



Swiss Research Network of
Clinical Pediatric Hubs



Annual Report 9 2021

SwissPedNet

c/o Swiss Clinical Trial Organisation

Effingerstrasse 35, 3008 Bern

T: 031 307 10 45

www.swisspednet.ch | info@swisspednet.ch

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Editorial

Dear reader,

As always, when writing the annual report we look back on the past year. And it can sometimes fill you with pride when you look at what has been achieved. However, we also see what can still be improved, and we would like to devote ourselves to this in the coming funding period.

2021 was the ninth year of SwissPedNet, our network of clinical pediatric hubs and two service platforms for registries and clinical pharmacology, and we started with the new funding period 2021 – 2024.

SwissPedNet - the pediatric research infrastructure - has more resources available in the new funding period to conduct high-quality clinical trials in all its pediatric clinical research centers (our "hubs"). This recognition is highly valued, and we are doing everything we can to use these resources properly. The goal remains the same: Swiss pediatrics initiates and participates in multi-center clinical trials in pediatrics. SwissPedNet creates the capacities in the individual hubs for this purpose, so that our largest children's hospitals with clinical research activities can actively participate in studies of national relevance and with a national and international impact.

Please see for yourself in this report what we achieved in this still special year 2021.

Enjoy the reading!



Prof. Klara Posfay Barbe
President SwissPedNet

SwissPedNet Highlights and Activities in 2021

During the second wave of COVID-19, more cases of Pediatric Inflammatory Multisystem Syndrome Temporally related to SARS-CoV-2 (PIMS-TS) have occurred in children and adolescents in Switzerland (currently estimated at approximately 50 cases). Julia Bielicki (UKBB) and Luregn Schlapbach (Children's Hospital Zurich) initiated **SwissPed-RECOVERY**, a sister study of the international RECOVERY study in Switzerland. With this study reliable data are collected for the efficacy of different medicines and therapies for the treatment of PIMS-TS.

Increasing quality of pediatric healthcare in Switzerland by research and improving children's health through research

In 2021, SwissPedPha intensified its collaboration with SWISSPEDDOSE. Medicines for which only limited information is available and for which no dosage recommendations for children can be given are identified by SWISSPEDDOSE and submitted for assessment to a team of experts, which also includes members of SwissPedPha. The expert team consists of Chantal Csajka, University of Lausanne/CHUV, Paolo Paioni, Kispil ZH, Marc Pfister and Verena Gotta, both UKBB/SwissPedPha. They then make recommendations to SwissPedNet on the need for clinical trials and/or to SwissPedPha for a pharmacometric modeling and simulation (PMX) project.

Regardless of this, our eleven member institutions are engaged in over 500 studies or research projects¹. A compilation of ongoing clinical and epidemiological studies can be found on our website (<https://www.swisspednet.ch/de/studies/>).

Connecting within Switzerland and abroad to facilitate conduct of pediatric clinical studies

On October 28, 2021 we resumed our "**Field Trips**" and all employees of our Hubs, the study coordinators and study nurses, were invited by our colleagues from PedNet Bern. It was an excellent meeting, participants listened to interesting presentations and enjoyed the opportunity to meet and share know-how and expertise.

SwissPedNet is a member of the Consortium of **c4c** (connect4children), the pan-European network that aims to facilitate the development of new drugs and other therapies for the entire pediatric population.

Our participation in c4c brought two interesting academic clinical trials to Switzerland:

TREOCAPA: This study investigates the efficacy of paracetamol on closure of the ductus arteriosus and increasing survival without severe morbidity in extremely preterm infants. The goal of the study is to recruit approximately 800 babies in 17 European countries. In Switzerland, Zurich, Geneva and Lausanne are participating.

cASPerCF: The study will evaluate posaconazole dosing in children and adolescents with cystic fibrosis and Aspergillus infection and will include a total of 135 children. In Switzerland, the University Children's Hospital Zurich will participate in this study.

In 2021, an industry study was added via c4c: the CHUV, département femme-mère-enfant, will participate in Bayer's study investigating a new therapy for chronic kidney disease. FILIA (FInerenone

¹ Multicenter studies open at multiple centers are named by each participating center.

for the treatment of children with chronic kidney disease and proteinuria) is investigating a new agent, already successfully tested in adults, for its proper use in children.

