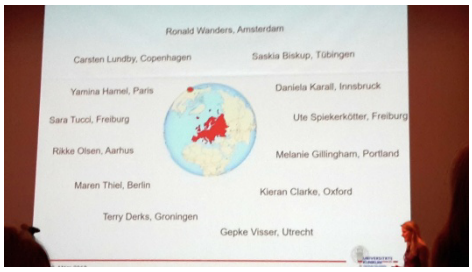
>>> Topics 3. Newsletters

Dear FAOD community (affected children, dear families, dear relatives and interested people,)

in the following we would like to inform everyone, who could not be there, about the successful weekend 7-10 March 2018 in Fulda: APS- conference and APS- seminar, as well as the foundation of the self-help group.
In addition, the elected board will introduce itself and we will report about the working groups established.
For this autumn, we would like to organize a family reunion with the help of a SSIEM grant.

>>> APS- conference and Seminar 7.-10.March 2018

The "Arbeitsgemeinschaft for Pediatric Metabolic Disorders" (APS) (www.aps-med.de) meets once a year in Fulda. This year's 32nd conference was chaired by Prof. Spiekerkötter (Freiburg) and focused on the topic: Inborn errors of fatty acid oxidation.



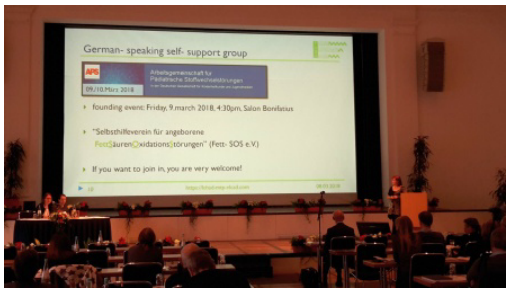
For the lectures on Thursday and Friday morning, international scientists from the USA, Austria, the Netherlands, Denmark, Great Britain and France were also invited to present the latest research results in this field to the participating metabolic physicians from Germany.

The APS seminar that followed from Friday afternoon to Saturday also revolved mainly around fatty acid oxidation disorders. Dr. Grünert and Mrs. Rosenbaum-Fabian (University Hospital Freiburg) gave a summary lecture on the topic "Update fatty acid oxidation disorders", in which many of the patient families who had arrived also took part. In addition, some families had the opportunity to discuss their personal history and experiences in small groups with junior metabolic physicians.

The company Sobi (Swedish Orphan Biovitrum GmbH, www.sobi-deutschland.de) brought a donation bicycle to the accompanying industrial exhibition. Donations to the self-help group in Freiburg SPATZ e.V. (Selbsthilfe für Kinder mit chronischer Stoffwechsel-, Hormon- oder Zuckererkrankung e. V.; www.spatz-ev.de) could be cycled.

>>> Foundation of the self-help group for inborn fatty acid oxidation disorders "Fett-SOS"

In the afternoon of 9 March 2018, the founding meeting of the self-help group for inborn fatty acid oxidation disorders took place in Fulda.
21 families from Germany and Austria with affected children aged 1 - 22 years (long-chain FAOD) took part.
The weekend was supported financially and through the provision of diet products by the companies Dr.Schär and Nutricia metabolics.
We received organizational support from many employees of the University Children's Hospital Freiburg and the project planning company of the APS conference "Zweiplan" from Munich.



In the following Marius (VLCAD patient) reports about the weekend:
On 9 March 2018 my parents and I set off for Fulda. I had received a school leave for this day. During the trip I was very excited who I would get to know from the newly founded self-help group. I was also very interested in what Prof. Spiekerkötter, Dr. Grünert and Mrs. Rosenbaum-Fabian would say about our previously collected questions.
I already knew Prof. Spiekerkötter and Mrs. Rosenbaum-Fabian, because once a year I go to Freiburg with my parents and mostly also with my healthy sister for a check-up.
Most of the questions could be answered within the planned two hours by the Freiburger experts.

After a short break we met again in the conference room, because we wanted to found our self- help group. We all introduced ourselves briefly and I was very impressed that a young man took the long way from Tyrol/Austria to meet us.

We all worked hard and I was very happy that the age of membership was reduced to 14 years. So I could now proudly announce to be a member of our new group Fett-SOS.
After a relaxed get-together and getting to know each other better, I fell into bed very tired at 11.30 pm.

The next day after breakfast, there was a professional session, which only my parents attended. I spent the morning playing cards with the other kids. We certainly had a lot more fun than our parents.
At the final lunch in the hotel we could enjoy the rich buffet once again. It was simply nice that they cooked for us and we could see what we were allowed to eat without any questions at the buffet. So we were just normal guests without any ado and without any questions.
After a big goodbye ceremony the way back home was started.
I am sure everyone is looking forward to the next meeting.
Your Marius

>>> Fett- SOS, the Executive Board about itself

At the founding meeting of the Fett- SOS the board for the next two years was elected:

Maren Thiel (Chairwoman): My 5-year-old daughter has an TFP- deficiency. I am a physician in training as a specialist in general practitioner. In the last 5 years I have been forced to deal more intensively with the long-chain fatty acid oxidation disorders. In the meantime I have contact with more than 50 families whose children have a LCHAD/TFP or VLCAD deficiency. The need for exchange and personal meetings has been expressed to me by all families, no matter how old the children are.
I am very happy that we now have a self-help contact point for all the big and small problems of FAOD- families in the German-speaking area.
A big thanks goes to my husband, my son, my family and Jette Schreiber, who supported me for the last 2 years intensively with the various preparations for the family reunion last November on Usedom, as well as the weekend in Fulda.

