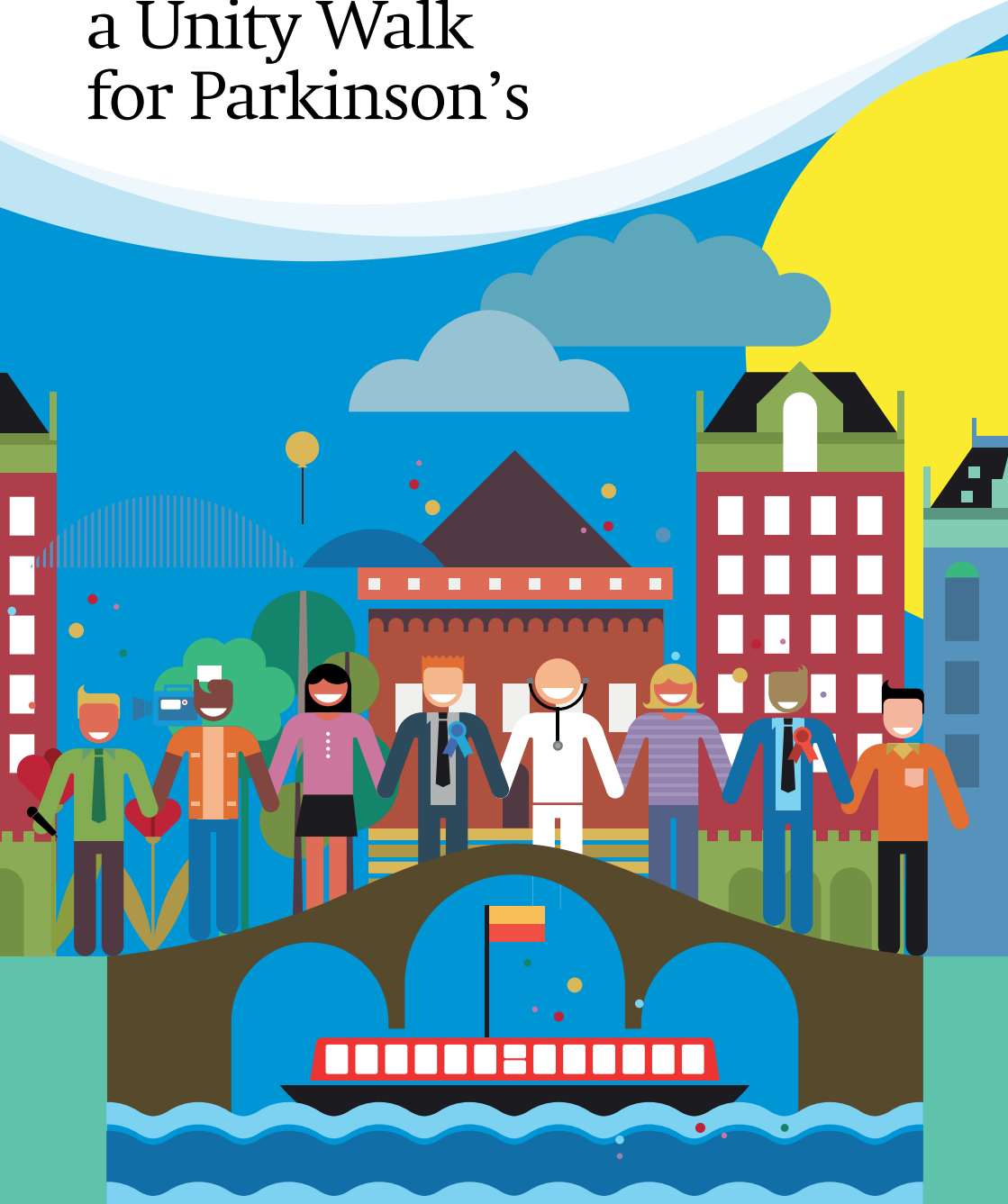


EPDA guide to



# Organising a Unity Walk for Parkinson's



# EPDA GUIDE TO... ORGANISING A UNITY WALK FOR PARKINSON'S



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## INTRODUCTION – A WORD FROM OUR PRESIDENT

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**T**HE SUCCESS OF THE EPDA'S first European Unity Walk in 2012, which brought more than 1,000 people from 25 countries to Amsterdam in the name of Parkinson's, will – we hope – inspire many others to follow in our footsteps.

Just as we were inspired by the long-established Unity Walks in the US, Canada and other parts of the globe that now attract people in their thousands, our vision is that many of our members will launch their own initiatives in the years to come.

Indeed, following our first walk, new Unity Walks were quickly announced in Ireland, Israel, the Czech Republic and Luxembourg – and we're supporting each of the member organisations in those countries by sharing our own experiences and resources.

The potential benefits to organisers and participants – and to our overall aim of improving lives for people with Parkinson's and their families – are numerous (as you'll see from the

comments and case studies in this guide). But above all, I believe our community desperately needs events such as the European Unity Walk to ensure the voice of Parkinson's does not get lost in these increasingly challenging times.

We know that organising a Unity Walk for the first time can seem daunting – particularly if you're part of a smaller organisation without any experience of planning and running major events.

That's why we created this guide – not only to inspire you, but also to show you, in the simplest way possible, all the practical things you need to think about and put in place to ensure your event is a great success.

Good luck with your Unity Walk – and don't forget to send us an invitation!

**Knut-Johan Onarheim**  
**EPDA President**

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# STEP 1 GET INSPIRED

## WHY HOLD A UNITY WALK?

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THERE ARE LOTS OF REASONS TO HOLD an event. Whether you want to raise awareness, funds or let people know about your organisation, a Unity Walk is an excellent way of achieving your aims. Here are some key benefits as expressed by people who have helped organise successful events around the world.

