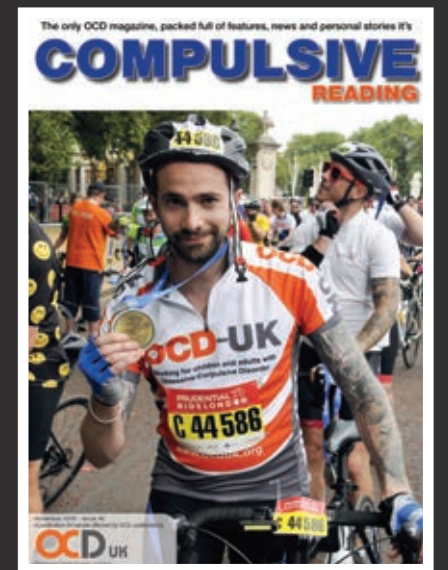
COMPULSIVE READING

Once again our members' magazine **Compulsive Reading** was published in 2021 and continues to receive high praise for its mix of content.

Content focused on timely subjects, first-hand experiences and news relevant for people with OCD.

We will continue to focus on inspirational first-hand experiences and recovery.

The online version of **Compulsive Reading** continues to be fully readable across both Android and Apple devices.



THANK YOU FOR READING

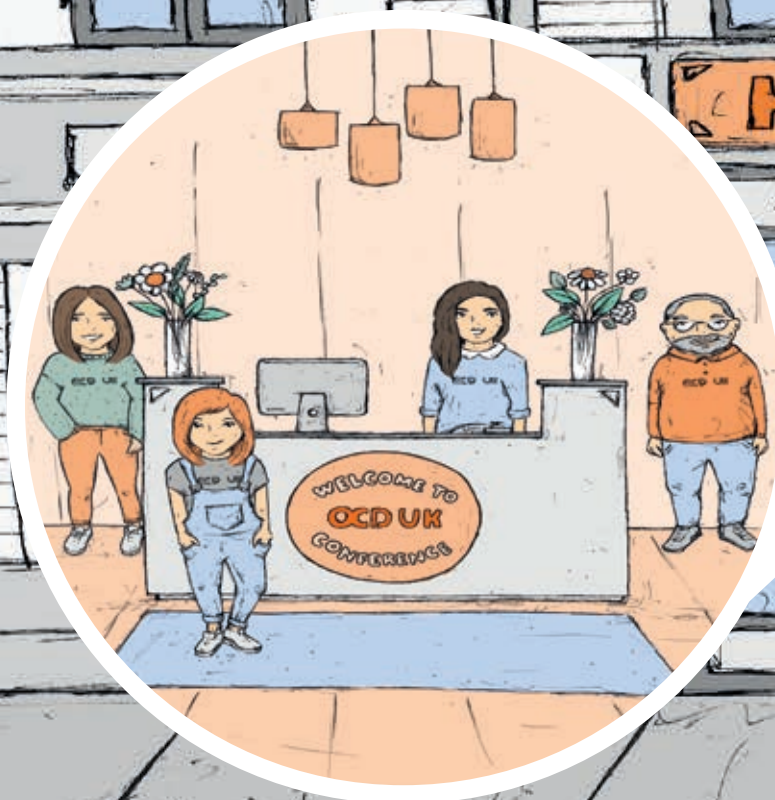
WE CAN BE
HEROES
JUST FOR ONE DAY

These are just some of our **2021 FANTASTIC FUNDRAISERS** who walked, swam, hiked, cycled or ran for OCD-UK this year.

Turn to page 35 to see more fantastic fundraisers and stories.



OCD-UK once again hosted its annual conference virtually during 2021. We re-opened our doors to our virtual Hotel OCD-UK venue, where we are flying the flag for recovery! The conference was made freely available to access!



ONLINE
CONFERENCE
FREE
ACCESS

www.ocduk.org/conference

Saturday 27th and Sunday 28th November 2021



OCD-UK patron Professor Paul Salkovskis at the 2019 OCD-UK conference in Northampton.

Structure, Governance and Management of OCD-UK during 2021

The chair of OCD-UK presents the annual report at the charity's Annual General Meeting (AGM) each year.

