

## HAS THE ICE BUCKET CHALLENGE REALLY INCREASED PEOPLE'S AWARENESS OF AMYOTROPHIC LATERAL SCLEROSIS? INSIGHTS AND ETHICAL IMPLICATIONS FROM GOOGLE TRENDS AND WIKIPEDIA: A 2 YEARS-FOLLOW UP

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### ABSTRACT

*Amyotrophic lateral sclerosis (ALS), commonly known as Lou Gehrig's disease, is the most common form of motor neuron diseases (MNDs), causing the death of neurons controlling voluntary muscles. In order to increase public awareness and to promote fundraising, a charity activity known as the "Ice Bucket Challenge" (IBC), initially started only as a joke, was launched in July and August 2014, by Pete Frates, ex Boston College baseball player and himself suffering from ALS. Immediately, it became "viral" among social media and social network users, worldwide. We used Google Trends (GT) and accessed to Wikipedia page to document interest towards ALS 2 years after the IBC. In coincidence with the IBC initiative, a peak in web queries could be noticed, as well as a burst in daily accesses to Wikipedia page. However, this increase in web activities (+450% for GT) was characterized by a brief memory and a short half-life: before and after IBC initiative, GT-based RSVs were  $18.2 \pm 1.7\%$  and  $17.8 \pm 1.9\%$ , respectively. Despite alleged claims of the effectiveness of social networks-based campaigns, apart from money donation and a temporarily burst of web queries and accesses to specialized web-sites, before and after the IBC the level of web-related activities has remained practically constant. The direct involvement of scientists and stakeholders, besides that of celebrities and famous people, would be of crucial importance. Only in this way, initiatives such as the IBC could turn from mere entertaining events even though money-attracting into real educational moments. Otherwise, they would be other missed opportunities.*

**Keywords:** amyotrophic lateral sclerosis, awareness campaign, big data, Ice Bucket Challenge.

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### Introduction

Amyotrophic lateral sclerosis (ALS), commonly known as Lou Gehrig's disease, is the most common form of motor neuron diseases (MNDs), causing the death of neurons controlling voluntary muscles<sup>(1)</sup>.

The etiology of this progressive and fatal disease is still not known in details<sup>(2)</sup> and there is no cure for ALS, apart from some supportive, symptomatic and palliative therapies and experimental drugs<sup>(3)</sup>. In order to increase public awareness and to promote fundraising, a charity activity known as the "Ice Bucket Challenge" (IBC), initially started

only as a joke, was launched in July and August 2014, by Pete Frates, ex Boston College baseball player and himself suffering from ALS. Immediately, it became “viral” among social media and social network users, worldwide<sup>(4)</sup>.

This activity has attracted a lot of participants and charity donations<sup>(4)</sup> which have enabled scientists to further advance in the molecular dissection of ALS etiopathogenesis and in differential diagnosis with other diseases<sup>(5)</sup>, in the effort of finding a potential cure and in the use of informal anatomical classification approaches<sup>(6)</sup>. Funding in the field of neurosciences is inferior to grants and money allocated to other areas, such as oncology and cardiology<sup>(7)</sup>. IBC, together with other initiatives like the White House’s Brain Initiative, has, at least partially, inverted this trend<sup>(7)</sup>.

IBC has been accompanied by a great production of tweets<sup>(8)</sup>, which have made ALS more popular than other more common neurological disorders. Further more than 6 millions of videos were uploaded on YouTube and received a lot of visualizations and comments.

At 2 years of distance from the launch of IBC, the current manuscript aims at exploring whether the effect of popularizing ALS has been only temporary or it has had longer-term implications.

## Material and methods

### Google Trends

GT is a freely available, online tracking system of Internet hit-search volumes accessible at <https://www.google.com/trends/> that recently merged with its sister project Google Insights for Search (Google Inc). GT has been successfully used in a variety of health-related disciplines, investigating the web activities concerning both non-communicable and communicable diseases, for different purposes, ranging from disease monitoring to assessment of public interest towards certain disorders, as recently reviewed by Nuti and collaborators in their systematic review<sup>(9)</sup>.

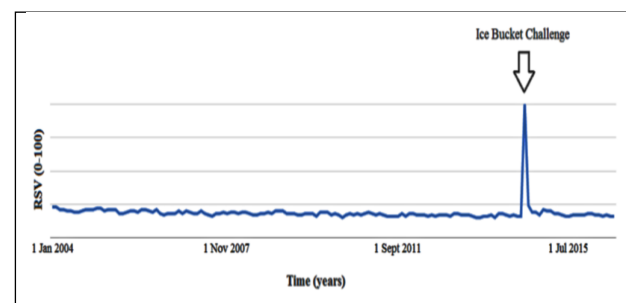
GT was searched for the period from 1st January 2004 to 21st August 2016 (as data before 2004 were not available), worldwide, using “amyotrophic lateral sclerosis” as keyword. Since queries can be performed with a certain term being used both as the “search term” and the “search topic”, “amyotrophic lateral sclerosis” was exploratively searched both as “search term” and “search topic”.