### TOGETHERNESS

One of the most important aspects of a Unity Walk is the feeling for everyone involved, especially people with Parkinson's and their families, that they are not alone in the world. Being part of a group of people brought together with one shared goal is vitally important – in fact it's what the 'Unity Walk' is named for.

**“The sense of community that is created when people come together with a shared purpose is palpable. I watched so many videos of the walk when I started but there is no substitute for what it feels like to be among that many people so committed to something. The hope created that day, the camaraderie, the feeling that you're not alone is phenomenal.”**

**– Helaine Isaacs, event director of the US Unity Walk, New York**



### CONNECTING WITH OTHERS

A Unity Walk gives everyone in our community the chance to spend time together in a relaxed, positive environment – away from the consultation room, the hospital or the office. People with Parkinson's, families, healthcare professionals, decision makers, the treatment industry and members of the general public can all come together in a unique setting to share their perspectives and support each other.

**“The Unity Walk belongs to everyone – everyone can be represented there. It's a neutral setting for all stakeholders to share and take part.”**

**– Lizzie Graham, EPDA director of fundraising and communications**



## **BOOSTING YOUR PROFILE**

Hosting a Unity Walk is a great way to put your organisation to the front of people's minds. A successful event can help you increase membership or boost the number of visitors to your website.

**"With more than 1,000 people from 25 countries around the world – all moving together for Parkinson's – no one could have failed to notice us! And that is exactly what we wanted."**

**– Knut-Johan Onarheim, EPDA president**

## **RAISING FUNDS**

Unity Walks are a great opportunity to raise funds that will help improve the lives of people with Parkinson's and their families. Ask your participants to raise money in advance or charge an entry fee on the day. That money could fund research, support services or the creation of new resources.

**"To start with we're looking to create a sustainable event, raising enough money from sponsors and participants to cover the costs – but our long-term goal is to be able to use the event to raise funds for rehabilitation, social activities and research."**

**– Heino Jespersen, Unity Walk organiser, Denmark**



## IMPROVING AWARENESS

Organising a Unity Walk is a chance to raise awareness of Parkinson's and educate the wider public about the realities of the disease, or even to focus on messages related to a specific campaign or theme (see Step 4 on page 12 for advice on how to develop your message). For instance, in Denmark the organisers theme their events around 'Exercise as Medicine' and include a host of fitness activities from yoga to a mini-football tournament.

"Not being here is not an option – you can call me any weekend for this! I think this should be at least a yearly event, not only in Europe but in other continents as well. And I hope that we're setting things in motion, an unstoppable train, to improve the lives of people with Parkinson's."

– Professor Bas Bloem, Radboud University, the Netherlands

## EMPOWERING PEOPLE

Taking part in a Unity Walk is a unique chance for people affected by Parkinson's to take action. Sometimes people with Parkinson's feel isolated, embarrassed or think that people do not understand their disease. Being involved in an event alongside others with shared perspectives is a great opportunity for those with the disease, and their families, to begin to feel more empowered.

"Sometimes people with Parkinson's can hide away. A Unity Walk is a way for them to take action against the disease. It is a chance to feel stronger through contact with others."

– Heino Jespersen, Unity Walk organiser, Denmark



“

I can now say that I was a part of a global community striving for the same goal – to find a cure

”

– Marissa Walton, European Unity Walk participant, Amsterdam

## HAVING FUN!

A Unity Walk is an event for everybody to take part in. It's not a marathon or a competition. Instead, it is a chance for everyone involved in Parkinson's to do something meaningful and – most importantly – to have fun together.



# STEP 2 DEFINE YOUR OBJECTIVES

## WHERE WILL YOUR WALK LEAD?

BEFORE YOU EVEN START YOUR planning and promotional activity, it's vital to know exactly what outcomes your event is setting out to achieve – whether that involves raising money for your organisation, gaining media coverage, or securing the participation of specific groups in your walk (for instance, healthcare professionals or representatives from the treatment industry).

It is vital that you and your team have clear goals so you can guide decision making for every aspect of your event – from budgeting to messaging – and ensure that participants and sponsors have a very clear and inspirational vision of the 'success' that they are being asked to contribute to.

### KEY QUESTIONS

Here are some key questions (and possible answers) to help you define clear aims and relevant audiences.

#### **As an organisation, what do you hope to gain from the event?**

- Increase membership?
- Raise funds?
- Promote a specific campaign or message?
- Promote specific support services?
- Raise public awareness?
- Gain media coverage?
- Develop relationships with new groups (e.g. healthcare professionals, treatment industry, health campaign groups)?
- Further your organisation's existing aims?

#### **Who do you want to attend?**

- People with Parkinson's?
- Families?
- Carers?
- The general public?
- Healthcare professionals?
- The treatment industry?
- Sponsors?
- The media?
- Decision makers?
- Celebrities?

#### **How do you want your walkers to benefit from their experience?**

- Have fun?
- Develop new friendships/relationships?
- Expand their support networks?
- Learn more about Parkinson's?
- Increase self-confidence/empowerment?
- Learn more about treatment options?
- Feel energised and have a greater sense of solidarity and recognition?





## MEASURING SUCCESS

You also need to think about how you will measure the success of your event – in other words, once it's over, how will you know if you have achieved your aims?

The simple table below shows the key objectives set by some of the existing Parkinson's Unity Walks, and their relevant success measures.

### HOW THEY DID IT

Event	Key Objective	Success measure
 Parkinson's Unity Walk (US)	Fundraising	Amount of money raised
 European Unity Walk	Raising awareness	Media coverage
 Danish Unity Walk	Raising organisation's profile	Website/Facebook activity and telephone/email enquiries

### TIPS

1. Be clear about your main objective(s)...
2. ... and how you will measure success
3. Keep it simple!
4. Know your audience
5. Draw up a simple planning document showing objectives and projected budgets, to share with sponsors and supporters

# STEP 3 SETTING A BUDGET

## KEEP AN EYE ON YOUR FINANCES

SETTING A BUDGET AND STICKING TO IT can be one of the biggest challenges when organising an event. Whatever your goals in organising a Unity Walk, the advice below will help you plan and manage your finances – something that will have a big influence on your overall success.

