

Alfie's Trust Annual Report and Year End Accounts

Reference and administration details

- Alfie Milne Lymphangiomatosis Trust
- Charity Registration Number : SCO43165
- Address : 49 Crown Crescent, Peterculter, Aberdeen, AB14 0SQ

Names of Trustees on date of approval of Trustees Annual Report

- Tracy Anne Milne : Chair
- Ashleigh June Reid : Secretary
- Myra Ann Repper Leiper : Treasurer
- Kathy Marie Mouser : Trustee

Structure, governance and management

Type of governing document : Trust Deed

Trustee recruitment and appointment : 27th April 2012

Objectives and activities

Charitable purposes

- a) Promoting awareness in the public of the needs of people affected by Lymphangiomatosis and related conditions and promoting supportive services that could benefit such people
- b) Supporting research into causes and treatment of Lymphangiomatosis and related conditions to advance knowledge about the conditions.

Summary of main activities in relation to these objects

- a) Promoting awareness by:
 - Media contact
 - Website
 - Events
 - Contact with MSPs
- b) Supporting research by:
 - Fundraising
 - Inviting interested parties to apply for grant of funds

Achievements and performance

Summary of main achievements of the charity during the financial period

Fundraising

Fundraising in support of the charitable purposes named above is the primary focus of Alfie's Trust. The fundraising strategy of Alfie's Trust in 2012-2013 has been to concentrate on few larger-scale events, namely:

- Balmoral Run
- Culter Gala
- Tea and Coffee Afternoon

In addition to these core events, a number of other fundraising activities have taken place – some organised by Alfie's Trust, others independently run and with proceeds donated to the charity. A full list of fundraising activities and breakdown of donations is available in the Annual Accounts and on the website www.alfiemilne.org.uk. In total, £60,806.03 was raised from the date of award of charitable status in May 2012 to the financial year-end on 31st March 2013.

Grants awarded

For Alfie's Trust to grant funds to projects relevant to its stated charitable purpose, an application form and process was developed. The first application form was issued to the Lymphangiomatosis and Gorham's Disease Alliance (LGDA), a US-based organisation who are working hard to progress research into lymphangiomatosis and to provide support for patients with the condition.

The completed application was received by Alfie's Trust on 14th March 2013 and the Board of Trustees responded to LGDA seeking clarification on a number of points. Funds will be issued only with the agreement of all Trustees. The application is for \$25,000 (approx. £16,500) towards three projects:

- The first International Conference in Science and Medicine on Generalized Lymphatic Anomaly (lymphangiomatosis) & Gorham-Stout Syndrome, to be held in June 2013
- Developing a patient registry to enable researchers and clinicians access to relevant patient and disease details
- Creating patient and doctor handbooks to aid in diagnosis and provide support to patients and their families

It is anticipated that the requested funds will be granted in the 2013-14 financial year, subject to satisfactory clarification from LGDA on queried points.

Awareness

Throughout 2012-13, Alfie himself and Alfie's Trust have featured regularly in local and national media. Fundraising events have been publicised in this way and press were also contacted at key milestones for Alfie, e.g. taking his first unaided steps in June 2012 and starting school in August 2012. Each press contact provided the opportunity to describe the challenges of living with a rare disease.

Alfie's Trust has an online presence in the form of a website (www.alfiemilne.org.uk) and a Facebook page (Alfie Milne Lymphangiomatosis Trust). Information about Alfie and his disease, fundraising events and results are published on the website, with links to other relevant sites, e.g. LGDA. The Facebook page has over 600 followers and is a more informal means of communicating details of Alfie's condition and charity events.

Rare Disease Day

28th February 2013 was International Rare Disease Day. This is an annual event which provides the rare disease community across the world the opportunity to increase awareness of rare diseases and highlight rare diseases as a public health priority to government and health departments.

Tracy and Mark Milne (Alfie's parents) attended a reception at the Scottish Parliament organised by Rare Disease UK (RDUK) and attended by MSPs. Personal invitations were sent to MSPs representing Alfie's local area. Three attended, but did not meet with the Milnes.

The focus of the reception was the publication of two reports, commissioned by RDUK, into the experience of patients and families living with a rare disease in Scotland. It is unclear whether there was any positive action or outcome arising from this event as regards rare disease policy in Scotland, but it did provide an excellent opportunity to meet with patients and care-givers who share a common goal – improving the lives of those suffering from rare disease.

Patient Support

As well as potentially funding projects run by LGDA, in order to further the aim of improving patient support in the UK, Alfie's Trust have investigated a UK initiative - Patients Know Best. This is an online system with clear benefits for individual sufferers, their families and clinicians involved in their care. Benefits for wider patient support and as a potential research tool are still to be evaluated. It is likely that the Milne family will subscribe to the service to act as a pilot of the system, allowing more detailed analysis before recommending it as a tool for other sufferers.

Financial Review

Brief Statement of the charity's policy on reserves

If no appropriate project is identified, the funds will be carried over for 12 months, in accordance with the Trust Deed.

Other optional information

The Trust has raised a considerable sum of money this year. Although no funds were allocated in the year to March 2013, we have, in April 2013, made a grant of £16,500 to the Lymphangiomatosis and Gorham's Disease Alliance.

Developing the grant application and approval process, and the ensuing discussion with the LGDA in clarifying the purpose and scope of the grant awarded, have given the Trustees a better understanding of where funds can be best utilised in the furtherance of research into, and development of diagnosis/treatment options of lymphangiomatosis and related conditions. This marks the first step in our quest to share and improve worldwide knowledge in this matter.