



# SAVE OUR SONS

DUCHENNE FOUNDATION

## **Our Mission**

Our mission is to find a cure for Duchenne. We strive to achieve this by funding research and clinical trials, improving care, funding nurses and providing quality of life enhancing equipment. Save Our Sons believes every Australian child impacted by Duchenne muscular dystrophy should have every opportunity to thrive. We do this by fundraising to provide innovative programs and services to develop life skills and strengthen the wellbeing of all affected by Duchenne muscular dystrophy and their families.

## **Save Our Sons Privacy commitment**

Save Our Sons respects and is committed to protecting the privacy of the people whose personal information it collects. We are bound by the Australian Privacy Principles in the Privacy Act 1988 (Cth).

We may update our Privacy Policy at any time to reflect changes required to provide our services.

## **What is Personal Information?**

Personal information means information or an opinion about a specific person who is identified by the information, or whose identity can be easily ascertained from the information. Examples of Personal Information that we may collect include your name, address, tax file number, credit information.

## **Whose Personal Information do we collect?**

Save Our Sons collects information from the children and families we assist, medical professionals, donors, fundraisers, participants at our events, volunteers, members and Directors of Save Our Sons and prospective employees.

For more specific information, as to the information we collect and how this information is used please refer to the Save Our Sons Collection Statement.

## **Why do we collect Personal information?**

Save Our Sons collects, holds, uses and discloses personal information:

- Administration: to enable us to conduct fundraisers, and administer your participation in these events;
- Marketing: to communicate with you about our initiatives, and if you provide your consent, to use your photograph and/or information you provide in an interview to promote our initiatives; and
- Compliance: to comply with our legal obligations.

## **Who do we disclose Personal Information to?**

Save Our Sons may disclose your personal information to:

- Internal support services: such as employees, volunteers, and Board Members of Save Our Sons;
- Contractors and service providers: who provide services to Save Our Sons (including parties that conduct fundraising on our behalf);
- Third parties required by law; and
- Anyone else you authorise.

Save Our Sons will not, without consent, disclose personal information for any purpose (a secondary purpose) other than for the main purpose (primary purpose) of fulfilling Save Our Sons's commitments to applicants, except where:

- it is required or authorised by law or for purposes of law enforcement and matters directly related to law enforcement or the prevention of unlawful activity;
- the secondary purpose is related to the primary purpose (or directly related when sensitive information is involved) and there is a reasonable expectation that Save Our Sons would use or disclose the information in the circumstances;
- Save Our Sons reasonably believes it is necessary to prevent any serious and imminent threat to any person's life, health or safety or the public's health or safety. Save Our Sons will not otherwise disclose your personal information to any other party without your consent.

## **What is Sensitive information**

Sensitive information includes information which may not identify a specific person but includes important details, such as specific health or medical information, a person's race, religion, political opinions, affiliations, philosophy, memberships or genetic information.

## **Whose sensitive information do we collect**

We may collect sensitive information from the children and families we assist. We collect sensitive information about you or your child relating to your health or your child's health.

### **Why do we collect sensitive information?**

For more specific information, as to the information we collect and how this information is used please refer to the Save Our Sons Collection Statement.

### **Website usage information and cookies**

When you access our website, we may use cookies. Cookies are small data files which ask permission to be placed on your computer's hard drive. Cookies collect personal information automatically from you including: your IP address and or domain name, your operating system (type of browser and platform) and the date, time and length of your visit to the website. Cookies are used by us to enhance your user experience and deliver content relevant to your behaviour.

No personally identifiable information is obtained. A cookie does not give us access to your computer or any information about you other than data you choose to share with us. You can choose to accept or decline cookies initially and through the settings on your browser.

### **Access to and updating your Personal Information**

Save Our Sons seeks to ensure that all personal information collected and stored in its files and database systems is correct and accurate. Individuals may at any time request access to, or correction of, the personal information Save Our Sons holds by contacting the Privacy Officer in the Head Office on (02) 9554 6111 or [info@saveoursons.org.au](mailto:info@saveoursons.org.au). Save Our Sons will endeavour to meet or advise of the outcome of such a request within five business days of receipt.

