

A note from our Chairman

Dear Friends,

On behalf of everyone at the Gauchers Association I would like to say that we are extremely proud of the benefits that have been reaped by the many people who have received awards through the Susan Lewis Memorial Award since its launch in 2008. We are sure that Susan herself would be equally proud to see her aim of educating and supporting doctors and healthcare professionals being achieved.

All those who form part of the Gaucher Community are extremely fortunate that there is now so much interest in rare diseases around the globe. This is true of Gaucher Disease, and more generally Lysosomal Storage Disorders, and there are now many opportunities for doctors and healthcare professionals to extend their knowledge of Gaucher Disease whether through visiting specialist centres in countries more advanced than their own, having the benefit of Gaucher/LSD specialists visiting their own countries or attending international conferences and presenting lectures.

Through the Susan Lewis Memorial Fund we hope that these opportunities can be grasped by even more doctors and healthcare professionals no matter where they are from and no matter what their current experience of Gauchers Disease is; ultimately with the hope of supporting the future generation of Gaucher experts and achieving Susan's ambition to improve the lives of as many Gaucher patients as possible.

Dan Brown



Our achievements

The Susan Lewis Memorial Award is available to provide grants and bursaries to doctors and healthcare professionals not only from developing countries but also the UK. Here are a few successful applications that have been approved since 2008:



Dr Rebecca Jones, a Senior House Officer at Chester Hospital was awarded a travel grant to attend the International Society of Haematology meeting in Mexico in 2012 to present a poster on a patient with Gaucher disease.

Dr Elad Shamash, from the Department of Clinical Biochemistry at Ben-Gurion University of the Negev Israel received a grant to attend the 10th European Working Group on Gaucher Disease (EWGGD) in Paris during 2012. Dr Shamash says The EWGGD was an interesting and educative experience.



Dr Filippo Vairo from Brazil visited the UK for a period of 4 weeks supported by the Susan Lewis Memorial Fund in 2013 spending time at various Hospitals, Research centres & Homecare offices. Dr Vairo says: *"During my visit I learned how a successful public health system works and I met incredible people who have the common objective to help patients with Gaucher disease."*

Dr Elena Pavlova from Addenbrookes, Cambridge writes: *"I am a clinician with several years of research experience in the Gaucher disease field. My current research focuses on studies of multiple myeloma and lymphoma in Gaucher disease. I attended the 19th European Study Group on Lysosomal Diseases (ESGLD) Workshop in September 2013. The comprehensive overview of the Lysosomal diseases that I gained during this meeting is of a great value and many of the discussed methodological approaches I now use in my current research work."*



In 2014 the Susan Lewis Memorial Fund provided travel grants to four leading scientists from the UK, France and USA to attend the Lysosome Related Organelle Conference in Spain. This meeting brought together many researchers allowing them to exchange findings and set up new collaborations in the Lysosomal Storage Disorder (LSD) field.

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Gauchers
ASSOCIATION

The Susan Lewis Memorial Award



www.gaucher.org.uk

- Bursaries for post docs to attend conferences
- UK specialists to visit overseas clinics to provide support and guidance to doctors in developing countries
- Specialists involved in the LSD field to travel to educational lectures and LSD conferences
- Medical students to do their electives overseas.

In the name of Susan Lewis we want to enhance and support the education of doctors and healthcare professionals who are interested and or involved in treating Gaucher disease and their teams to achieve greater knowledge and develop a level of expertise.

What is the award about?

In 2008, the Gauchers Association launched the Susan Lewis Memorial Fund in memory of Susan who passed away in May 2007. The fund was supported by donations from family, friends, Association members and the pharmaceutical and homecare companies involved in Gaucher disease.

The purpose of the fund was to provide grants and bursaries to doctors and other healthcare professionals from developing countries (particularly in Eastern Europe) to allow them to travel to UK Centres of Excellence to undertake mentoring and educational programmes in the treatment and management of Gaucher disease.

