

Alfie's Trust Annual Report and Year End Accounts – 31st March 2015

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 and social media
 - Events
 - Collaborating with other organisations where possible

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

1. Achievements and performance

Section A – Awareness and Support

Media

Throughout 2014 - 15, 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 provides an 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, his disease, and fundraising events 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 870 followers and is an informal means of communicating details of Alfie's condition and charity events. A measure of the success of this social media approach is that, due to the level of activity, Alfie's Facebook page ranks higher in online search engines than the formal patient organisations' websites.

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.

In 2014-15, local public relations company, Think PR, selected Alfie's Trust as the focus of a 12-month fundraising campaign to raise £10,000 celebrating 10 years in business. All events were successfully run by Think PR, with minimal involvement from Alfie's Trust. In addition, Alfie's Trust was supported by the Accounting Department of Marathon Oil who also ran a number of events for the charity's benefit. These types of contact are invaluable in extending the reach of awareness about Alfie and his disease, as well as raising funds.

Collaboration

Rare Disease Day

28th February 2015 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 we used our website and Facebook page to help make people aware of what Rare Disease Day stands for. We took part in activities online through the Rare Disease Day website to raise awareness of Alfie's Trust in the hope that we may reach other sufferers in need of our support.

Patient Support

In 2014, we established a closed group on Facebook to enable 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. New members from around the world are being added frequently with a current membership of over 130, more than double the number this time last year. The group continues to be a huge source of support.

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 2014-15 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 Patient Registry (see below for more information).

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 has been the primary focus of Alfie's Trust to date. The fundraising strategy of Alfie's Trust in 2014-2015 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, £51,843.69 has been raised over the financial year, ending 31st March 2015.

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.

- In May 2014, \$8,286 (£5,000) was granted to the Lymphangiomatosis and Gorham's Disease Alliance towards a patient conference in Dallas. Forty families from around the world attended the conference to hear presentations by 16 doctors, scientists and researchers. Social events were provided for the patients and families, as well as a question and answer session with the medical professionals attending the conference. The event was regarded as a success.
- In June 2014, £6250 was granted to Great Ormond Street Hospital in London to part-fund initial genetic research into lymphangiomatosis.

As at 31st March 2015, a further application is under consideration:

- £13,886.82 to the Lymphangiomatosis and Gorham's Disease Alliance (LGDA) to:
 - maintain and expand the LGDA's International Patient Registry (see below), and
 - hire a full-time Director of Patient Programs/Registry Coordinator for 1 year. Further funding will be sought by the LGDA to continue this position thereafter.

The International LGDA Registry for Lymphatic Malformations collects and stores medical information, family history, and other related information from patients with lymphangiomatosis and related conditions. Information provided by patients can be used for medical research and clinical trials to better understand these diseases and to develop new treatments. The Registry also helps scientists to locate patients to participate in research studies. It is hoped that the information gathered in the Registry will lead to better diagnosis and treatment of these diseases resulting in a better quality of life for those suffering with lymphangiomatosis, Gorham's disease, and other lymphatic and bone diseases.

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.

2. Challenges

In Autumn 2014, Alfie's Trust was invited by Findacure to take part in a 12-month mentoring programme. The aim was to pair small patient bodies with established charities, patient organisations, researchers and other appropriate institutions to enable the mentee to develop their organisation and overcome challenges with close support from an experienced mentor. Alfie's Trust board members attended an event where potential mentors and mentees met to select their ideal pairing.

During the event and conversations with the potential mentors, it became clear that there are a number of different directions in which Alfie's Trust may develop, each presenting different and sizeable challenges. It was recognised that more clarity is required on viable options to determine the future strategy for Alfie's Trust. Having reached this realisation, we declined the opportunity to take part in the time-intensive mentoring programme for 2014-15.

Future potential activities to be considered include:

- identification of medical/scientific projects in which to invest
- making contact with other rare disease organisations, hospitals, practitioners and researchers
- strengthening ties with LGDA and LGDA-E and formalising the relationship between Alfie's Trust and these bodies
- understanding the feasibility of suggested projects, such as establishing a UK-based tissue bank
- developing the Patient Support offering
- extending the awareness of lymphangiomatosis, specifically targeting the medical profession to aid diagnosis

Alfie's Trust has proven successful as a fundraising organisation with funds held in account awaiting identification of appropriate projects. However, as a small charity, with a limited but dedicated volunteer base, the Board of Trustees has decided to suspend charity-run fundraising activities for a period (approximately 6 months) to allow time for a clear strategy to be developed, exploring the options outlined above. Fundraising will recommence with the largest of the annual events – RunBalmoral 2016, for which planning starts in September 2015.