### FUNDING YOUR WALK

One of the biggest questions for any Unity Walk organiser is how to fund the event itself. Securing a sponsor can be one way of doing this, or you may choose to fundraise in advance to cover your costs. Treatment companies may be willing to finance a particular aspect of your event such as placards and banners. Alternatively, you may wish to ask your participants to raise a certain amount of money themselves, or charge a small entry fee to each walker.

*Need help putting  
together a budget?  
There's a template in Appendix 1  
(page 28) to help you get started.*

### WHERE WILL YOUR MONEY GO?

It is important to have a clear idea of your expected costs when you start organising an event. In the table below, we list some of the most common costs that arise when organising a Unity Walk.

#### Common expenses

Professional event organiser/exhibition company

Rental (tables/chairs/tents/toilets/stages)

Event materials (placards/t-shirts/banners/souvenirs)

Catering (before/during/after)

Insurance

Permits

Transport

Post-event clean-up

You will also need to think carefully about costs that are 'hidden' or specific to the event you are organising. Do you need to help participants get to the start of the walk? Will you be paying for a speaker or to film/photograph the event?

#### Other costs to consider

Recording (video/photo)

PR company

Entertainment and activities

Speaker expenses (e.g. travel reimbursement)

## MAKE THE MOST OF YOUR RESOURCES

One of the best ways of keeping costs low is by using all the expertise you already have available to you. There may be someone you know who has expertise in a particular area. A member of your organisation who has worked as a journalist might be able to help you with public relations. Or perhaps somebody who has organised events before could lend you their expertise.

**“We have a volunteer within the organisation who is an experienced journalist – they have used their contacts to help us gain exposure on TV and in the national press.”**

**– Heino Jespersen, Unity Walk organiser, Denmark**

## ASK FOR HELP

Depending on the size of your organisation you may not be able to afford to hire a public relations or communications agency to help you publicise your event. If this is the case, consider contacting agencies to see if they will work on a ‘pro bono’ basis (you might also seek support from the treatment industry). You can even make these companies ‘official partners’ of your event – these types of partnerships are good for the company’s public image and great for you, the organiser.

## STAY ON TRACK

Make sure you review your budget often. Keeping tightly to your budget is important but can only be achieved when you keep on top of any unexpected changes in your income and outgoings. By doing this you will be able to adapt your approach before going too far over or under budget – you may need to identify new streams of

income or you could discover you have some extra money to spend!

**“Think through all of your expenses. We are lucky to be flexible enough that if we spend more than planned in one area we can usually balance it out in another.”**

**– Helaine Isaacs, Event Director of US Unity Walk, New York**

## TOP TIPS FOR FINANCE

### 1. Ask for a discount

Many suppliers are happy to help a charitable cause by giving a discount on their products. When you are finding out costs for your event, make sure to ask if the company gives a discount for voluntary organisations.

### 2. Build long-term relationships

When you're raising funds, be sure to look for long-term sponsorship and donations. This means you'll have less to do when you're planning your next Unity Walk.

### 3. Approach other community institutions that local to you

Think about other organisations that might be able to help you. Local schools may be able to volunteer pupils to help with the event on the day. Churches and other community groups might also be happy to lend a hand.

### 4. Put the ‘fun’ in fundraising

If fundraising is a main focus for your event then try to think of ways to make the process fun. You could charge a small fee to take part in games and activities on the day or give a prize for the individual (or team) that raises the most money.

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# STEP 4

## DEVELOP YOUR MESSAGE

### GETTING THE WORD OUT

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ONCE YOU HAVE DEFINED YOUR objectives (Step 2), it's time to start thinking about how you will communicate them to potential attendees, partners and sponsors in order to secure their participation and support. Below is a simple, five-point plan for developing your message in a way that will ensure consistent, effective communications.

#### 1. DEFINE THE KEY MESSAGE

A strong and consistent approach to messaging goes beyond visual design – you also need to think about the key words and phrases that will appear across all your materials, particularly the event name and tagline. Don't choose something just because you feel it sounds good – try to ensure that your tagline reflects your event objectives, at the same time as being memorable, easy to understand, inclusive and emotive.

**Example:** The EPDA's messaging requirements for the 2012 European Unity Walk included: 'raising awareness of Parkinson's as a priority health challenge' and 'remove the stigma and discrimination of people with Parkinson's'. They therefore developed a tagline that reflected both these goals while also linking to the core sentiment ('unity') and the main activity (walking) of the day: "Moving together for people with Parkinson's".



#### 2. DEVELOP YOUR EVENT 'BRAND'

Before you begin promoting your event, you need to develop a visual identity that will ensure that all your event branding and communication materials remain consistent – from a website and email newsletters to leaflets and marching banners.

**Example:** The EPDA's 2012 European Unity Walk created a strong visual theme based around colourful representatives of different stakeholder groups holding hands with a cityscape (Amsterdam) in the background. This formed the basis for their website design and all promotional materials, including the main stage banners on the day of the event.



### 3. DEVISE A MARKETING STRATEGY

There are many tools at your disposal when it comes to marketing your event, but it's important to choose the ones that will give you the best chance of success, and which make the best use of your team's resources/budget. For instance, once you have decided on your key audience, work out which 'channel' they are most likely to respond to: your members might be best served with email invites to get them to attend the event (or sign up as volunteers); people outside of the organisation may follow you on social media (Facebook, Twitter etc); sponsors may be best approached with a branded sponsorship letter (see EPDA Unity Walk example in Appendix II on page 28). Also, think ahead to the promotion of future events – if you can capture videos, photos and quotes from participants on the day, these can be placed on your website or used in marketing materials to encourage more people to sign up next time!

