

Strategic Plan 2016-2019

Approved by the Board of Trustees on 14 June 2016

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Our vision

- A greater understanding among health professionals and the public about the functional and psychological aspects of facial palsy.
- For patients to achieve timely access to care to minimise the risks of physical and psychosocial complications of the condition.
- For treatments for facial palsy to be available to all in the UK.
- On-going support for anyone with facial palsy who desires more confidence and greater self-esteem.
- For there to be research into the causes and treatments of facial palsy.

Our mission

... to ensure that every person in the UK affected by facial palsy is given access to the best information, treatment and support available.

Our values

The core values of Facial Palsy UK have been identified after discussion with the trustees, staff and volunteers representing the facial palsy community.

Being person-centred and participative

We are committed to putting the needs of people with facial palsy first, actively seeking their feedback and involving them in our work and decision making.

Openness

We are committed to integrity and honesty, being transparent and only acting in the best interests of our external stakeholders including the general public, UK medical professionals, patients, private donors, charitable trusts and foundations, corporate donors, sponsors and more.

Accountability

We are committed to accounting for our actions and the decisions we make, the way in which we regulate and how we use charitable funds.

Quality

We will provide accessible, high quality services and support to our beneficiaries.

Research for public benefit

Research undertaken will be for public benefit and with the sole aim of improving the lives of people with facial palsy.

Introduction

The charity has been in existence for almost 4 years and this strategy builds on our inaugural strategy and reflects the developing maturity of the charity and the growth in the demand for our help and support. Facial Palsy UK is the only charity in the UK specifically supporting people affected by facial paralysis due to any cause.

Facial palsy, sometimes known as facial paralysis, is a condition resulting from damage or absence or impairment of the facial nerve that supplies the muscles of facial function and expression, and affects blinking, closing the eye for sleep, eating and drinking, speech, smiling and frowning. Facial palsy can be the result of multiple causes: disease, injury, stroke, birth trauma, cancer, or neurological condition – to name but a few.

The need for a charity specifically for facial palsy was recognised following the development of a specialist Facial Palsy Clinic in the south of England. In 2009, a survey was conducted at this clinic and in conjunction with patient feedback it was noted that:

- The average duration between the onset of paralysis and referral to a specialist for treatment was 5.6 years which means that there is a huge unmet need for help.
- Patients were travelling from across the UK (including Northern Ireland and Scotland) in order to be seen.
- The information that patients had been given by some health professionals was incorrect and might impact negatively on their outcome.
- There were limited resources in the community to support patients, their relatives and partners.

Our Strategic Plan for 2016 – 2019 provides a framework for our future activities. Our focus is aimed at raising awareness of facial palsy, providing support to those affected by the condition and improving access to health care treatments and services.

Facial palsy patients have historically struggled to access medical treatment which could greatly improve their quality of life and psychological wellbeing. Provisions for NHS care are currently changing and with no established pattern of treatment for people with facial palsy, we need to ensure access to health care services improves rather than declines further.

Awareness of facial palsy and the challenges it presents is also currently lacking within the Health Service. Delayed or inadequate treatments lead to poor outcomes and on-going disability; therefore we must educate health professionals about facial palsy and its impact on basic facial function and psychological health.

We must address the immediate needs of people with facial palsy by providing support groups across the country.

We also aim to raise funds to support medical research into the various causes of facial palsy and how it might be prevented, and new treatments for facial palsy.

Facial Palsy UK is currently registered as a charity in England and Wales, and also Scotland.

We intend to make best use of our funds and to work in partnerships with those who share our values, to improve the lives of our beneficiaries.

We are grateful to our many volunteers and supporters who have helped us with their commitment, expertise and funding. We are committed to working as a team with our volunteers and supporters to ensure a brighter future for people with facial palsy.

