



Swiss Research Network of
Clinical Pediatric Hubs



Annual Report 5 2017

SwissPedNet

c/o Swiss Clinical Trial Organisation

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Editorial

Much to our delight the current federal funding period 2017 to 2020 allows us to install and maintain the clinical pediatric research hubs within our member institutions throughout Switzerland.

The financial amount granted to SwissPedNet enables each hub, SwissPedRegistry and SwissPedPha to employ 0.5 to 0.7 FTE for their research infrastructures urgently needed to perform clinical research studies on a national and international level. Service Level Agreements with all our members regulate the use of the federal funds. The SwissPedNet General Assembly released in November 2016 rules of Procedures within each hub and between individual hubs, which are adopted by all member institutions. In addition, milestones and deliverables guide us to follow up on our target to become a reliable and well-working research infrastructure for pediatrics in Switzerland but also in Europe and overseas and to materialize our vision:

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.

Our General Assembly 2017 set the stage for a successful network – we had fruitful discussions with the main stakeholders and key players in pediatric clinical care and research in Switzerland. Most notably, representatives of the Swiss society of Paediatrics, the Foederatio paedo medicorum helveticorum, the Swiss association of the health of adolescents, the Swiss society of child and youth psychiatry and psychotherapy, the Swiss society of pediatric anesthesia, the Swiss pediatric surgery society, the Swiss society of neonatology and the Swiss pediatric oncology group followed our invitation and are eager to collaborate together.

As of 2018, Klara Posfay Barbe will preside SwissPedNet. She already collaborated in the board as president elect since the beginning of 2017, and we are all very happy that she takes over. I wholeheartedly wish her all success and support from the entire pediatric community of Switzerland.



Prof David Nadal
President SwissPedNet 2013 to 2017

SwissPedNet Highlights 2017

Entering as beneficiary into the funding period 2017 to 2020

SwissPedNet has eventually succeeded receiving federal funding for its member institutions. The SERI financially supports SwissPedNet, the clinical pediatric research infrastructure, with CHF 3.1 Mio. This amount enables each hub, SwissPedRegistry and SwissPedPha to employ 0.5 to 0.7 FTE for their research infrastructure urgently needed to perform clinical multi-center studies.

Collaboration with sgp/ssp

The Swiss Society of Pediatrics (sgp/ssp) officially mandated SwissPedNet to conduct pediatric clinical research in Switzerland. The Collège A supports this mandate via their clinical pediatric hubs.

SwissPedNet and sgp/ssp launched their scientific collaboration with a call for study projects in pediatric health services research in September 2017. The call is open until 28.2.2018 and the winner will be announced during the SwissPedNet Translational & Clinical Research Session on 24.5.2018 in Lausanne.

The topic of the proposed investigation must be relevant for outpatient care with a wide-ranging scope, must focus on patient-oriented research and may include healthy individuals as controls. No laboratory, early phase or proof of concept studies will be funded as well as no studies conducted for directly commercial purposes.

Activities and Projects in 2017

SwissPedNet entered into contract with each member institution

SwissPedNet concluded Service Level Agreements with each member institution for the use of the federal funds. Milestones and deliverables for each hub are defined and will be harmonized between each other.

SwissPedNet Translational & Clinical Research Session

SwissPedNet organized the 5th edition of the SwissPedNet Translational & Clinical Research Session on June, 2017 during the SGP/SSP congress in St. Gallen. Ten young researchers received the opportunity to present their work during 10 minutes talk and adjacent explanations and dialogue with the audience, after submitting their studies and research projects to the judging panel. The research projects covered all disciplines of pediatrics; beside clinical and epidemiological questions also studies in basic research have been presented. Along with the content itself, the judging panel evaluated the performance and the following discussion of the young researchers.

We congratulate the winners of the SwissPedNet Translational & Clinical Research Award 2017:

- Dr Tatjana Freye, University Children's Hospital Basel
- Dr Sebastiano Lava, Pediatric Pharmacology and Pharmacogenetics, Hôpital Robert Debré, Paris / University Children's Hospital and University of Bern / Institute of Pharmacological Sciences of Southern Switzerland, EOC Lugano

AbbVie kindly offered the award of CHF 3000. –.

