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Parkinson's Europe has created this short guidance document to help support individuals and groups plan a campaign for World Parkinson's Day (WPD). To learn more about Parkinson's Europe and all our collaborations and projects, visit us at www.parkinsonseurope.org

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Don't forget to email us what you are doing for World Parkinson's Day so we can share and promote your activity on the Parkinson's Europe online map and social media – see p.11 for full details



World Parkinson's Day – a brief background

The first World Parkinson's Day (WPD) was held in April 1997. It was set up by the European Parkinson's Disease Association (now known as Parkinson's Europe) and co-sponsored by the World Health Organisation (WHO). The date commemorates the birthday of Dr James Parkinson.

Dr James Parkinson (1755 – 1824)

Born 11 April 1755, James Parkinson is most famous for his essay 'An Essay on the Shaking Palsy' in 1817, which first recognised Parkinson's as a medical condition.



WHO working group 1997

WPD was set up by the European Parkinson's Disease Association (now known as Parkinson's Europe) and co-sponsored by

the World Health Organisation (WHO).

The inaugural WPD event in 1997 marked the launch of the Parkinson's Europe Charter, which provided the central focus and opportunity for people with Parkinson's, their families and healthcare professionals to work together to promote awareness and increase the profile of Parkinson's. The Charter gained the support of influential people around the world including UK royals HRH Princess Margaret and Princess Diana, UK prime ministers John Major and Tony Blair, Pope John Paul II, Italian opera singer Luciano Pavarotti and US boxing legend Muhammad Ali.

As a result of WPD 1997, the WHO formed the working group on Parkinson's Disease in May 1997. This led to the development of the first Global Declaration on Parkinson's Disease launched in Mumbai, India in December 2003 which aimed to encourage a change in attitude towards Parkinson's.



Photo of the Charter launched at the first WPD event in 1997

During the 9th WPD conference, which was organised by the EPDA and held in Luxembourg in 2005, the red tulip was adopted as the official symbol for the disease.

Each year there are now many World Day celebrations around the world as people come together on 11 April to raise awareness of Parkinson's. Activities include online awareness campaigns, webinars, conferences, wellbeing events, fundraisers and much more.

To read more on the history of World Parkinson's Day, visit this <u>article</u> in our online magazine Parkinson's Life.

2 What is 'The Spark'?

In 2022, a host of global Parkinson's organisations joined forces to develop and launch a new logo for *World Parkinson's Day* – dubbed 'The Spark'. The logo was designed to encourage the Parkinson's community to speak with one voice and create a universal symbol of Parkinson's.

The Spark is the result of an active collaboration between international Parkinson's organisations including: Parkinson's Europe, PD Avengers, Parkinson's Foundation, Davis Phinney Foundation, Brian Grant Foundation and Cure Parkinson's.

What is 'The Spark'?

The Spark design is inspired by dopamine

– the electro-chemical neurotransmitter
that people with Parkinson's are striving to
retain. The group of organisations aim for this
bolt to energise the Parkinson's community
around a more coordinated annual World
Parkinson's Day event, eventually bringing
organisations and individuals together under
one recognised umbrella that will lead to
greater awareness, impact and ultimately
positive change.

Any organisation, individual or group that wants to highlight and support the annual World Parkinson's Day are encouraged to



use The Spark on their promotional material for events, campaigns and communications. Organisations are able to select their own colour for The Spark, and more information can be found on the Parkinson's Europe website or The Spark toolkit, which contains a variety of resources and logos.

Guidance and resources for running a campaign



To help you get started with your campaign planning, below is a list of useful links and resources:

Six Parkinson's Europe toolkits* covering the following topics:

- Guide to developing an advocacy campaign (available in both EN and ES)
- Guide to working with social media (available in EN)
- Guide to organising a Unity Walk (available in EN)
- Guide to fundraising (available in EN)
- Guide to working with the treatment industry (available in EN)
- Guide to working with the media (available in EN).
 - *Please note that these toolkits were written some time ago but much of the content is still relevant*

The Spark toolkit

Further resources and links to help inspire your campaign

- A Parkinson's Manifesto for Europe
 - (Available in 9 languages)
- Parkinson's Carers Survey Report
- Fact sheet for new Parkinson's organisations
- Parkinson's Europe ExerciseCast.
- Sleep well with Parkinson's guide
- Parkinson's creativity

Communication workshop for Parkinson's Europe member organisations:

If you are a member organisation of Parkinson's Europe, you are also invited to an online communications workshop to learn more about running *World Parkinson's Day* campaigns, with a particular focus on social media.

The workshop will take place on Tuesday 28 February at 10.00 GMT.

Email Natalie@parkinsonseurope.org
to register your interest and receive a Zoom link. A recording of the workshop will be available for those unable to attend.

