



**Schweizer Cerebralparese Register  
Registre Suisse de la Paralyse Cérébrale  
Registro Svizzero della Paralisi Cerebrale  
Swiss Cerebral Palsy Registry**

## **Report 2022-2023**

### **Swiss Cerebral Palsy Registry**

For the Swiss Cerebral Palsy Registry:  
Anne Tschertter  
Sandra Hunziker

Bern, March 2024

University of Bern  
Institute of Social- and Preventive Medicine  
Mittelstrasse 43  
3012 Bern

[swiss-cp-reg.ispm@unibe.ch](mailto:swiss-cp-reg.ispm@unibe.ch)  
[www.swiss-cp-reg.ch](http://www.swiss-cp-reg.ch)

*Wie viele Kinder und Jugendliche in der Schweiz haben eine Cerebralparese? Welche Therapien sind wirksam? Welche Begleiterkrankungen treten häufig auf? Welche Bedürfnisse haben Menschen mit einer Cerebralparese und ihre Familien?*

*Das Schweizer Cerebralparese Register will diese und weitere Fragen beantworten. So möchten wir die Behandlung und Inklusion von Menschen mit einer Cerebralparese weiter verbessern und so langfristig ihre Gesundheit und Lebensqualität optimieren.*

*Combien d'enfants et d'adolescents sont touchés par une paralysie cérébrale en Suisse ? Quelles sont les modalités thérapeutiques efficaces ? Quelles sont les problématiques associées les plus courantes ? Quels sont les besoins des personnes atteintes de paralysie cérébrale et de leurs familles ?*

*Le Registre Suisse de la Paralysie Cérébrale a pour objectif de répondre à ces questions et à d'autres. Nous désirons ainsi améliorer le traitement et l'intégration des personnes atteintes de paralysie cérébrale et optimiser ainsi leur santé et leur qualité de vie à long terme.*

*How many children and adolescents have cerebral palsy in Switzerland? Which therapies are effective? What are the most common associated diagnoses? What are the needs of people with cerebral palsy and their families?*

*The Swiss Cerebral Palsy Registry aims to answer these and other questions. In doing so, we want to further improve the treatment and inclusion of people with cerebral palsy and thus optimise their health and quality of life in the long term.*

## Table of Contents

1	Summary / Zusammenfassung / Sommaire.....	3
2	Introduction .....	6
3	The Swiss Cerebral Palsy Registry .....	7
3.1	Objectives.....	7
3.2	Organizational structure .....	7
3.3	Methodology of Swiss-CP-Reg .....	9
3.3.1	Inclusion/exclusion criteria .....	9
3.3.2	Recruitment .....	9
3.3.3	Collection of data .....	9
3.4	Ethics approval / data protection /data sharing.....	10
3.5	Funding .....	10
4	Study population.....	11
5	Achievements of the Swiss-CP-Reg 2022-2023 .....	13
5.1	Development of the registry.....	13
5.2	Research projects.....	13
5.3	Dissemination and networking activities.....	16
6	Outlook .....	18
7	Acknowledgements.....	18

# 1 Summary / Zusammenfassung / Sommaire

## ENGLISH

The Swiss Cerebral Palsy Registry (Swiss-CP-Reg) collects medical information from people with cerebral palsy (CP) in Switzerland. It is led by specialized physicians and based at the University of Bern. The overall goal of the registry is to optimize care and improve the health and quality of life of people living with CP in Switzerland.

The aims of the registry are:

- To identify and register people living with CP across Switzerland, to determine the frequency and to characterize CP.
- To document diagnosis, treatments, quality of life, mortality, and risk factors.
- To provide a platform for research, to facilitate the recruitment of participants for studies and to answer questions on topics such as health, healthcare, education, social aspects, and quality of life.
- To provide a platform for knowledge exchange.

This report provides details on our achievements from 2022 to 2023.

Over the past two years, we have focused on the recruitment of participants and the collection of medical data. We have made efforts to ensure and improve data quality. By 31.12.2023, 951 individuals with CP were included in Swiss-CP-Reg. Forty-five percent of the participants are female and 55% are male. About 63% of the participants are between 5 and 15 years old. Seventy-six percent are treated in a clinic located in the German-speaking part of Switzerland, 22% in the French-speaking part and 3% in the Italian-speaking part. Most individuals have a spastic CP (76%), followed by ataxic CP (13%) and dyskinetic CP (9%). See pages 10-11 for an overview.

We work with experts in various fields to conduct research projects. Ongoing projects address the following topics: participation in children with CP in Switzerland, hip surveillance, topics of concern of individuals with CP and their families, pain, and improving medical care. In the last two years, 4 Master's theses were completed. Currently, 7 Master's and PhD theses are being carried out as part of or with the support of the registry. The theses cover topics as diverse as pain, participation in daily life, hip dislocation and epilepsy (see page 15).

We have participated in several symposia, e.g., from the Swiss Society of Neuropediatrics (SGNP), Swiss Society of Pediatrics, Swiss Academy of Childhood Disability (SACD), the European Academy of Childhood Disability (EACD), and Surveillance of Cerebral Palsy in Europe (SCPE). We successfully published three articles: on the cohort profile of the Swiss-CP-Reg, on pain in children and adolescents with CP, and on prescription practices of cannabinoids in children with CP.

In 2022 and 2023, the Swiss-CP-Reg was financed by the 'Schweizerische Stiftung für das cerebral gelähmte Kind (Stiftung Cerebral)', Anna Mueller Grocholski-Foundation and ACCENTUS Charitable Foundation (Walter Muggli Fund). In addition, the Ebnet-Stiftung and Stiftung Steinegg supported the work in St. Gallen, and Kinderinsel Bern and Batzebär the work in Bern. We thank these organisations for their support.

We would also like to thank all the children, adolescents and adults with CP and their families for agreeing to participate in the registry, and the physicians and their teams for their efforts in recruitment and data collection.

## DEUTSCH

Das Schweizer Cerebralparese Register (Swiss-CP-Reg) sammelt medizinische Daten von Personen mit einer Cerebralparese (CP) in der Schweiz. Das Register wird von spezialisierten Ärztinnen und Ärzten geführt und befindet sich an der Universität Bern. Das Hauptziel des Swiss-CP-Reg ist es, die Behandlung von Personen mit einer CP in der Schweiz weiter zu optimieren und ihre Gesundheit und Lebensqualität zu verbessern.

Das Register hat zum Ziel:

- Personen mit einer CP in der Schweiz zu erfassen, um die Häufigkeit der CP zu bestimmen und die CP zu beschreiben.
- Diagnose, Behandlungen, Lebensqualität, Überlebensrate und Risikofaktoren (Epidemiologie) zu untersuchen.
- Eine Forschungsplattform bereit zu stellen, um Personen mit CP zu Studien einzuladen und um Fragen zu Gesundheit, medizinischer Versorgung, Bildung, sozialen Aspekten und Lebensqualität zu beantworten.
- Eine Plattform zur Förderung des Wissensaustausches zu bieten.