A summary of the research session was published in Paediatrica Vol 28 (4/2017).

Ethic Standards for Pediatrics

swissethics published the “Leitlinie zur Forschung mit gesunden Kindern und Jugendlichen” / “Guide concernant la recherche sur des enfants et des adolescents sains”.

This document has been elaborated in collaboration with experts from SwissPedNet.

SwissPedRegistry

SwissPedRegistry started its activities for the entire Swiss pediatric research community in spring 2017.

The purpose of SwissPedRegistry is summarized as follows: SwissPedRegistry represents the interests of pediatrics in meetings relevant for registries and observational studies (national, international, federal), they develop methodologies and instruments for pediatric registries, facilitate exchange of expertise between pediatric registries, provide counseling to existing and planned pediatric registries, and host pediatric and all-age registries. It is the platform for registry based research.

SwissPedPha

SwissPedPha performs virtual experiments leveraging advanced pharmacometric modeling and simulation approaches to enhance both design and analysis of clinical trials conducted by SwissPedNet research centers. SwissPedPha also partners with SwissPedDose to analyze national databases and provide a scientific basis for enhanced and personalized treatment strategies in pediatrics.

The collaboration between the hubs and SwissPedPha has still to be increased.

SwissPedNet’s International Network

Enpr-EMA

Being a member of Enpr-EMA SwissPedNet is recognized on the European stage. In the past two years SwissPedNet has been invited to join several consortia of European projects.

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, launched on the 1st January 2017 (grant agreement number 731046).

IMI2 Call and c4c (CONNECT4CHILDREN)

SwissPedNet is part of the c4c consortium and 2017 has been used for preparatory work that includes two main topics: How to open studies efficiently and how to run studies efficiently. For the time being working groups elaborate documents, standards and processes for contracts, budgets, feasibility and ethics, site qualification and metrics.

c4c will demonstrate the effectiveness of the network by conducting 4 to 5 academic studies with the following timelines:

- May 2018: a call for non-industry projects will be opened for submission of clinical studies to be conducted via the infrastructure c4c.
- May 2019: selection of the projects.
- May 2020: Proof of viability – start of selected projects.

EPTRI – the European Paediatric Translational Research Infrastructure

The purpose of EPTRI is the creation of a framework for a new pediatric RI within the INFRADEV-2016-2017 single-stage call for proposals. Grant: € 3.00 million by the European Commission

Funding period: 2018 – 2019. The project is coordinated by CVBF Consorzio per valutazioni biologiche e farmacologiche, Italy.

Within this project, payment is only received when Switzerland participates in a clinical trial / project. Max. amount: € 40'000.-/year. (see also <https://www.teddynetwork.net/2017/09/01/id-eptri-approval-a-great-success-for-paediatric-medicines-development/>)

Swiss Clinical Trial Organisation SCTO

The pediatric clinical research hubs will not establish parallel infrastructures to the CTUs, therefore, the collaboration between the hubs and the CTUs should be fostered. The staff caring for pediatrics and hired with the federal funds could be embedded within a CTU but be dedicated as study employee of the children's hospitals. Models and best practices are in development and will be tested at individual hubs.

SwissPedNet and the SCTO are closely collaborating. As SwissPedNet has no legal entity according to European meanings, the SCTO acts as legal entity and is beneficiary for SwissPedNet within the European projects.

SwissPedNet and the Pharmaceutical Industry

SwissPedNet thanks for the support by individual pharmaceutical companies.

General Assembly 2017

During the 5th SwissPedNet General Assembly David Nadal passed the baton on to Klara Posfay Barbe, she will preside SwissPedNet for the coming three years.

The General Assembly elected a **new board** as of 2018, and the following members will take responsibility for defining the strategy and securing the future of SwissPedNet:

President: Prof. Klara Posfay Barbe, University children's hospital Geneva

Vice-president: Prof. Urs Frey, University children's hospital Basel

Assessors: Prof. Matthias Baumgartner, University children's hospital Zurich, Prof. Claudia Kühni, Institute for Social and Preventive Medicine, University of Bern, SwissPedRegistry, Prof. Roger Lauener, Children's Hospital of Eastern Switzerland St. Gallen, Prof. Marc Pfister, University children's hospital Basel, SwissPedPha.

