

EUPATI Schweiz / Suisse / Svizzera / Switzerland

EUPATI CH Association

(European Patients' Academy on Therapeutic Innovation)

Annual Activities Report of 2020



EUPATI Switzerland – #patientsinvolved, the missing puzzle piece in better medicines

Our vision for the future is informed and empowered patients, actively involved in medicines research and development.

Report date 24.03.2021

Authors Secretariat (Dr Caecilia Schmid) and President (Ivo Schauwecker), Vice-President (Dr Hansruedi Völkle) EUPATI CH

PRESIDENT'S MESSAGE

Dear Members
Dear Sponsors and Donors
Dear Friends of EUPATI CH



2020 was a special and important year in many ways.

For EUPATI CH, it was the year to have the tri-annual (re-)election of the Executive Board. After most important 6 years of establishing EUPATI CH as a strong voice in the patient and public engagement landscape in Switzerland, Hansruedi Völkle stepped back as president. I gained the trust of the EUPATI CH members and humbly stepped into Hansruedi's footprints as president. I am very grateful that Hansruedi was elected vice president and more than half of the board remained for re-election. This is crucial for a continuity of the business. Sametime I also am very happy to have welcomed 3 new members who have been elected for the term 2020-2023.

For us all, it has been a year of adaptation and, for some, dramatic impact on our lives. Many have been affected directly by COVID-19. Too many lost dear family and friends in this year. And all of us had to learn how it is to work and live with very limited personal and physical contact. Also, EUPATI CH could not perform business as usual. The Swiss Patient Forum could not take place in 2020 and the Executive Board did not have an opportunity to meet face-to-face yet in its new constitution.

Last but not least, we also learned again, how important it is and would be (!) to listen more to the directly affected: patients, so called risk-groups, heavily affected "not-at-risk" groups (pupils, students, the young generation), etc. We also realised that despite of quite well organised and involved patient advocates in certain fields, we are far from having an established system to ensure patient and public engagement in general and especially in crisis situations.

Even more important to be able and report for 2020 that the newly elected and consolidated Executive Board of EUPATI CH managed to maintain the main activities of the organisation. We also could rely on the continuing support of the Swiss Clinical Trial Organisation (SCTO) for our back office activities.

More so, we confirmed where the focus should be in the coming two years ensuring that EUPATI CH will remain a sustainable and reliable player in Switzerland. Based on the activities and our statutory mandate, we confirmed three main priority programs:

- 1) Consolidate and activate the network / define priorities of the networking activities and the main stakeholders
- 2) Develop and establish the Swiss Module to educate Swiss based patients, patient advocates, interested public, etc.
- 3) Perform the yearly Swiss Patient Forum

All of this, we can only successfully manage when we have a sustainable financial base to support the regular activities of EUPATI CH (back office) and a stable collaboration with the Stichting EUPATI Foundation.

I hope you enjoy reading the detailed reports on some of the many activities performed by members of EUPATI CH in 2020 in this annual report.

We all look forward continuing the journey with EUPATI CH.



Ivo Schauwecker

President EUPATI CH

PRESIDENT'S MESSAGE	2
ACKNOWLEDGEMENTS	5
FINANCING EUPATI CH	5
MESSAGE OF THE RETIRED PRESIDENT HANSRUEDI VÖLKLE	6
My four years as President of EUPATI Switzerland	6
UPDATE FROM THE EUPATI EXECUTIVE BOARD	9
Association meetings	9
Executive Board.....	9
UPDATE FROM THE EUPATI CH SECRETARIAT	11
Association members.....	11
Membership fees	12
Administrative activities.....	12
Communication activities	12
EUPATI Fellows.....	12
EUPATI CH and the COVID-19 restrictions	13
EUPATI CH ACTIVITIES 2020	13
The "Swiss Patient Forum" 2020 was postponed to 2021	13
EUPATI CH participation and contribution activities in 2020	14
eHealth Suisse working group "patient organisations and health leagues"	14
DayOne Health Hack 2020	14
EUPATI CH stakeholder analysis and networking / collaboration with other organisations	15
Swiss training module	15
EUPATI INTERNATIONAL ACTIVITIES IN 2020.....	16
EUPATI turned into a foundation.....	16
New EUPATI website and Open Classroom training.....	16
OUTLOOK.....	16
FINANCIAL REPORT 2020.....	17
AUDITOR'S REPORT 2020	18

ACKNOWLEDGEMENTS

We wish to sincerely thank all our colleagues of the Executive Board and members for supporting us as well as our EUPATI Fellows for their valuable and constructive cooperation and voluntary contributions.