Ideas and examples of previous World Parkinson's Day campaigns and events

If you haven't yet decided on an idea for your World Parkinson's Day campaign, there are a wide range of activities, campaigns and events you might consider. Here are some Parkinson's Europe member organisation ideas and examples from the past to get you started:

1 Awareness raising campaigns – why not create your own campaign to raise awareness about Parkinson's? Here are some great examples from previous years:

SLOVENIA – Drustvo Trepetlika (2016)



In 2016, the Parkinson's Disease Society of Slovenia organised a <u>street flash mob</u> to demonstrate the effects of freezing. They froze on the pedestrian crossing in front of the Slovenian Parliament. Dressed in T-shirts with the Trepetlika logo and carrying the association banner, they stopped traffic on one of the main streets in Ljubljana.

FRANCE – Association France Parkinson (2022)



As part of their 2022 WPD celebrations, France Parkinson launched a video campaign <u>'Parker – campagne de sensibilisation 2022'</u> to highlight the daily challenges of people living with Parkinson's and raise awareness of the seriousness of the condition.

SPAIN – Federación Española de Párkinson (FEP) (2020)



FEP and its member associations developed a World Parkinson's Day awareness campaign called **Invisible Signs** that aimed to shine a light on the invisible <u>symptoms</u> of Parkinson's. During this campaign, the President of FEP read the Federation's manifesto via a <u>video message</u>.

UK – Parkinson's UK (PUK) (2022)



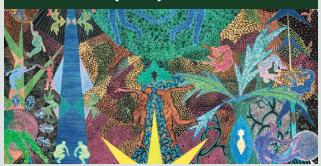
In 2022, PUK ran a campaign called '<u>Light Up Blue</u> <u>for Parkinson's</u>', which encouraged local attractions and iconic buildings across the UK to light up blue for Parkinson's on 11 April.

(2) Conference, workshop or webinar – some organisations organise in-person meetings while others opt for online webinars or workshops. Past examples include:

SWITZERLAND - Parkinson Schweiz (2021)

For WPD2021, Parkinson Schweiz launched: Parkinson - Chat und Weekend für Jugendliche (Chat and Weekend for Young People), a special offer for young carers. The pilot project in German-speaking Switzerland provided carers with a weekly two-hour counselling chat, as well as two weekends 'in nature' accompanied by a social counsellor.

ISRAEL - Israel Parkinson **Association (2021)**



In 2021, the national Israeli association organised an online conference in collaboration with the Offzine Center for the Treatment and Prevention of Parkinson's at Tel Aviv University. The programme included live scientific lectures for researchers, doctors, students and industry; in addition, there were lectures for people with Parkinson's, their families and health professionals, as well as exhibitions of artwork by people with Parkinson's.

FRANCE – Association France Parkinson (AFP) (2021)



AFP organised an online conference "Living better with Parkinson' disease", which included care pathway modules featuring a range of health professionals presenting their profession and their impact on people with Parkinson's. This took place Saturday 10 April and also involved lectures, debates, animations and tips to improve the daily lives of people with Parkinson's and their carers.

BELGIUM – Association Parkinson ASBL (2021)



In April 2021, Association Parkinson ASBL held a virtual conference on sleep and the problems faced by people with Parkinson's – especially during the COVID-19 pandemic. A recording of the conference can be found here.

GREECE - The Greek Caregivers Network EPIONI and PAR.KIN.S.O.N (2022)



On WPD2022, the Greek Caregivers Network EPIONI (in collaboration with the Greek association PAR. KIN.S.O.N.) organised a care webinar called 'Living with Parkinson's, from diagnosis to treatment' to address the need for people with Parkinson's and their families to have access to more and better health services.

(3) Physical activity, exercise and dance – Lots of World Parkinson's Day campaigns focus on physical activity and exercise. Here are just a selection of the exciting events that have taken place over the years...

DENMARK – Parkinsonforeningen Denmark (2018-2022)



From 2015-2019 and 2022, a Parkinson Unity Walk was held in Copenhagen to help increase public awareness of Parkinsons. Click here to access the Danish Unity walk website.



For WPD 2021, Parkinson's Europe contributed to the Together Apart global campaign (led by Parkinson's UK) with a wellbeing and exercise video. The video was developed by physiotherapist Josefa Domingos and speech language pathologist John Dean, featuring PwP Luis Leira and chef Fábio Bernardino from Portugal, with support from Portuguese pharmaceutical company Bial. The video's aim was to raise awareness of how Parkinson's can impact daily living activities such as preparing a meal in the kitchen, and to provide simple tips and strategies to overcome these – in a fun and light-hearted way.

FINLAND – Association of Movement Disorders ((2021)

In April 2021, the Association of Movement Disorders (Liikehäiriösairauksien liitto) held a virtual World Parkinson's Day dance and lecture event on the theme of exercise and rehabilitation. It covered the treatment of Parkinson's, the effects of social reform, and the importance of dance on wellbeing.

