

MEETING: 06/06/2013

ANNEX NUMBER: 8

ASSESSMENT CATEGORY - Positive Transitions to Independent Living

Society for Mucopolysaccharide Diseases

Ref: 11472

Amount requested: £77,434

Adv: Joan Millbank

Base: Outside London

Benefit: London-wide

Amount recommended: £77,400

Purpose of grant request: Improving daily life and prospects for young adult MPS patients whose recently-enhanced life expectancy leaves them in the largely-unchartered waters of transitioning into young adulthood.

Background

The Mucopolysaccharide and related Lysosomal Storage Disorders (MPS) are a group of twenty four rare, life-threatening genetic conditions. All forms of MPS are irreversibly degenerative and bring increasing physical disability, skeletal deformity and major organ damage. Approximately 50% of all MPS conditions also result in Progressive Neurological Degeneration (PND), leading to double-incontinence, the loss of the ability to walk, talk and feed oneself. Approximately 1 in 25,000 babies born in the UK have some form of MPS. Many die in early childhood although improved disease management and drug therapies offer enhanced life expectancy to some. Currently there are around 1200 families in the United Kingdom affected by MPS. MPS occurs in all communities, although people from the Indian sub-continent are in higher risk.

The Society for Mucopolysaccharide Diseases is the organisation for MPS sufferers in the UK and their families. It provides advice and support including a helpline and befriending network; raises awareness and provides specialist literature to health professionals; fundraises for and undertakes research including clinical trials; and campaigns for changes in national policy and practice. It collaborates with other MPS societies across the world. Founded in 1983 the Society incorporated as a charitable company limited by guarantee in November 2011.

Funding History

In 2005 you made a grant of £50,000 to fund a London-wide individual advocacy service to benefit 100 people suffering from Mucopolysaccharide diseases. The grant was satisfactorily monitored.

Current Application

Advances in medicine and the development of new treatments have meant that more individuals with MPS are living into their teenage years and beyond. This creates new challenges for the individuals, their families, health and social care professionals. In 2010, funded through a two-year grant from Henry Smith Charity, the Society began to identify and pilot services needed to help young people with MPS experience

successful transition into adulthood. Following extensive consultation, Best Practice Guidelines have been drafted to inform clinicians; these are currently awaiting adoption by the Department of Health. A Transition Passport has also been prepared to provide young people and their parent/carers with an accessible guide to issues involved in moving from paediatric to adult services including information on health and social care, benefits and education, and to help them share their views and wishes with parent/carers and the professionals involved.

The Society has identified the need to build on and further develop transition support. It is seeking your support towards the employment of a Transition Advocacy Support Officer. The postholder will develop a bespoke, culturally-sensitive, advocacy service for young people aged 14 to 26 years, assisting them to make informed life choices for themselves including living independently if desired. The postholder will also help parents/ carers to understand and respond appropriately as their children move towards young adulthood. You are also asked to contribute towards work associated with the implementation of the Best Practice Guidelines, the promotion of the Transition Passport supporting independent living, and the development of another transition passport for young MPS sufferers who cannot live independently. Costs include workshops and focus groups, events and conferences, literature and website.

There are approximately 200 young people with MPS conditions; your support will benefit up to 100 young people with MPS who either live in London or who have to come to London to receive treatment. Match funding is being sought from elsewhere to meet the costs associated for those who live or receive treatment elsewhere in the country. Benefits of this work include improved quality of life, increased access to life opportunities, increased numbers of young adults living independently, improved family relations, policy change and new services to benefit young people and young adults with MPS and related conditions. Monitoring will take place using case reviews, peer reviews and user feedback; mechanisms which are already well established within the Society.

