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Annual Report 2022
Swiss Paediatric Inflammatory Brain Disease Cohort Study

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Bern, March 2023

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1 Summary

EN:

«The Swiss Paediatric Inflammatory Brain Disease Cohort Study: A nationwide population-based registry to enhance epidemiological knowledge and improve care of paediatric-onset MS and related disorders»

The Swiss Paediatric Inflammatory Brain Disease Cohort Study (Swiss-Ped-IBrainD) has a registry at its core. Since its foundation in 2019 it is hosted at the Institute of Social and Preventive Medicine of the University of Bern (ISPM). Its purpose is to systematically collect medical data of people with a paediatric-onset inflammatory brain disease (IBrainD).

The Swiss-Ped-IBrainD aims to collect and evaluate data on the diagnosis, course, and treatment of people with a paediatric-onset IBrainD. The gained knowledge should help improve the health care situation of children with an IBrainD in Switzerland. The registry further aims to clarify which areas of daily life are affected by IBrinDs and to what extent.

However, the registry is not just a simple data collection. It is a platform that promotes the communication and collaboration of the participating clinics. The registry fosters a network of specialists in the field of IBrainDs. They do not only help to gather knowledge but also to implement the acquired knowledge in the best interest of their patients. **The overall goal of the Swiss-Ped-IBrainD is to improve the medical care and the quality of life of children with IBrainDs**.

In 2022 we focused on:

- Installing a Steering Board and governance strategies
- Collecting data
- Preparing the first registry-based survey study
- Writing a methodological manuscript

DE:

«Die Schweizerische Pädiatrische Kohortenstudie zu entzündlichen Hirnerkrankungen: Ein landesweites Register mit dem Ziel, Multiple Sklerose und verwandten Erkrankungen bei Kindern besser zu verstehen und zu behandeln»

Die schweizerische pädiatrische Kohortenstudie zu entzündlichen Hirnerkrankungen (Swiss-Ped-IBrainD) hat als Kernstück ein Register. Dieses wurde 2019 gegründet und wird seither am Institut für Sozial- und Präventivmedizin der Universität Bern geführt (ISPM). Das Register erfasst systematisch medizinische Informationen über Menschen, die als Kind an einer entzündlichen Hirnerkrankung (IBrainD) erkrankt sind.

Das Swiss-Ped-IBrainD hat zum Ziel umfassende daten zur Diagnose, zum Verlauf und zur Behandlung von Menschen mit einer pädiatrischen IBrainD zu sammeln und auszuwerten. Die so gewonnenen Erkenntnisse sollen dazu beitragen, die Gesundheitsversorgung von Kindern mit einer IBrainD in der Schweiz zu verbessern. Ausserdem soll das Register klären, wie sich die Krankheiten auf das tägliche Leben auswirken und in welchem Ausmass.

Das Swiss-Ped-IBrainD ist aber nicht nur eine einfache Datensammlung. Es ist eine Plattform, die die Kommunikation und Zusammenarbeit zwischen den teilnehmenden Kliniken fördert. Das Register pflegt ein Netzwerk von Fachleuten im Gebiet der IBrainDs. Diese helfen dabei Wissen zu schaffen und setzen es im besten Interesse ihrer Patienten um. **Das ultimative Ziel des Swiss-Ped-IBrainD ist die Verbesserung der medizinischen Versorgung und Lebensqualität von Kindern mit IBrainDs.**

Im Jahr 2022 haben wir uns auf folgende Themen konzentriert:

- Einrichten eines Lenkungsausschusses und erarbeiten von Governance-Strategien
- Sammeln von Daten
- Vorbereiten der ersten Fragebogenstudie
- Verfassen eines methodologischen Manuskripts

FR:

« L'étude de cohorte suisse sur les maladies inflammatoires du cerveau à l'âge pédiatrique : Un registre national pour mieux comprendre et traiter la sclérose en plaques et maladies apparentées chez les enfants ».

L'étude de cohorte suisse sur les maladies inflammatoires du cerveau à l'âge pédiatrique (Swiss-Ped-IBrainD) repose sur un registre. Depuis sa fondation en 2019, ce registre est géré à l'Institut de Médecine Sociale et Préventive de l'Université de Berne (ISPM). Le registre recueille des données médicales de patients atteints de maladies cérébrales inflammatoires d'origine pédiatrique (IBrainDs).

Le Swiss-Ped-IBrainD a pour objectif de recueillir et d'évaluer des informations détaillées relatives au diagnostic, à l'évolution de la maladie et au traitement des personnes atteintes d'une IBrainD d'origine pédiatrique. Les connaissances acquises doivent contribuer à améliorer la prise en charge des personnes concernées en Suisse. En plus, le registre devrait permettre de mieux comprendre quels domaines de la vie quotidienne sont affectés par les IBrainDs et dans quelle mesure.

