

APPENDIX 1



Trustees' Annual Report for the period							
Period start date				Period end date			
	Day	Month	Year		Day	Month	Year
From	1	04	2013	To	31	3	2014

Office of the Scottish Charity Regulator

Reference and administration details

Charity name	Alfie Milne Lymphangiomatosis Trust
Other names charity is known by	Alfie's Trust
Registered charity number	SC043165
Charity's principal address	49 Crown Crescent, Peterculter, Aberdeen
	Postcode AB14 0SQ

Names of the charity trustees on date of approval of Trustees' Annual Report

	Trustee name	Office (if any)	Dates acted if not for whole year	Name of person (or body) entitled to appoint trustee (if any)
1	Tracy Anne Milne : Chair			
2	Ashleigh June Reid : Secretary			
3	Myra Ann Repper Leiper : Treasurer			
4	Kathy Marie Mouser : Trustee			
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Reference and administration details

Names of all other charity trustees during the period, if any, (for example, those who resigned part way through the financial period)

Name	Dates acted if not for whole year

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 the main activities in relation to these objects

- a) Promoting awareness by:
 - Media contact
 - Website and social media
 - Events
 - Collaborating with other organisations where possible
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See **Section A- Awareness and Support** for detail
- b) Supporting research by:
 - Fundraising
 - Granting of funds towards appropriate projects

See **Section B – Fund Management** for detail

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Achievements and performance

Summary of the main achievements of the charity during the financial period

Section A – Awareness and Support

Media

Throughout 2013-14, Alfie himself and Alfie's Trust have featured regularly in local and national media. Fundraising events have been publicised in this way. Each press contact provided the opportunity to describe lymphangiomatosis, Alfie's story and the challenges of living with a rare disease.

Online

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. Lymphangiomatosis and Gorham's Disease Alliance (LGDA) and (Lymphatic Malformations Institute (LMI)). The Facebook page has over 750 followers and is a more informal means of communicating details of Alfie's condition and charity events.

Events

All Alfie's Trust fundraising events, and those where we are not the organiser, but are participating (e.g. Run Balmoral) are an opportunity to raise awareness of lymphangiomatosis, rare disease and Alfie's story. Many contacts have been made at these events and the Trust continues to develop our network of supporters to further our charitable purposes.

Collaboration

Rare Disease Day

28th February 2014 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.

This year, Alfie's Trust had the opportunity to work closely with NHS Grampian, Robert Gordon University (RGU) and Rare Disease UK (RDUK) to promote Rare Disease Day across five sites in Aberdeen and in the press. Information stands showing Alfie's family's story, among others, were placed in key NHS buildings. At RGU, Tracy Milne and Ashleigh Reid from the Trust, together with representatives from NHS Grampian and RDUK, had the opportunity to talk to Nursing and Physiotherapy students and RGU research and teaching staff about the issues and challenges facing patients with rare diseases. Information was available about The Trust and how we are working to improve the lives of those suffering from Lymphangiomatosis and Gorham's Disease.

The event was considered successful, and there are initial plans to develop the relationship with NHS Grampian and RDUK further for Rare Disease Day 2015.

Patient Support

This year, working in conjunction with the LGDA, we helped to set up a closed Facebook page enabling patients and family members to communicate freely with others who understand what they are going through, helping them to gain strength from knowing that they are not alone. There are now over 60 members of this closed group from all over the world.

Alfie's Trust is represented on the Board of LGDA-E, the European arm of LGDA and we regularly take part in virtual meetings with geographically remote representatives from other countries in Europe. The main objective of LGDA-E for 2013-14 has been to strengthen our relationships and develop the structure of the organisation with a view to developing closer links with LGDA and helping to promote the population of the LGDA/LMI Patient Registry.

With our growing profile, we have been contacted by several new patients looking for support. We are able to offer them emotional support, guidance on UK medical professionals with experience in the disease, and the chance to join the Facebook support group to communicate with others in a similar position.

Section B – Fund Management

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 2013-2014 has been to concentrate on few larger-scale events, namely:

- Balmoral Run
- Charity Golf Event
- 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, £47,762 has been raised over the last financial year, ending 31st March 2014. (Income from fundraising activities via Virgin Giving includes Gift Aid.)

Grants awarded

Alfie's Trust funds have been awarded to projects relevant to its stated charitable purpose, having been formally requested and approved by the Board of Trustees.

The first grant 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. A sum of \$25,000 (approx. £16,500) was granted and funds were transferred to the LGDA on 14th May 2013. The Alfie's Trust grant funded three projects:

- The first International Conference in Science and Medicine on Generalized Lymphatic Anomaly (lymphangiomatosis) & Gorham-Stout Syndrome, held in June 2013 and attended by medical and research professionals from around the world.
- Developing an online 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.

As at 31st March 2014, two further applications are under consideration:

- \$8,286 (£5,000) to the Lymphangiomatosis and Gorham's Disease Alliance for a patient conference in Dallas. Forty families from around the world will have the opportunity to attend the conference to hear presentations by 16 doctors, scientists and researchers. Social events will be provided for the patients and families, as well as a question and answer session with the medical professionals attending the conference. The Board will recommend approval of this fund application.
- £6250 to Great Ormond Street Hospital in London to part-fund initial genetic research into lymphangiomatosis. Following clarification and agreement on the terms of this donation, the

Financial review

Brief statement of the charity's policy on reserves

If no appropriate project is identified, the funds will be carried over into the next 12 month period, in accordance with the Trust Deed.

Details of any deficit

Donated facilities and services (if any)

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Other optional information

The Trust has had another successful fundraising year. Although, only one application was granted in the year to March 2014, we have, in April and June 2014, made two grants, one of \$8,286 (£5,000) to the Lymphangiomatosis and Gorham's Disease Alliance for a patient conference in Dallas. Forty families from around the world attended the conference to hear presentations by 16 doctors, scientists and researchers. The families got to talk to one another and there was an organised question and answer session that allowed them to put questions to the medical professionals attending the conference.

A donation of £6250 was made to Great Ormond Street Hospital in London. In the next few months a genetic research project on lymphangiomatosis will start. GOSH is the UK's largest charitable funder of medical research dedicated to paediatrics.

Declaration

The trustees declare that they have approved the trustees' report above.

Signed on behalf of the charity's trustees

Signature(s)		
Full name(s)		
Position (e.g. Chair)		
Date		