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

Report 2020-2021

Swiss Cerebral Palsy Registry

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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 affectés de paralysie cérébrale en Suisse ? Quelles sont les thérapies 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 voulons 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 so doing, 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.

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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 located 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 establish a platform for research, to facilitate the recruitment of participants for studies and to answer questions on topics like health, healthcare, education, social aspects, and quality of life.
- To establish a platform for knowledge exchange.

This report provides details on our achievements from 2020 to 2021.

Over the past 2 years, we focused on optimizing the recruitment of participants and collection of medical data. We undertook efforts to ensure and increase data quality.

By 31.12.2021, 632 individuals with CP were included in Swiss-CP-Reg. Forty-six percent of the participants are female and 54% are male. About 70% of the participants are between 5 and 15 years old. Seventy seven percent are treated in a clinic located in the German-speaking part of Switzerland, 19% in the French-speaking part and 4% in the Italian-speaking part. Most individuals have a spastic CP (77%), followed by ataxic CP (12%) and dyskinetic CP (11%). See pages 10-11 for an overview.

We collaborated with experts from various fields to realise research projects. Ongoing projects address the following topics: barriers and facilitators for participation in children with CP in Switzerland, hip surveillance, topics of concern of individuals with CP and their families, risk factors for and outcomes of unilateral CP, and data linkage with SwissNeoNet (registry for preterm high-risk infants). In addition, five master's theses have been carried out. They addressed epilepsy, nutrition, medical cannabinoids, magnetic resonance imaging (MRI) classification and age at diagnosis.

We participated in several symposia, e.g., from the Swiss Society of Neuropediatrics, Swiss Academy of Childhood Disability, the European Academy of Childhood Disability and Surveillance of Cerebral Palsy in Europe. We have also presented the Swiss-CP-Reg to aspiring physiotherapists. We have written two publications on the organisation and methodology of the registry.

In 2020 and 2021, the Swiss-CP-Reg was financed by the 'Schweizerische Stiftung für das cerebral gelähmte Kind (Stiftung Cerebral)' and Accentus Charitable Foundation (Walter Muggli Fund). In addition, the Children's Research Centre (University Children's Hospital Zurich) and Ebnet-Stiftung support the work in Zurich and St. Gallen, respectively. We thank these organisations for their support.

We also would 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) erfasst 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-Regs ist, die Behandlung von Personen mit einer CP in der Schweiz weiter zu optimieren und ihre Gesundheit und Lebensqualität zu verbessern.

Das Register bezweckt:

- 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 vertiefenden Studien einzuladen und um Fragen zur Gesundheit, medizinischen Versorgung, Bildung, sozialen Aspekten und Lebensqualität zu beantworten.
- Eine Plattform zur Förderung des Wissensaustausches zu errichten.

Dieser Bericht beschreibt die Ergebnisse des Swiss-CP-Regs in den Jahren 2020 und 2021.

In den letzten 2 Jahren fokussierten wir uns auf die Optimierung der Rekrutierung von Teilnehmenden und der Sammlung von medizinischen Daten. Wir stellten die Datenqualität sicher und erhöhten sie. Am 31.12.2021 waren 632 Personen im Swiss-CP-Reg erfasst. Sechsendvierzig Prozent der Teilnehmenden sind weiblich, 54% männlich. Etwa 70% sind 5 bis 15 Jahre alt. Siebenundsiebzig Prozent werden in der Deutschschweiz behandelt, 19% in der Westschweiz und 4% im Tessin. Die Mehrheit (77%) hat eine spastische CP, gefolgt von ataxischer CP (12%) und dyskinetischer CP (11%). Eine Übersicht befindet sich auf den Seiten 10-11.

