

## NEWSLETTER December 2016



Dear SWEET members, partners, and friends,

2016 is almost over and has been a very exciting and positive year for SWEET. With this newsletter we would like to look back on 2016 and give a short preview at our plans in 2017. We also would like to inform you that Katharina Klee is back from her maternity leave and will support the SWEET team in Hannover again.

But first of all we would like to thank all of you! SWEET wouldn't be such a successful and growing network without your support and work. We are looking forward to continuing our work with you in 2017.

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

Ines Hiller and Katharina Klee on behalf of the SWEET team from Hannover

### Action items

- Upload your data to SWEETBASE for analysis until January 31<sup>st</sup> 2017!
- **Urgent notification: The SWEET meeting in Paris, France, on March 9<sup>th</sup> & 10<sup>th</sup>, 2017 has to be postponed! The new date is not yet found.**
- **Please get in contact with us, if you have already booked your flights! We have to rebook them as soon as the new date is set!**

### Preview: Plans for 2017

#### Meetings and Webinars

##### SWEET meeting 2017

The eighth meeting of SWEET e.V. was planned to take place on March 9<sup>th</sup> and 10<sup>th</sup>, but unfortunately has to be postponed now to an unknown date at this point. It definitely will take place in spring, 2017, in Paris, France, supported by Sanofi, which hosts us on their premises. The date has to be postponed, because the ERN conference will take place on March 9<sup>th</sup> to 10<sup>th</sup>, where the final approvals will be granted, and which was announced yesterday. Members of the SWEET executive committee including the SWEET chairman Thomas Danne must visit this conference, and of course we can't carry out the SWEET meeting without him. Many apologies for all inconveniences this may cause for you! We try to make the switch to another date as smooth as possible and will support you with the rebooking of your flights. The extra costs and penalty fees will be paid by SWEET and can be reimbursed immediately, if needed.

##### ISPAD meeting 2017

We are also planning to have a meeting during the ISPAD 2017 in Innsbruck. Invitation and information will follow as soon as possible.

##### Webinars

Two webinars will take place as virtual meetings to update you in 2017 about our work and to provide the platform to discuss patient cases. We will invite you as soon as the dates are set.

### Activities and Publications

There are three ongoing publication projects.

1. Prevalence of underweight, overweight and obesity in children and adolescents with T1D:  
Abstract, to be submitted at the ADA 2017
2. The influence of age at onset and metabolic control on growth in children with type 1 diabetes in Sweet:  
Planned to be submitted at the EASD 2017
3. Pilot study with a short questionnaire about the current status of reimbursement of diabetes related investigations, medications, devices and education  
Planned to be presented at ISPAD 2017

The authors and co-authors are already defined.

All SWEET members who participate in benchmarking are always welcome to propose new projects by sending a proposal to the SWEET data, publication and presentation committee (DPPC), according to our publication policy. We will discuss the ongoing and new projects during our next meeting in March 2017.

