

**GOLD**  
**GLOBAL ORGANISATION FOR LYSOSOMAL DISEASES**  
**MINUTES of IST ANNUAL GENERAL MEETING**

Friday 11th June, 2004 AT 6.45 pm,  
Dijon room, Rheingoldhalle, Mainz, Rheinstrasse. 66, D-55116 Mainz, Germany

**Present: Steering Committee:**

John Hopwood (JH) (Chair)  
Michael Beck (MB)  
Christine Lavery (CL)  
Ed Kolodny (EK)  
William Sly (WS)

**Executive Director:**

Ann Hale (AH)

+ Member Organisation Representatives  
+ Guests

**Welcome & Introductions**

JH opened the meeting at 6.45 pm local time by welcoming everyone to the first AGM of GOLD, presented slides of member organisations present or represented by proxy at the meeting and summarised as: 44 member organisations from 17 countries, with 22 Research/academic or treatment centres, 19 patient organisations and 3 Commercial Members.

**Apologies**

JH presented slide of organisations not represented.

**Trustee's report - Report of GOLD's activities to date**

JH gave an overview of the reasons for international collaboration which led to the inaugural meeting at Cannes, where the concept of GOLD was developed. The prize of a bottle of champagne had been awarded to Professor Giugliani for suggesting the name "GOLD – Global Organisation for Lysosomal Diseases"

JH then reviewed the mission statement, founding Steering Committee, and objectives of GOLD.

He then spoke of the strategy of GOLD for 2003-4, comprising

- Develop organisational structure
- Incorporate GOLD as a company
- Obtain charitable registration
- Secure funding for operation
- Raise awareness in LSD community and develop membership
- Appoint Executive Director
- Organise AGM
- Management Council Elections

JH requested minuted praise for Ann Hale, appointed as Executive Director in January 2004.

He then reviewed progress of this to date. In 2004, GOLD Membership has expanded from 19 organisations to 64 in from January to June. This breaks down to 33 in North America, 25 in Europe and 6 in the rest of the world, with 27 Academic, research or treatment centres, 33 patient organisations and 3 commercial organisations. He expressed the hope that membership would reach 100 in the coming financial year, particularly with more representation from the rest of the world. He stressed the importance of the diversity of organisation types.

JH then reviewed the elections (which took place after the end of financial year 2003-4), and introduced members of first elected Management Council and the 2 Industry Advisory Group members appointed to the council.

***Elected Members:***

Professor Michael Beck, University of Mainz, Germany  
Ms Rhonda P Buyers, National Gaucher Foundation, USA  
Professor Robert Desnick, Mount Sinai School of Medicine, USA  
Ms Jayne C Gershkowitz, NTSAD, USA  
Professor John Hopwood, LDA, Australia  
Professor Edwin Kolodny, NYU School medicine, USA  
Mrs Christine Lavery, MPS Society, UK  
Professor William Sly. SLY LAB, USA  
Professor Steven U. Walkley, Sidney Weisner Laboratory, USA  
Ms Barbara Wedehase, National MPS Society, Inc, USA  
Professor Bryan Winchester, Institute of Child Health, University College London, UK

***Industry Advisory Group:***

William Aliski, TKT  
C. Geoffrey McDonough, Genzyme

JH reviewed the need for global collaboration to further knowledge and treatment options for LSDs, and commented that many presentations at the International Symposium had shown that these are just as relevant today as they were 2 or even 5 years ago.

He summarised by expressing the hope that GOLD will contribute to furthering collaboration on LSDs including the ultra-orphans, and that the Member Organisations will work in partnership with the Management Council, especially in providing feedback and developing task forces and working groups.

**Financial report**

JH handed over to AH to present the financial report for the year 2003-4.

AH welcomed members and guests and thanked the Organising Committee and conference organisers.

AH described the financial timeframe, putting into context the annual reporting period with the overall development of GOLD described by JH. Start up funding was provided by TKT Inc, Genzyme, BioMarin, OGS and Novazyme, with ongoing support from TKT, Genzyme and BioMarin. A one-off gift from Osiris Pharmaceuticals, and transfer of balance of start up funds from LDA were additional income.

In the reporting period,

Income	187,000
Expenditure	53,206
Balance	134,694
Designated funds	90,000
General funds	44,000

Gifts in Kind had been received from BioMarin (Logo and trade marking) and The Society for Mucopolysaccharide Disease, UK (Office space and administrative financial support, with thanks to Christine Lavery)

AH acknowledged the pharma companies who had supported GOLD in its initial development and also on an ongoing basis, especially TKT Inc, Genzyme and BioMarin, and expressed GOLD's appreciation for their continued support. She thanked Sophie Lazenkas of LDA, and Gina Page, Ellie Gunary and Cheryl Pitt of the MPS Society for their help on behalf of GOLD.

She finished by personally thanking the Steering Committee for their guidance and support in her new role.

JH requested any comments about the financial report. A member asked if an audit would be performed annually, and JH said yes. WS confirmed that it was a legal requirement under UK charity law.

Joe Meunzer asked how the auditors (Trustient) had been appointed. AH replied that she had invited applications to tender to 3 companies selected from Charity Direct's list of approved charitable sector auditors. Trustient had been selected as giving GOLD best value.

JH requested a proposal for appointment of auditors. CL proposed that Trustient, of Stanmore, Middlesex be appointed as GOLD's auditors for the financial year 2004-5. BGW seconded. JH put the proposal to the vote:

***Proposal carried unanimously.***

### **Management Council**

JH thanked the current Steering Committee (Interim management Council) who stood down at the end of the AGM for the newly elected Management Council. He specifically thanked Abbey Meyers (not present) , the one member of the Steering Committee who had not stood for re-election, acknowledging her significant and much appreciated contribution to the development of GOLD. He then thanked Jean Mossman (not present) who stood down as Trustee and Company Secretary, and thanked her for her important contribution.

JH concluded the agenda items and requested:

### **Any Other Business**

John Forman Spoke on the UN Special Committee of the UN on rights of disabled people, and his concerns for the lobbying to prevent prenatal screening for any genetic disease. He suggested that GOLD could be an advocate in issues of this type.

JH acknowledged the important issues involved and agreed that this could be considered by the Management Council.

JH invited suggestions from the floor for the venue for the next GOLD AGM.

CL suggested ASHG (Salt Lake City 2005)

Oddrun Grønvik proposed Frambu, Norway in May at the next International MPS meeting.

Bryan Winchester proposed the next ESGLD meeting, also Norway 2005.

JH said all these could be considered and that the wider membership should be consulted to ensure selecting the meeting with maximum participation opportunities.

**Consultation: Action AH**

With no other business, JH thanked all for attending and declared the meeting closed at 7.30 pm local time.

### **On Behalf of Management Council**

Signed



John J Hopwood  
Chairman

Date

17<sup>th</sup> June 2004