

Minutes of the 2016

Facial Palsy UK Annual General Meeting

Saturday 8 October 2016

The Great Northern Hotel, Station Approach, Peterborough, PE1 1QL

Facial Palsy UK representatives:

Charles Nduka (CN), Chair, Board of Trustees and acting CEO

Vanessa Venables (VV), Trustee

Janet Jutsum (JJ), Trustee

Gareth Price (GP), Trustee

Karen Johnson (KJ), Deputy CEO

Item Number		
1.	<p>Welcome and Apologies for absence</p> <p>The meeting commenced at 12pm. Charles Nduka - Chair and acting CEO - welcomed everyone to the meeting and briefly ran through the agenda.</p> <p>Alison Sweeting and Fiona Hawthorne (Trustees) sent apologies for absence. CN explained that the Trustees were the only voting members of the charity and votes had been previously collected for the following resolutions:</p>	CN
2.	<p>Resolution 1: The Minutes of the last AGM on 17 October 2015 were approved as a true and accurate record.</p>	CN
3.	<p>Resolution 2: To approve the report of the Board of Trustees and accounts for the period ending 30 June 2016. A vote was taken and the motion was carried unanimously.</p>	CN

4.	<p>One third of the Trustee Board per year need to retire by rotation at the AGM, with longest-serving retiring first. Louise Watson has retired and not sought re-election.</p> <p>Resolution 3 – To re-elect Alison Sweeting who is retiring by rotation. A vote was taken and the motion was carried unanimously.</p>	CN
5.	<p>Resolution 4 – To elect Jan Jutsum to the Trustee Board. A vote was taken and the motion was carried unanimously.</p>	
6.	<p>Resolution 5 – To elect Gareth Price to the Trustee Board. A vote was taken and the motion was carried unanimously.</p>	
7.	<p>Resolution 6: To re-appoint Goldwins Limited as Independent Examiners. A vote was taken and the motion was carried unanimously.</p>	
8.	<p>Review of 2015/16 – Deputy CEO</p> <p>KJ shared the aims of the charity and some key facts why the charity was set up.</p> <p>She explained the focus of our work over the past year.</p> <p>She referred to the key successes of the charity as:</p> <ul style="list-style-type: none"> • Directly supported 598 people via telephone, email, social media, our Health Unlocked forum, Family Days and Support Groups. • Launched two new support groups in London and Exeter, and relaunched our Midlands group. • Received pro bono help from a professional survey company in February 2016 and carried out a Facial Palsy Awareness Survey. • Received 290,000 unique visitors to our website, up 49% on last year. We also increased our number of Facebook Likes by 26% and Twitter followers by 23% on the previous year. • Sussex Family Day was our largest event of this type so far with 10 families attending. • Distributed our general literature to every Scottish hospital with a relevant department to facial palsy. <p>KJ gave statistics about the causes people contact us in relation to: Bell's palsy (50.5%), FP from birth (11.9%), Cause not identified (9.1%), RHS (6.7%), Bell's in pregnancy (6.4%), Tumour related</p>	KJ

(5.5%), Trauma related (2.7%), GBS (1.8%), Very rare causes (1.8%), Undiagnosed fp (1.8%), Surgical cause (0.9%), Lyme disease (0.6%), Stroke (0.3%).

Details were given about our Public Awareness Survey where 509 members of the general public were surveyed by a professional research company in February 2016. When shown a picture of someone with Bell's palsy, 70% identified a possible Stroke and 13% a possible Bell's palsy as the cause of facial weakness. In contrast only 0.3% of people who contacted the charity for support in the last 12 months had facial palsy due to Stroke compared to 51% with Bell's palsy.

41% of those surveyed considered difficulty smiling to have the least impact and speech difficulties to have the most impact which is very different to a recent separate survey of people with facial palsy who said difficulty smiling and the effect on self-confidence have the most impact, and speech and eating difficulties have the least impact.

97% of the general public surveyed believed that treatments for facial palsy should be routinely available on the NHS. 60% believe physiotherapy can help people with facial palsy yet there is insufficient research in this area and it is not routinely offered.

KJ shared a picture from the Family Day that took place in June 2016 and said feedback was very positive with one parent saying how it particularly helped them speaking to our adult volunteers who were born with facial palsy. Most of the parents and children exchanged contact details and the older children are beginning to develop their own support network outside of these events.

Details were given about a private Facebook Parents and Carers group for those looking after children with facial palsy. This group now has 55 members and gives parents the opportunity to talk to other parents experiencing similar situations.

It was stated that with Gareth Price agreeing to be a Trustee, we now have a parent of a child with facial palsy on our governing board which is a positive step forward for families.

A brief overview of the #ServeAlex campaign was given. This was run in conjunction with charity Changing Faces and the £1,170 raised was used to develop new guidelines for licensees and door staff on dealing with unusual-looking faces.

Details of the new self-help videos on our website were shared at the meeting.