#### TIP:

*Marketing isn't just about getting people to the event – on the day, you should aim to draw as much attention to your organisation's activities as possible, so make sure that large event banners, and stage backdrops carry your event branding and essential information such as website address, telephone number and social media details.*

## 4. SET A TIMELINE

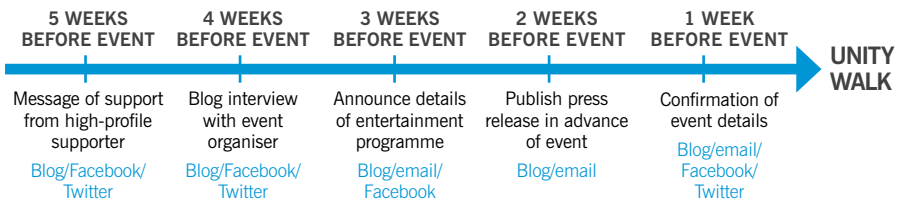
Much of your marketing activity (particularly on social media) will be ‘ad hoc’ – for instance, posting latest attendance or funding updates, or responding to queries and requests for information. However, you can make the most of promotional opportunities by planning which messages and stories you are going to publish in the weeks and months leading up to the event. You could even ‘piggyback’ on to other key Parkinson’s events – World Parkinson’s Disease Day, for instance. Below is an example – based on the blog publishing schedule for the EPDA’s European Unity Walk – of how your pre-event timeline could look.

## 5. GET THE MEDIA ONBOARD

Going beyond your organisation’s regular communication channels (website, social media, email), there can also be benefits of using traditional PR (public relations) to ensure coverage in mainstream media, such as local or national newspapers, radio and/or television. Before deciding whether or not to engage a PR agency or consultant, it is worth assessing what ‘in house’ resources you have in order to get your story into the press.

In Denmark the organisers of the Unity Walk identified a member of their association who is an experienced journalist – she was given the role of planning PR activities, and was successful in gaining coverage on TV news and large-circulation magazines. The EPDA on the other hand, used a local PR agent to plan and carry out most of the publicity – this required funding from the event budget, but generated free coverage with a media value equivalent to €270,000.

### Example social media schedule (based on the EPDA’s 2012 European Unity Walk)





There are more tips on fundraising, working with the media and working with social media in the EPDA's other toolkits. Download them at [www.epda.eu.com/toolkits](http://www.epda.eu.com/toolkits)



## Promoting your Unity Walk through social media

If your organisation has strong social media networks this can be an efficient, cost-effective way of communicating with your audience and promoting your Unity Walk. The EPDA, for instance, used its Facebook and Twitter platforms to create an exciting 'buzz' about the event. Anticipation steadily grew as news poured in about the on-the-day activities, with European policymakers voicing their support. There was a surge in the number of tweets on the day itself as large numbers of people with Parkinson's, healthcare professionals and members of the public joined in the #europeanunitywalk conversation. Remember – before the event – to send direct messages to your followers asking them to re-tweet and share information about your event to their followers.







## STEP 5 PLANNING YOUR EVENT

### ONE STEP AT A TIME

A GOOD EVENT PLAN IS ESSENTIAL TO the development of a successful Unity Walk. It can also make the organisational process less intimidating by breaking it down into manageable sections. Try to keep organised and start putting together an event plan or checklist as early as possible. You should always keep in mind how to make your event accessible to people with Parkinson's.

To get started on your own event plan, use the template in Appendix V (page 30).

### PLANNING A ROUTE

It is important to think carefully about where you want your Unity Walk to go – try to pick locations that are high profile so you can generate the most public awareness, perhaps a government building or through the centre of a city. The start and end points are important considerations, while the walking surface is also a key issue when planning your route.

### GRAB PEOPLE'S ATTENTION

To get the most attention for your event you should plan to walk at a time when the most people are out and about. The day of the event is just as important so consider whether to do it on a weekend or during the week. When are the most people going to be along your chosen route?



### **You don't have to do it alone!**

The number of things you need to organise for a Unity Walk can be daunting, especially if you are new to event planning. However, the good news is you don't have to attempt it all alone. There are specialist event organisers that can help you with everything from planning your event to keeping organised on the day. You will have to weigh up the benefits of this approach based on the size of your own event but for a medium to large sized walk, hiring an events agency is highly recommended – as long as you are confident of raising the funds needed to cover their fees.

### **WORK AS A TEAM**

Delegate responsibilities to different team members. One person can take responsibility for co-ordinating volunteers while another can make sure the entertainment is there on time. Sharing out tasks such as this means that each individual can focus on the job in hand and avoids one person having to carry the entire load.

“

As soon as one event is over you should be thinking about the next, especially if you are planning to make your Unity Walk an annual occurrence. It can take a full year to plan a successful event.

”

– Lizzie Graham, EPDA director of fundraising and communications

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## THINGS TO REMEMBER

If you've chosen to hire a professional event planner, then keeping on top of all the different areas to organise should be their responsibility. But that doesn't mean you should leave everything to them – you should have the final say on all the key decisions. You should also ensure you review their actions throughout the entire process to ensure they are on track in terms of your objectives, budget and schedule. Here's a list of some of the most common things to consider in the run up to your event.

### • Permissions and authorities

Make sure you have the right permits and have informed the local police authorities about your planned events. They may even be able to offer advice based on previous events.

### • Signage and directions

For your walk to be a success people have to be able to find it! Make sure people can make their way to the start point easily by putting up signs around the location you have chosen. Don't forget to put up signs at local train and bus stations so that people coming from further away know where to go.

### • Stalls and tents

Does your event require market stalls or tents? Think about whether your team can set these up themselves. If not, you may need to hire an events company to help you with the logistics.

