



HeartKids NSW

4th April, 2012

Charitable Fundraising Regulation Reform Discussion Paper
Infrastructure, Competition and Consumer Division
The Treasury
Langston Crescent
PARKES ACT 2600

By email: NFPReform@treasury.gov.au

Charitable Fundraising Regulation Reform Discussion Paper

Dear Sir/Madam,

HeartKids NSW welcomes the opportunity to support the submission made by HeartKids Australia to the *Charitable Fundraising Regulation Reform Discussion Paper* (the Paper).

HeartKids Australia and our affiliated State organisations are the only Not-For-Profit (NFP) federation in Australia focused on congenital childhood heart disease.

HeartKids Australia – National and State Organisations

HeartKids Australia and the State organisations operate as a federated model. HeartKids Australia has five members, being each of the five HeartKids State organisations –HeartKids New South Wales; HeartKids Queensland; HeartKids South Australia; HeartKids Victoria; and HeartKids Western Australia.

Each HeartKids State organisation is a separately incorporated entity that provides support to the members in their respective States. HeartKids Australia and each of the five State organisations align where appropriate and work in a coordinated and cooperative manner to optimise the many benefits of such a model.

Given the structure, this puts HeartKids Australia in a good position to provide the following principled comments in response to the Paper. We have addressed the Chapters or headings and made principled comments appropriately.

Again, HeartKids NSW welcomes the opportunity to support the submission made by HeartKids Australia to The Treasury's *Charitable Fundraising Regulation Reform Discussion Paper*.

Kind Regards

David Rose
State Manager
HeartKids NSW



HeartKids Victoria

PO Box 803
Parkville VIC 3052

T +61 3 9513 9030 F +61 3 9345 6765
E heartkids@heartkids.org.au W www.heartkidsvic.org.au
ABN: 16 338 986 918 ARN: A0021470B

4 April 2012

Charitable Fundraising Regulation Reform Discussion Paper
Infrastructure, Competition and Consumer Division
The Treasury
Langston Crescent
PARKES ACT 2600

By email: NFPReform@treasury.gov.au

Charitable Fundraising Regulation Reform Discussion Paper

Dear Sir/Madam,

HeartKids Victoria Inc. welcomes the opportunity to support the submission made by HeartKids Australia to the *Charitable Fundraising Regulation Reform Discussion Paper* (the Paper).

HeartKids Australia and our affiliated State organisations are the only Not-For-Profit (NFP) federation in Australia focused on congenital childhood heart disease.

HeartKids Australia – National and State Organisations

HeartKids Australia and the State organisations operate as a federated model. HeartKids Australia has five members, being each of the five HeartKids State organisations – HeartKids New South Wales; HeartKids Queensland; HeartKids South Australia; HeartKids Victoria; and HeartKids Western Australia.

Each HeartKids State organisation is a separately incorporated entity that provides support to the members in their respective States. HeartKids Australia and each of the five State organisations align where appropriate and work in a coordinated and cooperative manner to optimise the many benefits of such a model.

Given the structure, this puts HeartKids Australia in a good position to provide the following principled comments in response to the Paper. We have addressed the Chapters or headings and made principled comments appropriately.

Again, HeartKids Victoria welcomes the opportunity to support the submission made by HeartKids Australia to The Treasury's *Charitable Fundraising Regulation Reform Discussion Paper*.

Kind Regards

Terry Hopkins
CEO
HeartKids Victoria



HeartKids Australia
PO Box 444
Pennant Hills NSW 1715
T +61 2 9875 4090 F +61 2 9875 5460
E office@heartkids.org.au W www.heartkids.org.au
ABN: 72 652 162 549

5 April 2012

Charitable Fundraising Regulation Reform Discussion Paper
Infrastructure, Competition and Consumer Division
The Treasury
Langston Crescent
PARKES ACT 2600

By email: NFPReform@treasury.gov.au

Charitable Fundraising Regulation Reform Discussion Paper

Dear Sir/Madam,

HeartKids Australia welcomes the opportunity to make a short and principled submission to the *Charitable Fundraising Regulation Reform Discussion Paper* (the Paper).

