



CdLS Foundation UK & Ireland

The Cornelia de Lange Syndrome Charity Reg. No. 1054033

"The CdLS Foundation UK & Ireland is a family support organisation which exists to ensure early and accurate diagnosis of CdLS throughout the world, promoting research, and enabling individuals, families, friends and professionals make informed decisions and plan for the affected person's present and future."

Risk Management Policy

- 1.0 Purpose of this document.
- 2.0 Possible risks to the Foundation.
- 3.0 Risk management heat map.
- 4.0 Risk register.

1.0 Purpose of the document.

This document aims to identify and manage any potential risks to the CdLS Foundation UK & Ireland, (the Foundation within this document). By managing risk effectively, trustees can help ensure that significant risks are known and monitored to enable the Foundation to improve strategic planning and achieve aims more successfully and with minimal risk.

2.0 Possible Risks to the Foundation.

Possible risks to the Foundation moving into the future may include:

- Reduced fundraising below typical levels.
- Increased demand on the services provided by the CdLS Foundation UK & Ireland.
- Reduced capacity of Trustees and service providers.
- Negative public impression of the Foundation.
- Termination of support of medical consultants.
- Loss or damage to Foundation's equipment, stock or digital data.
- Lack of direction or drive within the Foundation.
- Trustee body lacks relevant skills.
- Health, Safety and Environment Issues



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3.0 Risk management heat map.

Possible risk to the Foundation can be given a risk classification based on a combination of the likelihood of an event happening and its impact on the Foundation. This risk factor can then be classified as one of the following:

- Major or Extreme risk, shown by a score of 15 or more.
- Moderate risk, shown by a score of between 8 and 14
- Minor or insignificant risk scoring 7 or less.

The risk classifications can be seen in the following table:

Impact	Extreme 5	10	15	20	25	30
	Major 4	8	12	16	20	24
	Moderate 3	6	9	12	15	18
	Minor 2	4	6	8	10	12
	Insignificant 1	2	3	4	5	6
	1 Remote	2 Unlikely	3 Possible	4 Probable	5 Highly Probable	
						Likelihood



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4.0 Risk Register

Possible Risk	Likelihood	Severity	Risk Factor	Potential Impact	Mitigation procedure
Periods of fundraising levels below norm.	4	4	20	<ul style="list-style-type: none"> Reduction of services provided. Unable to meet the Foundations' core goals. 	<ul style="list-style-type: none"> Ensure that cash reserves are held within the Foundation's accounts. Aim for 2 years' typical reserve. Reduce costs during lean years, possibility to reduce conferences to 1 per year in time of consistent underfunding. Ensure budgets and accounts are accurate and up to date.
Unexpected increase in demand on the Foundation's services.	3	3	12	<ul style="list-style-type: none"> Unable to meet the needs of all families requiring support and guidance. Unable to provide enough doctor consults at conferences. Unable to respond promptly. 	<ul style="list-style-type: none"> Monitor numbers of new families registering with the Foundation. Keep database up to date and current to reduce the chance of unexpectedly high turn out to conference. Ensure Trustee body is fully populated to cope with demand. Ensure office staff reports increased demand promptly to Trustees.
Reduced capacity of Trustees or service providers.	4	3	15	<ul style="list-style-type: none"> Reduced capacity to operate efficiently. Increased workload on remaining Trustees. 	<ul style="list-style-type: none"> Try to ensure maximum numbers of Trustees are on the board to cope with the resignation of members. Conduct regular reviews of the performance of service providers to ensure needs of families are being met. Ensure good communication between Trustees and service providers to mitigate any disruption to the Foundation.
Negative public impression of the Foundation.	2	4	12	<ul style="list-style-type: none"> Reduced donations and fundraising. Reduced uptake of services and support. Inability to obtain grants and funding. 	<ul style="list-style-type: none"> Keep open lines of communication between families and the Foundation. React to feedback promptly. Monitor and react to social media postings.



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Termination of support by medical professionals	3	4	16	<ul style="list-style-type: none"> Reduced level of support to people with CdLS and their carers. Reduced level of research. 	<ul style="list-style-type: none"> Communicate well with current medical board and be aware of any grievances. Open lines of contact with medical community so as to be prepared if replacement medical professionals are required.
Loss or damage to Foundation's equipment, stock or digital data.	3	3	12	<ul style="list-style-type: none"> Loss or corruption of data. Loss of family contact database. Inability to function efficiently. Breach of data protections. 	<ul style="list-style-type: none"> Ensure suitable, offsite backups of all critical data are made routinely. Ensure insurance policies are in place to cover lost equipment. Create "back up" plans in case of loss of database.
Lack of direction or drive within the Foundation.	2	3	9	<ul style="list-style-type: none"> Needs of people with CdLS and their carers are not met. Foundation fails to keep up to date with research and protocols. 	<ul style="list-style-type: none"> Hold 5-year strategy meetings with clear goals and action plans. Ensure plans are met and implemented in a timely fashion. Keep good contact between Trustees to maintain drive and enthusiasm.
Trustee body lacks relevant skills.	4	2	10	<ul style="list-style-type: none"> Foundation fails to meet its goals and 5-year strategies. Poor decision making. Poor use of funds. 	<ul style="list-style-type: none"> Agree skillsets required and ensure suitable Trustees are appointed. Ensure current Trustees are willing to learn and implement new skillsets. In house monitoring of performance.
Health, Safety and Environment Issues	4	4	20	<ul style="list-style-type: none"> Injury or near miss to volunteers, Trustees or public during conferences or fund-raising events. Foundation liable to legal action. Negative public perceptions. 	<ul style="list-style-type: none"> Ensure all events are properly risk managed using appropriate documentation. Communicate the need to assess and mitigate risks to volunteers holding events. Ensure adequate PL insurance policy is in place.

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