

NEW\$LETTER December 2015

Dear SWEET members, partners, and friends,

This year is coming to an end. 2015 was a year with a lot of activities for SWEET and 2016 will be also an exciting year. With this 7th edition of the SWEET newsletter we would like to give you a short review on 2015 and give you some information about the plans for 2016.

But first of all we would like to say thank you for your support and your efforts in 2015 regarding SWEET.



We are sending you and your families best season's greetings and best wishes for a Happy New Year.

Ines Hiller on behalf of the SWEET team from Hannover

Action items

- Upload your data to SWEETBASE for analysis until February 15th 2016!
- Save the date: SWEET Annual meeting in Tolochenaz, Switzerland: April 7th & 8th, 2016
- HbA1C Round Robin Test: First round during 19th and 22nd January 2016

Review: what happened 2015?

Meeting

The sixth legal entity meeting of SWEET e.V. was held on March 19th to 20th, 2015, in Paris, France. We had a great time with a lot of fruitful discussions.

There was a small SWEET meeting during the ISPAD in Brisbane, which was also very successful. Please find the presentation, which was held by Thomas Danne attached.

We had our first webinar where we had some interesting and informative presentations and discussions. Please find attached the presentation, which was held by Thomas Danne, Reinhard Holl and his team and Michael Witsch as well as a case presentation from the team of the Clinical Hospital Center Sestre milosrdnice, University Department of Pediatrics, Zagreb, Croatia.

The SWEET executive committee had several conference calls to discuss the strategy and actual topics regarding SWEET.

Brochure

We are glad to send you a digital version of the new SWEET brochure, which was published in October 2015. The printed version was already spread at the ISPAD in Brisbane in October.

T1 D Youth Challenge

We are also very proud that the third edition of the T1D Challenge was organized by SWEET e.V. in partnership with World Diabetes Tour and Sanofi Diabetes.

An international team of 11 young people living with type 1 diabetes from SWEET centers in 8 European Countries as well as in Brazil, Canada and India supported by a medical team and mentors started this challenge in August 2015 in Crete, Greece.

After 4 days of hiking along the sea and through the Samaria Gorge, the whole Team reached the summit of Mt. Gingilos, 2,080m above sea level.

The conditions during the trek were very challenging due to the laborious and long-lasting physical activity and the hot temperatures up to 37° Celsius, but the young people completed the trek while successfully managing their blood sugar levels without any complications.

The challenge was a great success to show that young people with type 1 diabetes can achieve everything if they strive for. Please watch the documentary <u>here</u> and visit our <u>Facebook page</u> to get more information and impressions.

EU-CDEC Leonardo da Vinci, Transfer of Innovation

In September 2015 the final meeting of the two year EU funded project, EU-Certified Diabetes Educator course (<u>http://www.eu-cdec.eu/</u>) took place as a pre-symposium of the EASD meeting in Stockholm entitled "Development of EU wide pediatric diabetes educator course".

In the session, Thomas Danne set the scene by discussing the pediatric diabetes situation in Europe and the USA. Liz Webster, the project leader from Leeds, UK, gave an overview of the work packages, Kasia Zinken, from Hanover, Germany presented the main outcome of the project: blueprint of the pediatric diabetes educator course. The blueprint is based on the German curriculum for diabetes educators and described in line with the ECVET principle, so it can be implemented and recognized EU-wide. Nicky Kime, from Leeds, UK, and two parents' representatives, Penny Robinson from the UK and Nataša Šmid from Slovenia, presented feedback on the blueprint received from the pilot diabetes course participants in the UK, as well as from the health care professionals and families Europe wide. Karin Lange, from Hanover, Germany, completed the talks by outlining future perspectives for the European education in pediatric diabetes addressing SWEET as an excellent platform for the implementation of the EU-CDEC course. For more information on the SWEET diabetes course based on the EU-CDEC see www.sweet-project.eu.

In the final panel discussion, diabetes experts from Portugal, UK, and Germany chaired by Nataša Bratina from Slovenia discussed the obstacles and opportunities to implement a European pediatric course for educators Europe-wide.

