Our impact 2013

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

Early 2013

Spring

Summer

Autumn

Winter

Life in my shoes

The world only sees me at my best – when my medication is working well. I do not appear when my symptoms are at full throttle. I am house-bound at these times.

“The full impact of Parkinson’s is seriously underestimated.”

I take medication every three hours, which masks my symptoms for a while. But then the medication wears off and they return. I lose my balance and have difficulty getting up from sitting. My gait becomes a shuffle and sometimes I cannot walk because my toes have curled up.

During this ‘off’ period my muscles contract, my movements become uncoordinated and I lose my dexterity. This means I cannot write, read a newspaper, cook or carry anything. My gut no longer works well and I have painful acid reflux from my stomach. Underlying all these symptoms is pain – a nagging ache from my neck to my feet.

The thought of being out in public when my medication wears off frightens me because I might ‘freeze’ and be totally immobilised. I am dependent on public transport, having fallen asleep at the wheel and crashed the car seven years ago. But catching a train or bus can be a nightmare – balancing in the queue, handling cash and tickets, getting on and off, and moving quickly can all be impossible with Parkinson’s.

My medication only works well if I time it very carefully around meals. If I go out for the day, I have to starve and rely on drinks alone – my life is dominated by my medication.

Like me, a lot of people with Parkinson’s just stay indoors when their symptoms kick in. For this reason, the full impact of Parkinson’s is seriously underestimated. Parkinson’s is perceived as only an older person’s condition, causing an inconvenient tremor.

But we do not have to face Parkinson’s alone. Parkinson's UK helps to raise public awareness of the devastating consequences of this condition and to get rid of the myths. The charity’s information, local support groups, specialist nurses and information and support workers help people like me to take control and manage life with Parkinson’s.
Briony Cooke, diagnosed 14 years ago

How we help

We’re here for people like Briony – and everyone living with Parkinson’s in the UK. Our work can’t stop until Briony can live a life free of pain and the devastating symptoms of Parkinson’s.

In 2013, we made significant steps towards better treatments and, ultimately, a cure. But we also poured our efforts into making a difference right now. We supported thousands of people living with the condition, helping them access better care, expert information, financial help and friendship.

“We know the right support, from the right person, at the right time, is crucial.”

There are many challenges to overcome if we are to improve life for those affected by the condition. But there is one constant: people with Parkinson’s are at the heart of everything we do. Their needs and views shape every aspect of our work.

Time and again, people tell us of the frustrations of dealing with the public’s misconceptions of Parkinson’s, and about a profound lack of understanding about Parkinson's among those who deliver care. We tackled this head on in 2013 – educating and raising awareness of the condition and campaigning for improved care.

We know the right support, from the right person, at the right time, is crucial to helping people with Parkinson’s stay in control of their condition. Our information and support service, and Parkinson’s nurses kept thousands of people independent and emotionally supported over the year.

We work hard to make sure that the needs of people with Parkinson’s get the recognition they deserve, and we motivate our staff, volunteers and supporters to make life better for those with the condition. In a survey conducted across the charity sector workforce, our consistently higher results were a testament to the commitment and passion of our staff. And in 2013, we won substantial investment from major funders, who can see the difference our work makes.

We’re determined people with Parkinson’s will have the understanding and support they need to manage everyday life until a cure is found. At certain points in the year, aspects of our work come into particular focus – so please read on to see how our work made a difference throughout 2013.
Steve Ford, Chief Executive

We work together with people with Parkinson’s to meet their needs

People with Parkinson’s are at the heart of everything we do. This is not just enshrined in our values – it’s something we put it into practice every single day.

In January 2013, we were delighted to welcome three new staff members to our User Involvement team – Anna, Bob and Richard, who all have Parkinson’s. Over the year, the team helped to develop guidance and good practice to better involve people with Parkinson’s in everything we do. They helped draw together networks of people affected by Parkinson’s with different skills and perspectives to provide essential insights for planning, shaping and influencing all our work.

In 2013 people living with Parkinson’s:

- helped determine what research we fund
- shaped our marketing and advertising campaigns to dispel myths about Parkinson’s
- sat on interview panels to ensure new staff understand Parkinson’s and the charity’s values
- helped persuade major corporate organisations to support us as their Charity of the Year

One small example of the impact of involving people with Parkinson’s is that we worked with parents, grandparents, kids and teens to co-create new resources for children and young people. Since these books launched, people have told us how they’ve really helped their family to talk about the reality of living with Parkinson’s.

> “People affected by the condition feel passionately about Parkinson’s UK and want their point of view to be taken into account. Our team helps them to get their voices heard. We encourage people to comment, compliment and complain and we make sure that they know the outcome of their feedback.”
>
> Richard Tyner, User Involvement Adviser

comments from our supporters helped shape our work in 2013.

Crucially in 2013, the views of people affected by Parkinson’s were the starting point for designing a new strategy for Parkinson's, to deliver a better future for everyone living with the condition.

Many hundreds of people shared their priorities to shape our work in the years ahead. We’re excited to take this forward in 2014, working in partnership to make sure we identify the most important goals and ambitions.

It cost **£5,800** to launch our four new children’s books. They're a simple and reassuring way of explaining Parkinson’s to the young people in your life.

We make sure people get the right help at the right time

Being diagnosed with Parkinson's turns people's worlds upside down. And as the condition worsens, people have questions and worries about how to manage everyday life. That's why our information and support service is so vital. We provide expert information, help with accessing benefits and services, and emotional support to enable people to take control of their lives.

In the spring, the Government made major changes to the benefits system, creating complex rules for welfare benefits. People with Parkinson's may not be able to work or they have higher living costs because of their disability. They turn to us for help accessing the welfare benefits they need to afford basic everyday costs and stay independent.