Very special thanks go to the SCTO who hosts and runs our secretariat and gives us much needed professional support, without which our work would not be possible. We also thank the Positivrat Schweiz for their valuable advice and accepting the presidency of the association.

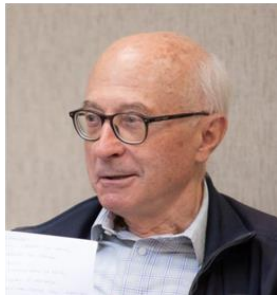
We gratefully acknowledge the pharmaceutical companies (Janssen-Cilag AG, Takeda Pharma AG, Roche Pharma (Schweiz) AG, Pfizer AG and Amgen AG) who support us financially in setting up our communication network and activities, in carrying out the Swiss Patient Forum and in further EUPATI CH projects.

Financing EUPATI CH

Full transparency of our work and how we are funded and what we are doing with the money we get from our sponsors is my personal concern as president. Patient organisations run primarily on great personal commitment and considerable volunteer work from those involved. However, for an organisation like EUPATI CH to be optimally professional and efficient, some funding is necessary. In order to ensure the integrity and independence fitting for EUPATI CH and to avoid adverse influence from third parties, we have established a “Code of Conduct” to regulate cooperation with external sponsors.

MESSAGE OF THE RETIRED PRESIDENT HANSRUEDI VÖLKLE

My four years as President of EUPATI Switzerland



The Swiss platform of EUPATI, hereinafter referred to as EUPATI CH, started in 2013 with the creation of a project group, the so-called National Liaison Team NLT. In the German speaking part of Switzerland, it was introduced to the interested public on December 11, 2014 in Bern and in the French speaking part of Switzerland on March 25, 2015 in Lausanne. The preliminary work began already in 2012 under the aegis of the SCTO, the Swiss Clinical Trial Organisation. Many meetings took place at the «Wildt'sches Haus», No. 13 of Petersplatz, in the medieval center of Basel, at the time headquarter of the SCTO.

On recommendation by David Haerry, I was delegated to this working group as a representative of the Positivrat Schweiz. SCTO was from the beginning the driving force for establishing EUPATI CH, with Caecilia Schmid for the secretariat and Annette Magnin as its director. Further members of the board were Cordula Landgraf, at that time representative of Swissmedic, Cristiana Sessa from the Istituto Oncologico della Svizzera Italiana in Bellinzona and Marie Mi Bonde Hansen from the University Hospital Basel, as well as other representatives from patient organisations, academic research institutions and pharmaceutical industries. We were further encouraged and coached by David Haerry and, from the European umbrella organisation of EUPATI, by Ingrid Klingmann and Matthew May.

The first public event we organised, was a workshop on December 11, 2015 in Bern with 52 participants on the topic: Patient involvement – EUPATI patient academy. It started by a

presentation of EUPATI and its offer for patient training and education, followed by statements on patient involvement by representatives from various health sectors such as patient organisations, research institutions, pharmaceutical industries and authorities.

Foundation of EUPATI CH

The official founding event of EUPATI CH with over 100 participants was then organised in Bern on February 3, 2016. The EUPATI CH Executive Board (EB) was constituted, and I was elected as its President for the first four years of my tenure. Regular general assemblies were held annually (on 26.10.2017, 26.04.2018, and on 25.04.2019), in order to approve the annual reports and accounts, to discharge the EB and to decide over the working program for the following year. My presidency ended with the virtual general assembly on April 23, 2020 (during the COVID-19 shutdown), where I handed over the scepter to my successor Ivo Schauwecker and his newly elected team. To ensure a transition without interruption I decided to remain in the board as vice-president.