### • Transport

Is your walk accessible? Think about the needs of a person with Parkinson's – will it be easy for them to get to the start point or do you need to provide transport? Buses, golf buggies and bicycle taxis have all been used at previous Unity Walks.

### • Insurance

You will need to be insured in case there are any accidents during the day. Be sure to look into this as early as possible. You may also need to write a risk assessment – a detailed list of any potential dangers on the route and how you will reduce the risks as much as possible.

### • Catering

Whether you're aiming for 100 walkers or 1,000, your participants will need something to eat and drink at some stage in the day. Think about the most cost-effective and efficient way of keeping everyone refreshed.

### • Contingency plans

Do you know what you will do if the weather is poor? Hiring an indoor space near to the start or end points of your walk means there will be somewhere for participants to congregate before or after the main event. Make sure the contingency plan is properly communicated to your team before the event.

### • Branding

Think about the best way to show your strong visual identity and messaging (see Step 4 on page 12). Here are some event materials you might decide to use on the day to ensure onlookers know exactly what your event is about – and to create a strong impression in press and TV images.

- o Placards
- o Banners
- o Caps/t-shirts
- o Tote bags
- o Signage
- o Flyers and posters
- o Balloons

### • Entertainment and activities

You can give your Unity Walk more of a carnival atmosphere by putting on entertainment, perhaps a band or a dance class. Remember that one of the benefits of a Unity Walk is raising the profile of your organisation and Parkinson's itself – so be sure to make as much noise as possible!

### • Cleaning up

Don't forget about cleaning up after your event. If you're walking in a park or public place you will have to make sure you leave the area tidy after the event.

## TOP TIPS FOR A TOP EVENT

1. Do a 'dry run' of your walking route to make sure it is as safe and effective as it can be.
2. A route for a Parkinson's Unity Walk should be no more than 2 miles/3km. Typically they are nearer to 1.4 miles/2.2km.
3. It can take a full year to plan a successful event.



## STEP 6 ON THE DAY

BE PREPARED FOR SUCCESS!

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BY THE TIME THE BIG DAY ARRIVES, ALL the important decisions will have been taken and everyone in your team should know exactly what's happening, when, and where they each need to be.

However, you don't want to leave anything to chance – so make sure you have a 'day plan' with a detailed schedule to help you co-ordinate activities, attendees, volunteers and VIPs. This will help you clarify the roles of everyone delivering the event, what equipment needs to be set up, and where people need to be, at specific times. (Use the template in Appendix III on page 29 to get started.)

### BRIEFING VOLUNTEERS

The day plan can also be used to brief your team of volunteers at the very start of the day, to ensure that everyone knows their roles and can take responsibility for various aspects of the event, even when you are not immediately available.

Ensure that all volunteers know about key activities, venues and facilities (refreshments, toilet stops) – and what to do (or who to contact) in the event of an emergency. The briefing is also a good time to remind everyone which members of the team are trained in first aid.

Make sure you give the mobile phone numbers of key people – yourself, the event planner and police contact – to everyone involved in organising and supporting on the day.



## WHAT TO INCLUDE ON YOUR DAY PLAN:

- Timings for every activity on the day, from event set-up to post-event entertainments/activities
- Roles/responsibilities (named individuals) for each activity
- Names and mobile phone numbers for all volunteers, staff and police/emergency contacts.

## FIVE ESSENTIAL TIPS FOR A SUCCESSFUL – AND ENJOYABLE – UNITY WALK

### 1. Use marshals to control the pace and keep everyone together

Remember that with people of varying physical condition on your walk, it could be easy for faster walkers to get ahead and leave many walkers – especially people with Parkinson's – trying to keep up. Naturally this would go against the principle of walking in unity, so make sure you ask marshals at the front (and back) of the procession to control the pace.

### 2. Consider additional support for people with Parkinson's

For instance, bicycle taxis or a mini-bus moving slowly at the rear of the walk could be used to pick up anyone who becomes too tired to complete the walk.

### 3. Allocate supervisors to particular areas or activities

For instance, one team could help people find the start point of the walk, while another team could oversee registration. Other helpers could then hand out refreshment vouchers, and a team could be waiting to help out at the end point.

### 4. Decide what role you want to play on the day itself

As the organiser, are you going to be 'hands on', managing the team and making yourself available as the main point of contact for everyone involved? Or do you want to be more of a host/ambassador figure, mingling with the crowds, meeting participants, welcoming guests, possibly giving 'welcome' speeches and generally setting the tone for the day?

### 5. Make sure your mobile phone is fully charged!

# STEP 7 EVALUATING YOUR EVENT

## SO, HOW DID WE DO?

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REMEMBER BACK AT THE START OF THIS guide when we talked about setting objectives – whether this was in terms of participant numbers, fundraising or press coverage – and deciding on how you would measure success?

Once the event is over, it's time to start looking at the numbers – or whichever criteria you set as your measures of success – and answer the question, 'how did we do?'

If you set a target, for example, for how many people you wanted to join in on the day, then the final number of registrations gives you a clear indication of whether the event was a success from this point of view and if your expectations were met or surpassed.

But it's not just about hitting the headline targets – it is also about capturing useful lessons that you can put to use as you start planning your next Unity Walk.

Here are some simple questions that you and your team should seek to answer and discuss immediately after the event as part of your review process:

What went well? **Why?**

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What didn't go so well? **Why?**

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What can you do to improve the event next time?

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Did you do everything on time, according to your pre-event timeline? **If not, why not?**

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Did you manage to stick to your budget? **If not, why not?**

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## POST-EVENT SURVEY

It's also important to find out how participants rated their experience – and in particular if your key messages were effective with them.

A post-event questionnaire given to participants on the day or emailed to everyone soon after the event (while the experience is still fresh in their memory) can be a great way to get their feedback. You will then hopefully receive some positive testimonials that can be used to promote – and seek sponsorship for – future events.