Le registre n'est toutefois pas un simple recueil de données, mais une plateforme qui facilite la communication et la collaboration entre les cliniques participantes. Il favorise un réseau de spécialistes du domaine, qui contribueront non seulement à rassembler les connaissances, mais aussi à les mettre en œuvre dans le meilleur intérêt de leurs patients. **L'objectif global du Swiss-Ped-IBrainD est d'améliorer les soins médicaux et la qualité de vie des enfants atteints de IBrainDs.**

En 2022, nous nous sommes concentrés sur :

- Installer un conseil de direction et des stratégies de gouvernance.
- Recueillir des données
- Préparer la première étude d'enquête
- Écrire un manuscrit méthodologique

2 Background

Paediatric-onset multiple sclerosis (MS) and other IBrainDs are severe diseases affecting children and adolescents in a period of critical brain development. This possibly leads to a variety of focal neurological deficits as well as early cognitive impairment. In turn, cognitive impairment can cause additional difficulties in daily life and affect school performance and vocational achievements.

Timely diagnosis and treatment initiation as well as individually tailored management are important for a favourable disease course. However, the diagnosis of the different IBrainDs can be challenging, especially in young children, since their first acute inflammation is often accompanied by unspecific symptoms common to all IBrainDs. A systematic assessment of similarities and differences between clinical signs, symptoms, and diagnostic workup of different IBrainDs will allow faster and more reliable diagnosis.

Furthermore, neither epidemiological data nor information on health care management and disease outcome of people with a paediatric-onset IBrainD exist in Switzerland. Therefore, we have set-up a national registry with the aim of understanding the epidemiology, clinical presentation and management of paediatric-onset IBrainDs. Ultimately, the registry will improve the care of children and adolescents with an IBrainD in Switzerland.

3 Description of the Swiss-Ped-IBrainD

3.1 Organizational Structure

The Swiss-Ped-IBrainD consists of three governing bodies: the Steering Board, the Executive Office, and the participating clinics (university and cantonal hospitals). The Steering Board members, Executive Office staff, and participating clinics are listed in Table 1.

Steering Board		
Sandra Bigi, PD MD	President	Department of Child Neurology, Luzerner Kantonsspital, Kinderspital Luzern, Luzern; ISPM, University of Bern, Bern
Stéphanie Garcia-Tarodo, PD MD	Vice president	Department of Child Neurology, University Hospitals of Geneva (HUG), University of Geneva, Geneva
Barbara Goeggel Simonetti, PD MD	Member	Department of Child Neurology, Paediatric Institute of Southern Switzerland, Ospedale San Giovanni, Bellinzona
Claudia Kuehni, Prof. MD	Member	ISPM, University of Bern, Bern
Executive Office		
Sandra Bigi, PD MD	Clinical lead	Department of Child Neurology, Luzerner Kantonsspital, Kinderspital Luzern, Luzern; ISPM, University of Bern, Bern
Claudia Kuehni, Prof. MD	Legal representative	ISPM, University of Bern, Bern
Anne Tscherter, PD PhD	Project advisor	ISPM, University of Bern, Bern
Lorena Hulliger, MSc	Project manager	ISPM, University of Bern, Bern
Susanne Hofer, MSc	Data manager	ISPM, University of Bern, Bern
Clinics		
University Hospital Bern, University of Bern, Bern		
Luzerner Kantonsspital, Kinderspital Luzern, Luzern		
Kantonsspital Aarau, Clinic for Children and Adolescents, Aarau		
University Children's Hospital Basel, University of Basel, Basel		
University Hospitals of Geneva (HUG), University of Geneva, Geneva		
Paediatric Institute of Southern Switzerland, Ospedale San Giovanni, Bellinzona		
University Children's Hospital of Zurich, University of Zurich, Zurich		
University Children's Hospital Lausanne (CHUV), Lausanne		
Children's Hospital of Eastern Switzerland, St Gallen		
Kantonsspital Winterthur, Social Paediatric Centre, Winterthur		
Kantonsspital Graubünden, Department of Child and Adolescent Medicine, Chur		

Table 1: Swiss Paediatric Inflammatory Brain Disease Cohort Study staff and participating clinics; ISPM: Institute of Social and Preventive Medicine

Figure 1 illustrates the organizational structure of the registry including the interactions between the governing bodies.