A table of Growth statistics 2016

	30 June 2013	30 June 2014	30 June 2015
Direct support	380	390	478
Unique visitors to website	18,000	72,500	194,000
Social media (Twitter & FB)	597	1033	2009
Newsletter signups	142	418	565
Local Support Groups	2	4	8
Volunteers	13	18	30
Medical Advisory Board members	29	32	37
Total incoming resources	£25,896	£54,632	£93,701
Total resources expended	£41,436	£41,990	£66,427
Net outgoing resources for year	(£15,540)	£12,642	£27,274
Charitable Status	England & Wales	England & Wales	England, Wales & Scotland

Strategic Goals

Our goals were agreed in consultation with our stakeholders. When reviewing what people need from the charity, we engaged trustees, the medical profession and people affected by facial palsy and their families. The ongoing goals of the charity remain relevant to the people and staff involved.

Goal 1: raise awareness

To increase awareness of facial palsy and how it impacts on the lives of those affected, and to challenge those who perceive this to be simply a cosmetic condition.

Many people do not understand what facial palsy is and how it affects those living with the condition. Facial palsy can happen to anyone of any age, at any time. Some people are born with the condition. Facial palsy can occur for many different reasons; sometimes it occurs as a result of surgery which is usually a curative or lifesaving procedure to remove benign or cancerous tumours.

The most common cause of facial paralysis is Bell's palsy, a condition that can resolve with the right treatment, but not in every case. Some people are affected by Bell's palsy multiple times throughout their life. The outcome for a person with Bell's palsy can be dependent on getting the correct treatment within 72 hours. The largest scale recent study¹ of Bell's palsy demonstrated that without the recommended treatment with steroids, only 57% achieved full recovery at 12 months. Even with timely treatment, only 72% of patients achieved full recovery at 12 months. For those who do not fully recover, they are often left with chronic disability.

Objectives

To be innovative and creative and find different ways to raise awareness of what it is like to live with limited or no facial expression.

To demonstrate the real physical and psychological consequences of living with facial palsy, particularly to health professionals responsible for their care.

To empower people with facial palsy and give them a voice.

¹ Engström M, Berg T, Stjernquist-Desatnik A, et al. Prednisolone and valaciclovir in Bell's palsy: a randomised, double-blind, placebo-controlled, multicentre trial. *Lancet Neurol* 2008; 7(11): 993–1000.

2013-16 plans that have been delivered

- We created a Facial Palsy Information Display which has been used at conferences and in hospitals around the UK. This included information about the causes of facial palsy and how to access further support.
- We raised awareness through traditional media channels, e.g. newspapers, TV, etc.
- We produced general literature about the charity which was distributed to doctors' surgeries, relevant hospital clinics and accident and emergency departments.
- We launched the first global Facial Palsy Awareness Week in March 2015, this will run every year now during the first week of March.

In the next three years we plan to:

- Create three children's books explaining what it is like for someone with facial palsy. Feedback forms will be issued with each book to assess the impact on a child's confidence, feelings of isolation and whether they communicate more with family and friends as a result of reading the book.
- Investigate how we can use modern technology to demonstrate the full impact of facial palsy.
- Continue raising awareness through traditional media channels and monitor the impact this has on beneficiaries.
- Update our general leaflet and continue to distribute information to GP surgeries, hospitals and other relevant clinics.
- Encourage the facial palsy community to share their stories on our website which often results in mutual support via comments on social media.
- Explore innovative themes to raise awareness.

Goal 2: provide support

To provide support to people affected by facial palsy, ensuring information and help is given responsibly without bias. Support will be offered via various channels ensuring it is accessible to all.

Facial Palsy UK is the only charity specifically supporting people in the United Kingdom affected by facial palsy for *any* reason. Due to the historic lack of support for people with this condition, many people report feelings of isolation. We surveyed people who have had facial palsy since childhood and astonishingly 83% had long believed that they were the only person in the world with the condition.

Objectives

To provide opportunities for people with facial palsy to meet others who share similar experiences, and to reduce their feelings of isolation.