Dieser Bericht beschreibt die Ergebnisse des Swiss-CP-Regs in den Jahren 2022 und 2023.

In den letzten zwei Jahren haben wir uns auf die Rekrutierung von Teilnehmenden und die Erhebung medizinischer Daten konzentriert. Wir haben besondere Aufmerksamkeit auf die Sicherung und Verbesserung der Datenqualität gelegt. Am 31.12.2023 waren 951 Personen im Swiss-CP-Reg erfasst. Fünfundvierzig Prozent der Teilnehmenden sind weiblich, 55% männlich. Etwa 63% sind 5 bis 15 Jahre alt. Sechsuundsiebzig Prozent werden in der deutschsprachigen Schweiz behandelt, 22 Prozent in der französischsprachigen und 3 Prozent in der italienischsprachigen Schweiz. Die Mehrheit (76%) hat eine spastische CP, gefolgt von ataxischer CP (13%) und dyskinetischer CP (9%). Eine Übersicht befindet sich auf den Seiten 10-11.

Wir arbeiten mit Spezialistinnen und Spezialisten aus verschiedenen Bereichen zusammen an Forschungsprojekten. Laufende Projekte untersuchen Themen wie: Teilhabe von Kindern mit CP in der Schweiz; Überwachung der Hüfte; Themen, die Menschen mit CP und ihren Familien Sorgen bereiten; Schmerzen; und Verbesserung der medizinischen Versorgung. In den letzten zwei Jahren wurden 4 Masterarbeiten abgeschlossen. Derzeit werden 7 Master- und Doktorarbeiten im Rahmen oder mit Unterstützung des Registers durchgeführt. Die Arbeiten befassen sich mit so unterschiedlichen Themen wie Schmerz, Teilhabe am täglichen Leben, Hüftluxation oder Epilepsie (siehe Seite 15).

Wir nahmen an mehreren Fachtagungen teil, z.B. von der Schweizer Gesellschaft für Neuropädiatrie (SGNP), pädiatrie schweiz, der Schweizer Akademie für Kinder mit Behinderungen (SACD), der Europäischen Akademie für Kinder mit Behinderungen (EACD), oder der Surveillance of Cerebral Palsy in Europe (SCPE). Wir haben erfolgreich drei Artikel veröffentlicht: über das Kohortenprofil des Swiss-CP-Reg, über Schmerzen bei Kindern und Jugendlichen mit CP und über die Verschreibungspraxis von Cannabinoiden bei Kindern mit CP.

In den Jahren 2022 und 2023 wurde das Swiss-CP-Reg durch die Schweizerische Stiftung für das cerebral gelähmte Kind (Stiftung Cerebral), Anna Mueller Grocholski-Stiftung und die Gemeinnützige Stiftung Accentus (Fonds Walter Muggli) finanziert. Zudem unterstützten die Ebnet-Stiftung und die Stiftung Steinegg die Arbeit des Swiss-CP-Reg in St. Gallen und die Stiftungen Kinderinsel Bern und Batzebär jene in Bern. Wir danken diesen Organisationen für ihre Unterstützung.

Wir bedanken uns herzlich bei allen Kindern, Jugendlichen und Erwachsenen mit einer CP und ihren Familien für die Teilnahme am Swiss-CP-Reg und bei den Ärztinnen und Ärzten und ihren Teams für ihren Einsatz für die Rekrutierung und Datenerhebung.

## FRANCAIS

Le Registre Suisse de la Paralyse Cérébrale (Swiss-CP-Reg) recueille des informations médicales de personnes atteintes de paralysie cérébrale (PC) en Suisse. Le registre est géré par des médecins spécialisés et se trouve à l'Université de Berne. L'objectif principal du registre est d'optimiser le traitement des personnes atteintes de PC en Suisse et d'améliorer ainsi leur santé et leur qualité de vie.

Le registre a pour but de :

- Recenser les personnes atteintes de PC en Suisse, afin de déterminer la fréquence et de caractériser la PC.
- Documenter le diagnostic, les traitements, la qualité de vie, la mortalité et les facteurs de risque.
- Fournir une plateforme de recherche, pour faciliter le recrutement de participants pour des études et pour répondre à des questions sur des sujets tels que la santé, soins médicaux, l'éducation, les aspects sociaux et la qualité de vie.
- Fournir une plate-forme pour l'échange de connaissances.

Ce rapport présente nos accomplissements de 2022 à 2023.

Au cours des deux dernières années, notre priorité a été de promouvoir le recrutement et la collecte de données médicales. Nous avons aussi assuré et amélioré la qualité des données. Au 31.12.2023, 951 personnes étaient incluses dans le Swiss-CP-Reg. Quarante-cinq pour cent des participants sont de sexe féminin et 55 % de sexe masculin. Environ 63% des participants sont âgés de 5 à 15 ans. Septante-six pour cent sont traités dans une clinique située dans la partie germanophone de la Suisse, 22% dans la partie francophone et 3% dans la partie italophone. La plupart des individus présentent une PC spastique (76%), suivie d'une PC ataxique (13%), et d'une PC dyskinétique (9%). Voir les pages 10-11 pour une vue d'ensemble.

Nous collaborons activement avec des experts dans différents domaines pour réaliser des projets de recherche. Les projets en cours portent sur les sujets suivants : la participation des enfants atteints de PC en Suisse, la surveillance de la hanche, les sujets de préoccupation des personnes atteintes de PC et de leurs familles, la douleur et l'amélioration des soins médicaux. Au cours des deux dernières années, 4 travaux de master ont été achevés. Actuellement, 7 thèses de master et de doctorat sont réalisées dans le cadre du registre ou avec son soutien. Les thèses portent sur des sujets aussi divers que la douleur, la participation à la vie quotidienne, la luxation de la hanche et l'épilepsie (voir page 15).

Nous avons participé à plusieurs congrès, par exemple de la Société Suisse de Neuropédiatrie (SGNP), de pédiatrie Suisse, de l'Académie Suisse du Handicap de l'Enfant (SACD), de l'Académie Européenne du Handicap de l'Enfant (EACD) et de la Surveillance of Cerebral Palsy in Europe (SCPE). Nous avons publié avec succès trois articles : sur la cohorte du Swiss-CP-Reg, sur la douleur chez les enfants et les adolescents atteints de PC, et sur les pratiques de prescription de cannabinoïdes chez les enfants atteints de PC.

