



# The Little Foundation

Annual Report  
Financial Year Ended  
31<sup>st</sup> December 2019



The Little Foundation was established in 1990 by Ian Dawson-Shepherd with the object to investigate the causes of neurodevelopmental disorders, of which cerebral palsy is the most severe, and seek wherever possible to prevent them. We do this by supporting world-class basic research, hosting multi-disciplinary workshops and conferences, and providing a forum for the exchange of ideas and best practice across all parts of the UK's CP sector.

As the father of a daughter with severe CP, Ian Dawson-Shepherd had been in the vanguard of campaigning for people with CP for forty years. He was chairman of the National Spastics Society, which he founded with three others in 1952. Later renamed Scope, our sister organisation has done much to change attitudes towards people with disabilities, to support those who are affected by CP, and to empower them to overcome its many challenges.

The Foundation is named after Dr William John Little (1810 – 1894), the English physician who first identified the condition that later became known as cerebral palsy.

The Foundation has broad objectives seeking to fund research into not only the causes of cerebral palsy but also allied disorders which include autism, dyslexia, epilepsy, deafness and blindness, learning difficulties, and other forms of neurodevelopmental disorder. However, our current focus is on research into the causes and thus prevention of CP, and working with other organisations to coordinate action in all matters relating to the prevention and alleviation of CP.

Research initiated and supported by the Foundation over the past 28 years included the seminal [European Cerebral Palsy study](#) that showed the majority of cases of CP were caused by injuries occurring in the baby's brain in early pregnancy and were not as a result of birth mishap. These, along with over 20 international seminars/workshops on related topics including Asphyxia, Infections, the Thyroid, Mid-trimester Monitoring, Specific Learning Disorders, Nutrition, the Placenta, Aids, HIV, Viruses and Brain Damage, MRI, Non-accidental Head Injury, Drugs in Pregnancy, Neuroprotection of the Infant Brain, Epidemiology and Folic Acid, have yielded substantial insight for the world's CP research community, influencing and informing the direction of much subsequent research elsewhere in the world.

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## Introduction

Name	The Little Foundation	
Registered Charity	803551	
Principal Address	Pinero House 115a Harley Street London W1G 6AR	
Trustees	Baron Hameed of Hampstead CBE DL	Chair
	Ms Libby Aird-Brown	
	Professor Michael Crawford	
	Ms Sara Cooke	Treasurer
	Mr Kasper de Graaf	
	Dr Jack Singer	Vice-Chair

The Trustees have pleasure in presenting their annual report and financial statement for the year ended 31<sup>st</sup> December 2019.

Since our founding in 1990, the Little Foundation has been able to initiate or enable a number of significant insights into the causes of cerebral palsy and other neurodevelopmental diseases, either through the funding of basic research or seminars and conferences for international groups of researchers. Activity over 2019 has centred on determining the future direction of the Little Foundation, in particular where we can credibly make the greatest impact in the shortest time in fulfilling our mission to prevent cerebral palsy (CP) and other neurodevelopmental disorders. This has meant putting in place a process to understand the global cerebral palsy research landscape, its leaders, its areas of focus/interest and its funding, as a means of determining gaps in research that had potential to be taken up by the Foundation or others in the CP research community.

Dr AnnieBelle Sassine, PhD graduate of Imperial College who had worked closely with both Prof Michael Crawford and Prof Mark Johnson, was retained to undertake a global research literature and funding review. This informed in turn a report on its implications for both the Foundation and the wider CP community commissioned from Dr Norman Freshney. This exercise has yielded substantial insights to inform both our organisational and research strategies, and I would like to acknowledge the considerable contribution to our thinking that Dr Sassine and Dr Freshney have made. Not only has this survey noted issues that need addressing by the UK CP research community, but the wider charity/NGO community as well. Further detail on these is provided in this Annual Report.

The Trustees met in October to make decisions about the direction of Little Foundation's future, taking into account the global view of cerebral palsy research, an understanding of some of the needs of the UK's cerebral policy sector and set against the reality the UK's current level of investment in cerebral palsy research and the care/support of those affected by cerebral palsy. Their decision maps an intended course for the Little Foundation that, while incorporating a change of emphasis, holds true to our founding objects of 29 years ago.

