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Setting the record straight: #BritainsTourettesMystery

Tourette syndrome (TS) is a much-misunderstood condition, during Tourette's Awareness Month the charity Tourettes Action, along with other Tourette's charities – T.I.C Hull, Tourette Scotland and TicTock Therapy – worked extremely hard to try and increase awareness and remove the stigma associated with the condition.

On the 19th July Channel 4 aired a documentary titled **"Britain's Tourette's Mystery"** hosted by Scarlett Moffatt. The program contained lots of inaccurate, misleading and harmful information. Tics can also be functional in nature and present in other conditions such as functional neurological disorder (FND) and PANDAS, but there was no clear explanation of this in the program and misleading information was given around Tourette's and functional tics.

Many think that a tic is a tic, why should this matter. It fundamentally does matter! The distinction needs to be made between tics and functional tics as treatment and outcome differ greatly. It is vital that the correct diagnosis is given to ensure that the individual is put on the correct treatment path and given the support they need.

TS is still very misunderstood and when asked, most members of the public will associate it with swearing. Coprolalia (involuntary swearing or profane outbursts) is in fact not a criterion for diagnosis. For a TS diagnosis, a person needs to have at least one vocal tic and multiple motor tics and they need to have had tics for more than one year.

Things to note:

1. Tourette's is not an infectious illness, Tourette's is not like a cold, Tourette's is not catching and it is not contagious
2. Watching TikTok **CANNOT** give you Tourette's. If you have Tourette's, it is possible that seeing someone else tic can make you tic more. Whilst social media such as TikTok can have a negative impact they categorically **DO NOT** cause Tourette's.
3. Tic disorders can be short-lived but Tourette's is a life-long condition. Symptoms can sometimes improve into adulthood but you **CANNOT** suddenly "recover" from Tourette's over night
4. Tic Disorders, Tourette's and functional tics (a part of FND) are **NOT** the same thing, they all cause tics or tic-like movements but they often present in different ways.
5. Tourette's is not comical, it is not a joke and is not your punchline
6. To be diagnosed with Tourette's, you need to have BOTH motor and vocal tics and you need to have had tics for more than one year
7. Yes, it is true there has been a rise in tics during the pandemic, the reasons for which are not clear and much more research needs to be done to determine why this is happening

Emma McNally, CEO of Tourettes Action, says: "During Tourette's Awareness month we worked extremely hard to raise awareness and get the real message out there, much of which we feel was undone during Channel 4's one hour documentary. It's shocking that a condition so prevalent is still so badly misunderstood, even by some medical professionals.

"Since the show we have been contacted by so many upset people in the community stating that the program has undone all our hard work. They have used Tourette's as an entertainment topic, something we have been trying extremely hard to stop. Many are extremely concerned by the mention throughout the program about tics being contagious and not wanting to catch them.

“We need the media to help us put the record straight. We want to raise awareness to ultimately bring about acceptance, so we fully encourage the media to talk about Tourette’s and tics, but want it to be done in an accurate, informative and sensitive way, not purely for entertainment value.

“The main issues currently facing people with all tic conditions is the lack of awareness within the general public and the sheer lack of medical care up and down the country. There is a lack of trained medical professionals, meaning that many individuals are often misdiagnosed and given the wrong advice and treatment.

At Tourettes Action we are fighting hard for NICE Guidelines for Tourette’s. Nice Guidelines would give clear guidance on service organisation and training needs. They are desperately needed.”

STATEMENTS FROM OTHER CONCERNED CHARITIES

Tictock Therapy http://www.tictocktherapy.co.uk

Sarah Sharp, CEO of Tictock Therapy, says: “I have spent the last 18months trying to educate the tic community on different causes of tics, helping individuals and families to understand the differences and why it is important to know what is truly going on and not have tic like symptoms clumped under the Tourette’s label as this can be detrimental to individuals’ presentation and mental health.

The documentary was the perfect example as to why the correct information and diagnosis needs to be given! The documentary was advertised as being about Tourettes syndrome, when in fact it was predominantly about functional tics. This alone is incorrect and has caused even more confusion. The entire documentary was lacking any form of education and, anything it did show was damaging and has caused uproar for our tic community.