Tasks of the EB

The main task of the EB in the early phase consisted in building up the organisation as an association according to Swiss legislation, in positioning it in the Swiss health care landscape, and in establishing a network, but also in consolidating the relationship with EUPATI as our European umbrella organisation and with the neighbouring national platforms of Germany and Austria. The more administrative activities included the association's statutes, business rules, keeping an address list, the production of information materials and the setup of a website in the three national languages, as well as in English. A code of conduct should regulate the relationship between EUPATI CH and its external sponsors. This is of particularly importance to

ensure the independency and autonomy of EUPATI CH that all projects which are carried out with financial support from external sponsors remain our sole property and are conducted under our sole responsibility. This clarification and also a full transparency over all financial aspects of EUPATI CH seemed necessary to refute any suspicions of EUPATI CH being driven by pharmaceuticals and focused solely on the development and marketing of medicines.

Highlights

during my presidency were the three Swiss Patient Forum:

- in 2017 on October 27th in Olten on the topic: *Patient information, what patients want and should know*,
- in 2018 on September 28th in Lausanne on the topic: *Quality of life of patients* and
- in 2019 on October 25th in Bern with the topic: *The digital patient*, i.e. opportunities and challenges of a digitalisation in health care for patients and their health care providers

I took also part in numerous conferences, seminars and training events, which gave me an insight into the various topics and activities going on in the Swiss health care sector. A stakeholder mapping in order to grasp the expectations of the EUPATI CH partners to improve and to optimise our cooperation with them was launched and performed by Cristiana Sessa. Discussions also took place in the EB as to whether and how EUPATI's patient training should be improved by a supplementary module tailored to the specific circumstances of Switzerland in terms of patient involvement and on research, testing and licensing of medicines.

EUPATI Patient Expert Training

From September 2017 to November 2018, I had the chance to complete the EUPATI expert training course on medicines' research and development and on patient engagement requiring more than 200 hours of home-study. The EUPATI e-learning course material, excellently designed in terms of didactics and

content, is focused mainly on drug research, development and testing, on clinical studies, on patient participation in Health Technology Assessment (HTA), on licensing, marketing and post-marketing surveillance of medicines and medicinal products. This course was supplemented and completed by two very stimulating Face-to-Face meetings of 3 days each, where the 50 course participants from all over Europe met in Madrid for presentations, workshops and further trainings. I was fascinated by the cultural and linguistic diversity of Europe, from Portugal to Moldova and from southern Italy and Greece up to Scotland and the Nordic countries.

Patient engagement landscape

It was for me as a pure natural scientist a challenging and exciting time in a new field. It gave me an insight into a network that I hardly knew before. I considered my task primarily in making EUPATI CH known and positioning it, a challenging task given the unbelievable variety of actors and organisations in the Swiss health care landscape. What impressed me the most – and what also showed me the limits of organisations like ours – is the wide range of areas of activity and interests of the various bodies and organisations in Switzerland in this field. Beginning by the authorities such as the FOPH (BAG), Swissmedic and Swissethics, the academic research and the national academies, the hospital-medicine-care sector, the pharmaceutical industries (which show significantly more interest in cooperating with patient organisations than the national authorities), the health insurance companies and the national health leagues, and, finally, the unmanageable variety of patient organisations. Few of them are big, well established, endowed with adequate funding and professionally organised, but most of them are rather small, often consisting only of 2 to 3 volunteers, focused on specific diseases, with only poor resources, are hardly visible and are almost not connected with others. Unfortunately, it is not always a working together, sometimes rather a working side by side or even against each other.

I was, however, impressed by the personal commitment and the quality of this mostly unpaid volunteer work. A limiting factor is that these unpaid volunteers also have to reconcile their commitment in patient organisations with their own professional duties and their families and for many of them, the physical and psychological burden of their own disease is an additional limiting factor.