Anticipating future development and innovation in clinical science

The successful SPHN project **SwissPedData**, harmonization of health-related data and biospecimens in children's hospitals, must now be implemented. SwissPedNet will actively support its member institutions so that all children's hospitals involved in clinical research will have access to harmonized data sets in the future.

Optimizing pediatric dosing regimens based on a clinical data warehouse SwissPKcdw: The SwissPKcdw (Swiss Pharmacokinetics clinical datawarehouse) develops and provides expertise and tools for "pharmacokinetic modeling". This should then allow prediction of dosing regimens for pediatric patients based on data in the clinical data warehouse. This project is ongoing.

Providing training opportunities for young pediatric investigators and researchers, fostering continuous learning and adaptation

The "**Next Generation Research Day**" has been part of our training program since 2018. Sandra Bigi and Nicolas Waespe, both University children's hospital Bern, again organized this interesting and innovative workshop. In 2021, 43 participants were offered workshops for STEP I (development) and STEP II (leadership). The workshops and small group discussions were highly appreciated. We are already looking forward to the fourth edition in 2022.

For the 8th time, the **SwissPedNet Translational & Clinical Research Session** was held at the sgp/ssp Annual Meeting. This year's meeting was a virtual meeting organized by the Fribourg Hospital on June 10/11, 2021. SwissPedNet also conducted its session virtually and selected the two best among the good:

Sven Strebel, ISPM, University of Bern for his research project "Prevalence and Clinical Risk Factors of Severe Hearing Loss in Swiss Childhood Cancer Survivors" (SPN9) and
Loretta Müller, University children's hospital Bern for her research project "The importance of a comprehensive Primary Ciliary Dyskinesia diagnostic center - Experience of the first 100 patients at the PCD-UniBe Diagnostic Center" (SPN15).

Also this year, pädiatrie schweiz (sgp/ssp) has provided the prize money of CHF 3000 twice. Many thanks.

General Assembly 2021

The 9th SwissPedNet General Assembly has been held on November 19, 2021 with the overall topic "increase interoperations between our hubs and platforms".

Federal funding period 2021 to 2024

SwissPedNet receives a higher amount from the SERI for the funding period 2021 – 2024, the yearly amounts slightly increase during the years. As decided on November 19, 2020 during its General Assembly the funds in 2021 are set as standard amount over the entire funding period. The additional amount will be shared with members and hubs for special improvement of infrastructure at the pediatric hubs and will be distributed according to applications before December 31.

The board elaborated a concept on how the funds will be distributed in the current funding period. In the future, the payment shall depend on the performance of the respective hub. The proposal is to introduce two levels of funding, i.e., standard funding and funding for low performers. The level of funding will be set according to individual annual reports assessed by the board.

We acknowledge that small hubs are more in danger to become downgraded, but still, the minimal requirements for all hubs are minimal and should be achieved by all, as they also set their own goals and milestones.

The remaining fund will be used for dedicated infrastructure projects in the individual hubs.

The proposal was put to the vote and was unanimously approved.

Election of the president and the board

The following board members have completed their three year's term and have been unanimously re-elected for a second term: PD Dr Julia Bielicki and Prof. Claudia Kühni, both assessors.

Succession planning for the president and the board:

As our president Prof. Klara Posfay Barbe will step down from the presidency in 2022, the board asked the vice-president Prof. Matthias Baumgartner if he is willing to become the next president. He agreed and is available for election. In order to give everyone the opportunity to stand for election, candidates for the office of president may claim interest. In December 2021, the General Assembly elected by e-mail voting unanimously Prof. Matthias Baumgartner as president-elect.

Appointing the Auditors

For the coming year, PD Dr Barbara Goeggel Simonetti and KD Dr Michael Büttcher act as auditors of SwissPedNet.

Hub staff group with regular meetings, updates, etc.

As learnt during our field trips, the group of study coordinators and study nurses of our pediatric hubs have many topics to share with each other and the exchange of the individual expertise is most helpful for all. The study coordinators and nurses present welcome this initiative and are interested in a deeper mutual exchange. They propose to initially start with meetings every 2nd month with all hub coordinators to align activities and exchange expertise.

Rahel Kuonen from Bern, Rebecca Oppenheim from Lausanne and Margarete von Wantoch from Zurich offer to co-lead the group which is gratefully accepted.