Refer to the post-event questionnaire template in Appendix IV (page 29) – this can easily be modified to suit your specific event.



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## CASE STUDIES: UNITY WALKS AROUND THE WORLD

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# 1. THE ESTABLISHED EVENT PARKINSON'S UNITY WALK, THE USA

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THE ANNUAL NEW YORK EVENT IS THE OLDEST Parkinson's Unity Walk and was started in 1994. The primary focus of the event is to raise funds for Parkinson's research; these funds are shared equally between the seven major US Parkinson's organisations. The event has seen a phenomenal development since its beginnings and, in 2012, more than 10,000 people took part raising a total in excess of \$1.8 million.

The event was founded by one woman, Margot Zobel, and was organised for the first few years from an apartment in Manhattan. From these humble beginnings, the US walk has grown steadily every year to the incredible size it is now. Event director Helaine Isaacs credits the recent

appointment of a PR agency with boosting the profile of the event even further and putting it clearly into the public domain.

Now that the event is well established, Isaacs and her team are able to draw on a wealth of experience every year. One of her tips for fledgling organisers is to keep speeches short at the beginning of the event to make sure the tone of the day is kept upbeat and focused on the walk.

"The most memorable moments are my conversations with the participants," she says. "They are so resilient, whether they are young or old. The people who take part are the ones who are fighting back. I have tremendous respect for them. The Unity Walk is a way for people with Parkinson's to feel like they are doing something."

“  
The walk is a  
way for people  
with Parkinson's  
to feel like they are  
doing something  
”

Website: [www.unitywalk.org](http://www.unitywalk.org)

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“

It was great to see so many people there – and we are aiming to double our numbers next time

”

## 2. THE GROWING EVENT PARKINSON'S UNITY WALK, DENMARK

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INSPIRED BY THEIR EXPERIENCE OF THE US Unity Walk in April 2011, Heino Jespersen and colleagues from Danish Parkinson's Association Parkinsonforeningen returned to Copenhagen and immediately started planning their own version of the event.

“We were very moved by seeing 10,000 people coming together in such a positive way in New York, sharing experiences and having fun,” recalls Jespersen.

“We know how hard it is sometimes for people with Parkinson's to participate in social events – the nature of the disease means that sometimes they prefer to hide away at home. We decided we could do something for people in Denmark – there

had never been an event like this, but we were determined to create one.”

And so, in May 2011, planning began for what would result in the first Unity Walk in Denmark – a 4km route from Copenhagen's City Hall to Fælledparken (the central park). In addition to the main walk, a variety of physical activities and entertainments took place – including line dancing, football and fitness exercises, all of which promoted the association's key message of ‘Exercise as Medicine’.

Jespersen expected up to 200 people to turn up – in fact, more than 500 attended, thanks to activity on the association's own Facebook page and website, as well as coverage on the radio and TV and in the national press. The event was also boosted by the appearance of the association's high-profile patron Alexandra Christina, Countess of Frederiksborg, formerly Princess Alexandra of Denmark. “It was great to see so many people there – and we are aiming to double our numbers next time!” he says.

They've already modified their plans for their next Unity Walk, based on feedback from those who took part in 2012. “Many people said the 4km walk was too long, so we've shortened it to 2km,” he explains.

**Website:** [www.parkinson.dk/aktiviteter/parkinson-unity-walk](http://www.parkinson.dk/aktiviteter/parkinson-unity-walk)

“

Having more than one walk will really enable us to create as much awareness as possible, by using local as well as national media

”

### 3. THE NEW EVENT PARKINSON'S UNITY WALK, IRELAND

---

THE PARKINSON'S ASSOCIATION OF Ireland (PAI) held its first Unity Walk in April 2013. PAI's main priority was to raise awareness of their organisation in Ireland, and to strengthen this aim, the association held more than one walk on the same day in different areas of the country.

This model is similar to the well-established Canadian 'SuperWalk', an annual event in which more than 14,000 people participate in fundraising walks across Canada during a single weekend. The 2012 event raised more than C\$3.2 million for the Parkinson Society Canada (PSC) and its regional partners.

Keith Adams, PAI's CEO, explains: "The challenge with a branch structure is deciding whether to have one big event and getting everyone to travel to one place

or to do multiple walks around the country. We thought this approach – of having more than one – would really enable us to create as much awareness as possible by using not just the national media but also local media – as well as having the physical presence of people walking in more than one town."

When running a new event, it can be difficult managing on a smaller budget. One creative way that the Irish organisers worked around limited resources was by approaching local secondary schools and asking their older students to volunteer as helpers at the walk.

Following PAI's event, Adams advised other first-time organisers to start planning their walk as early as possible.

**Website:** [www.parkinsons.ie](http://www.parkinsons.ie)

# GIANT STEPS

Inspiring facts and figures that show the impact of Unity Walks around the world



20,006

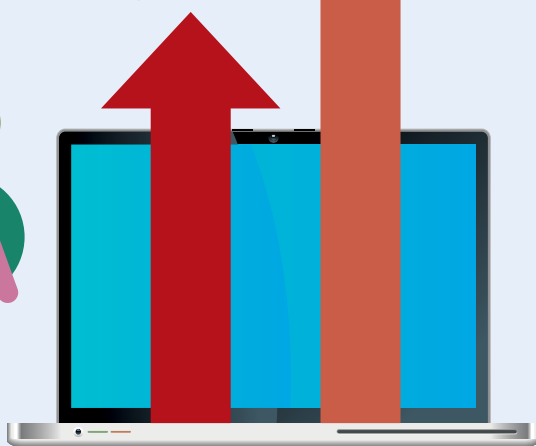
number of page views logged on the EPDA's European Unity Walk website in 2012

