

# Privacy Policy

## Introduction

The Committee of Management of Spinal Muscular Atrophy Association of Australia Inc. is committed to protecting the privacy of personal information which the organisation collects, holds and administers. Personal information is information which directly or indirectly identifies a person.

## Purpose

The purpose of this document is to provide a framework for Spinal Muscular Atrophy Association of Australia Inc. in dealing with privacy considerations.

## Policy

Spinal Muscular Atrophy Association of Australia Inc. collects and administers a range of personal information. The organisation is committed to protecting the privacy of personal information it collects, holds and administers. All information that is collected is not shared with any external organization without permission, and if used in research, funding or advocacy submission is always de-identified.

Spinal Muscular Atrophy Association of Australia Inc. recognises the essential right of individuals to have their information administered in ways which they would reasonably expect – protected on one hand, and made accessible to them on the other. These privacy values are reflected in and supported by our core values and philosophies and also reflected in our Privacy Policy, which is compliant with the Privacy Act 1988 (Cth).

Spinal Muscular Atrophy Association of Australia Inc. is bound by laws which impose specific obligations when it comes to handling information. The organisation has adopted the following principles contained as minimum standards in relation to handling personal information.

Spinal Muscular Atrophy Association of Australia Inc will:

- Collect only information which the organisation requires for its primary function;
- Ensure that stakeholders are informed as to why we collect the information and how we administer the information gathered;
- Use and disclose personal information only for our primary functions or a directly related purpose, or for another purpose with the person's consent;
- Store personal information securely, protecting it from unauthorised access;
- Provide stakeholders with access to their own information, and the right to seek its correction; and
- De- identify all data that is used in research, funding or advocacy submissions.

## Authorisation

Julie Cini, Spinal Muscular Atrophy Association of Australia Inc.