

**MEETING: 28/11/2013**

**Ref: 11930**

**ASSESSMENT CATEGORY - Positive Transitions to Independent Living**

**National Centre for Young People with Epilepsy (operating name Young Epilepsy)**

**Adv: Tim Wilson**

**Amount requested: £145,195**

**Base: Westminster  
Benefit: London-wide**

**Amount recommended: £72,600**

**Purpose of grant request:** To fund a Transition Support Worker in Greater London for 3 years, supporting young people with epilepsy to navigate difficult transitions to adult services.

**Background**

Epilepsy is the most common neurological disability. It can be debilitating and there is a strong correlation between childhood epilepsy and poor educational attainment. This in turn has consequences for employment outcomes in adulthood and has been associated with a much higher likelihood of poor mental health.

The work of Young Epilepsy (YE) dates back to the early twentieth century. Originally, the charity served both adults and children with epilepsy but since the 1950s it has focused on young people. Today, YE runs a special-needs residential school in Surrey for 5 - 19 year olds with neurological and behavioural conditions, and a college for young adults (19 - 25 year olds). For the past five years the charity has started delivering off-campus services, taking its expertise to schools and universities.

YE has three focus areas: ensuring that better information is available to parents at point of diagnosis; working with schools to raise awareness of epilepsy and how it might be managed; and providing support to young people to make the transition from the structured care they receive during childhood, into the less structured world of adult services.

Much of the charity's work is with young people who have learning disabilities in addition to their epilepsy, and for whom there is little alternative specialist provision.

**Funding History**

You received proposals from YE in 2009 and 2011 which were rejected for falling outside your criteria.

### **Current Application**

There is a widespread misperception that epilepsy can be managed through medication. This is often not the case with the most severe forms of the condition, and for young people this can result in lost schooling time and low self-confidence. By the time a young person with epilepsy has reached adulthood, and depending on the severity of their condition, he or she can miss up to 6 years of schooling as a result of seizures and associated time off. Whilst structured support is offered to under 18s, by adulthood far less assistance is available, and can often be harder to navigate.

YE seeks your support for a London-based Transitions Support Worker who will work with 300 young people whose life choices have been limited by epilepsy. Having piloted similar support programmes for young people across the UK, and having assessed needs at their Surrey campus, YE has developed a service delivery model which they plan to roll out across the capital. The post-holder, who the charity expects will be a qualified social worker, will deliver one-to-one and group support services, reaching young people through schools, colleges and epilepsy nurse specialists. The post-holder will also seek to engage with communities where epilepsy carries a social stigma. Work will focus on confidence building, improving employability skills, and navigating adult care services.

### **Financial Observations**

Audited accounts for the year ended 31 July 2012 show an operating deficit of £782,000 (3.2% of turnover). This comprised a surplus of £635,000 on restricted funds, offset by planned spending of £1,417,000 on unrestricted funds upgrading its Surrey campus. An actuarial loss on the defined benefit pension scheme of £1,847,000 and a net loss on revaluation of investment assets of £6,000 contributed to an overall decrease in funds of £2,635,000.

The charity's reserves policy is to hold 12 weeks of operating costs in free unrestricted reserves, which equates to £6,435,000 based on budgeted expenditure for 2013-14. At 31 July 2012, the charity held £4,875,000 in free unrestricted reserves, equivalent to 9.1 weeks' worth of expenditure. The charity also holds a further £3,026,000 in unrestricted reserves, however these funds have been designated for use towards the charity's five year campus works programme, an initiative which the charity states will require a total reserve commitment of £7m.

The draft outturn for 2012-13 shows a surplus of £1,181,000 (4.3% of turnover), comprising surpluses of £740,000 on restricted funds and £441,000 on unrestricted funds. The budget for the current year 2013-14 shows a further surplus of £787,000 (2.7% of turnover) comprising a surplus of £1,166,000 on restricted funds partially offset by a deficit of £379,000 on unrestricted funds. Total income of £28,672,000 is

anticipated, of which £25,878,000 (90.3%) has been confirmed as at 12<sup>th</sup> November 2013.

### **Officer's Appraisal**

YE is a well-established organisation with recognised expertise in supporting young people with epilepsy. There is a clear connection between epilepsy and reduced educational attainment, and this results in reduced opportunities in adult life. The proposed transitions support programme is based on evidence gathered from research at YE's residential campus as well as a national pilot delivered over 2.5 years. The charity has a credible plan to reach its clients through its existing networks.