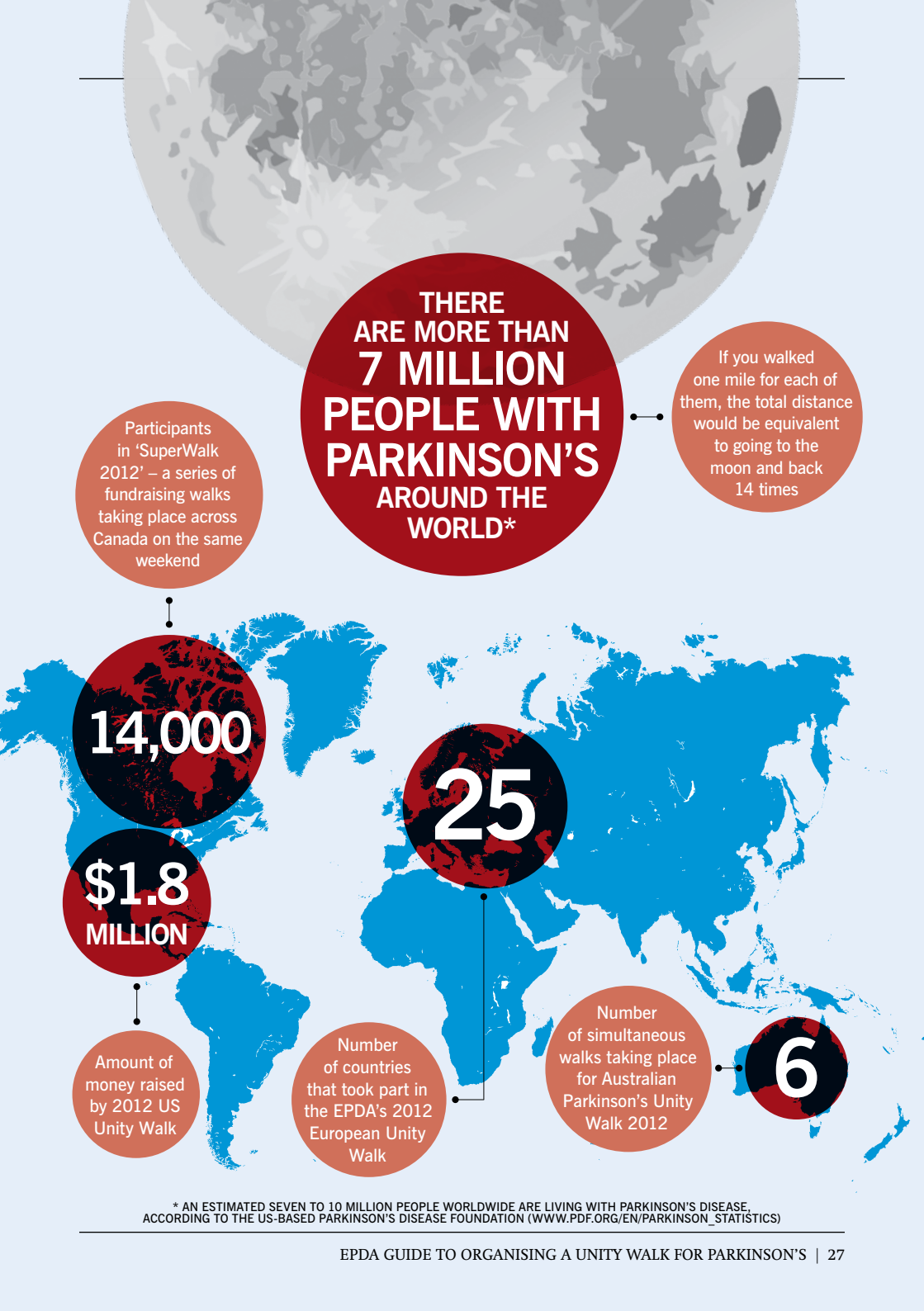
€270,000

Estimated value of 'free publicity' gained through press and TV coverage of the EPDA's 2012 European Unity Walk in the Netherlands

48%

increase in traffic to the main EPDA website during the month of September 2012





**THERE  
ARE MORE THAN  
7 MILLION  
PEOPLE WITH  
PARKINSON'S  
AROUND THE  
WORLD\***

Participants  
in 'SuperWalk  
2012' – a series of  
fundraising walks  
taking place across  
Canada on the same  
weekend

If you walked  
one mile for each of  
them, the total distance  
would be equivalent  
to going to the  
moon and back  
14 times

**14,000**

**\$1.8  
MILLION**

Amount of  
money raised  
by 2012 US  
Unity Walk

**25**

Number  
of countries  
that took part in  
the EPDA's 2012  
European Unity  
Walk

Number  
of simultaneous  
walks taking place  
for Australian  
Parkinson's Unity  
Walk 2012

**6**

\* AN ESTIMATED SEVEN TO 10 MILLION PEOPLE WORLDWIDE ARE LIVING WITH PARKINSON'S DISEASE,  
ACCORDING TO THE US-BASED PARKINSON'S DISEASE FOUNDATION ([WWW.PDF.ORG/EN/PARKINSON\\_STATISTICS](http://WWW.PDF.ORG/EN/PARKINSON_STATISTICS))

# APPENDICES

## Budget sheet

[Insert your event date here]

[Insert your location]

Income	2013	2014	2015
Walk entry fee			
Booth rental			
Catering (sales)			
Surplus (from previous year)			
Fundraising			
Participation in activities			
<b>TOTAL INCOME</b>			

Expenditure	2013
Event planner	
Marketing	
Rental (tents/chairs/tables)	
Catering (costs)	
Entertainment	
Clean-up	
Promotional items	
Video/photography	
<b>TOTAL EXPENDITURE</b>	

Balance	2013
<b>SURPLUS/COST</b>	

- Appendix I (left)  
Budget sheet

- Appendix II (below)  
Sponsorship letter

*Fully usable versions of all the templates included in this section can be downloaded from [www.epda.eu.com/toolkits](http://www.epda.eu.com/toolkits)*



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13 February 2012

Dear Sir/Madam

The first ever European Unity Walk will take place in the city of Amsterdam on the 28<sup>th</sup> September 2012, to raise awareness of Parkinson's disease, it's growing prevalence throughout Europe, and the actions that can be taken to improve lives and reduce the societal impact.

