

***Please circulate this update to all members of your organisation***

## **Online Metabolic and Molecular Basis of Inherited Disease**

GOLD Members will soon have access to Scriver's Online Metabolic and Molecular Basis of Inherited Diseases (OMMBID) through the GOLD website. The chapters on Lysosomal Diseases are being made available free of charge to GOLD's member organisations by McGraw Hill Education.

OMMBID is written and edited by internationally renowned contributors and is the definitive medical text on inherited diseases. The recently launched online version is regularly updated; ensuring that content is always current.

GOLD's members will be able to access the LSD section of OMMBID via the GOLD website's Education and Information section. We are working with McGraw Hill to finalise the technology, and hope to make this available by late April 2006. Further details on access will be issued when it is available.

## **Annual General Meeting 2006**

The GOLD AGM this year will take place on Saturday July 1<sup>st</sup>, 6.00-7.30pm at the 9th International Symposium on Mucopolysaccharidosis and Related Disorders, June 29-July 2, 2006, Venice, Italy. Our guest lecturer will be Professor Tim Cox, Professor of Medicine, University of Cambridge; Honorary Consultant Physician, Addenbrooke's Hospital, Cambridge.

## **GOLD Management Council Elections, 2006**

The next members to stand down are: Dr Ed Kolodny, Dr Bryan Winchester, Dr Steve Walkley and Ms Barbara Wedehase. Dr Kolodny will not be standing for re-election due to other commitments. Ed Kolodny has been an advocate for GOLD since its inception, and was a member of the Steering Committee prior to the election of the first Management Council. Ed says he will remain a strong supporter and advocate or, in his own words, "a great cheerleader for GOLD". We thank him for all his work on our behalf.

Bryan Winchester, Steve Walkley and Barb Wedehase are all eligible for re-election. Calls for nominations will take place in April.

## **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](mailto: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.

## Volunteers needed!

### *Newsletter*

A number of people have asked if GOLD will start producing a newsletter. If you would like to volunteer for the editorial board, contribute to this or have any comments, please email Annie ([ann.hale@goldinfo.org](mailto:ann.hale@goldinfo.org)) or Barb Wedehase ([barbara@mpssociety.org](mailto:barbara@mpssociety.org))

### *Fundraising*

Like all non profit organisations, GOLD needs to raise funds to continue our work and develop the organisation for the benefit of all our members and the patients we all serve. If you can help with fundraising for GOLD, or would like to suggest companies we could approach for funding, please contact Annie ([ann.hale@goldinfo.org](mailto:ann.hale@goldinfo.org)) or Rhonda Buyers ([rhonda@gaucherdisease.org](mailto:rhonda@gaucherdisease.org))

## Membership of GOLD

Membership continues to grow steadily - there are now 106 member organisations, in 24 countries, representing all LSDs.

## Upcoming Member Events

For further details, please see the Calendar of Events page on the GOLD website.

### **APRIL 2006**

#### **April 5-6th, 2006, Hilton Mark Alexandria Center, Alexandria, VA**

NINDS-sponsored scientific workshop, "Glycosphingolipids in Health and Disease" in collaboration with NTSAD, GOLD and LSD Research Consortium.

#### **April 6-9th, 2006, Hilton Mark Alexandria Center, Alexandria, VA**

National Tay-Sachs & Allied Diseases Association 28th Annual Family Conference

### **MAY 2006**

#### **May 2nd, London**

Lecture by Dr John Hopwood: The Research Pipeline for Lysosomal Storage Diseases.

#### **May 12-13th 2006, Halifax, Nova Scotia, Canada**

Annual GARROD Association Symposium

### **JUNE 2006**

#### **June 24-25th, 2006, Hilton Hotel, Northampton, UK**

Niemann Pick Disease Group UK Annual Family Conference "Forging New Relationships"

#### **June 29-July 2nd, 2006, Venice, Italy**

Department of Pediatrics, University of Padova Centre for Rare Disorders and the Italian MPS Association: 9th International Symposium on Mucopolysaccharidosis and Related Disorders: "Together for a Better Life"

July 1st 6-7.30pm: GOLD AGM.

### **JULY 2006**

#### **July 18 – 22<sup>nd</sup> 2006, Cambridge, UK**

7th Meeting of the European Working Group on Gaucher Disease

#### **July 20-24th 2006 Airport Marriott, Nashville TN USA**

Batten Disease Support & Research Association, Annual Family Conference

**July 27-29th 2006 Covington, Kentucky, USA**  
National MPS Society 21st Annual Family Conference

**Contact GOLD:**

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

Ann Hale: [ann.hale@goldinfo.org](mailto:ann.hale@goldinfo.org),

E-mail: [enquiries@goldinfo.org](mailto: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/forums/Login.aspx>