Wir arbeiteten mit Spezialistinnen und Spezialisten aus verschiedenen Gebieten zusammen an Forschungsprojekten. Laufende Projekte untersuchen Themen wie: Hindernisse und Förderer für die Teilnahme von Kindern mit CP in der Schweiz; die Entwicklung eines Programmes zur Überwachung der Hüfte; Themen, die Menschen mit CP und ihren Familien Sorgen bereiten; die Risikofaktoren und Folgen der einseitigen (unilateralen) CP; die Verknüpfung von Daten mit dem SwissNeoNet (Register für hoch-risiko Frühgeborene). Es wurden 5 Masterarbeiten im Rahmen des Swiss-CP-Regs abgeschlossen. Die Arbeiten untersuchten die Epilepsie, Ernährung, medizinische Cannabinoide, die Klassifizierung von Magnetresonanztomographie-Bildern (MRT), und das Alter zum Zeitpunkt der Diagnose.

Wir nahmen an mehreren Fachtagungen teil, z.B. von der Schweizer Gesellschaft für Neuropädiatrie, der Schweizer Akademie für Kinder mit Behinderungen, der Europäischen Akademie für Kinder mit Behinderungen, oder der "Surveillance of Cerebral Palsy in Europe". Das Swiss-CP-Reg haben wir angehenden Physiotherapeutinnen und -Therapeuten vorgestellt. Wir verfassten zwei wissenschaftliche Artikel über die Organisation und Methodik des Registers.

In den Jahren 2020 und 2021 wurde das Swiss-CP-Reg durch die "Schweizerische Stiftung für das cerebral gelähmte Kind (Stiftung Cerebral)", und die Gemeinnützigen Stiftung Accentus (Fonds Walter Muggli) finanziert. Zusätzlich unterstützen das Forschungszentrum für das Kind, Universitäts-Kinderspital Zürich, die Arbeit des Swiss-CP-Regs in Zürich und die Ebnet-Stiftung in St. Gallen. Wir danken diesen Organisationen für ihre Unterstützung.

Wir bedanken uns herzlich bei allen Kindern, Jugendlichen und Erwachsenen mit einer CP und deren Familien für die Teilnahme am Swiss-CP-Reg und bei den Ärztinnen und Ärzten und ihren Teams für ihren Aufwand für die Rekrutierung und das Erheben von Daten.

FRANCAIS

Le Registre Suisse de la Paralyse Cérébrale (Swiss-CP-Reg) recueille des renseignements médicaux 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.
- Établir 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.
- Établir une plate-forme pour l'échange de connaissances.

Ce rapport présente nos accomplissements de 2020 à 2021.

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 31.12.2021, 632 personnes étaient incluses dans Swiss-CP-Reg. Quarante-six pour cent des participants sont de sexe féminin et 54 % de sexe masculin. Environ 70% des participants sont âgés de 5 à 15 ans. Septante-sept pour cent sont traités dans une clinique située dans la partie germanophone de la Suisse, 19% dans la partie francophone et 4% dans la partie italophone. La plupart des individus présentent une PC spastique (77%), suivie d'une PC ataxique (12%) et d'une PC dyskinétique (11%). Voir les pages 10-11 pour une vue d'ensemble.

Nous avons collaboré avec des experts de différents domaines pour réaliser des projets de recherche. Les projets en cours portent sur les sujets suivants : les facteurs qui entravent et facilitent la participation des enfants atteints de PC en Suisse, le développement d'un programme de surveillance de la hanche, les sujets de préoccupation des personnes atteintes de PC et de leurs familles, les facteurs de risque et les conséquences d'une PC unilatérale, et le lien de données avec SwissNeoNet (registre des prématurés à haut risque).

Nous avons participé à plusieurs congrès, par exemple de la Société Suisse de Neuropédiatrie, de l'Académie Suisse du Handicap de l'Enfant, de l'Académie Européenne du Handicap de l'Enfant et de la 'Surveillance of Cerebral Palsy in Europe'. Nous avons présenté le Swiss-CP-Reg à de futurs physiothérapeutes. Nous avons rédigé deux articles scientifiques sur l'organisation et la méthodologie du registre. En plus, cinq travaux de master ont été réalisés. Ils portaient sur l'épilepsie, la nutrition, les cannabinoïdes médicaux, la classification par imagerie à résonance magnétique et le l'âge au moment du diagnostic.