Legal Status

OCD-UK was founded in December 2003 and formed as a charity under a constitution in January 2004. We were officially registered with the UK charity commission on the 14th April 2004. The charity registration number is 1103210.

Our Structure

The board of trustees is the governing body of the charity. It's their role to establish the policies, objectives and procedures for the charity to ensure the effective running of the organisation in pursuit of its long-term objectives.

Patrons

We are honoured to be supported in our work by two patrons, actor and writer Ian Puleston-Davies and highly respected Professor Paul Salkovskis from the University of Oxford.

We are also supported in our work by overseas ambassador Professor Adam Radomsky, from Concordia University, Montreal.

Staff

The charity had two full-time members of staff during 2021, the Chief Executive Officer (CEO), Ashley Fulwood, who is responsible for the day-to-day management of the charity and for implementing policies and working towards the objectives agreed by the charity's management trustees, and Zoe Wilson our Children, Young People and Parents lead. We were also supported by two part-time members of staff: Gemma Blueitt our Support Co-Ordinator (four days per week), and Kirstie McBryan our Online Groups Manager (three days per week).

Membership

Membership of OCD-UK is open to any individual with an interest in OCD or the charity's work. At the end of 2021 the charity had 895 active members (up from 769 at the end of 2020). Members are entitled to attend the AGM and to one vote per discussion.

Volunteers

OCD-UK had many committed and regular active volunteers across the UK during 2021, most of whom have been directly affected by OCD. Their selfless personal commitment has been the cornerstone of OCD-UK's success in delivering its aims and objectives. We estimate that our volunteers have donated at least 2,486 hours to OCD-UK during 2021, in monetary terms worth at least £36,345 to the charity.

These volunteers have helped us provide direct support online and offline, facilitated support groups, worked on our website and publications, or helped at our events or conferences. Other volunteers not included in the above figures have also contributed their time to actively support the research and media work that we promote.

The trustees of OCD-UK remain grateful for the donation of time that volunteers give to our charity. We recognise that we can achieve even more with their assistance, and we must provide them with regular support, training and supervision to help them in their role.

Professionals

We would also like to acknowledge our gratitude and thanks to the following accountancy, legal, anxiety charity colleagues, health professionals and media personalities who kindly donated their time to offer support and assistance during 2021. The number of people highlights the collaboration between OCD-UK and health professionals.

- | | |
|-------------------------------|--------------------------------|
| • Dr Hannah Baker | • Dr Zoe Kindynis |
| • Laura Barnes | • Nicky Lidbetter |
| • Kerry Boorman | • Georgia Lock (actress) |
| • Dr Victoria Bream | • Dr Claire Lomax |
| • Lauren Callaghan | • Sorchia and Monica McCaffrey |
| • Dr Fiona Challacombe | • Dr Josie Millar |
| • Chloe Chessell | • Dr Ilenia Pampaloni |
| • Jenny Cole | • Rebecca Pedley |
| • Eric O'Connor | • Professor Christine Purdon |
| • Ian Puleston-Davies (actor) | • Professor A Radomsky |
| • Paula Duncan | • Dr Alison Roberts |
| • Dr Lynne Drummond | • Professor P Salkovskis |
| • Jeanette Evans | • Professor Roz Shafran |
| • Dr Alice Farrington | • Steve Sharpe |
| • Mark Freeman | • Dr Blake Stobie |
| • Professor Mark Freeston | • Dr Clara Strauss |
| • Rose Gardener | • Dr Sasha Walters |
| • Dr Victoria Hallett | • Professor David Veale |
| • Dr Maxine Howard | |
| • Dr Gazal Jones | |

Apologies to anybody we have accidentally omitted from this list.





FANTASTIC FUNDRAISERS

More of our #FantasticFundraisers during 2021



These are some of our **2021 FANTASTIC FUNDRAISERS** who have run, cycled or hiked through the mud for OCD-UK. To one and all, thank you!

