



RESEARCH INFORMATION SHEET

- Name of Study: SWEET Study
- Who is Eligible: All patients of the Diabetes Clinic at the Alberta Children's Hospital are eligible for this study.
- Brief Description: The purpose of this study is to improve health and quality of life outcomes of young people with diabetes through the sharing of data between diabetes clinics across the world. In sharing data between centers of reference we hope to see an improvement of secondary prevention, diagnosis and control of type 1 and 2 diabetes in children and adolescents.

Want more information or have a question? Call Heidi at 403-8866 or email Heidi.Virtanen@ahs.ca



SWEET research project



Better control in Pediatric and Adolescent diabetes: S: Working to
crEate cEnTers of reference



We only want you to join if YOU want to

To participate, place your signed form in here
(Did you check the boxes & sign both sides??)

If you prefer NOT to participate
Put your BLANK form in here
(so we don't keep bugging you) 😊

You can keep the information sheets for your records,
or we can re-use them if you don't want them.



Signing means we may
review your Medical Chart



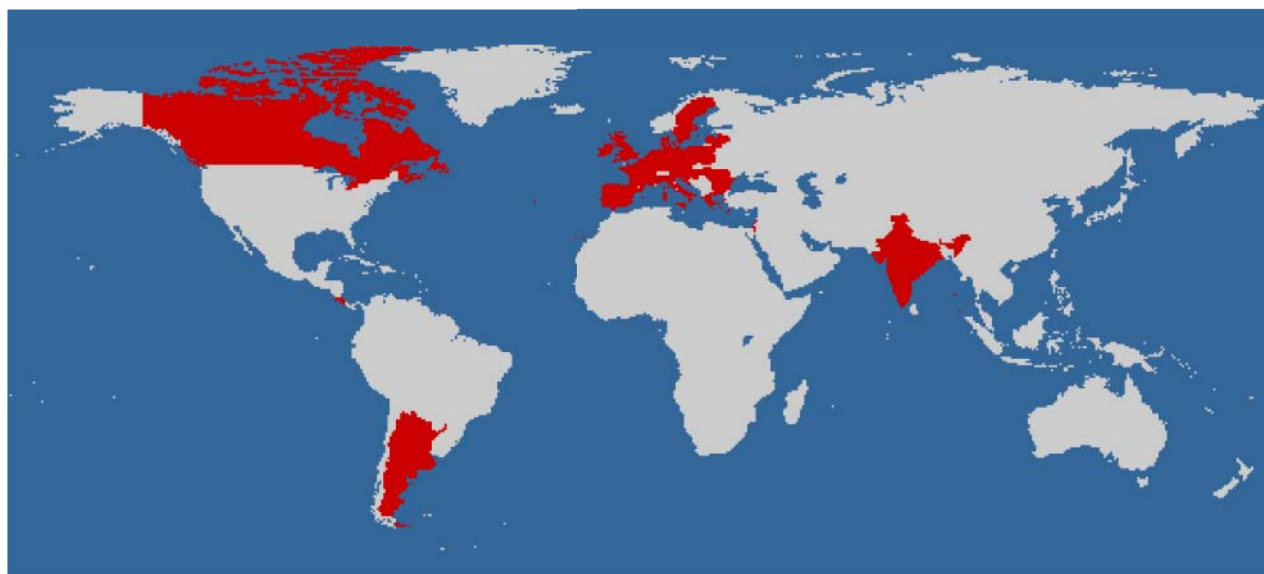
SWEET - The key to better care for children and adolescents with Diabetes

SWEET e.V. is an international network of Centres of Reference for paediatric diabetes care.

Initiated with support of the EU Public Health Programme in 2006, the SWEET group has over 6 years of experience in creating and sustaining a high quality professional network based on agreed standards of care, criteria for certification, international guidelines and quality control, including peer review and data collection, sharing and benchmarking. In the meantime, SWEET is organized as a registered charity with close ties to scientific organisations such as the International Society for Pediatric and Adolescent Diabetes (ISPAD) and NGO's such as IDF Europe. A Strategic Plan has been drafted to describe priorities and ensure a focused approach.