En 2020 et 2021, le Swiss-CP-Reg a été financé par la Fondation suisse en faveur de l'enfant infirme moteur cérébral (La Fondation Cerebral) et la fondation Accentus (Fonds Walter Muggli). En outre, le Forschungszentrum für das Kind, Universitäts-Kinderspital Zürich, et Ebnet-Stiftung soutiennent le travail du Swiss-CP-Reg à Zurich et à Saint-Gall, respectivement. 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 about 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 comorbidities, 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 numerous therapies that support affected persons in their everyday functions. However, many questions regarding the optimal care and assistance of people with CP and their families are unclear. For this reason, a group of CP experts founded the Swiss Cerebral Palsy Registry (Swiss-CP-Reg) in 2016. The registry obtained ethics approval in 2017 (2017-00873).

The Swiss-CP-Reg collects medical information of 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.

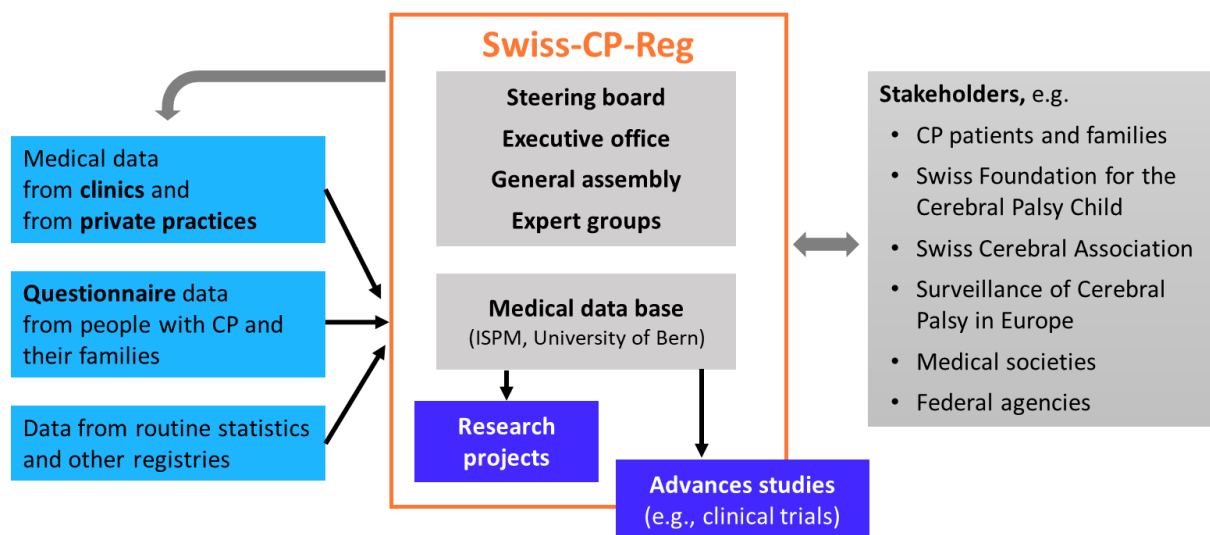


Figure 1: The Swiss Cerebral Palsy Registry – a platform for research and knowledge transfer.

3 The Swiss Cerebral Palsy Registry

3.1 Objectives

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

In detail, the aims are:

- 1) To identify and register people living with CP across 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 establish a research platform for clinical, epidemiological, and basic research to support participant recruitment for research studies and to answer questions on topics like health, healthcare, education, social aspects, and quality of life.
- 4) To establish a platform for knowledge exchange between clinics, researchers, therapists, national and cantonal health authorities, and international parties.