## About Cerebral Palsy

Cerebral palsy (CP) is the most common cause of motor disability in early childhood. It is described as a lifelong neurological disorder of movement and posture secondary to non-progressive malformations in the developing foetal or infant brain. The brain injury may occur *in utero*, at birth, during the postnatal period or in early childhood. CP is often accompanied by a combination of difficulties that may include intellectual deficits, disturbances of sensation, perception, and coordination, epilepsy, and secondary musculoskeletal problems. Adults with CP can also be at risk of non-communicable diseases due to lack of physical activity and muscle weakness. CP is a very heterogeneous disorder presenting with different clinical types and brain imaging patterns. Consequently, motor impairments can vary widely between affected children and adults; however, the poor quality of life and discrimination faced by those affected by CP are often similar.

### Types of Cerebral Palsy

CP is a heterogeneous disease presenting with different types:

**Spastic CP** accounts for 70% of cases and affects muscle control and coordination. It is the result of injury to the motor cortex and the pyramidal regions of the brain that link the motor cortex to the spinal cord, resulting in muscle stiffness and tightness. It includes three subtypes depending on the body area affected; hemiplegia, which affects one side of the body, with the upper body usually more influenced; diplegia which affects the lower extremities of the body (the legs); and quadriplegia which affects all four limbs.

**Dyskinetic CP** is the second type of CP prevailing in 10-20% of cases. It is responsible for slow and uncontrollable movements of hands, feet, arms or legs that can result in severe changes in muscle tone and posture and can be accompanied by learning disabilities and frequent epilepsy.

**Ataxic CP** (5-10%) is the least common and is characterised by difficulties in balance and coordination and results in shaky movements that can affect writing and speech. Exhibiting one or more type of CP is classified under

**Mixed CP** (10%). Rosenbaum *et al.* in their groundbreaking report that altered the definition of CP advised that classification of CP should be reliable and very specific to the symptoms. Indeed, CP has varying degrees and can range from a minor limp to severe incapability of movement and communication.

### CP Prevalence and Trends

The reported incidence of CP can range from 1.5 to more than 4 per 1,000 live births based on studies from around the world. The estimated prevalence from registries has been static over the past three decades with reported incidences ranging between 2-3 per 1,000 live

births for the developed world and 2 per 1,000 live births for the UK. It is estimated that there are circa 100,000 with the condition in the UK. As for low and middle-income countries (LMIC), the data on CP prevalence appear to be very scarce and systematic reviews seem to include data for high-income countries (HIC) mostly, although the prevalence of CP in LMIC is suspected to be higher than HIC. However, without a National CP Register, our understanding of its prevalence remains an estimate. If we cannot understand properly the scale of the problem, we cannot adequately combat it.

Extremely pre-term birth infants (born before 28 weeks of gestation) are greatly affected by CP, with an estimated prevalence of 40-100 per 1,000 live births. The increase in the survival of very premature infants has resulted in a modestly increased prevalence of cerebral palsy in developed countries from 1975-1999 that has now subsided.

Despite improvements in antenatal, delivery and postnatal care, CP incidence in term infants has not notably changed over the last 30 years. In fact, term infants (>37 weeks of gestation) account for 50 to 65% of CP cases although pre-term birth remains a strong risk factor of CP. Data from European databases in addition to USA, Australia and China shows that more than 50% of CP cases are among normal birthweight babies (>2500 g). Research on CP has primarily focused on very pre-term infants due to the strong association between pre-term birth and the risk of CP. However, infants born at or after 35 weeks of gestation contribute to two thirds of CP cases and are considered the most under-researched group with the majority of the literature fixating on birth asphyxia as the major cause of CP among this group.

## Research Review and Research Strategy Project

In line with discussions with the Trustees about steps towards the future, and following their approval of expenditure on a project to help us understand the state (and history) of research on the causes and prevention of cerebral palsy, the project brief was finalised and two individuals retained to take this forward: Dr AnnieBelle Sassine, PhD graduate of Imperial some of whose work in collaboration with Prof Michael Crawford and Prof Mark Johnson has been funded by The Little Foundation, and Dr Norman Freshney, who was retained as a research strategy consultant.

This was to be a systematic review of all scientific/medical research focused on the causes of and preventative action being taken in relation to cerebral palsy with a four-fold purpose:

1. To identify gaps in research.
2. To raise the profile of the Little Foundation as a source of innovative thought and insight, and as a central resource for information.
3. To assist the Little Foundation in determining its future research strategy, informing the selection of focus areas, identifying potential overlaps of interest, potential collaborations and partnerships, as well as identifying further sources of funds for research of this kind.
4. To provide the data for a publicly-available directory or database of research that is regularly updated with details (and outcomes) of all subsequent, new research.

