

## Potential Grant Awareness Opportunities (for direct application by families, carers etc)

Grant Provider	Steve Waugh Foundation
Nature of Assistance	Grant funding for medicines, treatment and equipment or items that improve the quality of life for the applicant and their family. Grants are not available for such things as vehicle or house modifications, respite care, conferences or travel.
Financial	No indication of amount of grant available or whether a co-contribution is required.
Grant Rounds	For 2018 Round 2 opens 1 June and closes 30 June 2018; Round 3 opens 1 September and closes 30 September 2018
Principal Eligibility Criteria	<ul style="list-style-type: none"> <li>○ Applicants (children and young adults – 0 to 25 years) must have a rare disease with a prevalence of 2:100,000 and a number of published cases or families 2 or less.</li> <li>○ The rare disease must be recognised by Orphanet which is a globally recognised source for the identification of rare diseases. EB is a listed rare disease on the Orphanet Register - <a href="http://www.orpha.net/consor/cgi-bin/Disease_Search.php?lng=EN">http://www.orpha.net/consor/cgi-bin/Disease_Search.php?lng=EN</a></li> <li>○ The condition must be formally and officially diagnosed by a Paediatrician and/or Geneticist.</li> <li>○ As the Foundation's philosophy is to only fund items that are ineligible to be funded from other sources certification is required that other alternative funding avenues e.g. NDIS, Medicare have been applied for and either rejected or all previously approved funding has been exhausted.</li> <li>○ Applications for grants funding are means tested.</li> </ul>
Grant Application	<ul style="list-style-type: none"> <li>○ Applications can be made on line - <a href="https://www.stevewaughfoundation.com.au/grants/">https://www.stevewaughfoundation.com.au/grants/</a>.</li> <li>○ Means testing proviso requires details on family income &amp; expenditures and e certification that other alternative funding avenues e.g. NDIS, Medicare, have been applied for and either rejected or all available funding has been used up.</li> </ul>
Other Matters	<p>Applications are assessed by a Medical Health Advisory Council (MHAC) comprising:</p> <ul style="list-style-type: none"> <li>○ Dr Felicity Collins, Clinical Geneticist and Head, Department of Clinical Genetics, The Children's Hospital at Westmead</li> <li>○ Dr Tracy Dudding-Byth FRACP is a consultant Clinical Geneticist at Hunter Genetics in Newcastle, NSW</li> <li>○ Professor Elizabeth Elliott MBBS, MD, FRACP, FRCPCH, FRCP is Professor of Paediatrics and Child Health, University of Sydney; Consultant Paediatrician, The Children's Hospital at Westmead; and a National Health and Medical Research Council of Australia Practitioner</li> <li>○ A/Professor Yvonne Zurynski BAPPSC, MAPPSC, PHD is the Assistant Director of the Australian Paediatric Surveillance Unit (APSU)</li> </ul>