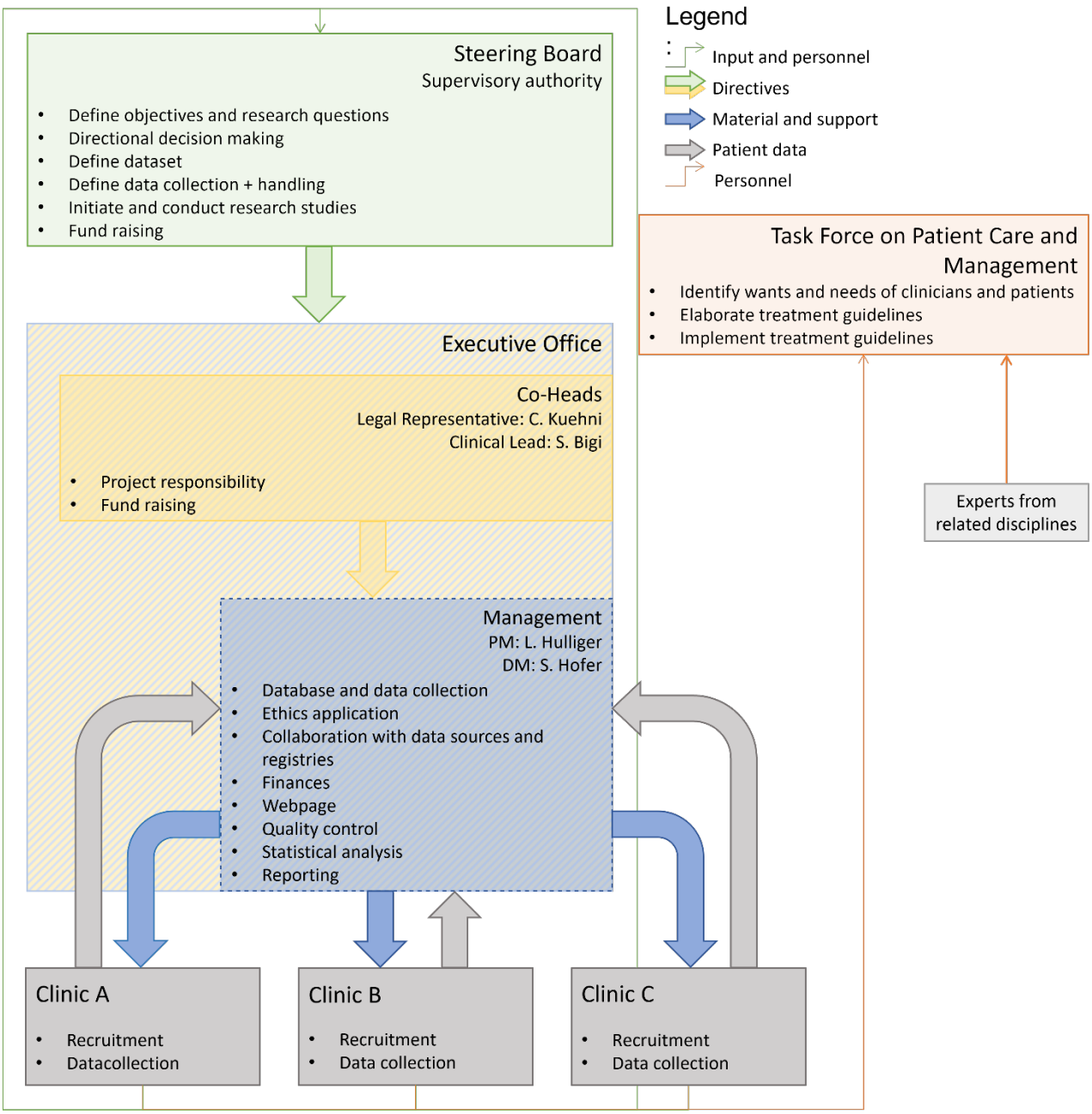

Figure 1: Organizational structure of the Swiss-Ped-IBrainD. The Executive Office shares gained knowledge with the clinics and provides a basis for future studies, which may be initiated by the clinics. PM: Project manager; DM: Data manager

The Steering Board supervises the Swiss-Ped-IBrainD, takes directional decisions and has steering function. It defines the objectives of the Swiss-Ped-IBrainD and protects its interests towards third parties. Other fields of responsibility include management and legal issues, database and data collection, communication (e.g., with stakeholders, funding agencies), finances, research, and data sharing and inquiries. (see Table 1).

The Executive Office represents the operative part of the Swiss-Ped-IBrainD. It is headed by the legal representative and the clinical lead. They share the project responsibility and are strongly involved in funding acquisition.

The Executive Office management (including project management and data management) organizes various tasks such as the development and curation of documents (study plan, patient information, case report forms, standard operating procedures, etc.), set-up of the electronic database (RedCap), collection of data, submission of documents to the ethics committee, management of the finances, preparation of legal documents (e.g., study agreements), and maintenance of ways of dissemination.

The clinics have the fundamental task of recruiting patients for the Swiss-Ped-IBrainD and providing data/data access to the Executive Office.

The constitution, rights and responsibilities of the Steering Board and Executive Office are recorded in the governance document «Collaboration Agreement on the Swiss Paediatric Inflammatory Brain Disease Cohort Study».