3.2 Organizational structure

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

The *Steering Board* includes specialised paediatricians from all seven large Swiss children's hospitals (Table 1). It is the Swiss-CP-Reg Head superordinate organ and acts as a supervisory authority. The Steering Board defines among other things the objectives, the research questions, and the dataset 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 recruiting people with CP and providing their medical data. These are currently the paediatric clinics in Basel, Bellinzona, Bern, Geneva, Lausanne, St. Gallen, and Zurich (Table 1). We are now ready to expand recruitment and data collection to smaller clinics and medical practices.

The *Expert Groups* support the registry and include specialists from different fields: People with CP and families; Social aspects; Quality of life and participation; Cognition and education; Nutrition and communication; Mobility and orthopaedics; Treatments; Comorbidities; Diagnosis and genetic syndromes; Neuroimaging.

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

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

Table 1: Key players of Swiss-CP-Reg in 2020 and 2021

Steering Board	
Sebastian Grunt, PD MD, Universitätsspital Bern, Swiss-CP-Reg president	
Joel Fluss, PD MD, HUG; Swiss-CP-Reg vice-president	
Claudia Kühni, Prof. MD, ISPM Bern; Swiss-CP-Reg head	
Christoph Künzle, MD, KISPISG	
Thomas Dreher, Prof. MD (since end of 2021), KISPIZH	
Stephanie Jünemann, MD, UKBB	
Andreas Meyer-Heim, Prof. MD, KISPIZH	
Christopher Newman, Prof. MD, CHUV	
Gian Paolo Ramelli, Prof. MD, EOC Bellinzona	
Peter Weber, Prof. MD (until end of 2020), UKBB	
Executive Office (ISPM, University of Bern)	
Claudia Kühni, Prof. MD; Swiss-CP-Reg Head	
Anne Tscherter, PD PhD; project manager	
Sandra Hunziker, PhD; project manager	
Clinical centres	
<u>Active:</u>	<u>Inclusion planned for 2022:</u>
Centre Hospitalier Universitaire Vaudois (CHUV)	Hôpital du Valais
Istituto Pediatrico della Svizzera Italiana (EOC Bellinzona)	Kantonsspital Aarau
Hôpitaux Universitaires de Genève (HUG)	Kantonsspital Fribourg
Ostschweizer Kinderspital St. Gallen (KISPISG)	Kantonsspital Graubünden
Universitäts-Kinderspital beider Basel (UKBB)	Kantonsspital Luzern
Rehabilitationszentrum für Kinder und Jugendliche Universitäts-Kinderspital Zürich and Universitätskinderspital (KISPIZH)	Kantonsspital Münsterlingen
Universitätsspital Bern	Kantonsspital Neuenburg
	Kantonsspital Winterthur
	Stiftung Wildermeth Biel and ZEN Biel
	ZKSK Solothurn

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 based on the Surveillance of Cerebral Palsy in Europe (SCPE) decision tree¹. CP diagnosis must be confirmed at the age of five if children are registered at an earlier age. Currently, our focus lies on the inclusion of children and adolescents with CP. Inclusion of adults with CP is foreseen.

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

¹ 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.

3.3.2 Recruitment

Physicians identify individuals with CP during routine medical visits and inform them and/or caregivers on the Swiss-CP-Reg orally and in writing. CP individuals who want to participate provide a signed 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, and routine statistics and other registries (Figure 2).

Medical data is collected from medical records of CP individuals in the participating clinical centres. The list of collected variables is based on the SCPE dataset² 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 enable the personal invitation of CP individuals to research projects (questionnaires, clinical trials). Medical data is collected at diagnosis, around 5, 10 and 15 years of age and at transition to adult healthcare. Follow-up during adulthood is foreseen. The minimal dataset includes the year of birth, year of death (if applicable), sex, gestational age, birth weight, and CP type. Available data up to the time point of registration is collected backwards. From then on, data is collected at future follow-up visits.

Data from questionnaires is collected from CP individuals and their families or treating physicians at regular intervals. Participation is voluntary. Covered topics can include e.g., healthcare, 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.

