

The fiscal year 2017-18 has been one of further consolidation for Alfie's Trust. The Board of Trustees have continued to establish structure and targets, enabling work to continue strengthening links with other patient organisations.

This report outlines activities and achievements for the year 1st April 2017 to 31st March 2018.

1. Networking

a. Lymphangiomatosis and Gorham's Disease Alliance (LGDA)

Alfie's Trust continues to have close ties with the United States-based Lymphangiomatosis and Gorham's Disease Alliance (LGDA). Our Chair, Tracy Milne, attends quarterly virtual meetings of the LGDA Board.

LGDA will host a patient conference in July 2018, Tracy has been involved in the planning of this event and Alfie's Trust is likely to provide some financial support.

Alfie's Trust, the LGDA and LGDA-E are continuing efforts to improve information-sharing, particularly with reference to contact information for patients, doctors, researchers and supporters. This year saw us investigate shared global databases, but challenges have been encountered in relation to legal jurisdiction. These issues are unresolved at time of writing.

b. Lymphangiomatosis and Gorham's Disease Alliance – Europe (LGDA-E)

In addition to the US LGDA involvement, Tracy also chairs the LGDA-Europe with bi-monthly virtual meetings. Following on from a patient and family conference held in 2016, a meeting of volunteers has been arranged for May 2018 to progress work group projects. Tracy has been involved in the planning of this event.

An attempt has been made to formalise the structure of the LGDA-E and its member organisations. This process is ongoing.

A grant of £2,000 was awarded to the LGDA-E to cover costs of translation of the LGDA-E website and brochure into various European languages. This sum came from funds which had been restricted for LGDA-E use by the fundraisers.

c. Rare Disease Communities

Vascular, Lymphatic and Overgrowth Syndromes Working Group

Following an Open Day held at Great Ormond Street Hospital in June 2016, a meeting was held specifically to cover the transition of care from children's hospitals to adult. This led to a survey being issued to patients suffering from vascular, lymphatic and overgrowth syndromes to enable analysis of services available and gaps in care to be addressed. Survey responses were collated and have been handed to GOSH and other centres for further action.

Local Rare Disease Community

Efforts continue to build contacts in the local rare disease community, using NHS Grampian contacts to run a media campaign in the local press around Rare Disease Day in February. Working with Rebecca Stewart of Rare Revolution, an open event is planned for April to which individuals and organisations associated with rare conditions have been invited.

2. Patient Support

a. Lymphangiomatosis Facebook Groups

Alfie's Trust continues to work with the LGDA to administrate, monitor and participate in Facebook support groups. There are two groups with a combined membership of over 300 - a Patient Group (patients and parents only) and a Friends and Family group. These remain active communities.

b. Ad-hoc Enquiries

The charity also handles e-mails and telephone calls from those looking for information on lymphangiomatosis, and actively introduces ourselves to any new contacts received via GOSH, LGDA or other means.

3. Research

a. Great Ormond Street Hospital (GOSH) Genetic Research

Part-funded by Alfie's Trust in June 2014 and led by Dr Veronica Kinsler, a genetic research project at Great Ormond Street Hospital continues. This was expected to be a two-year project but is ongoing. Details are expected on further development of this project.

b. LGDA Research

Funds granted in 2016 have been directed towards research into screening and treatment of lymphangiomatosis and Gorham's Disease. No results have been received as yet.

c. Rudy Study

Details have emerged on the first UK rare bone disease study – The Rudy Study. Patients with lymphangiomatosis and Gorham's Disease have been invited by Alfie's Trust to take part. It is an online-based study which will track symptoms and collate data on the conditions. Due to the success of this study, it is to be expanded to cover all rare diseases in the near future.

4. Awareness

a. LGDA-E Website

As mentioned earlier, Alfie's Trust has contributed funds towards translation of the LGDA-E website. Further translation will continue to help reach non-English speaking patients, with further funds to be provided by Alfie's Trust early in the next financial period.

b. General Awareness Raising

As always, Alfie's Trust maintains a presence in local community press, and with our Alfie's Trust T-shirts and fundraising efforts at various local events throughout the year – see below.

2017 saw the inaugural global Lymphangiomatosis and Gorham's Disease Day on 26th May. This is registered with Eurordis and offers a terrific opportunity to engage the patient community and raise public awareness of the conditions. The week of Lymphangiomatosis and Gorham's Disease Day was used for a social media campaign featuring patients and their families telling their stories - "What it's like to be rare".

Alfie's Trust has subscribed to Rare Revolution, an organisation who publish an online magazine and have a social media presence with over 1,100 followers. An article was prepared and published in Rare Revolution, with a contribution from the Lymphatic Malformation Institute in the United States.

5. Fundraising

Over £25,000 has been given to the Trust in this financial year, the Financial Report contains full details of funds received during the year. We are pleased with this total, having met our stated fundraising target for the year.

Successful fundraising events included The Kiltwalk (which yielded a 40% bonus in funding, thanks to The Hunter Foundation), a Golf event, the annual Craft and Tea Afternoon and a very well-attended ceilidh.