We also want to reduce the distances patients have to travel to access local support.

To give people more information about facial palsy. People newly diagnosed with Bell's palsy need to understand what has happened to them, what to expect from recovery and how to minimise long term complications, especially those relating to care of the eye and preservation of vision. Pre-operative support to patients at risk of developing facial palsy as a result of surgery is important. Historically consenting procedures for these types of surgeries, whilst referring to facial palsy as a risk of surgery, rarely explain the consequences of living with facial palsy. Other groups of people that are often isolated and without help are parents of newborn infants with facial palsy, parents of young children who acquire facial palsy and pregnant mothers who are at increased risk of developing facial palsy themselves and who are often a hard to reach group.

Fact-finding to establish what treatments are routinely available through the NHS for people with facial palsy and who the providers are, enabling us to better answer the high volume of questions we receive on this topic.

To provide advocacy services to ensure that the facial palsy community can be influential in the development of service provision, education and research.

To register as a charity in Northern Ireland so we can extend support groups across the border.

2013-16 plans that have been delivered

- We set up 6 new local support groups, including our first group in Scotland.
- We employed a part-time coordinator of Facial Palsy Support Networks.
- We implemented a secure online support forum using Health Unlocked, which is linked to the NHS website.
- We grew our database of treatment providers so we can signpost people effectively.
- We acquired charity status in Scotland.
- We liaised with the facial palsy community to ensure their voices continue to be heard. We listened to any feedback and acted on it accordingly (regular surveys were sent out and direct feedback noted).
- We organised two family day events bringing together children with facial palsy and their families.

In the next three years we aim to deliver:

Support via Information

- Add to our database of treatment providers so we can signpost people more effectively and add guidance online as to which hospitals offer which services.
- Create an information pack for people affected by Bell's palsy with details about how to care for the eye, the importance of not trying exercises at home without medical guidance and more. This is aimed at reducing secondary problems of muscle stiffness and tightness as well as synkinesis.
- Update our website to be mobile friendly and more easily viewed by people with vision impairment. Make information easier to find and the website more community focused. We've already surveyed people about how the website should be improved and will continue to seek feedback during the redevelopment phase.
- Produce eight Patient Information Leaflets for distribution by the charity, GPs and hospital clinics and monitor and review their usefulness, how they can be improved, etc.

Support networks

- Seek to improve the way people connect with us via our website or offline, enabling them to join our community and be kept updated via the method they prefer.
- Become registered as a charity in Northern Ireland so we can develop services there.

Support for those who support others

- Provide support group facilitator training online and face to face as required. We will survey group leaders to ensure we are addressing their needs.

Face to Face support

- Provide support workshops or videos for people with facial palsy: back to work; Confidence; parents and children; managing photographs; intimacy issues; non-verbal communication skills; understanding what facial palsy is and the way the face recovers; how to explain facial palsy to co-workers and Bell's palsy in pregnancy. We will liaise with other charities working with people with a facial difference and seek opportunities for partnership. We will collate feedback to understand what is working and what needs improvement.
- Organise a national Facial Palsy conference for patients. Service users have already been surveyed about topics for breakout sessions, where the conference should be located and the duration. We will also collect feedback at the event to ensure we can improve on it for future conferences.
- Explore how we could safely implement a buddy-up or mentor programme.
- Deliver two Family Days per year rotating around the UK, collecting feedback from the families so we can improve future family days.
- Explore how we can use existing counselling techniques to provide a service model benefiting people with facial palsy.

Goal 3: education and training

Increase awareness of the needs of facial palsy patients.

Standardise assessment procedures.

Promote training of more specialists so treatments are more widely available and easier to access.

A survey of people with facial palsy found that 26% had been told there were no specialist treatments available to help them. Unfortunately, many health care professionals mistakenly believe facial palsy is purely a cosmetic issue, rather than a functional one affecting communication (facial expression), eating and drinking, and the closure of the eye. There's also a lack of specialists available to treat people with facial palsy, so we aim to provide training and educational materials to improve the situation.