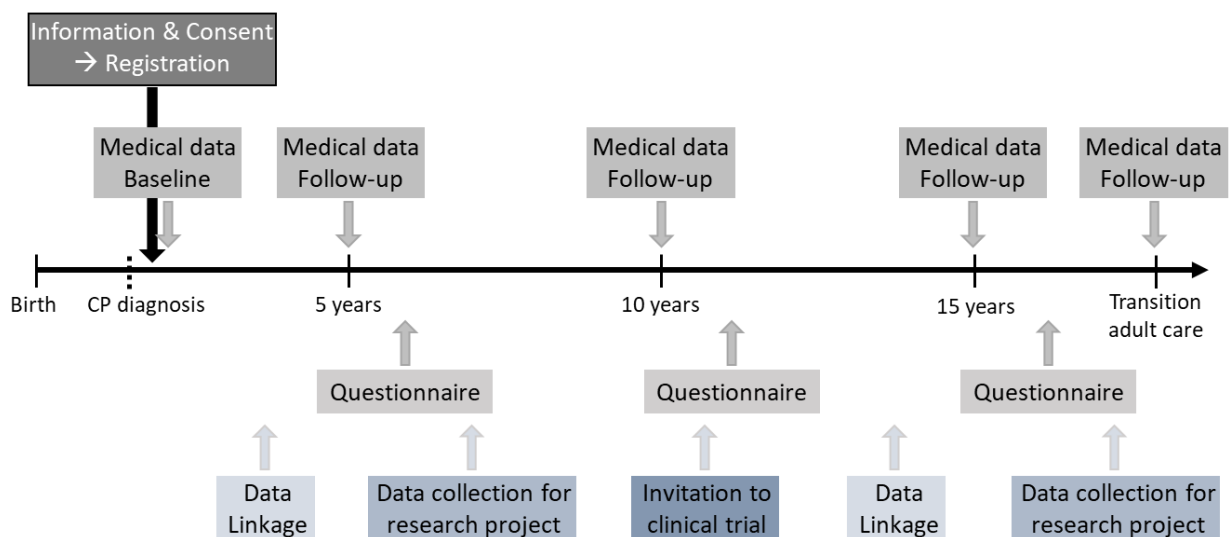


Figure 1: Schematic flow chart of registration and data collection management.

² 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.

3.4 Ethics approval / data protection /data sharing

In 2017, the Swiss-CP-Reg obtained 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 CP individuals and families, and to link data.

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

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

3.5 Funding

During the last years, the Swiss-CP-Reg (salaries, consumables, equipment) was financed by several funding bodies: 'Schweizerische Stiftung für das cerebrally 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 organizations and foundations for their support.