Your usual policy for large charities such as YE is to fund 50% of total project costs. Your officer has discussed this with YE and they are happy to seek match funding for this work.

### **Recommendation**

**£72,600 over three years (£23,500; £24,200; £24,900) towards the salary of a full time Transitions Support Worker and related costs, on condition that the balance of funding is raised from other sources.**



# The City Bridge Trust

Charity Registration Number: 1035628

## Working with Londoners: Application for a grant

Please read the guidance notes before completing this form

Reference:  
(office use only)

11930

Date Received:

02/07/2013

Programme  
Area:

06

### 1. About your organisation

Name of organisation applying for grant: <b>National Centre for Young People with Epilepsy (operating name Young Epilepsy)</b>	
If the organisation is part of a larger organisation, what is its name?	
Address for correspondence: <b>St Piers Lane Lingfield Surrey</b>	
Postcode: <b>RH7 6PW</b> Is this your home address? <b>No</b>	
Contact person: <b>Miss Julia Phillips</b>	Position: <b>Trusts and Campaigns Fundraising Manager</b>
Phone: <b>01342 831 538</b>	Fax: <b>0207 630 0809</b>
E-mail: <b>jphillips@youngepilepsy.org.uk</b>	
Website: <b>http://www.youngepilepsy.org.uk</b>	
Legal status of organisation: <b>Registered Charity</b>	
If registered, please give charity number: <b>311877</b>	
Date organisation established: <b>01/04/1897</b>	

### 2. Request for funds

Under which of the Trust's themes are you applying (see our website or brochure for further details)? <b>Positive Transitions to Independent Living</b>
Purpose for which funds are requested: (25 words maximum) <b>To fund a Transition Support Worker in Greater London for 3 years, supporting young people with epilepsy to navigate difficult transitions to adult services.</b>
How much funding is requested? <b>Year 1: £46,985 Year 2: £48,395 Year 3: £49,815 Total: £145,195</b>

### 3. Aims of your organisation

Young Epilepsy aims to achieve better futures for young lives with epilepsy. Our vision is:

- to support the 112,000 children and young people in the UK with epilepsy and their families through challenges and transitions in life by delivering a range of services and interventions, and through campaigning and influencing key decision makers in government, health and education.
- to continually seek to obtain a full understanding of the needs of children and young people with epilepsy and their parents so we can deliver specialist care to this group -- especially where needs are not met by mainstream services
- to deliver excellent specialised multi-disciplinary health, education and residential services in a nurturing and high-quality environment where young learners can develop their skills and confidence to maximise their potential and to prepare them for their future lives.
- to improve the lives of young people with epilepsy through delivering world class and life-changing research

### 4. Main activities of your organisation

We strive to raise awareness and understanding of epilepsy and the many issues associated with the condition to improve the lives of young people. We do this by providing support, direct interventions and information nationwide for children, young people, parents, and training for professionals who need to know how best to support these 112,000 vulnerable young people.

We provide unique, specialist education, residential and health services for young people severely disabled by epilepsy at our School and College. Our expertise, built over 100 years in supporting those children worst affected by the condition, has enabled us to develop resources, training programmes and support services such as our helpline that can help all families affected by childhood epilepsy in the UK.

We aim to achieve valuable insights into epilepsy through our work with this group of vulnerable young people and through our world class medical and educational research programmes. We always put the needs of young people at the centre of everything that we do, treat young people with respect, involve them fully in planning services and keep them safe.

### 5. Number of staff

Full-time	Part-time	Management committee members	Active volunteers
507	303	17	59

### 6. How do you support your volunteers?

Our volunteering policy ensures we fully support the health and safety needs of our volunteers. The HR team hold meetings with volunteers to ensure they feel their needs are met, their time valued and their skills are best utilised in the workplace.

### 7. Property occupied by your organisation

Is the main property owned or leased/rented by your organisation?	If leased/rented, how long is the outstanding lease/rental agreement?
Owned	

## 8. Finance

From your most recent audited or independently examined accounts, complete the following:

Financial year ended - **Month: July**

**Year: 2012**

Income received from:	£
Voluntary income	1,995,000
Activities for generating funds	419,000
Investment income	108,000
Income from charitable activities	21,638,000
Other sources	0
<b>Total Income</b>	<b>24,160,000</b>

Expenditure:	£
Charitable activities	24,347,000
Governance costs	32,000
Cost of generating funds	563,000
Other	0
<b>Total Expenditure:</b>	<b>24,942,000</b>
<b>(Deficit)/surplus for the year:</b>	<b>(782,000)</b>