In the open part of the General Assembly SwissPedNet welcomed the following guests: Swiss Society of Paediatrics (ssp/sgp), Foederatio Paedo medicorum helveticorum (fPmh), Swiss Pediatric Surgery Society SPSS, Swiss Paediatric Oncology Group (SPOG).

The afternoon session allowed the people to mutually introduce themselves, and their societies were invited to approach SwissPedNet, if they see synergies and to pursue collaborative projects.

SwissPedNet needs to improve its marketing activities as it became clear during the discussions, for many pediatricians still do not know the research infrastructure for pediatrics.

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.

Next steps

Now we have to share our experience with our hubs and harmonize our processes. We will invite for a visiting day at an individual hub twice per year. Geneva starts with their visiting day in spring 2018.

SwissPedNet will introduce a practical workshop for young researchers to increase their skills. It is planned to hold the workshop timely close to the General Assembly; therefore, first workshop will be held in November 2018.

Finally, SwissPedNet will set a strategy to promote itself and its activities throughout Switzerland.

Annual Financial Statement

Accounts 1.10.2016 to 30.9.2017 and Balance sheet as per 30.9.2017

Accounts 1.10.2016 - 30.9.2017

Balance sheet 30.09.2017

	2015	2016	2017
	CHF	CHF	CHF
1. Income			
Membership fees	4'000.00	5'500.00	5'500.00
Educational Grant Pfizer	5'222.90	6'406.02	4'431.50
Sponsoring	0.00	7'500.00	3'000.00
EnprEMA workshop (allowance participation PW)	190.83	284.72	0.00
Postfinance credit interest	38.50	9.05	0.00
Total income:	9'452.23	19'699.79	12'931.50
2. Expenses			
General Assembly - Guest speaker / Advisory Board Members	1'321.86	2'456.27	3'458.39
Website Hosting	648.00	648.00	648.00
Website Maintenance/domain name	83.50	1'080.40	186.10
Public awareness (translations for Paediatrica)	702.00	1'123.20	0.00
Award SwissPedNet Clinical Research Session	3'000.00	3'000.00	3'000.00
SwissPedNet Travel Award	0.00	5'500.00	0.00
National Study Nurse / Study Coordinator Meeting	3'020.38	910.45	0.00
SwissPedNet Retreat	310.50	515.40	490.95
SwissPedNet (general costs & expenses)	945.50	932.00	684.40
Postfinance account management	0.00	2.00	60.00
Total expenses:	10'031.74	16'167.72	8'527.84
Total income:	9'452.23	19'699.79	12'931.50
Total expenses:	10'031.74	16'167.72	8'527.84
Total profit margin/loss of profits:	-579.51	3'532.07	4'403.66

3. Balance as per 30.9.2017

	Liabilities	
Account balance PC 60-488628-5	125'114.18	
Deferred charges to income	0.00	
Deferred charges to expenses*		3'959.00
Capital of the association		121'155.18
	125'114.18	125'114.18

4. Association assets

	CHF
Asset as per 30.09.2016	116'751.52
Asset as per 30.09.2017	121'155.18
profit of assets:	4'403.66

*remaining travel award CHF 2459.- and research award CHF 1500.-

Team of SwissPedNet

Members of the Board as of 17.11.2017

President:	Prof. Dr. med. Klara Posfay-Barbe
Vice-president:	Prof. Dr. med. Urs Frey
Assessors:	Prof. Matthias Baumgartner Prof. Claudia Kühni Prof. Roger Lauener Prof. Marc Pfister

Auditors

Prof. Christoph Berger (CB), University Children's Hospital Zurich

Prof. Ulrich Heininger (UH), University Children's Hospital Basel

Member institutions and their representatives

University Children's Hospital Basel, Prof. Urs Frey and Prof. Ulrich Heininger

University Children's Hospital Bern, Prof. Christoph Aebi and Dr Sandra Bigi

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

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

Children's Hospital EOC Ticino, Bellinzona, Prof. Giacomo Simonetti

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