## SWEET Strategic Plan 2016/2017

	Governance	Centre Network	Data Collection and Technology	Research and Dissemination
	<b>Ensure appropriate governance</b>	<b>Peer Review &amp; Quality Control</b>	<b>Quantitative Data Collection maintain frame for IT and website</b>	<b>Data evaluation and public affairs</b>
<b>Goals</b>	<ul style="list-style-type: none"> <li>Staff</li> <li>Executive committee</li> <li>Finance</li> <li>ISPAD link</li> <li>Benchmark</li> <li>Best practices</li> <li>Communication</li> </ul>	<ul style="list-style-type: none"> <li>Development &amp; recruitment of CoR</li> <li>Continuity in auditing</li> </ul>	<ul style="list-style-type: none"> <li>Continued integration of DPV and eHealth</li> <li>Improve data quality</li> <li>Develop SWEET parameter list</li> <li>integrate the patient perspective into SWEET</li> </ul>	<ul style="list-style-type: none"> <li>Benchmarking reports</li> <li>Statistical evaluation &amp; Scientific analysis of data (Dashbord)</li> <li>Publication / Presentations</li> <li>Publicity and Communication</li> </ul>
<b>Strategies</b>	<ul style="list-style-type: none"> <li>One official annual meeting</li> <li>One meeting at ISPAD</li> <li>Virtual meetings</li> <li>Regular Newsletters</li> <li>Investigate new sources of financing</li> <li>Meet with ISPAD leadership</li> </ul>	<ul style="list-style-type: none"> <li>Secure regular peer review</li> <li>Promote small center concept</li> <li>Promote SWEET as a "quality certificate"</li> </ul>	<ul style="list-style-type: none"> <li>Monitoring of submitted data according to the SWEET Dataset and Query structure</li> <li>Promoting DPV as ehealth solution for pediatric diabetes</li> <li>Develop a patient portal</li> </ul>	<ul style="list-style-type: none"> <li>SWEET Data, Publication and Presentation Committee (DPPC)</li> <li>Create a plan for communication and publicity</li> </ul>
<b>Objectives</b>	<ul style="list-style-type: none"> <li>Strategic plan</li> <li>Objectives</li> <li>Information material</li> <li>Newsletter</li> <li>Website</li> </ul>	<ul style="list-style-type: none"> <li>Establish new centres</li> <li>Sustain existing centers</li> <li>Number of existing professionally peer-reviewed centres</li> </ul>	<ul style="list-style-type: none"> <li>Track number of patients uploaded</li> <li>Quality and Integrity of data uploaded</li> <li>New DPV language versions</li> </ul>	<ul style="list-style-type: none"> <li>Benchmarking reports</li> <li>Number of research projects</li> <li>Scientific Publications/ Presentations</li> <li>Presence in social media</li> <li>Publicity for SWEET as a "quality certificate"</li> </ul>
<b>Measurements</b>	<ul style="list-style-type: none"> <li>Updated Strategic plan</li> <li>New website</li> <li>2 Newsletters/year</li> <li>Executive TC four times a year</li> <li>2 Webinars/ year</li> </ul>	<ul style="list-style-type: none"> <li>5 more audited centers</li> <li>5 more small centers</li> <li>Establish SWEET in U.S.A. and Australia</li> <li>increase overall number of centers</li> <li>SWEET data upload established in 10 more centers</li> </ul>	<ul style="list-style-type: none"> <li>2 new language versions</li> <li>2 annual dashboard updates</li> <li>2 parameters with sustained improvement of data quality</li> <li>Agree on measure for patient portal</li> </ul>	<ul style="list-style-type: none"> <li>2 benchmarking reports / year</li> <li>2 research projects</li> <li>1 manuscript submitted</li> <li>1 Abstract to 2017 ADA, ISPAD and EASD</li> <li>Social media hits</li> <li>SWEET Youth Challenge 2018</li> </ul>

The new strategic plan was developed by Thomas Danne (Chairman) and Peter Gerhardsson (Vice-Chairman). Please see the SWEET pillars to get more information about our strategic plans for the next year. There are four pillars we are focusing on. Governance, Peer Review and Quality Control, Data Collection and Technology, Research and Dissemination

## Peer Review

A new round of peer review visits will start. You are still welcome to register as a volunteer to participate as a reviewer. Just let us know by email.

The peer review process is described on our [homepage](#).

As SWEET is growing and more and more centres from outside Europe are joining us, we are still planning how to organize their peer review visits cost-effectively.

## Miscellaneous

### ISPAD fellowship

Please note that you can apply for an ISPAD fellowship. We would be happy to welcome you in Luxembourg, Ulm or Hannover to work on a publication. You can find more about the fellowship at the ISPAD homepage: <http://www.ispad.org/?page=ISPADEllowships2017>

### New SWEET Homepage

We are looking forward to releasing an updated SWEET homepage in spring 2017. At the moment we are very busy with revising and writing texts. All SWEET members (centres and corporate partners) will get the opportunity to introduce themselves. We will get in contact with you soon.

## Review: what happened 2016?

### Meeting

The seventh legal entity meeting of SWEET e.V. took place on April 7<sup>th</sup> to 8<sup>th</sup>, 2016, in Tolothenaz, Switzerland. The meeting was very successful. The main topics we discussed were:

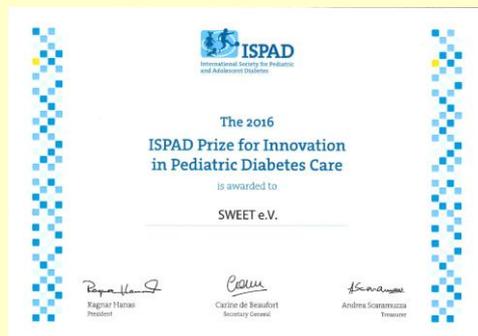
- New centres, current applications, future strategies
- ISPAD and SWEET, Small SWEET –(ISPAD)-Centres, and small centres in emerging countries
- Ongoing and New Scientific projects
- How to achieve meaningful data sets to be a participant in the scientific projects
- Lessons from the SWEET Peer Review Process
- T1D Youth Challenge
- European Reference Networks
- Centres presentations
- Report from the work in Mali and India
- Benchmarking - learning from each other on the basis of SWEET data
- DPV Training
- Benchmarking Report
- SWEET business plan and strategy
- Case discussions

### ISPAD 2016

The ISPAD 2016 conference was a great success for SWEET. There were two oral presentations from SWEET members about our work. Ioanna Kosteria (“Aghia Sophia” Childrens Hospital in Athens, Greece) presented “The SWEET Initiative: targeting harmonized diabetes care through high quality data registry from 48 centers worldwide” in the oral session “Diabetes Care” and Michael Witsch (Pediatric Clinic CH de Luxembourg, Luxembourg) was talking at the symposium “Diabetes registries” about “SWEET going international”. The small SWEET meeting was well attended and a lot of “new faces” joined the group. The main issues we discussed were:

- Current update on SWEET database
- New and ongoing research projects, and publication strategy
- New strategic plan (SWEET pillars)

We are also very happy that SWEET has been awarded with the ISPAD innovation prize. This prize shows that SWEET and our work becomes more and more recognised.