At the end of 2021, we founded the «Swiss-Ped-IBrainD Task Force». The task force consists of the local principal investigators of the participating clinics and additional members from complementing disciplines such as paediatric neuroradiology and neuropsychology.

The purpose of the task force is to discuss challenging cases from the sites and to develop and implement treatment guidelines. The paediatric IBrainD patients thus benefit directly from the knowledge exchange within this expert panel.

In 2022 the task force has met every two months. During these hybrid meetings 11 challenging cases from different neuropaediatric clinics were discussed. The task force meetings were further used as a networking opportunity and a platform to discuss pressing matters in the field of IBrainDs such as the organization of the participation in large international studies.

3.2 Objectives

The Swiss-Ped-IBrainD pursues the following objectives:

1) Gathering representative, population-based epidemiological data on paediatric-onset IBrainDs in Switzerland.

2) Monitoring treatment, clinical course, education, social aspects, and outcomes of paediatric IBrainD patients.

3) Providing a platform to facilitate research, national and international collaboration and exchange of knowledge between experts.

The Swiss-Ped-IBrainD thus addresses the increasing requests for medical trial participation and promotes the exchange with existing adult registries (e.g., Swiss MS Registry).

3.3 Inclusion/Exclusion Criteria

The following patients qualify for inclusion: All patients living and/or treated in Switzerland living with an IBrainD specified in Table 2 with an onset before the age of 18.

Demyelinating diseases
Optic neuritis
Transverse myelitis
Acute disseminated encephalomyelitis
Multiple sclerosis

Neuromyelitis optica spectrum disorders
Antibody-associated diseases
MOG-antibody disease
Anti-NMDA-R associated autoimmune encephalitis
Anti-GAD65 associated autoimmune encephalitis
Anti-AMPA-1/2 associated autoimmune encephalitis
Anti-Lgi-1 associated autoimmune encephalitis
Anti-CASPR-2 associated autoimmune encephalitis
Anti-GABA-1/2 associated autoimmune encephalitis
Onconeuronal antibody (Hu, Ri, Yo, Amphiphysin, CRMP-5, Ma-1, Ma-2, SOX-1) associated autoimmune encephalitis
Hashimoto encephalopathy
Other IBrainDs
CNS vasculitis
CNS sarcoidosis
CNS Lupus
Rasmussen's encephalitis

Table 2: Included inflammatory brain diseases

Excluded are patients with:

1) Neurological symptoms due to infectious diseases of the CNS

2) Genetic/metabolic causes of central demyelinating diseases

3) Neurological symptoms due to Guillain-Barré-Syndrome

3.4 Registration of Patients and Collection of Medical Data

Specialized physicians at the participating clinics are responsible to identify children with the listed IBrainDs (see Table 2) during regular medical consultations. They inform patients and their parents/legal representatives orally and in writing about the Swiss-Ped-IBrainD. Patients who cannot be informed because they are e.g., no longer treated for their IBrainD, have transitioned to adult care, have relocated, are sent an invitation to participate. Once a patient (and his/her legal representative[s]) consents to participate, his/her medical data is collected and entered in the database of the registry. The data collection focuses on diagnostic data, follow-up data, and data on relapses.

Medical data is sourced through medical records and reports, oral/written information from treating physician(s), oral/written information from patient/family, routine statistics and other medical registries, questionnaires for patients and families.

The diagnostic workup and treatment of patients continue as usual and are independent from participation; no examination is carried out specifically for the Swiss-Ped-IBrainD.

If informed consent is not obtained after informing a patient and his/her family, the patient is registered in the Swiss-Ped-IBrainD with a minimal dataset. This minimal dataset consists of the following variables:

- Birth year
- Sex
- Status (alive, dead, unknown)
- Diagnosis
- Year of diagnosis

The minimal dataset is essential to properly calculate the incidence and prevalence of paediatric-onset IBrainDs in Switzerland. Furthermore, collecting the minimal dataset prevents a systematic bias by not excluding very mild cases and very severe cases with fatal consequences of paediatric-onset IBrainDs.

3.5 Ethics Approval / Data Protection

The Swiss-Ped-IBrainD project (title: «Swiss Paediatric Inflammatory Brain Disease Cohort Study», project number: 2019-00377) has been approved by the ethics committees of Bern, the Ethikkommission Nordwest- und Zentralschweiz (EKNZ), the Ethikkommission Ostschweiz (EKOS), and the ethics committee of Zürich. In 2021 the Swiss-Ped-IBrainD has additionally been approved by the remaining ethics committees of Lausanne, Geneva, and Bellinzona.

The transmission, storage, and analysis of health-related personal data within this project follow the current Swiss legal requirements for data protection and the Human Research Ordinance Art. 5. Data is always pseudonymized for analysis.