HeartKids Australia and our affiliated State organisations are the only Not-For-Profit (NFP) federation in Australia focused specifically on childhood congenital heart disease.

About Childhood Heart Disease (CHD)

Approximately 1 in 100 children are born with heart disease – that is six babies are born every day with CHD (**HeartKids**). Heart disease is one of the most common birth abnormalities, of which 20 per cent of heart defects are gen-linked abnormalities. CHD has nothing to do with diet. Some children acquire heart conditions during childhood.

CHD is one of the greatest killers of infants under the age of one; and each week four children pass away as a result of CHD.

About half of the children diagnosed with heart disease require surgery to correct the defect. It is estimated that about 32,000 children under the age of 18 are currently living with CHD in Australia.

In the last 20 years great strides have been made in researching the causes of CHD, and in improving treatment and care for those affected by it. More and more Heart Kids are now surviving into adulthood to lead active and productive lives, even if that means a little more care and support is needed to help them along the way. It's no longer simply about babies and toddlers, now it's about a growing cross-section of the teenage and adult Australian communities.

About HeartKids Australia and our affiliated State Organisations

Our vision: Life unaffected by Childhood Heart Disease (CHD).

Our mission: As the public face of CHD and through our active partnering with the medical community and Government, Australia will adopt best practice in the intervention, treatment and support for all those affected. This will result in a reduction of incidence, decreased mortality, significantly improved quality of life and best outcomes for those affected by CHD. This will be achieved through our work in Support, Awareness, Research and Advocacy.

Support

We support families who have a child and teenagers with heart disease. We do this through various ways, including employing Family Support Coordinators in each of the major children's hospitals throughout Australia; assisting families with travel and accommodation needs and holding Teen Camps for teenagers with CHD. We run seminars and information events, where experts provide practical advice to families affected by CHD.

Awareness

We are striving to increase awareness of CHD through various campaigns and awareness programs. Our goal is to educate the public to the whole of family impact that having a child with CHD has and our objective to support the families affected

Research

With the support of its sponsors and donors, HeartKids Australia is proud to have committed over \$1,500,000 of funding for research projects looking to advance the diagnosis, treatment and prevention of CHD, and the affiliated State organisations have made significant further donations towards local research projects. These funds are allocated with peer review of our Research Advisory Committee, often in partnership with the National Health and Medical Research Council and other credible organisations.

Advocacy

HeartKids Australia also advocates the recognition of the needs of heart children and their families in terms of medical, social and other support needs, including making cases to federal and State governments about public policy and programmes better accommodating them.

In 2011 HeartKids Australia, in conjunction with the Cardiac Society of Australia and New Zealand, commissioned a White Paper, *Childhood Heart Disease in Australia – Current Practices and Future Needs*. The White Paper reviewed the CHD environment, current and emerging patient and family needs, the available treatment and support services for CHD; identified service gaps; and made a number of recommendations for clinicians, the HeartKids community and Commonwealth, State and Territory governments.

HeartKids Australia also is endeavouring to improve parliamentarians' awareness of CHD and heart kid families through direct engagement and organised events. These activities are done on a voluntary basis based on our own networks (ie no lobbyists are engaged to assist us).

HeartKids Australia – National and State Organisations

HeartKids Australia and the State organisations operate under a federated model.

HeartKids Australia has five members, being each of the five HeartKids State organisations – HeartKids New South Wales; HeartKids Queensland; HeartKids South Australia; HeartKids Victoria; and HeartKids Western Australia.

Each HeartKids State organisation is a single and separately incorporated entity that provides support to the members in their respective States. HeartKids Australia and each of the five State organisations align where appropriate and work in a coordinated and cooperative manner to optimise the many benefits of such a model. HeartKids Australia also plays a leading role as a custodian of the HeartKids “brand” and as a coordinator of larger-scale corporate and philanthropic support that is distributed through the HeartKids federation.

Given this structure, this puts HeartKids Australia in a good position to provide the following principled comments in response to the Paper. We have addressed the Chapters or headings and made principled comments appropriately. These comments reflect consultation with State HeartKids organisations.