En 2022 et 2023, le Swiss-CP-Reg a été financé par la Fondation suisse en faveur de l'enfant infirme moteur cérébral (La Fondation Cerebral), la Fondation Anna Mueller Grocholski et la fondation Accentus (Fonds Walter Muggli). En outre, les fondations Ebnet et Steinegg ont soutenu le travail à Saint-Gall, et Kinderinsel Bern et Batzebär le travail à Berne. Nous remercions ces organisations pour leur soutien.

Nous tenons également à remercier tous les enfants, adolescents et adultes atteints de PC et leurs familles d'avoir accepté de participer à ce registre, ainsi que les médecins et leurs équipes pour leurs efforts dans le recrutement et la collecte des données.

## 2 Introduction

The term cerebral palsy (CP) refers to a group of chronic disorders of movement and posture. CP results from a non-progressive brain lesion or malformation of the developing brain. CP is the most common cause of motor disability in childhood. We estimate that around 3,000 children and 12,000 adults live with CP in Switzerland. In addition to motor dysfunction, people with CP are affected by a wide variety of co-morbidities, such as epilepsy, problems of speech, hearing, or vision, cognitive dysfunction, behavioural disorders, and secondary musculoskeletal problems. Thus, many people with CP need ongoing medical care and personalised support for their education, in their professional life and for social integration.

There are many therapies available to help persons with CP in their everyday functions. However, many questions about the optimal care and assistance of people with CP and their families remain unclear. For this reason, a group of CP experts founded the Swiss Cerebral Palsy Registry (Swiss-CP-Reg) in 2016. The registry obtained ethical approval in 2017 (2017-00873).

The Swiss-CP-Reg collects medical information from people with CP in Switzerland. It provides the necessary platform for research on CP and knowledge exchange (Figure 1). Its goal is to optimise treatment and improve the health and quality of life of people living with CP.

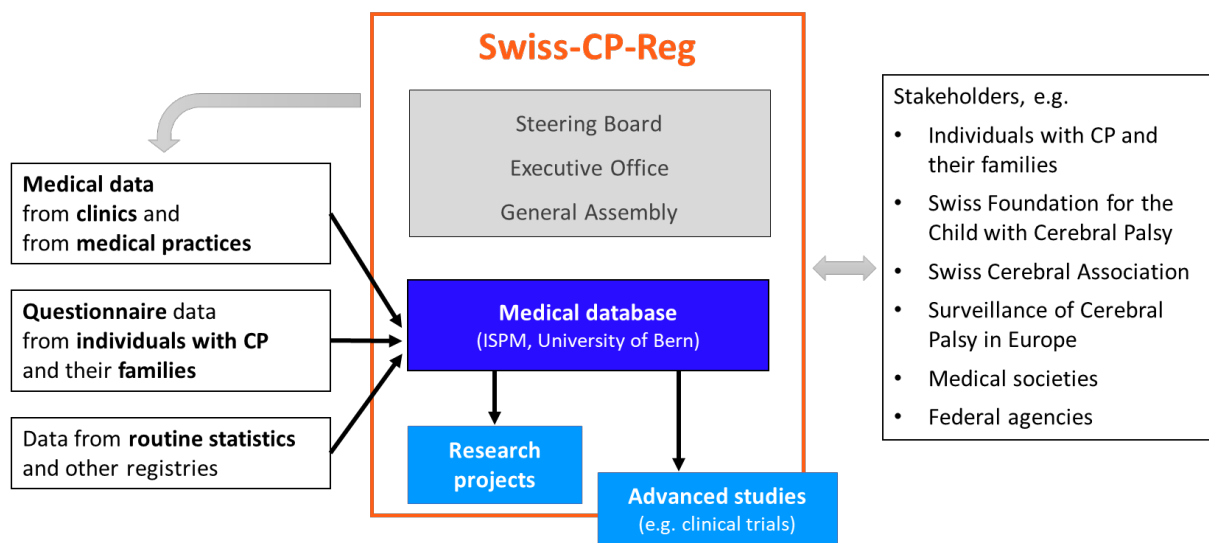


Figure 1: The Swiss Cerebral Palsy Registry – a platform for research and knowledge transfer.

## 3 The Swiss Cerebral Palsy Registry

### 3.1 Objectives

The main objectives of Swiss-CP-Reg is to optimize care and improve the health and quality of life of people living with CP in Switzerland.

More specifically, the objectives are:

- 1) To identify and register people living with CP throughout Switzerland, to determine incidence, prevalence, time trends, and regional differences and to characterize CP.
- 2) To document diagnostic evaluations, treatments, quality of life, morbidity, mortality, and risk factors.
- 3) To provide a research platform for clinical, epidemiological, and basic research to support recruitment of participants for research studies and to answer questions on topics like health, healthcare, education, social aspects, and quality of life.
- 4) To provide a platform for knowledge exchange between clinics, researchers, therapists, national and cantonal health authorities, and international parties.

### 3.2 Organizational structure

The governing bodies of the Swiss-CP-Reg are the Steering Board, the Executive Office, and the Swiss-CP-Reg General Assembly.

The *Steering Board* is a group of specialized physicians from several Swiss children's hospitals (Table 1). On August 23, 2023, the Steering Board members decided to include a patient representative. We are very pleased that Konrad Stokar, co-managing director of the Swiss Cerebral Association, has been elected to the Steering Board at the General Assembly of the Swiss-CP-Reg on January 25, 2024. The Steering Board is the governing body of the Swiss-CP-Reg and acts as a supervisory authority. It defines among other things the objectives, the research questions, and the data set of the Swiss-CP-Reg.

The *Executive Office* is located at ISPM Bern. It hosts and maintains the database, takes care of the legal aspects and public relations, supports the centres, and promotes research.

The *Clinical Centres* are participating clinics, medical centres or institutions that recruit people with CP and provide their medical data. These are currently the centres in Aarau, Basel, Bellinzona, Bern, Biel, Geneva, Lausanne, Lucerne, Neuchâtel, Solothurn, St. Gallen, Valais, and Zurich (Table 1). We are currently establishing recruitment and data collection in five further clinics (Table 1).

When the registry was set up, *Expert Groups* on different CP topics were formed to assist the registry in defining the dataset, to support research projects, and to act as a point of contact for the operational management for enquiries relating to these topics. At the end of 2023, the Steering Board decided to disband these groups. In future, project-based working groups will be formed as needed. The Expert Group 'People with CP and families' remains in place.