Health-related personal data are strictly confidential. They are handled with utmost discretion and are only accessible to authorized personnel. Direct access to source documents for purposes of monitoring, audits, or inspections is permitted.

The data protection concept of ISPM ensures the secure handling of all sensitive data at ISPM and within Swiss-Ped-IBrainD. All employees are subject to the duty of confidentiality.

3.6 Funding

The Swiss-Ped-IBrainD is financed through third-party funds. We differentiate between peer-reviewed funding, funding provided by the pharmaceutical industry, and funding from other sources.

Peer-reviewed funding

Our peer-reviewed support comes from the **Swiss MS Society** and the **Anna Mueller Grocholski-Stiftung.** The Swiss MS Society has supported the Swiss-Ped-IBrainD since its inception, providing more than a third of our total funding (see Table 3). **The Anna Mueller Grocholski-Stiftung** has provided the financial resources to hire staff for the registry-based survey study (See section 4). Their contribution makes up almost a tenth of our total funds.

Pharmaceutical industry

Roche Pharma (Switzerland) Ltd, **Novartis Pharma Schweiz AG**, and **Sanofi-Aventis (Schweiz)** are further sponsors of the Swiss-Ped-IBrainD. In 2022, we added **Biogen Switzerland AG** to our list of supporters from the pharmaceutical industry. To date, the pharmaceutical industry has provided Swiss-Ped-IBrainD with just over half of its total funding.

Other funding

The **PedNet Bern** has supported the Swiss-Ped-IBrainD in its beginning with a start-up aid. Additionally, the **Fondation Johann Dürmüller-Bol** has donated money to the Swiss-Ped-IBrainD for the coverage of material costs.

Source	Contribution to total funding
Pharmaceutical industry	52%
Peer-reviewed funding	47%
Other funding	1%

Table 3: Funding contributions in percent by source

4 Achievements of the Swiss-Ped-IBrainD 2022

In 2022 we focused on:

- Installing a Steering Board and governance strategies
- Collecting data
- Preparing the first registry-based survey study
- Writing a methodological manuscript

Installing a Steering Board and governance strategies

We have installed a Steering Board consisting of four representatives from different participating clinics. Together, we have defined the organizational structure of the Swiss-Ped-IBrainD and set the rules on constitution, rights, and responsibilities in the document «Collaboration Agreement on the Swiss Paediatric Inflammatory Brain Disease Cohort Study». See section 3.1 for further information.

Collecting data

Data collection has been successfully initiated in 9 of the 11 participating clinics.

We have adapted the procedures to meet the requirements of each clinic. However, establishing these workflows has been (and continues to be) more difficult and time-consuming than expected. Based on our growing experience and success in the other clinics, we are confident that we will be able to start data collection in the remaining two clinics by mid-2023.

The heterogeneity of the participating clinics (including differences in structure, clinic information system, team sizes, patient emergence, etc.) requires different levels of support by the Executive Office. We have therefore hired a data manager who is responsible for data collection. The data manager visits the clinics at regular intervals to collect and update the medical data of registered IBrainD patients. Thereby relieving the PIs and their teams of the burden of extracting data (from medical records) and entering them into the registry database. For patients with a long medical history – we collect continuous data from initial symptoms to present and include patients who were diagnosed as far back as 2005 – this can be a lengthy and time-consuming process. However, the data manager has been granted remote access to some clinic information systems of participating clinics. This makes data collection more time- and cost effective.

Preparing the first registry-based survey study

We are preparing the first registry-based survey study. It consists of two parts: a questionnaire on the quality of life (QoL) and a questionnaire on the perception of the diagnostic process of patients with paediatric-onset MS and other IBrainDs. Some of the milestones we have reached include selecting and acquiring a validated instrument to evaluate the QoL of children with MS and other IBrainDs (PedsQL), securing funds for a dedicated research assistant, adapting the questionnaire on the perception of the diagnostic process for different age groups, finding and committing subjects for a pilot study to validate the questionnaire.

We are currently in the process of hiring a research assistant and setting up the electronic database (RedCap) to record the responses we receive. The next steps will be to conduct the pilot study with the questionnaire on the perception of the diagnostic process, integrate the feedback, and then translate the questionnaire into French and Italian.

We aim to be ready to distribute both questionnaires once we have reached our target of 100 informed consents.

Writing a methodological manuscript

The study protocol manuscript is undergoing peer review and will be submitted to PLOS ONE in the first half of 2023.

Collaborations

We are discussing a collaboration with Prof. Kevin Rostásy MD of the Witten/Hardeck University, Children's Hospital Datteln, Germany, in his project «Diagnostische Bedeutung von Biomarkern in der Differentialdiagnose und Langzeitverlauf von Kindern mit einer ersten demyelisierenden ZNS Erkrankung».

We are further working together with Rinze F. Neuteboom MD PhD and the 'Dutch registry for acquired demyelinating syndromes in childhood' to consolidate our dataset and compare quality of life outcomes of Dutch and Swiss children with IBrainDs.