There was a 10% rise in calls to our helpline about benefits compared to the previous year. Across the whole of 2013, our helpline nurses and advisers supported nearly 14,000 people, and 96% surveyed said the service was good or excellent.

People living with Parkinson's can also count on our local information and support workers, who transform the lives of people in their communities. Paul, who lives in the north east, had to stop working because of his Parkinson's, and was on the verge of becoming homeless because he couldn't afford to pay his rent. But his information and support worker, Sue, liaised with his previous employer to get his occupational pension released early so he was able to afford day-to-day expenses and stay independent.

98% said our information helped them to manage their condition in 2013.

> "When my husband was first diagnosed aged 44 last year, it was a scary time, especially when he had a reaction to the first set of medication he was on. But the caring people on your helpline were great and offered so much advice and support. Thank you for being there."
>
> Debbie, via Facebook

In 2013, our information and support workers answered nearly 30,000 enquiries and gave in-depth support 14,500 times. They helped people affected by Parkinson's claim nearly £10.5million in benefits, which they need to manage everyday life.

As well as one-to-one support, people with Parkinson's need accurate, high-quality information they can use to make informed choices. In 2013, people read more than one million of our information resources and 98% said this helped them to manage their condition.

Complementing our information and support services, our Mali Jenkins fund provides financial assistance towards equipment, adaptations and respite breaks to improve people's quality of life. In 2013, we made £100,000 worth of grants to 139 people with Parkinson's with low incomes, who were in need of help to manage everyday life.

It cost **£318,000** to run our helpline in 2013. Once again we saw an increase in people needing our help, with more than 29,700 queries received by our advisors.

We improve knowledge of Parkinson's, so people are treated with more sensitivity

We've heard many stories about people with Parkinson's being laughed at, hassled, accused of being drunk and even arrested because of misunderstandings about the condition and a lack of empathy towards those living with it.

In 2013, our UK-wide public awareness campaign that aimed to tackle public misconceptions of Parkinson's won four major marketing and advertising awards – the D&AD, Hermes, Cannes Lions and Campaign Big awards.

We built on the messages from this campaign during Parkinson's Awareness Week in April. We asked the public to 'put themselves in the shoes' of someone with Parkinson's to help them gain a better understanding of the impact that Parkinson's has on everyday life.

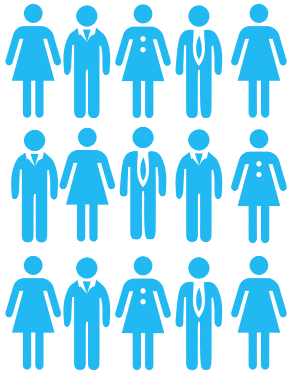
Our local groups, supporters and social media followers widely shared our materials and messages, along with their own experiences, to demonstrate the everyday challenges of living with the condition.

Their help meant we reached a huge audience. On Facebook we engaged with 21,500 people, and support for the campaign on Twitter gave 23 million people worldwide the chance to find out about us. This helped us gain 4,000 new social media followers.

Our high-profile supporters used their networks to raise awareness. Popstar Harry Styles' tweet about his grandad's Parkinson's was retweeted 25,000 times. Comedian Rob Deering, presenter Graham Norton, writer and presenter Michael Palin, presenter Gary Lineker and our President Jane Asher were just a handful of celebrities who added their support.

This year's Parkinson's Awareness Week was the most successful in the charity's history for generating media coverage. More than 1,000 pieces of media coverage were secured for the week, with more than 60 articles appearing in national print and broadcast media.

We're starting to see real change in public awareness of Parkinson's. In 2012, just 28% of the public who were surveyed could list Parkinson's as an issue related to disability, sensory impairment or health, and by the end of 2013 this had increased to 43%. While this is a big improvement, there's still work to do to make sure the public understands Parkinson's and the impact it has on everyday life.



Public understanding of Parkinson's increased by **15%** in 2013.

> "I didn't know anything about the awareness week and I'm ashamed to say I didn't know anything about Parkinson's either. I've put up a status online through Muslim Women Network UK to let others know and to raise awareness in the Muslim and black and minority ethnic communities. I'm probably a prime example of why awareness raising is so vital!"
> Nazim, via Facebook

We spent an extra **£29,000** to help us deliver our most successful Parkinson's Awareness Week media campaign ever. We secured 1,000 pieces of coverage valued at **£3.5million**.

Our campaigning makes sure people get the help they are entitled to

Access to benefits can be crucial for people with Parkinson's, who may be unable to work and have higher everyday costs because of their condition.

People told us they were being unfairly and insensitively treated in assessments to prove their eligibility for benefits, because assessors don't understand Parkinson's. So in 2013, we challenged the Government and assessment bodies to make sure assessments are appropriate and fairly judge how Parkinson's affects someone.

In March, we achieved a crucial change in the assessment for a new disability benefit. This ensures people are now more fairly assessed not just on whether they can complete a task, but also how long it takes and how safely they can do it.

We also drew attention to the scandal of people with Parkinson's having to endure ongoing reassessments to keep their disability benefits, even though they have a condition that can only get worse over time. This causes unnecessary stress, with individuals worrying about having to prove yet again that they are too disabled to work and fearful they may lose their benefits. Stress can make the symptoms of Parkinson's worse, so we were determined it had to stop.

As a result of our campaigns, an independent inquiry recommended an end to the distressingly frequent reassessment of those with severe Parkinson's.

Our commitment to ensuring people with Parkinson's get fair treatment continued throughout the year.