The *General Assembly* meets once a year to discuss e.g., ongoing research, therapies, general Swiss-CP-Reg issues, and to promote study participation. The General Assembly acts as reflecting board and elects the Steering Board. It currently includes:

- Representatives of clinical centres (Table 1)
- Expert Groups (until end of 2023)
- National patient organizations and medical societies (see <https://www.swiss-cp-reg.ch/generalversammlung/>)



Table 1: Key players of Swiss-CP-Reg in 2022 and 2023

<b>Steering Board</b>	
Christopher Newman, Prof. MD, CHUV; Swiss-CP-Reg president (since January 2023)	
Joel Fluss, CC MD, HUG; Swiss-CP-Reg vice-president	
Claudia Kühni, Prof. MD, ISPM Bern; Swiss-CP-Reg head	
Christoph Künzle, MD, KISPISG; Swiss-CP-Reg secretary	
Thomas Dreher, Prof. MD, KISPIZH	
Sebastian Grunt, Prof. MD, Universitätsspital Bern (Swiss-CP-Reg president until January 2023)	
Stephanie Jünemann, MD, UKBB	
Andreas Meyer-Heim, Prof. MD, Kinder-Reha Schweiz und KISPIZH	
Gian Paolo Ramelli, Prof. MD, EOC Bellinzona	
<b>Executive Office</b> (ISPM, University of Bern)	
Claudia Kühni, Prof. MD; Swiss-CP-Reg Head	
Anne Tscherter, PD PhD; project manager	
Sandra Hunziker, PhD; project manager	
Anna Born; data manager (since May 2023)	
<b>Clinical centres</b>	
<u>Established: recruitment / procedures defined:</u>	<u>To be established: initial contact made, procedures are being planned:</u>
Centre Hospitalier Universitaire Vaudois (CHUV)	Hôpital fribourgeois (HFR)
Istituto Pediatrico della Svizzera Italiana (EOC Bellinzona)	Kantonsspital Graubünden
Hôpitaux Universitaires de Genève (HUG)	Kantonsspital Münsterlingen
Ostschweizer Kinderspital St. Gallen (KISPISG)	Kantonsspital Winterthur
Universitäts-Kinderspital beider Basel (UKBB)	Spitalzentrum Biel
Kinder-Reha Schweiz and Universitätskinderspital (KISPIZH)	
Universitätsspital Bern	
Kantonsspital Aarau (KSA)	
Zentrum für Entwicklungsförderung und pädiatrische Neurorehabilitation der Stiftung Wildermeth, Biel (ZEN)	
Réseau hospitalier neuchâtelois (RhNe)	
Zentrum für Kinder mit Sinnes- und Körperbeeinträchtigung, Solothurn (ZKSK)	
Centre hospitalier du Valais Romand (CHVR)	
Kantonsspital Luzern (LUKS)	

### 3.3 Methodology of Swiss-CP-Reg

#### 3.3.1 Inclusion/exclusion criteria

Swiss-CP-Reg includes all children, adolescents, and adults diagnosed with CP who have been born, are treated, or live in Switzerland. CP is diagnosed according to the decision tree<sup>1</sup> of the Surveillance of Cerebral Palsy in Europe (SCPE). The diagnosis of CP must be confirmed at the age of five if children are registered at an earlier age. Our current focus is on the inclusion of children and adolescents with CP. Inclusion of adults with CP is planned.

Participants with pure muscular hypotonia, neurometabolic diseases or other progressive neurological diseases are excluded.

#### 3.3.2 Recruitment

Physicians identify individuals with CP during routine medical visits and inform them and/or their caregivers orally and in writing about the Swiss-CP-Reg. Individuals with CP who wish to participate provide signed informed consent and are registered in the Swiss-CP-Reg. For those who do not consent, the registry collects an anonymized minimal data set (see 3.3.3).

#### 3.3.3 Collection of data

The Swiss-CP-Reg collects data from medical records, questionnaires, routine statistics, and other registries (Figure 2).

*Medical data* is collected from medical records of individuals with CP in the participating clinical centres. The list of variables collected is based on the SCPE data set<sup>2</sup> and includes additional information on specific topics (therapies, scoliosis, hip surveillance, and pain). Medical data includes personal information (name, contact information, date of birth, treating physician). This information must be collected to ensure long-time follow-up and to enable the personal invitation of individuals with CP to research projects (surveys, clinical trials). Medical data is collected at diagnosis, at approximately 5, 10 and 15 years of age and at the transition to adult health care. Follow-up during adulthood is planned. The minimal data set includes the year of birth, year of death (if applicable), sex, gestational age, birth weight, and CP type. Data available up to the time point of registration is collected retrospectively. From then on, data is collected prospectively at future follow-up visits.

*Data from questionnaires* is collected at regular intervals from individuals with CP and their families or treating physicians. Participation is voluntary. Topics covered may include e.g., health care, nutrition, sleep, pain, use of medical devices, school performance, participation, or quality of life.

*Data from routine statistics and other registries* can be collected to answer specific research questions. For example, the Federal Statistics Office (FSO) Live Birth Registry can provide information on gestational age, birth weight, birth length, and parental age.

---

<sup>1</sup> Surveillance of Cerebral Palsy in Europe. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Surveillance of Cerebral Palsy in Europe (SCPE). *Dev Med Child Neurol.* 2000;42(12):816-824.

<sup>2</sup> Surveillance of Cerebral Palsy in Europe. *Surveillance of Cerebral Palsy in Europe (SCPE): Scientific Report 1998-2018.* [https://eu-rd-platform.jrc.ec.europa.eu/scpe\\_en2018](https://eu-rd-platform.jrc.ec.europa.eu/scpe_en2018).

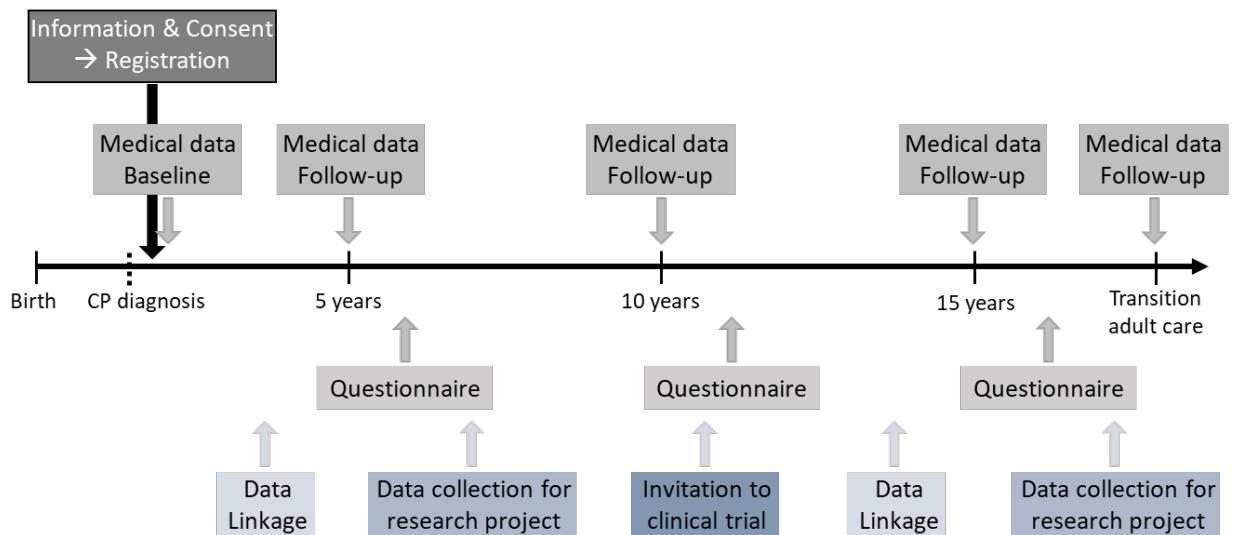


Figure 1: Schematic flow chart of registration and data collection management.

