Patient Organisation Audit: Switzerland

Aim

The aim of the audit is to:

To identify charities that are focused on health or chronic conditions
To identify charities that are patient organisations, that is, provide patient support, information or advocacy
To produce a contact directory of all patient organisations in Switzerland
To understand the breadth of disease areas covered by patient organisation in Switzerland

Method and results

In Switzerland, the two forms of legal entities that are commonly used for charitable purposes are foundations and associations.

According to the Swiss Civil Code, there are two non-corporate legal entities that can be registered in Switzerland:

- foundations
- associations

The main difference between a Swiss foundation and association resides is that the latter is made of members. It is required for an association to have at least 2 members for it to be created.

Switzerland recognises three main categories of foundations including family foundations and private foundations, foundations operating as pension funds or foundations set up for the benefit of the general public.

The Federal Supervisory Authority for Foundations sits under the Federal Department of the Interior and is responsible for overseeing foundations operating at the national and/or international levels.

The registration in the Register of Commerce is not mandatory for associations having a non-profit purpose. This is therefore not reliable data on the number of associations established in Switzerland and this audit has only used the federal register.

Stage 1: Long list development

A directory of charities is kept by the Federal Department of the Interior[1] All foundations subject to Confederation supervision are registered in the electronic directory. There are 4,899 organisations registered in the database.

The directory was accessed on 1 February 2022. Within the directory's search function, it is possible to filter charities and associations by key words. Each organisation may be tagged with more than one keyword. The following inclusion and exclusion criteria were applied to develop an initial list of charities and associations for review. 1516 organisations were identified in the initial list of which 379 were duplicates leaving a total of 1137 organisations for review.

[1] https://www.edi.admin.ch/edi/fr/home/fachstellen/eidgenoessische-stiftungsaufsicht/stiftungsverzeichnis.exturl.html/aHR0cHM6Ly9lc3YuZGVpbW9zLmNoLz9MYW5nPWZy.html
[Accessed 1 February 2022]

Table 1: Search terms included

Keyword	Yield
Accident	15
Age	78
Aide à la mobilité	3
Aide aux mères	4
Alcool	8
Alimentation	36
Alzheimer	16
Anesthésie	2
Assistance	99
Association	14
Audiovision	5
Aveugles	34
Bien-être	4
Bienfaisance	109
Caisse maladie	17
Cancer	87
Chiens d'aveugles	4
Chimie	3
Chiropratique	3
Chirurgie	16
Dépendanc	8
Déséquilibrés mentaux	16
Diabète	8
Don d'organes	1
Don de moelle osseuse	1
Drogue	11

Keyword	Yield
Handicapés cérébraux	6
Handicapés'	152
Insuline	0
Leucémie	3
Maladie	158
Maladies cardiaques, de la cir	25
Maladies génétiques	1
Maladies musculaires	0
Malaria	3
Mère et enfan	7
Moyens auxiliaires	9
Neurologie	12
Ophtalmologie	30
Ostéoporose	0
Planning familial	1
Prévention	29
Psycho-Physique	1
Psychologie	32
Psychothérapie	9
Schizophrénie	0
Sclérose en plaques	8
Sante	320
SIDA	21
Soins infirmiers	28
Thérapeutique	16
Thérapie	39
Transplantation	3
Transplantation de moelle osse	1

Table 2: Search terms excluded

Keyword	Yield
Activité économique	74
Afghanistan	4
Afrique	144
Agriculture	72
Aide au développement	147
Aide du développement	87
Aide en cas de catastrophe	24
Aide humanitaire	244
Aliments	7
Alpes	14
Aménagement du territoire	3
Aménagement intérieur	1
Amérique du sud	47
Animaux	125
Anthroposophie	12

Keyword	Yield
Antiquité classique	4
Antiracisme	11
Archéologie	17
Architecture	26
Archives	37
Arménie	7
Art	284
Artisanat	9
Artiste	42
Asie	53
Assurance	20
Aviation	8
Bâtiment	14
Bénéficiaires de rente	1
Bhutan	1