The future

What seems to me to be indispensable for the future may be summarised in following three points:

First, patients and their organisations should be recognised by the authorities, in particular by the FOPH, as equal partners and should also be supported, promoted and included in health care affairs, and this not only ideally, but also in terms of financial support. This should apply to all areas and processes, starting with establishing health policies and legislation, but also on the prioritisation of research, on cost optimisation, on care and support for patients, on drug development and evaluation and on HTA, provided that Switzerland finally decided to get active in this field. Almost 10 years ago, Swiss parliamentarians called for patient involvement (see patient rights and patient participation in Switzerland – report in fulfillment of postulates 12.3100 Kessler, 12.3124 Gilli and 12.3207 Steiert), but, despite this request having been approved in 2015 by the Federal Council on June 24, nothing has changed so far among the responsible national authorities.

Second, there is a need for a minimum of national coordination among patient organisations so that they can work on and raise their most important concerns in cooperation and to enable them to act together and not against each other. But this requires a certain amount of professionalism and the willingness for cooperation. This, however, wouldn't work without some funding for professional back offices, to realise projects, to conduct seminars and meetings and to reimburse travel and other fees for their participation in scientific

congresses. It is obvious that patient organisations should not only rely on the sole goodwill of the pharmaceutical industries as sponsors, but they should also be supported financially by state organs and offices. Patient organisations make an important contribution to prevention, and it is well known that prevention is better – and in particular cheaper – than cure.

Thirdly, it remains the concern of EUPATI CH to train patients and their representatives to enable them to advise on important questions in medicine and health care and to participate actively in relevant commissions and working groups. It is to be hoped that in the future patients will be perceived more and more as equal partners at the same level. For this purpose, a specific Swiss module should integrate the national specificities in patient involvement, on development, testing and licensing of medicines in the EUPATI expert training material and offer.

My very special thanks go to Cäcilia Schmid and Annette Magnin from the SCTO. Without their professional support through their network and by their offer to run our secretariat, it would never have been possible to run EUPATI CH. I would also like to thank my colleagues from the Executive Board for their active cooperation and constructive discussions and, of course, all members of EUPATI CH for their support and advice. My thanks also go to our sponsors of the Swiss pharmaceutical industries, because only thanks to their financial help EUPATI CH exists and can perform its events, such as the annual Swiss Patient Forum.

During these four years as part of my networking I met many interesting people within the Swiss health care landscape, an enormous enrichment and stimulation for me. I wish Ivo Schauwecker, as my successor as president of EUPATI CH, and his new team in the board, joy, success and fulfilment, but also perseverance and the necessary persistence in making patients concern a reality.

Fribourg, December 2020, Hansruedi Völkle.

UPDATE FROM THE EUPATI EXECUTIVE BOARD

Association meetings

EUPATI CH held four Executive Board meetings in 2020, in February still in person but thereafter due to the COVID-19 pandemic only virtually. The General Assembly 2020 had to be cancelled and instead an online survey and voting was organised for the mandatory agenda items and an Executive Board meeting held instead.

Executive Board

The General Assembly 2020 elected the Executive Board for the term 2020 – 2023, following members were newly or re-elected. Short portraits of each of the members:

Ivo Schauwecker (President, Positivrat, new)



Ivo Schauwecker holds a master degree in biochemistry and has over 25 years of operational experience in international clinical research in the pharmaceutical, medical device, and CRO industry. In recent years, he has also been active in the field of clinical research training and, among other things, he has been significantly involved in the development of the AO PEER programme of the AO Foundation (www.aopeer.org). For the last few years he has been gaining experience as an HIV+ patient and study participant from a patient's perspective.

Hansruedi Völkle (Vice-President, Positivrat)



Hansruedi Völkle studied physics and radiation protection, obtained his PhD, and became Professeur Titulaire at Fribourg University. He worked for many years at the Swiss Federal Office of Public Health in the domain of environmental radioactivity and radiation protection. He was a longstanding member of the board of Swiss Aids Federation (Aids-Hilfe Schweiz) and ran it 2008-2011 as president. He is member of the Positive Council Switzerland (Positivrat) and has been EUPATI CH President 2016-2020. Hansruedi is a trained EUPATI fellow.

Rosmarie Pfau (Lymphome)



Rosmarie Pfau is the founder and president of the Lymphome.ch patient network Switzerland (formerly ho/no). 1999 Rosmarie Pfau was diagnosed with follicular lymphoma and received treatments.

