

GOLD
GLOBAL ORGANISATION FOR LYSOSOMAL DISEASES
ANNUAL GENERAL MEETING 2005 - MINUTES

Saturday July 1st 6pm
Sala Perla, Venezia Lido Congress Centre, Venice, Italy.

Present: Management Council members

Executive Director

Guest Lecturer: Prof Tim Cox

+ Member Organisation Representatives in person or by proxy
+ Guests

Welcome

John Hopwood, Chair of GOLD, called the meeting to order at 6.05pm, and welcomed all present.

Apologies

A number of organisations whose representatives could not be present sent apologies and assigned proxy votes to members present.

Minutes of last AGM

The minutes of the last GOLD AGM have been distributed previously to all member representatives and posted on the GOLD website. JH asked if membership accepted those minutes as an accurate representation of that meeting.

Proposed: Bryan Winchester
Seconded: John Forman
Vote: Carried unanimously

Report from the Management Council

Ann Hale presented the report on behalf of the Management Council.

The GOLD website was launched in March 2005. In the time to January 2006 it had received over 260,000 hits, and was regularly updated over the year.

Membership increased from 79 to 105 groups, and had increased again since the end of the reporting period.

3 Updates to membership had been issued

GOLD held its first Guest lecture at the AGM in 2006, with Dr Charles Scriver, who spoke on the subject of "A phenome project? What might that be?"

Work had been done towards developing new member only areas for the website, which had been launched after the end of the reporting period. These are:

- ◆ Video Streaming
- ◆ OMMBID

Ann Hale showed a short demonstration of how to access these areas of the website, and said that the video site was available for any member group who wished to use it. If interested, please contact her.

Financial report

Ann Hale then presented the financial report for the financial year April 1st 2005 – March 31st 2006. A copy of the annual report and accounts has been sent to all member organisations. Income for the year was lower than expected at £15,775. Net expenditure was £45,592, this figure including a write-back of £17,039 from a provision made the previous year which was deemed not payable. Ann Hale said that income for the current year was already higher than received in 2005-6.

Management Council Elections

John Hopwood reviewed the nominations for the Management Council. Four members were standing down (Dr Ed Kolodny, Dr Steve Walkley, Ms Barbara Wedehase and Dr Bryan Winchester). Dr Ed Kolodny did not stand for re-election due to pressure of work. John Hopwood thanked Dr Kolodny for all his work on behalf of GOLD; Ed was instrumental in developing GOLD, and has said he will continue to be a strong supporter.

The nominees for the Management Council were:

- ◆ Dr Joe Clarke
- ◆ Dr Greg Grabowski
- ◆ Dr Greg Pastores
- ◆ Dr Steve Walkley
- ◆ Ms Barbara Wedehase
- ◆ Dr Bryan Winchester

Following the ballot, which was very closely contested, the members elected were:

- ◆ Dr Joe Clarke
- ◆ Dr Steve Walkley
- ◆ Ms Barbara Wedehase
- ◆ Dr Bryan Winchester

Management Council Resignation & Co-option

John Hopwood said that Jayne Gershkowitz, Vice Chair, had resigned effective of 12th June 2006, to take up a role with Amicus Therapeutics. Jayne had also been involved with the development of GOLD, and, like Ed Kolodny will be missed. On behalf of the Management Council, he wished her well in her new position. He then explained that when a member of the Management Council resigned before the end of their elected term, according to the Articles of Association, the remaining Council members may co-opt a member to sit on the council for the remaining period of that term. The Management Council had voted to co-opt Dr Greg Grabowski, as he was the nominee for the elected positions with the next highest number of votes.

Special Resolution

Notice of the special resolution had been issued to all members on June 9th. The purpose of this resolution is to define the terms for non-profit and commercial group membership of GOLD more clearly, and to introduce an additional category of membership, that of Invited Individual Member. The Management Council approved the special resolution at their meeting on 29th June. John Hopwood asked if there were any comments or questions. None were received, so he recommended that the resolution be put to the vote of the membership.

Proposed: Joe Clarke
Seconded: Bill Sly
Vote: Carried unanimously

Appointment of auditors

John Hopwood recommended that GOLD should continue to use Trustient of Stanmore, Middlesex, UK as auditors.

Proposed: Bill Sly
Seconded: Bryan Winchester.
Vote: Carried unanimously.

Next Meeting

John Hopwood suggested that the next meeting be held during ASHG 2007, (October 23 - 27th, San Diego, California, USA)

If there are any other suggestions, please contact Annie Hale.

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Contact to Management Council members sent to these addresses will be forwarded.

Any Other Business

With no other business, John Hopwood thanked all for attending and declared the business section of the AGM meeting closed at 6.30pm

Guest Lecture

John Hopwood introduced GOLD's Guest Lecturer, Professor Tim Cox, who delivered a lecture on the subject "Medicine for Lysosomal Diseases: Past Imperfect Future Tense". We hope to place the slides from this talk on the GOLD website soon.

From the membership, John Forman thanked Professor Cox for an excellent and thought provoking lecture on a topic which is very important to all those in the LSD community.