**Financial Review 2016 / 2017**

**The following review should be read in conjunction with the Report and Financial Statements for the year ended 30 April 2017**

We are extremely grateful to all those who support of our work. The Group would not be able to meet the needs and expectations of families affected by this group of diseases without donations, the fund raising activities of our members, families, friends, and funding from grant providers who are acknowledged throughout this report.

All restricted donations were used for the purpose specified and all general donations and money raised by families during the financial year, 2016/2017, was allocated to our Care and Support Service and Research Service.

We recognize the tremendous effort that goes into organising fund raising events and, at a time of continuing economic uncertainty, we will work hard to diversify and develop funding streams that are capable of sustaining the future of the Group.

The following charts show the source of funds and how the Group uses these funds to meet its aims and objectives. They also demonstrate the continuing need and importance, of your support and that of our grant providers, which is vital to the continued funding of our support services.

**Sources of Income**

**Financial Year 2016 / 2017**

Total income for the financial year was £244,025, of which, 32% was received in grants from the Big Lottery, Children in Need and the Hollie Foundation.

Unrestricted grants received from pharmaceutical companies (20%) were used to support our Annual Family Conference and the Professionals’ Interactive Workshop. It is important to state that these companies had no control or influence over the contents of the programme or the selection of speakers.

At a time of continuing financial uncertainty, we are fortunate to have the amazing support of our members, families and friends who, through fundraising events and voluntary donations, contributed a combined 31% of our income. We are truly grateful for their support.

Investment income (3%) and gift aid (1%) were small, by comparison, and over the coming year we will review investment opportunities to ensure the best return on our investments and encourage donors to make a Gift Aid declaration in order to maximise donations.

**Allocation of Expenditure and Support Costs**

**Financial Year 2016 / 2017**

Expenditure for the year amounted to £358,400. This was £114,375 more than the income received and reflected the opportunity to reduce our reserves by converting the balance of an unrestricted legacy (£154,560 in 2016) into care and support for our families.

As a charity, we are driven by our objectives and the needs of the families we support. This means that in 2016 / 2017 we spent 46% of our expenditure on Care and Support followed by 25% on Research and Collaboration and 13% on Information and Social Media..

- Care and support takes into account the work of our Clinical Nurse Specialist and Families Officer with additional support from our Chief Executive. This includes managing the 24 hour help line, providing emotional support and help with managing disease progression, attending clinics and making home visits, giving practical advice and support for home adaptions and advocating on behalf of families facing difficulties with matters relating to housing and benefits

- Research and collaboration reflects small grants for to universities for specific research projects and collaboration with pharmaceutical companies in support of providing information about clinical trials and working with the NHS England to gain NICE approval for new therapies, collaborating with clinicians and the NHS Expert Advisory Group and working with the LSD Collaborative to influence National Policy on welfare and NHS reform.

- Information and Social Media(13%) captures the costs of providing information through all channels including the web site, social media platforms, newsletters and information leaflets.

- Central Office and Administration Costs(7%) reflect the expenditure associated with running the Central Office and include rent, overheads and the Finance and Administration Officer role.

We are fortunate to share the roles of the Social Media and Communications Officer and the Finance and Administration Officer with the INPDA. This has the effect of sharing associated costs and reducing the NPUK cost of overheads and administration.

Please refer to the Report and Financial Statements for the year ended 30 April 2017 for additional information about the financial accounts, reserves policy and endowment fund or contact the Central Office on 0191 415 0693