

THE EPILEPSY Foundation

of Victoria Incorporated

REG. NO. A0022674D

The Victorian member of **Epilepsy*Australia** Australia's peak consumer-led epilepsy organisation

* **National Epilepsy Helpline 1300 852 853**

Head Office: 818 Burke Road, Camberwell, Victoria, Australia, 3124 *Tel:* +61 [0]3 9805 9111 *Fax:* +61 [0]3 9882 7159

Email: epilepsy@epilepsy.asn.au *Websites:* <http://www.epinet.org.au> <http://www.epilepsyaustralia.org>

Grampians Regional Office: The Cooina Centre, 10 Learmouth Road, Wendouree, Ballarat, 3355 *Tel:* +61 [0]3 5338 1277

Loddon Mallee / Hume Regional Office: Community Health, Seymoure Street, Eaglehawk, Bendigo, 3556 *Tel:* +61 [0]3 5434 4300

Barwon / South West Regional Office: Barwon Design Park, 400 Pakington Street, Newtown, Geelong, 3220 *Tel:* +61 [0]3 5223 1645

PATRONS COUNCIL

Chairman:

Dame Beryl Beaurepaire

AC OBE

Ted Baillieu MLA

John Blackman

The Hon Justice Bernard Bongiorno

Philip Brady

Michael Brereton

Julian Burnside QC

Professor Ed Byrne

The Hon John Cain

The Hon Joan Child

Paul Cronin

Sean Cummins

The Hon Justice Linda Dessau

Ivan Deveson AO

Melanie Eagle

David Galbally QC

Rhonda Galbally AO

Bev Genser

Petro Georgiou MHR

Stera Gutnik

David Hayward

The Hon Brian Howe

John Jost

Robert Kirby

The Hon Joan Kirner AM

Judy Maddigan MLA

Neil Mitchell

Dame Elisabeth Murdoch

AC CBE

Emeritus Professor Sir Gustav

Nossal AC CBE

Janet Powell

Barbara Rozenes

Ross Smith AM

Richard Stanley QC

The Stillwell Family

Claude Ullin

Luisa Valmorbidia

President:

Professor Mark Cook MD

Vice President:

Dr Lindsay Vowels

Treasurer:

Dr Christine Walker

CEO:

Graeme Shears

Client Service Managers-

Metropolitan Region:

Jean Ewing & Lisa Rath

Grampians Region: Ira Effret

Loddon Mallee Region: Lisa Rath

Barwon Region: Jan Burns

Development Manager:

Jeremy Maxwell

Principal Social Researcher:

Dr Jaya Pinikahana

29 August 2008

Committee Secretary
Senate Economics Committee
Department of the Senate
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

Submitted by email: economics.sen@aph.gov.au

Epilepsy Foundation of Victoria welcomes the opportunity to provide comment to the Senate Standing Committee on Economics.

The Epilepsy Foundation of Victoria is Victoria's major consumer support agency for all people affected by epilepsy.

We estimate that 10% of Victorians will have a seizure during their lifetime, over 3% will develop epilepsy, approximately 140,000 people. Of these 12.5% will be children under the age of 14. Many of these will be under the age of five with nearly 800 children being newly diagnosed each year.

Until recently, epilepsy was believed to be predominantly a childhood disorder. Research now shows that the incidence of epilepsy in people age 75 and over is higher than in the first ten years of life. In fact, statistics in the United States have shown that approximately 7% of seniors have epilepsy.

We provide a range of support services for people who presently have epilepsy, as well as their families and friends and the communities they live and work in. Sometimes it may involve talking through the situation with one of our counsellors or special education sessions for staff, students and parents. We have available a wide range of resources to supplement the work we will do with you, including videos, information sheets and epilepsy management plans for individual children.

In 2003, 86% of adult Australians put their confidence in the non-profit sector. Their confidence deserves government attention. Indeed, the non-profit sector itself has been calling for reform. We welcome the Senate's interest and prioritisation of our work and urge you to act on the body of evidence put to this inquiry and not to allow it, like previous inquiries, to be ignored.