### 3.4 Ethics approval / data protection / data sharing

In 2017, the Swiss-CP-Reg received approval from the Cantonal Ethics Committee of Bern (2017-00873, risk category A, observational study). This approval allows the collection of medical data from clinics and private practices, self-reported data from individuals with CP and their families, and data linkage.

The Swiss-CP-Reg database is managed using Research Electronic Data Capture (REDCap; Nashville, TN, USA) and is hosted at ISPM. REDCap is a secure, web-based software platform supporting data capture for research studies. The personal data collected is strictly confidential and all staff members of the Swiss-CP-Reg are bound by professional secrecy.

Data is coded for research purposes (names or identifying information are removed). Coded data can be shared with other research projects if legal requirements are met. This includes the use of data by regional, national, or international research projects. The Swiss-CP-Reg Steering Board decides on collaborations.

### 3.5 Funding

In recent years, the Swiss-CP-Reg (salaries, consumables, equipment) has been funded by several funding bodies: 'Schweizerische Stiftung für das cerebral gelähmte Kind (Stiftung Cerebral)', Anna Mueller Grocholski Foundation, Swiss Academy of Childhood Disability (SACD), 'Hand in Hand Anstalt', 'Ostschweizer Kinderspital' and ACCENTUS Charitable Foundation (Walter Muggli Fund). Stiftung Cerebral was the main sponsor during the build-up phase of the registry. In addition, some clinical centres obtained financial support from local sponsors. ISPM, University of Bern, local hubs of SwissPedNet and SwissPedReg support the Swiss-CP-Reg. We are very grateful to all these foundations and organizations for their support.

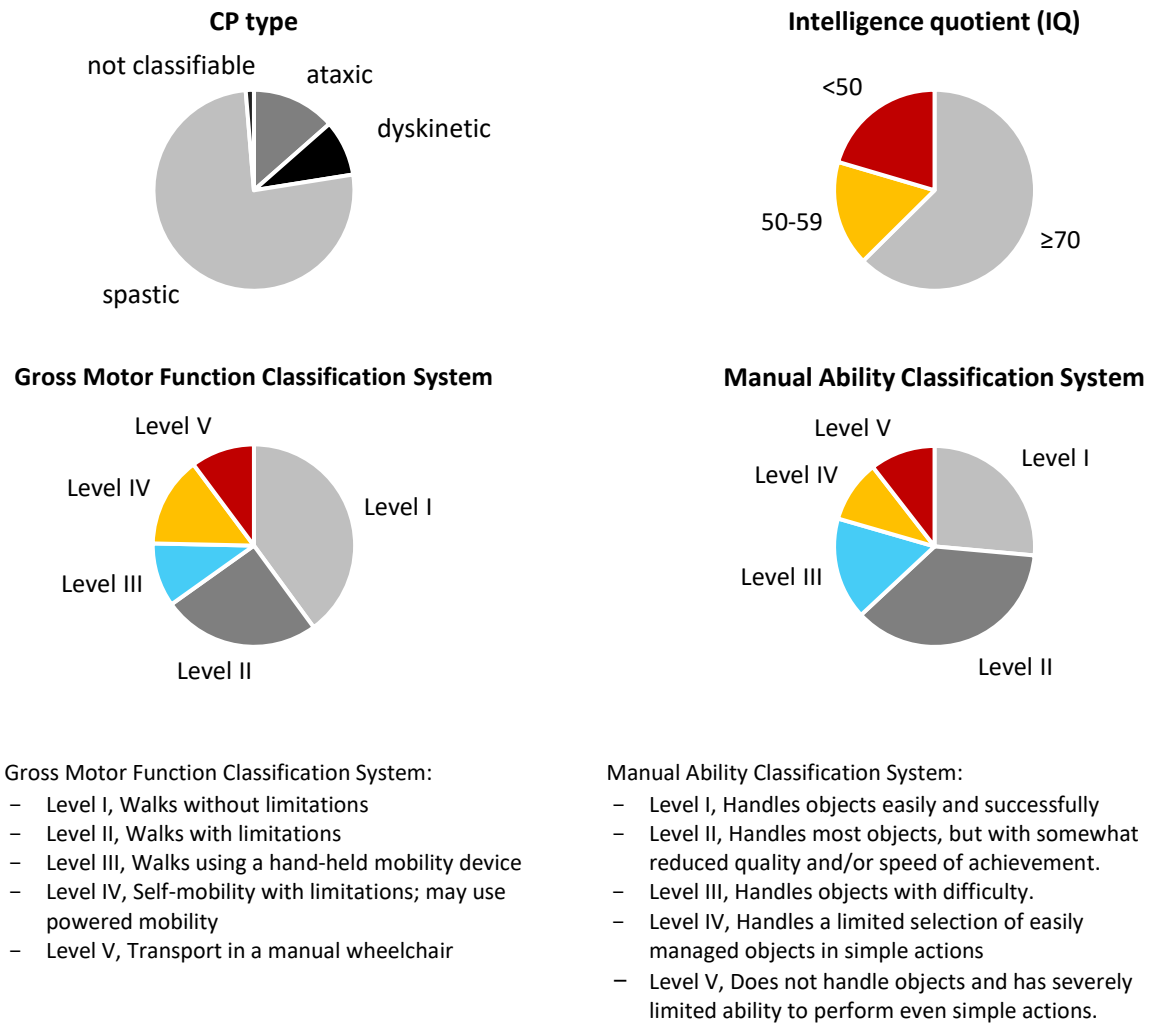
## 4 Study population

On December 31, 2023, Swiss-CP-Reg included 951 people with CP, 319 more than 2 years ago. Of the eligible participants who were approached, 6% refused to participate and 3% were informed several times but did not consent or refuse. Only a minimal, anonymised data set was collected from these two groups. See table 2 and figure 3 for more information.