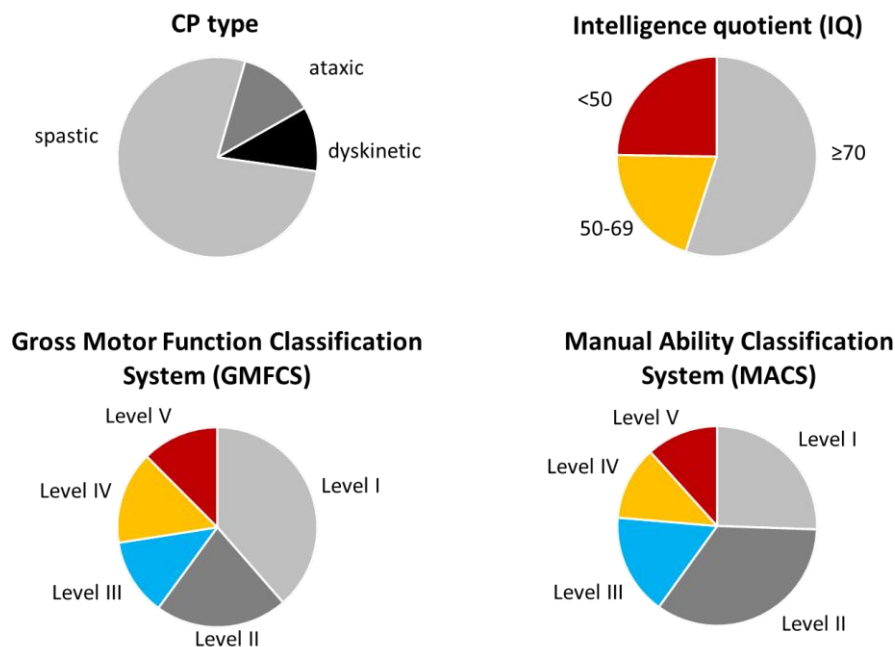
4 Study population

By December 31st, 2021, Swiss-CP-Reg included 632 people with CP. Among eligible participants who were approached, only 6% refused participation. See table 2 and figure 3 for more information.

Table 2: *Demographics of study participants in the Swiss Cerebral Palsy Registry (n=632, status at 31.12.2021).*

Demographics	Registered persons n (%)
Sex	
Female	288 (46)
Male	244 (54)
Language region of Switzerland	
German speaking	487 (77)
French speaking	121 (19)
Italian speaking	24 (4)
Age (years)	
0 - 4.9	78 (12)
5 - 9.9	220 (35)
10 - 14.9	230 (36)
15 - 19.9	92 (15)
>=20	12 (2)

46% of the participants are female and 54% male. About 70% of the participants are between 5 and 15 years old. 77% are treated in a clinic located in the German-speaking part of Switzerland, 19% in the French-speaking part and 4% in the Italian-speaking part. Most individuals have a spastic CP (77%), followed by ataxic CP (12%) and dyskinetic CP (11%). See page x for an overview. Most individuals were diagnosed with spastic CP (77%), followed by ataxia (12%) and dyskinetic CP (11%). Motor impairment was mostly mild (Gross Motor Function Classification System [GMFCS] level I and II, 60%), but 13% live with a moderate (GMFCS level III) and 27% with a severe impairment (GMFCS level IV and V). Most CP individuals showed normal or only slightly impaired manual ability (Manual Ability Classification System level I and II, 60%). Intelligence quotient (IQ) was usually not impaired (IQ \geq 70, 55%). However, impaired IQ correlates with reduced motor function.



Gross Motor Function Classification System:

- Level I, Walks without limitations
- Level II, Walks with limitations
- Level III, Walks using a hand-held mobility device
- Level IV, Self-mobility with limitations; may use powered mobility
- Level V, Transport in a manual wheelchair

Manual Ability Classification System:

- Level I, Handles objects easily and successfully
- Level II, Handles most objects, but with somewhat reduced quality and/or speed of achievement.
- Level III, Handles objects with difficulty.
- Level IV, Handles a limited selection of easily managed objects in simple actions
- Level V, Does not handle objects and has severely limited ability to perform even simple actions.

Figure 2: Distribution of CP type and severity (status at 31.12.2021).
 Data collection is ongoing. CP type n=478; Intelligence quotient n=198; Gross Motor Function Classification System n=433; Manual Ability Classification System n= 317.

5 Achievements of the Swiss-CP-Reg 2020-2021

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

Recruitment is the limiting factor of a medical registry. Thus, the past two years the Swiss-CP-Reg team focused on optimization of recruitment. Procedures were improved and individualized for each clinic. By December 31, 2021, 632 CP individuals were registered (593 accepted participation, 38 refused; chapter 4). The Covid-19 pandemic slowed down recruitment and data collection in 2020 and 2021.

In Spring 2019, the Cantonal Ethics Committee of Bern requested that we transform Swiss-CP-Reg from a monocentric to a multicentric study. We had to temporarily suspend recruitment and data collection all over Switzerland until this change was completed. For CHUV Lausanne, we could only resume our activities in June 2020 after the development and signature of a data transfer and use agreement between CHUV Lausanne and ISPM.