Congress participation

We presented the Swiss-Ped-IBrainD and its achievements at the following congresses:

- 14th European Neurological Society Congress, 28 April - 2 May 2022, Glassgow, United Kingdom; The Swiss Paediatric Inflammatory Brain Disease Cohort Study: Setting up a national registry for children and adolescents with paediatric onset MS and related disorders
- Jahreskongress Pädiatrie Schweiz 2022, 2-3 June 2022, Lucerne, Switzerland; The Swiss Paediatric Inflammatory Brain Disease Cohort Study: Setting up a national registry for children and adolescents with paediatric onset MS and related disorders
- General assembly of the Swiss Multiple Sclerosis Society, 11 June 2022, Zurich, Switzerland; Multiple Sklerose im Kindesalter besser verstehen und gezielter behandeln: Das schweizweite Register für Kinder mit MS und anderen entzündlichen Hirnerkrankungen
- 47th annual meeting of the Swiss society of neuropediatrics, December 12-13 December 2022, St. Gallen, Switzerland; The Swiss Paediatric Inflammatory Brain Disease Cohort Study: Experience of the first year

5 Numbers

5.1 Population and Demographics

Until December 31, 2022, we have identified 262 eligible patients with a paediatric-onset IBrainD in 11 Swiss clinics (see Table 4). So far, 88 patients have agreed to participate in the Swiss-Ped-IBrainD (consented). By signing the informed consent, they allow us to access their medical data and collect the full dataset. The demographics of the participants are shown in Table 5. We have informed an additional 124 patients of the registry but have received no response from them (informed, not consented). Most of these patients are adults who are no longer accompanied by their neuropaediatricians and can therefore not be informed orally in a face-to-face setting (which might explain the response rate). Fifty eligible patients remain to be informed (eligible, not informed). No patient/family has yet refused participation (refused).

We have collected and registered the minimal dataset of the patients who have agreed to participate (consented) and those who were informed but did not consent (informed, not consented). The demographics of the patients in the minimal dataset are shown in Table 6.

Population as per 31.12.2022, n=262	
Consented	88
Informed, not consented	124
Eligible, not informed	50
Refused	0

Table 4: Categories of study population

Demographics of participants (consented), n=88	
	n (%)
Sex	
Female	55 (63)
Male	33 (37)
Language region of Switzerland	
German speaking	74 (84)
French speaking	10 (11)
Italian speaking	4 (5)
Age	
0-4	3 (3)
5-9	13 (15)
10-14	27 (31)
15-19	27 (31)
20-24	8 (9)
25-29	9 (10)
≥30	1 (1)

Table 5: Demographics of patients with a paediatric-onset inflammatory brain disease living or treated in Switzerland who have agreed to participate in the Swiss Paediatric Inflammatory Brain Disease Cohort Study.

Demographics of patients in the minimal dataset (consented + informed, not consented), n=212	
	n (%)
Sex	
Female	130 (61.3)

Male	82 (38.7)
Language region of Switzerland	
German speaking	178 (84)
French speaking	30 (14.2)
Italian speaking	4 (1.9)
Age	
0-4	3 (1.4)
5-9	18 (8.5)
10-14	44 (20.8)
15-19	55 (25.9)
20-24	53 (25)
25-29	25 (11.8)
≥30	14 (6.6)

Table 6: Demographics of patients with a paediatric-onset inflammatory brain disease living or treated in Switzerland of whom the minimal dataset has been collected and registered.

5.2 Diagnoses

Among the 88 participants (consented), paediatric-onset MS (29, 33%) was the most common diagnosis, followed by myelin oligodendrocyte glycoprotein antibody-associated disease (14, 16%). Optic neuritis (12, 14%) and acute disseminated encephalomyelitis (12, 14%) tied for third place. See Figure 2 for more details.

