



Swiss Research Network of
Clinical Pediatric Hubs



Annual Report 6 2018

SwissPedNet

c/o Swiss Clinical Trial Organisation

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Editorial

Dear reader,

SwissPedNet is growing and prospering. Our network of clinical pediatric research hubs and the two specialized platforms SwissPedPha and SwissPedRegistry - the former dedicated to pediatric pharmacology and pharmacometric research, the latter is experienced with pediatric registries and databases – established or further developed their services for clinical pediatric researchers during 2018.

Take a look at our website, we published the on-going clinical study activity in our member institutions. Within our network almost 200 pediatric clinical study projects are running.

<https://www.swisspednet.ch/studies/>

It is anyway worthwhile to visit our website, during the past year we updated and refreshed it, it has now a slightly new look.

We appreciate the funds we receive from the federation. The amount to each individual pediatric hub is small, but it gave the impetus to develop our existing infrastructures to become a reliable nation-wide network. And we are grateful for the close collaboration with and on-going support from the SCTO which gave us access to the European research infrastructure projects funded for the pediatric community.

In 2018 the new board consolidated. During face-to-face meetings and our retreat in summer we worked on our vision, mission and its strategy to achieve our goals.

The vision remains unchanged: All children in Switzerland have access to high-quality research in well-equipped research infrastructures, independent of their age, pathology, and living location. Pediatricians and other health professionals caring for children in Switzerland conduct clinical research at international highly competitive level, exhibit impressive charisma, and are uniquely recognized with all its disciplines and sub-disciplines within their own country and abroad.

We focused on networking within our network to facilitate collaboration of our hubs in the multi-center setting and to train young pediatricians aiming to conduct their own clinical study projects. We will follow up on these new activities in the years to come and remain with our already traditional event for young researchers, the SwissPedNet Translational & Clinical Research Session during the sgp/ssp annual conference.

We look forward to strengthen and consolidate our activities in 2019!



Prof. Klara Posfay Barbe
President SwissPedNet

SwissPedNet Activities in 2018

Field Trip

On May 31, 2018 the pediatric hub Geneva invited all SwissPedNet staff from all hubs and platforms to Geneva. 15 people from 10 member institutions followed the invitation. The Geneva team presented how they work in their research hub and how they got there.

It was a great success in regards networking within our network, getting each other know and sharing best practices and experience.

The group of study coordinators, research nurses and young pediatricians enjoyed this initiative and would like to visit other hubs in the format of field trips, preferably once or twice each year.

The next field trip will be hosted by the hub Basel on April 4, 2019.

Call for Study Project in Pediatric Health Services Research

The call we made together with the sgp/ssp in 2017 was won by two women from Zurich with their project SPhAERA:

SPhAERA: Specialised Paediatric Palliative Care: Assessing family, healthcare professionals and health system outcomes in a multi-site context of various care settings.

Dr Karin Zimmermann and PD Dr med. Eva Bergsträsser from the University-Children's Hospital Zurich received the amount of CHF 120,000.- to support their project jointly from SwissPedNet and the ssp/sgp. They will report about the proceedings and outcomes of this study.

6th SwissPedNet Translational & Clinical Research Session

In 2018 hosted at the sgp/ssp annual conference in Lausanne, we had the possibility to present mission, vision and activities of SwissPedNet during the plenary session. This was a great opportunity to reach all pediatricians at the congress and we could do some advertising for ourselves.

The session itself in the afternoon was not well attended, however, the contributions from 15 young researchers were very interesting. We congratulate the winners of the SwissPedNet Translational & Clinical Research Award 2018:

Eva S.L. Pedersen, Institute of Social and Preventive Medicine, University of Bern for her research project "The simple 10-item PARC tool predicts childhood asthma in an external validation cohort." and *Christian Juvet*, Département femme mère enfant, CHUV, Lausanne for his research project "Early postnatal overfeeding induces transient overexpression of senescence promoting factors in the mouse kidney."

A summary of the research session was published in *Paediatrica* Vol 29 (3/2018).

AbbVie kindly offered the award of CHF 3000.-.

Next Generation Research Day, November 22, 2018

A new activity that had its first edition in 2018 was successful. Directed by Sandra Bigi and Ulrike Halbsguth from PedNet Bern and Nicolas Waespe from SwissPedRegistry 20 young researchers had an educational day with different workshops and "meet the expert" sessions. The session "meet the

expert” followed the innovative structure of “scientific speed dating” and has the format of an “elevator speech”, where the young researchers present their research projects in limited time to find collaborators or to get funds.

A great highlight to conclude the SwissPedNet activities in 2018.

SwissPedNet Projects in 2018

SPHN funded project: Harmonizing health related data and biospecimens across pediatric hospitals

Under the leadership of Claudia Kühni, SwissPedRegistry, the project team creates an inventory of health-related data collected from children in Switzerland. In collaboration with the five university children’s hospitals and the cantonal hospitals in Bellinzona, Luzern and St. Gallen, the project team develops a consensus among all major pediatric hospitals on which data and samples should be collected. In addition, they assess whether parents are willing to provide health-related information via paper or electronic questionnaires.