### T1 D Youth Challenge

This year the 2<sup>nd</sup> T1D Youth Challenge, organized by SWEET in partnership with World Diabetes Tour and Sanofi, took place in Iceland. An international team of 12 young people living with diabetes (10 from SWEET centres and 2 IDF young leaders), two mentors and a medical team from all over the world hiked 5 days through the rough nature of Iceland to show that anything is possible despite diabetes. The conditions were tough because of the long endurance /physical stress, but in the end everybody reached the summit of the Hekla Volcano and completed the challenge while successfully managing their blood sugar levels without any complications. Please visit our [Facebook page](#) to get more information and impressions.

### Publications

In October 2016 the SWEET supplement in Pediatric Diabetes sponsored by AstraZeneca was released. If you are interested you could get a printed version, but it is also available at the Wiley online Library (<http://onlinelibrary.wiley.com/doi/10.1111/pedi.2016.17.issue-S23/issuetoc>). Additionally, SWEET was represented with a poster and oral presentation at the ADA and with an abstract at the ATTD.

### European Reference Network – for rare diseases

In 2016 the call for European Reference Network for rare diseases was launched. Several European SWEET centres applied within the subgroup **Genetic disorders of Glucose and Insulin Homeostasis** of the Rare Endo ERN to be certified as an ERN. On March 9<sup>th</sup> and 10<sup>th</sup>, 2017, at the ERN conference in Vilnius the final approvals will be granted.

## New SWEET Centres

SWEET is still growing and in 2016 we welcome the following centres in our network: United Arab Emirates, Dubai; Australia, Gold Coast; Canada, Vancouver; Canada, Markham; Algeria, Algiers; Iraq, Duhok; New Zealand, Auckland; Serbia, Belgrade; USA, Stanford; Ireland, Limerick  
We would also like to welcome the new small (ISPAD) centers, who participate in benchmarking with less than 150 patients.

## Data Upload and Benchmarking

The benchmarking reports were sent in November 2016. We would like to thank Reinhard Holl and his team for collecting the data and the support regarding DPV. We also would like to thank Michael Witsch for creating the benchmarking reports and supporting the SWEET data group.

Please don't forget to upload the data in time. Next deadline for the upload: **January 31<sup>st</sup> 2017**

## Announcements from SWEET Centres

### Our Experience with Summer Camps (Sujata M. Jali from Belgaum, India)

We are conducting a Free Summer Camp on every International Mother's Day since 16 years. The objective of the camp is to promote unity among the children with Type1 DM & team. Every year 150 children attend this camp with their parents. The theme is different every year. The agenda for the camp: In the morning biochemical tests are performed followed by breakfast. Inaugural function is attended by well-known personality as chief guest, team and parents with kids. Achievements and feedback are discussed. Orientation talks related to Diabetes are given. The main attraction of the camp is awarding Best Boy, Girl and Mother. We conduct drawing, painting, story, essay writing, cultural programme & games and the winners are awarded. We have won 13 prizes at the LFAC Art Competition at the ISPAD conference in Brisbane 2015. Children undergo clinical examination by Pediatricians. We handout useful materials like nutritional charts, insulin cold containers, T-shirts, caps, school & tiffin bags. Healthy lunch is served for children, parents & the team. The camp ends at 5pm and we say goodbye with heavy hearts and wait for the next camp.

### Access to insulin in Africa (Stéphane Besancon from Bamako, Mali)

Almost 100 years after insulin was discovered not every child with type 1 diabetes has access to insulin. Please read the column on access to insulin in Africa from Stéphane Besancon (SWEET centre in Mali) signed with Prof. Jeffrey Sachs released during the World Health Day 2016 to find out what needs to be done to change this situation.

<http://ideas4development.org/en/almost-100-years-after-it-was-discovered-lets-make-access-to-insulin-a-reality-in-africa>

These four priorities have been indicated:

1. Conduct advocacy towards the pharmaceutical industry in order to reduce the purchase price of insulin and medical devices:
2. Improve geographical and financial access in African countries themselves:
3. Integrate Non-Communicable Diseases (NCD) as a priority, including diabetes, in health coverage schemes:
4. Fully integrate NCDs into health development policies and humanitarian crisis responses

# Happy Holidays and all the best for 2017!

