



## Families of Spinal Muscular Atrophy NZ

*Advancing Research. Supporting Families.  
Balancing Life's tough times.*

Registered Charitable Trust No: 1814538

IRD No: 94-092-116

P.O. Box 4152

Christchurch

0800 FSMANZ

[www.sma.org.nz](http://www.sma.org.nz)

A group of SMA affected families has recently set up a chapter of FSMA in NZ. We would like to ask all SMA families to join this chapter. We will not be charging membership fees, but requesting donations only. Membership is reciprocal with FSMA so if you are a member of the NZ chapter you will automatically be joined to FSMA and vice versa (although if you would like to receive the Directions magazine you will need to pay the full US membership fee of US\$40.)

### **Why join Families of SMA? - To help find a cure!**

**Mainly through research funded by FSMA**, we are closer than ever to finding a cure! FSMA-funded research has led to:

- the mapping and cloning of the SMA gene
- identifying the SMN2 protein
- developing of carrier testing
- creating multiple mouse models
- identifying a pathway capable of restoring full length SMN2

**FSMA is the largest private funder of SMA research in the world.** Currently FSMA is funding 14 different research labs to find a cure. In addition, FSMA has initiated the most comprehensive SMA drug screening program to date and is funding the development of clinical protocols in preparation for clinical trials. We are receiving more research funding requests than ever and we need your help to fund the additional work that is needed.

**FSMA has a Scientific Advisory Board** which evaluates and guides all research funding, to ensure the funds are wisely allocated and supports many researchers all over the world.

**FSMA sponsors the** only annual global conference devoted entirely to SMA research. Dedicated researchers gather from around the world to share results and exchange ideas, fostering a spirit of cooperation and moving us toward our goal of finding a cure sooner.

**FSMA provides disease-specific information** to families, healthcare professional, and educators. In addition, we refer families to appropriate resources for assistance and support.



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### I would like to join FSMA NZ

Name: \_\_\_\_\_

Address: \_\_\_\_\_  
\_\_\_\_\_

Phone number: \_\_\_\_\_ E-mail: \_\_\_\_\_

### I am/have/had a family member or friend affected with

SMA Type \_\_\_\_\_ Affected person's name \_\_\_\_\_ Male/Female

Date of Birth \_\_\_\_\_ Relationship to you \_\_\_\_\_

Diagnosis date \_\_\_\_\_ Date of Death (if applicable): \_\_\_\_\_

Father's name \_\_\_\_\_ Mother's name: \_\_\_\_\_

### I would like to receive e-mail updates on research: (tick box)

Yes  No

### I would like to be included in the support network: (tick box)

Yes  No

### I would like to make a donation of: (tick box)

\$5  \$10  \$20  \$50 Other \_\_\_\_\_

(Please note donations can be made via cheque or at any ANZ bank. If donating via ANZ Bank, please use the reference 'Families of SMA NZ'.)