

Please circulate this update to all members of your organisation

Happy New Year

On behalf of the Management Council of GOLD, I would like to wish all our members a very happy New Year, and hope you had an enjoyable Holiday Season.

AGM Guest Lecture by Professor Tim Cox.

Professor Tim Cox's Guest Lecture from the GOLD AGM, "Medicine for Lysosomal Diseases: Past Imperfect, Future Tense" is now available to view on the GOLD website. The lecture reviews the development of therapies for LSD, and discusses the important issues of funding and access to treatment.

To view this and other video presentations, go to "Education and Information" on the GOLD website, then select Video Presentations from the sub-menu. You need to register (first time only) and state which member organisation you belong to. When you have registered, you can then access this and other member only areas of the website by entering your username (email address) and password (which you chose when registering).

Sponsored Swim for GOLD.

As many of you know, I (Annie Hale) am doing a sponsored swim, the distance of the English channel (34Km) in a limited time. All sponsorship raised will go to GOLD. Thanks to all the people who have already pledged support for this. If you haven't, there is still time! I haven't finished yet, and am a little behind schedule, so please encourage me by sponsoring this event! I have to finish the 34Km challenge (1360 lengths of the swimming pool) by February 6th.

You can confirm your support by returning this by email:

I, support the Channel Swim Challenge for GOLD by

pledging if Annie Hale completes the challenge by 6th February 2007.

Or by downloading a sponsorship form from the GOLD website. If you are a UK tax payer, you can check the box to Gift Aid the money, so that means GOLD gets an extra 28% from the taxman at no additional cost to you.

Help requested by member of GOLD.

Professor Milan Elleder, Institute of Inherited Metabolic Disorders, Charles University, Prague is seeking access to archived biopsy or post mortem samples from defined LSDs. He is particularly seeking skin biopsies of patients with type II Gaucher disease or samples of the lung of Fabry disease Patients.

If anyone can help Prof Elleder, please contact him by email: melleder@beba.cesnet.cz or via enquiries@goldinfo.org

Requests for Proposals from GOLD member organisations.

The UK Gaucher Association are administering funds of UK£40,000 raised for research into Type II Gaucher Disease by the ELF (Eleanor Lily Foundation) set up in memory of Ellie Carter, who died from the disease in February 2004, aged 7 months.

The Gaucher Association is inviting **research applications in the area of Type II Gaucher disease** for consideration. All applications must be made directly to the Gaucher Association in writing. Applications will be reviewed by the Association's Medical Advisory Board. To submit an

application, or for further details, contact Tanya Collin-Histead , Executive Director, Gaucher Association. ga@gaucher.org.uk or telephone +44 (0) 1453 549231.

The National Tay Sachs and Allied Diseases Association (NTSAD) is calling for proposals for **innovative research projects in the area of neurodegenerative LSDs and pediatric leukodystrophies** (eg Canavan & Krabbe.) Funding would be US\$30,000 – 45,000 for one year. The deadline for proposals is 5pm EST Friday, February 16th 2007. Further details, and application guidelines can be found on the GOLD website www.goldinfo.org or the NTSAD website <http://www.ntsad.org/>

The Canadian MPS Society is issuing a call for research proposals involving MPS diseases. The grant is for \$40,000 CAD. Guidelines and application forms can be downloaded from the GOLD website.

Please note – do not contact GOLD, regarding these proposals. Please contact the funding organisation directly.

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.

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

APRIL 2007

April 19 - 22nd, Quincy, MA, USA

National Tay Sachs and Allied Diseases Association, Inc, (NTSAD)
29th Annual Family Conference.

MAY 2007

May 4-5th, Paris, France

EURORDIS Annual Membership meeting

JUNE 2007

June 1 - 2nd, Tucson, AZ, USA

Ara Parseghian Medical Research Foundation
Scientific Conference on Niemann-Pick Type C Disease.

June 16 - 19th Nice, France

European Society of Human Genetics
European Human Genetics Conference.

June 23 -24th UK

Niemann-Pick Disease Group Uk Family Conference

June 29th - July 1st, Northampton , UK

Society for Mucopolysaccharide Diseases
MPS (UK) Family Conference.

JULY 2007**July 12-15th, Rochester, NY**

Batten Disease Support and Research Association (BDRSA) Annual Meeting.

July 14 - 17th, Rochester, NY

11th International Congress on Neuronal Ceroid Lipofuscinosis (Batten Disease)

July 12-15, 2007, Ellicottville, NY, USA

Hunter's Hope 10th annual Medical and Family Symposium.

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

International Society for Mannosidosis and Related Diseases.

2nd International Symposium for Glycoprotein Storage Diseases. More Information

Date TBC: Milwaukee, WI, USA

National Niemann Pick Disease Foundation
15th Annual Family Support and Medical Conference.

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

September 27 - 30th, Perugia, Italy

European Study Group for Lysosomal Diseases
16th ESGLD Workshop.

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

American Society of Human Genetics

Contact GOLD:

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