In 2009, Dr Daniela Avdijeva from Bulgaria was given the first award and spent four weeks in the UK visiting three of the Centres of Excellence for Lysosomal Storage Disorders (LSDs) and two homecare companies.

In the same year, in collaboration with the original donors to the fund, the Association awarded six bursaries to young scientists to attend the first ever Gordon Conference in Texas. All recipients provided a



write up on the meetings and their work into Gaucher disease and other LSDs in Gauchers News.

Following the success of the awards to the Gordon Conference, the Board of the UK Gauchers Association undertook a review in collaboration with the original donors and the members of the Medical Advisory Board for the Fund. It was agreed to expand the scope of the Fund to provide support in other areas of education including bursaries for post-doctoral students to attend conferences; UK specialists to visit overseas clinics to provide support and guidance to doctors in developing countries; specialists involved in the LSD field to travel to educational lectures and LSD conferences and medical students to do their electives overseas.

Full details of the five areas of funding opportunities can be found within this leaflet.

About The Gauchers Association

The Gauchers Association was formed in 1991 to meet the needs of those suffering from Gaucher disease, its main aims remain:

- To provide information on Gaucher disease and keep families and medical advisors in touch and up to date with the latest developments in the field.
- To encourage the availability of treatments for patients
- To encourage fundraising for medical research
- To publish a half yearly newsletter. It is now sent to over 1300 readers worldwide
- To maintain and keep updated its website at www.gaucher.org.uk
- To hold periodic conferences and workshops
- To represent the interest of Gaucher patients at all times to ensure that the voice of the Gaucher patient is heard.

The Gauchers Association is the only organisation in the UK that provides information and support to those with Gaucher disease, their families and healthcare professionals.

The Gauchers Association is managed by a Board of Directors consisting of Gaucher patients, their parents and their relatives who volunteer their time to achieve the aims of the Group.

A brief history of the award



Susan Lewis (1945-2007) was a founder member of both the UK Gauchers Association and the European Gaucher Alliance (EGA). The constant focus of all of Susan’s Gaucher activities was to help Gaucher patients and their families.



In 1991 when the UK Gauchers Association was first established patients’ prime need was information. One of the first things Susan did was to gather information from all sources and published a newsletter to disseminate everything that the Association had learned. She knew that the collective knowledge and experience would help patients. It quickly became

clear that the patients needed access to healthcare professionals experienced in treating Gaucher disease. In the UK relationships quickly developed with doctors and their teams who had both interest in Gaucher disease and had exposure to Gaucher patients.

Through the establishment of national patient associations, their contacts with other patient groups and the European Gaucher Alliance and through the internet and newsletters, patients throughout the world now have access to a considerable amount of information about Gaucher disease.

Susan’s contribution to the plight of the Gaucher patient was immeasurable. It spanned from the individual words of comfort and support to influence on national governments and international industry. Her aim was always to achieve what she believed to be the just entitlement of patients who had inherited Gaucher Disease.

Undoubtedly her greatest public challenge and her greatest achievement was her work through others in the EGA in helping, supporting and ultimately achieving treatment for patients in Eastern Europe.

In some parts of the world patients are unable to access expert doctors experienced in diagnosing, managing and treating their disease. Susan recognised that simply dispensing lifesaving treatment in urgent situations would not be an overall solution to the problems that Gaucher patients faced in the developing countries of Central and Eastern Europe. Structures needed to be put in place and physicians and other health care professionals needed to be educated in this rare genetic disorder and the sophisticated treatment possibilities. Initially she supported and encouraged efforts to bring doctors and health care professionals to public meetings and the Executive of the Gauchers Association in the UK felt that it would be a tribute that the Susan Lewis Memorial Fund be established to continue and enhance that work.



What are the areas of opportunity?

There are currently five areas of opportunity:

1. Providing funding to help doctors with little experience in treating Gaucher disease to achieve the excellent levels of expertise available to patients seen in the long established centres.