The challenge is that we have eight children’s hospitals and five different clinical information systems and the pediatric health records are not (yet) standardized. To agree all together on a pediatric minimal dataset the group will now start a Delphi process (Q1/2019).

General consent in pediatrics

A working group installed by the SAMS and under the lead of David Nadal, past-president of SwissPedNet, elaborates a guiding document and factsheet for pediatricians seeking to obtain general consent from pediatric patients. It will summarize what has to be considered when addressing children, adolescents and their parents or care-givers. The document will be handed over to the SAMS in Q1 2019.

The group has also been involved in the review of version 2 of the general consent information texts for adults. Once these texts are released they will be the base for harmonized general consent documents also for children, adolescents and their parents.

SPHN funded project: E-General-Consent

Under the leadership of Christiane Pauli-Magnus from the University Hospital Basel a team elaborates the prerequisites and requirements that people may give their general consent with an electronic signature. The project team works for a solution in adult medicine. SwissPedNet is involved to bring in the pediatric view once the proceeding is settled for adults.

Beneficiary of the funding period 2017 to 2020

The first half of the funding period is over. The employment of 0.5 to 0.7 FTE research staff for our pediatric research hubs, SwissPedPha and SwissPedRegistry gave the impetus to proceed with the establishment of our nation-wide research infrastructure for pediatrics. Slowly but steadily we increase our collaboration and the number of multi-center clinical research projects.

At the beginning of the first funding period, we had decided to redistribute the funds equally, but this will be re-discussed by the board in the future so that the funding goes to where it is the most

useful. During our General Assembly on November 23, 2018 we passed minimal requirements for each individual hub to be fulfilled to receive the full funding in 2019 and 2020.

SwissPedNet's International Network

SwissPedNet is member in the consortium of three research infrastructure projects funded by the European Union.

PedCRIN – the Pediatric Clinical Research Infrastructure Network in Europe

PedCRIN develops capacity for the management of multinational pediatric non-commercial clinical trials. The PedCRIN Consortium is led by ECRIN.

Funding period: 2017 to 2020

SwissPedNet is the Swiss Hub of this four-year project funded by the European Union's Horizon 2020 program. For the time being PedCRIN is testing its network capacities with three academic pediatric clinical studies running in at least three countries. Unfortunately, there is no Swiss study site involved, hence our contribution remains more in an observer role.

c4c - conect4children

c4c is a large collaborative European network that aims to facilitate the development of new drugs and other therapies for the entire pediatric population. It is a pioneering opportunity to build capacity for the implementation of multinational pediatric clinical trials whilst ensuring the needs of babies, children, young people and their families are met.

c4c is committed to meeting the needs of pediatric patients thanks to a novel collaboration between the academic and the private sectors, which includes 33 academic and 10 industry partners from 20 European countries, and more than 50 third parties and around 500 affiliated partners.

c4c will demonstrate the effectiveness of the network by conducting 4 to 5 academic studies during 2019 to 2021. There has been a call and the winners will be elected in May 2019.

The Swiss clinical pediatric research hubs have been involved in about 20 proposals as potential study sites.

EPTRI – the European Pediatric Translational Research Infrastructure

EPTRI is the idea to bring different research groups together to increase translational research in pediatrics. They receive funding for two years (2018/2019) and the beneficiaries work to make it in this time a new European research infrastructure for translational research. Soon a new survey will collect information about existing research groups. This survey will be shared via SwissPedNet to institutional research groups.

Enpr-EMA

Being a member of Enpr-EMA SwissPedNet is recognized on the European stage. This membership enabled SwissPedNet to become part of the above-mentioned European projects.

General Assembly 2018

The 6th SwissPedNet General Assembly has been held on November 23, 2018.

Changes in the composition of the SwissPedNet Board

Prof. Urs Frey, one of the initiators and founding member of SwissPedNet, left the board in August 2018. The board assigned Matthias Baumgartner during its retreat as vice-president.

The General Assembly elected two new board members: Dr Sandra Bigi from the University children's hospital Bern and Dr Julia Bielicki from the University children's hospital Basel. We welcome the young forces in our board and look forward to the collaboration.

SwissPedNet collaborators

In the open part of the General Assembly SwissPedNet welcomed their collaborators in the member institutions. Study coordinators and young investigators from our hubs, SwissPedPha and SwissPedRegistry joined our meeting. The aim was to discuss workflows between the coordinator and each other and to improve communication where it is necessary.

A common interest and topic has been identified: As it would be most helpful to have harmonized SOPs, a working group will share and harmonize SOPs for the entire network. Results will be presented next year during the General Assembly 2019.

Acknowledgment

A big thank goes to the SCTO and their continuous support for the pediatric research infrastructure and their support in collaboration with European projects.

AbbVie granted the SwissPedNet translational and clinical research award and Pfizer offered an educational grant. Both grants are highly appreciated.

Outlook and next steps

We have not yet arrived in the ideal world. We have to continue with our endeavors to enhance clinical research in pediatrics both by supporting pediatric clinician scientists to foster their commitment to high-quality clinical research and by encouraging an overall increased acceptance in the community of trials in children.