My emails, phone and website have been nonstop since the airing of the documentary, questioning if pupils will catch tics from their friend, of parents heartbroken as their child’s friends have messaged saying they don’t want to hangout anymore and even a company asking anonymously if it’s safe for their employees to have the worker with Tourette’s working there still.

There are many of us doing our upmost to support the tic community through this time, but realistically they deserve a new, factual, and informative documentary created.

Furthermore, we need all medical professional to be retrained around these conditions to they can diagnoses and support accordingly”

T.I.C Hull http://www.tic-yorkshire.co.uk

“Kim Mitchell, CEO of Tourettes-syndrome, Inclusion in the Community (T.I.C.) supporting individuals of all ages living with Tourette Syndrome and tic disorders in Hull, Yorkshire, and Northeast Lincolnshire, says “We were devastated to receive so many heartbroken responses from our community. No thought was given to how those living with Tourette’s would be affected by this program. We have been left very concerned for individuals’ mental health after hearing how scared they are to leave their homes for fear of been judged as a “faker”. How difficult would it have been for the producers to reach out to the National Charity to verify statements they made? This program was made purely for ratings. You simply would not get away with this with any other disability, so why Tourette’s?”.

Tourettes Scotland http://www.tourettescotland.org

Kyla McDonald Tourette Scotland said: “Tourette Scotland has been working tirelessly since the 1990’s to educate people and reduce the stigma and ridicule that many of our members face daily. We’ve battled to stop Tourette’s being used as a punchline and for our community to get the understanding and support they need and we feel that, in the space of 1 hour, much of that work has been undone and we now have a brand new stigma to overcome.

Our members are upset and concerned at the very damaging messages that were broadcast. People with Tourette’s deal with a difficult, often distressing, physically and mentally painful condition every day. It can be a very isolating condition and the last thing they need is for people to think they can somehow ‘catch’ it from them.

Our members have to fight for medical care, for assistance in schools, and to be accepted by their peers and society at large. It shouldn’t be so hard and the narrative of Britain’s Tourette’s Mystery has only made it harder.”

PANS PANDAS UK http://www.panspandasuk.org

Dan McLean, CEO of PANS PANDAS UK, said: "Britain’s Tourette’s Mystery was an opportunity lost. A large increase in neurological conditions in children and young people is a potential healthcare crisis. The programme could have busted myths instead of broadcasting fresh ones. Scarlett Moffatt is a fine advocate for demystifying complex and stigmatised conditions, sadly the programme has bemused and hurt so many of the people it might have supported".

FND Action http://www.fndaction.org.uk

Kim Hearne, CEO of FND Action, says: “ It was very disappointing to see how Tourette’s and functional tics/FND were misrepresented in this Channel 4 documentary, and astounded that the documentary had been put together with very little clinical information, or input from related charities who have first-hand knowledge of these conditions. We fully support Tourette’s Action with their endeavour to follow up on this documentary given it has caused a lot of unnecessary upset within all related communities.”

FND Hope http://www.fndhope.org

Dawn Golder Executive Director FND Action says: “We agree with the statements of Tourettes Action in that there is a clinical distinction between the different disorders, despite tics being present as a symptom across these conditions. The terminology used in describing the symptoms and diagnosis impacts upon the recommended medical interventions.

Functional tics can occur as part of Functional Neurological Disorder. This is a different condition to Tourette's syndrome. An individual can have tics associated with Tourette’s, and also experience functional tics, however it is important to understand which is affecting an individual in order to accurately diagnose and treat people as treatment plans will usually differ considerably.

We would encourage collaboration with medical experts when sharing content relating to specific conditions in order to avoid misinformation. For further information on FND please follow: www.fndhope.org or https://www.neurosymptoms.org/en_GB/symptoms/fnd-symptoms/functional-tics/ “

END

Note to Editors:

Tourettes Action works in England, Wales and Northern Ireland and is the leading support and research charity for people with Tourette’s Syndrome and their families. We want people with TS to receive the practical support and social acceptance they need to help them live their lives to the full.

Find out more about Tourettes Action on our website http://www.tourettes-action.org.uk
Watch our awareness video here: #ThisIsTourettes #ItsNotWhatYouThink - YouTube
Watch our video to find out about our work from the people we support: https://youtu.be/eJRGDITFCv0

Please contact us with any questions or queries via our online contact form here. If you are a journalist read how we can help with media enquiries.