

INFORM

International Network for Fatty Acid Oxidation Research and Management



Report for Sponsors of the 2020 INFORM Virtual Meeting

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About INFORM

First, thank you to all sponsors that made a commitment to support the International Network for Fatty Acid Oxidation Research and Management (INFORM) prior to the worldwide COVID-19 pandemic and subsequent travel restrictions and lockdowns. We are incredibly grateful for your trust, permission, and flexibility that enabled us to repurpose your sponsorship dollars for this year's virtual event.

Our sincere thanks goes out to our sponsors: Acer, Admera, American Gene Technologies, Arcturus Therapeutics, the Herber Giving Fund (Donna Herber), Homology Medicines Inc., Moderna, Reneo, Ruben Bonilla Guerrero, Stealth, Ultragenyx and Vitaflo. We could not have held such a unique and spectacular event without your continued support and trust in the INFORM mission.

INFORM 2020 was originally planned to be held in Freiburg, Germany in late August preceding the SSIEM. Due to COVID-19, we transformed our in-person meeting to a virtual event to best protect our INFORM sponsors, presenters, and attendees. We did our best to present the first ever virtual INFORM meeting with a robust creative virtual platform and to provide a different experience with more value than a typical Zoom meeting.

The INFORM meeting was held on this creative, virtual platform on October 27th & 28th, 2020. Once again thanks to all involved, the meeting proved to be a great success. Our meeting drew approximately **180 registered attendees** for this year's scientific presentations. Researchers, clinicians, nurses, nutritional counselors, research coordinators, and patient families had the opportunity to listen to and watch presentations as well as interact with our guest speakers in discussions into the cause, diagnosis, and management of inborn errors of fatty acid oxidation.

Our attendees represented 26 countries hailing from: Australia, Austria, Belgium, Brazil, Canada, Denmark, Finland, Germany, Great Britain, Israel, Italy, Japan, Kuwait, Malta, Netherlands, Norway, Philippines, Portugal, Saudi Arabia, Sweden, Switzerland, United Arab Emirates, United Kingdom, United States of America, and Vietnam –proving once again that INFORM is truly living up to its name, the ***International Network for Fatty Acid Oxidation Research and Management***. On behalf of the Organizing and Scientific Committees of INFORM 2020, we thank you for joining the 7th Annual International Network for Fatty Acid Oxidation Research and Management.

By working together, our Network will provide a collaborative framework for ongoing communication and research in a very open and interactive meeting format. Our main objective is to make everyone familiar with recent advances in the diagnosis and treatment of disorders of fatty acid oxidation and of the carnitine cycle and clinical advances in our field.

Our meeting began with a "Tribute to Professor Toshiyuki Fukao" who passed away earlier this year. His tribute was presented by Jörn Oliver Sass, of Germany. Toshi was not only one of the founding members of INFORM and a great colleague, but he became an instant friend with everyone he met.

Our Keynote Plenary Speaker; Sander Houten, Ph.D. Associate Professor, Genetics and Genomic Sciences, Icahn School of Medicine at Mount Sinai, USA kicked off our lecture series presenting on ***Transfer of the End products of Peroxisomal Beta Oxidation to Mitochondria***, followed by a lively question and answer session.

The INFORM virtual platform also provided a Poster Hall where 20 posters could be viewed. Four of the award-winning Investigators had the opportunity to have an interactive poster display where they could answer questions in real-time about their research.

These four investigators were selected by the INFORM Scientific Committee as the best posters and honorable mention posters and received not only a medallion and certificate but also a cash award sponsored by Reneo and Ultragenyx.

Details about INFORM 2020

This year's meeting was developed in a robust virtual platform in collaboration with the design and development teams of Dynamic Conferences & Events from the UK, iVent, Olya Hock our international meeting and planning consultant and the INFORM Coordinator, Keith McIntire.

2020 AGENDA:

Tuesday October 27, 2020

SESSION 1: WELCOME AND KEYNOTE SPEAKER

Welcome & "Tribute to Professor Toshiyuki Fukao"
Jerry Vockley, USA & Jörn Oliver Sass, Germany

Keynote Speaker: Transfer of the End products of Peroxisomal Beta Oxidation to Mitochondria **Sander Houten, USA**

SESSION 2: MITO COMMUNICATION

Presentation of a Tango 2 Case
Nadja Mingirulli, Germany

Mitochondrial Dysfunction Associated with TANGO2
Deficiency **Lina Ghaloul Gonzalez, USA**

SESSION 3: NEW INSIGHTS INTO MAAD

Natural history of Multiple Acyl-CoA Deficiency
(MADD) **Terry Derks, Netherlands**