Asset position at year end:	£
Fixed assets	12,379,000
Investments	5,747,000
Net current assets (liabilities)	3,944,000
Long-term liabilities	(4,397,000 )
<b>*Total A:</b>	<b>17,673,000</b>

Reserves at year end:	£
Endowment funds	0
Restricted funds	6,148,000
Unrestricted funds	11,525,000
<b>*Total B:</b>	<b>17,673,000</b>

\* Total A and Total B must be the same and should be taken from your balance sheet

## 9. Statutory funding

For the financial year above, what % of your income was from statutory sources?  
**90%**

## 10. Material changes

Describe any material changes to the organisation's activities, structure or financial position since the date of the most recent accounts:

**We receive statutory income (£22m) from commissioners for providing specialist education/residential care for young people on our campus. We receive no government funding towards additional expenditure including research, specialist equipment and National Services to support the 112,000 young people with epilepsy in the UK. This must be funded from voluntary income (£2m). All reserves are allocated for critical capital improvements including building a new school.**

## 11. Previous applications to the Trust

Have you applied to the Trust before? If so, please give details:					
Month/Year:	08/11	Ref:	10819	Grant received: £0	OR application rejected? Yes
Month/Year:	10/08	Ref:	9141	Grant received: £0	OR application rejected? Yes
Month/Year:		Ref:		Grant received:	OR application rejected?

## 12. Previous funding received

Funding received by your organisation from the following sources during the last **THREE** years:  
**(i)** City of London (other than the City Bridge Trust) **(ii)** London boroughs **(iii)** London Councils (formerly ALG)  
**(iv)** Health authorities **(v)** Central government departments **(vi)** Other statutory bodies (e.g. Housing Corporation, Arts Council) - List source, years and annual amounts:

	Year: 2010	Year: 2011	Year: 2012
(i)			
(ii) Over 20 boroughs including Bexley, Tower Hamlets, Hackey, Croydon, Ealing	376,009	603,005	4,028,976
(iii)			
(iv)	586,320	199,945	1,419,106
(v) Education Funding Agency	9,204,241	8,913,621	9,567,881
(vi) BIG Lottery Fund	1,000	72,005	95,924

## 13. Previous grants received

Grants received by your organisation from charitable trusts and foundations (other than the City Bridge Trust) during the last **TWO** years. List source, years and annual amounts:

	Year: 2011	Year: 2012
Garfield Weston Foundation	0	250,000
Ian Karten Charitable Trust /	117,679	0
Eranda Foundation	100,000	0
James Lewis Foundation	0	100,000
Fidelity Foundation	97,000	0
37 x grants 2011/ 43 x grants 2012	266,504	317,385

## 14. What steps is your organisation taking to reduce its carbon footprint?

All staff and students at Young Epilepsy follow environmental policies aimed at reducing the carbon footprint of the organisation including recycling paper, light bulbs and other equipment, offsetting waste on site and sending IT equipment for refurbishment and donation abroad.

Young Epilepsy's facilities team analyse our energy efficiency and running costs of buildings. In 2015 we will replace the school on our campus, which supports young people severely affected by epilepsy, many of whom also struggle with complex physical and behavioural needs. The new school is predicted to produce around a 65% saving on energy costs and usage compared to the current buildings which were built in the 1950s. The new school footprint is 2,723 sq.m in comparison to the old of 2,894 sq.m, this marginal size difference will further reduce energy needs and demolition of the old buildings will give back further land to Green Belt.

## 15. Purpose

Complete this section whatever the amount of grant requested. **In addition**, if the request is for £25,000 or more in total, a fuller proposal should be sent with this form. Also, if your application is for all or part of new or existing post(s), please enclose a copy of the relevant job description(s) including the salary level.

**In order to provide the right information, please refer to guidance note 15 before completing this section.**

Despite epilepsy affecting 112,000 young people in the UK, it remains a largely ignored condition that creates a devastating legacy of isolation and underachievement. Around 50% of young people with epilepsy will not reach their educational potential due to memory problems, seizures and learning disabilities. They are less likely than peers to go to university, have professional careers and even families of their own. Epilepsy affects all aspects of life including development, learning and self-esteem in addition to its potentially disabling physical affects. The unpredictability of seizures can make young people feel permanently disempowered meaning they are four-times more likely to have a psychiatric condition, like depression or anxiety. They face serious disadvantage at school and when 'transitioning' into employment, independent living, further education or parenthood.