Financial Observations

The charity has changed its financial reporting period following incorporation as a new company limited by guarantee on 2nd August 2011. Therefore, audited accounts are for the period 2nd August 2011 to 31st December 2012. They show income of £3,279,503 and an end-of-year surplus of £1,490,739 (45.5% of turnover), comprising a surplus of £1,011,916 on restricted activity and £478,823 on unrestricted funds. However, the overall surplus has arisen due to the transfer £1,653,641 of funds previously held by the unincorporated charity (unrestricted funds of £567,951 and restricted funds of £1,085,690). Without these transfers, the remaining operating activity would have been an overall deficit for the

96
period amounting to £162,902, comprising a restricted funds loss of £73,774 and unrestricted fund deficit of £89,128.

The charity's reserve policy states that Trustees aim to hold free unrestricted reserves equivalent to six months' running costs, which based on current year expenditure equates to £956,800. At 31st December 2012 there were no free unrestricted reserves; they were in a negative position amounting to £133,064. The charity does have equity of £582,701 in its premises (outstanding mortgage of £175,000 and a book value of £757,701) and the Trustees view this as its reserve fund until the charity manages to build up free unrestricted funds. However, this could be considered a vulnerable position given that this equity is not readily available.

The budget for the current year 2013 shows projected income of £1,919,600 against expenditure of £1,913,602; with the small surplus of £5,998 on unrestricted funds. MPS has secured £1,270,176 (66% of total income) to date through grants and generated income including agreements for clinical trials.

Officer's Appraisal

The application provides you with an opportunity to support a particular group of young people experiencing acute disadvantage and emerging needs as advances in treatment mean they can live longer and move into adulthood. The request clearly addresses your area of interest in regards to positive transitions to independent living and as such a full grant is recommended, albeit with a condition reflecting the current finances of the organisation.

Recommendation

£77,400 (£25,000; £26,800; £25,600) towards a salary and running costs of a transition advocacy project on condition that match funding is secured. Release of the grant in year 1 is subject to receipt of satisfactory quarterly management accounts.



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)

11472

Date Received:

08/11/12

Programme
Area:

6

1. About your organisation

Name of organisation applying for grant: Society for Mucopolysaccharide Diseases	
If the organisation is part of a larger organisation, what is its name? N/A	
Address for correspondence MPS House Repton Place White Lion Road Amersham BUCKS	
Postcode: HP7 9LP	
Is this your home address? No	
Contact person: Mrs Christine Lavery	Position: Chief Executive Officer
Phone: 0845 389 9901	Fax: 0845 389 9902
E-mail: mps@mpssociety.co.uk	
Website: www.mpssociety.co.uk	
Legal status of organisation: registered charity	
If registered, please give charity number: 1143472 SC041012	
Year and month organisation established: 05/1982	

2. Request for funds

Under which of the Trust's themes are you applying (see our website or brochure for further details)? Positive transitions to independent living
Purpose for which funds are requested: (25 words maximum) Improving daily life/prospects for young adult MPS patients whose recently-enhanced life expectancy leaves them in the largely-unchartered waters of transitioning into young adulthood.

93

How much funding is requested?

Year 1: £25,050 Year 2: £26,728 Year 3: £25,656

Total: £77,434

3. Aims of your organisation

The MPS Society's prime objectives are to:-

- Support all those affected by MPS and related lysosomal diseases
- Raise awareness of these conditions among professionals and the public
- Promote research into cause, cure, prevention and relief of these diseases
- Ensure useful research findings of such research are published

4. Main activities of your organisation

The MPS Society is the sole voice representing and supporting all MPS patients in the UK, their families, other carers and healthcare professionals. Core activities include:

- An individual, needs-led advocacy and support service
- A palliative, end-of-life and bereavement service
- A telephone helpline, including out-of-hours support
- MPS Befriending network
- Bespoke MPS clinics & disease-specific information days/workshops
- Sibling workshops and respite activity weekends
- Extensive library of specialist literature and other information resources
- Quarterly MPS Magazine and MPS Children's Newsletter
- Regional, national and international conferences
- Funding into research and therapies
- Clinical trials support
- Developing new services as patients' needs change - i.e Transition Services for young MPS adults now offered longer life expectancy, and to which this application relates

5. Number of staff

Full-time	Part-time	Management committee members	Active volunteers
10	4	12	150

6. How do you support your volunteers?

Office v'teers are inducted & trained in work they will do; specific staff manage/support them. Childcare V'teers are trained in general m'ment of MPS patients & more complex procedures. All are CRB-checked, paid expenses, valued & respected.