The project had three elements:

### Phase 1

Led by Dr Sassine, this sought to produce an understanding of current trends, areas of major investment, points of influence and potential areas of commonality with the current approach of the Little Foundation.

Objective	Description / queries
1. Literature review – reviewing published articles, systematic reviews/state-of-the art papers: not only noting conclusions but also suggestions for future research that will highlight areas that lack investigation or need closer examination. In addition, undertaking research of the key, prominent and influential journals – reviewing key concepts.	Literature review / report
2. Geographical/academic survey – identifying significant and influential individuals and institutions.	Within or as an appendix to literature review

3. Topical survey – i.e. drilling down into the focus is cell biology, mechanistics, nutrition etc.	Described in the literature review.
4. Clinical trial database review – establishing what data is publicly available to investigators using platforms such as ClinicalStudyDataRequest.com, Yale University Open Data Access Project (YODA) and the Supporting Open Access for Researchers (SOAR) initiative; <a href="http://www.clinicaltrials.gov">www.clinicaltrials.gov</a>	Clarify outputs from this objective.
5. Funder review – identifying the key funders of this research (where publicly available i.e. likely philanthropy and governments predominantly) and reporting on their funding strategies and remits.	Overview of current research; using grants databases.
6. Conference review – tracking national/international conferences relating to this subject area, or other events likely to be of interest.	Overview of key conferences

## Phase 2

Led by Dr Freshney, Phase 2 gathered insight from the research community to inform research priorities that will advance our understanding of the causes of Cerebral Palsy. This phase also incorporated insight gathered through the literature and funder review and resulted in the production of a research strategy report, describing current knowledge, research priorities and proposed mechanisms for deploying research funding.

The key elements of Phase 2 were:

Objective	Description / queries
1. Assessment of what is significant in what has been discovered.	Identify key themes; assess landscape, strengths, gaps.  Extract key points & themes from the literature review.
2. Obtain stakeholder insights on development of the research strategy.	Stakeholder interviews to identify priorities



3. Assessment of underlying assumptions that are open to challenge on the basis of the outcome of the Little Foundation's historical and current research.	How does the proposed Research Strategy & future direction fit with current strategy?
4. Outputs: Research Strategy Report	Provide report to describe i) landscape, ii) key priorities to inform future direction

### Phase 3

While the shaping and timing of this phase, the exercise of taking the findings from both our reports out the medical/clinical, research, charity and policy communities, will be dependent on available resource it is, nevertheless, an equally essential element of the whole initiative.

<b>Objective</b>	
1. Organisation of suitable events (workshops? seminars?) to share this analysis with potential collaborators and supporters	Engagement in delivering the research strategy
2. Creation of a publicly available, searchable database – recognising that this will require an investment of time and resource in agreeing the most useful format, structure and how it should be maintained and kept up to date.	

## Insights

### Report Observations

- **Progress in research into CP globally has been slow over the last 30 years**
- **There remains no robust understanding of CP's causes**
- **There have been few therapeutic advances in either reducing risk or improving recovery**
- **Incidence of CP is likely to increase as the world improves its ability either to prevent or mitigate pre-term birth**
- **There has been some localised priority setting in CP research, but there is a lack of an international convening function to make this global**
- **There is not yet a genuine global picture of CP incidence**
- **There is not yet a genuine global picture of the range of CP-related research**

Several points stand out from both papers that have helped inform next steps for the Foundation.

### CP Incidence / Prevalence

We confirm that there is no genuine picture of CP incidence either nationally in the UK or globally, and that this is mainly due to a lack of national registers, with the UK being a particularly stark example. What measurements have been made/estimated perpetuate a view that CP is comparatively rare. While this may be the case, our report takes the view that incidence is likely to rise as the world improves its ability to prevent pre-term birth, although by what degree we cannot estimate.

Attempts have been made by some charities individually to campaign for regional and national registers for the UK. There are registers now in N Ireland, Wales and Scotland. Registers initiated in Oxfordshire, Mersey & Cheshire and the North of England have been closed down for lack of funding. 2019 saw a second attempt in 3 years by [Action Cerebral Palsy](#) to get Parliamentary attention for a UK-wide CP register, but there has been little progress. Discussions with Action Cerebral Palsy suggest that further pressure on this from the medical research community in addition to NGOs would be both timely and welcome.