General comments

As well as commenting on the issues raised in specific chapters of the Discussion Paper, we also wish to make some basic points about our policy position on the regulation and governance of NFPs like HeartKids. In short, we believe that related policy, legislation and regulation need to take into account that:

- Public policy, and regulation flowing from it, should encourage the volunteer spirit in Australian society, encourage people to volunteer their time, expertise and labour, and to encourage Australian individuals and corporations to give generously to good causes.
- Smaller NFPs or charities (of which HeartKids is just one example) are run by volunteers, contributing passion and enthusiasm, and willing to take some personal risks (eg as a Board member) to further a cause they believe in.
- They may have a small core of paid staff, but they also largely depend on volunteer labour to function.
- While accountability to the community and to donors, and prudence and responsibility to employees and volunteers are essential, excessive regulation and compliance may make an NFP or charity unviable, which potentially affects the better interests of those that the organisation is established to help, and conversely may increase Government costs to administer.
- Increases in regulatory or compliance burdens should only be considered if existing arrangements are proven to be inadequate, not simply because they seem a good idea to a well-intentioned regulator or Parliament.
- Regulatory change should not become a disincentive for NFPs and charities to operate prudently and ethically, nor should they inappropriately deter or bar donors, sponsors and other supporters from making vital financial and in-kind contributions.
- Compliance costs are operating costs: each dollar spent on compliance and red tape is a dollar not spent directly on the primary purposes of the NFP or charity. This is not saying that complete deregulation is the way to go, but that regulation and compliance should be kept to the minimum needed to protect the public interest.

As a federation of organisations, we support tighter regulation and compliance where it is justified, but we have reservations that this is part of a general enthusiasm for increased regulation or re-regulation that is affecting the NFP sector.

For example, while noting that it is beyond the direct scope of this Discussion Paper, we are seriously concerned about the application of the new national uniform legislation on workplace safety, which classes volunteers as employees, with associated work cover, director liability and other on-cost obligations. Compliance with this regime will increase our costs, the implied responsibility on honorary directors may deter qualified people from serving in those roles and, crucially, our fundraising and accountability tasks in a crowded “market” may become a great deal

harder as more costs need to be covered. Effectively, the new workplace safety laws risk creating problems far greater than those they are intended to solve.

In short, it is essential that commissioners and staff of the new Australian Charities and Not-For-Profits Commission (ACNC), as well as Commonwealth and State officials dealing with charities and NFPs, always attempt to put themselves in the shoes of those organisations, and try to see issues from that side of the fence. Often what seems right in policy theory has significant practical but unintended consequences when being implemented by small but dedicated organisations operating on very limited budgets and resources but a lot of goodwill.

Chapter 2 – Defining the scope of regulated activities

As the Paper correctly outlines, generic laws that apply to fundraising include criminal laws, corporations and associations incorporation law for already incorporated entities, law dealing with unincorporated associations and the common law. Additionally, State and Territory fund raising laws as appropriate.

Streamlining regulatory requirements and reducing duplication, inconsistency and complexity delivers benefits across the economy. These are the foundations of successful regulatory reform – and these foundations they must be kept in close sight.

Any regulatory impost carries a cost burden, and generally an administrative burden – which too has a cost. It is important that any reforms to charitable funding raising laws – whether at national or state level, do not duplicate existing regulations and requirements, do not have unintended consequences, and do not create inconsistencies and do not create increased complexity.

It is important that the Australian Charities and Not-for-profits Commission (ACNC) does in fact deliver a reduced regulatory burden on the charity and not-for-profit sectors. An outcome whereby the ACNC duplicates the work of other regulatory bodies enforcing their relevant legislation and regulation would be a suboptimal outcome for the charities and not-for-profits, all Australian taxpayers – and most importantly the people, services and facilities that are recipients of the benefits delivered by the not-for-profit sector in Australia.

To ensure streamlining and non-duplication it would be appropriate for the Commonwealth to pursue agreement with all States and Territories regarding a common approach and way forward regarding the interaction of proposed national and existing State regulatory frameworks. We therefore support uniform legislation, where appropriate, to ensure that the Commonwealth, States and Territories' regulatory regimes are consistent and easier to comply with. This obviously is important where an NFP or charity operates across State borders – as our HeartKids State organisations often do (especially when a child has to travel for surgery or treatment).