1. **Leanne** – preparing for her Great Manchester Run in September.
2. **Orla** – 10 year old Orla smashed her original target and went on to raise a staggering £1,730 for OCD-UK by running a mile each day of February, in fact she ended up running a mile for 100 days in a row, ending on her cats and dad's birthday!
3. & 4. **Millie** – raised £595 in 2020 by running her own local 5k run during lockdown for OCD-UK. Cheered on by family and neighbours.
5. **Will** – raised £1390 during lockdown by challenging himself to run 5k every day for seven days, with a final day run up Pendle Hill.
6. **Stuart** – and his friend Mark along with Deborah and Sophy raised over £4,200 by cycling all the way from Stroud to Edinburgh, pictured on page 37 with the team on Calton Hill in Edinburgh.
7. **Zoë** – congratulations to our very own Zoë who completed the Great North Run for OCD-UK in a time of 1hr 49min.
8. **Katherine, Michael and Flora** – all ran the Royal Parks Half marathon in October. Although not running together, amongst thousands of runners they found each other post race to get this fantastic group picture. Flora raised £3,022, running in memory of her brother Tom who previously ran the race for OCD-UK in 2017.
9. **Conor** – managed to raise £1,605 by running three half marathons in three weeks this summer.
10. & 17. **Evelyn** – OCD-UK volunteer Evelyn pictured in Scotland during her 30-day 1.2 Challenge.
11. **Christopher, Emily and Danielle** – after completing their Great North Run in September.
12. & 13. **Candice** – leaping across the finish line of this year's Vitality London 10,000 in Hatfield Park in Hertfordshire where she was running in loving memory of her friend James.
14. & 15. **Sean** – in the Brecon Beacons whilst doing a 20 mile race called the Beast of Beacons, which itself is training for the 180 mile Black Bear Ultra Challenge. Sean raised £1,213 split between OCD-UK, Epilepsy Action, Mind, British Heart Foundation and Young Minds, all of which are of special importance to Sean.
16. **Emily** – running the Great North Run in September.
18. **Hannah and Jamie** – during the Cambridge Half Marathon in October.
19. **Danielle and Emily** – raising awareness on the train to the start of their Great North Run in September.
20. **Nigel, Dave, Steven and Clive** – were part of a team of ten from Nuvola Distribution in Reading who completed the Great North Run for OCD-UK in September.

From those who participate in the wacky or endurance fundraising and those who donate, thank you, we value your support so much.

If we have forgotten to mention anybody or share your fundraising pictures please forgive us and do let us know so that we can remedy that in the next magazine!

We really recognise that we would not be here without you, so...

THANK YOU!



Thank you to our supporters

Special thanks to all our supporters and charitable trust donors, including:

- Every single person who has fundraised or donated in 2021 Hannah and Jamie (right) and all those who took part in the 1.2 Challenge.
- Rose G
- BBC Children in Need
- Boots Charitable Trust
- Community National Lottery Fund
- Coronavirus Mental Health Response Fund
- National Lottery Community Fund - Coronavirus Community Support Fund
- National Lottery Community Fund - Pep Talk (Parent Education Project)
- Other grant funders and donors who wish to remain anonymous

Thank you to everyone who has campaigned for us, made donations, volunteered their valuable time and skills, or supported us financially.

Because of your generosity we've been able to keep supporting both young people and adults who are suffering from Obsessive-Compulsive Disorder.

Your stories of courage and tenacity, despite the anxiety created by OCD, continue to inspire us all, and drive everything that we do.

We remain committed to working to make a positive and meaningful difference in the everyday lives of children and adults affected by OCD.



2021

£229,664

2021 Income

£169,006

2021 Expenditure



Accounts Comparison	Income	Expenditure
Jan 2021 - Dec 2021	£229,664	£169,006
Jan 2020 - Dec 2020	£226,291	£160,990
Jan 2019 - Dec 2019	£137,479	£113,344
Jan 2018 - Dec 2018	£88,263	£102,164
Jan 2017 - Dec 2017	£80,978	£92,595
Jan 2016 - Dec 2016	£81,099	£90,925

Financial Review 2021

Our financial year mirrors the calendar year, and runs from 1st January to 31st December annually.

