

# **OCD-UK**

## **Annual Report**

for the year ended 31st December 2015.





# OCD-UK Changing Perceptions

OCD-UK are proud to have been serving people affected by Obsessive-Compulsive Disorder since 2004, raising awareness and changing perceptions about recovery.

Our work creates a legacy that continues to inspire many, for the benefit of all those with OCD.

#### **OUR LEGACY**

includes being the first dedicated OCD charity to:

- Host days out for children with OCD.
- Create minimum standards for independent support groups to adhere to.
- First mental health charity to speak out vociferously about Channel 4's Obsessive Compulsive Cleaners.
- To develop use of virtual technology to involve volunteers from all over the whole of the UK.
- Become full time (Mon-Fri) along with offering out-ofhours services through use of virtual technology.
- First and only charity to fund venue hire costs for regional OCD support groups.

#### **OUR UNIQUENESS**

We want to continue to be innovative in the way we work for people affected by Obsessive Compulsive Disorder.

These are just some of the ways that OCD-UK is unique in being a dedicated OCD charity that:

- Is completely service-user led, run by OCD sufferers, for sufferers.
- Publishes the only dedicated OCD magazine Compulsive Reading made available for members.
- Delivers events all across the UK.
- Continues to deliver events in Scotland, Northern Ireland and Wales.

#### **OUR PLEDGE AND VALUES**

Our pledge is to serve all those who suffer because of the impact of Obsessive-Compulsive disorder.

#### Our values include:

- Dedicated to hosting awareness campaigns that focus on the message, rather than ourselves.
- Transparent and honest in our service reporting to our members.
- To continue to be the voice for people with OCD, and to be vocal about misrepresentations of OCD.
- To continue to be the voice for people with OCD, challenging unethical or unsafe research or treatments.



## We are OCD-UK

OCD-UK is a national charity representing children and adults affected by Obsessive Compulsive Disorder (OCD).

Uniquely, the charity is completely led by people with first-hand experience of OCD.

Since 2004, we have been helping to advise, educate, inspire, encourage and guide people suffering with OCD through their recovery journey.

Our mission is to make a positive and meaningful difference in the everyday lives of children and adults affected by Obsessive Compulsive Disorder.

OCD-UK changing user perceptions about recovery.

OCD-UK changing public perceptions through awareness.

# 2015 at a glance

OCD-UK is 11-years-old

We handled **5,398** telephone calls on our support line.

We ended 2015 with 744 OCD-UK members.

Our support email account answered **749** emails from people across the world.

**732,039** people visited our website and between them viewed almost **2 million** webpages on our site during 2015.

60,645 people visited our forums for community and OCD-UK support during 2015, spending an average of 12 minutes each on our forums and viewing over 2 million webpages.

We concluded our East Midlands 'Are you a little Bit OCD?' awareness project, funded by **Time to Change**.

We hosted our annual conference in the North East of England, in **York** for over **160** people affected by OCD.

We funded 6 regional support groups throughout the year, and offered help and support to many other support groups.

We became partners with **Nottingham Recovery College** to develop, launch and co-host a brand new course for people living with **obsessions and compulsions**.

Funded a training workshop for health professionals with international OCD specialist, **Dr Adam Radomsky**.

We became partners with **Nottingham Healthcare** Foundation Trust to develop a brand new **peer supported** OCD treatment pathways group.

OCD-UK delivered a national **OCD Awareness Tour**, with Professor Paul Salkovskis and Ashley Fulwood cycling from John o Groats to Lands End, delivering OCD presentations along the way in **Scotland, Liverpool, Wales and Truro**.

"As a charity, we have seen the devastating impact that OCD has on peoples' lives and that is why it will always put the sufferer at the heart of everything it does."

Catherine Mills Chair, OCD-UK



# Chairs Report

by Catherine Mills, chair of OCD-UK

OCD-UK is a national charity that puts the OCD sufferer at the centre of its work. It achieves this in a number of ways. For example, it lists support groups on its website, but only those groups that abide by standards that have been set by sufferers. This ensures that only quality support groups are promoted.

The charity takes on a lot of advocacy work where the sufferers are struggling to access appropriate treatment. In the last year, OCD-UK has worked with the Department of Health to ensure that sufferers have the right to choose their IAPT provider, meaning they can receive treatment from a provider that has better treatment outcomes. Where sufferers meet national criteria for specialist care, OCD-UK will also support people in accessing this.

#### Unique

OCD-UK is unique in that all its staff and trustees either suffer from or care for someone who suffers from OCD. It is the charity's belief and ethos that these are the people who are best placed to make the important decisions and offer the appropriate support to people who use our services.

#### **National**

OCD-UK believes in taking its services around the UK, as seen by the range of venues selected to host its conferences and 'audience with' events. Whether it be Wales, Scotland, Northern Ireland or England, OCD-UK has held public events there.

#### **Awareness**

One of the constant battles OCD-UK has to fight is the poor understanding that the public and media still hold about OCD, as seen by its trivialisation. Recently, the charity has been working on putting the 'D' back into 'OCD'. This is to try and emphasise that it is a disabling and debilitating disorder, not merely the presence of a few quirky characteristics. What other illness would like to be the subject of disrespectful and trivial humour?

As a charity, we have seen the devastating impact that OCD has on peoples' lives and that is why it will always put the sufferer at the heart of everything it does.

Catherine Mills, Chair



# OCD-UK 2015 Passion and Committment

Chief Executive's Report

by Ashley Fulwood, Chief Executive of OCD-UK

much from the project that will drive our ethos on challenging stigmatic comments about OCD for years to come.

The project was ably led by **Beth Hemus** who worked with a team
of volunteers and I watched with
pleasure as Beth brilliantly helped
develop the skillset, the confidence
and the opportunities for some of
these volunteers.

Beth and her team demonstrated that when the 'little bit OCD' term is used in a way to describe quirks rather than a disorder, or when OCD is used in a derogatory way (through a lack of education rather than malice), that calm and reasoned conversation really does help change people's understanding. People will listen and are interested if we engage them calmly.

When the project concluded at the end of March I took the decision to ask Beth to stay with us, and I was delighted when Beth accepted my invitation to remain with team OCD-UK.

One of those volunteers Beth and I have both worked with, and I believe have supported and given him confidence to acheive, is **Nick Marlow**. Nick is one such whose own recovery and volunteering with OCD-UK has helped him deliver groups for people affected by OCD and his passion and commitment to show people that they can recover is contagious. I have seen people in those groups be lifted by his passionate word. You can read more about one of his projects on page 38.

