

2015-16 has been a pivotal year for Alfie's Trust. The charity is evolving from an organisation mainly focussed on fundraising to one with longer-term strategic focus, whose fundraising is simply an enabler for pro-actively meeting its charitable purposes. In particular, the aim to further research into lymphangiomatosis and related conditions is extremely challenging. Development of the Trust is ongoing as we enter the 2016-17 reporting period. This report outlines activities and achievements for the year 1<sup>st</sup> April 2015 to 31<sup>st</sup> March 2016.

## **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 and has increased communication directly with the Patient Program Director at LGDA, Lisa Klepper.

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

In addition to the United States LGDA involvement, Tracy also chairs the LGDA-Europe with bi-monthly virtual meetings. This year has seen the LGDA-E become a more formal organisation with the Dutch representative, Aaike van Oord taking the lead in progressing this. It was agreed that the LGDA-E will have an umbrella-type identity to which each national organisation is affiliated. Working together, broad aims and objectives are agreed and progressed whilst each national body retains financial autonomy.

### **c. Supergroup**

Through the main research contact at Great Ormond Street Hospital (GOSH), Dr Veronica Kinsler, Alfie's Trust has been introduced to a group of similar organisations representing patients whose conditions are also subjects of research at GOSH. An initial meeting took place in Manchester on 9<sup>th</sup> July where there was the opportunity to share and learn from each other's experiences. Since then, contact has been maintained in a Facebook Group. This has the potential to be extremely valuable to all the organisations involved.

### **d. Rare Disease Communities**

Locally, a meeting with other families who care for rare disease patients took place in February 2016. There is an intention to make this type of informal meeting a regular occurrence because opportunities to offer and receive emotional support with others in a similar position are scarce. To that end, further connections are being made within NHS Grampian and at Charlie House – the local children's hospice.

## **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, both closed groups. There are two groups with a combined membership of 300 - a Patient Group (patients and parents only) and a Friends and Family group. This is a valuable and active community, with around 20-30 posts per month, with each post receiving anything from 10 to 30 comments.

### **b. Ad-hoc Enquiries**

The charity also handles a number of e-mails and telephone calls from those looking for information on lymphangiomatosis. These typically come from recently diagnosed patients and their families and less frequently from Doctors looking for direction. There is currently a blend of routes to receiving these enquiries, for example they may be UK patients directed to Alfie's Trust via the LGDA in the US, or vice versa, or may be picked up through another line of enquiry.

### **3. Research**

#### **a. Great Ormond Street Hospital (GOSH) Genetic Research**

The genetic research project at Great Ormond Street Hospital continues. Part-funded by Alfie's Trust in June 2014, and led by Dr Veronica Kinsler, this is a two-year project so a final report and results are expected later in 2016.

#### **b. Great Ormond Street Hospital (GOSH) General Research**

A grant of £2,000 was awarded to Dr Maria Gnarra in January 2016 to carry out a 6-week project at GOSH. Maria worked on 4 projects:

- i. Assessment of patients with vascular anomalies, mainly lymphatic, treated with sirolimus.
- ii. Evaluation of patients referred to GOSH as haemangiomas.
- iii. Review of more than 600 patient notes/records with vascular anomalies treated at GOSH within the last 5 years with multiplex Cynergy laser.
- iv. Preparation of the Generalised Lymphatic Anomalies leaflet for the families.

Her final report points to some interesting connections which will be followed up by Alfie's Trust in the near future, e.g. apparent research in Cambridge by Dr Victoria Parker.

#### **c. Sparks - Children's Medical Research**

Initial contact has been made with Sparks who facilitate research into children's medical issues. Their focus over the next 5 years is rare diseases. This could be our window of opportunity to fund a further research project here in the UK. This will be further investigated by the Board in the coming year.

#### **d. LGDA Research – Thoracic Lymphangiomatosis**

Early discussions have taken place with LGDA in the US with regard to Alfie's Trust potentially part-funding research specifically into thoracic lymphangiomatosis. Funds were received from the funeral collection of a UK thoracic lymphangiomatosis patient. These funds are to be ring-fenced for such a research opportunity.

