

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

## **New Areas on GOLD Website**

Two new areas, restricted to GOLD's member organisations, have been developed on the GOLD website, under the "Education and Information" section of the menu. These areas are:

### ***Video Presentations***

GOLD is developing video-streamed LSD education via the website. This has been piloted at 2 meetings:

- National Tay Sachs & Allied Diseases Association Annual Conference, Alexandria, VA, USA April 2006, Medical and Research Update which included:
  - ♦ "Genomics and Beyond" by Paula Gregory PhD,
  - ♦ "Clinical Trials in Late Onset, Juvenile and Infantile Tay-Sachs", by Edwin Kolodny, MD, David Korosec, RN, Gustavo Maegawa, MD and Cynthia Tifft, MD, PhD
  - ♦ Overview of Current Research efforts: A summary of a NINDS workshop "Glycosphingolipids in Health & Disease" by Bruce Bunnell PhD
- GOLD's UK Meeting in collaboration with the Institute of Child Health, University College London. Plenary Lecture "The Research Pipeline for Lysosomal Diseases" by John J Hopwood PhD

The video presentations, with more to be added in the future, will enable member organisations that are unable to travel to workshops to have the invaluable opportunity to keep abreast of cutting-edge research and new treatment protocols, help raise awareness of LSDs and continue to build collaboration between constituent members of the LSD community.

We will be able to offer the facility for member organisations to use this area of the GOLD website if they wish to extend the audience for their own meetings. If you are interested, or for further information, please email Annie ([ann.hale@goldinfo.org](mailto:ann.hale@goldinfo.org))

Instructions for viewing the Video Presentations can be found on the relevant entry page of the website.

### ***Scriver's Online Metabolic and Molecular Basis of Inherited Disease***

GOLD has developed a partnership with McGraw Hill Education Publishing to provide 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.

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.

Thanks to Dr Charles Scriver, Dr Bill Sly and McGraw Hill Education for helping us to provide access to this valuable publication for our member organisations.

Access to both the Video Presentations and Scriver's OMMBID are restricted to GOLD's member organisations. Please let the members of your own organisation know that this is available.

If you would like to include an item in your organisation's newsletter, or website, regarding these new additions to the website, please contact Annie ( [ann.hale@goldinfo.org](mailto:ann.hale@goldinfo.org)) who can provide a template newsletter item for you to edit for your own use. This includes full instructions for how to register, log in and navigate the sites.

Individuals wishing to view either area will need to register as a user, selecting the member organisation to which they belong in doing so.

## **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. The title of his Guest lecture is "Medicine for Lysosomal Diseases: Past imperfect, Future tense"

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

The ballot for The Management Council elections is underway and due to close on Friday June 16<sup>th</sup>. All Member Organisation representatives have been sent a ballot form. These must be returned by the closing date, or will not be counted. The candidates (in alphabetical order) are: Dr Joe Clarke, Dr Greg Grabowski, Dr Greg Pastores, Dr Steve Walkley, Prof. Bryan Winchester and Ms Barbara Wedehase. Further details are available on the website.

## **Volunteers Still 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 113 member organisations, in 25 countries, representing all LSDs.

## Upcoming Events

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

### JUNE 2006

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

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

#### **June 24-25th, 2006, Sacramento, CA, USA**

2nd Lysosomal Diseases and the Brain Conference

Sponsored by the National Institutes of Health and the Children's Gaucher Research Fund

#### **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. Guest Lecture Professor Tim Cox: Medicine for Lysosomal Diseases: Past Imperfect, Future Tense.

#### **June 30 - July 2nd, 2006, Noordwijkerhout, the Netherlands.**

4th International Cystinosis Conference

### JULY 2006

#### **July 1- 8th 2006, UK**

National Metabolic Disease Awareness week

#### **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

### AUGUST 2006

#### **August 6 - 10th 2006, Brisbane, Australia**

11th International Congress of Human Genetics

### SEPTEMBER 2006

#### **September 12-16th 2006, Chiba, Japan**

10th International Congress of Inborn Errors of Metabolism (ICIM)

#### **September 16-19th 2006, Awagi, Hyogo & Tokushima, Japan**

6th Meeting of International Society for Neonatal Screening.

#### **September 28th - October 1st 2006, Hyatt Regency Hotel, Bethesda, MD, USA**

NORD Annual Conference

## Contact GOLD:

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

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