Keyword	Yield
Bibliothèque	23
Biologie	30
Bouddhisme	11
Bourses	132
Centre de consultation	8
Chant	3
Cheval'	7
Chômage	11
Cinéma	7
Cirque	1
Collection	41
Collectivité (publique)	9
Commerce	10
Communications	25
Comptabilité/présentation des comptes	1
Conscience	11
Construcion de logements	16
Construction	17
Consultation	10
Contr. aux coûts d'impression	10
Contributions	12
Coopération	20
Croix-Rouge	12
Culture	499
Danse	9
Déminage	5
Démocrati	17
Denrées alimentaires	3
Désavantagé	93
Design	7
Détenus libérés	1
Développement durable	110
Diplomatie	3
Domaine social	124
Droit	19
Droit des étrangers	1
Droits de l'homme	63
Eau	31
Echange culturel	49
Echecs	1
Ecoles	80
Ecologie	91
Economie	34
Education	236
Education/formation/formation complémentaire	142

Keyword	Yield
Eglise	74
Elimination des déchets	6
Encouragement de la relève	4
Encouragement/promotio	121
Energie	23
Enfants	502
Enfants de la rue	13
Enfants placés	2
Enseignement	29
Entraide'	42
Entreprise	47
Environnement	228
espace	1
Espagne	2
Essais sur les animaux	3
Ethique	45
Ethique sociale	6
Etranger	12
Etudiant/es	41
Europe	20
Europe de l'est	26
Famille	58
Familles monoparentales	2
Femmes	66
Film	13
Fonds national	1
Forestiers	4
Forêt	19
Formation	435
Formation des adultes	33
Formation professionnelle	93
garantie de qualité	9
Garde forestier	0
Génie génétique	2
Gens du voyage	2
Géologie	2
Graphisme	2
Guerre	17
Hautes écoles	23
Héraldique	1
Histoire	44
Homéopathie	1
Homes/Foyers	15
Horlogerie'	6
Hôtellerie	13
Indigence	98
Industrie	10
Information	27
Informatique	65

Keyword	Yield
Ingénierie	15
International	53
Internet	22
Islam	20
Israël	31
Jeunesse	254
Journalisme	24
Langue	17
Le Pérou	4
Littérature	46
Loisirs	6
Lutherie	2
Maltraitance	5
Management	12
Mathématiques	5
Médailles (attribution)	3
Médecine	372
Médecine vétérinaire	4
Médias	21
Médicaments	14
Mer	8
Migration	9
Militaire	25
Mission	11
Montagnes	21
Monuments	2
Monuments historiques	35
Moyen-Orient	12
Musées	64
Musicien/ne	25
Musique	114
Nature	109
Nécessité	122
Népal	17
Oeuvres sociales	63
Olympique	4
Organe de médiation	7
Orphelins	43
Paix	68
Pauvreté	139
Pays (natal)	5
Pédagogie	13
Peinture	19
Pharmacie	5

Keyword	Yield
Philosophie	35
Photo	15
PME	7
Politique	26
Pompes funèbres	2
Pompiers	0
Population de montagne	37
Prévention des accidents	**1**
Prix (attribution)	84
Professions	15
Protection de la nature	70
Protection des animaux	140
Protection des consommateurs	8
Protection des eaux	11
Protection des espèces	24
Protection des sites	14
Protection du clima	22
Protection juridique	16
Rayons	1
Recherche	591
Recherche fondamentale	9
Rééducation	12
Réfugiés	23
Religion	152
Rencontre	12
Restaurant	3
Salarié/e	4
Sauvetage	14
Science	191
Sciences naturelles	21
Sciences sociales	10
Scouts	6
Ski	8
Société	61
Sol/terrain	4
Sources juridiques	2
Soutien	595
Spiritualité	26
Spitex	3
Sport	110
Subventions	3