These are just a few examples of why OCD-UK is different. This is not just a charity for us, because of our own experiences we want to deliver projects and a charity that will improve the quality of life for other people affected by OCD. This is a passion for us.

In delivering those services, we are driven by three core principles for service delivery:

#### Hope Understanding Kindness

A message of hope is something so incredibly important, and the day someone calls OCD-UK and leaves without hope is the day I know we have failed that person.

I don't shy away from saying that OCD is a condition that people can and do recover from. Of course, recovery is personal and unique to each individual. It might be a journey for some, or a destination for others.

Our job in offering hope is to ensure people are aware that with the right support, guidance and motivation then recovery is real and is possible.

2015 was another challenging year financially, or was likely to have been had it not been for later in the year receiving a £30k unexpected windfall because of **Mikey North** and *ITVs All Star Mr and Mrs*. You can read more about that on page 31 and how that all came about.

During these times of economic uncertainty, many charities are struggling. Whilst OCD-UK is doing ok, I am mindful of the fact that we are simply treading water, and Mikey's amazing generosity is a real boost. However, that said we are keeping our head above water. One aspect I am particularly proud of is our financially stable business model, which means that we continue to be able to offer a consistent and quality level of core support services, and that

OCD-UK is not reliant on external grant funding to deliver our core services of support, advocacy and advancing awareness.

Financially the charity remains self-sufficient on our current level of operation, but this is restrictive in allowing us to grow, so the charity will continue to explore avenues to boost income and allow self-sufficient expansion. The charity must not expand by being reliant on grant income for core development costs

I feel I should also pay special mention to my friend, mentor and co-founder **Steve Sharpe**.

I remain incredibly grateful for Steve's support and long-standing commitment to supporting and representing OCD-UK; even in his global business endeavours he can be seen with his OCD-UK pin badge adorning his suit.

#### The Future

The future for the charity will bring fresh challenges, but with the amazing team of trustees, volunteers and staff I am assured that we will find solutions for the challenges ahead.

The charity constantly seeks new ways to innovate and none of this would be possible without its members, staff, trustees, supporters and volunteers. Thank you to you all.

I am proud of the fact that the trustees allow OCD-UK to put our users first, and I make no apology for running a 'charity' for our users, rather than a self-serving organisation.

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

Ashley Fulwood, CEO

# A YEAR OF IMPACT SUPPORTING PEOPLE

I honestly believe you guys **saved my life** 2 years ago.... when I couldn't get the right therapy/right medication.

10-years a member, and love the support and the friendship that the charity gives.

Just wanted to tell you that receiving your magazine always makes my day and your latest one was particularly great. Thank you so much for helping people with OCD!

Just wanted to thank you for the amazing support and help you gave us when we were in trouble a few years ago. **Your advice made all the difference** and helped us move forward. Thank you - you do a great job!!!

I've never told anyone about this but when I found your website I felt such relief I cried.

Thank you so much for your prompt reply. That's all very helpful. You have clearly understood how difficult it is to persuade someone to seek help, which from my point of view is so precious. You've given me an alternative way to speak to her.

Just want to say what a fantastic job you've done and continue to do with OCD-UK, though that sounds an inadequate way to express you commitment and achievement in helping so many thousands recognise and cope with the condition.

I'd just like to thank you for your work in advocating OCD awareness. I am 16 years old and a sufferer of OCD and GAD and even though I am not from the UK (I am from California) I appreciate your work very much, and for what it's worth, I've always wanted to go to the UK. But OCD is a borderless issue, and I and many others around the world are in debt to organisations like yours for giving us a voice. Thank you again, you guys are awesome!!

Thank you so much for your help and advice. It can be a lonely illness without much understanding from society and getting good advice is difficult which is why I contacted OCD-UK. Keep up the good work.

Thank you from the bottom of my heart for arranging this conference. Last year was the first time we attended and it was a real turning point for K in her life - this year we took L and he felt the same sense of a huge step forward out of isolation and helplessness.

I just wanted to send you a quick email to say how much I enjoyed the workshop on Friday with Prof Radomsky. It was really inspirational and I'm sure will be so useful for my own practice as a therapist.



























## FANTASTIC FUNDRAISERS

### Will you use the #ProudFundraiser hashtag?

It shows a great deal of dedication to a cause not only to participate in a charity fundraising event, but to ask friends, family and colleagues to support you in the task at hand when often we are all so secretive about our OCD! So on these pages we want to celebrate our 2015

FANTASTIC FUNDRAISERS and thank them, in fact they deserve their #ProudFundraiser hashtag because between them they helped fundraise a fantastic £30.815.

These are some of our **2015 FANTASTIC FUNDRAISERS** who have run, cycled or hiked through the mud from Scotland to Madrid and even Singapore for OCD-UK. To one and all, thank you! If we have failed to acknowledge someone, please forgive us and let us know so we can recognise your efforts in our **Compulsive Reading** magazine.

- Sofia Koch Cambridge Half Marathon
- Vicky Turner Brentwood Half Marathon
- Dan Ellingworth (pictured top row, second image) Greater Manchester Marathon
- Michael Cooper, Charlotte Digby and Heather Nethercott Brighton Marathon
- Dean Bergner, Yvonne Dudley and Preeti Virgin London Marathon
- Isobel Dixon Madrid 10k
- Jan van Niekerk Madrid Half Marathon
- Beth Symons Regent's Park 10K
- Chloé Moore (pictured top row, third and fourth image) Leeds Half Marathon
- Tracey Taylor Hackney Half Marathon
- Sophie Warren Great Manchester Run
- Jess Yates (pictured third row, second image) Chester Half Marathon
- Sharon and Stacey Dennelly (pictured fourth row, first image) Birmingham 10k
- Rachel Mepham and Glenn Slater (pictured third row, first image) London to Brighton run/walk
- Melanie Crouch Bupa London 10k
- Sarah Bennigsen Pennine Lancashire 10K
- Emma-Louise Downe, Serena Henderson and Henry Wakefield British 10K
- Professor Paul Salkovskis, Dr Lisa Marnell and Ruth Clarke Ride4OCD
- Anneka Hardcastle (pictured top row, first image) Leeds 5K Big Fun Run
- Max Duggins 20 mile cycle challenge
- Sorcha McCaffrey and Coral Sinclair Tough Mudder
- Chloe Morefield Cheltenham Half Marathon
- Robbie Hamilton, Carl May, Simon Ripley, Rebecca Smith, Ross Wilson (pictured second row, second image) and Michael Wright Great North Run
- Sarah Beacock Run or Dye
- Stacey Dennelly Cardiff Half Marathon
- Ciara Ayre (pictured fourth row, fourth image) Great South Run
- Anna Geeson (pictured fourth row, third image) Pen Y Fan charity hike
- Clare and Jessica Bergner, Tamsin Doar and Lexi Wells Royal Parks Half Marathon
- Thaya Than Tun Singapore Marathon

We value your support so much, from those that donate to those that participate in the wacky or endurance fundraising. We very much recognise that we would not be here without you **THANK YOU!** 





2015 National Conference - York









Once again in November we showed our commitment to host our annual conference across different parts of the UK by visiting the beautiful walled city of York.