KJ described how challenging PR and raising awareness can be but confirmed we now have good relationships with two trustworthy journalists. Awareness raising activities were detailed as follows:

- 11 print/online articles
- 2 television interviews
- 6 new personal stories on our website
- Official partners of Northampton Town Football Club 2015/16 season
- 2nd Facial Palsy Awareness Week
- Distribution of charity literature
- Design a Christmas Card Competition

Fundraising Review

It was stated that individual fundraisers raised over £36,000 (44% of which was raised during Awareness Week). Direct debit and standing order income for the year increased by 39%. Supporters raised £466 through the Give as you Live shopping scheme, a 116% increase on the previous year. We received a large gift from the Hans and Marit Rausing Charitable Trust of £25,000 in February. In total we received £27,100 from trusts during the year that is not restricted to a specific project. We received £1,500 from corporates during the year. Excluding the £25,000 gift, our total income from donations and fundraising decreased by 1.9% compared to the previous year, so fundraisers, as with previous years, have made a vital contribution to the financial health of the charity this year. We received Pro bono support from JGR Bureau Service who manage our payroll for us and also Research Now who helped us with our public awareness survey.

Restricted funds included:

- The Worshipful Company of Grocers - £5,000 towards Research Appeal.
- The Nationwide Building Society Citizen Champions scheme - £804 towards our Conkers Family Day, which took place in July 2016.
- The Rayne Foundation - £16,000 to continue with our Support Services Project.

KJ expressed gratitude to all fundraisers for supporting the charity.

KJ mentioned those who took part in marathons raising funds for the charity and thanked them.

KJ described our Facial Palsy Awareness Week 2016 activities as a global event with people affected by facial palsy from all over the world getting involved. People's stories and awareness week fundraising activities were featured in local press and an article was also published by the Chartered Society of Physiotherapy. The ParliAble Workplace Equality Network agreed to hold a facial palsy awareness event on 2 March. There were also plenty of fundraising activities taking place throughout the week. Special mention was made of the Ben Lomond Climb which 120 people took part in. A chain of events was also described whereby a 17 year old had taken part in some local fundraising which led to an invitation to Prime Ministers questions, greatly empowering the individual concerned. A total of £15,756 was raised during Facial Palsy Awareness Week.

KJ thanked every person and organisation who has supported Facial Palsy UK in any way throughout the year and explained that every gift is used carefully to improve the lives of people affected by facial palsy.

KJ then went on to describe the work of our volunteers and stated they are integral to our success and thanked them.

Financial Review

KJ summarised the financial situation year ending 30 June 2016 as follows:

- Total unrestricted income from donations and fundraising decreased by 1.9% to £52,601. £25,000 was excluded from this figure for comparison purposes which was the large one-off donation received in February.
- Unrestricted expenditure decreased by 1.4% to £53,623.
- Our principal funding sources came from Individual fundraisers (£36k), Trusts (£22k) and Major Donors (£27.5k) with the rest of our income made up from general donations, merchandise sales, event income, affiliate scheme income, payroll giving and regular giving such as direct debits.

KJ gave details of our Reserves Policy – a target of 6 months of core

expenditure (£26.5k). Free reserves currently held are £12.5k.

Finally KJ described our future plans. Our Strategic Plan was reviewed in June 2016 and is available for download from our website. In summary:

- We plan to create 3 children's books to support children with facial palsy and children of adults with facial palsy.
- Our general leaflet has now been updated and we believe it is a more accurate reflection of the work we do and our community. We received a grant in a previous financial year which will enable us to get these leaflets out to more hospitals and GPs around the UK, this will be undertaken during the coming months.
- We are currently working on 8 Patient leaflets about different causes of facial palsy which GPs and Hospitals will be able to download, they will also be available on our website.
- We also received funding from the National Lottery which is enabling us to update our website and make it mobile friendly. This work is currently underway.
- We are still hoping to put on a Facial Palsy Conference in the not too distant future. We are currently applying for funds to enable this to go ahead.
- We have just over £9,000 towards our Research Appeal now. The original target was to raise £20,000 in order for this to go ahead. We are investigating different options to see if we can achieve the same goals at a lower cost. The aim of the project is to work with Patients, Carers and Health Professionals to obtain a top 10 list of research priorities, these would then be put forward to researchers.
- We have funds for two future family days during the year.
- The charity is currently collaborating with teams at Nottingham Trent and Coventry University to develop facial remote activity monitoring eyewear.
- We recently received just under £9,000 to be used for GP Education. We plan to create GP downloads and training DVDs about facial palsy covering topics such as diagnosis, holistic patient care and more.
- We are continuing to develop our Support Services with a new support group launching in Liverpool on 12 November. This coming year we will be looking at the geographical areas of greatest need around the UK and also improving our support for the volunteers who help us run these groups.
- We completed an expression of interest form to become

	<p>registered as a charity in Northern Ireland in June 2015, there is a long waiting list. We received confirmation from the Northern Irish Charity Regulator in March 2016 that we can provide services over there while we wait for our registration, so we plan to develop support for people in Northern Ireland.</p> <ul style="list-style-type: none"> • We have many more plans but in order to survive we need to improve our funding situation. We are stretched very thin in terms of resources and really need additional staff. We will be looking at the return on investment of employing a dedicated fundraiser. <p>We also invited people to put forward ideas for themes for Facial Palsy Awareness Week 2017. We plan to launch the first children's book during Awareness Week and asked to hear from families who are willing to be featured in the media talking about the need for the book.</p> <p>KJ said that for a more detailed overview of our future plans please see our Annual Report which will be available to download from our website shortly.</p>	
8.	<p>Any Other Business/Questions</p> <p>No other business was declared or discussed.</p>	
9.	<p>Close of formal business</p> <p>There being no other formal business the Chairman thanked those present and declared the formal business part of the meeting closed at 1 pm.</p>	

Signed off:

Date:



18/11/17

Name:

Charles Nduka

Position:

Chair and Acting CEO