Keyword	Yield
Suisse	25
Suisses de l'étranger	10
Suisses/Suissesses	8
Syndicat	6
Tanzanie	1
Technologie	107
Télécommunication	8
Théâtre'	16
Tibet	25
Tiers-monde	106
Tourisme	16
Toxicologie	2

Keyword	Yield
Tradition	4
Trafic	15
Transports routiers	5
Travail'	33
Université	33
Urgence	11
Vacances	13
Veuves, veufs'	3
Victimes	12
Vietnam	6
Voyages	5
Vulcanologie'	0

Stage 2: Long list manual review

For each of the 1137 organisations identified, a spreadsheet was developed with a broad description of the organisation's purpose. The broad description was taken from the register kept by the Federal Department of the Interior and translated into English.

Two researchers reviewed the list of organisations to identify those that aimed to provide service to a specific patient population or the health of the general population.

Following this review 267 organisations were marked as potential patient organisations and 1249 were marked for exclusion.

Table 3: Organisation classification for exclusion

Classification
Animal ethics/protection or vegan/vegetarian promotion/food security or access
Cultural events or cultural purpose
Disaster, accident or crisis support
Duplicate
Environment protection
Financial Assistance/Awarding body/Grants
Health service or health service foundation (Including infrastructure)
International organisation - primarily aid, development or emergency-related organisations
Multi-purpose charity
No information available
Professional body/Professional training
Research organisation or foundation
Restricted services to specific members/groups
Social Support/Community Innitiatives

Stage 3: Organisation review for inclusion/exclusion

A final review was conducted on the 267 organisations marked as potential patient organisations. In this review, the website of each organisation was searched to verify that the organisation met minimum criteria as a patient organisation including:

- Organisations that provide information to support a specific patient population or for the general health of the broad population and/or
- Organisations that provide information to services to a specific patient population or for the general health of the broad population (housing and accommodation were excluded as a service) and/or
- Organisations that advocate on behalf of a specific patient population or for the general health of the broad population

A second review of all excluded organisations was also conducted to confirm the classification of the organisation, that is, the reason for exclusion.

Table 4: Organisation classification and yield for inclusion/exclusion

Include/Exclude	Classification	No. of organisations
Include	Patient organisation	107
Exclude	Patient organisation – no website available	77
Exclude	Animal ethics/protection or vegan/vegetarian promotion/food security or access	29
Exclude	Cultural events or cultural purpose	47
Exclude	Disaster, accident or crisis support	15
Exclude	Duplicate	379
Exclude	Environment protection	7
Exclude	Financial Assistance/Awarding body/Grants	94
Exclude	Health service or health service foundation (Including infrastructure)	66
Exclude	International organisation - primarily aid, development or emergency-related organisations	243
Exclude	Multi-purpose charity	66
Exclude	No information available	12
Exclude	Professional body/Professional training	48
Exclude	Research organisation or foundation	207
Exclude	Restricted services to specific members/groups	37
Exclude	Social Support/Community Innitiatives	82

