

UNITED FOR PARKINSON'S

A Global Awareness Campaign



United for Parkinson's

Claire M. Jones
Omotola A. Thomas

Table of Contents

| | |
|--|-----------|
| <i>INTRODUCTION</i> | 3 |
| The Beginnings of the Campaign | 3 |
| Background Information | 4 |
| The Objectives of the Campaign | 4 |
| <i>THE CAMPAIGN</i> | 5 |
| Phase I: The Travelling “United Hashtag” Race | 5 |
| Phase II: This is Me PD | 6 |
| Parkinson’s Eve | 9 |
| Phase IV: Art Exhibition and Gala | 9 |
| <i>CONTACT</i> | 10 |

INTRODUCTION

The Beginnings of the Campaign

In October 2018, the European Parkinson's Disease Association (EPDA) invited a group of advocates from across Europe, all diagnosed with Young Onset Parkinson's Disease (YOPD), to a photographic art exhibition at the European Union Parliament in Brussels. Following the exhibition, the invitees were given the opportunity to meet with a few MEPs and present their ideas on policy changes that would benefit people with YOPD. The EPDA also organised a brainstorming session between the attendees to identify areas and/or projects the group, supported by the EPDA, could collectively work on.



EU Parliament Art Exhibition – Organised by the EPDA (Photographer: Anders Leines)

It was at this meeting that Claire Jones and Omotola Thomas met, having both been diagnosed with YOPD. Both women have extensively volunteered, in various capacities, within the Parkinson's community, and have a genuine desire to make a positive impact in the lives of all people with Parkinson's (PWP). One conversation led to another and, within a few weeks, the concept for the "United for Parkinson's" campaign was born.



In 2017 and 2018, Parkinson's UK and the EPDA jointly ran a "Unite for Parkinson's" campaign where they called on the global Parkinson's community to unite to advance causes related to Parkinson's disease. That call was heeded and this "United

for Parkinson's" campaign seeks to demonstrate just that. Using very simple, but engaging and interactive mechanisms, the United campaign seeks to unveil a truly united global Parkinson's community.

Background Information

We believe that the current depictions of PWP's are not only misrepresentative, they are also detrimental – especially to those of working age. On one end of the spectrum, we are portrayed as people who are frail, helpless, and to be felt sorry for. One only has to google "Parkinson's disease" and the predominant image that comes up is that of an old and feeble-looking white male, shown below.



Wikipedia image of Parkinson's disease

This distorted view is what often gives rise to the stigma that so many PWP's feel, the psychological impact of which cannot be overstated. Additionally, this generalisation that PWP's are to be pitied adds an extra layer of difficulty for those seeking employment as it fuels any pre-existing bias that may already be held by potential employers. For the newly diagnosed PWP, and their family members, it also paints an unnecessarily bleak picture of what lies ahead.

On the flip-side of this coin are the "heroes" that are publicly celebrated for performing feats (skydiving, running marathons, etc.) that are incredibly challenging, even for a person with no health issues. The problem with this is that it creates a rose-tinted view of what can be achieved by a PWP. It is important to note that we are not even remotely suggesting that these individuals should not be celebrated or publicised – we wholeheartedly believe they should be; and that there is an enormous amount of inspirational value that comes from these stories. What we are trying to highlight are the two extreme representations of PWP's and the fact that the majority of PWP's fall in between those extremes.

We need a more accurate representation of PWP's.

The Objectives of the Campaign

In addition to the general, broader goal of raising awareness of the seriousness of Parkinson's disease, this campaign seeks to change the way Parkinson's disease is portrayed and perceived. Every aspect of this campaign has been carefully crafted to address many of the inaccurate depictions of PWP's; furthermore, the campaign puts PWP's in the front seat of driving this change.