Our annual accounts are also subject to review by an independent chartered accountant. We are grateful to **Eric O'Connor** and the team at Nicholson Tax & Accounts of Derbyshire for examining our accounts. A copy of the full 2021 accounts can be found on our website and accompanying this annual report.

OCD-UK income for 2021 was £229,664 with expenditure of £169,006. It's worth noting that some of the funds carried forward is restricted grant funding and is due to be spent in 2022. Therefore, whilst the charity's financial situation is healthy, we still have less than one year's running costs in reserve which we need to work towards.

OCD-UK is relatively self-sufficient in the respect that most of our core email and helpline support services are not reliant on charitable grant income, with the majority of our income arriving through the kind generosity of our supporters.

Donations, fundraising and membership remain our primary source of core continuing income, with membership numbers increasing again during 2021. Donations decreased in 2021, in part because during the start of 2020 we received a single generous legacy left to the charity. We also believe an increase in small donations during the first part of the pandemic in 2020 was because people were not going out and were able to make more smaller donations.

However, fundraising income increased significantly in 2021 as events like the Great North Run took place again after being cancelled during the pandemic in 2020. Your virtual and 1.2 Challenge fundraising was utterly amazing and continued into 2021 so we thank you!

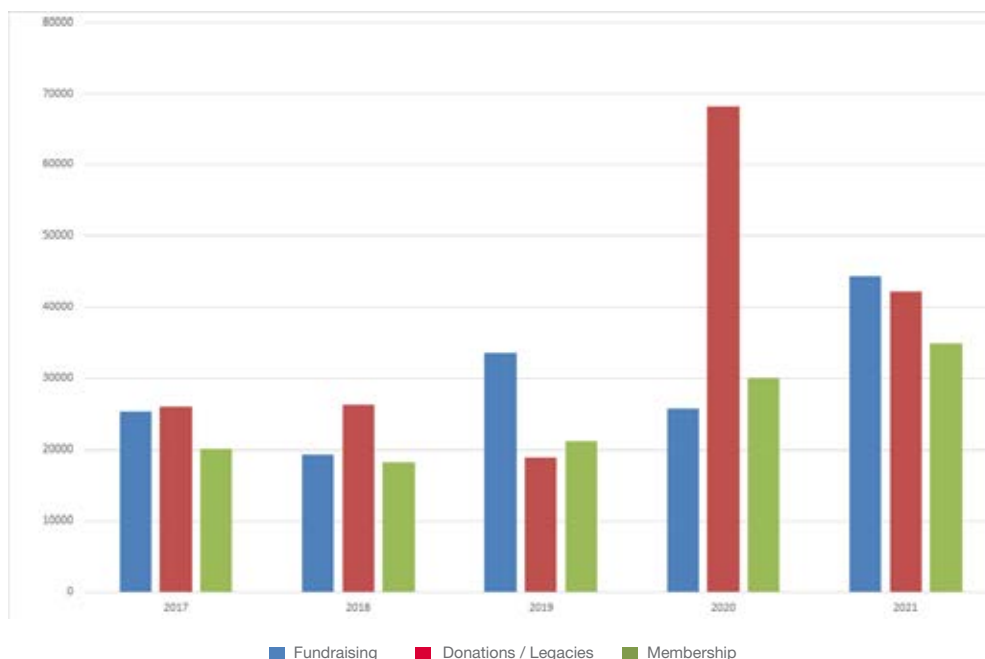
We do see a fluctuation in fundraising income as a trend in cycles every 2-3 years. We have some very loyal supporters and members who are happy to fundraise for our charity, but are unable to fundraise every year. We do still face the dilemma of stigma still preventing some people with OCD being able to ask family and friends to sponsor them for an OCD charity.

Throughout these difficult economic times that the pandemic created, the support for our vital work has been astonishing, for which we remain incredibly grateful.

Our charity is managed prudently, vital in these times of economic uncertainty, but our core expenditure in 2021 did increase, primarily because of increased staffing hours.

We are always exploring new opportunities to make our limited resources go further and we work hard to get the most from our income by making our organisation's operating structure as efficient as possible. We are proud of the fact that our services were operated by just four members of staff (only two are full-time) in 2021.