New insights into the pathophysiology of multiple acyl-CoA dehydrogenase
deficiency **Rikke Katrine Jentoft Olsen, Denmark**

Wednesday October 28, 2020

SESSION 4: BIOCHEM UPDATE

FAO in the Gut
Gary Wu, USA

Ketone Body Treatment of VLCAD
Deficiency **Gepke Visser, Netherlands**

SESSION 5: CLINICAL TRIALS/GUIDELINES

Overview of Clinical Trials for Fatty Acid Oxidation Disorders
Nicola Longo, USA

FAO Treatment Guideline Workgroup
Update **Sarah Grünert & Sara Tucci,**
Germany

Closing Remarks
Jerry Vockley, USA

Details about INFORM 2020 Cont.

- ◆ 20 poster presentations were available for viewing in the Virtual Poster Hall which included four Poster Awards sponsored by Reneo and Ultragenyx.
- ◆ One \$1000 cash award sponsored by Reneo was given to the BEST Overall poster. Three \$500 cash awards sponsored by Ultragenyx were given to the BEST Junior Investigator Poster and two Honorable Mention awardees.

Reneo / Best Poster Award / Alatibi Khaled

The emerging role of the mitochondrial fatty-acid synthase (mtFASII) in the regulation of energy metabolism

Ultragenyx / Best Jr. Investigator Poster Award / Meicheng Wang

A cardiolipin-binding peptide improves cellular bioenergetics in mitochondrial trifunctional-deficient (TFP) mice and patient fibroblasts

Ultragenyx / Honorable Mention Poster Award / Yudong Wang

Defining the structural and functional role of VLCAD in the FAO/ETC-SC through recombination with VLCAD to VLCAD KO mice heart mitochondria

Ultragenyx / Honorable Mention Poster Award / Johannes C.W. Odendaal

Semi-stochastic and patient-models of human mFAO suggest CoASH oversequestration as possible cause of hypoglycaemia in MCADD

- ◆ 180 participants registered to attend INFORM 2020 virtual meeting representing 26 countries.
- ◆ Representatives from 14 companies attended INFORM 2020.
- ◆ 10 corporate sponsors and two individuals supported INFORM 2020 meeting.

Future Sponsorship and Collaboration Plans

- ◆ The INFORM 2021 meeting is tentatively planned as 1½ day symposium in Sydney, Australia preceding the ICIEM.
- ◆ **Save the Date** communications will go out in collaboration with the ICIEM to all companies solicited for sponsorship; we will begin solicitations for sponsorships in January of 2021 with the goal of raising enough in sponsorship to cover conference expenses.
- ◆ Research into additional international companies to add to the sponsorship solicitation list will also begin in early 2021; We plan to enlist greater assistance from planning committee members to raise funds from their respective countries.
- ◆ We also plan to look for opportunities to keep INFORM top of mind during 2021 through website improvements and live on-line presentations.
- ◆ The INFORM Committee will assist in the planning of the FAO and OAA Family meeting with MitoAction.
- ◆ In addition to the excitement generated by the outstanding scientific presentations this year, additional positive outcomes and action items were generated through the meeting. The highest priority items slated for attention by INFORM members in the coming year include:
 - **PI's are going to be encouraged** to enter data in our web-based, password protected, Virtual Tissue Bank (VTB) for FAODs. This will make it easier for researchers to collaborate and enlarge the sample size for their studies.
 - **Continued emphasis will be placed on families in 2021.** Dr. Jerry Vockley and INFORM Coordinator, Keith McIntire assisted Kira Mann of MitoAction the FAO Family Groups in holding their virtual conference in July of 2020 and hope to continue this collaboration in 2021.

SAVE THE DATE: INFORM 2021 will be held in Sydney, Australia (Dates TBD), preceding ICIEM.

INFORM Coordinator Keith McIntire, in collaboration with the international INFORM planning and scientific committees, will work to identify the venue, program, and fundraising efforts.

Continued Sponsor Marketing: As part of our thanks to the vendors, sponsors, and attendees of INFORM 2020, we are keeping the entire INFORM meeting platform up on our website through the month of April 2021. Anyone who registered for the live event can access the site as often as they would like. They can watch the lectures along with the Q&A and Panel discussions. They can also view all the posters in greater detail in the Poster Hall and visit the Exhibition Hall where they can read about your companies, access information, and contact them through email.

Access the meeting here; <https://informnetwork.org/annual-meeting/> by using the email address and password that was create upon registration.

For those who have not registered they can go to the link below and will be charged a registration fee of \$50 USD to have the same access. <https://inform-2020.online-event.co/registration/dynamic-inform-3>



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