

**GOLD**  
**GLOBAL ORGANISATION FOR LYSOSOMAL DISEASES**  
**ANNUAL GENERAL MEETING 2005 - MINUTES**  
Tuesday 25<sup>th</sup> October, 12.30pm  
Arizona Room, Little America Hotel, Salt Lake City, Utah, USA.

**Present: Management Council:**

Michael Beck  
Rhonda Buyers  
Jayne Gershkowitz (Vice Chair)  
Ed Kolodny  
Christine Lavery  
William Sly  
Steven Walkley  
Barbara Wedehase  
Bryan Winchester

**Executive Director:**

Ann Hale

**Guest Lecturer:**

Dr Charles Scriver

+ Member Organisation Representatives in person or by proxy  
+ Guests

**Welcome & Introductions**

Jayne Gershkowitz, Vice Chair of GOLD, called the meeting to order at 12.45pm and introduced the Management Council members present.

**Apologies**

John Hopwood, Chairman sent his apologies and was disappointed not to be at the AGM, but could not attend due to illness. JG wished him a speedy recovery on behalf of those 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. JG asked if membership accepted those minutes as an accurate representation of that meeting.

Proposed: W Sly  
Seconded: E Kolodny  
Vote: Moved unanimously

**Report from the Management Council**

Ann Hale was asked to present the report on behalf of the Management Council.

The first Management Council was elected prior to the first AGM, held in Mainz at the International MPS and Related diseases Symposium. At the start of F/Y 2004-5, there were 79 member organisations of GOLD, representing 20 countries. (As of Oct 2005, this has increased to 98 members.) All LSDs are represented by the member organisations.

GOLD's office has relocated, and independent financial systems and policies have been developed.

A website has been developed at [www.goldinfo.org](http://www.goldinfo.org). This has information on the Management Council, online membership application, a searchable database of LSDs, member directory (full access only available to logged-in member organisations) forums (some only available to logged-in member organisations) and a donations page. It can be updated easily, and further development will continue.

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.

### **Financial report**

Ann Hale then presented the financial report for the financial year 2004-5. The year runs from April 1st 2004 – March 31st 2005 (in line with UK tax year.) A copy of the annual report and accounts has been sent to all member organisations.

Income for the year was £53,716.00, expenditure £71,779.00. The balance was taken from reserves. AH thanked Amicus Therapeutics, Genzyme and Shire (formerly TKT) for their support of GOLD in the reporting period.

Jayne Gershkowitz said that this has been a busy year for GOLD, in which much of the work to develop policies, reporting systems and an independent office had been successfully completed. She thanked Ann Hale for her hard work.

### **Appointment of auditors**

Jayne Gershkowitz proposed that Trustient, of Stanmore, Middlesex, be appointed as GOLD's auditors for the financial year 2005-6. Bryan Winchester seconded. Motion carried unanimously.

### **Management Council**

Jayne Gershkowitz reviewed the nominations for the Management Council. Four members standing down (Ms Rhonda Buyers, Dr Robert Desnick, Dr Roberto Giugliani and Mrs Christine Lavery) were all re-nominated, along with 2 new nominees, Ms Tanya Collin-Histead and Dr Ed Wraith.

Following a ballot of the membership, Ms Rhonda Buyers, Dr Roberto Giugliani, Mrs Christine Lavery and Dr Ed Wraith were elected to the Management Council. All will serve for 3 years.

Jayne Gershkowitz thanked Dr Robert Desnick for his service and contribution to the Management Council.

### **Next Meeting**

The next AGM should be held in Europe or Rest of World region, in line with GOLD's policy of rotating meetings around member regions. It is proposed that the next meeting be held during the 9th International Symposium on Mucopolysaccharidosis and Related Disorders, June 29-July 2, 2006, in Venice, Italy

Other alternatives would be:

11th International Congress of Human Genetics, August 6–10, 2006, Brisbane, Australia  
10th International Congress of Inborn Errors of Metabolism (IClEM), September 12-16th 2006, Chiba, Japan

The membership will be consulted to determine which member organisations will be attending meetings.

**Consultation: Action AH**

At the next AGM, 4 more members of the Management Council (Dr Ed Kolodny, Dr Bryan Winchester, Dr Steve Walkley and Ms Barbara Wedehase) are due to rotate off the Council.

All will be eligible for re-election. Calls for nomination will take place not less than 8 weeks before the AGM.

### **Any Other Business**

Jayne Gershkowitz invited all members to contact GOLD with suggestions or comments. Contact details were given as:

**Email:** ann.hale@goldinfo.org  
enquiries@goldinfo.org

**Via website** [www.goldinfo.org](http://www.goldinfo.org) – contact page or forums

**Mail:** PO Box 609  
Chalfont St Giles  
HP8 4WU  
UK

**Phone/fax** +44 (0) 1494 870708

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

With no other business, Jayne Gershkowitz thanked all for attending and declared the business section of the AGM meeting closed at 1.05pm.

### **Guest Lecture**

Jayne Gershkowitz handed over to Dr William Sly.

Dr Sly introduced GOLD's Guest Lecturer, Dr Charles Scriver.