1,800

campaigner actions, big and small, drove the success of our campaigns in 2013.

> "I find it difficult to comprehend that the same system that found I had limited capability for work two years previously, now, despite my condition being substantially worse, found me fit for work. This made me feel stressed and almost like a criminal."
>
> Person with Parkinson's who shared evidence with us for an inquiry

To ensure assessments are based on a proper understanding of the condition, we worked with the Department for Work and Pensions and assessment bodies to educate staff. We'll continue this work so no one living with Parkinson's has to fear an unreasonable assessment of their needs.

Every single campaign we run is driven by people with Parkinson's. We fight to resolve the issues they tell us they have to confront. This means we achieve results that really make a difference.

Our Policy Panel, made up of people affected by Parkinson's, shapes the stance and messaging for campaigns. And people living with Parkinson's are involved in all aspects of campaigns to get the change they want to see – taking part in steering groups, sharing hard-hitting evidence with decision-makers, lobbying politicians and building local support for better services.

In 2013 it cost **£22,500** to influence decision-makers and secure changes that ensure the benefits system is fairer for people living with Parkinson's.

We improve life by educating those who care for people with Parkinson's

Parkinson's is a complex condition. Those living with it need expert support from their health and social care professionals to help them manage symptoms, and access the right care to help them stay in control of their lives. It's crucial that health and social care professionals fully understand the condition and the services that can help, so they can provide the best possible service.

It's especially important that we educate professionals working in care homes or delivering home care, as the sustained care they provide has a really big impact on the quality of life of vulnerable people with Parkinson's.

So we developed a new education model in Scotland to educate this group in an effective and sustainable way. We trained healthcare professionals as facilitators, who then rolled out a six-week training course for their colleagues about good Parkinson's care. Everyone who passed the course received Scottish Qualification Agency accreditation, which was an added professional incentive. In the summer, the first 26 students graduated with a 100% pass rate, and we'll continue to train more facilitators throughout Scotland in 2014 and then across the UK in 2015.

We worked hard to make sustainable improvement in future care by educating healthcare students and professional audiences that we hadn't reached before. Our team educated solicitors, prison service healthcare managers, paramedics and social care managers, improving care standards for every person with Parkinson's.

Our expert staff and volunteer educators provided training to almost 21,000 health and social care professionals and students in 2013. And 98% said they would change their practice as a result of the training to improve the care people with Parkinson's receive.

We also support education for Parkinson's specialists to improve the expert service they offer, through our Parkinson's Academy taught by leading consultants. In 2013, 185 professionals went through the Academy, getting cutting-edge information so they can provide the best possible care. All graduates have a mentor, and stay in contact with their Academy peers, so they can continue to improve their practice.

98%

of professionals said they would improve the care they offer, as a result of our training in 2013.

> "We were working with a man who was really agitated and difficult to work with. Because some of our staff had training with Parkinson's UK, they learned that medication times really do make a difference. We made some changes and he's like a different man. I wanted to be a Parkinson's UK facilitator because I had seen the difference the training made and we want all our staff to access the learning programme."
>
> Laura McNee, home care provider

We spent **£23,000** producing resources so that 18,500 professionals could continue to learn after their face-to-face training had finished.

We make sure people never have to face Parkinson’s alone

We hear that when people are first diagnosed, they’re often not told about Parkinson’s UK or the support and information we offer. We’re committed to changing this so no one has to deal with the shock of diagnosis alone.

A key way people find vital information, at any time of day or night, is through our website. In June, we launched a brand new site, built in collaboration with people affected by Parkinson’s and professionals involved in their care, so that it’s easy for everyone to find exactly what they need.

In 2013, people visited our website 1.57 million times to get information and connect with others affected by Parkinson’s.

We also launched our new web forum – a much-needed space for people affected by the condition to share experiences and support each other. Since its launch, the number of unique visitors to the forum every month has almost doubled.

But not everyone is online, so it’s crucial we have a strong presence in local communities too. In 2013, nearly 14,000 people attended our information events to meet local support staff. We also continued our Turn to Us campaign, systematically placing information in community healthcare settings across the UK.

Over the two years since launching this campaign, we estimate 81% of people with Parkinson’s will have had a chance to see our information. And they are turning to us for the support they need. With the help of local volunteers, we’ll continue working to make sure everyone affected by Parkinson’s has a chance to see our information.

We had 1.57 million visits to the website in 2013.

> “I must mention the great support and information provided by your website. If ever I have a query I can find the solution there and the forum is a great help in realising you are not alone in facing this challenge. If only the NHS were run like Parkinson’s UK.”
>
> Forum user

Some communities need specialist resources and services to meet their needs and we’ve been working to fill this gap. For example, health and social care staff told us they couldn’t find information suitable to explain Parkinson’s to their clients with learning disabilities. So working with the charity Mencap and people with learning disabilities we produced an ‘easy read’ guide to Parkinson’s that is suitable for this audience and those who have lower literacy levels.

There were more than **1.57 million** visits to **parkinsons.org.uk** in 2013. The extra **£117,000** we invested in 2013 to create our new website and forum means every visitor gets information relevant to them.

We involve people in research to improve Parkinson's treatments

We haven't found a cure for Parkinson's yet – but our commitment to world-leading research has moved some promising treatments to the stage where they're safe enough to be tested with people with Parkinson's. This gives real hope to people affected by the condition.