### CP Research

We have so far identified over 150 institutions globally (20 UK and 103 overseas) where CP-related research is/has been undertaken. This is not comprehensive, as there remain questions over what research is underway in Russia, China, India and South America: there are references to research in the last 3 regions, but no detail available.

We have confirmed that progress in CP research has been slow over the last 30 years, that there is yet no robust understanding of the causes, neither have there been any significant therapeutic advances in reducing risk or improving recovery.

Our report reflects a generally held view that there is “very little low-hanging fruit” among research topics that could be pursued that would have a significant effect in the short-term but has, nevertheless, identified 5 broad areas where further research would yield substantial, helpful insight:

1. Identify the causes of preterm birth and how it can be prevented
2. Identify the factors that increase risk of Cerebral Palsy
3. Understanding the normal development of the foetal and infant brain
4. Understand the molecular events that lead to brain injury
5. Accurate data on CP prevalence and risk factors in Low Income Countries

On cause, interviewees generally considered there to be good evidence that infection, inflammation and genetics played a role, however they felt more evidence was required to pin down how the brain injury occurs. *Nature* published a comprehensive review<sup>1</sup> of the causes of CP in 2018, and while it cited no evidence about nutritional factors aside from obesity and lower socio-economic status, nevertheless did conclude:

*If the modest information about pregnancy that is currently available from maternal recall and medical records years later can be supplemented with data sources that provide clear information about exposures to infections, nutrients, environmental toxins, allergens and many other phenomena during pregnancy, our limited knowledge could give way to an era in which the widespread prevention of CP is a feasible goal.*

Our review also notes areas of potential interest in current research, particularly in the field of imaging<sup>2</sup> towards early diagnosis at or soon after birth, which, if successful, could be relevant to identifying injury during pregnancy.

While there is little to disagree with the suggested 5 areas of potential exploration, they do not represent a national, let alone global, view of research priorities for CP, although there have been some attempts to define these.

One initiative by the Australia-based Cerebral Palsy Alliance has been to set-up [IMPACT for CP](#), “an international research network whose objective is to promote and support high quality research in the prevention and cure of cerebral palsy, and improve outcomes for those with the condition”. While it is keen to recruit researchers to join its research clusters on themes, it is not clear who their members are. It has hosted small international conferences (‘Summits’ of circa 30-40 participants) that have sought to define priority areas but, again, the outcome and impact of these conferences are unclear as little has been published by their organisers since their inception in 2011.

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<sup>1</sup> [The Complex Aetiology of Cerebral Palsy](#) - Steven J. Korzeniewski, Jaime Slaughter, Madeleine Lenski, Peterson Haak & Nigel Paneth – *Nature* 13 Aug 2018

<sup>2</sup> Tomoki Arichi at King’s / St Thomas’ is leading the [Developing Human Connectome Project](#) (dHCP), which is mapping human brain connectivity during and shortly after pregnancy, with the aim of detecting abnormalities, while Ilias Tachtsidis at UCL, in collaboration with Wellcome, is developing non-invasive [Functional Near-Infrared Spectroscopy](#) (fNIRS) imaging, which can help with early diagnosis of CP / neurological problems / brain damage.

While IMPACT for CP is focused on basic and translational science, the US-based [Cerebral Palsy Research Network](#) focuses more on linking basic scientists with clinical researchers and has recently launched a research strategy<sup>3</sup> that has taken a patient-centred approach.

However, most of this work is focused on national priority setting and, for all the activity including a reasonable sweep of international conferences, it appears there is a lack of any mechanism to identify and drive global priority setting. Indeed, in the UK, there appears to be even no national consensus, beyond a general acceptance that large-scale epidemiological studies should be central to any future research policy and that a national CP Register is urgently needed at the core of this if it is to have any meaning.

The lack of understanding of the genuine scope of CP's current, global incidence (particularly the potential threat of incidence increasing as pre-term birth cases reduce) and of the necessary global priorities for research means that it is difficult for the sector to understand, let alone articulate, a sense of what critical mass is required to have an impact on causes or prevention. Without a sense of "what-it-will-take" to achieve specific, positive impact, the CP sector's ability to motivate the world's most influential funders of research is going to be extremely limited.

The Trustees noted that these gaps in knowledge are reflected on a national basis in the UK and represented the best opportunity for the Little Foundation to make an impact on CP research in the short- to medium-term.