We were joined by 160 people from across the country who were given the opportunity to listen to and pose questions to some of our best OCD specialists here in the UK. Speakers included Dr Claire Lomax, Professor Mark Freeston and Professor Karina Lovell, Dr Ben Marram and Rebecca Pedley all of whom shared their expertise. Subjects included how to make best use of the treatment available, a look at religion and OCD and a review of the OCTET research trial.

We were also fortunate enough to hear from some remarkable people sharing their experiences of OCD. The day was launched by the amazingly fantastic and positive story of Sandy Nisbet. We also heard from previous MIND blog award winner Ellen White in conversation with Charlotte Rowe, and blogger the Lone Bee.

The audience were captivated by the OCD experiences and story of our patron, the writer and actor, lan Puleston-Davies, pictured above.

We also hosted our first workshop for young people and were fortunate enough to have the amazingly talented Laura Barnes lead it, superbly aided by Josh Jerrard (both of whom are pictured on the front cover).

Thank you to all our volunteers who made the day possible, including Nick Marlow and Yolanda Jerrard who hosted workshop sessions.







# Our OCD awareness champions

In 2015 we helped some of our volunteers become OCD champions and gave them a platform to talk about their experiences of living with OCD.

We spoke to two of our volunteers about what's involved, Claire and James

#### **CLAIRE**

I've got a neighbour who loves his car. He cleans it with great pride every weekend.

One day, I as I walked past his shiny sports car to my battered old hatchback which hadn't seen a bucket and cloth since early 2013, I told him that he put me to shame. "I've got OCD" he laughed.

Comments like this aren't unusual. They used to make me very angry. But when people make these comments they don't mean any offence. They just don't know what OCD actually is.



When I heard about the South West Trains event during Mental Health Awareness Week in May I jumped at the chance to speak to people about OCD. So I joined OCD-UK's Beth at Southampton Central Station.

I was a nervous before I got started. How would I even begin a conversation with random commuters? What if they asked me something I couldn't answer? What if they made a really insensitive comment?

After 10 minutes of standing with Beth my concerns disappeared. I was surprised at the number of people who approached me wanting to talk about it.

No one asked me a question I couldn't answer. I've had OCD a long time, I know quite a lot about it!

Lots of people knew exactly what OCD is. I spoke to people who were happy to be able to talk to someone who understood.

There were also a number of people who thought OCD was alphabetising their CDs or keeping a tidy house. These were the people I'd been nervous about speaking to, but they were understanding and acknowledged they had misunderstood it!

I learned a lot from my day at Southampton Central. You can educate people about OCD without going into detail about how it affects you. You can tell someone they're reinforcing the negative stereotypes of OCD without telling them off. Instead of telling someone they're wrong, give them the correct information and just as importantly, ask them to pass the message on.

I found it empowering and confidence building to realise how much people were open to chatting to me. I know I've made a difference to perceptions of OCD, and it's made more people aware of our charity - I can't wait to do it again one day!



#### **JAMES**

I volunteered for OCD-UK after receiving a diagnosis of OCD after around 15 years of suffering in silence.

Prior to that my understanding of people with mental health problems was completely misguided and clouded by my OCD thoughts. Are you a little bit

OCD?

Think you or a loved one might suffer with tsessive-Compulsive Disorder?

I was convinced that all people

with mental health problems were completely out of control and a danger to society, but I was wrong. After working with the OCD-UK team I immediately felt at ease with all the volunteers and realised that we all had a common goal and that was to change perceptions about mental health and OCD.

I suffered with obsessions ranging from fears of having cancer, HIV, heart failure to suicidal and homicidal thoughts.

Initially it was a scary thought that I would open my head and heart to the general public. I was bowled over by how well the OCD-UK volunteers were received by people.

There were some stigmatising comments but the vast majority of people were very understanding and some actually sought help as a result of our discussions.

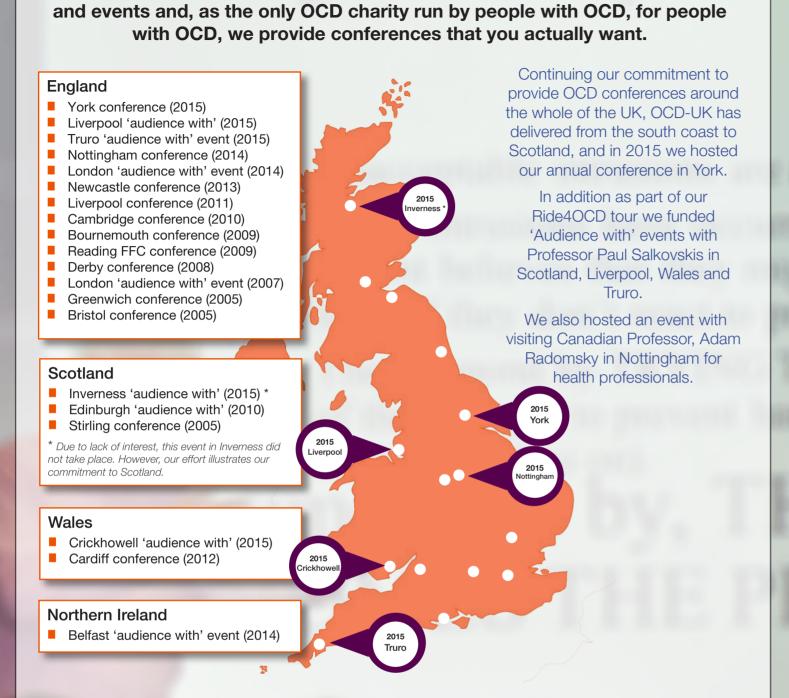
For me, this means we have really achieved something fantastic. If only I had such guidance as a child then I could have had a much better grip on my mental health.

Beth, the OCD-UK volunteer manager, really made me and all the volunteers feel as ease with themselves and personally made me feel liberated and able to express vulnerability without feeling ashamed.

I really think the public responded to the honesty the volunteer team and I shared about our mental health problems.

