

## **STRATEGY- AND WORK-PLAN OF THE ASSOCIATION EUPATI CH**

### **2017 – 2020**

#### **Introduction / Background**

The "European Patients' Academy on Therapeutic Innovation" (EUPATI)<sup>\*</sup> provided scientifically reliable, objective, comprehensive information to patients on the research and development (R&D) process of medicines. With this education material patients, lay persons, patient advocates or anyone interested can be trained on the medicines R&D processes which eventually will increase the capacity of patients and the lay public to be effective advocates and advisors in medicines R&D processes.

The training material is available as an internet library ([www.eupati.eu](http://www.eupati.eu)) and contains training modules, flyers, presentations, starter kits for trainers and above all, EUPATI offers an expert training course for patient advocates.

To support the wider dissemination and multiply the effect of EUPATI, national platforms in more than 18 European countries have been established. These are led by patients and are composed of representatives of patient organisations, academia and industry and usually work in partnership with regulators or other relevant stakeholders. The EUPATI National Platforms are the main vehicles for implementing the EUPATI project at the national levels.

The Swiss national platform has been transformed into a legal form, an association according to Swiss laws on October 4, 2016, EUPATI CH. Its functional bodies are the General Assembly (GA), the Executive Board (EB), the Auditors and the Advisory Board (AB) (see Annex I).

#### **MISSION of the EUPATI CH association**

We – EUPATI CH – provide access to scientifically reliable, objective, comprehensive information to patients on the research and development (R&D) process of medicines. Thereby we contribute to patient empowerment for active involvement in medicines R&D.

#### **VISION of the EUPATI CH association**

EUPATI CH - Patient input for better medicines!

#### **SWOT Analysis**

Summary of Strengths (S), Weaknesses (W), Opportunities (O) and Threats (T). - To derive potential options/strategic objectives.

*To be developed in near future.*

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## Core Values

Objectivity, transparency, ethical conduct, equity, and independence are vital prerequisites to ensure that EUPATI CH achieves its goals and is accepted and valued by both the patient community and the wider public. Core to this are transparency, independence and trust.

The members of the EUPATI CH serve in their individual capacities as experts in their fields or as representatives of their respective patient organisations, academic or research institutions, health authorities or pharmaceutical companies.

## Strategic OBJECTIVES of the EUPATI CH association and measures

The aims of EUPATI CH are to act as the central point for inquiries and cooperation platform for patient empowerment and involvement in medicines R&D processes in Switzerland:

- (1) To contribute to patient empowerment for active involvement in medicines R&D
- (2) To raise public awareness for the EUPATI education material

In this regard EUPATI CH seeks to cooperate with existing patient organisations without the intention to compete them in any way.

As a consequence, the following measures shall be undertaken or promoted:

Measure (1) EUPATI CH will disseminate the EUPATI education material by several means:

- presentation of EUPATI at events (oral, poster, booth)
- information campaigns (newsletter, social media, flyers, poster),
- training module at events (starter kit use on special topics),
- webinars on specific topics
- support applicants for and during the EUPATI expert training course

Measure (2) EUPATI CH will continuously expand the network to reach a critical mass to cover the different local needs and languages:

- to all geographic regions, in all national languages by organising events and information campaigns in the different regions
- EUPATI CH will address all relevant stakeholders and institutions that can support the reach to a wide public, e.g. patient organisations, media experts, journalists, hospitals, general practitioners, nursing staff, universities and research institutions, regulatory bodies and government departments.
- Increase the membership of EUPATI CH

Measure (3) Establish the EUPATI CH as a sustainable partnership and a key interlocutor for all medicines R&D stakeholders

- Professionalise and stabilise the EUPATI CH Secretariat for effective support
- Secure respective funding (for events and operational costs)
- Increase the, opportunities and public involvement in research in Switzerland
- Establish a database of experts and patient involvement opportunities

## Implementation and Revision of Strategy-Plan

The strategy is defined and adopted by the Executive Board Meeting. The strategy is reviewed every 3rd year or upon request by the Assembly.

## **WORK-PLAN OF THE ASSOCIATION EUPATI CH (and identified task forces)**

To cope with the above-mentioned measures, five main areas for activities were defined in order to structure the work-plan and to reflect potential taskforces responsible for specific activities:

### **1. Administrative management of EUPATI CH and Governance (SCTO, HV)**

- administrative and financial management of EUPATI CH by its secretariat
- management of membership requests, applications and general requests
- administrative support to campaigns, events and trainings
- management of the general assembly
- management of the executive board (EB) and advisory Board (AB meetings)
- ....

