



## Human Genetics Society of Australasia

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### **AUSTRALASIAN SOCIETY FOR INBORN ERRORS OF METABOLISM** (ASIAM) Special Interest Group ABN No. 17 076 130 937 002

10<sup>th</sup> November 2014

To Whom It May Concern:

**RE: Public consultation on the post-market review of the Life Saving Drugs Programme (LSDP)**

Please accept this response from the Australasian Society for Inborn Errors of Metabolism (ASIAM) to the Pharmaceutical Benefits Scheme request for submissions to consult on the post-market review of the LSDP.

The ASIAM response was formulated with input from The ASIAM Orphan Drugs Committee comprised of senior clinicians practicing in Australian Metabolic Units: Dr Avihu Boneh, Professor John Christodoulou, Dr Jim McGill and Dr Drago Bratkovic.

The ASIAM supports the establishment of a committee that will review the current practice and formulate future directions in the treatment of rare diseases, subsidised by the Department of Health. We believe that this committee is worthy, its task is important and we support the terms of reference of this committee.

The ASIAM will be happy to support the work of the committee by providing detailed input regarding specific issues. As the representatives of multidisciplinary teams that manage patients with rare diseases, we think that it is our role to provide evidence (where available) and clinical judgment that will serve as buffer between the desires of patients and their families (which are understandable and usually justified), the industry (which provides orphan and expensive drugs/enzymes), and the Government, which funds the program. We therefore hope that ASIAM will have a strong voice, as appropriate, in the discussions and the formulation of recommendations.

If more information or clarification is required, please do not hesitate to contact me.

Yours sincerely

Anita Inwood  
Chair