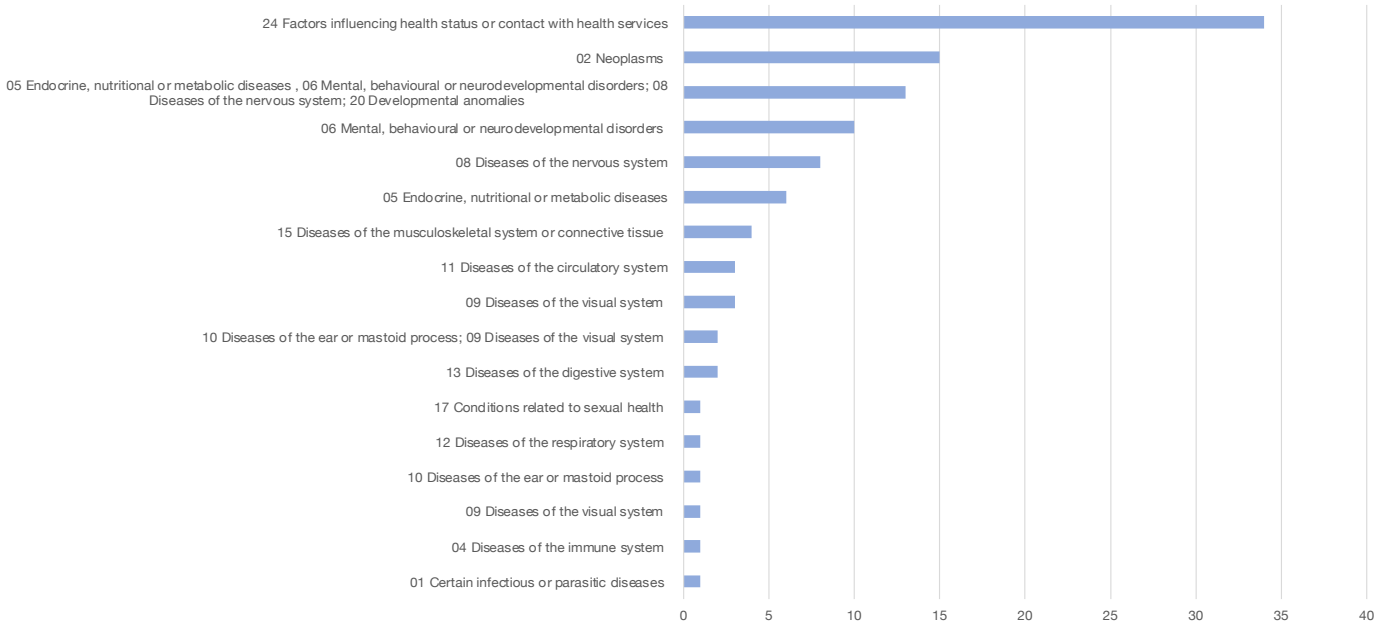
Stage 4: Classification of organisations

A review of the 107 patient organisations was conducted to assign the disease area that the organisation primarily focuses on. This was done using main level of nomenclature from the International Classification of Disease (ICD-11)[2] An additional descriptive classification was also given using common terms for disease areas.

Table 5: ICD 11 classification of organisations

ICD-11 classification	No. of organisations
24 Factors influencing health status or contact with health services	34
02 Neoplasms	15
05 Endocrine, nutritional or metabolic diseases , 06 Mental, behavioural or neurodevelopmental disorders; 08 Diseases of the nervous system; 20 Developmental anomalies	13
06 Mental, behavioural or neurodevelopmental disorders	10
08 Diseases of the nervous system	8
05 Endocrine, nutritional or metabolic diseases	6
15 Diseases of the musculoskeletal system or connective tissue	4
09 Diseases of the visual system	3
11 Diseases of the circulatory system	3
13 Diseases of the digestive system	2
10 Diseases of the ear or mastoid process; 09 Diseases of the visual system	2
01 Certain infectious or parasitic diseases	1
04 Diseases of the immune system	1
09 Diseases of the visual system	1
10 Diseases of the ear or mastoid process	1
12 Diseases of the respiratory system	1
17 Conditions related to sexual health	1

