



Swiss Research Network of  
Clinical Pediatric Hubs



# 11<sup>th</sup> Annual Report 2023

## **SwissPedNet**

c/o Swiss Clinical Trial Organisation

Effingerstrasse 35, 3008 Bern

T: 031 307 10 43

[www.swisspednet.ch](http://www.swisspednet.ch) | [info@swisspednet.ch](mailto:info@swisspednet.ch)

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## Editorial

Dear reader,

SwissPedNet has been on the move for more than ten years as a network: what we have built up is something to be proud of, but also something of constant change and development. We look forward to consolidating what we have already built and actively support the development of the future of clinical research in pediatrics.

2023 was my first year as President. In this first year, we experienced some major changes but were also able to lay the foundation for the coming years. The biggest change was the resignation of Pascale Wenger at the end of September 2023. Pascale was the SwissPedNet coordinator from the very beginning and, as the heart and soul of SwissPedNet, has played a decisive role in shaping our network.

Also in 2023, SwissPedNet has drawn up a Master Service Agreement. This agreement sets out the general principles of the collaboration. It is designed to be flexible and can be adapted to the various studies. In contrast to previous templates, all parties involved in a given study sign only one agreement. The Master Service Agreement was approved at the general assembly and can be considered as a major achievement.

Finally, we contributed to the training of the next generation of pediatric clinical researchers with our well-established “SwissPedNet Translational & Clinical Research Session” during the annual conference of pédiatrie suisse, this year with new, exciting formats. For the first time the “NextGenResearch Program” 2024 will be held the day before the conference of pédiatrie suisse. Keep your eyes open and be part of the NextGen program in June in Sursee LU.

With this report we summarized our activities and highlights during 2023, we wish enjoyable reading!



Prof. Matthias Baumgartner  
President SwissPedNet

## SwissPedNet Highlights and Activities in 2023

SwissPedNet relaunched its website in 2023. The site has been modernised and is now more user-friendly and responsive. The content is easier to find and the hubs' activities are more visible.

SwissPedNet has also made a significant contribution to the activities of SPHN with the Pediatric Personalised Research Network.

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

In June, we conducted the second point-prevalence study (PPS) within our network investigating the prevalence of traumatic brain injuries in children treated in Swiss Children's hospitals. Michelle Seiler from Kispi Zurich presented the project at the GA 2023.

The results of the first PPS on perioperative measures for surgical site infection prevention done in 2022 with a dataset of 331 procedures were also presented during the GA 2023 by Isabella Bielicki from UKBB Basel. This quality survey illustrated one of the biggest challenges in Switzerland, i.e. the different ways in which information is collected. Different documentation systems make it difficult to consolidate and extract information.

All 10 sites were part of the two PPS and collected and entered their data. Publication of both PPS is planned. These point prevalence studies show two things: On the one hand, SwissPedNet is able to conduct clinical studies covering the entire country; on the other hand, data collection is highly individualized, different from site to site and far from being automated - something we want to improve in the coming years.

On top of this, our twelve member institutions are engaged in over 350 studies or research projects.

A compilation of ongoing clinical and epidemiological studies can be found on our website ([Studies - SwissPedNet](#)).

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

In 2023 we had two Field Trips: In May, all employees of our hubs, the study coordinators and study nurses, were invited by our colleagues from SwissPedPha, our pediatric pharmacology and pharmacometrics research center in Basel. It was an excellent meeting with insights into the world of our SwissPedPha colleagues. In October, we resumed this activity in Luzern at our colleagues from children's hospital Luzern. This time the focus was on Epic, the new electronic health record system at the Luks. The day was as interesting and educational as we value it. During both events, the opportunity to meet and share know-how and expertise was highly appreciated.

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. As part of this, SwissPedNet hubs participate in two studies:

**TREOCAPA:** This study enters in a follow-up to investigate the well-being of the TREOCAPA patients after 2 years of exposure to acetaminophen for the prophylactic treatment of the ductus arteriosus in preterm infants. The neonatology of the university hospital Zurich is coordinating the Swiss study sites Zurich, Geneva, and Lausanne.

The **FIONA** trial from Bayer is also in a follow-up phase: **FIONA-OLE** to learn more about how safe the study treatment finerenone is in long-term use when taken with an ACE inhibitor or angiotensin receptor blocker over 18 months of use in children and young adults from 1 to 18 years of age with chronic kidney disease and proteinuria (FIONA OLE). In 2021, the hub Lausanne initiated the study in Switzerland, in 2022 and 2023 additional study sites (Basel and Geneva) joined.

### Anticipating future development and innovation in clinical science

We gave our network a new governance structure with a Master Service Agreement (MSA). The MSA is a strategy for consolidating research collaboration: The MSA replaces the traditional model of clinical study agreements (CTA), that need to be done individually with each study site. During the General Assembly all members agreed to this new governance structure.

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

For the 10<sup>th</sup> time, the **SwissPedNet Translational & Clinical Research Session** was held at the annual conference of pédiatrie Suisse. We congratulate the winners of the SwissPedNet Translational & Clinical Research Award 2023:

**Nora Fritschi**, University Children's Hospital Basel UKBB, for her research project «Discrimination of tuberculosis infection and disease using cytokine response to novel M. tuberculosis antigens» (SPN7) and **Michelle Seiler**, University Children's Hospital Zurich for her research project «Artificial intelligence in a pediatric emergency department: The end of misdiagnosis of pediatric fracture detection?» (SPN13).