Acknowledgment

Our thanks go again to the SCTO and their continuous support for the pediatric research infrastructure and their support in collaboration with European projects.

The sgp/ssp granted the SwissPedNet translational and clinical research award, Pfizer offered an educational grant, Bayer, Eli-Lilly and Novartis financed the NextGen Research Day.

These grants are highly appreciated.

Outlook and next steps

We are planning to conduct a multi-center "Point Prevalence Study" (PPS) this year. We would like to show that after 5 years of financial support we have built a well-functioning network, participation is mandatory for all our member institutions.

Possible topics of this PPS are harmonization and/or dosing of drugs, possibly combined with selected retrospective data from SwissPedData. The PPS should review our infrastructure and test our system, i.e. a kind of research on research infrastructure.

Next steps: already in the first quarter of 2022 we will publish a call for proposals for the PPS on our website. The board will select a project and set a date at the end of 2022 for data collection. The project should be completed in 2023 so that the result can be used for the SERI application for the 2025-2029 funding period.

Please visit our website: www.swisspednet.ch. Here you will find more information about the activities of our network.

Annual Financial Statement

Accounts 1.10.2020 to 30.9.2021 and Balance sheet as per 30.9.2021

Accounts 01.10.2020 - 30.09.2021			
Balance sheet 30.09.2021			
	2019	2020	2021
1. Income	CHF	CHF	CHF
Membership fees	11'000.00	11'000.00	11'000.00
Educational Grant Pfizer	4'729.70	4'129.70	0.00
Sponsoring (sgp/ssp) Research session	6'000.00	0.00	6'000.00
Sponsoring NextGen RD	0.00	7'700.00	4'500.00
Registration fee NextGen RD	0.00	0.00	480.00
Transfer from deferred charges to expenses "SwissPedNet Travel Award"	2'459.00	0.00	0.00
Total income:	24'188.70	22'829.70	21'980.00
2. Expenses			
General Assembly	2'222.70	3'300.73	0.00
Website Hosting	597.74	549.28	274.64
Website Development and Support	2'841.99	51.16	3'683.34
Website domain name	68.00	99.00	83.50
Award SwissPedNet Clinical Research Session	6'000.00	0.00	6'000.00
SwissPedNet NextGen Research Day	1'719.00	4'616.50	0.00
SwissPedNet Retreat	328.00	117.90	182.95
SwissPedNet (general costs & expenses)	1'113.25	1'242.51	363.70
Postfinance account management	60.00	60.00	60.00
Total expenses:	14'950.68	10'037.08	10'648.13
Total income:	24'188.70	22'829.70	21'980.00
Total expenses:	14'950.68	10'037.08	10'648.13
Total profit margin / loss of profits:	9'238.02	12'792.62	11'331.87
3. Balance as per 30.9.2021			
	Liabilities		
Account balance PC 60-488628-5	94'840.53		
Deferred charges to income	0.00		
Deferred charges to expenses		4'980.00	
Capital of the association		89'860.53	
	94'840.53	94'840.53	
4. Association assets			
	CHF		
Asset as per 30.09.2020	83'508.66		
Asset as per 30.09.2021	89'860.53		
profit margin:	6'351.87		

People of SwissPedNet

Members of the Board

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

Auditors

KD Dr Michael Büttcher

PD Dr Barbara Goeggel Simonetti

Member institutions and their representatives

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

University Children's Hospital Bern, Prof. Christa Flück, PD Dr Philipp Agyeman

University Children's Hospital Geneva, Prof. Klara Posfay Barbe and Prof. Constance Barazzone

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 Dominik Müller-Suter

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, Pediatric Pharmacology and Pharmacometrics Research Center at the UKBB, Prof. Marc Pfister and Prof. Johannes van den Anker

Coordinator SwissPedNet

Pascale Wenger, Swiss Clinical Trial Organisation SCTO

SwissPedNet Advisory Board

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

Mrs Pirkko Lepola, Executive Secretary FinPedMed, General Secretary NordicPedMed, HUS Helsinki University Hospital, Finland

Prof. Michael Levin, Paediatrics and International Child Health, Imperial College London, UK

Dr Simon Rotzler, Interpharma Switzerland

Prof. Johan Vande Walle, Department of Internal Medicine and Pediatrics, Ghent University Hospital, Belgium