Using the first option, GT searched the exact string of text typed by the user, while using the second option all searches related to the query and automatically suggested by GT via its auto-complete service were included; therefore, this latter option usually results into a broader search, even if this function is still under testing (beta function).

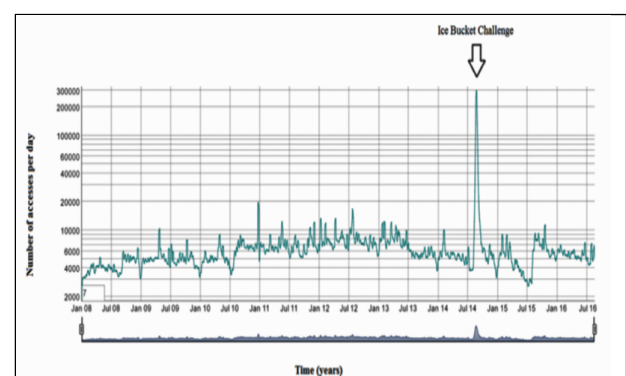
Wikipedia Wikitrends (accessible at <http://www.wikediatrends.com/>) is a freely available tool, launched in April 2014, that enables to track and monitor traffic volumes related to single Wikipedia pages. Wikitrends has been used to explore information-seeking behavior for several diseases. Wikitrends was mined since its inception to 21st August 2016.

## Results

In coincidence with the IBC initiative, a peak in web queries could be noticed (Figure 1), as well as a burst in daily accesses to Wikipedia page (Figure 2). However, this increase in web activities (+450% for GT) was characterized by a brief memory and a short half-life: before and after IBC initiative, GT-based RSVs were  $18.2 \pm 1.7\%$  and  $17.8 \pm 1.9\%$ , respectively.



**Figure 1:** Web behavior related to amyotrophic lateral sclerosis (ALS), as captured by Google Trends (GT).



**Figure 2:** Digital interest towards amyotrophic lateral sclerosis (ALS), as captured by accesses to Wikipedia page.

## Discussion

An activity like the IBC is noteworthy in that it has undoubtedly contributed to raise public understanding of ALS and to collect funding<sup>(10)</sup>. Activities such as the IBC can be particularly useful for those countries in which health-care systems are characterized by barriers and resources are limited. Also research for a cure of rare diseases could benefit from these events<sup>(4)</sup>.

On the other hand, there has been an increasing interest in bibliometric research, especially in medical sciences, for quantitative analysis of literature published subsequent to the launch of IBC<sup>(11)</sup>.

Many features have contributed to the success of IBC, such as the fact that it was characterized by a positive, ironic message, despite the severity of the disease, differently from public health awareness campaigns<sup>(12)</sup>. Also the innovative use of social networks, such as Twitter, Instagram and Facebook, played a major role<sup>(12,13)</sup>.

On the other hand, the IBC has been criticized for a different number of reasons, including the waste of water, eventual safety concern<sup>(4,14)</sup>, and its emphasis on publicity and spectacularization rather than on the delivery of a scientific message<sup>(12)</sup>.

According to our obtained results, the IBC has not been accompanied by a longer-term effect. We have confirmed the findings of Wicks and Van der Linden<sup>(14,15)</sup>: they documented a transient effect of increased accesses to the Wikipedia ALS-related page. After a lead-in mean of approximately 3,000 accesses per day and the peak of 436,035 page-views reached the 21st August 2014, the post-challenge mean was of about 6,000 daily accesses and continued to decrease.

Even though this “one-off” nature of the IBC may be compatible with the goal of fund-raising<sup>(12)</sup>, a long-lasting effect would be desirable in order to raise awareness and promote healthy behaviors such as the adoption of preventive measures. Workers in the health-care field should exploit the initial impact of such initiatives to disseminate plain but high-quality and rigorous information and communicate with the public opinion.

For example, they could actively engage in social networking<sup>(8)</sup>. Up to day, only have a small fraction of scientists have a Twitter account<sup>(8)</sup>. A mutual collaborations between scholars and patients affected from ALS would be fundamental for really educating people<sup>(14)</sup>.

## Conclusion

Despite alleged claims of the effectiveness of social networks-based campaigns, our findings show that apart from money donation (16-19) and a temporarily burst of web queries and accesses to specialized web-sites, before and after the IBC the level of web-related activities has remained practically constant. The direct involvement of scientists and stakeholders, besides that of celebrities and famous people<sup>(20)</sup>, would be of crucial importance. Only in this way, initiatives such as the IBC could turn from mere entertaining events even though money-attracting into real educational moments. Otherwise, they would be other missed opportunities.

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