Further consultation across organisations in the UK with an interest in CP revealed a similar lack of collective thinking across the differing sub-sectors that make up this community. Our reporters noted that this does and will compromise the development of coherent, national policy around not only research but also the development of better (and better resourced) models of integrated medical and social care. This is a further area where the Little Foundation will seek to make a positive impact.

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<sup>3</sup> [Setting a patient-centered research agenda for cerebral palsy: a participatory action research initiative](#) - Paul H Gross, Amy F Bailes, Susan D Horn, Edward A Hurvitz, Jacob Kean & Michele Shusterman – Developmental Medicine & Child Neurology, August 2018

## Where Can the Little Foundation Achieve the Greatest Impact?

### Report Observations

- **Research needs to be funded at minimum £1m pa level if it is to have credible impact**
- **TLF could fill the gap in UK as organisation that looks across CP and helps drive priority setting**
- **TLF could build influencing role highlighting chronic underfunding of CP research and influencing others either to commit funding or undertake their own work on CP**
- **TLF could act as convenor of scientists, research charities, government and patient advocates to drive promotion of need and solutions**
- **TLF could act as information source – providing authoritative voice on CP causes and treatments**

Recognising that our resources were currently insufficient to make investment of any significance in these areas, particularly our assessment that an annual research budget of at least £1m would be required to fund work of the necessary scale to result in meaningful impact, the Trustees have considered how best the Foundation can continue making an impact.

While not setting aside the ambition of future research funding, they determined it was important that we build a credible role that delivers impact for the cerebral palsy sector while also building public recognition of the Foundation, which would in turn improve our ability to fundraise. There is a role the Foundation could usefully undertake in which, using models helpfully tested in the USA and Australia and the insights delivered by our own recent studies, we would seek to drive/facilitate a national research priority-setting exercise for CP research in the UK, a role that would evolve into promoting and informing a global approach to priority-setting.

A number of benefits would spring from this exercise that would help resolve issues raised in the report, particularly the lack of coordination and communication between the different agencies and disciplines that have a shared interest in CP research but which have not acted in developing a national, cross-disciplinary approach. This would require the Foundation to act as a convenor to a range of interested parties – scientists, medical practitioners, research and care charities, policy makers and patient/family advocates – providing appropriate forums to discuss need and solutions.

The Foundation's overview is viewed as playing a helpful role in reiterating where there has been progress, where there have been blocks to progress and, most importantly, where there are under-explored areas that represent the greatest potential for leaps forward in our understanding of CP. Being able to reflect back to policy-makers the benefits of a revised approach to funding CP research with a collective voice – stressing not just the need for greater investment in research, but also the need for a national CP register – will have a greater impact than organisations making the case individually.

Equally, as referenced when starting the research review process earlier this year, there is an additional role for the Foundation as an authoritative central information resource point. While there are many information hubs providing practical advice for families affected by CP, some of which make limited reference to current research, there remains no UK resource that provides an up-to-date, global (within the constraints referenced above) summary of historical and current CP-focused research that would usefully inform both the research community and a lay, interested audience.

## Action 2020

In the light of the insights gained above, the Trustees have agreed for the Little Foundation to pursue 3 courses of action over 2020.

### Priority Setting Partnership for Research

There have been recent exercises in priority setting for CP research in both the USA<sup>4</sup> and Australia<sup>5</sup>, focused on national priorities, in the USA's case additionally taking a patient-centric approach, but there is no evidence that the UK has taken this step at a national level, although there are some examples of institutions seeking cross-sector involvement in priority setting<sup>6</sup>. There has, crucially, been no national engagement with The Little Foundation will take the lead in establishing a Priority Setting Partnership for CP research in association with the James Lind Alliance.

The James Lind Alliance, backed by the National Institute of Health Research, approach to facilitating priority setting is well established since its foundation in 2004: its [Priority Setting Partnerships](#) (PSPs) “enable clinicians, patients and carers to work together to identify and prioritise evidence uncertainties in particular areas of health and care that could be answered by research”.

JLA have facilitated one PSP on Childhood Disability (with only marginal reference to CP), one on neurodevelopmental disorders in Canada (but only focused on Ontario's population) and is currently developing another focused on paediatric neurology, led by a specialist in brain inflammation based at Guy's/St Thomas'. Discussions with the leader of this group confirm that they would be keen for us to pursue a CP-focused PSP that would complement the broader focus of the other. There is a further opportunity to collaborate with a further PSP, this time focused on stroke (research has confirmed that it is a form of stroke that causes lesions in babies' brains before birth that appears to trigger CP in the majority of cases). This is currently adult-focused, but we are in discussion with them to broaden the scope into paediatrics, which would similarly benefit both neurodevelopment and CP PSPs.