The pädiatrie schweiz | pédiatrie suisse kindly offered two awards of CHF 3000.- each

## General Assembly 2023

The 11<sup>th</sup> SwissPedNet General Assembly has been held on November 17, 2023 in Bern.

### Federal funding period 2021 to 2024

In 2023, a standard amount has been paid to the ten clinical pediatric research hubs of SwissPedNet. The remaining funds were used to (1) provide central coordination for the data extraction project in relation to SwissPedData and SwissPedHealth which we initiated in 2022, (2) allow SwissPedRegistry to build up the structure to establish and maintain required resources to keep the Swiss Rare Disease Registry running in collaboration with our hubs that need to act as data source, and (3) to build capacities for registry entries and/ or to invest in General Consent activities in all hubs and SwissPedPha.

### Election of the president and the board

After two terms of three years Roger Lauener and Marc Pfister ended their contribution in the SwissPedNet Board. We thank them for their valuable support!

Two seats were free and two applications were received: François Angoulvant, CHUV – Département femme - mère – enfant and Barbara Goeggel Simonetti, EOC Bellinzona – pediatria.

The GA unanimously voted for François Angoulvant and Barbara Goeggel Simonetti as new SwissPedNet Board members in the role of assessors.

Klara Posfay Barbe left the board at the end of 2023, as with the elections the Romandie is back in the board.

### **Appointing the Auditors**

For 2024, Csongor Deak and Philipp Agyeman will act as auditors of SwissPedNet.

### **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.

pädiatrie schweiz | pédiatrie suisse granted the SwissPedNet translational and clinical research award. Pfizer donated an educational grant. All are most appreciated!

### **Outlook and next steps**

We plan to further simplify collaboration and improve support in multicentre studies. To this end, we will provide our hubs with supportive documents to promote multicentre studies, increase quality and save resources.

For SwissPedHealth the first data transfer from SwissPedNet hubs will be expected in Summer 2024 which is an impatiently expected achievement.

Please visit our website: [www.swisspednet.ch](http://www.swisspednet.ch). Here you will find more information about the activities of our network.

## Annual Financial Statement

Accounts 1.10.2021 to 30.9.2023 and Balance sheet as per 30.9.2023

	2021	2022	2023
	CHF	CHF	CHF
<b>1. Income</b>			
Membership fees	11'000.00	11'000.00	12'000.00
SERI funds - dedicated for Master Service Agreement			10'926.00
Sponsoring (sgp/ssp) Research Award	6'000.00	6'000.00	6'000.00
Sponsoring NextGen RD	4'500.00	5'500.00	0.00
Registration fee NextGen RD			300.00
Transfer from deferred charges NextGen RD 2022			507.65
<b>Total income:</b>	<b>21'500.00</b>	<b>22'500.00</b>	<b>29'733.65</b>

<b>2. Expenses</b>			
General Assembly	0.00	1'997.35	2'357.99
SwissPedNet 10y celebration			3'522.00
SwissPedNet Retreat	182.95	226.00	88.45
Website Hosting	274.64	744.26	488.85
Website Development and Support	3'683.34	1'066.23	8'648.31
Website domain name	83.50	93.80	38.20
Master Service Agreement - expenses Bär&Karrer			8'013.65
Award SwissPedNet Clinical Research Session	6'000.00	6'000.00	6'000.00
SwissPedNet NextGen Research Day	0.00	9'989.20	3'007.75
SwissPedNet (general costs & expenses)	363.70	2'992.45	3'285.90
Postfinance account management	60.00	62.40	60.00
<b>Total expenses:</b>	<b>10'648.13</b>	<b>23'171.69</b>	<b>35'511.10</b>

Total income:	21'500.00	22'500.00	29'733.65
Total expenses:	10'648.13	23'171.69	35'511.10
<b>Total profit margin / loss of profits:</b>	<b>10'851.87</b>	<b>-671.69</b>	<b>-5'777.45</b>

3. Balance as per 30.9.2023	Liabilities	
Account balance PC 60-488628-5	86'903.74	
Deferred charges to income	2'000.00	2x membership fee HU
Deferred charges to expenses		2'912.35 MSA CHF 2912.35
Capital of the association		85'991.39
	<b>88'903.74</b>	<b>88'903.74</b>

4. Association assets	CHF
Asset as per 30.09.2022	91'768.84
Asset as per 30.09.2023	85'991.39
<b>profit margin:</b>	<b>-5'777.45</b>

## People of SwissPedNet 2023

### Members of the Board

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

### Auditors

PD Dr Barbara Goeggel Simonetti

PD Dr Philipp Agyeman

### Member institutions and their representatives

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

University Children's Hospital Bern, PD Dr Philipp Agyeman, Rahel Kuonen

University Children's Hospital Geneva, Prof. Klara Posfay Barbe, Prof. Patrick Petignat

University Children's Hospital Lausanne, Dr Manuel Diezi, Prof. François Angoulvant

University Children's Hospital Zurich, Prof. Matthias Baumgartner, PD Dr Patrick Meyer Sauter

Children's Hospital Aarau, Prof. Henrik Köhler, Dr Csongor Deak

Children's Hospital Luzern, KD Dr Michael Büttcher

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

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

Hôpital fribourgeois HFR, Dr Petra Zimmermann

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

SwissPedPha, Pediatric Pharmacology and Pharmacometrics Research Center at the UKBB, Prof. Marc Pfister, PD Dr Verena Gotta

### Coordinator SwissPedNet

Pascale Wenger (until 30.09.2023), Swiss Clinical Trial Organisation SCTO

Micaela Belendez (October – December 2023)

### 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