Twitter Event March 24th, 2021

First, thank you for considering taking part in the Twitter Event we have scheduled for Wed. March 24th at 9:00 AM EDT. We're hoping to get as many people's stories out there to help people understand the issues we are facing.

We are still looking at the potential hashtag(s) for this event. We would like one unifying hashtag for all tweets, but perhaps also some specific illnesses or topics. Thinking this could help raise awareness of the diversity of the issues faced. One we are considering is #SavingUsToDeath

We will be addressing the tweets to a small group of individuals who sit in key positions related to our issues.

We know we will be sending to Dr. Rochelle P. Walensky, the new director of the CDC.

We are investigating cabinet members and congressional committee members who play powerful roles in the oversight of agencies we have struggled with.

At most, we are probably looking at five people. Why so few? We don't want to dilute the impact of this event. There are also some practical considerations, like leaving enough characters to write our tweets. Think of it like this. When an accident happens, if there are one to two people present, they typically jump in to help. If there is a larger crowd, the sense of responsibility is dissipated so that people are slower to act because they all expect the others to do something. We want these people to know we are counting on them to help us. That the horrors we've experienced need to be exposed, and steps are taken to resolve those issues.

For most of us, our stories are long and difficult and can be hard to boil down. I'm going to provide a few samples below to help keep our tweets focused and clear.

The tweets for this event should be 1-3 tweets long. We need to make it easy for the reader to:

1) Understand - avoiding jargon like CPP, MME, etc.

2) Take our side - while avoiding combative language, give a sense of the injustice.

3) See us as credible - we need people to listen and believe us. Due to the intensity of our experiences, we need to avoid rants. It might be helpful to list our professions as well.
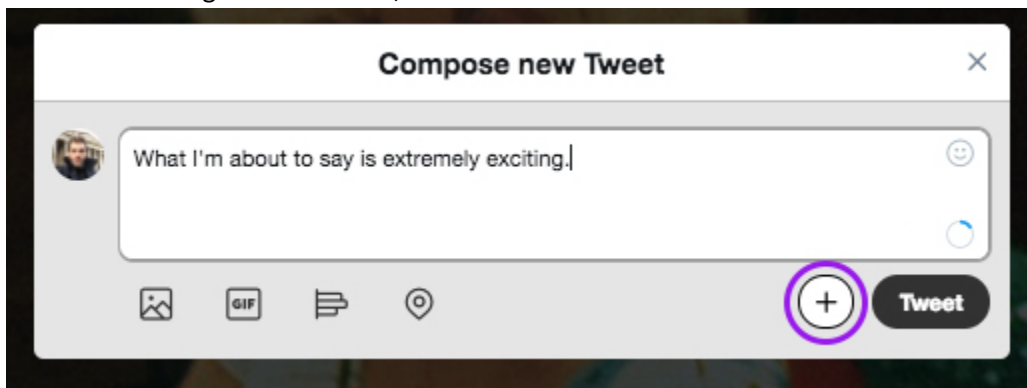
Example 1 (Single Tweet)