The PSP process is to establish the 'Top 10' research priorities. The likelihood of some shared or overlapping questions across the 3 PSPs will be helpful in reinforcing the message to research funders that investment in these areas will have significant benefits beyond the single focus areas, such as hemiplegia, potentially enabling greater impact for which the Foundation would be among those credited.

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<sup>4</sup> [Paul H Gross, Amy F Bailes, Susan D Horn, Edward A Hurvitz, Jacob Klein, Michele Shusterman - Setting a patient-centered research agenda for cerebral palsy: a participatory action research initiative.](#)

<sup>5</sup> [McIntyre S, Novak I, Cusick A - Consensus research priorities for cerebral palsy: a Delphi survey of consumers, researchers, and clinicians.](#)

<sup>6</sup> [Engaging with Families About Cerebral Palsy Research](#), Christina Smith, UCL Division of Psychology & Language Science, 2013.

The timing of the paediatric neurology and stroke PSPs represents an ideal opportunity for the Little Foundation to assert this adjusted role by instigating one that is purely CP-focused. The geographical scope of this would be the UK but extending this subsequently warrants further discussion.

### Association of Researchers in Cerebral Palsy UK

While there are examples of associations that seek to act collectively on specific conditions (American Academy for Cerebral Palsy & Developmental Medicine, European Academy of Childhood Disability, Neurological Alliance<sup>7</sup>, National Orthopaedic Alliance etc.), who seek to coordinate priority-setting, some holding international conferences<sup>8</sup>, there is no UK, or indeed European, equivalent body focused on CP. While some UK entities suggest themselves as activities that would perform this function, they tend to be project- rather than theme-related: i.e. UKCP is actually the UK Collaborative Network of Cerebral Palsy Registers and Surveys, which was set up in 1999 to pool data from currently shrinking number of UK CP registers. In consequence, we shall seek to establish a UK Association of Researchers in Cerebral Palsy. This could possibly seek to cover Europe if there was sufficient appetite from prospective members.

Formation of the association could spring naturally from the PSP process, helping to build a diverse community of researchers from across all disciplines, particularly Paediatrics, Neonatology, Obstetrics, Gynaecology, Diet / Nutrition, Health Psychology, Genetics with an interest in pursuing research in CP, or whose work in other fields potentially directly informs or benefits CP research, such as large-scale study specialists.

The Little Foundation could act as a combined secretariat / information resource for the association, while also coordinating / facilitating suitable forums to ensure new developments, insights and opportunities for innovation are shared swiftly. The Association would be largely a 'virtual' community, with the majority of interactions being web-/social media-based, but there would be benefit in regular (if not necessarily frequent) set-piece events to bring this community together.

A first action for this association would be to push for a national UK CP Register. Action Cerebral Palsy's 2 attempts in the last 3 years to raise Parliamentary interest in this topic have failed to have the required outcome. Subsequent consultations by ACP suggest that this approach would have greater impact coming from the medical research sector, aimed not at government initially but at the major research institutions, emphasising how its benefits would spread beyond simply that of the CP community.

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<sup>7</sup> "The Neurological Alliance is a coalition of more than 80 organisations working together to transform outcomes for the millions of people in England with a neurological condition. We campaign for high quality care and support to meet the individual needs of every person with a neurological condition, at every stage of their life. Our work is shaped by the experiences of people with neurological conditions and aims to address the causes of poor care." - <https://www.neural.org.uk/about-us/>

<sup>8</sup> [AACPDM Annual Meeting 2019](#); [European Academy of Childhood Disability](#)



## Cerebral Palsy Alliance UK

Again, while there are many vested interests in CP in the UK charity sector with potentially as many as 65 UK charities with an interest in CP, there is little evidence of a collective voice regarding national policy in areas like research investment, CP registers or the funding/models of social care. Unless the broad sector can agree what national priorities should be, the approach will continue to be piecemeal, unfocused and less effective than it could be. The Foundation consider establishing a UK Cerebral Palsy Alliance – an entity that is influenced by, but is not based on, existing models in the USA and Australia.