We are writing in support of Fundraising Institute Australia's submission, recommending a **commission of inquiry** be established to further develop the initiatives explored in this Senate Inquiry, in particular 'model' fundraising legislation, the shape of a national regulator and the elements of a compact to underpin the values and funding of this sector.

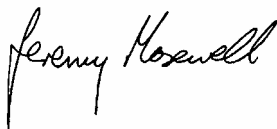
We would like to make the following additional points to FIA's submission: -

- The establishment of a single regulator **might not occur immediately**, we urge a real effort be made to reduce the regulatory burden of conflicting regimes, in particular, through the COAG agenda 'cutting red tape' and **bringing state legislation into harmony** as an interim.
- **Accountability is not a level playing field, therefore it undermines transparency.**
The lack of accounting standards, particularly in relation to investment and development of capacity, means it is almost impossible for many organisations to attempt meaningful reporting. Firstly, what do they report, there is no consistency on what to include; Secondly, **they are disadvantaged** when compared against many other not-for-profits who are often shielded by exemptions; Thirdly, many major organisations, whose fundraising is a proportionally smaller part of their income mix can absorb expenses into their infrastructure creating unrealistic results.
- **Accountability is not just financial.** There is no reasonable measure of real outcomes for the people we serve, our clients never ask what have you spent raising money they just want to know how you can help. Presently all measurement is around profitability because commercial business practices, accounting and reporting standards are being used. The problem with that is their overarching imperative of profitability is not what this sector is about nor should it ever be.

FIA is also proactive in working towards self regulation by creating mandatory Principles and Standards of Fundraising Practice. The Principles codify general ethical behaviour for fundraisers; the Standards are tailored to provide guidelines on specific disciplines of professional fundraising. The project was initiated in response to FIA's perception of an urgent need to establish standards for professional fundraising in order to improve public trust and confidence in accountability for and transparency in the use of publicly donated funds.

Please find attached a summary of FIA's recommendations to the Senate Inquiry into disclosure regimes for charities and non-profit organisations.

Yours sincerely,



Jeremy Maxwell FFIA CFRE

Development Manager

Appendix 1: SUMMARY OF RECOMMENDATIONS

a) the relevance and appropriateness of current disclosure regimes for charities and all other not-for-profit organisations

A new single regulator for the entire non-profit sector should:

- regulate proportional to risk and not in accordance with exemptions
- reduce multiple reporting requirements reducing the regulatory burden
- develop an appropriate accounting standards and reporting mechanisms that measures effectiveness (outcomes) not efficiency (ratios).

b) models of regulation and legal forms that would improve governance and management of charities and not-for-profit organisations and cater for emerging social enterprises

A new single regulator should:

- be based on principles similar to the Charity Commission (England and Wales)
- enable the work of the sector (light touch regulation proportional to risk)
- close the gap between statutory and non-statutory regulation (national industry self-regulation)

c) Other measures that can be taken by government and the not-for-profit sector to assist the sector to improve governance, standards, accountability and transparency in its use of public and government funds.

A new single regulator should:

- cut red tape
- allow for diversity (light touch regulation proportional to risk)
- support development of a national toolkit
- focus on effectiveness (outputs, public benefit) not efficiency (financial ratios)
- adopt a standardised disclosure regime
- encourage benchmarking
- assist non-profit organisations in annual reporting
- provide meaningful information for the public
- promote the public interest in charity and non-profit activities

d) The Senate Inquiry has sought further comment on the recommendations from the inquiry into the definition of charities and related organisations (2001).

- decide the name of the sector!
- promote responsibility for this sector to ministerial level

e) The Senate Inquiry opens discussion on a number of initiatives that must be further explored.

Establish a Commission of Inquiry to:

- develop 'model' fundraising legislation
- determine the 'shape' of a national regulator
- determine a national accounting standard and reporting mechanism
- review the elements of a compact to underpin partnerships with the sector.