

Joost, #Neknomination and #Icebucketchallenge... which raised the most awareness of MND/ALS?

 By Leigh Andrews

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Did Joost's appearance at this weekend's Bokke match do more to raise awareness for MND/ALS than #Neknomination and #Icebucketchallenge? Did you even realise they're one and the same thing?

Checking in on Twitter on Monday morning, I noticed that a whopping seven of the top 10 local trending topics were rugby-related. We had #bokke, #SSRugby, #SAvsNZ, De Gea, Springboks, All Blacks and South Africa. With 'United' and 'Wenger' rounding out the trends, sport was clearly on local tweeters' minds this weekend.

But it wasn't just the Bokke's win that had the nation talking - make that 'typing'. It was the appearance of Joost Van Der Westhuizen on field. That's 'appearance' in both senses of the word - the fact that he was brought out on field, as well as how he looked.



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Joost's condition has long gripped our attention, with *You* and *Huisgenoot* launching a [special iPad app about his life](#) last December.

His J9 Foundation has been raising awareness for Motor Neuron Disease or MND from the get-go of his diagnosis. As with most so-called 'rare diseases', MND/ALS research is underfunded and care under-resourced. An important driver of funding is awareness. That's why in February 2014, Bizcommunity.com [reported](#) that Joost and other J9 Foundation colleagues were Neknominated in the #J9MomentsOfMagic CSI initiative.

Neknomination and Icebucketchallenge; MND and ALS... one and the same?

Yet it's the supposedly similar, but in reality oh-so-different #IceBucketChallenge, meant to raise awareness for amyotrophic lateral sclerosis or ALS - a different name for much the same thing as MND - that's actually gotten everyone's hackles up. Odette Schwegler, Joost van der Westhuizen's media representative at [Blink Pictures](#), explains that Motor Neuron Disease (MND) encompasses a spectrum of diseases, in which the common symptom is the degeneration of motor neurones, causing paralysis. Amyotrophic Lateral Sclerosis (ALS) is the most aggressive form of MND, as these patients

exhibit 'muscle wasting' or amyotrophy, as well as scarring of the spinal cord.

Schwegler says Joost and the J9 Foundation join global organisations and MND warriors, the likes of Euan MacDonald and Steve Gleason, in a common cause: To conquer MND (ALS). As such, they fully support all initiatives that move closer to a cure - including the #icebucketchallenge, which has translated into meaningful funding for global research. Joost uses the platforms available to him to contribute to the global awareness campaign. His appearance at Saturday's test is the latest example of his commitment to the cause.

Bizcommunity [explains](#) that through the #icebucketchallenge, individuals share videos of themselves online being drenched in ice water, and then nominate others to follow suit. If nominees refuse, they have to donate money to the disease - but that's the kicker, you're meant to make a donation whether you succumbed to the drenching or not.

The results are in! Kind of...

When I asked "would you say you know more about ALS from the #IceBucketChallenge, or #MND from @9Joost's appearance with #Bokke?" Rhodé Marshall, entertainment producer for the [@mailandguardian](#), says it was definitely from @9Joost.

Albi Denoon, Ethno Healthcare Practitioner at [FlowFreely](#) also thinks Joost's appearance with the #Bokke helped raise awareness of MND/ALS "... a little. People realised with all the technology, we still have serious illnesses to find cures for." But she cautions, "Doing charity work is a lifestyle and not an one-off social media stunt."

That's what really hits home - raising awareness should be an ongoing effort. That's why Schwegler says that although he's unable to walk and struggling to speak, Joost is beating the odds - devoting much of the energy and time he has towards supporting others with the disease, contributing towards research and raising awareness locally and internationally.

So to the question of whether it raised awareness and will continue to do so, the answer is, "Most definitely." If you prefer the hard cold stats, [The Telegraph](#) reported on Tuesday that £7 million had been raised for the Motor Neurone Disease Association by mid-September in Britain alone, so watch this space.

Speaking of 'watching', you can also [click here](#) for a teaser of Joost's feature length documentary, 'Glory Game', [here](#) for more on the Joost Africa Centre and on the clip below to see celebs such as Taylor Swift, Justin Bieber and One Direction getting drenched in a compilation of #IceBucketChallenge clips.

ABOUT LEIGH ANDREWS

Leigh Andrews AKA the #MilkshakeQueen, is former Editor-in-Chief: Marketing & Media at Bizcommunity.com, with a passion for issues of diversity, inclusion and equality, and of course, gourmet food and drinks! She can be reached on Twitter at @Leigh_Andrews.

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