David is a bright 18 year-old but left school with no qualifications, feeling he cannot '...even get a job at McDonalds'. Epilepsy meant his education was frequently interrupted and he was excluded. For 3 years Young Epilepsy has worked to reduce bad practice in schools which leaves children with epilepsy lagging behind peers. Epilepsy Education for Schools (EE4S) improves lives by combating stigma and supporting children to reach their potential. However, for David, already at the point of transition, there is little specialist support available. We desperately need to address this situation. Teenagers need expert help to identify options as support of friends and family alone is not enough. EE4S supported 1,500 children with epilepsy in 500 London schools, but we urgently need to offer transition support to these vulnerable young people as they embark on adulthood.

David was promised local support to enrol in college. However, help materialised too late, meaning he faces another year not in education/employment, feeling 'worthless'. 90% of 106 young people with epilepsy we surveyed agree transition support is needed. Families report to our helpline it's like falling 'off a cliff edge' when paediatric services are cut off, just at the point this group must take control of their lives, making the decisions that parents/carers often made. Our research shows specialist support does not currently exist in London and students with epilepsy in mainstream schools/colleges are some of the most in need. They are often sidelined by educational professionals who do not understand the complexity of epilepsy.

Partnership from the City Bridge Trust can transform these futures. By listening to young people's concerns, we have designed a service to support them in becoming independent and confident adults. They deserve a high quality, reliable support service that is not discontinued simply because an individual reaches their 18th birthday. Our Transition Support Worker will help young people identify choices and take control of their lives. Over 3 years their specialist epilepsy knowledge, supported by the wider organisation, will help young Londoners to make positive differences, raise aspirations, take up employment, manage their condition, move into further education and live independently.

Connections to beneficiaries will be made via our contact with London schools, links to Epilepsy Clinics/local authorities and through direct contact with families. The service will target those newly diagnosed to offer the additional support they need. Our connections, long-standing expertise and fact our services are designed with beneficiaries make us the right organisation to deliver this work. In 2013 we are delivering Transition Workshops to 60 teenagers in London/Surrey. Feedback from these interventions will influence the Support Worker's 2014 programme of activity. If valuable to beneficiaries similar workshops may be delivered.

### Objectives

More young people with epilepsy will:

- access further education/employment/work experience
- live independently
- achieve greater independence/control in epilepsy management
- feel more positive about their choices



**16. Explain how you will monitor and evaluate both your own outcomes and those of the programme under which you are applying.**

Beneficiaries will complete a base-line survey prior to support and a post-intervention survey. These will evaluate the impact of activity by measuring changes in young lives including reports of increased:

- choice/control
- engagement in education/employment
- independent living/lifestyle management
- health-related knowledge
- positive attitudes towards lifestyle choices
- self-esteem and lower instances of 'risky' behaviours
- engagement with health services

These measures will help us to track provision of more positive transitions to independent living. We will also record relevant data such as incidences of hospital admissions, exclusion from education/employment and key steps such as job interviews. This data will be used to monitor if lifestyle has been improved with a full impact report after 3 years. Case studies will be collected to candidly reflect how wellbeing has been affected. We will continually incorporate user feedback into the design and delivery of interventions.

**17. Beneficiaries**

In line with our anti-fraud policies, we may, in exceptional circumstances, require you to provide contact details of your beneficiaries (see Guidance Notes).

How many people will benefit from the grant per year?

**100**

What age group will benefit? **Over 16 years, Adult**

In which local authority is your organisation based?

**Westminster**

Which borough(s) of Greater London will benefit from this grant?  
(if more than one, please give % for each)

**Support from the Transition Support Worker will be available to young people across all Greater London boroughs**

At what address will the activity be located?

**The Transition Support Worker will provide group and one-to-one activities in schools, community centres and health clinics across all London boroughs where beneficiaries reside.**

What will the ethnic grouping(s) of the beneficiaries be?

	%		%
White - British		Black - Caribbean	
White - Irish		Black - African	
White - Other (please describe)		Black - Other (please describe)	
Asian - Indian		Black - British	
Asian - Pakistani		Chinese	
Asian - Bangladeshi			
Asian - Other (please describe)		Other (please describe)	
Open to everyone			<b>100</b>

What proportion of the beneficiaries will be disabled people?

**100%**

### 18. Funding required for the project

What is the total cost of the proposed activity/project?