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?
0%Owned, under mortgage	

8. Finance

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

Financial year ended - 31st Month: December

Year: 2012

Income received from:	£
Voluntary income	62,489
Activities for generating funds	171,775
Investment income	4,682
Income from charitable activities	1,386,916
Other sources	1,653,641
Total Income	3,279,503

Expenditure:	£
Charitable activities	1,562,005
Governance costs	21,235
Cost of generating funds	70,797
Other	134,727
Total Expenditure	1,788,764
(Deficit)/surplus for the year:	1,490,739

Asset position at year end	£
Fixed assets	757,701 763,801 <i>SM</i>
Investments	6,100 25,000 <i>SM</i>
Net current assets	872,751 847,751 <i>SM</i>
Long-term liabilities	(145,813)
*Total A	1,490,739

Reserves at year end	£
Endowment funds	0
Restricted funds	1,011,915
Unrestricted funds	478,824
*Total B	1,490,739

* 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?
0

10. Material changes

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

The Trustees decided to incorporate a new company limited by guarantee ("the new company") which acts as the successor to the unincorporated entity took place in October 2011 when all the assets were transferred.



11. Previous applications to the Trust

Have you applied to the Trust before? If so, please give details:					<input checked="" type="checkbox"/>
Month/Year: Dec	/ 2005	Ref: 6813/1	Grant received: £50,000	OR application rejected	<input type="checkbox"/>
Month/Year: -	/ -	Ref:	Grant received: £	OR application rejected	<input type="checkbox"/>
Month/Year: -	/ -	Ref:	Grant received: £	OR application rejected	<input type="checkbox"/>

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: 2009	Year: 2010	Year: 2011
(i) Leathersellers Company		3000	3000
(ii) Mercers Company	7000		
(iii) Help a London Child		1075	
(iv) Bernard Sunley		5000	10000
(v)			
(vi)			

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: 2010	Year: 2011
Bailey Thomas		10000
Bernard Sunley	5000	10,000
Constance Green		5000
Eveson Charitable Trust	15000	15000
Hobson Charity Ltd	20000	
The Henry Smith Charity	30000	30000

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

Biggest challenge is car use, as our Advocacy Officers cover the UK. Whilst some aspects of their work with/for patients/families can be undertaken by phone/e-mail, a significant amount of travel is still necessary to visit patients/families in person, especially newly-diagnosed families or those at key stages in the progress of their MPS condition. MPS Officers also facilitate specialist MPS Clinics held in all UK countries; visit healthcare & educational professionals, local government agencies, research centres etc; staff arrange visits/appointments to optimise on their time & mileage; they liaise before attending meetings/training sessions etc to see if travelling with colleagues is an option if public transport is not feasible. Moving to modern premises in 2006 provides a more eco-friendly building; we ensure temperature settings are low/off when rooms are not in use, overnight & at w'ends; lights are switched off; computers, printers/other electronic equipment not left on standby. We use eco-friendly cleaning materials and recycle all possible materials. With new equipment we aim to identify items kind to the environment, made from sustainable materials. We actively encourage members to accept/send information from/to us electronically, saving paper & postage. We plant saplings in our Childhood wood yearly.



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.