I really do look forward to working with the charity for as long as they want me to!

Thank you Claire and James, you are both OCD champions.



OCD-UK has an excellent reputation for delivering high-quality conferences

"The conference was great. Friendly presenters and of course lots of special people with OCD! No sense of us and them. So good to feel understood." – **Louise** 

"Thank you so much for the conference and just the entire charity as a whole! It's been a wonderful day and everything ever done by the charity has been a great source of support for me!" – Sarah

"Thank you for an excellent conference, it was well organised, varied and informative. As an OCD sufferer I found it to be very helpful and it made me feel less isolated and troubled by my anxiety." – Susan

# Delivering across the UK



# One conversation at a time

To coin a phrase from the *Time to Change* website, "There are no hard and fast rules for talking about your mental health" OCD-UK project coordinator, **Beth Hemus** reports on our *Time to Change* awareness project which ran throughout 2014 and was completed between January and March 2015.



uring Autumn 2013 OCD-UK were awarded funding by *Time to Change* to deliver an anti-stigma themed public interface project across the East Midlands.

Time to Change is England's biggest programme to end the stigma and discrimination faced by people with mental health problems. The programme is run by the charities Mind and Rethink Mental Illness, and funded by the Department of Health, Comic Relief and the Big Lottery Fund.

OCD-UK has long sought out opportunities to challenge stigmatic and discriminatory attitudes towards OCD and associated mental health issues, and this project gave the charity the opportunity to do so on a regional level. Several outcomes were set by the charity and our funder; namely that the project would seek to:

- Demonstrate to the public that OCD is very different to the phrase 'I'm a little bit OCD' used in every day parlance, shift stigmatic perceptions about OCD (especially with individuals that present as "cold" to mental health issues) and offer information, advice and guidance to those in need.
- Engage up to 60 volunteers, all with lived experience of OCD and other mental health issues, in the co-creation and delivery of the
- Improve the confidence and ability of people involved in the project to take action to tackle stigma and discrimination and to engage in and contribute to their own quality of life and the life of their community.
- Host 36 events across the East Midlands (with at least one event in each of the following counties: Nottinghamshire, Derbyshire, Leicestershire, Northamptonshire and Lincolnshire).
- Achieve 1440 social contacts, documenting as many as possible with the use of TTC's Audience
- Build professional partnerships that serve the charity beyond the life of this project.

March 2015 heralded the end of the "Are You a Little Bit OCD?" project and we can say with confidence that it proved an enormously beneficial experience for all the organisations and individuals involved. The outcomes achieved far exceeded those that were set; indeed a myriad of unexpected achievements were attained. Below is a summary of some of the most pertinent examples.

The project lead. Beth Hemus, renovated all OCD-UK's existing policies and procedures as well as making several additions, making the charities quality assurance model even more robust. Beth also created a team member induction, management and exit pathway as well as the associated paperwork; a legacy that has been adapted and is now employed in the charities wider volunteer management strategy. 56 volunteers expressed an initial interest in the project, 40 were trained and inducted, 27 were active at one event or more and 19 were active at three or more events. Of these, six became volunteer team leads and received extra training so they could effectively support events organisation and deliver peer to peer support.

The majority of volunteers had first-hand experience of mental health issues and had experienced some form of discrimination and stigma as a result. Two volunteers have stepped into employment in the third sector in Nottinghamshire as a direct result of being involved in the project and several volunteers are pursuing careers in the mental health sector in their region as a direct result of involvement with the

Several volunteers plan to extend their voluntary commitment to OCD-UK in a different capacity i.e. helpline operator, administrative support, regional support group facilitator, fundraiser, event's organiser

report continued on page 24.





The wilfully ignorant and unsympathetic are far outnumbered by the curious and the kind.















#### 697 meaningful conversations were held around public attitudes to mental health.

Of the audience survey contacts submitted only 34.3% identified themselves as someone who has, or has had, mental health problems. This evidences clearly that our project successfully targeted people that are "cold" to mental health problems.

The provocative project title was a great tool for initiating conversations with audience contacts who possessed an uneducated or stigmatic attitude towards OCD.

97.4%

#### of our conversationalists

found the activity very or fairly effective in demonstrating how stigma and discrimination might affect people with mental health problems.

97.2%

#### of our conversationalists

found the activity very effective or fairly effective in demonstrating that people with mental health problems can face stigma and discrimination.

#### We are moving in the right direction.....

The quality and subsequent impact of these conversations shows significant shift in public attitudes.



93.1% of conversationalists found the activity very or fairly effective in demonstrating that people can recover from mental health problems.



95.8% of conversationalists found the activity very or fairly effective in demonstrating that mental health problems are common.



96.1% of conversationalists found the activity very or fairly effective in demonstrating that sometimes the hardest part of dealing with mental health problems is facing stigma.



69.4% of conversationalists found the activity very effective or fairly effective in demonstrating that it's easier to talk to people about their mental health problems than most people expect.

#### But we've still got work to do, one conversation at a time.....



### **VOLUNTEER FEEDBACK**

Feedback from volunteers about different aspects of being involved in our project.



Number of respondents 16

Volunteers were consistently asked for feedback based on their experience and the data above indicated that, as a result of being involved in the project our volunteers were happy with their volunteering experience.

Out of 52 organised events with partner organisations, 36 were delivered, with at least 1 being delivered in each of the 5 East Midland counties. 697 meaningful conversations were recorded as being held at these events. Of the audience survey contacts submitted only 34.3% identified themselves as someone who has, or has had, mental health problems. This evidences clearly that our project successfully targeted people that are "cold" to mental health problems, i.e. have no lived experience and are therefore more likely to present with a stigmatic or discriminatory attitude. The provocative project title was a great tool for initiating conversations with audience contacts who possessed an uneducated or stigmatic attitude towards OCD.

Time to Change agrees that the quality and subsequent impact of these conversations more than compensates for

OCD-UK's provocative choice of project title ('Are you a little bit OCD?') has served as a conversational bridge time and time again.

This type of conversation can and does result in a **p**ositive shift of attitude in our audience members.

this deficit in relation to the original target. It is important to note that this figure is not representative of the number of effective anti-stigma themed conversations held with contacts, which is approximately double that figure (based on ticker counting completed by the project leader at events). The reasons that not every valuable conversation was recorded are many e.g. fundraising connotations associated with clipboard/ tablet based forms, which largely makes people suspicious. The previous page shows some of the audience survey results collected.