Data quality:

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

- Redefinition of the data set, variables were simplified or removed, a few relevant variables were added.
- Examination and adaption of procedures for data collection at each centre.
- 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 linkages 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* (PD Dr med S. Grunt, Prof. H. van Hedel, Prof. C. Schulze, PD Dr. A. Tscherter):
International studies show that children with CP participate less in social life than their peers. Interventions aim to improve the independence and participation of children with CP, but data are lacking in Switzerland. This project investigates how children with CP, their siblings, and their parents experience participation in Switzerland. Swiss-CP-Reg and collaborators are preparing the application for funding by SNF to realize this project.
- *Hip Surveillance* (Prof. Dr med T. Dreher):
It is important to monitor the hips of individuals with CP to detect and treat luxation at an early stage. The aim of this project is to establish a hip monitoring program in Switzerland. Currently, the data set and the data collection procedure are being validated in Zurich.

- *Survey on topics of concern of individuals with CP and their families* (PD Dr A. Tschertter, 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 CP individuals and families (such as quality of life, nutrition, communication, use of aids). Data of children with CP and their families living in Switzerland is collected via questionnaires. The questionnaire is currently in preparation.
- *Risk factors and outcomes of unilateral CP* (PD Dr A. Girardet, PD Dr J. Fluss): This project assesses different motor and cognitive patterns in Swiss children with unilateral CP. The results are compared with imaging, clinical, and socio-demographic data.
- *Collaboration with SwissNeoNet* (PD Dr M. Adams, PD Dr A. Tschertter): The Swiss Neonatal Network & Follow-up Group (SwissNeoNet) routinely collects data from paediatric units on the care and outcomes of high-risk new-born infants. Partial pseudonymized data from SwissNeoNet and Swiss-CP-Reg are regularly linked to identify missing children in both Swiss-CP-Reg and SwissNeoNet and facilitate collaborative research. In the first data linkage in August 2021, 186 preterm children not yet included in Swiss-CP-Reg were identified.

Several theses were conducted within Swiss-CP-Reg or are ongoing. These focus on a broad range of topics and use different approaches.

- Report on the Zurich cohort and evaluation of predictors of age at diagnosis. Doctoral thesis by L. Räss; ZH.
- Prescription practices of medical cannabinoids in children with CP. Master thesis by F. Morosoli; BE.
- CP and motor function in children - Data from Bern from the Swiss-CP-Reg. Master thesis by O. Jäger; BE.
- Nutrition in CP. Master thesis by C. Fanger; BE.
- CP and epilepsy in children - Data from Bern from the Swiss-CP-Reg. Master thesis by L. Graf; BE.
- Relation between neuroimaging patterns and upper limb function in unilateral spastic CP. Master thesis by J. Greuter; BE; ongoing.
- Timing, type, and treatment of epileptic seizures. Master thesis by L. Studer; BE; ongoing.
- Access to dental care for children and adolescents with motor disabilities. Master thesis by L. Zumsteg; VD; ongoing.
- Pain in children and adolescents with CP. Master thesis by L. Bischoff; SG; ongoing.

5.3 Dissemination and networking activities

The website 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 created information material on Swiss-CP-Reg, such as a flyer and roll-up, and we regularly updated the website and published news.

In 2021, we registered Swiss-CP-Reg 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.

Networking and knowledge exchange:

- In the last 2 years, 5 meetings of the Steering Board took place, mostly via videoconference because of Covid-19. 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.
- The Swiss-CP-Reg General Assembly was previously held during the Swiss Academy of Childhood Disability (SACD) Annual Meeting. In 2020, the SACD Annual Meeting was replaced by a webinar. The Swiss-CP-Reg General Assembly was held on the same afternoon as the SACD webinar via Zoom (November 12, 2020). Representatives from hospitals, medical societies, and the registry's Expert Groups, as well as other guests, participated. At this event, the status of the registry was presented. In addition, the re-election of the members of the Steering Board took place. We congratulate all members on their successful re-election. Prof. Peter Weber has retired from the Board. We thank him for his very valuable work for the Registry!
- No General Assembly took place in 2021 as we decided to hold the next General Assembly as part of the first SACD Research Day (January 20, 2022; per videoconference).
- A. Tscherter participated in all SCPE events (March 23, May 11, and Nov. 25, 2021; Webex).
- Several members of the Steering Board and the Executive Office attended the annual meeting of the Swiss Society of Neuropediatrics (SGNP) (June 16-17, 2021; online meeting), the SACD webinar (November 12, 2020) and the 32nd European Academy of Childhood Disability Annual Meeting 2020 (November 25-28, 2020; online).
- A. Tscherter also works as project manager of SwissPedRegistry, a research platform of SwissPedNet (the Swiss network of pediatric research centers). 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. Since July 2021, Sandra Hunziker has also been working for SwissPedRegistry as a project manager.