MPS diseases are a group of extremely rare genetic conditions & until recently most patients died in early childhood. Improved disease management & early drug therapies now offer enhanced life-expectancy to some young patients; but also present new, very testing challenges for young patients/their families; also for health, social care & educationalist involved in their care. The Society has needed to extend its expertise in all legal, medical & social areas affecting MPS children, to understand & respond to the uncharted challenges faced by those transitioning to adulthood who want to exercise choice over further education, independent living, employment, travel, relationships, having children etc. Given the extreme mental & physical disabilities caused by many MPS diseases, such options are not open to all those surviving childhood. For these young people we need to understand & advise on other issues: suitable care provision, who should manage finances, make decisions re social care, medical/clinical management etc. We are in direct contact with 99% of all MPS patients, providing a unique insight into new needs, such as those of transition. It has allowed us to collect direct evidence of ways in which health, social care & educationalists are ill-equipped to understand/respond effectively to the transitioning needs of MPS patients, with case-work examples of young MPS adults suffering serious medical complications, even death, through this ignorance/insensitivity. In 2010 a 2-year grant from Henry Smith Charity enabled us to start to explore transition issues affecting those with MPS, & develop appropriate responses. We work closely with those facing transition, from those aged 14 - a watershed age in education - through to the few MPS patients surviving into their early 20's. We now understand barriers that ensure poor, even life-threatening experiences; & the battles of those overcoming such barriers -e.g. many young people with MPS IV are intellectually capable of succeeding at university but, trapped in a body the size of a 4 or 5 year-old, are invariably denied the opportunity; others with different forms of MPS want to live independently, but cannot, unless agencies understand their particular needs re accessible accommodation, personal care, access to training/ employment etc. Where successful transition & greater independence is achieved, it is invariably through the forceful intervention of our embryonic Transition Service. To sustain its momentum we need to work in 4 specific areas, each dependent on securing the funds to meet the costs of our Transition Advocacy Officer for at least 3 more years.

1. 'Best Practice' Guidelines on transition of all patients with MPS or related Lysosomal storage disease: we submitted these to the Department of Health & want to ensure they are reviewed, to be adopted by end 2013;
2. Health Transition Passports: we have developed a Passport for use by patients at various stages of transition & which service providers also need to adopt; we need to audit its use, efficacy & sustainability & see it published by end 2013;
3. Once the Passport is proven, we will develop an alternative Passport for those young patients who do survive childhood but cannot live independently; they too need to know their options, particular re palliative care; to be ready by mid 2015;
5. Develop a bespoke Advocacy Service for young people seeking independence: we receive an increasing number of requests to advocate for young people wanting to become independent, but whose parents have different ideas as to what their 'child' can do; even instances of patients refusing regular treatments, feeling this is the only control they have over decisions affecting their lives. We started as a small parent-led support group & we remain committed to our 'volunteer-led' roots. Volunteers help in the office, fundraise, give talks and train to support MPS children at various Society events. Most Trustees have/had a child with MPS. Like all our services, MPS Transition Services are being shaped by the experiences, views and aspirations of patients. Services for younger children reflect greater input from parents who care daily for their child; by contrast Transition Services support/encourage the natural 'letting go' that most parents of healthy children welcome. MPS affects people of all backgrounds/races/ethnicity, with some 10% of those in the UK being from the Indian sub-continent; we ensure services reflect the cultural needs of these patients/families.

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

Rigorous established monitoring/evaluating processes of all aspects of our work ensure we sustain highest service delivery standards & respond rapidly to new/changing needs. Regular case-work reviews & peer-review sessions by Advocacy Officers & the CEO also identifies best practices, shared with external partners. We encourage formal & informal feedback from all users (patients, parents/carers, healthcare professionals, researchers, educationalists); Conferences, workshops, family days etc often include focus group & feedback questionnaires. Views of children/siblings are important & monitoring the situations they face on becoming teenagers highlighted the need for an MPS-specific response to transition issues. To monitor & evaluate Transition work we will use a cross-section of the 203 young MPS adults aged 14-25, including 48 who live in, or attend MPS Centres of Excellence in Greater London. The 203 young adults are the first significant cohort to survive beyond childhood & will provide data & empirical evidence to show:

- continuing improvement in the transition experience;
- impact of the Guidelines we have written, submitted & anticipate the Department of Health will adopt;
- value of the new MPS Passport in enabling young MPS adults to champion/secure their own rights to the treatments/services they want/know to be appropriate.