ITALY – Parkinson Italia ONLUS (2020)



To mark WPD2020, a Dance Well event called #citofonareDanceWell took place involving several Italian Parkinson's associations, including Parkinson Italia ONLUS and the Italian Young Parkinsonian Association (#AIGP). Everyone was invited to dance at home – while connecting virtually via Zoom with the Dance Well Dancers.

MALTA – Malta Parkinson's (2021)

For WPD 2021, Malta Parkinson's organised a virtual event on the importance of exercise. This included a talk by a physiotherapist and a short exercise class. Previous to this, in 2018, Step Up For Parkinson's a dance group collaborated with Malta Parkinson's to hold a Gala Night to commemorate WPD.

GERMANY & SWITZERLAND - No More Parkinson's - Germany and Switzerland PD Avengers Group (2022)



For WPD 2022, a virtual challenge called AktivZeit was launched in Germany and Switzerland called 'Together against Parkinson's in 500,000 minutes! AktivZeit'. The campaign aimed to help the public learn more about the complex symptoms of Parkinson's and motivate people with Parkinson's to exercise regularly and thus improve their quality of life. Individuals and teams were encouraged to sign up to and share their active time centrally on the AktiviZet website.



Music, drama, poetry and art... Are you interested in running a more creative activity or campaign? Take a look at some of these past activities and events:

Greece – Northern Greece Parkinson's Disease Association (2017)



To commemorate the 200-year Parkinson's anniversary, Despina Anastasiadis from the Northern Greece Parkinson's Disease Association wrote a <u>short play</u> for an event in Thessaloniki, Greece. Entitled 'Without Her', the play uses light-hearted conversations to educate the audience and guide them through the Parkinson's diagnosis experience. Read the play on <u>Despina's blog</u>.

LITHUANIA – Lietuvos Parkinsono ligos draugija (2020)



In 2020, the Lithuania member organisation created a moving poem entitled 'The Little Vincent and Mr Parkinson' to celebrate World Parkinson's Day.

AUSTRIA – ParkinSong (2021)



In 2021 the non-profit organisation <u>ParkinSong</u> released 'Parkinson's Blues', a special World Parkinson's Day song, recorded live by founder Gerald Ganglbauer with Austrian band Badhoven at the Stattegg ROCKS event.

THE NETHERLANDS - ParkinsonNL



For WPD 2022, <u>ParkinsonNL</u> invited everyone in the Netherlands to sing the song 'The music always continues' by Rob de Nijs and Ernst Daniel Smid. According to ParkinsonNL, music is the best medicine to use on World Parkinson's Day so they encouraged people to play, sing or listen to themselves, take a photo or video and share it on social media. Click <u>here</u> to read more about this campaign.

UNITED KINGDOM – Parkinson's UK (2022)

For WPD 2022, Parkinson's UK ran a campaign called <u>Poems for Parkinson's</u>. They invited the Parkinson's community to share their stories through poetry and tell the world what it's like to live with the condition.

UNITED KINGDOM – Nate Kitch (2022)



In 2022, a new campaign 'Putting Parkinson's in the Picture' was launched to raise awareness and understanding of Parkinson's. The campaign aims to change the public perception of Parkinson's and encourage people to think more broadly about the condition, going beyond its visible symptoms to its impact on the way people think and feel.



(5) Political advocacy and lobbying

IRELAND - Parkinson's **Association of Ireland (PAI)** (2018-2019)

In 2018, the association held a silent protest outside the Gates of Leinster House at the parliament of Ireland. In attendance was Marian Harkin MEP. EU Ambassador for people with Parkinson's.

In 2019, the PAI protested at the Irish Parliament on the lack of services and support for PwPs. CEO Paula Gilmore, Dr Richard Walsh and Gary Boyle also gave a briefing inside the Dáil (lower house of the Oireachtas of the Irish parliament) as part of Ireland's Parkinson's Awareness Week.

General support and information

ICELAND – Parkinsonsamtökin (2020)



Throughout April 2020, the Icelandic Parkinson's association provided online occupational therapy, online phone support meetings and chat groups with social workers and family therapists. Click here to listen to the World Parkinson's Day interview with their Chairperson - Vilborg jónsdóttur.

FRANCE – Association France Parkinson (AFP) (2020)

DOPAMINE.CARE

Informations : la vaccination, la covid-19, la maladie de Parkinson

In 2020, the <u>www.dopamine.care website</u> was specifically developed to help AFP members during the COVID-19 crisis. The site includes lots of information and resources such as exercise videos and links to artistic and cultural activities that can be accessed for free. The website constantly evolves as new recommendations and suggestions are added by their members.

5 Sharing and promoting your activity

Tell us what you are doing and we will add you to our World Parkinson's Day 2023 map



Parkinson's Europe is creating an online map of activities and events across Europe for World Parkinson's Day 2023. If you would like to share your World Parkinson's Day campaign with the Parkinson's community, contact us and we'll add your activity to the map.





Email: info@parkinsonseurope.org **Web:** www.parkinsonseurope.org

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