*Table 2: Demographics of study participants in the Swiss Cerebral Palsy Registry (n=951, status at 31.12.2023).*

<b>Demographics</b>	<b>Registered persons n (%)</b>
<b>Sex</b>	
Female	428 (45)
Male	523 (55)
<b>Language region of Switzerland</b>	
German speaking	720 (76)
French speaking	206 (22)
Italian speaking	25 (3)
<b>Age (years)</b>	
0 – 4.9	65 (7)
5 – 9.9	295 (31)
10 – 14.9	301 (32)
15 – 19.9	233 (25)
>=20	57 (6)

Forty-five percent of the participants are female and 55% male. About 63% of the participants are between 5 and 15 years old. Seventy-six percent are treated in a clinic located in the German-speaking part of Switzerland, 22% in the French-speaking part and 3% in the Italian-speaking part. Most individuals have a spastic CP (76%), followed by ataxic CP (13%) and dyskinetic CP (9%). See Figure 2 for an overview. In 1%, the CP type could not be classified. Motor impairment was mostly mild (Gross Motor Function Classification System [GMFCS] level I and II, 65%), but 10% live with a moderate (GMFCS level III) and 25% with a severe impairment (GMFCS level IV and V). Most individuals with CP showed normal or only slightly impaired manual ability (Manual Ability Classification System level I and II, 63%). Intelligence quotient (IQ) was usually not impaired (IQ $\geq$ 70, 63%). However, impaired IQ correlates with reduced motor function.



**Figure 2:** Distribution of CP type and severity (status at 31.12.2023).  
 Data collection is ongoing. CP type n=839; Intelligence quotient n=323; Gross Motor Function Classification System n=727; Manual Ability Classification System n= 612.

## 5 Achievements of the Swiss-CP-Reg 2022-2023

The Swiss-CP-Reg has been built up over the last few years thanks to the financial support of the Swiss Foundation for the Cerebral Palsy Child and other sponsors, and thanks to the great commitment of all the members of Steering Board, the registry team at the ISPM, and all the centres involved.

### 5.1 Development of the registry

#### *Recruitment and data collection*

The recruitment of patients with CP is the limiting factor for all projects of the registry. We can only collect medical data or invite a family to participate in a study if consent has been obtained. Therefore, we aim to recruit individuals with CP from all over Switzerland. During the last two years the Swiss-CP-Reg team focused on initiating patient recruitment and data collection in new clinics. In addition to the 7 already active centres (see Table 1), procedures were established and/or recruitment and data collection initiated in 5 additional centres (KSA, RhNe, ZKSK, CHVR, LUKS; see Table 1). Contact was established and procedures are currently being planned in 5 more clinics (HFR, KSGR, KS Münsterlingen, KSW, Spitalzentrum Biel; see Table 1). By December 31, 2023, 951 individuals with CP were registered (865 accepted participation, 54 refused, and 32 were non-responders; chapter 4). Recruitment and data collection were difficult during the pandemic. Procedures have now been re-established in most clinics, although many clinics have fewer resources than before the pandemic.

#### *Data quality:*

The Swiss-CP-Reg team undertook the following efforts to ensure and increase data quality:

- Redefinition of the data set, variables were brought up to date, simplified, or removed, a few relevant variables were added.
- Examination and adaption of procedures for data collection at each centre.
- Update of Consent Report Forms (Version 6) and data base
- Update of guidelines for recruitment, data collection and data entry.
- Quality inspection procedures were used to verify the data for completeness and correctness.

### 5.2 Research projects

The Swiss-CP-Reg collaborates with experts from various fields to realize research projects that aim to standardize and improve CP therapies. It supports the monitoring and research of a wide range of outcomes and data exchange via linkage with national and regional projects led by interested investigators.

The Swiss-CP-Reg team is involved in several long-term research projects.

- *Barriers and facilitators for participation in children with CP in Switzerland* (Prof. Dr med S. Grunt, Prof. H. van Hedel, Prof. C. Schulze, PD Dr A. Tschertler):  
International studies show that children with CP participate less in social life than their peers, but data are lacking in Switzerland. The Swiss National Science Foundation (SNSF) accepted the application of the Swiss-CP-Reg and collaborators for a study on the participation of children and young people with CP in October 2022 (<https://data.snf.ch/grants/grant/212587>). Our aim is to investigate how children with CP in Switzerland, their siblings and the family as a whole experience participation and what the barriers and facilitators of participation are. In 2023, we conducted interviews with almost 20 families. The findings will be used to develop scientific measurement instruments (questionnaires) for participation. These will be used in a representative survey across

Switzerland. Ultimately, we will formulate recommendations to optimize the participation of children with CP, their siblings, and families. We recruited a research assistant (J. Graser, Children’s Hospital Zurich), and two PhD students (J. Linimayr, ZHAW; S. Gredig, Inselspital and ISPM) for this project.

- *Hip Surveillance* (Prof. Dr med T. Dreher):  
Early detection of hip subluxations is an essential part of the strategy to prevent hip dislocations and their consequences. Therefore, a hip surveillance program is currently being developed in Switzerland - following the example of other countries. A working group consisting of pediatric orthopaedic surgeons has defined the methodology and frequency of hip monitoring and developed a flyer with the support of Foundation Cerebral. The data set was developed and the monitoring program is well established in Zurich, where T. Dreher and his team collected data from over 100 patients. Currently, the monitoring program and data collection is being set-up in St. Gallen and the inclusion of further clinics is in preparation. The Swiss-CP-Reg is central for interregional communication and the development of the data base.
- *Survey on topics of concern of individuals with CP and their families* (PD Dr A. Tscherter, Dr S. Hunziker):  
People with CP live with numerous comorbidities which can cause concern. The aim of this study is to uncover the most prominent sources of concern of individuals with CP and their families (such as quality of life, nutrition, communication, use of aids). In addition, we aim to find out which topics should be researched in the future from the perspective of people living with CP. The questionnaire was developed based on the Health, Functioning and Well-being Traffic Light Communication Tool (P. Ireland and K. A. Horridge, 2016). After a small pilot study, we sent the questionnaires to 610 families in August 2022. The response rate was 61% for parents and 35% for adolescents. Among the main topics causing concern were the development of physical limitation, independence, use of hands, mobility, speech, communication and getting enough information (e.g. on CP, insurance, aids). Topics causing concern were often similar between parents and adolescents. Thus, we uncovered several areas of major concern for families of children and young people with CP and where families need more support. We plan to publish our findings in a scientific journal and to tackle specific topics together with patient representatives and patient organizations, especially Foundation Cerebral. This study lays the foundation for addressing the needs of families of children and adolescents with CP in Switzerland.
- *Academic skills and achievement of children with unilateral CP* (Dr A. Girardet, PD Dr J. Fluss):  
The first part of the project has assessed reading and writing skills of school-age children with unilateral CP.
- *Improving medical care for children and adolescents with CP in Switzerland* (Steering Board):  
The aim of the Swiss-CP-Reg is to improve the medical care of people with CP in Switzerland. To achieve our goal, we want to examine the medical care of CP in Switzerland more closely, especially with regard to diagnosis (brain imaging), hip monitoring and assessment of cognitive abilities. The Anna Mueller Grocholski Foundation has agreed to support this project end of November 2022. A first analysis of our medical data shows that medical care for children with CP can be improved in certain areas. In Switzerland, however, unlike in other countries, there are still no national guidelines on standard examinations for children with CP. We will compare our results regionally and with international standards. This will highlight areas where care needs to be improved. We will develop guidelines for these areas together with experts and families living with CP. Currently, data collection is intensified to improve coverage for statistical analysis.