Anke Medek (Vice-Chairwoman): My one-year-old son has a VLCAD deficiency. I am an architect and have no medical background. Therefore, I am above all a user - I know what to do and when to do when it comes to the metabolic disorder. I also listen to my maternal instinct and leave it to my husband to understand everything exactly.

Since I deal also a lot with authorities and regulations during my regular work, I established already a good network to helping offices, the integration commissioner as well as the youth welfare office. Sometimes this communication can be very difficult. Therefore I would like to assist you when it comes to the application for the care compensation and similar things.

When we met Maren and her family on Usedom in November last year, she told us about the idea of the self-help group with a lot of enthusiasm. We were immediately fascinated and it was clear to us that we would like to be an active part of it.
I am really excited about what has already happened and I am looking forward to what is coming!

Liane Ehrhardt (Treasurer): I am a passionate grandmother and have a 6-year-old grandchild with VLCAD deficiency. We live in Thuringia/Germany and I work as an employee in a computer company.
We wanted to meet other affected people knowning how important it is to see how others solve the daily problems. This became true after 5 years in November last year on Usedom- thanks to the founders Maren Thiel, Janette Schreiber and Erik Thiel.
I am pleased to take part actively in the self-help group.

Janette Schreiber ("Secretary-in-chief"): I am the mother of a 7-year-old son with a TFP deficiency. Since the diagnosis I have been intensively studying long-chain fatty acid oxidation disorders and their treatment in the medical, social, therapeutic and psychological fields.

My family and I live in Magdeburg, where I also work as a doctor's assistant in an internal medicine office. More than 3 years ago I got to know the Thiel family. Back then, we shared our thoughts for the first time. The common desire for more information was seeded and help for FAOD affected families was growing continuously...
and here we are... Thanks to all supporters. Something big is on the way...and I can be part of it...
...Thanks for this.
(Due to an acute illness I was unfortunately unable to attend the meeting in Fulda and was not eligible for election to the board. I nevertheless continue to support the official board with all my energy.)

>>> Working groups in the self-help group Fett-SOS

On Saturday we distributed the upcoming tasks of the self-help group to several shoulders and formed working groups. Who would like to help, writes an e-mail to info@lchad-mtp-vlcad.com, then the contact to the working group members is established.

Hello, we are the working group for public relations:

Leon, 16 years old, affected by LCHAD,
Denise Hoffmann, mother of a 9 year old boy with LCHAD,
Erik Thiel, father of a 5-year-old daughter with TFP deficiency and
Simone Lehmann, mother of a 9 year old daughter with LCHAD deficiency.

As the name of the working group already says, we take care of the public appearance of the group, i.e. homepage and social networks: facebook, instagram and twitter. At first, everything revolves around structures, i.e. we work on the contents for the homepage and our communication in general. Step by step, we want to offer information and open a discussion forum for affected persons and relatives, other interested parties and the media.
If you would like to participate or to share ideas, please contact us at: simone.lehmann@lchad-mtp-vlcad.com

Working group newsletter: The newsletter appears (so far) in irregular distances and is sent to all families concerned and interested ones, which announced themselves over the homepage for it. We are always grateful for your help and support.

Working group low-fat food guide: We would like to prepare a list of low-fat foods for the German-speaking region and where they are available. Unfortunately, many products are only available regionally. If you find interesting low-fat products, you are welcome to send us a photo, nutrition table and point of sale.

Working group Low-fat MCT recipes: Fortunately, there are nowadays many recipes for low-fat and/or fat-modified meals. In the course of time, many families have also experimented, modified known recipes or developed new recipes themselves. We want to collect these and make them available to everyone. A template will be available for download on the homepage soon. Please send us your favorite recipes.

Working group Family Meeting (autumn): We would like to implement the wish for a family reunion, which has been repeatedly expressed to us, once again this year in autumn. Currently, Anke is looking for suitable accommodation with the support of the SPATZ- self- help group from the University Children's Hospital Freiburg.

Explaining book (about the disease) for children: Jette Schreiber has wanted to write a book for children for many years, similar to the children's book for the protein metabolism disorder "Lukas has PKU". In English-speaking countries, there is already a book for the long-chain FAOD (My special body) as well as for the MCAD deficiency (Max the monkey has MCADD). We are happy to put you in touch with Jette if you have ideas, if you are good at drawing and/or texting and would like to help.

>>> Funding by the SSIEM – Society for the Study of inborn errors of metabolism

Since April 2017, SSIEM (www.ssiem.org) is supporting patient initiatives representing a rare inborn metabolic disorder twice a year. The application deadline for spring funding was 01.03.2018.
With the help of a supporting letter from Prof. Spiekerkötter and Dr. Grünert, we successfully applied for this position.
Among other things, this is to support the family reunion in autumn.

Society for the Study of Inborn Errors of Metabolism (SSIEM)
Registered Office: 130-132 Tooley Street
LONDON SE1 2TU
Phone +44 (0) 20 7940 8990
FAX +44 (0) 20 7403 8006
Email: admin@ssiem.org

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Kind regards,
Maren Thiel, Anja Ortmann und Marius