Overall, we will be able to monitor & demonstrate those factors most effective in emancipating young MPS adults now, & offering a better, more aspirational future for those who will follow - a number set to increase as research allows longer life-expectancy to more MPS patient.

17. Beneficiaries

How many people will benefit from the grant per year? **up to 100**

In which local authority is your organisation based?
Buckinghamshire; The Chilterns

Which borough(s) of Greater London will benefit from this grant?
(if more than one, please give % for each)
We will work with all transition-age patients living in Greater London, and/or attending MPS hospitals/clinics in Greater London

At what address will the activity be located? **The Transition Advocacy Officer is based at our Amersham office**

What age group will benefit? **14-26**

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

	%		%
White - British	54	Black - Caribbean	6
White - Irish	4	Black - African	6
White - Other (please describe) Australian	2	Black - Other (please describe)	
Asian - Indian	6	Black - British	
Asian - Pakistani	6	Chinese	
Asian - Bangladeshi	6		
Asian - Other (please describe) Sri Lankan	4	Other (please describe) Turkish/Polish	4/2
Open to everyone			yes

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 £
Staff costs Transition Advocacy Officer	31800	32436	33085	
Travel & subsistence	4500	4590	4680	
Training	350	350	350	
W'shops with healthcare/other agencies	750	750	250	
Focus gp mtg wits transition patients	1000	750	500	
W'shops for parents/profs/patients	1000	750	500	
Finalising/producing 1 st Trans. Passport	250	1000	250	
Drafting/testing/prod 2 nd Trans Passport	250	250	750	
Running Transition Conferences	250	1200	750	
It/tel/post/ etc	350	350	350	
M'ment o'heads, incl mon/eval work	2500	2550	2600	
P/T admin support,	4500	4590	4680	
2 region social transition events	2000	2040	2082	
Transition literature/webpages	350	850	350	
TOTAL	48850	52456	51177	

What income has already been raised?

(List amounts and main sources)

49850

Source	Year 1 £	Year 2 £	Year 3 £	Total £
TOTAL	0	0	0	0

What other funders are currently considering the proposal?

The J P Getty Trust. Others going to Lennox & Wyfold & Norton Foundations as each considered Transition applications before we secured Henry Smith grant. We also will ask Henry Smith to consider further funding this work.

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 £
50% of staff costs (Adv post+Admin)	18150	18513	18825	
50% of travel/subs	2250	2295	2340	
50% of all workshop/focus gp mtgs	1375	775	625	
50% of all work on Transition Passports	250	625	1000	
Transition Conference	250	1200	0	
50% of project o'heads, in m'ment	1425	1450	1475	
London social transition event	1000	1020	1041	
Transition literature/webpages	350	850	350	
TOTAL	25,050	26,728	25,656	77,434



20. Funding requested from the Trust (continued)

When will the funding be required? **April 2013- March 2016**

Is the activity to continue beyond the period for which funding is requested?

If so, how will it be resourced? **Yes; we piloted Transition Services in 2011 with a grant from Henry Smith Charity which ceases 03/13. We hope City Bridge Trust will part-fund the work 'till 03/16, with other grant-making trusts providing the balance & continuation after; we will also secure income from corporates; also from individuals keen to see Transition Services fully developed & universally available**

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

Declaration on behalf of applicant organisation

I, **Christine Lavery** (your name)

am an authorised representative of

The Society for Mucopolysaccharide Diseases (your organisation)

within which I am **Chief Executive Officer** (your position)

To the best of my knowledge, all the information that I have provided in this application form is correct

Signature

Date **5 Nov 2012**

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