

How Water & Ice Made Supporting ALS Research “Cool”

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SLACKTIVISM

Noun.

The self-deluded idea that by liking, sharing or retweeting something you are helping out. (*Urban Dictionary*)



Where did the **#ALSicebucketchallenge** come from?



What the #ALSicebucketchallenge did for us?

1. Raised unprecedented awareness of ALS/MND globally
2. Raised more than USD\$200 million for organizations
3. Unified the global ALS/MND community behind the same call to action



A few examples of fundraising

Organization Name	Amount Raised from IBC (from websites)
ALS Association	120 million
Motor Neuron Disease Association	7 million
ALS Therapy Development Institute	3.5 million
Project ALS	500,000
ALS Foundation Netherlands	1 million
MND Australia	2.5 million
MND Scotland	450,000

I'd love folks to tell me what their organization raised!



How did it work?

- A person on social media gathered water into a bucket and put some ice into it.
- They then dumped it over their head
- They then “Challenged” friends or family members to “Accept” the challenge themselves OR give to ALS research

The Facebook logo, consisting of the word "facebook" in white lowercase letters on a dark blue rectangular background.

3 million challenges on Facebook
30 million people liked,
commented, etc on Facebook

The YouTube logo, featuring the word "You" in black and "Tube" in white on a red rounded rectangle.

2.3 million challenge YouTube videos

The Google logo, with the word "Google" in its multi-colored font.

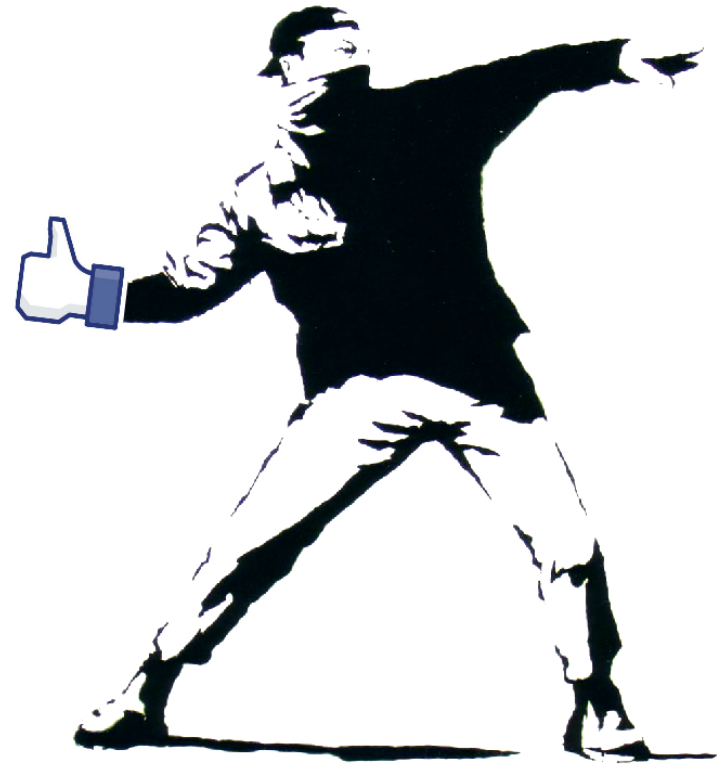
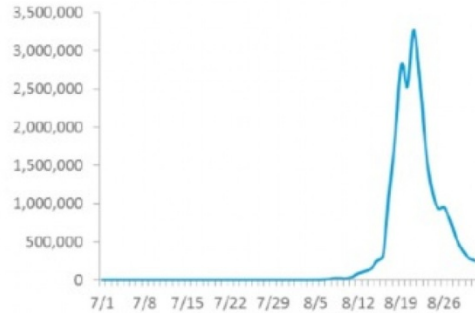
Trended higher than Iraq, Ferguson,
Gaza combined during August



ICE BUCKET CHALLENGE

WHO TRENDED THIS SOCIALLY CONSCIOUS SOCIAL TREND ?

SOCIAL MEDIA MENTIONS OVER TIME



WHO WAS WATCHING THE VIDEOS ?



68% WERE MALE



90% WERE 18-49

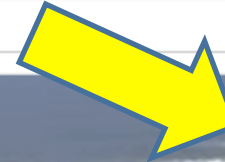


14% MORE LIKELY TO DISCUSS FANTASY FOOTBALL



Why did it work?

ouTube^{GB}



0:10 / 2:10



International Alliance of ALS/MND Organizations – 2014 Meeting –



Where do we go from here?

- Social media is important to your marketing (messaging) strategy
- You should be creating advocate nodes on social media and help them build their networks
- If you are going to try to do the challenge again, be careful, things can go wrong:
 - You could over invest time in a social media campaign to raise money rather than educate (educated donors give more and give more often)
 - People could get hurt (several people died in the USA as a result of challenges)
 - You may compete with other ALS/MND organizations in your country and come across self-serving (there was an example of this in the USA)



Some words of caution!

- I gave a talk 3 years ago here on social media and how it is impossible to be the best-in-class in every channel and at every time.
- Need to choose your own way.
- Don't start and stop.
- This is your credibility!



So, first, what is ALSTDI doing with its windfall?

- **~\$3.5 million raised, split three ways**
 - \$1 million on Precision Medicine Program to enroll upwards of 300 people (originally thought only 20). We are up to 40 enrolled now and booked through March at 5/week.
 - \$1.5 million in Neurimmune SA partnership to advance anti-SOD1 compound toward the clinic. Will primarily pay for manufacturing the compound. Matching funds from Neurimmune investors to help pay for Phase I/II trial.
 - \$1 million to advance the anti-CD40L project toward the clinic. We started with Biogen Idec and UCB Pharma, but they have since pursued other priorities.

Our philosophy is to ask ourselves not how much we can raise, but rather how much can we spend.





Thank you. Discussion?