During the session, in a short film, children, young people with type 1 diabetes and their parents from all six countries participating in the EU-project: Czech Republic Germany, Greece, Portugal, Slovenia, and the UK, spoke about their experiences with diabetes educators. The most often acknowledged characteristics of diabetes educators across Europe were their availability, presence and their clarity in conveying complex information. The film can be seen via http://www.eu-cdec.eu/.

European Reference Network – Conference in Lisbon

SWEET was represented by Kristina Casteels, Bärbel Aschemeier, Michael Witsch and Reinhard Holl, who was invited to present SWEET as a network on rare diabetes in children at workshop 1: How to prepare a successful proposal to build an ERN. At the poster session SWEET presented a poster regarding rare forms of diabetes. For more information regarding the conference please visit the <u>homepage</u>.

SWEET is still working on an application to be recognized as an ERN, the call for the application is planned for February 2016.

New SWEET Centers

SWEET is still growing and in 2015 we welcome the following centers in our network:

Austria: Vienna; Brazil: Curitiba-Parana; Spain: Barcelona, Barakaldo-Bilbao; France: Clermont-Ferrrand, Angers, Tours, Tolouse, Bordeaux; Croatia: Zagreb; India: Belgaum; Japan: Osaka; Mali: Bamako; United Kingdom: Mansfield.

SWEET is also cooperating with the ISPAD to include small centers with less than 150 patients. In 2015 we welcomed 4 centers with less than 150 patients in our network and there are still several small centers who already expressed their interest in joining SWEET.

Peer Review Visit

Peer reviewed centers in 2015:

Denmark, Århus; Greece, Athens; Ireland, Cork; Lithuania, Kaunas; Portugal, Porto We thank the NHS for their support regarding the peer review visits as well as the reviewers from the SWEET group for attending these audits.

Upload and Benchmarking Report

The benchmarking reports were sent in November 2015. Many thanks to Reinhard Holl and his team for collecting the data and for supporting the SWEET members regarding DPV. And a big thank you to Michael Witsch for creating the benchmarking reports.

For the future, please don't forget to upload the data in time and please give some feedback to Michael Witsch, so that we can improve our work. Next deadline for the upload: **February 15th 2016**

Preview: Plans for 2016

HbA1C Round Robin Test

To harmonize the quality of our data we will make a first round of a HbA1C round robin test in January 2016. At the moment about 20 European centers will participate in this round and will get some blood samples to test during 19th and 22nd of January 2016. For the future there are plans to include more European centers, as well as non-European centers.

Activities and Publications

SWEET is planning to publish a supplement in Pediatric Diabetes in October 2016, prior to the ISPAD in Valencia, Spain supported by AstraZeneca. These are the planned articles:

- 1. Improving care for diabetic children: Mission of ISPAD and SWEET (Hanas, Danne)
- 2. Benchmarking pediatric diabetes care and outcome (Witsch)
- 3. Lessens from the SWEET peer-review process (Hill, Parsons)
- 4. Ttype-2-diabetes and rare forms in children and adolescents around the world. (Pacaud)
- 5. Is there seasonality of birth in children with diabetes (Gerasimidi-Vazeou)
- 6. Use of insulin pumps in different age-groups (Szypowska)

There are also plans to present a poster during the ADA conference 2016 as well at the ISPAD conference 2016 to give an overview about the work of SWEET.

Meetings

The seventh legal entity meeting of SWEET e.V. takes place on April 7th and 8th, 2016, in Tolochenaz, Switzerland, supported by Medtronic. The invitation and more information will follow in the beginning of January 2016.

We are planning to have a meeting prior/during the ISPAD 2016 supported by Sanofi. As soon as we know the date we will inform you.

Peer Review Visit

A new round of peer review visits will start. There are plans to make the first visits outside from Europe as well as audits in European centers. You are still welcome to register as a volunteer to participate as a reviewer. The peer review process is described on our <u>homepage</u>.

