

Sebastian's Action Trust: The Bluebells 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	

Sebastian's Action Trust

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

Tel: 01344 622500

info@sebastiansactiontrust.org

www.sebastiansactiontrust.org

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

Difficulty with maintaining sitting position (Gross Motor Function Classification System Level V)	
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
Home address	
County	
Postcode	
Primary guardian's name	
Relationship to child	
Occupation	
Contact number	
Email address	
Secondary guardian's name	
Relationship to child	
Occupation	
Contact number	
Email address	
Child's condition	
How does the condition affect his everyday life?	
Being treated at	
Consultant Name and Contact details	Name Telephone Email
CCN (Children's Community Nurse)	Name Telephone Email

I give permission for my consultant/GP/CCN to confirm my child's medical condition

Signed:

.....

Please list other people who will be staying with the child:	
Name and date of birth	
Name and date of birth	
Name and date of birth	
Name and date of birth	
Name and date of birth	

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Will your child need a hoist and a wet bed? Yes No

Is your child under a Palliative Care Team? Yes No

What equipment will you bring with you? (Wheelchair, oxygen, etc)

.....
.....

Any other information

.....
.....

Signed:

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