(List main expenditure headings and amounts)

Expenditure heading	Year 1 £	Year 2 £	Year 3 £	Total £
Transition Worker Salary	30,000	30,900	31,827	92,727
On costs @20% of salary	6,000	6,180	6,365	18,545
Travel	2,985	3,075	3,136	9,196
Materials/ Organisational support costs	8,000	8,240	8,487	24,727
<b>TOTAL</b>	<b>46,985</b>	<b>48,395</b>	<b>49,815</b>	<b>145,195</b>

What income has already been raised? (List amounts and main sources)

Source	Year 1 £	Year 2 £	Year 3 £	Total £
N/A				
<b>TOTAL</b>				

What other funders are currently considering the proposal?

Funder	£
N/A	
<b>TOTAL</b>	

### 19. Funding requested from the Trust

How much is requested from the Trust? (List main expenditure headings and amounts)

Expenditure heading	Year 1 £	Year 2 £	Year 3 £	Total £
Transition Worker Salary	30,000	30,900	31,827	92,727
On costs @20% of salary	6,000	6,180	6,365	18,545
Travel	2,985	3,075	3,136	9,196
Materials/ Organisational support costs	8,000	8,240	8,487	24,727
<b>TOTAL</b>	<b>46,985</b>	<b>48,395</b>	<b>49,815</b>	<b>145,195</b>

## 20. Funding requested from the Trust (continued)

When will the funding be required?

**01/01/2014**

Is the activity to continue beyond the period for which funding is requested?  
If so, how will it be resourced?

**We expect the work will need to continue after 3 years. Over the grant period we will monitor and evaluate the success of the work, gathering a body of evidence of the need for the service and its positive impacts into young lives. We hope this evidence will attract additional voluntary funding in future.**

If any planning or other statutory consents are required for the project to proceed, what stage have the applications reached?

**N/A**

## 21. Referee

Please provide us with the contact details of a current or recent funder of your organisation who is willing to act as a referee.

### Referee

**Name:** Abigail Knipe

**Organisation:** Paul Hamlyn Foundation

**Address:**

5-11 Leeke Street  
London  
WC1X 9HY

**Tel:** 0207 8123300

**E-mail:** aknipe@phf.org.uk (preferred contact method)

## Declaration on behalf of applicant organisation

I, JULIA PHILLIPS (your name)

am an authorised representative of

YOUNG EPILEPSY (NCYP) (your organisation)

within which I am FUNDRAISING MANAGER (your position)

**To the best of my knowledge, all the information that I have provided in this application form is correct. I fully understand that the City Bridge Trust has zero tolerance towards fraud and will seek to prosecute and recover funds in every instance.**

Signature  Date 3/7/13

### How your information will be used by the Trust

City Bridge Trust (which is administered as part of the Bridge House Estates by the City of London Corporation) processes personal data in compliance with the Data Protection Act 1998. The Trust obtains and uses information, including personal data, as part of the process of assessing grant applications and monitoring the use of grants. The information you provide on the application form may be made public as part of the assessment of this application. In addition, the Trust may share this information with third parties, including other funders, its external consultants and external auditors, police and regulatory bodies for the purpose of determining, preventing or detecting crime; or ensuring that no organisation is receiving duplicate funding; or the validation of contracts; or where this is otherwise required by law.

**By signing and submitting your application form you give your explicit consent for us to use data relating to your application as set out above.**

Our contact details for enquiries about how we process your information are:

The City Bridge Trust, City of London, PO Box 270, Guildhall, London EC2P 2EJ. Telephone: 020 7332 3710

### Concerns over fraud and corruption

Should you, at any time, have concerns of fraud and corruption within your organisation relating to the grant, then please raise your concerns with us using our Whistle Blowing facilities. You may use our Audit team's 24 hour answer phone number, 020 7332 3663, to report the details or email [raiseyourconcern@cityoflondon.gov.uk](mailto:raiseyourconcern@cityoflondon.gov.uk)

**Return the completed form to: The City Bridge Trust**

City of London  
PO Box 270  
Guildhall  
London EC2P 2EJ

### Please

- **do not send this application by fax or e-mail** - unless applying online, applications must be posted to the Trust
- **do send the information in the checklist** - if items are missing, your application will be returned to you
- **do send only the information in the checklist** - if further information is required, we will contact you
- **do ensure you have signed and dated this form** - we cannot accept forms which have not been signed and dated
- **do use the correct postage** - the completed form and additional materials are likely to exceed 100g in weight