

## Sebastian's Action Trust Referral Form

Sebastian's Action Trust operates on a set of criteria where the child must have a life-shortening condition according to NICE Guidelines where life expectancy is less than 25:

Group 1 – Life threatening conditions for which curative treatment may be feasible but can fail. (E.g. cancer, irreversible organ failures of heart, liver, kidneys.)

Group 2 – Conditions where premature death is inevitable. (E.g. cystic fibrosis)

Group 3 – Progressive conditions without curative treatment options. (E.g. Batten disease, mucopolysaccharidoses, muscular dystrophy.)

Group 4 – Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death.

For children in Groups 3 and 4, we also consider additional vulnerabilities (outlined below). Please review these factors carefully and take into account whether the child is affected by one or more of them before making a referral.

### Data protection statement

All the information collected in this form is necessary and relevant. We will treat all personal information with the strictest confidentiality and in line with current data protection legislation. Should this form show that you meet our criteria, the information provided, and further information which will be gathered at a later date, will subsequently be used to register you on our secure CRM system. For more information on how we use the information you have provided, please contact us.

### Please tick all that apply:

Group 1	
Group 2	
Group 3	
Group 4	
Requirement for long term oxygen therapy or non-invasive ventilation at home	
Tracheostomy and / or 24-hour ventilation	
Severe uncontrolled reflux despite maximum treatment	
Pain / distress associated with feeding, necessitating progressive feed reduction	
Poor seizure control despite numerous drugs	
Frequent use of rescue medication (daily basis)	
Episodes of status epilepticus requiring intensive treatment (IV infusions / PICU)	
Dependent on a wheelchair driven by a carer	
Difficulty with maintaining sitting position (Gross Motor Function Classification System Level V)	

### Sebastian's Action Trust

The Bluebells, Popham Lane, North Waltham, Hampshire, RG25 2BD

Tel: 01344 622500

[info@sebastiansactiontrust.org](mailto:info@sebastiansactiontrust.org)

[www.sebastiansactiontrust.org](http://www.sebastiansactiontrust.org)

Registered charity No.: 1151146 & a company limited by guarantee in England no.: 8339436

Baclofen pump (as a marker of severe hypertonia / very difficult spasms)	
Severe visual impairment (registered blind)	
VP shunt with frequent need of review	

Child's full name	
Child's date of birth	
Gender	Male          Female
Child's condition	
Home address	
County	
Postcode	
Primary guardian's name	
Relationship to child	
Occupation	
Contact number / email	
Secondary guardian's name	
Relationship to child	
Occupation	
Contact number / email	
Referred by	Name Telephone Email
Medical Professional (consultant/CCN)	Name Telephone Email
Being treated at	
How does this condition affect daily life?	
Eating/drinking?	
Walking?	
Communicating?	
How often does child require medical intervention in the form of hospital visits/clinic appointments/need for A&E?	
Any other comments?	
Main reason for referral:	

Siblings	
Name and date of birth	
Name and date of birth	
Name and date of birth	
Name and date of birth	
Any safeguarding concerns for this family (to include persons close to the family that may pose a risk)?	

## Notable Safeguarding Concerns

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All information disclosed will remain confidential and no judgements will be made. Please do not share any information which the family has not given consent to share.

This information is being requested as staff are lone workers and we host communal events bringing together at-risk children, in the interest of keeping staff and other service users safe please disclose any relevant information, such as:

- History of/current domestic abuse
- History of/ current substance misuse
- History of/ current mental health diagnosis/concerns
- Parental special needs
- History of/ current sexual abuse
- Current child protection plan
- Any other relevant information that you feel we should be aware of in supporting the family

Please give details of other organisations/support services the family is accessing so that we can work collaboratively to provide the best care for the family:

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Parent/Guardian signature to confirm they agree to this referral and to the possibility that Sebastian's Action Trust personnel might have to contact a medical professional named on this form:

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