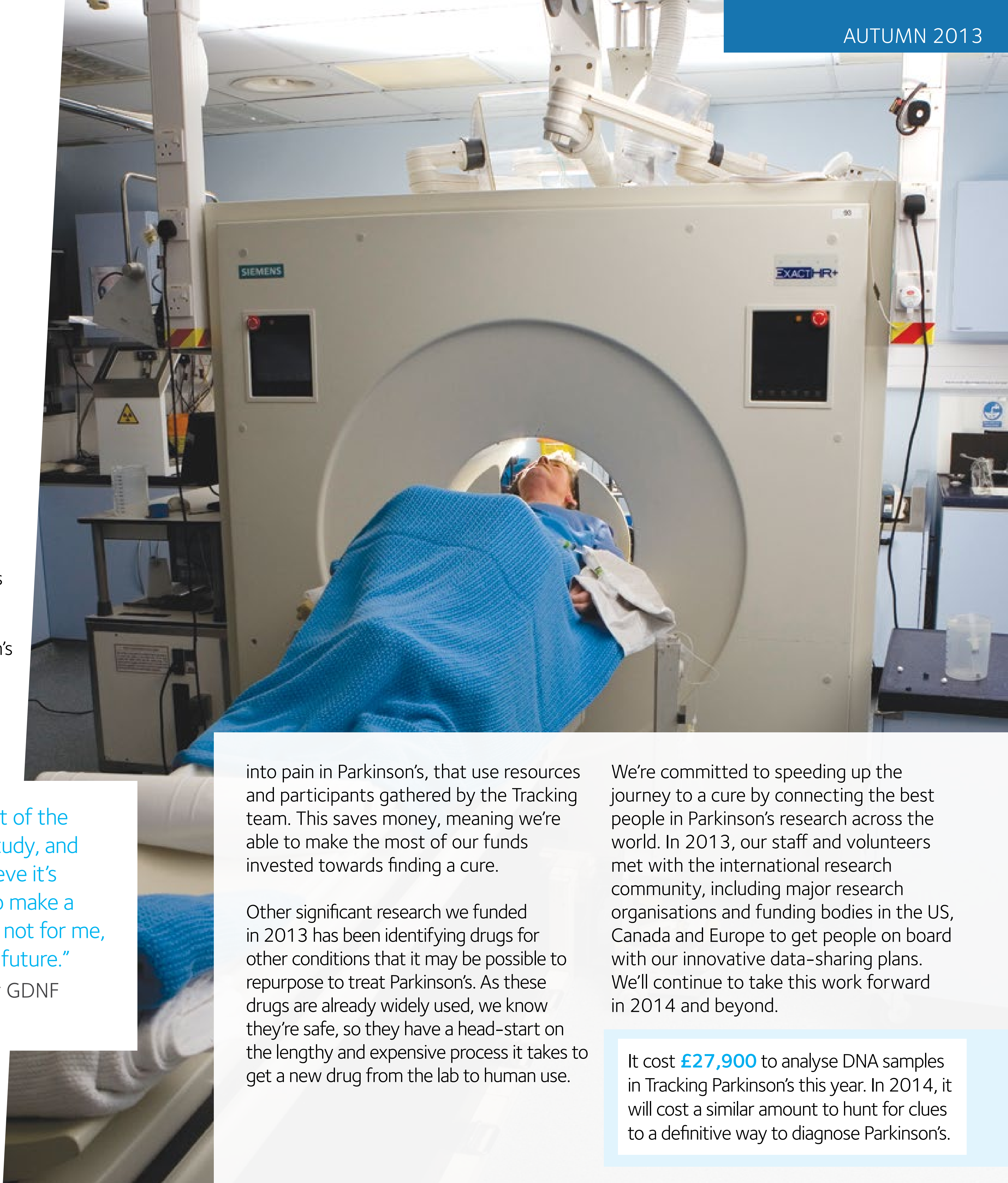
In October, we launched a call for people to take part in a pioneering second-stage clinical trial into a potential new treatment. The trial will find out if a chemical called GDNF delivered into the brain can ease the symptoms of Parkinson's. We needed 36 participants and more than 200 people offered to take part. We're delighted that research we've funded has moved to this stage – and that people with Parkinson's are so involved in the search for a cure.

In fact, in 2013 we shared more than 50 opportunities for people with Parkinson's to take part in research. And we make sure every trial we promote is safe and legitimate, and people fully understand their rights and what to expect.

2013 also saw us funding nearly 100 highly promising research projects. These included Tracking Parkinson's, the world's largest ever in-depth project into people with Parkinson's that is looking for 'biomarkers' – changes in the body that we can use to measure how severe someone's Parkinson's is and speed up the search for a cure. By the end of 2013, more than 2,000 people with Parkinson's were involved in this study. We also funded 'add-on' studies, for example the world's largest study into pain in Parkinson's, that use resources and participants gathered by the Tracking team. This saves money, meaning we're able to make the most of our funds invested towards finding a cure.

Other significant research we funded in 2013 has been identifying drugs for other conditions that it may be possible to repurpose to treat Parkinson's. As these drugs are already widely used, we know they're safe, so they have a head-start on the lengthy and expensive process it takes to get a new drug from the lab to human use.

We're committed to speeding up the journey to a cure by connecting the best people in Parkinson's research across the world. In 2013, our staff and volunteers met with the international research community, including major research organisations and funding bodies in the US, Canada and Europe to get people on board with our innovative data-sharing plans. We'll continue to take this work forward in 2014 and beyond.



opportunities for people with Parkinson's to take part in research were offered in 2013.

"It's been a privilege to be part of the trial. It is quite an intensive study, and a big commitment, but I believe it's worth it and that it's going to make a difference for somebody – if not for me, then I hope for people in the future."

Tom, who is taking part in our GDNF clinical trial

It cost **£27,900** to analyse DNA samples in Tracking Parkinson's this year. In 2014, it will cost a similar amount to hunt for clues to a definitive way to diagnose Parkinson's.