Outline: To enable doctors or healthcare professionals from countries which do not have a well-developed system for the treatment of Gaucher disease (principally Eastern Europe although applications will be considered from other developing countries) to travel to the UK Centres of Excellence where a programme will be individually tailored to take into account the applicants experience and special areas of Gaucher interest. It is essential that all applicants are currently involved in the field of Gaucher disease or other Lysosomal Storage Diseases.

Award: Maximum award will be £5,000 to cover travel costs, accommodation and will provide a small daily subsistence allowance.

Application process: A formal application to the Gauchers Association can be downloaded from our website at www.gaucher.org.uk with an agreement to provide a written report post attendance for the Gauchers News. All applications will be submitted to the medial advisory board for approval.

2. To provide bursaries for Post-Doctoral (fellow or researcher) to attend conferences i.e. B4B, WORLD and Gordon Conference

Outline: This bursary will be available to post docs working in research laboratories in the UK who are working on projects involving Gaucher disease.

Award: Maximum bursary awarded will be £1,500 to support travel, accommodation, registration fees and a daily subsistence of £50.

Application process: Written request to the Gauchers Association outlining the conference, reason for wanting to attend, benefit to the Gaucher field of research, expected outcomes of attendance. Written report required post attendance for the Gauchers News. All applications will be submitted to the medical advisory board for approval.

3. Providing funding for UK Specialists to visit clinics overseas to provide support and guidance to doctors in developing countries

Outline: To enable experienced doctors in the field of Gaucher and lysosomal storage disorder field to visit Gaucher and lysosomal storage disorder clinics overseas to share their knowledge on clinical management e.g. India, Jordan.

Award: Maximum award of £5,000 to cover travel costs, accommodation and a daily subsistence of £50 (or equivalent)

Application process: Written request to the Gauchers Association outlining the reason for the visit, an outline of the benefit to the Gaucher and lysosomal storage disorder field of research with expected outcomes of attendance and agreement to provide a written report required post attendance for the Gauchers News. All applications will be submitted to the medical advisory board for approval.

4. Providing funding for specialists involved in the LSD field to travel to educational lectures and LSD conferences

Outline: To enable specialists, e.g. orthopaedics; ophthalmologists; neurologists, to travel to meetings and where appropriate to present presentations/posters.

Award: Maximum awarded will be £1,500 to support travel, accommodation, registration fees and a daily subsistence of £50

Application process: Written request to the Gauchers Association outlining the nature of the lecture/conference, an outline of the benefit to the Gaucher and lysosomal storage disorder field of research with expected outcomes of attendance and agreement to provide a written report required post attendance for the Gauchers News. All applications will be submitted to the medical advisory board for approval.

5. To support the cost of medical students to do their elective overseas

Outline: To enable medical students to visit clinics or hospitals to do their elective overseas

Award: Maximum awarded will be £5,000 to support travel, accommodation, and a daily subsistence of £50

Application process: Written request to the Gauchers Association outlining the reason for visiting clinic/hospital and agreement to provide a written report post attendance for the Gauchers News. All applications will be submitted to the medical advisory board for approval.

Your questions answered

What will the fund cover?

Grants will cover travel costs, accommodation, registration fees and will provide a small daily subsistence allowance.

What is expected of the applicant?

All successful applicants will be required to provide a written report on the experience gained through being a recipient of an award which will be published in an edition of Gauchers News.

Who can apply?

Healthcare professionals from all over the world who are involved in the field of Gaucher disease or other lysosomal storage disease. Applicants wishing to apply to visit the UK Centres of Excellence; spending up to 6 weeks in the UK on the programme are required to read, speak and understand English to a high level.

How to apply?

Interested parties should complete an application form which is available in hard or electronic form from the Gauchers Association. Email ga@gaucher.org.uk or telephone **01453 549231**.

Electronic copies must be returned to ga@gaucher.org.uk and hard copies to **The Gauchers Association, 8 Silver Street, Dursley, Gloucestershire GL11 4ND.**

If you have any queries or would like to discuss this fund further please contact Sarah Allard, Information & Charity Officer on **01453 549231** or ga@gaucher.or.uk.