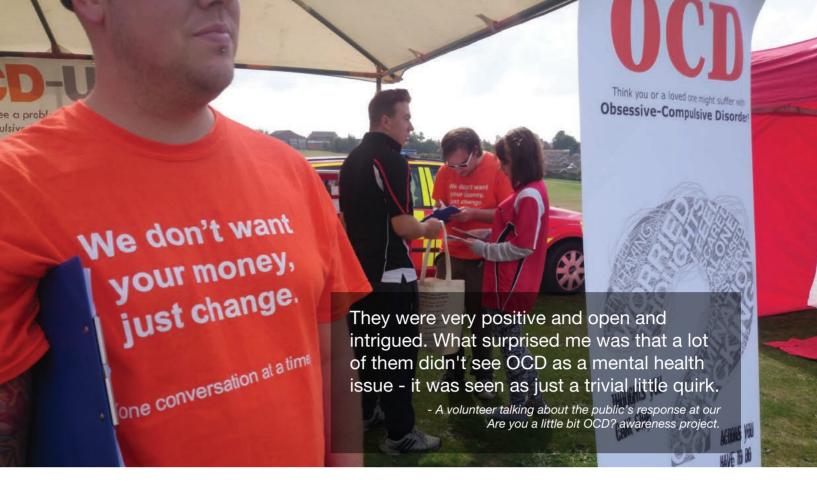
The project has yielded multiple training opportunities with large scale organisations e.g. DWP, Nottingham Police, Nottingham Fire Service and various Mental Health Care Partnership Trusts throughout the East Midlands. Multi-use training programs and resources have been created via this project, and will continue to be used by the charity internally and externally.

The charity's profile was significantly raised with statutory services, private practitioners and the general public. This identified a need for the expansion of regional support groups and several project volunteers are about to embark on training to become lead or co-facilitators.

Time to Change identified OCD-UK's project as a model of best practice with specific relation to volunteer management, and as such invited Beth to host a talk at a national partner's event in October 2014. OCD-UK have offered Beth an extended contract, based on the success of the project, and she will continue to work for the charity for the foreseeable future as national volunteer manager.

As the first targeted project tackling stigma and discrimination that OCD-UK has delivered, it has infinitely increased the charities efforts in this important area.

The misconception, trivialisation and poor taste jibes that surround OCD have been starkly evidenced by the conversations had throughout this project, as has the effectiveness of hosting anti-stigma themed public interface events, led by sufferers.



Many volunteers have expressed an interest in hosting like events in the future. The team leader volunteers are primed to lead on such events and the project has yielded multiple partnerships with venues and event's organisers that can be drawn upon in the future.

The evidence gathered throughout this project will enable OCD-UK to succinctly demonstrate its capacity for successful management of large grants on target, increasing the likelihood of acquiring more funding in the future. This has reinforced to the charity how important measuring the impact of its activity is so that the good work being done can be evidenced.

We hope this information goes some way to illustrate the success of this important project. We have learned and grown so much as a charity throughout this experience, and are now better equipped than ever to serve our beneficiaries, members, volunteers and professional partners. It is with no small degree of sadness that we draw this project to a close, but the future's bright for us and for so many that were involved; this can be illustrated no better than by the sharing of the below personal statement, submitted to our funder as a case study by one of our volunteer team leads.

"This has been a challenging experience that has forced me out of my comfort zone. The opportunity to be a team leader has helped me see myself differently and it's made me realise that I have skills and qualities that I had underrated before. As a result this experience feels like a very important part of my recovery process. It's also solidified my suspicion that I would like to work in the mental health sector and has confirmed that my own life experience can help me to affect positive change in other people. I've had so much fun with the team. It has been exactly the right level of personal and professional support for me in the project. I feel like I am a more rounded person now. The act of volunteering has changed me in all sorts of ways that I never imagined. I have also been able to access lots of training since volunteering. I have accessed some Time to Change ambassador training which may result in a part time paid role. I am about to start some addiction focused training with Double Impact (who I met through an OCD-UK event) which will help me to work as a peer worker with people in early recovery from addiction. I am also stepping onto peer support training with Nottingham NHS Mental Health Care Partnership. This is exactly what I need to do and what I've been trying to find for ages. Thank you OCD-UK and Beth for all your support with this. I am really pleased and it's really exciting. It feels right to be carving out a vocational path that earns me enough money, that I enjoy and that enables me to help others."

Wishing you the very best mental health and happy talking. Beth (beth@ocduk.org)

Thank you to **Time to Change** for funding this project, and allowing us to prove that positive change around mental health beliefs can happen, even if it is one conversation at a time.



The act of volunteering has changed me in all sorts of ways that I never Imagined.





In August, OCD-UK's Ashley Fulwood, patron Professor Paul Salkovskis and members Dr Lisa Marnell and Ruth Clarke took part in...

RIDE40CD

JOHN O' GROATS TO LAND'S END

They cycled 1200 miles from John O'Groats to Land's End (JOGLE), through Scotland, England and Wales in aid of OCD-UK, delivering a message of awareness, support and inspiration.

Ride4OCD had five key objectives:

- 1 Improving OCD awareness
- 2 Fundraising for OCD-UK
- 3 Highlighting treatment inequalities between England, Scotland and Wales
- 4 Demonstrating that mental challenges can be overcome
- 5 Bringing the OCD community together



#### **Trustees**



L-R - Charlotte Rowe, Joanne Sharman and Yolanda Jerrard at our 2014 annual conference in Nottingham.

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 of the charity who have all 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 AGM, unless otherwise stated:

#### **Catherine Mills**

Chair, Merseyside.

#### Claire Gellard

Trustee, London.

#### Mark Bartlett

Trustee, Kent.

#### Yolanda Jerrard

Trustee, Lincolnshire.

#### **Nick Marlow**

Trustee, Nottingham (appointed May 2015)

#### **Charlotte Rowe**

Trustee, Coventry.

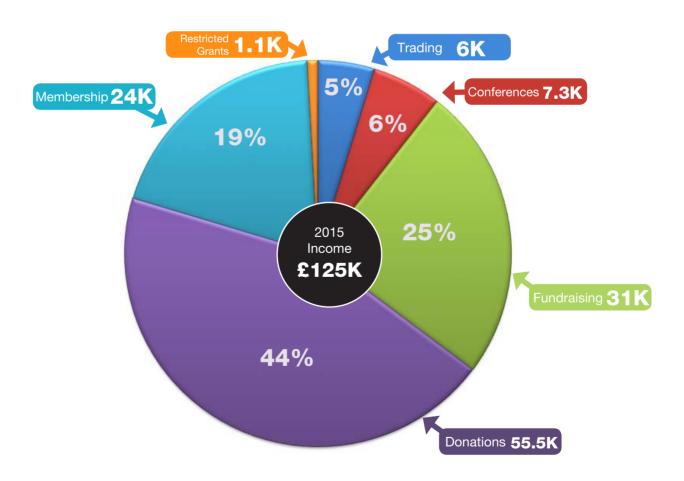
#### Joanne Sharman

Trustee, Cornwall.