Objectives

To raise funds for the development of software to produce a standardised assessment of facial palsy patients. Research into treatments of facial palsy is currently hampered by the lack of a simple objective method of assessing, documenting and comparing the severity of facial palsy in patients treated in different centres. Previous attempts have been cumbersome, expensive or not widely adopted by practicing clinicians. New, cheaper technologies such as video-enabled tablet computers offer a platform on which such an assessment tool could be built. However, the niche nature of this subject makes it unlikely that a commercial company would invest in the creation of the required software, without the certainty of widespread adoption. Such a software tool could be the basis of a National Register of Facial Palsy which would help to ensure that outcomes are uniformly good across the UK.

To raise the profile of facial palsy and its consequences through education and training of health care professionals not normally provided by the statutory authorities.

To build a comprehensive Health Professionals' facial palsy resource via our website.

To ensure that treatments for facial palsy are available nationally.

2013-16 plans that have been delivered

- We supported the early development of a portable vision-based computerised tool to allow uniform data entry and outcome assessment in facial palsy clinics. A prototype has been delivered and stage 2 is subject to funding.
- We created a GP's guide to Bell's palsy and an Eye Care guide for health professionals working with facial palsy patients.
- We added educational information, videos and other resources to our website aimed at health professionals.
- We identified some of the geographical gaps in NHS treatment provision for patients with facial palsy and supported patients by writing to NHS Commissioning Groups and GP practices to endeavour to improve services.

In the next three years we plan to:

- Offer a guest speaker option for universities educating trainee speech and language and physiotherapists. A qualified facial therapist will explain the difference between lower and upper motor neurone palsies and highlight the differences to traditional physiotherapy. This is with the aim of preventing incorrect techniques being used and raising awareness of the further training resources available. We will collect feedback about knowledge before and after each presentation and also encourage students to subscribe to our health professional section of our website.
- Aggregate current training materials into a course which can be used for professional development with best practice downloads. We will collect feedback, update and improve as required.
- Establish how we educate health professionals about the importance of preparing a patient who is at risk of facial palsy after surgery and identify the best method to deliver pre and post-operation support. We will trial with specific clinics and gather patient feedback comparing to clinics where different types of support is available.
- Establish a more comprehensive website section devoted to health care professionals with information about past research papers, new research, best practice and more. Enable a subscription option to ensure we can regularly update professionals with new content and research. This will also make it easier to collect feedback.
- Work with specialist facial palsy multidisciplinary clinics to produce a business model that can be replicated across other parts of the country.

Goal 4: research

To instigate research projects for the long-term benefit of people affected by facial palsy.

Very few research projects investigating the causes and treatments of facial palsy are being undertaken. A key reason for setting up Facial Palsy UK was to raise funds for medical research into the various causes of facial palsy and how it might be prevented, the effects and consequences for people living with the condition, and new treatments for facial palsy.

Objectives

Identify areas for medical research which will be beneficial to people with facial palsy.

To raise funds to support or sponsor research and training for professionals involved in the management and treatment of facial palsy within the UK which is not normally provided by the statutory authorities.

2013-16 plans that have been delivered

- We established a research committee through the Facial Palsy UK Medical Advisory Board. This committee will prioritise areas for research and funding applications. Feedback should be sought from representatives of the facial palsy community.

In the next three years we plan to:

- Instigate a pilot study to evaluate the psychological, social and physical impacts of facial palsy in the UK. This could be a collaborative study between centres with track records in the areas of psychosocial research and health economics, or an academic researcher could be used. It is envisioned that the pilot data would be the basis of a larger study to be funded through the Department of Health's National Institute for Health Research (NIHR) scheme (e.g. Research for Patient Benefit, RFPB).
- Employ a suitably qualified research assistant.
- Encourage patients to sign up for the Public Involvement Programme with NIHR to influence research.
- Demonstrate evidence to NICE to improve guidelines for care of patients with facial palsy.
- Patient, Carer and Clinician Priority Setting Exercise – establish a top 10 list of priorities for research. We can assess success by the number of research trials carried out.