Scientific publications:

- Tscherter A, Kuehni C, & Grunt S (2020). German: Das Schweizer Cerebralparese Register: eine Forschungs-und Kommunikationsplattform. French: Registre Suisse de la Paralyse Cérébrale : une plateforme de recherche et de communication. *Paediatrica*, 31(3), 19-24. www.paediatrichschweiz.ch/schweizer-cerebralparese-register
- Sellier E, Goldsmith S, McIntyre S, Perra O, Rackauskaite G, Badawi N, Fares A, Smithers-Sheedy H, & Surveillance of Cerebral Palsy Europe Group and The Australian Cerebral Palsy Register Group (2021). Cerebral palsy in twins and higher multiple births: a Europe-Australia population-based study. *Dev Med Child Neurol*. 2021;63(6):712-720. doi.org/10.1111/dmcn.14827
- Belle FN, Hunziker S, Fluss J, Grunt S, Juenemann S, Kuenzle C, Meyer-Heim A, Newman CJ, Ramelli GP, Weber P, Kuehni CE, Tscherter A (2021). Cohort profile: the Swiss Cerebral Palsy Registry (Swiss-CP-Reg) cohort study. *Swiss Med Wkly*. 2022;152:w30139 <https://doi.org/10.4414/smw.2022.w30139>
- Morosoli, F, Hunziker, S, Zuercher, K, Tscherter, A, Grunt, S (2021). Prescription Practices of Medical Cannabinoids in Children with Cerebral Palsy - A Survey of the Swiss Cerebral Palsy Registry. *EJPN*, under review. Preprint on *medRxiv*. <https://doi.org/10.1101/2021.11.18.21266388>

Presentations:

Due to the coronavirus pandemic, several conferences were held virtually or postponed. Members of the Swiss-CP-Reg steering Board and/or of the Executive Office represented the registry at the following meetings in 2020 and 2021:

- 32nd European Academy of Childhood Disability. Annual Meeting 2020, online.
Poster presentations: Challenges in setting up a national cerebral palsy registry, A. Tscherter and Prescription Practices of Medical Cannabinoids in Children with Cerebral Palsy- A Survey of the Swiss Cerebral Palsy Registry, S. Grunt
- Forschungstag der Kinderklinik Bern. Bern, October 19, 2021.
Oral presentation: Prescription Practices of Medical Cannabinoids in Children with Cerebral Palsy - A Survey of the Swiss Cerebral Palsy Registry; S. Hunziker.
- A. Tscherter presented the work of the Swiss-CP-Reg as example of a functioning paediatric registry at the Kinder-Reha Schweiz (Affoltern am Albis, September 18, 2020), as a lecture of the Master of Advanced Studies (MAS) Entwicklungsneurologische Therapie (University of Basel, webconference, September 8, 2021, and at the SwissPedNet General Assembly (Bern, November 19, 2021)

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.
- Initiate data collection in additional centres.
- Optimize feedback on data collection and outcomes to centres.
- Implement the hip surveillance program.
- Submit the grant application to the Swiss National Funds (SNF) to realize the project on barriers and facilitators for participation in children with CP in Switzerland.
- Launch 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., access to dental care in CP children, pain in children and adolescents with CP).

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