Chapter 3 – Regulating the conduct of fundraising

HeartKids Australia supports the position that well-targeted regulation delivers benefits. However, as outlined above, there can be unintended consequences of even the most well targeted regulation.

To that end, we support principle-based, outcome-focused laws and regulations to achieve transparent, sustainable and committed organizations that provide charitable services and outcomes that government cannot economically provide. It should always be front-of-mind that regulation is designed for the lowest common denominator, and that the vast majority of entities to which laws and regulations apply are not inherently behaving badly.

Chapter 4 – Information disclosure

Information provision is an important aspect of many regulatory frameworks. HeartKids supports the provision of an appropriate level of information disclosure, but is concerned that regulatory measures in this arena designed to address the lowest common denominator will increase the regulatory burden on the charity and 'not for profit' sector. Information provision is important, and it is important that it is proportional. It has been the case in many sectors that proposed requirements for information provision have been excessive and disproportional to the issue at hand.

It is also important to keep in mind that while it is more cost effective to provide information online in a one-to-many world than it is in a one-to-one communication, such as via direct mail, it is important that the parameters of the information required are proportional to the risk being addressed. Requesting increasing volumes of, and increasingly detailed, reports and information for publication under the auspices of 'reporting requirements' – as is often what happens with regulatory creep – is an administrative burden and adds to the cost of the sector and its participants.

It is also vital to understand that many entities in this sector do not have teams of financial analysts available to cut data in many and varied ways. It is important that reporting requirements are manageable and do not impose undue burden on these entities.

HeartKids Australia supports the streamlining of reporting requirements such that there would be single reporting requirements that are fit for purpose, and relative to the size of the organisation.

We also believe that it is essential to protect personal privacy in any routine information disclosure regime. For example, while many donors (notably in the corporate sector) are happy to be recognised for their generosity, many others prefer anonymity. Provided that anonymous donations are made from lawful sources they should be able to be kept confidential between the donor and the organisation. It is up to the donor to disclose their own giving activities where necessary (for example to the Australian Taxation Office in terms of tax assessment).

Chapter 5 – Internet and electronic fundraising

HeartKids Australia appreciates the challenges that the online environment brings. HeartKids Australia also appreciates the opportunities that the online environment brings. We support the growing opportunities the online world offers the sector, to raise awareness and also raise funds.

It will be important that regulatory approaches proposed and applied in this realm do not have unintended consequences. For instance, constraints in defining or limiting electronic fundraising when the advancement of social media such as someone tweeting, or re-tweeting, or emailing or forwarding an email, be counter productive to our sector ?

For many years there has been a range of ever changing and evolving online frauds and scams. HeartKids suggests that this is an arena where educating the public of scams and frauds would be of value. We suggest that this is an area where the Australian Competition and Consumer Commission – for example ScamWatch – and Fair Trading authorities in the States have experience that could be leveraged and utilised. As indicated above, our considered view is that this is a very grey area. But rather than assume that it can be regulated comprehensively it may be better to take a "loose hand" regulatory approach by Government setting out broad principles, and assuming that prudence and common sense can bring about the desired public policy results.

This is perhaps an area where there can be early engagement between the NFP sector and the ACNC.

Chapter 6 – Fundraising by third parties on behalf of charities

It seems appropriate that fundraising undertaken by third parties should comply with the same information disclosure requirements as those of the entities they are collecting on behalf of, in addition to disclosing their own details.

On the other hand, it seems to us that some common sense would help here. We are sure that the Government does not want inadvertently to stamp out the sort of traditional grass-roots fundraising (such as lamington drives, or more localised activities like our Cuppa For HeartKids) that relies very much on individuals and small groups adopting causes and promoting them in their local communities.

Again, HeartKids Australia welcomes the opportunity to provide this principled response to The Treasury's *Charitable Fundraising Regulation Reform Discussion Paper*. We would be very happy to have further discussions if desired.

Yours sincerely

A handwritten signature in dark ink, appearing to read 'Brian Pereira', with a long horizontal flourish extending to the right.

Brian Pereira
Chairman
HeartKids Australia