The proposed Alliance would act as a forum for developing best practice, promoting new ideas as much as expressions of need/urgency, and connecting a sector that has not historically worked together. As with the researchers' community, the Alliance would be largely 'virtual' but would still require a regular forum to determine collective priorities. If established as a charity in its own right, the proposed alliance could have a useful fundraising role in putting forward collective, cross-sector proposals such as a national CP Register for the UK – reinforcing its importance for the whole sector.

We recognise that this is potentially difficult objective to achieve, in terms of the wide range of interests in CP organisations in the UK, but it is important that this is as representative of breadth of the sector as possible – representing an authentic, collective 'voice'.

Our thinking of an issue-specific alliance is wholly consistent with an increasing trend across the UK voluntary sector, the most recent example of which is the [Loneliness Action Group](#), a coalition established by the British Red Cross and the Co-operative Group. Since its formation in December 2017, it has already succeeded in growing its membership to over 50 NGOs, companies and other organisations, presented loneliness as a single, collective area of concern for charities supporting elderly, disabled or socially excluded groups with the [Campaign to End Loneliness](#), and has succeeded in driving establishment of an All-Party Parliamentary Group on Loneliness and influencing the first Government strategy on loneliness<sup>9</sup>.

Initial contact with a number of NGOs in this sector to test the concept has met with a strongly positive response, with the caveat that this would require considerable preparation and consultation to ensure that it is able to deliver the collective, influential voice that it is generally agreed the sector needs. Responses from circa 14 included a willingness to join a core but representative group that would determine the initial terms/objectives/benefits of an alliance before promoting it to the wider NGO community<sup>10</sup>. Conversations with potential partners confirm a preference for a 'neutral' convenor and the views expressed to date confirm that this suggestion is timely and that the Little Foundation would be viewed as suitably non-aligned.

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<sup>9</sup> [A Connected Society: A Strategy for Tackling Loneliness - Laying the Foundations for Change](#)

<sup>10</sup> This has already resulted in invitations to a multi-disciplinary conference and a cross-sector roundtable in Westminster to discuss these ideas further.

As with an association of researchers' first action being a call for a national UK CP register, the Alliance's first collective action alongside calling for a register could be to call on MPs to recognise that the CP-affected population is of equal scale to those with Parkinson's Disease or Multiple Sclerosis by establishing an All-Party Parliamentary Group on Cerebral Palsy<sup>11</sup>.

These acts could be characterised as the first steps towards defining 'a national strategy for cerebral palsy'.

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<sup>11</sup> Both [Parkinson's Disease](#) and [Multiple Sclerosis](#), conditions with similar population sizes, have their own APPGs.

## Steps Beyond 2020

The sections above set out a short- and medium-term future for the Little Foundation in helping drive a national strategy for CP. Thus, with an over-arching target of establishing a funding base that will enable the Foundation to return to funding research, over 2020 the Foundation will seek to build and administer 2 representative bodies and initiate a programme of information provision and priority setting based on these additional building blocks.

Our recent review, coupled with the insight from Dr Freshney's report, will provide helpful data and arguments with which to engage these target audiences.

### Network Building

The Foundation will build cross-sector/disciplinary networks of interested parties, going beyond our historic community of researchers and political decision-makers to include patients' organisations and the wider charity sector.

As referenced above, we have already started to contact some of the circa 60 UK NGOs **Error! Reference source not found.** with a direct or indirect interest in CP to test some of the thinking and to establish where there is interest in potential collaboration, but without seeking or making any commitments at this stage. Response has been encouragingly positive.

Engaging with the circa 20 UK research institutions with a similar interest in CP will need to follow a similar path in terms of a small primary group that helps define the association proposition and then assists in promoting it across the research community.

### Communications

The insights from Dr Sassine's research review make it worthy of publication in its own right and will be a vital tool in engaging our key stakeholders. This will be published in 2020 to be used to inform and to engage with researchers, charities and those interested in the issues around CP

Our approach will be built around the key themes that emerged from our research, framed as 'strategic goals for CP', on which the Foundation will aim to build cross-sector consensus.

Detail of the research identified over the course of both reviews will be uploaded into a searchable database on the Foundation's planned, new website, with newly-published research being added as it appears, as a growing, freely-available reference resource for the research community and others with an interest in CP.

## Conclusion

There is evidence in our research to show that the CP research and NGO sectors recognise the value of and the need to collaborate but have not acted on it. What the Little Foundation proposes for 2020 will provide a catalyst for action, based on precedents/models elsewhere in the UK and overseas. This view is confirmed by discussion with fellow-CP charities with which we have discussed the concepts, who agree the range and sequence of proposed activities/events is necessary, logical and possible.