I've suffered from chronic pain for over twenty years, but it's been these last five that have been the worst. I can't get the help I need to live because the CDC interferes with my doctor-patient relationship.
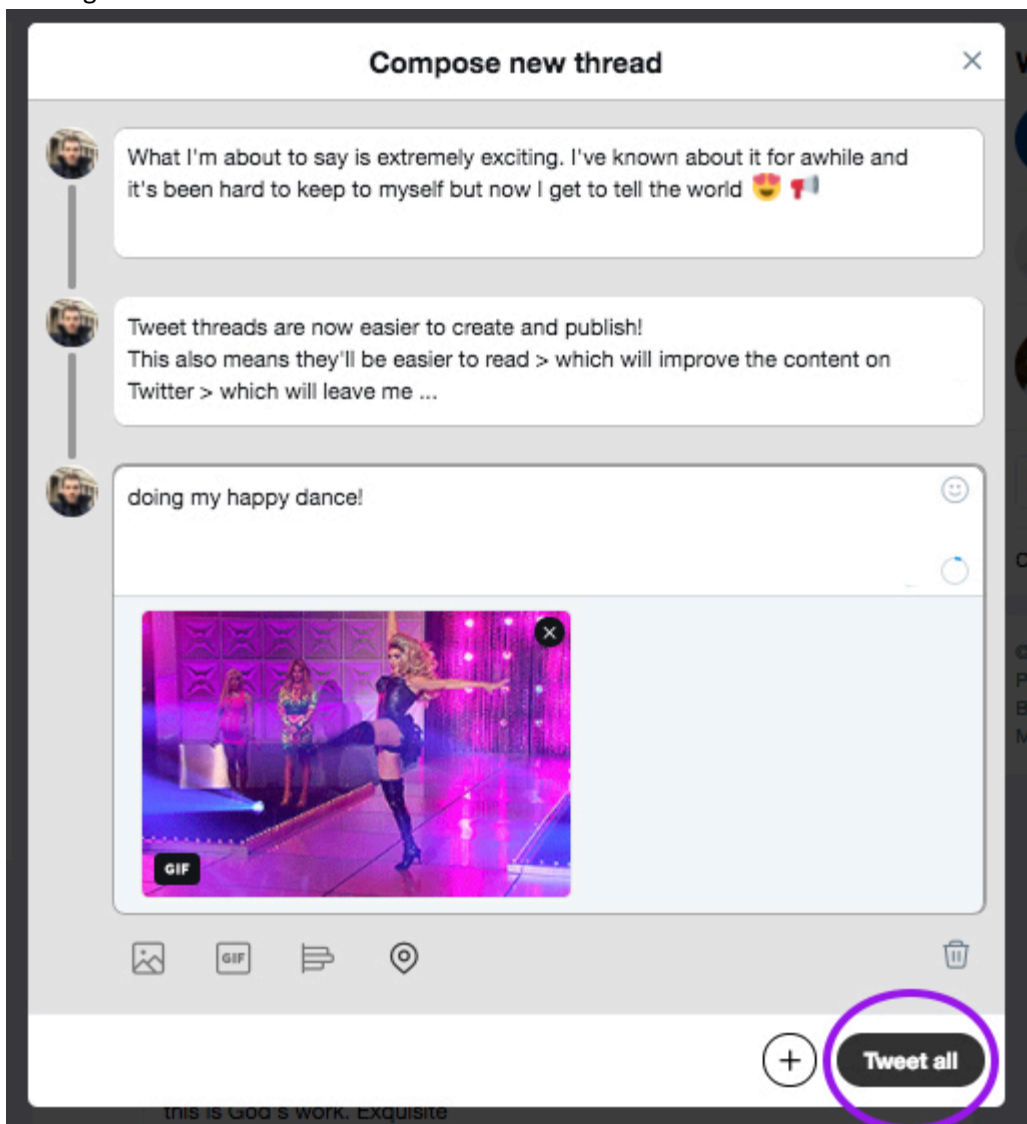- programmer

Example 2 (Two Tweets)

I've followed all the rules, done everything the doctors asked me to do. I've been on the same amount of pain meds for six years until a year ago. My doctor told me there were some new rules.

After six months of struggling each day with the amount of pain I was in and not being able to my work like I used to, I got fired. I've tried for disability but that's not looking good. I've been living off my life savings but between the loss of insurance and everything else well ...
- mechanic

To tweet multiple tweets at once, you can use a Tweet thread. While writing the first tweet, you should see a button for adding another tweet, like this:

Clicking on it adds successive tweets so that the editor looks like this:

But don't push that tweet all button just yet!

We want all the tweets to arrive more or less at the same time. I'm still new to Twitter as a platform, so I was bummed to discover there aren't many free options for scheduling tweet threads. For veterans of the platform, I'm guessing they are well aware and have discovered their preferred method.

For the rest of us, we have a few options. Tweetdeck supports it but requires a monthly subscription. There was one website called OneUp that has an interesting offer. It's a little convoluted to get it for free, but I'll leave the link here https://blog.oneupapp.io/how-to-schedule-twitter-threads/. I'll be reaching out before our event to see if they can help us out.

Obviously, you don't have to schedule it, but simply send it at 9 AM EDT on the 24th.

Regardless, I hope you choose to participate, and I will be continuing to look for ways to facilitate your participation.