



A. Policy Statement

ALD Life aims to provide good quality information to all those concerned with Adrenoleukodystrophy (ALD) and Adrenomyeloneuropathy (AMN) including patients, families, carers and medical professionals.

As such, we are fully committed to adopting the Information Standard, and ensure criteria set out in, and all requirements of, the Information Standard scheme are met.

We will ensure, by adhering to strict guidelines, and by adopting rigorous methods and systems, that information is:

- Clear
- Relevant
- Evidence-based
- Authoritative
- Complete
- Secure
- Accurate
- Well-designed
- Readable
- Accessible
- Up-to-date

ALD Life is fully committed to:

- a) producing good quality information for all those concerned with ALD or AMN including patients, families, carers and medical professionals.
- b) ensuring all information that fall within the scope of the information production system meet the requirement of the information standard.
- c) regularly reviewing all information materials for continued suitability and relevance, and update them as necessary.
- d) ensuring all those involved in the production of information are aware of, and fully comply with this policy statement, and requirements of the Information Standard.
- e) maintaining records to show acknowledgement of this policy statement and its implications by all those involved in the production of information.

ALD Life has communicated and will carry on communicating its commitment to the Information Standard scheme to staff, volunteers and Board of Trustees at meetings (a record of meetings is included in this document). A record of acknowledgement and agreement by all those involved in producing information to the policy statement is kept securely in the spreadsheet [C:\Documents and Settings\ALD Penge\My Documents\ALD Life\Information Standard\A. Policy Statement\Record of



Policy Acknowledgement-Version 1.xls]. The policy statement is fully accessible and available for all those involved in the production of information.

The Information Standard is fully supported by our CEO and Board of Trustees. The CEO is responsible for ensuring that ALD Life is fully compliant with the Information Standard scheme at all times.

Date adopted Jan 2013

Review Date Jan 2015

Signature **Sara Hunt, ALD Life CEO**

A handwritten signature in black ink, appearing to be "Sara Hunt", written over a dotted line.