We're working to make sure no one needs to fear going into hospital

One key message we hear repeatedly from people with Parkinson's is that medication is often mismanaged when they are in hospital. This can have devastating effects. When Parkinson's medication is missed or delayed, symptoms quickly get worse. This leaves people with little control over their bodies. Some people never recover and lose their independence as a result.

Solving this issue is complex as every hospital in the UK has its own policies and individual decision-makers who we need to influence to get things changed. But it's a challenge we must overcome – and we'll keep up the pressure to make hospitals safer for people with Parkinson's.

In October, we focused a spotlight on medicine management and hospital care issues by collecting compelling data and case studies that attracted the attention of the BBC's current affairs programme *Newsnight*. The hard-hitting report exposed how the NHS in England systematically fails people with Parkinson's.

It revealed high rates of unplanned hospital admissions for people with Parkinson's, the costs of these, and the problems people have when they don't get their medication on time.

During the year we worked with hospitals to look for solutions to the issue. We educated decision-makers, consultants and ward staff to improve understanding.

Getting medication even five minutes late can mean Parkinson's symptoms start to get out of control.

> "I can't overstate the importance of the health service educating its staff on how crucial it is for people with Parkinson's to get their medication on time. If there had been a better understanding of this when Maureen went into hospital, she would have a much better quality of life."
>
> Graham, who featured on *Newsnight* talking about his wife who was left needing residential care after not getting her medication on time in hospital

We also campaigned for hospital policy change so people with Parkinson's are allowed to take their own medication when they need to, rather than waiting for set drug-round times.

We have audited hospitals to help improve practice. In Northern Ireland, for example, we carried out an audit to identify the systematic factors that were preventing people with Parkinson's from getting their medication on time in hospital. After the audit results were published, we were asked by some hospitals to train staff, including ward staff and pharmacists, around medication management.

We also gained the support of senior healthcare professionals to implement the recommendations from the audit results throughout Northern Ireland, including improving policies and educating staff.

We invested **£130,000** to pilot a new kind of Parkinson's nurse service to see if it would lead to shorter stays and better care when people are admitted to hospital.

We empower people affected by Parkinson’s to support others

No one understands Parkinson’s better than those who live with it. That’s why we think it’s crucial to enable and support people affected by the condition to help their peers with everything from emotional support, to personal insights into the practicalities of everyday life.

In September we launched our first self-management groups. We trained volunteers who were affected by Parkinson’s to run six-week courses for people with Parkinson’s, partners and carers. 56 people joined the groups to learn how to navigate their future with Parkinson’s, and 100% rated the course as good or very good.

Learning from feedback from the launch groups, we’ll adapt and evolve the programme, train more volunteers and roll it out to more locations in 2014.

Complementing this programme, we also have a telephone peer support service where people can speak to trained volunteers who have a similar experience of Parkinson’s. In 2013, they helped 56% more people than the year before and 92% using the service said they’d recommend it to others.

People looking for longer-term support from others affected by Parkinson’s in their community can turn to one of our 370 volunteer-run local support groups. In 2013, they supported thousands of people affected by Parkinson’s – offering local friendship and a range of therapeutic and social activities.

> “My partner has had Parkinson’s for six years and we know how valuable it’s been to meet and learn from other people in a similar situation. I wanted to do something to support others, so I volunteered to become a self-management facilitator. Over the six weeks, people had time to explore their feelings and plan positively for the future in a safe, confidential environment.”
>
> Angela, volunteer

2,900

volunteers help deliver our work to improve life for people with Parkinson’s in 2013.

In Wales, volunteers from a local group in Cardiff, working together with local staff, launched a new Parkinson’s café. The informal, drop-in nature of the monthly meet-up attracts people who haven’t been in touch with local support staff or the group before. This successful model is being rolled out by volunteers in more locations in 2014.

Our volunteers’ expertise helps us achieve the best results for people with Parkinson’s. As well as supporting others with the condition, volunteers have helped us work more effectively, for example by writing volunteering policies and analysing data to help us target our support services to where they can do the most good.

Our 2,900 fantastic volunteers help us meet the needs of everyone affected by Parkinson’s, so we’re committed to making sure they’re well supported. In 2013, we put together an ambitious volunteering strategy and improved the way we register volunteers so they get the information, support and training they need to carry out their roles.

We spent **£59,000** establishing and delivering the first phase of our self-management programme. We’ll roll it out in at least 10 more areas of the UK in 2014.

We're getting closer to 100% Parkinson's nurse coverage in the UK

Parkinson's nurses are a lifeline for people with Parkinson's. They provide medical and emotional support that enables people to stay independent and manage their condition.

NHS guidelines recommend access to a Parkinson's nurse, but the service is not universally available. We believe everyone living with Parkinson's in the UK deserves access. Evidence shows that the service cuts hospital admissions – saving the NHS money – and makes a huge difference to peoples' lives. That's why we're campaigning and fundraising to get Parkinson's nurses in place for everyone in the UK by the end of 2015.

This year, we've funded Parkinson's nurses in 14 regions of the UK, meaning thousands more people with Parkinson's will receive expert care.

In December, after a hard-fought campaign, we secured a Parkinson's nurse for a community in East Lancashire. In this area there were more than 800 people with no access to specialist nurse care.

We supported a dynamic team of local volunteer campaigners to ramp up pressure on local NHS decision-makers in East Lancashire. We engaged the six local MPs, showed the weight of local support through a petition, wrote letters and met with decision-makers to present the evidence and a business case in support of Parkinson's nurses. We also engaged local organisations to increase pressure on the decision makers and our local campaigners attended meetings to speak out about the campaign – leading to increased local media coverage.

