

Please circulate this update to all members of your organisation

New Areas on GOLD Website

A new area, "Members' News" has been added to the website. If you would like to add any news items from your organisation, department, laboratory or company, please contact enquiries@goldinfo.org. This will help to share your news with other members of the LSD community, and make more people aware of your organisation.

New Video Presentations Added to GOLD Website

Presentations from the Children's Gaucher Research Fund's 2nd Lysosomal Diseases and the Brain Conference, held in Sacramento, June 2006 have now been added to the Video Presentations area under "Education and Information"

We are 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 Hale (ann.hale@goldinfo.org)

Instructions for viewing the Video Presentations can be found on the relevant entry page of the website, under the "Education and information" menu.

OMMBID

McGraw Hill Digital Publishing regularly updates chapters of OMMBID. Instructions for access can be found on the relevant entry page of the website, under the "Education and information" menu.

Informing your members

Access to both the Video Presentations and Scriver's OMMBID are restricted to GOLD's member organisations – this means all individuals within your organisation.

I have often spoken with people, who when they hear about GOLD say what a great organisation it is, and ask how they can become a member. Then, it turns out that they already belong to a member organisation. For convenience, communication is sent to one representative from a member organisation, and we rely on that person to disseminate information about GOLD within their organisation. ***Please let the members of your own organisation know that they are part of one of GOLD's member organisations and that these resources are available.***

If you would like to include an item in your organisation's newsletter, or website, regarding new additions to the GOLD website, please contact Annie Hale (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.

Annual General Meeting 2006

The GOLD AGM took place on Saturday July 1st, 6.00-7.30pm at the 9th International Symposium on Mucopolysaccharidosis and Related Disorders, June 29-July 2, 2006, Venice, Italy. Minutes are posted on the GOD website.

Our guest lecturer was Professor Timothy Cox, Professor of Medicine, University of Cambridge and Honorary Consultant Physician, Addenbrooke's Hospital, Cambridge. Prof Cox gave an excellent and thought-provoking talk "Medicine for Lysosomal Diseases: Past imperfect, Future tense" in which he described the changes which have taken place in treatment for LSDs, especially since ERT became available. He then discussed inequality of access to treatment, especially problems in funding treatments for rare disorders.

GOLD Management Council 2006

The results of the ballot for the Management Council elections were announced at the AGM. Dr Steve Walkley, Prof. Bryan Winchester and Ms Barbara Wedehase, already Management Council members were re-elected. Dr Joe Clarke was newly elected. Ms Jayne Gershkowitz resigned from the GOLD Management Council in July, when she left the National Tay Sachs and Allied Diseases Association to take up the position of Director, Public Policy at Amicus Therapeutics. Her remaining term on the Management Council is filled by co-option, and the Management Council unanimously voted to invite Dr Greg Grabowski to take that position. The Management Council are pleased that Dr Grabowski accepted the co-option.

Next Annual General Meeting

The next AGM will be held during the American Society of Human genetics meeting (ASHG), October 23 - 27th, San Diego California, USA

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) or Barb Wedehase (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) or Rhonda Buyers (rhonda@gaucherdisease.org)

Membership of GOLD

Membership continues to grow - there are now 136 member organisations, in 31 countries, representing all LSDs. Since our last Update, we have welcomed the following groups to GOLD Membership:

Academic or Research Groups

Biomedical Center, Quito, Ecuador

Department of Clinical Biochemistry, Addenbrooke's Hospital, UK

Department of Clinical Genetics, University Pediatric Hospital, Sofia, Bulgaria

Hospital Nacional Docente Madre Niño San Bartolome, Peru

Instituto de Biomedicina - Universidad Catolica de Santiago de Guayaquil, Ecuador

Research group at Facultad de Medicina, Pontificia Universidad Católica de Chile, Chile
University Research Foundation for Lysosomal Storage Diseases Inc, Florida, USA
Weizmann Institute of Science, Department of Biological Chemistry, Israel

Clinic or Treatment Centres

Asociación Nicaraguense para la Integración Comunitaria (ASNIC), Nicaragua
Clinical Lysosomal Diseases, Children Hospital, Panama
Genetics Service- Luis Vernaza Hospital, Ecuador
Hospital de los Valles, Ecuador
Instituto del Cancer Solca, Cuenca, Ecuador
Servicio de Neonatología- Hospital Vera Barros -La Rioja, Argentina
University of Sao Paulo - Medicine School of Ribeirao Preto, Brazil

Patient Organisations

Childrens Gaucher Research Fund, USA
Fabry Society Brazil
Gaucher Society of South Africa
Italian MPS Society
National Contest for Life-foundation, Germany

Upcoming Events

For further details, please see the Calendar of Events page on the GOLD website. If you are organising a meeting, which is not yet listed, and would like to have it listed on GOLD's website or in the next Update, please contact enquiries@goldinfo.org.

2006

NOVEMBER 2006

November 17 - 19th, San Antonio Texas.

International Pompe Association/Acid Maltase Deficiency Association Patient Conference. More information

DECEMBER 2006

December 7-9th 2006, Orlando, FL, USA.

Lysosomal Diseases Network (WORLD) Symposium University of Minnesota

2007

JANUARY 2007

January 20 - 21st, Wembley, London, UK

Gaucher Association, UK.
UK Family Conference

MARCH 2007

March 4 - 6th, Washington DC, USA

National MPS Society Family Conference

March 21 - 25th, Nashville, Tennessee USA

American College of Medical Genetics
Annual Clinical Genetics Meeting. More information

March 25 - 28th , Nashville, Tennessee USA

Society for Inherited Metabolic Disorders
Annual Meeting. More information

JUNE 2007**June 16 - 19th Nice, France**

European Society of Human Genetics

European Human Genetics Conference. More Information

JULY 2007**July 26 - 28th 2007, Ann Arbor, MI, USA**

International Society for Mannosidosis and Related Diseases.

2nd International Symposium for Glycoprotein Storage Diseases. More Information

SEPTEMBER 2007**September 4-7th 2007, Hamburg, Germany**

44th Annual Symposium: Society for the Study of Inborn Errors of Metabolism (SSIEM)

International meeting, open registration

OCTOBER 2007**October 23 - 27th, San Diego, California, USA**

American Society of Human Genetics

Contact GOLD:

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

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GOLD forums: <http://www.goldinfo.org/forums/Login.aspx>