

Sponsorship Policy

LDA has a number of objectives. To achieve these, LDA receives sponsorship from a variety of sources, which are listed in this newsletter. The sponsors are

presented in alphabetical order, which does not in any way reflect the amount or type of sponsorship received.

The Board has developed a Sponsorship Policy to guide our

acceptance of donations/ sponsorship. This Policy is reproduced below and is also posted on the LDA website. Paper copies can be obtained from the Public Officer if required.

Sponsors:

BioMarin Pharmaceuticals, Inc. (USA)

Genzyme Corporation (USA)

Transkaryotic Therapies, Inc. (USA)

GUIDING PRINCIPLES and FUNCTIONS of POLICY

Lysosomal Diseases Australia (LDA) was established in December 1998 as a non-profit company limited by guarantee.

It is likely that LDA will receive donations or sponsorship from a variety of sources, including corporations. As a consequence it is necessary for LDA to define and establish clear guidelines for the acceptance of such sponsorship. For the purposes of this Policy, 'sponsorship' means both donations and sponsorship, and includes both private and corporate donations or sponsorship.

This policy seeks to:

- set clear parameters and terms for the acceptance of sponsorship, which include the rights and obligations of both LDA and its sponsors;

- ensure that confidence in LDA's independence and reputation is retained by full disclosure of sponsorship and declaration of conflicts of interest to avoid the perception of bias.

1. LDA will remain autonomous from any sponsor. Sponsorship of LDA does not entitle the sponsor to control LDA in any way, nor does it confer any benefits, privileges or rights to the sponsor.

2. In accepting a sponsorship, LDA will not endorse, or give the impression of endorsing, the actions or products of a sponsor. LDA publications will contain the standard disclaimer, "LDA gratefully acknowledges the above sponsors and wishes to make known that LDA remains independent of its sponsors and does not necessarily endorse any products or services of its sponsors".

3. To avoid perceptions of conflict of interest in pursuing its objectives, LDA will in all cases clearly set out its relationship with sponsors at the outset of any discussions in which this could be an issue, and declare that LDA does not endorse the products or services of any of its sponsors. This is important in those areas of activity where a particular outcome may be perceived as directly benefiting a sponsor.

4. The LDA Board of Management reserves the right to refuse a sponsor if the Board considers the sponsor is incompatible with the objectives of LDA. The decision of the Board is final.

5. To ensure transparency and remove perceptions of bias, sponsors will be acknowledged alphabetically on the LDA web site and newsletters, and any other publications as deemed appropriate by the LDA Board of Management. Details concerning the amount or type of sponsorship

provided by any sponsor will not be divulged.

6. In the case of corporate sponsors, LDA will not publish company logos in any of its publications. The LDA web site will not provide links to corporate web sites.

To reduce the potential for perceptions of bias, sponsors will be advised at the outset that LDA aims for a mix of sponsors who are considered compatible with LDA's objectives. This is important in the case of corporate sponsors who may be competitive within a related field.

7. Sponsors may be approached by LDA from time to time to provide material for publication that is of direct educational interest and relevance to LDA's objectives. The material provided will be reviewed prior to publication and all references to specific companies, their products or services will be removed at the discretion of LDA, consistent with (2).

8. Sponsorship of LDA does not in any way make the sponsor liable for the actions or statements made by members of LDA.

9. Sponsors are able to request an audited report, which details the manner in which LDA funds are spent.

10. Sponsors will receive copies of newsletters and regular up-dates of LDA's activities.