The main objectives of the campaign are to:

- Give a voice to all PWP's, across the globe, to express how they want to be seen, and their journey with Parkinson's to be viewed.
- Provide a platform for everyone affected by, or connected to, Parkinson's (family members, carers, doctors, colleagues, researchers, policy makers, etc.) to share how Parkinson's has impacted them and what they have learned on their journey.
- Promote a better understanding of the seriousness of Parkinson's disease and show its wide-reaching impact.
- Foster a lasting sense of community between everyone affected by, or connected to Parkinson's disease, across the globe.

THE CAMPAIGN

The campaign, which was launched December 11, 2018, in the United Kingdom, consists of four phases:

Phase I: The Travelling "United Hashtag" Race

Phase II: This is Me PD

Phase III: Parkinson's Eve:

Phase IV: Art Exhibition and Gala

Phase I: The Travelling "United Hashtag" Race

The hashtag race is an engaging and interactive way to achieve the objectives of this campaign. It was launched in Leicester, UK on December 11, 2018.



Launch of the "Hashtag Race" in Leicester, UK on December 11, 2018

The race involves an international team of seven "captains", each diagnosed with Parkinson's disease, competing in a race to see whose physical, plastic "united hashtag" will travel the most miles between the December launch date and April 11, 2019 – World Parkinson's Day. Each team captain was given possession of a different-coloured physical, plastic "united" hashtag and they have already started sending it around the world.

The recipients of these hashtags must be individuals or organisations affected by, or connected to, Parkinson's disease. This includes not just PWPs or their friends and family, but also healthcare professionals, researchers, scientists, and policy makers.

At each stop, the hashtag recipient takes a picture and video of themselves, holding the hashtags. They state their name, connection to Parkinson's, how the illness has impacted them, how they best handle the challenges that come with the illness, and any other Parkinson's information, knowledge, or wisdom they wish to share. At the end of the race, many of the images and videos received will form part of a video that links the stories received on each hashtag's journey. Some of the stories that have been received so far and the acts of kindness from strangers in facilitating the movement of the hashtags, have been truly inspirational.

As of January 17, 2019, a little over a month since the hashtag race was launched, the hashtags had visited four continents, and travelled a combined total of over 40,000 miles! Go to www.unitedforparkinsons.com/blog for the latest hashtag update (starting no later than February 1, 2019).

The race will end shortly before World Parkinson's day (WPD) on April 11, 2019 and stories, based on information received, will be published and presented at the World Parkinson's Congress in Kyoto in June 2019.

HOW YOU CAN BE INVOLVED

We need to get our hashtags into the hands of as many people affected by, or connected to, Parkinson's as possible. If you, or someone you know, is willing and able to receive a hashtag and participate as outlined above, please contact us (contact details below). We also need help transporting the hashtags from place to place, so if you are a frequent traveller, and are able to help facilitate the movement of the hashtags, we would also love to hear from you.

Phase II: This is Me PD

"This is Me PD" affords PWPs the opportunity to clearly express who they are and how the context of Parkinson's impacts everything they do. The strength of this campaign is dependent on participation. We therefore request that you kindly encourage as many people as possible to do the following.

Three focused asks for PWPs. Please send us (unitedforparkinsons@gmail.com):

- 1) A photo of how you wish to be seen
- 2) This is me - a short paragraph of who they are independent of their diagnosis
- 3) This is my PD - a message from the individual which they would like the world to know about their Parkinson's

Each participant will need to complete a consent form.

Each photo will be communicated with the description through Instagram, and will appear on a page where you can scan over the image to read the description. All of these images will be collated into an art work that will feature on billboards around the country and be the centrepiece of the exhibition mentioned below.

Here are two samples of a "This Is Me" submission:



Claire Jones
THIS IS ME

I'm busy. I'm busy all the time, my mind flies around the room trying to find things to do, and to learn, and people to gain learning from. I am a proud auntie and Leicester Tigers supporter. I love to dance and sing in my living room at full volume, and I'm in out of the closet EMO kid - never really grown out of it. I love dying my hair - it's been so many colours. I'm obsessive about tatty divine jewellery, I'm never without it. I am a technology junkie, book addict, a crossword fiend, and a loyal and passionate friend- these same things can be said about my advocacy and volunteering. I'm considered a force of nature – but I'm just me.