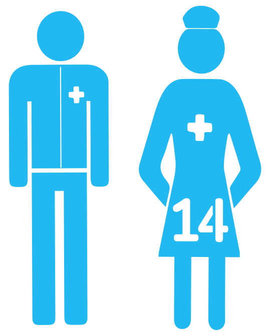
Once Parkinson's nurses are in post, we continue to support them – offering training and helping to secure and protect their posts in the long term.

People with Parkinson's fight hard for Parkinson's nurses because the care they provide is absolutely crucial to their quality of life. We're here to support their campaigns, help with funds to get the post established and provide the evidence and business case the local NHS needs.

Getting Parkinson's nurses in post takes passion, dedication and expertise from staff and volunteers working effectively together, spending considerable time and effort convincing local NHS organisations to commit to better care.

We've made significant progress this year, but there's still more complex and time-consuming work needed to secure 100% nurse coverage by 2015.

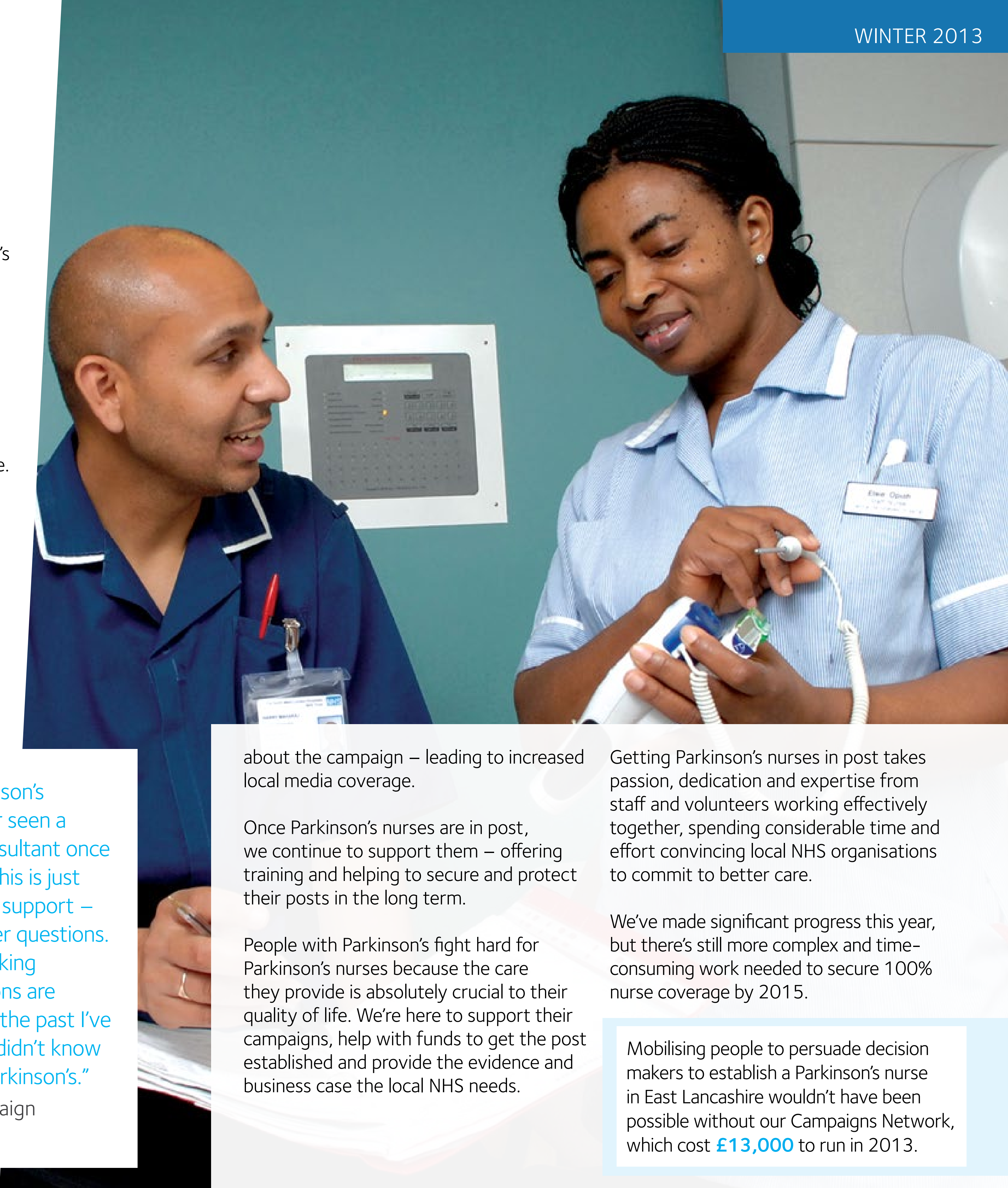
Mobilising people to persuade decision makers to establish a Parkinson's nurse in East Lancashire wouldn't have been possible without our Campaigns Network, which cost **£13,000** to run in 2013.



more areas have a Parkinson's nurse funding in 2013, so thousands more can get specialist care.

> "I have been living with Parkinson's for eight years and I've never seen a Parkinson's nurse. I see a consultant once a year, sometimes less, and this is just a brief visit. I get no ongoing support – I have no one that can answer questions. I found out recently, from talking to other people, that infections are common with Parkinson's. In the past I've had terrible problems – and didn't know it had anything to do with Parkinson's."