### **Data Security**

Save Our Sons takes reasonable steps to protect the security of the personal information and sensitive information it holds or that it engages service providers to hold on its behalf, from misuse, interference, loss, unauthorised access, modification or disclosure.

### **These steps include:**

Save Our Sons takes reasonable steps to ensure that when the information is no longer needed, it is destroyed or permanently rendered anonymous.

### **Confidentiality**

Save Our Sons will only disclose information that we hold about you to the extent required by law, as outlined in the Save Our Sons Collection Statement and for the purposes of achieving our Mission.

We will adhere to the Privacy Act 1988, including the National Privacy Act Principles, when we collect, use, disclose, store, provide access to, or otherwise deal with your personal information.

### **Complaints**

For any privacy issues or concerns, including a complaint that Save Our Sons has breached the Australian Privacy Principles, contact our Privacy Officer in the Head Office on (02) 9554 6111 or [info@saveoursons.org.au](mailto:info@saveoursons.org.au).

We may request that you make your complaint in writing. Save Our Sons will respond to your complaints within a reasonable period (usually 30 days). An unresolved complaint may be made to the Office of the Australian Information Commissioner (visit [oaic.gov.au](http://oaic.gov.au) for further information).

- Administration: to enable you or members of your family to be involved with our care platforms or be involved in other programs run by us, to receive financial or domestic support, and to enable us to communicate with you about our services;
  - Marketing: to communicate with you about our initiatives, and if you or a parent/guardian provides consent, to use photographs and/or information provides in an interview to promote our initiatives;
  - Support Services: to provide medical assistance to you while participating in our programs; and
  - Compliance: to comply with our legal obligations.
- using PCIDSS (payment card industry data security standards) software and processes; and restrictions on the employees who have access to personal files.

# Children and Families - Privacy Collection Statement

## What information do we collect about you?

We collect sensitive information about you or your child relating to your health or your child's health.

We also generally collect the following personal information about you or your child: name, date of birth, weight, phone number, address and email address, gender and information about siblings, school records, and if you provide consent, your photograph or your child's photograph and information you or your child provide in an interview.

## How do we collect your personal information?

With your consent, we collect your information from third parties such as social workers, guardians and siblings. We also collect your information or your child's information from you when you provide information to us in writing, via email, via the telephone or on our website when applying, enquiring, or registering for camp/activity opportunities with Save Our Sons. We hold your and your child's personal information for the duration of your relationship with Save Our Sons or as required by law.

## Why do we need your personal information?

Save Our Sons collects, holds, uses and discloses personal information relating to you and your child:

- Administration: to enable you or members of your family to attend our camps or be involved in other programs run by us, to receive financial or domestic support, and to enable us to communicate with you about our services;
- Marketing: to communicate with you about our initiatives, and if you or a parent/guardian provides consent, to use photographs and/or information provided in an interview to promote our initiatives;
- Support Services: to provide medical assistance to you while participating in our programs; and
- Compliance: to comply with our legal obligations.

## To whom does Save Our Sons disclose personal information?

Save Our Sons discloses your personal information to:

- Patients and families of patients: but only if you have volunteered to be a companion to a patient;
- Internal support services: employees, volunteers and Board Members of Save Our Sons;
- Contractors and service providers: who provide services to Save Our Sons and who provide medical assistance to those assisted by Save Our Sons;
- Third parties required by law including the Australian Federal Police to conduct working with children checks; and anyone else you authorise.

Our privacy policy contains further information about how Save Our Sons may collect, use and manage personal information, including information about how you may access and correct your personal information or make a complaint about a breach of privacy and how we will deal with such a complaint. Our Privacy Statement is available <https://www.saveoursons.org.au> or from us on request (at the contact details below).



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