Figure 1: ICD 11 classification of organisations



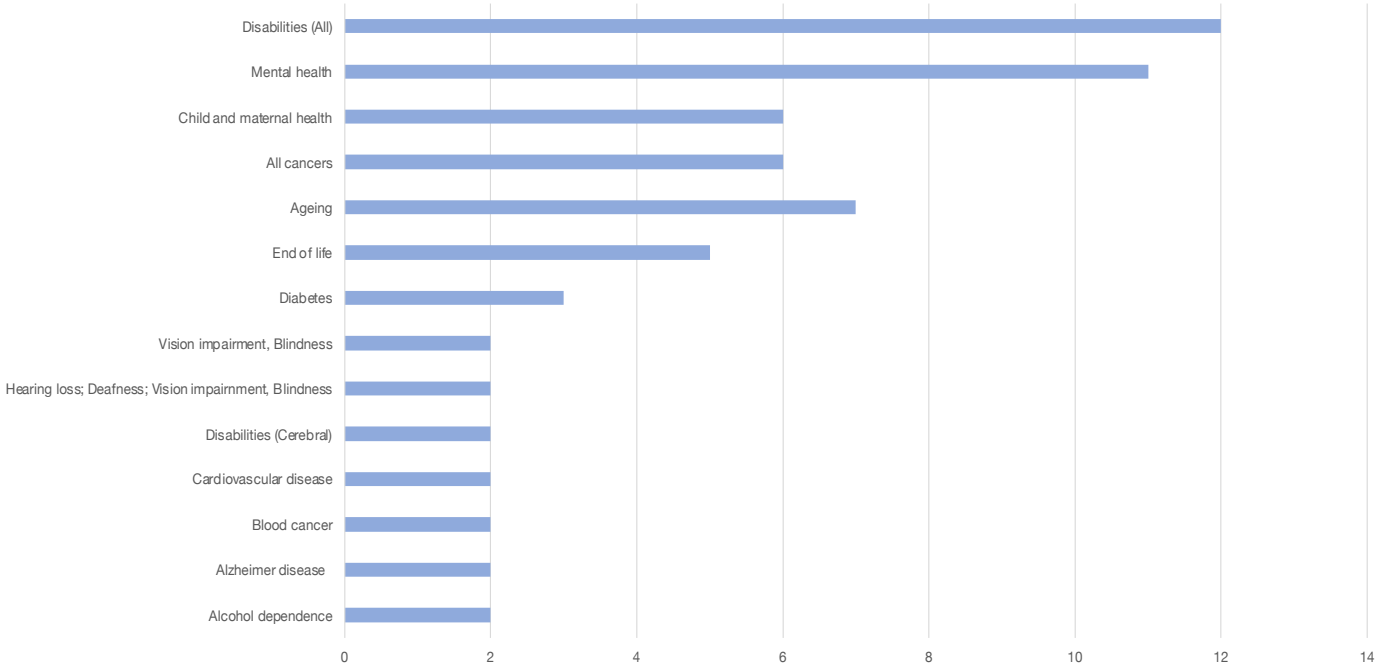
[2] World Health Organization. (2019). *ICD-11: International classification of diseases* (11th revision). Retrieved from https://icd.who.int/

Table 6: General classification of organisations by disease

Organisations by disease	No. of organisations
Disabilities (All)	12
Mental health	11
Ageing	7
All cancers	6
Child and maternal health	6
End of life	5
Diabetes	3
Alcohol dependence	2
Alzheimer disease	2
Blood cancer	2
Cardiovascular disease	2
Disabilities (Cerebral)	2
Hearing loss; Deafness; Vision impairnment, Blindness	2
Vision impairment, Blindness	2
Allergies	1
Ankylosing spondylitis	1
Arrhythmias	1
Asbesdos disease	1
Autism	1
Brain cancer, Schizophrenia	1
Cerebral dysrhythmia	1
Childhood cancer	1
Complementary medicine	1
Corneal disease	1
Dementia	1
Dental healtth	1
Emergency services	1
Epilepsy	1
Exercise and wellness	1
Folic acid	1
Glaucoma	1
Hearing loss, Deafness	1
Injury prevention, Accident prevention	1
Keratoconus	1
Liver cancer	1
Liver disease	1
Lung cancer	1
Marfan syndrome	1
Neuroendocrine tumors	1
Obesity and overweight	1
Organ donation	1
Osteoporosis	1
Ovarian cancer	1
Paediatircs	1

Organisations by disease	No. of organisations
Patient safety	1
Prostate cancer	1
Rare disease	1
Rheumatic disease, Musculoskeletal diseases	1
Sanfilippo	1
Self help	1
Sexual health	1
Spinal Muscular Atrophy	1
Suicide prevention	1
Transgender	1
Viral hepatitis	1
Well being	1
Youth wellbeing	1