Richard, who joined our campaign for a nurse in East Lancashire



We change consultants' practice for the better

Since 2011, we've been raising awareness of impulsive and compulsive behaviour. This is a potential side effect of some Parkinson's medication that causes some people to compulsively carry out activities such as gambling, excessive shopping or binge-eating that could lead them to harm themselves or others.

Research shows that certain people are more at risk of experiencing this side effect. Pre-screening patients and being upfront about the potential side effect can help the person with Parkinson's and the consultant choose the best treatment path together. It also means that behaviour can be monitored and early warning signs spotted and acted upon before any real damage is done.

Back in 2011, our research showed that only 48% of Parkinson's consultants were pre-screening patients and warning them and their families of this potential side effect. Since then we have developed targeted resources and a film for professionals about this side effect and the importance of pre-screening.

The film included influential Parkinson's consultants talking peer to peer about best practice. A survey conducted in December 2013 demonstrated a significant change in consultants' practice because of better awareness – now 68% pre-screen for risk factors and warn patients.

The significant change in consultant behaviour means that many more people will be protected from this potentially devastating side effect, and their treatment can be effectively managed if they are unfortunate enough to experience it.

In 2013, we continued to raise awareness of this issue by launching a film for people with Parkinson's and their families, in which people who had been affected by the behaviour talked about their experiences and the help they got to manage it. The film educates and reassures people who may be affected in the future, and encourages them to talk to their consultant about any concerns they have.

20%

more consultants screen for potential risk factors as a result of being more aware of impulsive and compulsive behaviour.

> "Impulsive and compulsive behaviour destroyed my family and took away my future, but I believe that if we'd had better support, things may have been different."
>
> Elaine, whose husband experienced impulsive and compulsive behaviour

We raise awareness to inspire new support

We've worked hard to raise awareness of Parkinson's and the challenges it creates for those living with it. We are entirely reliant on donations, and raising the profile of the charity has meant more organisations and individuals take notice of us, and want to be part of what we do.

In December we were delighted to announce we'd been chosen as Credit Suisse's Charity of the Year for 2014. The money Credit Suisse raise will be used to fund vital research into whether Parkinson's dementia can be predicted – hopefully leading to better treatments for the condition.

The partnership with a major international bank will also help to further raise our profile.

When people invest in us, we make sure we really make the most of the support. For example The Monument Trust committed to match pound for pound every donation we received towards funding Parkinson's nurses up to £1million – and we raced to meet the challenge, raising our £1million 18 months early. This meant we were able to fund Parkinson's nurse posts as soon as we could negotiate them with NHS decision-makers.

We were also thrilled to be granted platinum status for the world's most popular half-marathon, The Great North Run. This prominent position means at least a further 110 runners can fundraise for us, putting us in great position to match other more high-profile charities pace-for-pace.

> "The partnership with Credit Suisse gives real hope. Not only will it bring necessary funding, but it will also raise public awareness of this terrible condition."
>
> Vivienne, whose husband has Parkinson's dementia. The couple featured in a video showing what life is like with the condition

people jumped 143,000ft raising nearly £142,000 for Parkinson's UK in 2013.

And it's not just large organisations that make a difference. Across the UK thousands of committed runners and walkers pounded streets, fearless adventurers leapt out of planes, individuals collected money and raised awareness in shopping centres, and creative fundraisers held dinners, golf days and parties to raise vital funds.

We are hugely grateful to every single person and organisation – we couldn't do anything without your support.

Plans for 2014

2014 is the last year of our current strategic period and we're committed to achieving the ambitious goals we set together with people affected by Parkinson's.

We'll also continue to listen to what people with Parkinson's tell us would make the biggest difference to their lives to shape and plan for our 2015–19 strategy.

GOAL 1

No one should have to face Parkinson's alone.

We'll reach out to make sure everyone affected by Parkinson's has the opportunity to hear about the information and support we offer. We'll continue to build our digital platforms to engage an even wider audience through our website, forum and social media channels, and promote the charity in community healthcare settings.

GOAL 2

We will listen and respond to the needs of everyone affected by Parkinson's.

We'll continue to increase user involvement in all the charity's work, including working towards becoming a model for best practice for employing people with Parkinson's.

We'll build the involvement of people affected by Parkinson's and supporters in all our research work, including involvement in clinical trials and by helping us identify the top 10 unmet needs in Parkinson's research.

GOAL 3

We will improve life for everyone affected by Parkinson's.

In preparation for our new strategy, we'll launch a UK Parkinson's Excellence Network to bring together the passion and expertise of leading professionals and the voice of people affected by Parkinson's, to drive sustainable improvement in health and social care services.

GOAL 4

Our research will have resulted in better treatment and progress towards a cure.

We'll promote our grants scheme to ensure we're funding cutting-edge projects focused on finding a cure for Parkinson's.

We'll continue collaborating with researchers to work more efficiently towards a cure. This includes starting to unite world Parkinson's research and ensure data, models and findings are being shared effectively.

GOAL 5

We will raise more than £110million to meet the costs of delivering our ambitious plans.

We'll make our fundraising activities even more cost effective. We'll grow existing activities and develop new ones that meet the needs and expectations of supporters.

We'll meet our 2010–2014 target to double the number of people who give a regular gift, and will increase income from individual donors, trusts and other organisations.

GOAL 6

We will be a united, focused and effective organisation.

We'll work with our local groups to pilot innovative ways of working to support people with Parkinson's in local communities.

We'll grow our volunteering programme to ensure we're empowering our volunteers to use their expertise and passion to support others living with Parkinson's.