### **2. Communication (CS, EJ, support SCTO, MB)**

- Periodic newsletters, social media postings, media releases, website update
- Communication tools: presentations, flyers, posters, factsheets, handouts
- ....

### **3. Events and trainings (MH, LI, HV, AM, collaboration MB)**

- Organising training events, modules,
- Supporting EUPATI expert patients applications and participation
- ....

### **4. Fundraising (RP, support HV & SCTO)**

- Raising funds for events
- Raising operational funds for association and its management,
- ...

### **5. Collaboration with others (PL, LI, HV, AM)**

- Collaboration with pharmaceutical industry (Codex)
- Collaboration with similar platforms (e.g the german speaking D, A and CH national platform exchange group)
- Collaboration with relevant stakeholders in Switzerland: patient organisations, authorities, health care organisations, research groups, education groups...
- ...

## **Implementation and Revision of Work-Plan**

The work-plan is discussed and adopted by the Executive Board Meeting. The work-plan is reviewed every year or upon request by the Assembly and serves to draft or adapt the annual budget.

**Work-Plan 2017 – 2020 - (Priority 1: short / 2: mid / 3: long-term; TF: Taskforce)**

Activity	Deliverables	Date	Measurable indicator	Priority 1/2/3
<b>Communication</b>	Communicate to members and public	periodic	Newsletters, social media, website and media releases;	1
	Communication tools		Poster, roll up, flyers, presentation slide deck, templates	
<b>Participation Opportunities</b>	Patient participation at various occasions	Ongoing	Presentations as patient representative, advocate at events, database of patient experts and involvement opportunities	1
<b>Events and Training</b>	Swiss Patient Forum	27.10.17	Annual full day training & event	1
	Webinar on selected EUPATI toolbox module	Tbd	Live event and recording available on website	1
	EUPATI CH patient / advocate expert level training	Tbd	First Swiss expert patient training adapted to local needs offered	2/3
<b>Administration</b>	Functional secretariat		(10% position)	2
	Annual and financial report	Before GA	Reports	2
	Membership administration and database	Before GA	Number of members	1/2/3
	General Assembly, Executive Board, Advisory Board meetings	Annually	Meetings held	1/2/3
	Consumables and travel funds	annually	Handout material, patient reps. travel covered	1
	Fundraising	Ongoing	Sufficient funds raised to cover administrative expenses and events	1
<b>Total</b>				

<b>Topics of actual interest and need</b>	<b>Subtopics</b>
EUPATI specific topics	<ul style="list-style-type: none"> <li>- Aims and offer of EUPATI</li> <li>- EUPATI toolbox and internet library</li> <li>- What are the other national platforms doing?</li> </ul>
General topics of patient-oriented medicinal research and development	<ul style="list-style-type: none"> <li>- Participation in clinical studies</li> <li>- Patient information</li> <li>- Patients' rights</li> <li>- Health technology assessment (HTA) &amp; Cost- Benefit analysis in medicine</li> <li>- Development and approval of medicines</li> <li>- Research priorities (who, how...?)</li> <li>- Role of ethics committees</li> <li>- Approval of drugs (national, international)</li> <li>- Pricing of medicines (who, how...?)</li> <li>- Academic research vs pharmaceutical research</li> </ul>
Specific health topics	<ul style="list-style-type: none"> <li>- Specific disease and its treatment</li> <li>- Treatment of drug side effect</li> <li>- Role of early diagnosis, screening, prevention (breast cancer, prostate cancer, ..),</li> <li>- Fitness of the immune system: How to measure or strengthen?</li> </ul>
Health policy topics (with respect to Switzerland and research)	<ul style="list-style-type: none"> <li>- General consent, e-consent, e-health, etc.</li> <li>- Personalised medicine, targeted medicine</li> <li>- Medical costs (how to reduce them without losing quality?)</li> <li>- Role of the different players in the Swiss health care landscape</li> <li>- Role of the health insurance funds / insurers</li> </ul>
Patient involvement	<ul style="list-style-type: none"> <li>- EUPATI CH Fellows present themselves and their activities / engagement</li> <li>- Patient involvement in e.g. advisory boards, ethics committees, etc</li> <li>- Advocacy training for patient representatives</li> <li>- Collaboration with the pharmaceutical industry</li> <li>- What is a conflict of interest and can it be omitted</li> <li>- What are patient organisations expecting from EUPATI CH</li> <li>- Requirements for a national coordination platform</li> </ul>

## Annex 1

### EUPATI CH Governance Structure