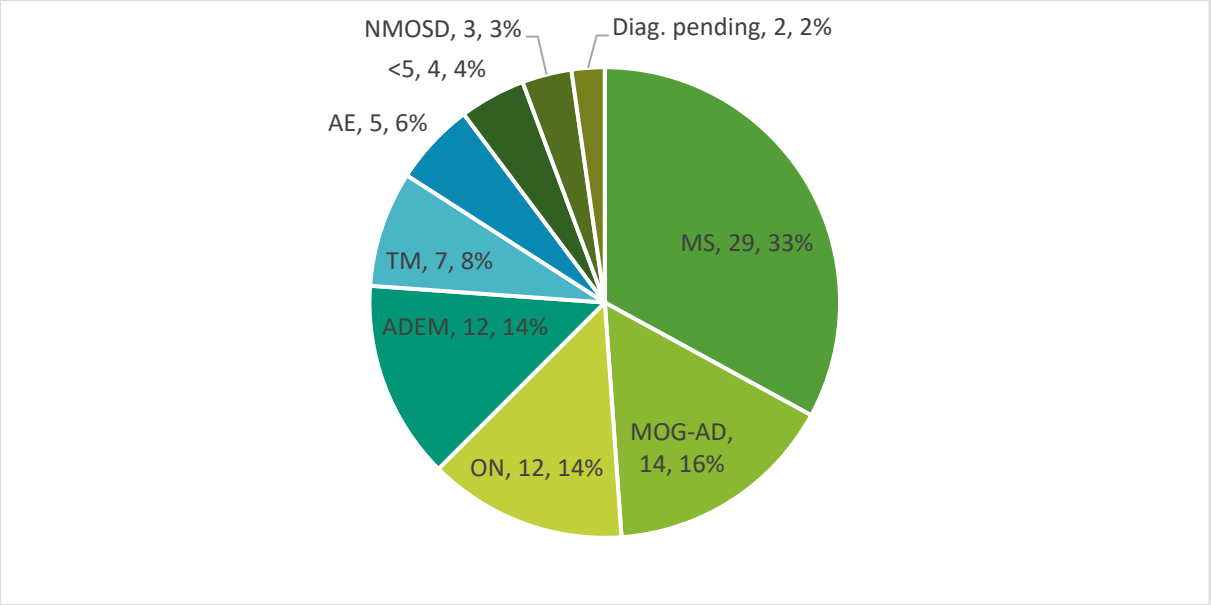

Figure 2: Diagnoses of patients with a paediatric-onset inflammatory brain disease living or treated in Switzerland who have agreed to participate in the Swiss Paediatric Inflammatory Brain Disease Cohort Study (n=88). MS: multiple sclerosis; MOG-AD: myelin oligodendrocyte glycoprotein antibody-associated disease; ON: optic neuritis; ADEM: acute disseminated encephalomyelitis; TM: transverse myelitis; AE: autoimmune-encephalitis; <5: inflammatory brain diseases diagnosed in less than 5 cases; Diag. pending: inflammatory brain diseases with final diagnosis still pending; NMOSD: neuromyelitis optica spectrum disorders

The most frequent initial symptoms among the 88 participants (consented) were visual deficits (28), nausea/vomiting (26), and headaches (25). See Figure 3 for more details.

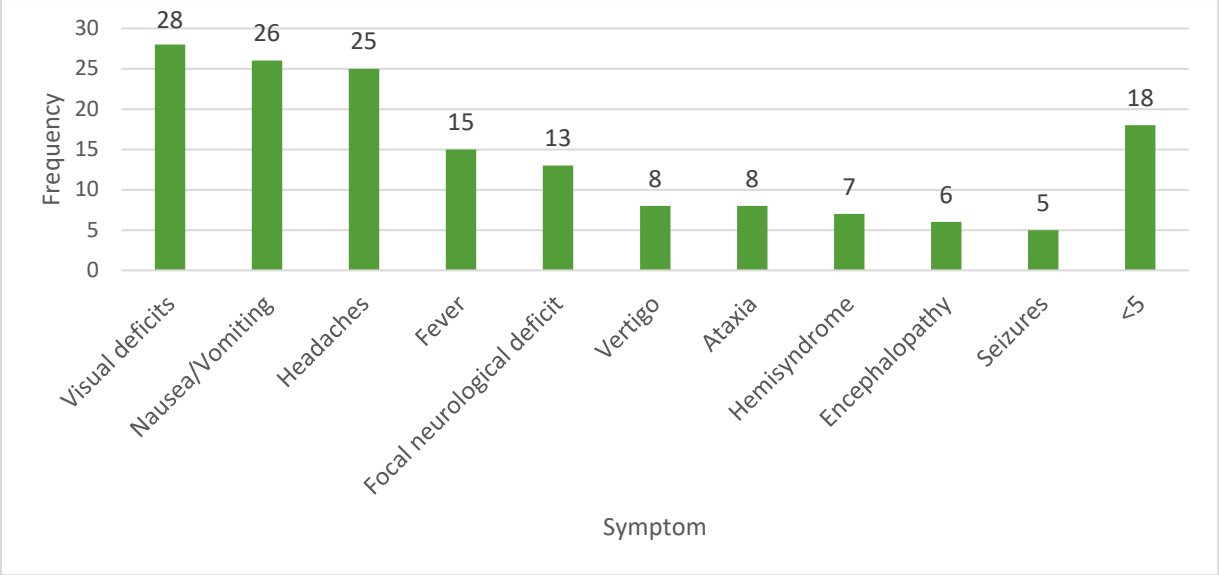

Figure 3: Frequency of initial symptoms of patients with a paediatric-onset inflammatory brain disease living or treated in Switzerland who have agreed to participate in the Swiss Paediatric Inflammatory Brain Disease Cohort Study (n=88).

