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Annual General Meeting

GOLD's AGM took place on Tuesday 25th October, as an ancillary meeting during the American Society of Human Genetics Annual Conference in Salt Lake City, Utah, USA. Minutes will be posted on the GOLD website.

Guest Lecture

We were very pleased and honoured to welcome Dr Charles Scriver to deliver our Guest Lecture. The theme of this lecture was "A phenotype Project? What might THAT be?" Dr Scriver described GOLD as a unique organisation, which, by uniting scientists, clinicians, patient organisations and commercial organisations created a network which could be a prototype for other orphan genetic diseases. The abstract is posted on the website.

Next Annual General Meeting - 2006

Please send your comments, suggestions and requests for the next GOLD Annual General Meeting. We would like to ensure that the next meeting is held where most member organisations will be able to attend, and it is GOLD's policy to rotate the meeting locations to be accessible to all members. As this years meeting was held in the USA, possible venues for 2006 are:

- 9th International Symposium on Mucopolysaccharidosis and Related Disorders, June 29-July 2, 2006, Venice, Italy
- 11th International Congress of Human Genetics, August 6 - 10 2006 Brisbane, Australia
- 10th International Congress of Inborn Errors of Metabolism (ICIM), September 12-16th 2006, Chiba, Japan

A questionnaire will shortly be sent out, to see who will be attending these meetings, or to collect suggestions for other venues. Please also let us know (at ann.hale@goldinfo.org) what topics you would like to see at the meeting.

GOLD Management Council

Elections, 2005

The ballot for the Management Council elections closed on Sept 30th, and results were announced at the AGM.

Rhonda Buyers and Christine Lavery were re-elected to the Management Council. Roberto Giugliani, previously co-opted to the Council was newly elected. Ed Wraith was elected and is new to the Management Council. The Management Council is pleased to welcome Ed to the board, and we are sure he will be an asset to the Council. These elected members will serve for 3 years.

Dr Robert Desnick was not re-elected. The Management Council thank Bob very much for his insight and input into GOLD and we are sorry that he is no longer on the Board. GOLD is extremely fortunate that it can call from such a number of eminent and talented members for the election process.

Other changes to Management Council

Another loss to our Management Council is from the Industry Advisory Board's appointed members. Bill Aliski has left Shire Pharmaceuticals, formerly TKT Inc, so no longer represents Shire for the IAG on the Management Council. We thank Bill also for his work on the Management Council, and for his support of GOLD since its inception. The Management Council send Bill best wishes for the future.

Shire's new representative on the Management Council will be Dr David Whiteman, Principal Medical Director, Shire Pharmaceuticals. The Management Council welcome David to the board, and thank Shire for their continued support of GOLD.

As part of enhanced reporting procedures for charities registered in the UK, the Management Council reviewed the skills base of the Board members. Due to the Management Council members being elected from the membership, it is not possible to select certain skills areas, and GOLD lacks a board member with legal expertise. The Management Council took the decision to co-opt a new member with legal expertise, in addition to UK charity law experience. Mr Jeremy Manuel has agreed to be co-opted to the board. Jeremy is a lawyer and is also Chairman of the UK Gaucher's Association, and therefore brings to the Management Council a wealth of experience in addition to an involvement with LSD.

Next year, 4 more members of the Management Council will stand down. All will be eligible for re-election. Calls for nominations will take place not less than 8 weeks before the next AGM. The next members to stand down are: Dr Ed Kolodny, Dr Bryan Winchester, Dr Steve Walkley and Ms Barbara Wedehase.

Website

GOLD's website is updated regularly. Please send news items, requests for links or details of conferences and meetings to be added to the calendar of events to enquiries@goldinfo.org or contact Annie Hale, Executive Director. Discussion forums are also available. You will need to register as a user to access the full details of the membership directory or the discussion forums (there is a public forum for non-members.) You only need to register once - the first time you use either the member directory or the forums.

Registry

Registry scoping has commenced. GOLD is piloting an international independent registry using GM1, GM2 gangliosidoses and Niemann Pick C as a model. A Medical Advisory committee has been appointed and diagnostic criteria and data sets are being developed. The MAC members are: Dr Michael Beck, Dr Roberto Giugliani, Professor John Hopwood, Dr Marc Patterson, Dr Cynthia Tiff, Dr Marie Vanier and Dr Ed Wraith.

Membership of GOLD

There are now 99 member organisations, representing all LSDs.

Contact GOLD:

If you have any comments or suggestions, please send them to:

Ann Hale: ann.hale@goldinfo.org,

E-mail: enquiries@goldinfo.org

fax/phone +44 (0) 1494 870708

Mail: Global Organisation for Lysosomal Diseases
PO Box 609

Chalfont St Giles
HP8 4WU
UK

GOLD forums: <http://www.goldinfo.org>