#### **e. International Patient Registry**

Alfie's Trust has funded the LGDA International Patient Registry, an online database containing details of lymphangiomatosis patients which can be made available to researchers. This grant was awarded to the LGDA in May 2015 and covers the licensing cost of the database and a full-time Registry Co-ordinator/Patient Programs Director (Lisa Klepper).

### **4. Awareness**

#### **a. GOSH Leaflet**

Alfie's Trust worked with GOSH to prepare an information leaflet about General Lymphatic Anomalies (of which lymphangiomatosis is one condition). This is in the final stages of approval and due for online publication by GOSH imminently.

#### **b. Alfie's Trust and LGDA-E Websites**

We were very fortunate to receive a donation of professional assistance from Engage PR to update and refresh the Alfie's Trust website content. The content has been prepared and is almost ready for upload to the refreshed site. In addition, the LGDA-E has been working to update their website with direct links to the Alfie's Trust site. This is now published.

#### **c. Alfie Slideshow**

A short video slideshow about Alfie, raising awareness of both the disease and the charity was prepared in 2015. This has now been translated into a number of European languages and is available on YouTube. The video can be found by a YouTube search for "lymphangiomatosis".

**d. General Awareness Raising**

As always, Alfie's Trust maintains a presence in local community press. In addition, the charity was visible at Run Balmoral in April 2015, thanks to our sponsor Apex Tubulars, and at the Aberdeen Kiltwalk in June 2015, thanks to Tough Mothers. These events raise the profile of the charity and create opportunities to raise general public awareness. Within local schools, the Catch Challenge saw Alfie's Trust represented at the final event, with thanks to Amy Sinclair's group from Cults Academy for their excellent efforts.

**5. Fundraising**

As reported in the 2014-15 Annual Report, the Trust decided to pause charity-run fundraising events for a period this year to enable the Board to focus on developing a long-term strategy.

However, we are delighted that over £56,000 has been received by the Trust in this financial year, with almost half of that sum as a result of the efforts of our supporters at Run Balmoral and the Aberdeen Kiltwalk. Again, we have been fortunate to benefit from the generosity of individuals and organisations who have organised events and donated funds to Alfie's Trust, in particular Think PR who nominated Alfie's Trust as the charity to support throughout their 10<sup>th</sup> anniversary year. The Financial Report contains details of all funds received during the year.

It should be noted that approximately £4,000 of funds received have been accepted with the understanding that they are to be restricted for use by the LGDA-E as a whole.

**6. Trust Management**

**a. Volunteers**

In line with plans for the year, great efforts have been made in Alfie's Trust to clarify vision, objectives and strategy. In order to maximise the Board's time to work on these, more volunteers have been recruited and some activities delegated. The new volunteers have delivered over and above their brief, providing ideas, introductions to professional services and donations that were wholly unexpected and greatly appreciated. The Board of Trustees would particularly like to express their gratitude to Stewart and Denise Gardiner.

**b. Strategic Development**

As well as working with new volunteers, the Board have employed the advisory services of experts at the Aberdeen Council of Voluntary Organisations (ACVO). This assistance has helped shape the direction of the charity in both the short and long-term. A volunteer business mentor has also been engaged, with a very positive initial meeting taking place in early March 2016. It is anticipated that the mentor will guide the charity through our evolution to one where measurable delivery against charitable purposes is more pro-actively sought.

**c. New Appointments**

It became apparent that, in order to develop, Alfie's Trust needs to increase the number of people and skillset, both sitting on and available to, the Board of Trustees. To this end, two new Trustees have been invited to join the Board with formal appointment taking place at the AGM on 30<sup>th</sup> March 2016. They are Moira Reid and Lynne Huckle – welcome to the Board. A Fundraising Co-ordinator volunteer position has also been identified. Discussions on the scope of this role are ongoing.

**d. Visual Identity**

Following update of the Trust's logo in 2015 by long-standing volunteer Tracy Ridge, it has been incorporated into new designs for banners, posters, T-shirts and business cards. The design service has been provided by Nicola Moir. The new visual identity of Alfie's Trust will be rolled-out in 2016, including the new website.