Goal 5: funding

We will develop a diverse range of funding streams to ensure our activities are sustainable.

Facial Palsy UK is still a very young charity and is only just starting to establish more regular income streams such as direct debit income. We have been supported by individual fundraisers from the beginning and this continues. We are now trying to ensure our income streams are diverse without relying too heavily on one source of funding. We are becoming more successful when applying for grants as we can now demonstrate a track record of success. Our website was set up at the start of the charity's life and as such is primarily an information resource. Our plans to update the website include giving it more of a community feel which will more accurately reflect the work we do as well as still continuing to be a much needed information resource. This will make it easier for people to find out how they can support the work of the charity. We plan to use more pictures and video content explaining how to get involved, and will promote other ways of supporting the charity such as leaving a gift in your will, workplace giving, etc.

It is important that we grow our staff numbers and skills are transferable so that risk is reduced should one person be unavailable for work. We also need to consider best use of funds, continuing to make direct support available but also investing in meaningful online resources that will be useful to larger numbers of people in the long term and less labour intensive to maintain. We need to take advice about employing a dedicated fundraiser. We have now established 2.5 months of reserves which we intend to build on to a maximum of 6 months core expenditure.

One of the areas that we have reviewed this year is the return on investment of buying charity marathon places. While these events are also important for raising awareness, we have decided to concentrate on the events where we are sure we can sell more places. Now we are more established we are attracting runners who have purchased their own places which is less labour intensive for us and frees up our time to plan support and awareness projects and write grant applications.

We have never used high pressure fundraising techniques and are diligent about our responsibilities regarding data protection and contact preferences of those we communicate with.

Objectives

To work within the guidelines of the Institute of Fundraising (IOF) and the Fundraising Standards Board.

To keep updated about changing legislation in relation to fundraising, data protection, and the proposed merger of IOF and the Public Fundraising Association.

To adhere to a fundraising strategy in line with the Strategic Plan, and to diversify our income mix so as to support the resilience and the sustainability of the charity.

To employ robust accounting methods ensuring funds are used wisely and effectively, with a strong focus on value for money and measuring the real benefits to people with facial palsy.

To develop and manage donor relationships carefully and respectfully.

2013-16 plans that have been delivered

- We increased income from community fundraising year on year.
- We secured grant income to fund time-limited projects.

In the next three years we plan to:

- Employ a dedicated fundraiser.
- Increase income from community fundraising function year on year.
- Increase level of grant income to fund time-limited projects.
- Develop a legacy fundraising strategy.
- Explore alternative funding streams.
- Make it easier for people to donate or fundraise by making our website more user friendly and improving our downloadable fundraising pack.
- Set up a donor database for improved efficiency and management of donors.

How will we measure our success?

The charity will monitor delivery of each of the five goals through the successful implementation of its business plan. It will review delivery of its objectives at each quarterly trustee meeting alongside assessing progress through regular monitoring against the charity's Key Performance Indicators (KPIs). The KPIs cover the areas of financial stability, support to people with facial palsy, governance and policy. It will also actively engage people to provide feedback on the charity's impact on their lives.

The AGM is a key annual event in which we share our successes with the people who access the services we provide and we will ensure that this event provides a transparent articulation of our progress within the year.

Growth strategy

This strategy details the 3-year plan for our charity. In the longer term (spanning 10 years plus) we intend to build a charity that can be replicated in other countries. Consolidating what we have learnt in the UK, our vision is for there to be a global network of support and information across the world for all people affected by facial palsy. Part of this long term plan is for there to be established nationally funded research bringing hope to those newly diagnosed, where previously there has been none.

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