Figure 2: General classification of organisations by disease



Future inclusion and national register

As noted, registration in the Register of Commerce is not mandatory for associations having a non-profit purpose. While this audit has only used the federal register, future inclusion of patient organisations will be open to any associations having a non-profit purpose including:

- Organisations that provide information to support a specific patient population or for the general health of the broad population and/or
- Organisations that provide information to services to a specific patient population or for the general health of the broad population (housing and accommodation were excluded as a service) and/or
- Organisations that advocate on behalf of a specific patient population or for the general health of the broad population

These organisations will then be added to the register, with a report of patient organisations in Switzerland updated annually.

An online version of the register of Swiss patient organisations is available at www.cc-dr.org/ch/pon where organisations can be searched by ICD-11 classification, website, disease area, location, and name of organisation.

Annex 1: List of patient organisations within this audit

Patient organisations included from audit
Action FRSA Fondation Romande SourdAveugles
Aladdin-Stiftung
Alter.swiss/Ageing.swiss/Senilita.swiss/Ageir.swiss - Stiftung für das Älterwerden der Menschen
Andreas Weber Stiftung
Bernstein - Stiftung
CXIO Foundation
Diabetes Center Berne Foundation
DIGNITAS Academy
EASL International Liver Foundation
EnableMe Foundation
European Glaucoma Society Foundation
Familie Larsson-Rosenquist Stiftung (Family Larsson-Rosenquist Foundation)
Fondation Diabette Soleil Enfant (FDSE)
FeelGood Präventionsstiftung
Fond'Action contre le cancer
Fondation Anouk
Fondation Art-Therapie
Fondation ASA jfk
Fondation CONTEURS SANS FRONTIERES, Prévention en faveur des enfants et recherche fondamentale sur la cécité
Fondation First Responders
Fondation Harlet Snug
Fondation JAEC (Justice, Action and Education in Compassion)
Fondation just4smiles
Fondation Let it beat
Fondation Mentor Internationale (Mentor International Foundation)
Fondation pour la famille
Fondation Préforma Croix-Bleue romande
Fondation Reload
Fondation Sanfilippo Suisse
Fondation suisse contre le cancer du foie (Schweizerische Stiftung gegen Leberkrebs) (Fondazione svizzera contro i tumori del fegato
forom écoute
Foundation for Cerebral Dysrhythmia (Stiftung für zerebrale Dysrhythmia)
Greenhope Foundation
Guido Fluri-Stiftung
Hans & Annelies Swierstra Stiftung
Hatt-Bucher-Stiftung
Institut Kinderseele Schweiz - Schweizerische Stiftung zur Förderung der psychischen Gesundheit von Kindern und Jugendlichen
Jasmina Soraya Fondation
Krebsforschung Schweiz (Recherche suisse contre le cancer) (Ricerca svizzera contro il cancro)
Les Marmettes FRSA Fondation Romande SourdAveugles
Light for Sight Foundation
Look Good…Feel Better

