

22 June 2017

Senior Adviser
Individual and Indirect Tax Division
The Treasury
Langton Crescent
PARKES ACT 2600

Email: DGR@Treasury.gov.au

Dear Sir/Madam,

Re: Tax Deductible Gift Recipient Reform Opportunities Consultation

I represent people across Australia who have Prader-Willi Syndrome (PWS), their parents and supporters. Our association is small, and highly dependent on donations, as it has no other income. It provides a variety of volunteer services to its members, and also pursues the best interests of any community members who have PWS. All administrative work is done by volunteers, so this burden should not be increased by the reforms.

PWS is a rare and complex condition. Parents and carers of people who have PWS spend a lot of time supporting their loved one. Their condition includes multiple health, behavioural and cognitive problems for which services must be sought and coordinated. Furthermore, all people and organisations involved with supporting or caring for an individual with PWS require specialized training in the complexities of the Syndrome.

We believe that all people with PWS will be eligible for the NDIS. Parents and carers of people with PWS are stressed, time-poor and often naive about rules and regulations that will impact their loved one. Given the above circumstances, it means they:

- need the PWS association to provide emotional support
- depend on the association for education and advice about PWS
- require the expertise of the volunteers in the group for individual and systemic advocacy
- expect the Board to keep abreast of developments in policy and programs that impact people with PWS, and formulate ways to navigate the system (eg NDIS)
- rely on the association to put forward common concerns of the membership, plus ideas for improvements, to forums, organisations and departments that are charged with assisting those with PWS.

The NDIS is a new and complicated scheme. PWSA members value their association for its roles in both helping individuals to participate fruitfully in the scheme, and contributing to the scheme, thus enabling the NDIS to evolve in a way that recognises the complex needs of people with PWS.

Given the range of services the PWSA provides to its members, it rejects the idea of changes to the DGR program that would either reduce donations, or put further constraints on the way the association chooses to use its donations.

PWS Australia cautiously welcomes a review of the Deductible Gift Recipient arrangements, particularly if it reduces administrative complexity for organisations like ours, and provides better monitoring and accountability overall. We also support the standardisation and possible nationalisation of the approval and permit process for fundraising events.

Of concern are reports about charitable organisations that appear to have spent a highly disproportionate sum on administration and employee benefits, compared with spending on activities that progress 'the cause'. Additionally, there are "many other benefits on offer for patrons and directors of charities, including the opportunity to host 'celebrity events', and at the same time tax effectively distribute funds and provide benefits to associates"¹ which is not the intent of the DGR status. Despite not adhering to rules, like submitting reports to authorities, they are allowed to continue operating. Those are the kind of flaws the DGR reforms should address.

The focus of the reforms must be to remove abuse of the DGR status. Lobbying activities of groups, such as environmental groups who act in the public interest, must not be impacted by any reform, as long they are not spending most of their funds on administration and holding events that cost more than the proceeds. DGR status should not be granted to organisations that stand to make a commercial gain from their activities in the absence of clear evidence that the profits are intended to be applied to the organisations charitable aims.

In relation to the specific questions you pose in your Paper, PWS Australia agrees that:

- All DGRs should be subject to robust reporting and governance standards and be monitored and held accountable, much more than in the past
- Regular, formal reviews should be made of the medium to large organisations; Registration should not be indefinite for these sizes, sunset should be built in. Review priority should start with the largest organisations, based on the highest donations claimed and where the cost of fund raising is higher than proceeds for the cause
- There must be more transparency around the structure and finances of medium and large DGR organisations, with their data available to the public
- DGR's should *not* have an added burden of reporting on their advocacy activities. Instead, a measure of performance and suitability should be based on a DGR spending less than 50% of its costs on administration
- However, registering as a charity may place undue constraints on the public benefits available from some organisations that are eligible for DGR status alone. This unintended consequence should not be caused by mandating charitable registration. The ATO could apply its regulatory processes under Not-for-Profit criteria, instead of 'charitable', to the four topic specific registers.
- Environmental groups should not have to commit to a percentage spend on remediation. Instead, with better availability of organisational information to the public, potential donors can make their own choice. They can look at how an organisation prioritises its spending. Then the donor can choose to those organisations that focus on remediation works, if the donor prefers.

Thank you for the opportunity to contribute to this review.

Yours sincerely,



James O'Brien
President
PWS Australia

m. 0451 797 284 e. info@pws.org.au w. www.pws.org.au

<http://theconversation.com/shane-warne-foundation-a-wake-up-call-for-charities-regulator-51034>