# 2015 key facts and figures

### 2015 Income



Membership, donations and fundraising remained our primary source of income, with our membership numbers remaining around the same level, this is indicative that our charity remains highly respected by users, and remains the largest member charity dedicated to supporting people with OCD.



£125,012

£102,398

2015 Expenditure

#### **Financial Review 2015**

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 **Steve Collings** of *Leavitt Walmsley Associates* for examining our accounts. A copy of the full 2015 accounts can be found on our website.

OCD-UK income for 2015 was £125,012 with expenditure of £102,398. Accordingly, we are reporting an overall surplus of £22,614 leaving the charity with £54,027 of surplus funds.

£7,408 of our expenditure was for the final three months (Jan-Mar 2015) of the 'Are you a little bit OCD?' project funded by *Time to Change*. The income for that was received during our 2014 accounting period. What this imeans is that our actual 2015 expenditure was £94,990 without the TTC project spend.

Our income was boosted considerably by the unexpected donation from the actor Mikey North who won ITV's *All Star Mr* and *Mr*s and chose to donate his charity winnings to OCD-UK.

We were also fortunate enough to receive a grant of £600 from the *Boots Charitable Trust* to help fund the cost of our Nottingham OCD Support Group.

Membership and fundraising remained our primary source of income, with our membership numbers remaining static between 700-800 members, indicative that our charity remains highly respected by users, and remains the largest member charity dedicated to supporting people with OCD.

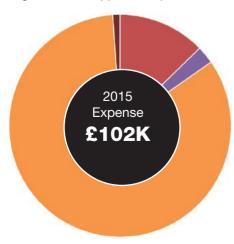
Our income from fundraising was up significantly to £30,815 in 2015 (compared to £19,338 in 2014).

This fluctuation in fundraising income is a trend we see 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 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, the support for our vital work has been astonishing for which we remain incredibly grateful.

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, and we are proud of the fact that our services are operated by just two members of staff.

Our charity is managed prudently, vital in these times of economic uncertainty, and our core expenditure in 2015 did not increase significantly from 2012 and 2013 (excluding the Time to Change project funding expenditure of 2014 and part 2015).



#### **Expenditure Breakdown**

84% - Charitable Activities

(During 2015 we had just two members of staff working for the charity, which we feel is remarkable when you consider all we have achieved. Activities include awareness work, conferences, support groups, helpline, cost of information leaflets, posters or other materials we distribute freely.)

- 13% Costs of generating voluntary income
- 2% Fundraising trading costs
- 1% Governance



# Structure, Governance and Management of OCD-UK

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

#### **Legal Status**

OCD-UK was formed as a charity under a constitution in January 2004 and was officially registered with the UK charity commission in 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 those long-term objectives.

#### **Patrons**

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

We are also supported in our work by two overseas ambassadors, Professor Adam Radomsky from Concordia University, Montreal and Dr Jeffrey Schwartz from UCLA.

#### Stoff

The charity has one full-time member of staff, the chief executive officer (CEO), 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. During 2015 we had one part-time (22-hours per week) staff member responsible for the Time to Change project management and at the end of that project became our volunteer co-ordinator.

#### **Membership**

Membership of OCD-UK is open to any individual with an interest in OCD or the charity's work. At the end of 2015 the charity had 744 active members. Members are entitled to attend the AGM and to one vote per discussion.

#### **Volunteers**

OCD-UK had approximately 30 committed and regular active volunteers across the UK during 2015, 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 2000 hours to OCD-UK during 2014, in monetary terms worth at least £25,000 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 research and media work that we promote.

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

#### **Professionals**

We would also like to acknowledge our gratitude and thanks to the following accountancy, legal, health professionals and media personalities who kindly donated their time to offer support and assistance during 2015:

- Lesley Anderson
- Dr Lauren Callaghan
- Steve Collings
- Virginia Cooper
- Ian Puleston-Davies
- Stephanie Fitzgerald
- Dr Elizabeth ForresterProfessor Mark Freeston
- Dr Lucy Hale
- Dr Eucy HaleDr Brynjar Halldorsson
- Dr Claire Lomax

- Professor Karina Lovell
- Dr Ben MarramMikey North
- Rebecca Pedley
- nebecca redie
- Dr Victoria Bream-Oldfield
- Dr Adam Radomsky
- Karen Robinson
- Professor Paul Salkovskis
- Professor Roz Shafran
- Dr David Veale

#### **Corporate Support**

We also occasionally receive support from companies and charitable trusts and we would like to acknowledge Time to Change, Melissa Linley-Adams and the Le Marchant Trust Charitable Trust, the Boots Charitable Trust, Dr Lucy Hale from Healthcare on Demand and the Diocese of Portsmouth who have made contributions to OCD-UK during 2015.





**Charitable Trust** 



# **OCD** in the MEDIA 2015

Talk to us... office@ocduk.org www.ocdforums.org

f

Become a fan at www.facebook.com/OCDUK Follow us @OCDUK





#### Online Reach

Over the past 12 months our website had 732,039 visitors to the main OCD-UK website at www.ocduk.org, with a total of 1,745,672 web pages visited on our website.

50.39% (496,385) of visitors came from the UK, but our global reach is highlighted by the following stats

that 26.57% (261,751) of visitors came from the US, 4.05% from Canada, 3.29% from Australia and 2.87% from India.

On social media, our Facebook 'likes' have continued to increase, now standing at 6,083 (up from 5,123 at the end of 2014) and 6,075 Twitter followers (up from 4,795 in 2014).



# OCD in the MEDIA 2015

#### **OCD ON TELEVISION**

A few OCD related storylines ran across UK's soaps during 2015.

In *Casualty* the character Dr Dylan Keogh (pictured left) played out a magical thinking storyline across the entire series.

OCD-UK had a number of conversations with the Casualty researchers earlier this year, guiding them on their scripts and making suggested changes from an OCD perspective, some of which we know they acted on.

During 2014 and 2015 we also worked closely with the script writers on the BBC daytime soap **Doctors** to consult over their long-running OCD storyline for Dr Jimmi Clay (pictured right) During that time we made a number of suggestions which we are pleased the writers took on board and made several scene changes based on our feedback.