We will work on our application to the SERI for the funding period 2021-2024. The clinical pediatric research will need further federal funds to continue the development of a sustainable research infrastructure in pediatrics.

Do good and talk about it: SwissPedNet will set a strategy to promote itself and its activities throughout Switzerland.

Annual Financial Statement

Accounts 1.10.2017 to 30.9.2018 and Balance sheet as per 30.9.2018

	2016	2017	2018
	CHF	CHF	CHF
1. Income			
Membership fees	5'500.00	5'500.00	11'000.00
Educational Grant Pfizer	6'406.02	4'431.50	5'037.39
Sponsoring	7'500.00	3'000.00	3'000.00
EnprEMA workshop (allowance participation PW)	284.72	0.00	0.00
Postfinance credit interest	9.05	0.00	0.00
<i>Total income:</i>	<u>19'699.79</u>	<u>12'931.50</u>	<u>19'037.39</u>
2. Expenses			
5 th General Assembly (incl. 5y celebration dinner)	2'456.27	3'458.39	3'556.00
Website Hosting	648.00	648.00	646.20
Website Update (CMS Typo3 V8LTS)			10'477.85
Website domain name	1'080.40	186.10	83.50
Public awareness (translations for Paediatrica)	1'123.20	0.00	0.00
Award SwissPedNet Clinical Research Session	3'000.00	3'000.00	3'000.00
Study Project in Pediatric Health Services Research			60'000.00
SwissPedNet Travel Award	5'500.00	0.00	0.00
National Study Nurse / Study Coordinator Meeting	910.45	0.00	0.00
SwissPedNet Retreat	515.40	490.95	148.00
SwissPedNet (general costs & expenses)	932.00	684.40	698.00
Postfinance account management	2.00	60.00	105.00
<i>Total expenses:</i>	<u>16'167.72</u>	<u>8'527.84</u>	<u>78'714.55</u>
Total income:	19'699.79	12'931.50	19'037.39
Total expenses:	16'167.72	8'527.84	78'714.55
<i>Total profit margin/loss of profits:</i>	<u>3'532.07</u>	<u>4'403.66</u>	<u>-59'677.16</u>

3. Balance as per 30.9.2018

	Liabilities	
Account balance PC 60-488628-5	63'085.02	
Deferred charges to income	1'000.00	
Deferred charges to expenses*		2'607.00
Capital of the association		61'478.02
	<u>64'085.02</u>	<u>64'085.02</u>

4. Association assets

	CHF
Asset as per 30.09.2017	121'155.18
Asset as per 30.09.2018	<u>61'478.02</u>
<i>loss of profits:</i>	<u>-59'677.16</u>

*remaining travel award CHF 2459.-, CHF 148.- (open bill No. 43)

People of SwissPedNet

Members of the Board as of 23.11.2018

President:	Prof. Dr Klara Posfay-Barbe
Vice-president:	Prof. Dr Matthias Baumgartner
Assessors:	Dr Julia Bielicki Dr Sandra Bigi Prof. Claudia Kühni Prof. Roger Lauener Prof. Marc Pfister

Auditors

Prof. Christoph Berger, University Children's Hospital Zurich

Prof. Ulrich Heininger, University Children's Hospital Basel

Member institutions and their representatives

University Children's Hospital Basel, Dr Julia Bielicki and Prof. Ulrich Heininger

University Children's Hospital Bern, Dr Sandra Bigi and Prof. Christa Flück

University Children's Hospital Geneva, Prof. Klara Posfay Barbe and Prof. Claire-Anne Siegrist-Juillard

University Children's Hospital Lausanne, Dr Manuel Diezi and Prof. Umberto Simoeoni

University Children's Hospital Zurich, Prof. Matthias Baumgartner and Prof. Christoph Berger

Children's Hospital Aarau, Prof. Henrik Köhler and Dr Katrin Scheinemann

Children's Hospital Luzern, Dr Michael Büttcher and Dr Franziska Righini

Children's Hospital of Eastern Switzerland, St. Gallen, Prof. Roger Lauener and Dr Christian Kahlert

Children's Hospital EOC Ticino, Bellinzona, Prof. Giacomo Simonetti and PD Dr Barbara Goeggel

SwissPedRegistry, Pediatric Registry Center, ISPM, University of Bern, Prof. Claudia Kühni

SwissPedPha, Prof. Marc Pfister and Prof. Johannes van den Anker

Coordinator SwissPedNet

Pascale Wenger, Swiss Clinical Trial Organisation SCTO

SwissPedNet Advisory Board

Prof. Saskia de Wildt, Radboud University, Nijmegen, the Netherlands

Prof. Evelyne Jacqz-Aigrin, CHU Paris - Hôpital Robert Debré, France

Prof. Christian Kind, Pediatrician, President Central Ethics Commission of the Swiss Academy of Medical Sciences

Prof. Martin Offringa, Child Health Evaluative Sciences, Toronto, Canada

Dr Simon Rotzler, Interpharma Switzerland

Dr Mark Turner, Institute of Translational Medicine, University of Liverpool, UK