THIS IS MY PD

It's brutal, it's tough, I work hard to be me. I'm in a constant pain, and often I can't get people to find the thingy on the thingy by the thingy. I have to do a warmup to be me every day yet I'm still unfit. Some days I can barely say a sentence, when I'm used to being most eloquent person in the room. Some of the symptoms that I have are so humiliating I can't even bear to write them down, for they become real. I don't look to the future so like so many of my friends, it's too frightening and too full of pain. PD has bought me the death of my dreams, but it has also bought me my best friends.



Omotola Thomas
THIS IS ME

I am a self-proclaimed *Reckless Optimist*, I tend to see the glass as half-full. The fabric of my personality is woven together by paradoxical qualities which result in me being simple, but complicated; fearless and anxious; vulnerable, yet strong. Music unlocks my soul; writing unleashes it. I love singing, reading, and doing handstands. I am a wife, I am a mother, I am a sister, I am a friend, but most importantly, I am me.

THIS IS MY PD

It is a ruthless and scornful adversary that constantly tries to break me. It follows me around every day, every hour, every second, ceaselessly reminding me of the limitations it has imposed on me. When I walk, when I talk; when I sleep, or as I weep; when I pull out a fork to eat, or I attempt to dance to a beat; it doesn't matter what I am doing, my PD is always there, interfering. But...

Inasmuch as it is my weakness, it is also my source of strength. It has become an unexpected "ally" of sorts, and turned me into an opportunity-in-adversity seeker. In exposing my vulnerabilities, it revealed my purpose.

It is where my pain and power coexist.

Parkinson's Eve

The day before World Parkinson's Day, we will be holding a conference specifically focused on Parkinson's and women, but open to all. To ensure that this is a success, we need assistance with:

- Sponsorship or branding
- Promoting the event - we need people to come!

By creating a conference that is primarily focused on women with Parkinson's, we hope to create a safe space in which to discuss the boundaries that exist that prevent women advocating for Parkinson's. We also intend to highlight areas in which there needs to be further research, and to challenge the agenda of gender in research. An example is that for many women, the drugs do not work for one week in 28 days-something that we do need to address.

Through this massed group of women with Parkinson's disease we intend to be able to more eloquently demonstrate that it is not just a male diagnosis. Conferences of this nature have been run in the United States but, as far as we are aware, never before in Europe.

Registration for this free event is available on the website at www.theparade.me/events.

Phase IV: Art Exhibition and Gala

The New Walk Museum in Leicester will be our host for the first exhibition of art produced and inspired by people with young onset Parkinson's disease, working alongside artists. It features many different styles of artwork including ceramics, glass work, acrylics installations and music. The intention is to challenge the views of those who attend on what they think Parkinson's is and, of course, get to learn about art in the process.

The exhibition opens on World Parkinson's Day, with the unveiling between 3PM and 5PM UK time. The work, and the people who participated, will be celebrated by various well-known speakers at the unveiling which we are hoping will be well attended.

The exhibition will feature talking events, discussion and art workshops-all of which will challenge the perception created in the media of people with Parkinson's.

The gala which starts at 6 PM features:

- Make-up by MAC artists, glamming you up for a donation.
- The Parkinson's choir, serenading your arrival.
- A three course dinner.
- A full cabaret performance from the legendary artist Ceri Dupree.

We will also see the conclusion of all of our projects that evening including the hashtag race, along with an international crowd celebrating the hard work of all involved.

Please come along and assist, or just enjoy the celebrations that are being held on the day with us.

CONTACT

www.unitedforparkinsons.com

unitedforparkinsons@gmail.com

For tickets and conference registration, please visit: www.theparade.me/eventss