Over on *Coronation Street*, the character Cathy played by Melanie Hill *(pictured below)* was shown to be living as a hoarder. In a scene where her friend Roy Cropper tried to help her discard items, she showed typical hoarding response of making excuses not to discard items.



Another 'alleged' OCD programme that was back on our screens during the year was Channel 4's **Obsessive Compulsive Cleaners**. OCD-UK once again wrote to Channel 4 to raise our concerns, which sadly fell on deaf ears

In our opinion the three fictional dramas offered more fact about OCD and hoarding than Channel 4's programme!

In August BBC2's *Horizon* broadcast a one-off documentary about OCD. This focussed on neurosurgery for OCD, but ironically the person who underwent this was less successful than the person who went through psychological treatment.

OCD-UK also participated in several regional media pieces throughout the year, contributing to BBC local radio and local newspapers. The tone for the coverage was virtually all positive. We featured in multiple newspaper and radio broadcasts throughout the year.

### We also published a website to allow people to follow all the Ride4OCD action at: www.ride4ocd.org





#### **OCD AWARENESS WEEK**

CD Awareness Week is a global effort to raise awareness and understanding about OCD, with the goal of educating people and working towards removing the misunderstanding and stigma often caused by the misrepresentation of OCD. Launched in 2009 by the International OCD Foundation (a US based charity), OCD Awareness Week is now promoted by a number of organisations across the world, and OCD-UK was the only UK based charity to proactively promote and support OCD Awareness Week in the second week of October.

In advance of the Awareness Week we had created a number of media opportunities, including several local

radio pieces and had spoken to ITV's Good Morning Britain programme about running a feature on OCD.

In the run up to OCD Awareness Week it was obvious that GMB intended to run a feature that was suggesting OCD can be positive, contrary to our message that OCD is a debilitating illness. We advised them of this, but they continued regardless.

They interviewed entrepreneur Michelle Mone, who said she had undiagnosed OCD. She went on to say that she 'loved' having the condition. She suggested the condition had been 'useful' in helping run her lingerie company and helps her keep her wardrobe organised.

Quite rightly, Mone and the show came under widespread criticism after the segment was broadcast for not portraying OCD symptoms accurately.

We still don't know if Michelle Mone does have OCD or not, but the programme may have done significant awareness damage



by adding to the misconceptions that OCD is a simple quirk that people choose to be helpful. In fact, the way Good Morning Britain portrayed OCD is the public perception of OCD that we hoped OCD Awareness Week would challenge and change. During the controversy that followed over the next couple of days, many other media opportunities opened up to discuss OCD. There were features across national press and on primetime breakfast slots for BBC Radio 2 and LBC radio. We now believe that whilst the GMB interview was unfortunate and unhelpful, it did have a positive in generating a national debate about OCD across the national media.

We have developed a better understanding about what the national media are looking for and need, which should serve us well in the future. Nottinghamshire Healthcare NHS Trust

Positive about integrated healthcare

Review of Peer support work and the Nottinghamshire Healthcare OCD Pathway Project by OCD-UK Volunteer NICK MARLOW

"You are ill. You are not alone. You can recover."

These words changed my life. It was September 2012, and I was sat opposite a psychiatrist in a rehab clinic. I was being treated for addiction, and had just been diagnosed with acute Obsessive Compulsive Disorder.

Fast-forward to February 2015, and I found myself on a NHS Peer Support Worker training programme in Nottingham. I had been in recovery for over two years, and something had become very clear to me during that time. Peers had played, and continue to play, an intrinsic part in my journey.

Read **Nick's** story...



By Nick Marlow (pictured left), Peer Support Worker and OCD-UK Trustee.

#### "You are ill. You are not alone. You can recover."

These words changed my life. It was September 2012, and I was sat opposite a psychiatrist in a rehab clinic. I was being treated for addiction, and had just been diagnosed with acute Obsessive Compulsive Disorder. For the first time in a very long time, I no longer felt isolated. Just as importantly, in the midst of what I now knew to be an illness, I had a sense of hope for the future – a glimmer of light at the end of a deep, dark tunnel. Armed with a diagnosis, and fuelled by the gift of desperation, I jumped into recovery.

Fast-forward to February 2015, and I found myself on a NHS Peer Support Worker training programme in Nottingham. I had been in recovery for over two years, and something had become very clear to me during that time, that peers had played, and continue to play, an intrinsic part in my journey. I was reminded of a quote from a recovery text, "the past thus becomes the principal asset. This may be of infinite value to others still struggling with their problem." My story could be of practical use to others. Like many before me, I could become a source of experience, strength and hope to those still struggling with mental health. I began volunteering with organisations rooted in recovery, determined to turn the course of my illness into a positive force for change. This culminated with my enrolment into, and subsequent graduation from, "Peer Support School" run by the Nottinghamshire Healthcare NHS Trust. Once formally qualified, I was excited to be asked to join a new team with

a remit to improve patient pathways post-OCD diagnosis, in-line with NICE recommendations. A bespoke client assessment would be introduced, along with two groups – a 2-week information course, focusing on delivering an understanding of the disorder (with signposting to recovery opportunities), and an 8-week treatment group, whereby cohorts of clients would be guided through a therapeutic course of action. Both groups would be led by an experienced Cognitive Behavioural Therapist, and supported by a Peer Support Worker, myself. Both also enabled clients to undertake intensive, personalised therapy both within, and adjacent to, the weekly group. Whilst only a pilot scheme, and not intended to fully replace existing one-to-one therapy, this clearly demonstrated the NHS's commitment to improving services and exploring new opportunities for therapeutic interventions. I had heard of the Trust's pioneering use of Peer Support Workers in dynamic, recovery-orientated roles. Here it was in action, and I was privileged to play a part.

As I write this, we are approaching the end of the project, having successfully developed and delivered two information groups and two treatment groups, alongside multiple opportunities for focused, individual exercises. Underpinning the objectives of improving treatment pathways sat two key recovery models – therapy via group sessions, and peer involvement in the process. There were risks associated with both models. Would individual needs get lost in a group environment?

"Like many before me, I could become a source of experience, strength and hope to those still struggling with mental health" Would clients be uneasy sharing personal information in front of others? Would clients be able to relate to a peer, and would this strengthen or diminish the impact of therapy?