Patient organisations included from audit
MAKE-A-WISH FOUNDATION OF SWITZERLAND AND LIECHTENSTEIN(MAKE-A-WISH FOUNDATION DER SCHWEIZ UND LIECHTENSTEIN)(MAKE-A-WISH FOUNDATION DE SUISSE ET DU LIECHTENSTEIN)(MAKE-A-WISH FOUNDATION DELLA SVIZZERA E DEL
Manja Gideon Stiftung
Marfan Stiftung (Schweiz), Fondation Marfan (Suisse), Fondazione Marfan (Svizzera), Marfan Foundation (Switzerland)
Pro Pallium - Schweizer Palliativstiftung für Kinder und junge Erwachsene
Pro Senectute
RheumaCura Foundation
Rising Tide Foundation (Rising Tide Stiftung)
Santé sexuelle suisse Fondation
Schtifti Foundation (Stiftung Schtifti) (Fondation Schtifti) (Fondazione Schtifti)
Schweizerische Bechterew-Stiftung
Schweizerische Diabetes-Stiftung
Schweizerische Epilepsie-Stiftung
Schweizerische Gesundheitsstifung Radix
Schweizerische Herzrhythmus-Stiftung (Swiss Heart Rhythm Foundation) (Fondation Suisse du Rythme Cardiaque) (Fondazione Svizzera del Ritmo Cardiaco)
Schweizerische Herzstiftung, Fondation Suisse de Cardiologie, Fondazione Svizzera di Cardiologia, Swiss Heart Foundation
Schweizerische Hilfe für Mutter und Kind (SHMK)
Schweizerische Stiftung für das cerebral gelähmte Kind
Schweizerische Stiftung Pro Mente Sana
SICK CHILDREN FOUNDATION
SK WelcomeHome - Die Transgenderstiftung
Special Olympics Switzerland
Stiftung "Vision Zukunft"
Stiftung aha! Allergiezentrum Schweiz (Fondation aha! Centre d'Allergie Suisse) (Fondazione aha! Centro Allergie Svizzera)(Foundation aha! Swiss Allergy Centre)
Stiftung autismus link - Kompetenzzentrum für Menschen mit Autismus
Stiftung Bonjour (Fondation Bonjour) (Fondazione Bonjour) (Bonjour Foundation)
Stiftung Denk an mich
Stiftung Entschädigungsfonds für Asbestopfer (EFA)
Stiftung Folsäure Offensive Schweiz
Stiftung Freude herrscht
Sttiftung Für Inklusion und Gemeinschaft (Foundatiton Inclusion and Community)
Stiftung für Lungendiagnostik
Stiftung für Patientensicherheit
Stiftung für Schulzahnpflege-Instruktorinnen (SZPI)
Stiftung Humor und Gesundheit
Stiftung Kinder-Brücke
Stiftung Kinderhilfe Sternschnuppe
Stiftung Kinderhospiz Schweiz
Stiftung Leukämiepatientenvertreter (Leukemia Advocates Foundation)
Stiftung Mütterhilfe
Stiftung ORBETAN
Stiftung Osteoporose Schweiz (Fondation Suisse pour l'Ostéoporose) (Fondazione Svizzera per l'Osteoporosi) (Swiss Osteoporosis Foundation)
Stiftung Pro Handicap

Patient organisations included from audit
Stiftung pro Hopespiz
Stiftung Pro offene Türen der Schweiz
Stiftung Prostatakrebsforschung
Stiftung Roger Kessler für das cerebral gelähmte Kind
Stiftung Schweizerische Schule für Blindenführhunde
Stiftung Solidarität mit Sehgeschädigten
Stiftung Sonnenschein - Unterstützung krebskranker Kinder
Stiftung Sonnweid
Stiftung Synapsis - Alzheimer Forschung Schweiz AFS (Fondation Synapsis - Recherche Alzheimer Suisse RAS) (Fondazione Synapsis - Ricerca Alzheimer Svizzera RAS)
Stiftung Wunderlampe (Fondation Lampe Magique) (Fondazione Lampada Magica) (Magic Lamp Foundation)
Stiftung zur Förderung der Knochenmarktransplantation
Stiftung zur Unterstützung der Schweizerischen Alzheimer-Vereinigung
Stillförderung Schweiz, Promotion allaitement maternel Suisse, Promozione allattamento al seno Svizzera, Siwss Promotion of Breastfeeding
Swiss Cancer Foundation (Schweizer Krebsstiftung)
Swiss Cornea Stiftung
Swiss Foundation for Research on Orphan Diseases
Taubblinden-Hilfe
technologies and digital therapeutics
terzStiftung
The Hepatitis Fund
Victory NET Foundation
Viventis Stiftung
Zugang für Alle, Schweizerische Stiftung zur behindertengerechten Technologienutzung (Accès pour tous, Fondation suisse pour une technologie adaptée aux handicapés)