

| 2020 UK Patient Group Support                 |             |   |
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| Organization                                  | Amount      | Description   |
| Rare Disease UK                               | £ 12,000.00 | Yearly membership 1st April - 31st March 2021.<br>Policy work in UK working with stakeholders such as All Party Parliamentary Group on Rare Genetic and Undiagnosed Conditions in Westminster. And includes activities such as: helping develop the rare disease 'Framework' designed to replace the UK Strategy for Rare Diseases. Monitoring the rare disease policy landscape. Working alongside government and NHS officials to ensure the needs of rare disease community are met. |
| Specialised Healthcare Alliance               | £ 14,500.00 | 2002 Membership request. To enable SHCA to continue to advocate and raise the profile of specialised commissioning, that supports people with specialised medical conditions by: advocacy and campaigns, using communication channels and collecting and disseminating authoritative information about the effectiveness of arrangements for specialised commissioning.   |
| Genetic Alliance UK                           | £ 6,000.00  | Unrestricted core funding to support a campaign of activities planned around Rare Disease Day 2020, such as: developing a microsite for patients, Rare Disease Day special event – award ceremony for the best awareness raising video produced by a patient organisation, engagement in schools, and selected advertising around Westminster (target politicians and policy worker)  |
| Pompe Support network                         | £ 10,000.00 | Unrestricted core to support its work for the year ahead to include activities such as: website and social media, conference for attendance of trustees and volunteers, developing a Pompe app, overheads such as home-based staff costs and training for volunteers.   |
| AGSD-Association for Glycogen Storage Disease | £ 5,000.00  | Unrestricted core to support a number of activities during 2020 including: Specialist Care Advisor Service, and support for Pompe publications and resources.   |
| Metabolic Support                             | £ 15,000.00 | Core funding for resources towards 2020 programme to: enable Metabolic Support to significantly increase the capacity of their work, continuing to build new patient communities, providing platforms for them to share information and support that will empower them to get involved and be effective advocates for access.   |
| MPS Society UK                                | £ 25,000.00 | The MPS Society runs a support service programme to benefit UK patients with Fabry, MPS and related diseases. They currently have 1,329 members in the UK, including around 450 with Fabry, that benefit from the free programme of support, information and advice. In addition, they also continue to offer support to families following the loss of a loved one to one of these conditions.   |
| Genetic Alliance UK                           | £ 15,000.00 | Support for Emergency COVID 19 appeal – a programme of work to create, maintain, facilitate virtual safe spaces – where members of the rare disease community and organisations who support them can come together to ask questions, share resources and experiences. Link to hub <a href="https://covid-19.geneticalliance.org.uk/">https://covid-19.geneticalliance.org.uk/</a>   |
| MPS Society UK                                | £ 6,000.00  | Expert Consensus on self-directed action for people with a Lysosomal Storage Disease in times of high levels of community transmission of SARS-CoV-2. This will include reviewing existing literature on clinically vulnerable populations, bringing together a group of expert clinicians from the UK LSD centres, to share experiences, discuss the evidence, highlight uncertainties and put forward recommendations for future actions for this community                           |
| Find a Cure UK                                | £ 5,000.00  | Findacure's Empowerment Programme provides a range of face-to-face training and online learning opportunities to educate patient groups. These include webinars, e-learning portal, Workshops and patient group monitoring  |
| Battens Disease Family Assoc - BDFFA          | £ 7,500.00  | To redevelop website with new content, technology and governance and provide new up to date materials for Batten community. BDFFA believe their website is a window to Batten disease in the UK and should be a virtual "centre of excellence" for information on the condition, not just for families but also for healthcare professionals in the UK and globally..   |
| Genetic Alliance                              | £ 6,500.00  | Activities around Rare Disease Day 2021, (are starting earlier than usual due to COVID) and include; Online storytelling activities aimed to engage rare disease community and build on success of 2020 Rare Film FestivalThe aim of the campaign is to reach over 5.5 million people in UK and engage over 100 organisations.  |
| Patient Association                           | £ 10,000.00 | To raise the voices of patients and their experience of services in order that PA can work to ensure the best health outcomes for all patients – including those with rare diseases. PA works closely with UK policy makers in their work with changing systems.  |