My experience during the process suggests that, correctly managed, these concerns were unfounded, that both the group setting and peer involvement had added value for the clients. Watching a room of clients burst into spontaneous applause when one of their number shook hands with the therapist spoke volumes. They understood that the client had avoided contact with people over many years, for fear of contamination. They understood the fear and anxiety that this had caused for so long. They understood the bravery needed to reach out his hand. They understood the leap of faith that this required, faith that had been earned by both the therapist and the peer. They understood all this because they felt all this. They felt part of something bigger than themselves, motivating each other to push onwards, to challenge their illness, to share their recovery. Like me, they no longer felt alone. As peers had given hope to me, so I passed it on to others. I watched hope turn into faith, and faith turn into trust, and trust turn into action. We were determined that these groups would be so much more than generic support groups. They were designed to instigate change, and I was honoured to be witnessing individuals' change as the courses progressed. They began collating their own recovery experience, experience which

If the group format had proved to be successful, it was apparent that the peer role had also demonstrated its value. This professional position validated my recovery experience. This doubtless aided the impact of my words, and demonstrated that I could "walk the walk" as well as "talk the talk." Seeing eyes widen as experiences were shared, and the realisation slowly dawn that they were not the only one, was humbling and testament to the power of peerness in recovery. You could almost see the hope developing. My role as peer helped validate the therapy team's suggestions, as though I was providing proof of concept to their therapeutic theories. It felt very much like a team effort. We were all pulling together and we were all pulling in the same direction. The groups drove individual action, and individual action further consolidated the group's strength. This proved as effective a tool for change as one-to-one therapy. The format instilled hope, and provided ample opportunity for each client to test their experiences within a safe therapeutic environment. There was a growing sense that individuals were slowly clawing control of their lives back from this debilitating condition. Hope, opportunity and control - the watchwords of recovery.

An analysis of the second treatment group is ongoing. However, analysis of both information groups and the first treatment group has been completed.

**87.5**%

of clients found the treatment groups to be a helpful instead of waiting for individual therapy.

Enablement 100%

of clients felt that the treatment group would enable them to continue working on their OCD independently.

Beneficial Peer Support 100%

of clients found the involvement of a Peer Support Worker to be beneficial.

Key quantative and qualitative results are highlighted here:

- Groups experienced around 85% attendance rates.
- 100% of clients felt they benefited from the information groups.
- Four assessment tools and measures were used in treatment groups to assess change in clients' OCD presentation (OCI, PHQ9, GAD & WAS). Overall mean scores demonstrated a decrease of 14.1% - a notable recovery rate.
- 87.5% of clients found the treatment groups to be a helpful option instead of waiting for individual therapy.
- 100% of clients felt that the treatment group would enable them to continue working on their OCD independently.
- 100% of clients found the involvement of a Peer Support Worker to be beneficial.

"Talking to other people who have had similar experiences – realising that my experiences are part of a disease, a disease that can be treated."

"(the PSW) was very good at sharing their experience, and offered valuable insight into how to overcome OCD."

"(the PSW) understands the reality of living with OCD as much as he understands the theory."

"I think that groups like this are essential for people like us. One of the worse things about having OCD is that it can be incredibly isolating and there can be periods of complete despair."

The pilot thus demonstrated a successful model for improving patient pathways in the treatment of OCD. A decision is pending as to the future of these pathways. However, it should be noted that care was taken to ensure the process is both replicable and scalable. There is no reason to suggest it couldn't either be expanded in its current format, or rolled-out to other areas.

I am extremely grateful that I have been able to put into practice all that I was taught on the Peer Support Worker training course. More importantly, I have witnessed peer work in action, and seen the positive change it can drive. It has proven to be an extremely effective resource for recovery, and demonstrated its value alongside both individual and group therapeutic practice. Much of the content of the courses was derived from the Salkovskis model of treatment, and it seems appropriate to conclude with an extract from his text in *Break Free from OCD*.

"To be restored to health does not mean not having a past, but we can use our experiences of getting better to stay better."

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## COMPULSIVE READING

### The OCD-UK members magazine with a global reach

Once again our members' magazine *Compulsive Reading* was published in 2015 and continues to receive high praise for its mix of content.

Content focused on some timely subjects and news relevant for people with OCD and first-hand experiences. We make no apology that our magazine will continue to focus on inspirational first-hand experiences and recovery.

The online version of **Compulsive Reading** has been growing from strength to strength, with investment in new software which allows the magazine to be fully readable across devices.





















Our promise to you
To offer kindness,
understanding and hope
whenever we support
people affected by OCD

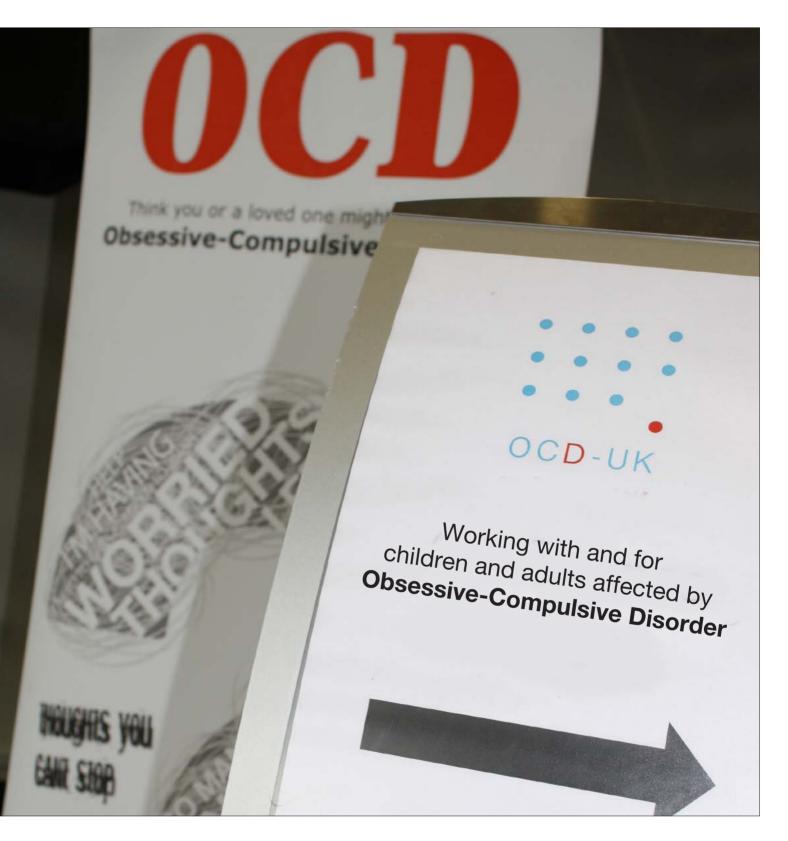












# **OCD-UK**

## **Annual Report**

Thank you for your support in 2015

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