

Report of the Trustees of 'KIDS LIKE US' for the year 2018- 2019

Aims of 'KIDS LIKE US':

1. To educate the public in all matters relating to arthritis and particularly as it pertains to children._
2. Fund research into the causes of arthritis particularly in children._
3. To alleviate the suffering of those with arthritis particularly children, and to provide support to those who by reason of caring for a person with arthritis are leading a restricted life and are in need of assistance. _

Fund Raising

This year we have continued to concentrate on outreach events to offer the opportunity for young people, siblings and parents to come together with the charity and offer mutual support. The Outreach Team, consisting of Kirsty, Marion, Moira, Gemma & Louise, set aside dates in advance for the events and advised the families of these. Over the year we organised a Family Day at Drayton Manor, an afternoon learning Circus Skill, the annual Christmas Party and a day at Thinktank, Birmingham in March 2019. The events were all well attended and enjoyed by the families. In addition to Children and families from Birmingham Children's Hospital, we have been able to welcome families from University Hospital Coventry and Warwickshire and New Cross since we introduced the Charity to them at their JIA clinic.

Donations to the Charity have continued, some regular supporters and some new. Once again, the 'Gentlemen's Night Out' now called 'We Are All Making A Difference' (WAAMAD) have awarded KLU £1,000. Specsavers Bloxwich raised £281.13, North Warwickshire Ladies Club donated £231.00 and Blue Coat School raised £1,500. The Stathan Family were involved in raising funds through School, Friends and Employers (Wishaw CC fun day £1249, Hanbury Farm Primary School £118.02, Jaguar Cars £300 and Leigh Coalfield Trust £300). Rosaleen Sketchley asked for donations for her 50th Birthday and raised £88.03, Ward End Social Club donated £50.66, Dr Roseman donated £125.00 to KLU as part of his 80th Birthday celebrations. Lynda & Carl Copson asked for donations for their wedding and sent KLU £630, Evendon Family had a Halloween party and raised £40 and Simon Reed donated £430 and his employer, DHL, have agreed to match this through a scheme they run. Selby and District Young Farmers invited members of the Committee to talk to them

about Kids Like Us and they generously presented KLU with a cheque for £1500 on the night.

A Quiz Night was organised by the Committee on 21st April 2018 which was well supported and very enjoyable. The evening raised £900 and due to its success, it was agreed to make this an annual event.

In December we submitted our film to the Charity Film Awards and although many people voted we were not shortlisted.

During the year we were asked to endorse a book that was being written by a supporter of KLU about young people with JIA. We discussed the availability of this sort of material and the Committee agreed that we were supportive in principle and would like to see drafts of chapters. We later heard the publishers had turned down the book proposal, however we are exploring if this material would be suitable for our website.

We have introduced Car Stickers to the merchandise available to purchase via the website and at events.

Applications for funding 2018-2019

Limoges Trust granted us £250 this year, following a funding application, which will be used towards the Breakaway weekend.

Mason Samaritan Fund granted us £850 of which they specified £500 to be used towards the Breakaway. The remaining £350 we allocated to The Outreach Project, which we advised the Trust of.

We are very grateful for their continued support and have discussed looking at other Trusts we can apply to for funding.

Requests for funding 2018-2019

(a) Continued funding of the residential programme, 'Break Away' for young people with rheumatic diseases, organised and run by staff at the Birmingham Children's Hospital. Estimated Cost £4700

(b) Request for funding for Outreach Activities

It was agreed by the committee to continue the outreach activities as they were proving beneficial to the children and families who attend them, and they were also raising awareness of the charity. It was felt the budget of £500 was appropriate for each event but would be assessed for each time.

(c) Funding for Communications Plan: To include printing leaflets, merchandise and information sheets Estimated cost £2000.

(d) A funding application was received from a family whose teenage child was receiving treatment at Birmingham Children's Hospital. The child was suffering with Granulomatosis with polyangiitis (GPA) Vasculitis and after a 3 week stay in hospital was looking forward to going home soon. GPA is a rare inflammatory condition in which the blood vessels become inflamed. It mainly affects the ears, nose, sinuses, kidneys and lungs. The Patient had been slowly recovering however had significant and permanent lung damage which was now impacting on their ability to walk short distances. The child would have to sleep downstairs at home where the family felt privacy would be limited and as they were away from their mother, it was requested two screens and a video monitor be provided to allow privacy and reassurance whilst they slept downstairs. The committee felt that while the screens were beneficial the monitor may be intrusive and granted part of the application. The two screens, costing £150, were purchased for the family.

Application (d) was part funded, as noted above, and the other applications were all granted by the Committee.

During the last year we have highlighted areas to be addressed;

1. Clinical representation on the KLU Committee – a letter was sent inviting members of the team from BCH to the meetings and on 5th November 2018 Claire and Lottie attended and participated in the meeting. We look forward to seeing members of the team at future meetings.
2. Policy Documents – the issue was trying to keep these proportionate. It was agreed these were short and to the point, but it was felt the Permission form & the First Aid Policy should be reworded. At the meeting in August the Permission form was agreed with the appropriate wording, the forms would be updated going forward.
3. Governance Policies and Constitution.
 - a) Exceptional Expenses - Guidance notes from the Charities Committee were circulated – some principles were to be drafted to include travel and overnight stays that might arise. At the meeting on 2nd April 2019 the Trustees Exceptional Expenses Policy was formally adopted.

- b) Reserve Policy – Charities should review their Reserve Policy regularly and it should be available on the website. At the meeting on 2nd April 2019 the Committee agreed certain reserves should be in place – the Breakaways would be supported for 5 years (approx. £25,000), Outreach activities supported for 3 years (£6,000) and operational costs supported for a year (£3,000).

- c) Charities Constitute – the Deed was circulated and reviewed by Committee members. At the meeting on 2nd April 2019 it was agreed the document would be re-circulated with the amendments the Chair had suggested.

On behalf of 'Kids Like Us' I would like to formally offer our thanks to Ena Evans who is the independent examiner of our accounts. We are most grateful for her continued support in this way.

Finally, I would like to acknowledge the time and effort that each member of the committee has given to 'Kids Like Us' over the last year and to thank them, their family and friends for their continued support. Unfortunately, during the last year Carl Clinton stepped down from the committee and we recently learned that Gemma is moving abroad in May 2019. We wish them both well and thank them for the support they have given over many years.

With the strategy still foremost in our minds and the achievements of the last year acknowledged, the focus over the next year will be to reach out to more families at Birmingham Children's Hospital, University Hospital Coventry & Warwickshire & New Cross. This will ensure the charity will go from strength to strength.

On behalf of the Trustees of 'Kids Like Us'