Today, the SWEET network is more alive than ever, with 40 centres across 28 different countries and a database with over 18.000 patients. Most recently, SWEET has received notions of interest and applications from paediatric centres outside of Europe, such as India, Costa Rica, Argentina, Brazil and Canada.

In addition, SWEET has been put forward as a best-practice model in several countries. In the UK for example, the SWEET guidelines and recommendations have been used as a foundation to work towards improving and standardising many aspects of care.



Map of SWEET centres: Countries which are represented in the SWEET network are marked in red (1-3 centres/country).

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Executive Committee

Chairman: Prof. T. Danne, MD, Hannover
Vice-Chairman: P. Gerhardsson, Lund
Treasurer: B. Aschemeier, RN, MPH, Hannover

Register of association

Tax office: Finanzamt Hannover-Nord
Tax number: 25/207/45392
Reg. under VR 201430 with
the Amtsgericht Hannover

Bank details:

Name of bank: Bank für Sozialwirtschaft
Account No: 7499300
BLZ: 251 205 10
IBAN: DE 8772 5120 5100 0074 9930
Swift Code/ BIC: BFSWDE33HAN

A collaboration between SWEET and the NHS Diabetes, England: Paediatric Diabetes Peer Review Programme has been established for the certification of the SWEET centres. The NHS peer review team is charged with reviewing the paediatric healthcare teams and services to determine compliance with SWEET criteria and to assess quality of care and treatment in relation to clinical outcomes and patient experience.

Since one of the most important goals of the SWEET network is benchmarking and research, safe and reliable databases are essential. For data collection, statistical analysis, final evaluation and benchmarking, SWEET collaborates with Prof. Reinhard Holl, founder of the DPV programme. DPV is a quality-management software programme, allowing for structured collection and analysis of diabetes-related patient data. The programme is provided to all SWEET centres and feeds into the joint database, used for benchmarking and research as indicated in the figure below.

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graph TD
    subgraph Sources
        A[DPV Documentation system]
        B[Other electronic Health records]
        C[Download from existing longitudinal registries]
        D[Individual documentation via Excel-Spreadsheet using a unique patient identifier]
    end
    subgraph Pseudonymized
        E[Pseudonymized SWEET dataset]
        F[Pseudonymized SWEET dataset]
        G[Pseudonymized SWEET dataset]
        H[Pseudonymized SWEET dataset]
    end
    subgraph Feedback
        I[Feedback on completeness and validity]
        J[Feedback on completeness and validity]
        K[Feedback on completeness and validity]
        L[Feedback on completeness and validity]
    end
    subgraph JointDB [Joint SWEET Database]
        M[Joint SWEET Database]
    end
    subgraph Outputs
        N[Comparison among Centers / Benchmarking (M. Witsch, Luxemburg)]
        O[Biostatistical Analyses for research (R. Holl, Ulm, Germany)]
    end
    A --> E
    B --> F
    C --> G
    D --> H
    E --> I
    F --> J
    G --> K
    H --> L
    I --> M
    J --> M
    K --> M
    L --> M
    M --> N
    M --> O
    M <--> P[Local pediatric diab. center]
    M <--> Q[Data Center Epidemiology Ulm University]
    Q <--> R[Luxemburg / Ulm]
  
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In order to become a SWEET Centre of Reference (CoR) or Collaborative Centre (CC), a paediatric diabetes centre will need to fulfil particular criteria and will be submitted to a SWEET/NHS peer review. More information on this application process, the requirements and criteria can be found in the accompanying brochure.

For children aged 7 to 17 to read
The SWEET Studygroup of diabetes in children:
Study of centre differences

We write to you today because we need your help with a research project in our hospital.