There is an opportunity for your organisation to support this unique initiative, which will reach out to the millions of people affected by Parkinson's throughout Europe.

*[Option to tailor introduction to each company, eg: We have approached [insert name here] because... synergy between our organisations... etc]*

The event is organized by the European Parkinson's Disease Association, an umbrella organization representing 45 European associations, advocating for the rights and needs of more than 1.2 million people with Parkinson's and their families. On the day, those from the healthcare and treatment industry as well as policy makers from both national and European Parliaments will join representatives from this group as they walk the busy 1-mile route from the start point at Thorbeckeklein to the final congregation at Beursplein, Amsterdam.

In addition to attendance on the day, we will be raising awareness via local and national media along with sustained marketing activity commencing in April (see [www.europeanunitywalk.com](http://www.europeanunitywalk.com) for details).

We've many ways for your organisation to get involved with this great cause, from sponsorship of activities on the day, to partnering the event alongside the EPDA and Parkinson Vereniging. Placing your company at the heart of our cause will offer great awareness and PR opportunities, as well as engaging and motivating staff, helping you to achieve your CSR objectives. A list of sponsorship opportunities has been provided overleaf, although please feel free to contact [insert name here] for further details or to discuss alternative ways to get involved.

Parkinson's is a growing disorder, with those affected set to double by 2030 – we hope you will join us in raising awareness of this issue through the European Unity Walk, and look forward to discussing potential ways for our organisations to work together.

Thank you for taking the time to consider our cause.

Yours faithfully

Lizette Graham  
Secretary General



Your Parkinson's Unity Walk

[Insert your event date here]

[Insert your location]

Timeline & responsibility chart

TIME	ACTION	RESPONSIBLE PARTY
3:00am	Event set-up team arrives at event location. Start putting up tents/tables/chairs	Event planner Tent hire company
3:30am	Set-up of start point and end point	Tent hire company
6:00am	Arrival of catering vans	Catering company Overseen by event planner
9:00am	Team and volunteers begin arrive	
9:00am	PA system arrives	
10:00am	Team briefing	
10:15am	Safety briefing	
10:30am	Volunteer briefing	
10:45am	Volunteer teams move to assigned positions	
11:00am	Entertainment arrives	
11:00am	Open registration tent	

- Appendix III (left)  
Day planner
- Appendix IV (below)  
Post-event questionnaire

Fully usable versions of all the templates included in this section can be downloaded from [www.epda.eu.com/toolkits](http://www.epda.eu.com/toolkits)

Post-event questionnaire template

Thanks for attending our Unity Walk event. We'd like your views on the various aspects of the event, so that we can improve things next time.

1. Overall how would you rate the event?  
Excellent  
Good  
Ok  
Bad  
Very bad
2. Please rate the following aspects of the event:

	Excellent	Good	Ok	Bad	Very bad
Timing					
Location					
Route					
Distance					
Food/drink					
Facilities					
Accessibility					
Directions/signs					
Speakers					
Warm-up exercises					
Exhibitor stands					
Pre-event information					
Entertainment/activities					

3. What was your favourite part of the event?
4. What was your least favourite part of the event?
5. How did you hear about the event?



• Appendix V (below) Forward planner

Fully usable versions of all the templates included in this section can be downloaded from [www.epda.eu.com/toolkits](http://www.epda.eu.com/toolkits)

Responsibility	Parkinson's Unity Walk timeline	May/12 months before walk	June	July
	<b>Location/route</b>			
Event planner	Submit application for route			
Event planner	Apply for permits (sound, route)			
Event planner	Insurance coverage for route			
Event planner	Confirm site plans for start and end point			
	<b>Website/communications</b>			
PR team leader	Update website	X	X	X
Event planner	Notify PR team leader of content for update to website	X	X	X
PR team leader	Promote event on social media	X	X	X
PR team leader	Have PD organisations add to their calendar/website			
PR team leader	Update media/press contacts/press release			
PR team leader	Obtain supporter descriptions for website			
PR team leader	Create list of phone numbers for key people			
	<b>Vendors/arrangements</b>			
Entertainment team leader	PA and sound hire company			
Event planner	Clean-up team			
Entertainment team leader	Entertainment			
Event planner	Catering			
Event planner	Photographer/videographer details			
Event planner	Security			
Event planner	Transportation			
Event planner	First aid			
	<b>Promotional products</b>			
Event planner	Order promotional products			
Event planner	Design promotional products			
Event planner	Send out t-shirts to team and volunteers			
	<b>Sponsors</b>			
Event planner	Review/update sponsorship opportunities	X	X	
Event planner	Send letters to existing sponsors			
Event planner	Approach new sponsors			X
	<b>Volunteers</b>			
Volunteer team leader	Recruit volunteers			
Volunteer team leader	Volunteers for day of walk/specific assignments			
Volunteer team leader	Lead volunteers responsibilities/pre-walk meeting			

	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	April/ month before the walk
				X					
								X	X
								X	
									X
	X	X	X	X	X	X	X	X	X
	X	X	X	X	X	X	X	X	X
	X	X	X	X	X	X	X	X	X
						X	X	X	X
						X	X		
					X	X			
									X
					X	X			
					X	X			
					X	X			
					X	X			
					X	X			
				X	X				
					X	X			
				X	X	X			
		X	X			X			
									X
	X	X							
	X	X	X	X	X				
							X		
							X	X	X
								X	



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