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RARE DISEASE CHARITIES ON THE INVISIBLE FRONTLINE MISS OUT ON EMERGENCY FUNDING

RING FENCE A SHARE OF FUNDING FOR SMALL NATIONAL CHARITIES

#EveryDayCounts #NeverMoreNeeded #SaveTheInvisibleFrontLine

'The Batten Disease Family Association is facing unprecedented funding challenges as we are almost entirely reliant on community fundraising which ceased overnight. Our families are scared, exhausted and isolated and they need our support now more than ever. 'Amanda Mortensen CEO BDF A and parent of a young adult with a rare, undiagnosed condition

'Rett UK faces the real prospect of failing unless Emergency Funding can be accessed to fill some of the holes. Our families are in the extremely vulnerable group for COVID-19. 12 weeks (at least) of shielding someone who needs 24/7 care is exhausting and stressful. We have stepped up for them, now we need you to step up for us.' Becky Jenner, CEO Rett UK and parent of a young adult with Rett syndrome.

We are writing to you as the Chief Executives of two small rare disease charities, the Batten Disease Family Association and Rett UK. Both organisations are members of the national charity Together For Short Lives.

Both conditions are rare, neurological conditions that cause profound disability in children and both are life limiting. Families are under unimaginable stress and as the patient organisations we are absolutely key to their wellbeing and resilience.

The current situation with Covid-19 has had a devastating effect on our fundraising ability as both charities are largely reliant on community fundraising activity. We have lost between 50 and 70 per cent of our income overnight.

We were pleased to hear that the government recognised the jeopardy that charities were in only to discover we are not eligible for government support and have 'fallen through the gap'. We are national (so it is difficult for us to access local 'community' funds which are aimed at small charities but not us), we are vital but not 'frontline' (so not eligible for the fund supporting, for example, hospices and domestic abuse victims) and we do not work directly with government departments. We feel invisible.

In fact, we are on the frontline but it feels as if it is an invisible one. Families need us more than ever. We are here from diagnosis and through bereavement and beyond and we have never been needed more than now. Our families are caring for children and young people with complex health needs and the current lockdown has heightened levels of stress and anxiety. The 'infrastructure' of support that enabled our families to cope has mostly broken down with schools closed, respite at hospices and elsewhere paused and home care limited or ceased.

We can't imagine not being here for families, for whom we are an essential life-line but we are both currently keeping the charity going using our reserves, which won't last forever. The families we support are some of the most vulnerable in our society.

We are asking you to consider supporting charities like us who can't access any of the current support. We are an essential part of the charity landscape and provide support in a way no other organisations can.

We need you to ensure that a share of the funding you have allocated to charities does not all go to the Community Foundation (that only supports local, area-based charities) and **that a share of that funding is ringfenced for the small but vital national charities**, particularly those supporting rare disease groups and life limiting conditions, do have a source of funding. THE NCVO, The Small Charities Coalition and Genetic Disorders UK are all aware and have tried lobbying on this point. They back our position.

Without that many of these charities will close in the summer. The fall-out from that will put health, social care and education services under even more pressure and more lives at risk.

Yours sincerely



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About Batten Disease

Batten disease is a rare, devastating diagnosis. The disease affects children and causes a progressive loss of skills. Children become blind, lost their ability to speak, walk and swallow and experience epilepsy and dementia. Batten disease causes profound disabilities and the condition profoundly affects the whole family. Families have to become skilled carers, siblings become young carers, finances and relationships are all deeply affected. The BDFa is there for families from the point of diagnosis through the loss of a child and beyond with two support workers covering the UK. We offer emotional and practical support, build resilience and train professionals as well as playing a crucial role in the rare disease landscape working on access to treatments and heightened awareness.



About Rett Syndrome <https://www.rettuk.org/>

Imagine being told the toddler you thought was healthy, in fact had a rare and devastating disability that would leave them needing lifelong 24/7 care. That is the reality for parents receiving a diagnosis of Rett syndrome (RTT) for their child. It changes lives irrevocably and Rett UK is there to pick up the pieces. RTT is a life limiting genetic neurological disorder causing profound disabilities mainly in females (1 in 12,000). Although present at birth, it is usually undetected until a major regression occurs at around the age of 2, when children lose acquired skills and the complexity of the disability is revealed. Multiple comorbidities exist. Rett UK provides the emotional and practical support needed to deal with the everyday challenges that Rett syndrome presents. Our national telephone helpline answers calls from desperately worried parents, not just at the point of diagnosis but also at key transitions and moments of crisis; life changing information & advice.