We know that it can be difficult to live with diabetes, so we would like to know how well we are helping you treat your diabetes.

Doctors and nurses all over the world are part of this study. If you agree, we will share information or stuff we know about you, like what type of diabetes you have, how long you had it, how old you are, what your blood tests say and things like that. We will not share your name, address, phone number or Alberta Health number.

We hope that if we share this with other diabetes doctors and nurses, we can find out what else affects your diabetes and find the best way to treat it so that, in the future, we can help you better.

Of course, we will care for you the same as usual even if you decide not to take part in this study.

We would be very happy if you would help us.

See you soon!

Your diabetes team

The “SWEET” Studygroup of diabetes in children
(Better control in Pediatric and Adolescent diabetes: Working to crEate CEnters of Reference).

INFORMATION FOR PARENTS

This is a study of centre differences between pediatric diabetes centres

We would like you and your child to take part in a study regarding diabetes in children. It is very important to us that you know exactly why we conduct this study and what this study means for you. Please read this information carefully. Of course, you can talk about this study with third parties or question us if you need to know more.

WHAT IS THE PURPOSE OF THE STUDY?

To improve health and quality of life outcomes of young people with diabetes through the sharing of data between diabetes clinics across the world.

WHY DID WE CHOOSE YOU?

We have approached you because your child is being treated in one of the international reference centres for children with diabetes.

DO YOU HAVE TO PARTICIPATE?

If you don't want to, you don't have to take part. It will not influence how we treat you or your child in our clinic if you don't take part.

WILL YOUR CHILD'S RECORDS AND ANSWERS TO THE QUESTIONNAIRE BE KEPT CONFIDENTIAL?

The doctors and nurses in the clinic will not know which answers you have given because no addresses or names will be documented with the questionnaire or the clinical data. The data will be kept strictly confidential. In that way your answers will have no influence on how we will treat you and your child in the future.

WHAT WILL HAPPEN TO YOU AND YOUR CHILD IF YOU PARTICIPATE?

Your child's data (month and year of birth, gender, date of diagnosis, type of diabetes, height, weight, blood pressure, labs, medications including insulin treatment, hospitalisation and diabetes-related complications) will be documented as usual and – if you approve – will be centrally and anonymously evaluated in Ulm, Germany.

ARE THERE ANY BENEFITS IF YOU PARTICIPATE?

There will be no quick direct benefits for you or your child if you help us with this study, but we hope the results will eventually help us to care better for children with diabetes here in this clinic and worldwide.

WHAT WILL HAPPEN TO THE RESULTS OF THE STUDY?

The clinical data will only be used for this study. They will not be given to any third party.

Later, the results of the study will be passed on to the leader of your diabetes team during a meeting of the SWEET studygroup so that she can discuss them with you and the whole diabetes team. Results will be presented at professional diabetes meetings and published in medical journals. In that way, the data can help diabetes centres worldwide optimize the care for families like yours. We also intend to share publications and results with you by making them available in our waiting room and/or in our clinic newsletter.

WHO ORGANIZES AND SUPPORTS THE STUDY?

The study is supported by the European Union and the SWEET studygroup (www.sweet-project.eu).

WHO CONTROLS AND MONITORS THE STUDY?

The study is monitored by the participating diabetes centres. The University of Calgary Conjoint Health Research Ethics Board has approved this research study.

WOULD YOU LIKE FURTHER INFORMATION?

If you have further questions concerning matters related to this research, please contact:

Dr. Danièle Pacaud (403) 955-7819 or Heidi and Claire (403) 955-8866

If you have any questions concerning your rights as a possible participant in this research, or if you have any complaints or concerns about the way the trial doctor has carried out the trial, please contact the Chair, Conjoint Health Research Ethics Board., University of Calgary, at 403-220-7990.

**THANK YOU FOR READING THIS INFORMATION:
WE HOPE THAT YOU WILL SUPPORT US.**

YOUR DIABETES TEAM.