Alan, Haley and Taylor

Our people

> "Everything you have read in this report has been made possible by the generosity, commitment and passion of our supporters. As a charity funded entirely by voluntary donations, we can only go on making a difference to the lives of people affected by Parkinson's because of the thousands of people and organisations who donate their money and time to our work. I'd like to take this chance to thank every one of you for all you do to ensure no one has to face Parkinson's alone."
> Jane Asher, President

Although it's not possible to thank every single person or organisation who has supported us, we'd like to give particular thanks to:

Our Patron

HRH The Duchess of Gloucester GCVO

Our President

Jane Asher

Our members

The size of our membership gives us a strong position to influence decision-makers. Thank you to everyone who joined Parkinson's UK or renewed their membership in 2013.

Our volunteers and local groups

Our volunteers bring skills, experience, energy, enthusiasm and commitment to Parkinson's UK. Our trustees, 370 local groups, fundraisers and volunteers are integral to our work and they make a real difference to the lives of people affected by Parkinson's. Thank you for everything that you do.

Our staff

Our staff are highly skilled people who are passionate about their work. Their tremendous effort across the year means that Parkinson's UK has made huge progress on all fronts.

Charitable trusts and foundations

We continue to value the generosity of all charitable trusts and foundations that support Parkinson's UK. Our special thanks, however, go to the following for making a special contribution to our work in 2013.

The A M W Charitable Trust
The Childwick Trust
The Constance Travis Charitable Trust
The Doughty Hanson Charitable Foundation
Edith Murphy Foundation
The Emmanuel Kaye Foundation
The Eveson Charitable Trust
Frank Brake Charitable Trust
The George John and Sheilah Livanos Charitable Trust
Gwyneth Forrester Trust
The Harry Bacon Foundation
The Henry Smith Charity
The Hirschel Foundation
J Macdonald Menzies Charitable Trust
The Kip and Alison Bertram Charitable Trust
The Light Fund Company
The Loseby Charitable Settlement
The Oddfellows
The Peacock Charitable Trust
The Monument Trust
The Rowlands Trust
The W & M Morris Charitable Trust
William Brake Charitable Trust

Companies and other organisations

The contribution of our corporate supporters remains crucial to our success as a charity. We would like to thank them for their important support.

Aberdeen Asset Management
Association for Public Service Excellence
Home Retail Group
The National Gardens Scheme
Northwood and Pinner Liberal Synagogue
Tecton Ltd
Tile Giant

Those who remembered Parkinson's UK in their Will

Without the generosity of these people, our work wouldn't be possible. Legacies are vital to our work – enabling us to carry out our support and research.

Individual supporters

Our thanks also go to these individuals who have made a special contribution to our work in 2013.

Mr and Mrs Michael F Buchanan
Mr Tom Campbell
Miss Margaret Chamberlain
Damian D'Oliveira and Jane Palmer, The Basil D'Oliveira Parkinson's Appeal
Mr Mark Dumas
Mr Charles Easterman
Mr Bob Fisher, The Vintage Motor Cycle Club, West Wiltshire Section
Nick Fitzpatrick
Mr Spencer Hudson
Jonny and Caroline Hulbert
Mr Nick Johnston
Louise and David Kaye
Mr Ronald Leighton
Mrs Cilla Massey and Mrs Ann Monk, New Chapter Book Group
Mr Robert Marshall-Lee
The My House 2 Your House Team
Mr Eric Parkinson
George Peele & Friends, Paris to Amsterdam
Mr and Mrs Bernard and Monica de Salis
Mr Derek Williams-Freeman, The SF Wickham Charity
Mrs Fiona Wilson MBE

High profile supporters

Thanks to the supporters below for helping to raise our profile and awareness of Parkinson's in 2013.

Jo Brand
Fern Britton
Mark Butcher
Adina Campbell
Jim Carter
Jarred Christmas
Dave Clark
Jilly Cooper OBE
Alan Davies
Rob Deering
Nick Easter
Mick Ferry
Nazaneen Ghaffar
Helen Glover MBE
Joanna Harris
Gavin Hastings OBE
Fergus Henderson MBE
Jane Hill
Mark Homer
Sophie Hosking MBE
Gabriela and Monica Irimia
Virginia Ironside
Boris Johnson, Mayor of London
Lucy Kite
Kwame Kwei-Armah OBE
Gary Lineker OBE
Sian Lloyd
Roger Lloyd Pack
Max & Ivan
Paul Mayhew Archer
Margo MacDonald MSP
Graham Norton
Michael Palin CBE
Piff the Magic Dragon
Dr Mark Porter
Susanna Reid
Paul Sturrock
Mike Tindall MBE
Paul Tonkinson

OUR VISION

To find a cure, and improve life for everyone affected by Parkinson's.

Goal 1: No one should have to face Parkinson's alone.

Goal 2: We will listen and respond to the needs of everyone affected by Parkinson's.

Goal 3: We will improve life for everyone affected by Parkinson's.

Goal 4: Our research will have resulted in better treatment and progress towards a cure.

Goal 5: We will raise more than £110million to meet the costs of delivering our ambitious plans.

Goal 6: We will be a united, focused and effective organisation.

To find out more about our achievements in 2013 and plans for 2014, email **hello@parkinsons.org.uk** or visit **parkinsons.org.uk/impact**

We're the Parkinson's support and research charity. Help us find a cure and improve life for everyone affected by Parkinson's.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

Parkinson's UK
215 Vauxhall Bridge Road
London SW1V 1EJ

Free* confidential helpline **0808 800 0303**
(Monday to Friday 9am–8pm, Saturday
10am–2pm). Interpreting available.
Text Relay **18001 0808 800 0303**
(for textphone users only)
*calls are free from UK landlines and most mobile networks.

hello@parkinsons.org.uk
parkinsons.org.uk

The Helplines Association Member

FRSB give with confidence