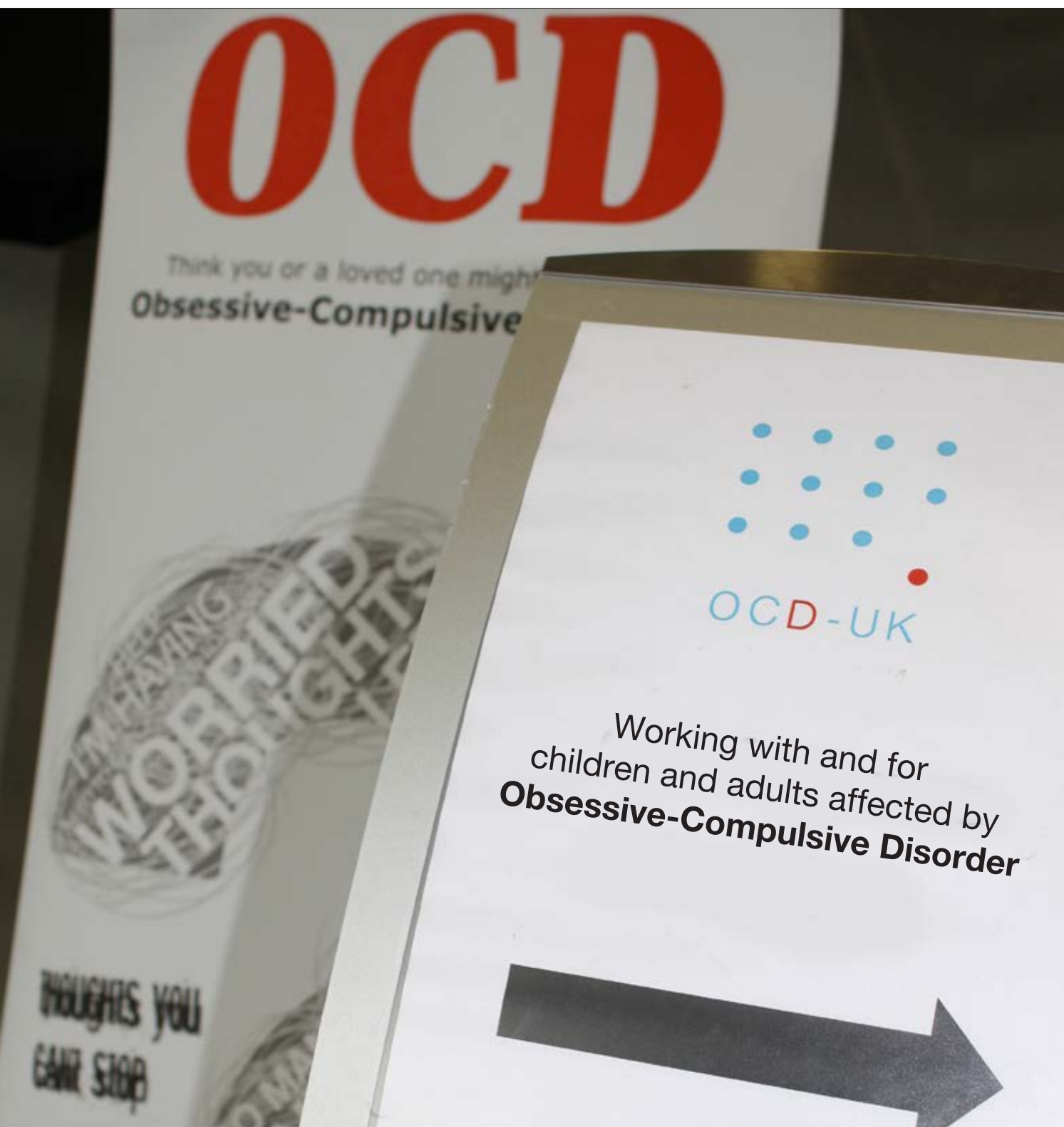
The chart below shows a comparison over the last five years of our income from fundraising, donations and membership.



**THANK YOU
FOR YOUR CONTINUED SUPPORT OF**



THROUGHOUT 2021



OCD-UK

Annual Report

Thank you for your support in 2021