The minimal dataset (n=212) revealed paediatric-onset MS (102, 48%) to be the most common paediatric-onset IBrainD diagnosis, followed by acute disseminated encephalomyelitis (25, 12%), and optic neuritis (21, 10%). See Figure 4 for more details.

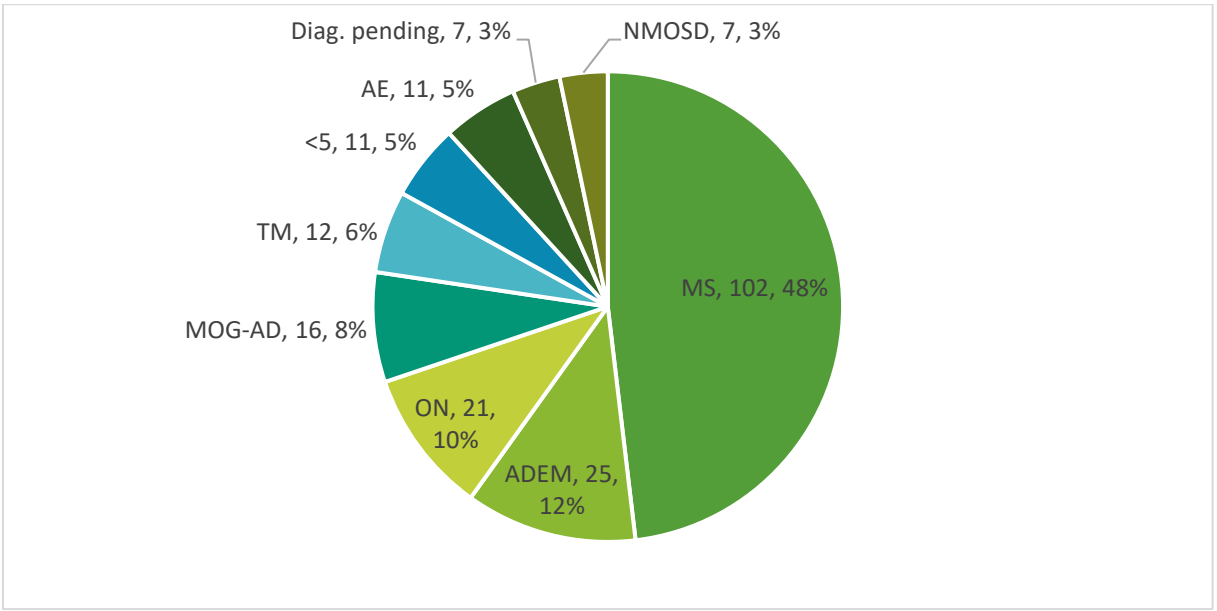

Figure 4: Diagnoses of patients with a paediatric-onset IBrainD living or treated in Switzerland of whom the minimal dataset has been collected and registered (n=212). MS: multiple sclerosis; ADEM: acute disseminated encephalomyelitis, ON: optic neuritis; MOG-AD: myelin oligodendrocyte glycoprotein antibody-associated disease; TM: transverse myelitis; <5: inflammatory brain diseases diagnosed in less than 5 cases; AE: autoimmune-encephalitis; Diag. pending: inflammatory brain diseases with final diagnosis still pending; NMOSD: neuromyelitis optica spectrum disorders

6 Outlook

In the year 2023 we will focus on the following activities:

1) Continue recruitment and data collection

2) Optimize dataset to conform with international collaborators

3) Registry-based projects:

- Analyse registry data; focus on epidemiology of IBrainDs in Switzerland
- Conduct the survey on QoL and perception of the diagnostic process
- Harmonize treatment/disease management in collaboration with the Swiss-Ped-IBrainD Task Force

We will also continue to raise funds to secure the further existence of the Swiss-Ped-IBraiD.

7 Acknowledgements

We would like to thank all the participants and their families for taking an interest in the Swiss-Ped-IBrainD and allowing us to access their data. We are further very thankful to the local principal investigators for their collaboration and effort to advance the project.

We are also very grateful to the patient organization Swiss MS Society not only for their financial support but also for their inspiring commitment to the cause.

Further we express our thanks to Biogen Switzerland AG, Roche Pharma (Switzerland) Ltd, the Anna Mueller Grocholski-Stiftung, Novartis Pharma Schweiz AG, Sanofi-Aventis (Schweiz), the Fondation Johanna Dürmüller-Bol, and the PedNet Bern for funding us.

8 References

1. Bigi S, Bauder F, Mori AC, et al. The Swiss Pediatric Inflammatory Brain Disease Cohort Study: Setting up a National Registry for Children and Adolescents with Pediatric Onset MS and Related Disorders. *Neuropediatrics.* 2021;52(S 01):P1.21.