The accumulated insight from research that we are gathering, matched with the collective action of a sector that increasingly works together, form the foundation for setting strategic goals for combatting CP in the UK

### Strategic Goals for CP

- **Doubled UK research spend on CP by 2025<sup>1</sup>, with an increased proportion devoted to seeking evidence of unmet need in prevention**
- **Reduced disparity between costs of CP (£1.5b annually) and that committed to researching it (£4.6m)**
- **A new, national longitudinal study collecting data pre-conception and throughout pregnancy**

However, there are further crucial questions the CP sector needs to answer to put forward a comprehensive strategy. We hope that 2020 will provide some of these answers.

### Strategic Questions for the CP Sector

- **What is a credible target by which incidence of CP in the UK can be reduced?**
- **What would it take to reduce the level of preterm birth in the UK by 50% from 7.3% of live births to 3.6% by 2050?**
- **Where we can reduce the severity of and increase recovery from CP?**

We rely on the generosity of supporters to enable these essential initiatives. They can be assured that pursuing this change of emphasis in our work, by concentrating on informing and enabling necessary changes in the direction of research rather than simply seeking to fund individual research projects, represents the best and most effective use of the to-date limited resources available to the CP sector. We are truly grateful for your help and hope very much that it can continue in the future.

Jonathan Badger  
Chief Executive

December 2019

## Accounts

### STATEMENT OF FINANCIAL ACTIVITIES For Year Ended 31<sup>st</sup> December 2019

	<b>2018</b>	<b>2019</b>
<b>Income</b>	<b>£</b>	<b>£</b>
Donations received	30	4,000
G W Lee Legacy	0	0
	30	4,000
Fund raising		24
Investment Income	5,687	5,794
<b>Total Income</b>	<b>5,717</b>	<b>9,818</b>
	<b>2018</b>	<b>2019</b>
<b>Expenditure</b>	<b>£</b>	<b>£</b>
Fees		(617)
Travel	(261)	(1,145)
Secretarial costs (inc travel)	(500)	(450)
Website, Printing, Stationery	(158)	(326)
Legal/Recruitment Costs	(9,488)	
Research Funding	(4,630)	
Consultancy/CEO	(3,250)	(7,370)
CEO	(8,333)	(53,125)
Fundraising Costs	(180)	
	(26,800)	(63,033)
<b>Surplus (deficit)</b>	<b>(21,083)</b>	<b>(53,215)</b>
Unrealised Investment Gain	(4,588)	26,381
<b>Net Surplus (deficit)</b>	<b>(25,671)</b>	<b>(26,834)</b>
Opening General Fund Surplus	235,559	209,888
<b>Closing General Fund Surplus</b>	<b>209,888</b>	<b>183,054</b>

The notes on page 22 form part of these financial statements

**BALANCE SHEET**  
**As at 31<sup>st</sup> December 2019**

		<b>2018</b>	<b>2019</b>
	<b>Notes</b>	<b>£</b>	<b>£</b>
Investment	2	161,408	173,580
Cash at Bank	3	48,480	11,262
Total Funds		209,888	184,842
Opening General Funds		235,559	209,888
Funds movement in the Year		(25,671)	(26,834)
Closing General Funds		<b>209,888</b>	<b>183,054</b>

The financial statements were approved by the Trustees on

30<sup>th</sup> October 2020



Kasper de Graaf

Treasurer

The notes on page 22 form part of these financial statements

Sara Cooke

Treasurer

**NOTES TO THE ACCOUNTS**  
**31<sup>st</sup> December 2019**

**1 Accounting Policies**

The accounts are prepared under the historical cost convention and in accordance with applicable accounting standards.

**2 Investments**

The Charity held units in the COIF Charities Income Fund - Income Units, throughout the year.

Movements in the units were:

	<b>2018</b>	<b>2019</b>
	<b>£</b>	<b>£</b>
Units Held, beginning of year	11,240	11,240
Units sold/purchased		(986)
Units Held, end of year	11,240	10,254
Value at beginning of year	165,996	161,408
Value of units (sold)/purchased		(14,159)
Unrealised Investment gain	(4,588)	26,331
Value, at end of year	161,408	173,580
Proceeds of units realised	0	16,000
Value of units sold	0	(14,159)
Realised Investment gain	0	1,841

**3 Cash**

Business Reserve Account	36,390	7,409
COIF Deposit	12,090	3,853
	48,480	11,262