- *Pain in children and adolescents with cerebral palsy* (Dr. med. C. Künzle, Prof. Dr. S. Grunt): Several studies indicate that people with CP suffer from chronic pain, but the data on the prevalence of pain in children and adolescents with CP vary widely. We conducted a questionnaire study on the topic of pain in the canton of St. Gallen at the end of 2021 (Master thesis, Lena Bischoff). The survey took place in a similar form in the canton of Berne in spring 2023. The aim of the study is to use a standardised German pain questionnaire to find out how children and young people with CP are affected by pain. A first analysis of the overall data (St. Gallen and Bern, PhD thesis Lena Bischoff) shows, among other things, that pain affects participation in various areas of life. This study will help to better understand the nature of pain symptoms in children and adolescents with CP, to identify pain earlier especially in non-verbal patients and to develop better therapeutic approaches.
- *Prescription Practices of Cannabinoids in Children with Cerebral Palsy* (Prof. Dr. S. Grunt): The aim of this study was to determine the current status of the use of cannabinoids in children with CP. For this purpose, an international survey of medical professionals was conducted. The survey was completed by professionals from Europe, North America and Australia. The most common indication for cannabinoids was epilepsy (69%), followed by spasticity (64%), and pain (63%). The preparations and doses prescribed varied considerably. Despite the lack of evidence to date, cannabinoids are used to treat children with cerebral palsy in a wide variety of indications. Doi: 10.3390/children10121838

In 2022 and 2023, several theses are or were conducted within Swiss-CP-Reg or with its support. These focus on a broad range of topics and use different approaches.

- How do siblings of children with CP experience participation in daily life in Switzerland. PhD thesis, J. Linimayr, ZHAW; Zurich.
- Barriers and facilitators for participation in children with CP in Switzerland. PhD thesis, S. Gredig; Bern.
- Correlation between CP and amnestic data, neuroradiology findings and meta-analysis findings. PhD thesis, M. Koeckemann; St. Gallen.
- Assessing the impact of weight load by gait on the central nervous system. PhD thesis, M. Gwerder, ETH; Zurich.
- Functional electrical stimulation to improve hand function in unilateral spasticity. PhD thesis, A. Gschaidmeier; Bern.
- Pain in children and adolescents with CP. Master thesis followed by PhD thesis, L. Bischoff; St. Gallen.
- Communication and speech ability in children with bilateral spastic CP and periventricular leukomalacia. Master thesis, J. Greuter; Bern.
- Timing, type, and treatment of epileptic seizures. Master thesis, L. Studer; Bern.
- Access to dental care for children and adolescents with motor disabilities. Master thesis, L. Zumsteg; Vaud.
- Hip surveillance. Master thesis, M. Schöni; Zurich.
- Hip surveillance in GMFCS levels III to IV. Master thesis, M. Zimmerli; St. Gallen.
- Everyday school life of people with CP – survey. Matura thesis, RB; Zurich.

The team of the Swiss-CP-Reg also supports the planning and conduction of research projects, e.g. by evaluating the number and characteristics of potential study participants, by summarizing contact information on selected population groups, by guidance on ethics, surveys, or database, and by administrative work. Non-exhaustive list of supported projects:



- CP and chiropractic care: semi-structured interviews and transition study to access pain. A. Langenfeld; ZH; SG (on hold).
- Age at diagnosis of CP and genetic analysis. BS.
- Assessment of muscle tone reduction by Mollii suit in GMFCS levels II and III. SG; ongoing.

### 5.3 Dissemination and networking activities

The website [www.swiss-cp-reg.ch](http://www.swiss-cp-reg.ch) provides information on the registry, organization, participation, research, and donations. The consent forms are available for download. In the last two years we regularly updated the website, informed on new research articles, and published news.

Swiss-CP-Reg is registered on the clinicaltrials.gov website (NCT04992871), the international database of clinical studies. The website contains information on study design, outcomes, inclusion criteria, contacts, and recruitment sites. Swiss-CP-Reg is also listed on the online platform “Platform forum medizinische Register Schweiz” / “Plateforme suisse des registres médicaux by the Swiss Medical Association (FMH). This platform gives an overview on registries in Switzerland and collects information on type, coverage, status, and more. We are updating the entries on both platforms upon need.

#### *Networking and knowledge exchange:*

- In the last 2 years, 7 meetings of the Steering Board took place. At these meetings, there was a lively exchange on topics relevant to the registry, e.g., on the data set and on research projects. Often, various aspects of the diagnosis and care of children and adolescents with CP were also discussed in detail. Guests were invited to discuss possible collaborations, or to present their research on CP.
- The Swiss-CP-Reg General Assemblies of 2022 and 2023 were held during the annual Research Day of the Swiss Academy of Childhood Disability (SACD). Representatives from hospitals, medical societies, and the registry's Expert Groups, as well as other guests, participated. At the General Assemblies, the status of the registry and research projects were presented. In addition, the General Assembly elected on January 20, 2022 Prof. Dr. med. Thomas Dreher as additional member of the Swiss-CP-Reg Steering Board and on January 26, 2023 Prof. Dr. med. Christopher Newman as new president. We congratulate T. Dreher and C. Newman on their successful election. Prof. Dr. med. Sebastian Grunt stepped down as president of the Steering Board end of 2022, he remains member of the board. We thank him for his very valuable work for the registry as president!
- A. Tscherter participated in all 6 SCPE meetings in 2022 and 2023.
- Several members of the Steering Board and the Executive Office attended the annual conferences/congresses of the Swiss Society for Neuropaediatrics (SGNP), the Academy for Children with Disabilities (SACD), Focus CP rehaKIND congress and the European Association for Children with Disabilities (EACD).
- Several members of the Steering Board were members of societies and organisations, which strengthens the network of Swiss-CP-Reg. E.g. C. Newman was the Chair of the Scientific Committee and Member of the General Administration Committee June 2018 - May 2023 in the EACD and S. Grunt co-president of the SACD. S. Jünemann was the national coordinator for Switzerland in the EACD until May 2023, when she was succeeded by S. Grunt. C. Kuehni is Vice President of the 'SNSF Research Council - Biology and Medicine Division', member of the National Steering Board of the Swiss Personalized Health Network (SPHN) and of the SwissPedNet Board, Head of the Children's Cancer Registry and Co-Head of the Swiss Registry for Rare Diseases.

