PWS Network Switzerland

6th International Prader-Willi Syndrome Caregivers' Conference 21-23 May 2024, Berlin, Germany

arkadis gemeinsam lebensqualität schaffen

Bastian Bühler







#PWSCARE24

Introduction – or who am I?



Bastian Bühler
Switzerland
Social educator worker

Working with people with disabilities since 2007
Group home team leader for individuals with PWS since 2018

Board member of the Prader-Willi Syndrome Association Switzerland

Caregiver Delegate Switzerland



Structur



- About Switzerland
- Parts of the PWS network
- Co-operations and synergies
- Benefits
- Outlook to the future



About Switzerland

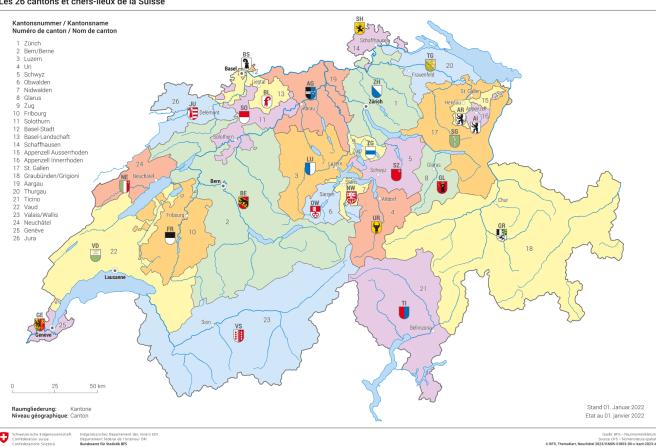


Switzerland is located in the middle of the European Union



About Switzerland





- A population about 9 Mio.
- 41.290 square kilometres
- Four languages (german, french, italian, romansh)
- 26 cantons
- Based on the population: 400-600 people with PWS



Parts of the PWS Network Switzerland



- Residential Group Homes
- Association
- Institutions without a specific residential programme for people with PWS

PWS specialised medical Doctors



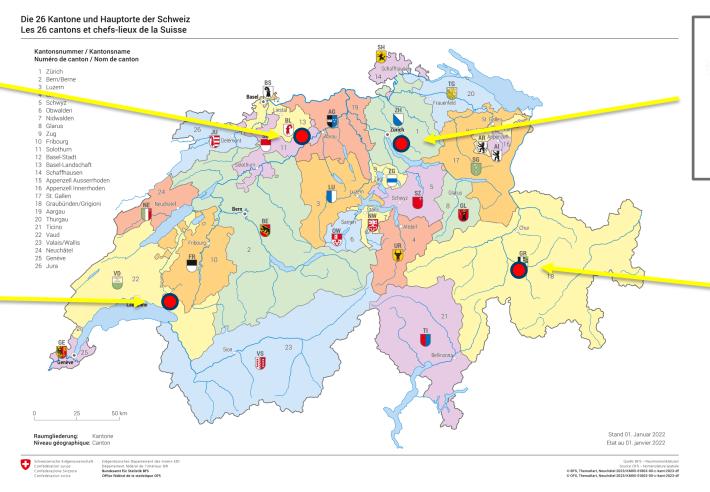
Residential Group Homes for People with PWS

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Residents: 8 (german)

Residents:
5-7
(french)



MASTIN STIFFUNG

Residents: 7 (german)



Residents: 15 (german)



PWS Association Switzerland



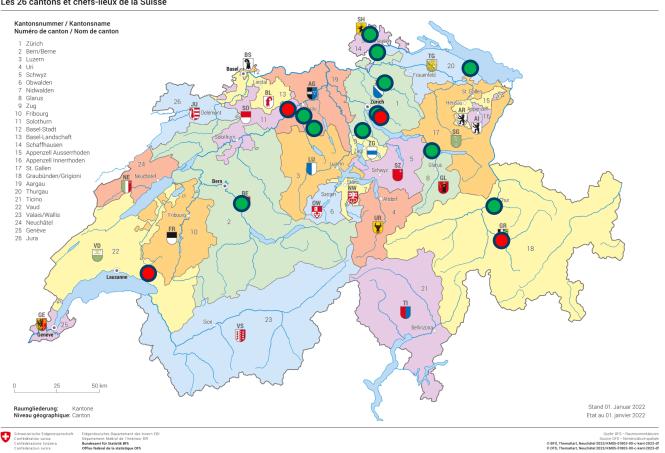


- Founded in 1991
- 144 members
- mainly consisting of parents, but also medical specialists
- 7 board members (parents and professionals)



Non specific residental group homes

Die 26 Kantone und Hauptorte der Schweiz Les 26 cantons et chefs-lieux de la Suisse



- Residental group homes
- Non specific residental group homes



- No official cooperation between the residential groups until 2015
- Intervision with case discussions
- Possibility for residents to swap institutions
- Possibility for residents to join the holiday programme offered by other institutions
- Job shadowing of staff in the other teams
- Joint organisation and implementation of pws-specific training courses
- National waiting list for people with PWS who are looking for a place in a PWS residential group





Joint participation at conferences in Ireland

Development and realisation of a parents' seminar





 Joint participation in the unified run



 Family Day of the PWS Association





Mountain hut weekend



Benefits

- We know the different residental offers
- We can share and exchange experiences and knowledge
- Mental hygiene
- Exchange among defined contact persons
- Residents know each other well, have a network, maintain friendships with each other



Outlook for the future

- Expanding connections to Austria and Germany
- Use of the common language German for cross-border exchange and cooperation





Thank you

6th International Prader-Willi Syndrome Caregivers' Conference





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