- A. Tscherter and S. Hunziker also work as project manager of SwissPedRegistry, a research platform of SwissPedNet (the Swiss network of pediatric research centres). SwissPedRegistry manages several national paediatric registries and offers consulting in the development and management of registries. This provides optimal networking with all major paediatric hospitals and other paediatric registries.

*Scientific publications:*

- Belle FN, Hunziker S, Fluss J, Grunt S, Juenemann S, Kuenzle C, Meyer-Heim A, Newman CJ, Ramelli GP, Weber P, Claudia CE, Tscherter A (2022). Cohort profile: the Swiss Cerebral Palsy Registry (Swiss-CP-Reg) cohort study. *Swiss medical weekly*, 152, w30139. <https://doi.org/10.4414/smw.2022.w30139>.
- Bischoff L, Tscherter A, Hunziker S, Broser P, Kuenzle C (2023). Schmerzen bei Zerebralparese – eine populationsbasierte Studie mit Kindern und Jugendlichen. *Pädiatrie*, 01/2023. <https://www.rosenfluh.ch/media/paediatrie/2023/01/Schmerzen-bei-Zerebralparese.pdf>
- Hunziker S, Morosoli F, Zuercher K, Tscherter A, Grunt S on behalf of the Swiss Cerebral Palsy Registry Group (2023). Prescription Practices of Cannabinoids in Children with Cerebral Palsy Worldwide—A Survey of the Swiss Cerebral Palsy Registry. *Children*. 10(12):1838. <https://doi.org/10.3390/children10121838>.
- Zesiger P, Girardet A, Fluss J, Campos Baltodano M, Comtat S (2021). ANAE. Approche neuropsychologique des apprentissages chez l'enfant. vol. 174, p. 531-541. <https://archive-ouverte.unige.ch/unige:164335>. (Not mentioned in the 2020-2021 biennial report)

*Presentations, including prizes:*

Members of the Swiss-CP-Reg steering Board and/or of the Executive Office represented the registry at the following meetings in 2022 and 2023:

- AMG-prize of the SACD: **Künzle C**, Bischoff L (2022). Second prize, category 'preliminary results': 'Pain in children and adolescents with cerebral palsy: a population-based study. *Research Day of the SACD, 20.01.2022, Bern*.
- AMG-prize of the SACD: **Hunziker S** (2022). Third prize, category 'finalized results': 'Prescription Practices of Medical Cannabinoids in Children with Cerebral Palsy - A Survey of the Swiss Cerebral Palsy Registry'. *Research Day of the SACD, 20.01.2022, Bern*.
- **Hunziker S** (2022). Cerebral palsy in Switzerland - insights from a national clinical registry and cohort study. *Annual Congress of the Swiss Society of Pediatrics (SSP), 0.2 – 03.06.2022, Lucerne*. Abstract published in *Supplementum 258 ad Swiss Med Wkly 2022; 152, p.9, 27.05.2022*.
- **Hunziker S** (2022). Concerns of families with children and adolescents with cerebral palsy – a national survey by the Swiss Cerebral Palsy Registry. *Annual Congress of the Swiss Society of Neuro Pediatrics (SSNP), 12.-13. December 2022, St. Gallen*.
- **Bischoff L** (2022) . Pain in children and adolescents with cerebral palsy: a population-based study. *Annual Congress of the der SSNP, 12.-13. December 2022, St. Gallen*.
- **Grunt S** (2022 / 2023). Cerebral palsy – an interdisciplinary challenge. *Pädiatrie Update Refresher, Forum für medizinische Forschung (FOMF), 24.10.2022, Zurich / 27.04.2023, online*.
- AMG-prize of the SACD: **J. Graser** (2023). First prize, category 'studyprotocols': Barriers and facilitators for participation in children with cerebral palsy, their siblings, and families in Switzerland. *Research Day of the SACD, 26.01.2023, Bern*.
- **Dreher T** (2023). Swiss CP hip registry. *Research Day of the SACD, 26.01.2023, Bern*.
- **Hunziker S** (2023). Concerns in the daily life of families with children and adolescents with cerebral palsy. *Research Day of the SACD, 26.01.2023, Bern*.
- **Zumsteg L** (2023). Survey on the access to dental care for children and adolescents with motor disabilities in Switzerland. *Research Day of the SACD, 26.01.2023, Bern*.

- **Künzle C** (2023). Swiss CP Registry – possibilities and hurdles. *Congress 2023, Focus CP rehaKIND, 01. – 04.02.2023, Dortmund, Germany*. Abstract published in the congress brochure.
- **Hunziker S.** (2023). Families with children and adolescents with cerebral palsy: concerns in everyday life. *Annual Congress of the European Academy of Childhood Disability (EACD), 24. – 27.05.2023, Ljubljana, Slovenia*. Abstract published in *Developmental Medicine & Child Neurology / Volume 65, Issue S2 /p.5-47*. <https://doi.org/10.1111/dmcn.15594>.

## 6 Outlook

Swiss-CP-Reg will continue its main tasks:

- Recruit individuals with CP, collect data, and foster data quality.
- Develop, conduct, and promote research projects.
- Provide a platform for communication and knowledge exchange.

Furthermore, we will focus on the following:

- Request funds to enable the running of Swiss-CP-Reg, in particular to strengthen the recruitment, data collection and registry management so that projects can be implemented.
- Finalize the initiation of data collection in additional centres.
- Optimize feedback on data collection and outcomes to centres.
- Implement the hip surveillance program nation-wide.
- Advance the project on barriers and facilitators for participation in children with CP in Switzerland.
- Collect data and analyse it for the project on improving medical care for children and adolescents with CP in Switzerland
- Disseminate findings of the first national survey on topics of concern of individuals with CP and their families.
- Continue to support research projects nested within Swiss-CP-Reg (e.g., functional electrical stimulation to improve hand function; correlation of findings in amnestic data, neuroradiology, and meta-analysis; muscle tone reduction by Mollii suit.).

## 7 Acknowledgements

We would like to thank all the children, adolescents and adults with CP and their families for agreeing to participate in the registry.

We are very thankful to the Steering Board members and local principal investigators and their teams for their efforts in recruitment and data collection.

We also thank all physicians and scientists who lead their own research projects on CP or support us for our own projects. We appreciate the support of SwissPedNet, its clinical hubs supported the Swiss Cerebral Palsy registry with their infrastructure.

We are also very grateful to all funding bodies for their financial and ideological support. In 2022 and 2023, the Swiss-CP-Reg was financed by the 'Schweizerische Stiftung für das cerebral gelähmte Kind (Stiftung Cerebral)', Anna-Mueller-Grocholski-Foundation and ACCENTUS Charitable Foundation (Walter Muggli Fund). In addition, Ebnet-Stiftung, Stiftung Steinegg, Stiftung Kinderinsel Bern, and Batzebär support the work in St. Gallen, and Bern, respectively.