Since 2001 she is running the contact point for lymphoma patients and relatives in Switzerland and she leads four regional lymphoma patient support groups, she is vicepresident of the International Lymphoma Coalition, board member of the KLBB – Krebsliga beider Basel, member of the SAKK Patient Advisory Board and the Swissmedic working group for Patient- and Consumer Organisations. Rosmarie is active in the EUPATI CH Executive Board since its foundation and she is a trained EUPATI Fellow.

Larisa Aragon (Europa Donna, new)



Larisa has experience as a patient, caregiver, and advocate. She is an active member of the Board of [Europa Donna](#) Switzerland and Patient Advisory Board of the Inselspital Bern. She brings professional experience in Product Development, Project Management, Global Quality and Technical Operations in the pharmaceutical industry. Larisa was born in Mexico and studied Master in Business Administration. She is currently enrolled at the University of Bern for the Executive MBA program in Digital Transformation and Marketing Management.

Stephan Schobinger (Myeloproliferativen Neoplasie (MPN), new)



Stephan Schobinger studied human medicine, he obtained a doctorate in human medicine with a dissertation in the field of oncology, awarded in 2005 as FMH Medical Oncology Specialist. He is working at the Inselspital, Clinic for Medical Oncology.

Stephan was diagnosed with a malignant blood disease and was operated. The knowledge of disease as a doctor and patient give him an advantage in the treatment of his patients.

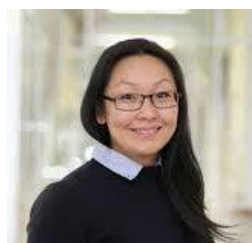
Catherine Bates (Freelance writer, new)



Catherine has a background in the life sciences and worked at Merck Serono/Merck. In this position she led communications with patient advocacy groups and was actively involved with EUPATI since 2012.

Catherine is a Canadian and Swiss national, living in Rolle (VD). She has a Bachelor of Arts from Wellesley College (USA) and an Master in Business Administration from the *Institut d'Etudes Politiques de Paris* (France).

Marie Mi Bonde Hansen (Department of Clinical Research, University Hospital of Basel)



Marie Mi Bonde Hansen studied Human Biology and completed her PhD in molecular pharmacology. Since 2015, she has been working at the Department of Clinical Research (DKF) at the University of Basel and represents the DKF in EUPATI CH as member of the Executive Board since 2016. At the DKF she develops and organises trainings in clinical research, was working as a monitor of investigator-initiated trials and is now responsible for establishing a patient engagement framework at the University Hospital Basel.

Cristiana Sessa (Ente Ospedaliero Cantonale Ticino)



Professor Cristiana Sessa graduated in Medicine and Surgery, followed by a Degree in Pharmacology and a Specialisation in Obstetrics and Gynaecology. She has a Diploma in Palliative Medicine, a Masters in Economics and Health Management, and a Diploma of Advanced Studies in Pharmaceutical Medicine. She has been a Professor at the University of Bern, then at the Oncology Institute of Southern Switzerland.

Since 2014, she has been a member of the Scientific Board of the Swiss Group for Clinical Cancer Research (SAKK). Cristiana Sessa joined the EUPATI CH Executive Board in 2016.

Annette Magnin (SCTO)



Annette Magnin is the managing director of the Swiss Clinical Trial Organisation ([SCTO](#)). She holds a degree in pharmacy and has worked in the field of clinical research for over 20 years. Annette is the delegated Swiss representative in [ECRIN](#) (European Clinical Research Infrastructures Network). She is contributing to multitudinous national and international expert workshops in clinical research, interaction with all relevant stakeholders in clinical research. Annette supported from the beginning the EUPATI movement and is member of the EUPATI CH Executive Board since 2016.

Caecilia Schmid (SCTO, secretariat)



Caecilia Schmid has studied biology and obtained her PhD in Epidemiology. She is the appointed ECRIN European Correspondent for Switzerland, based at the SCTO. She has experience in the coordination, management and implementation of clinical research. Caecilia supported the creation of the national platform since the beginning and acts as the secretary of EUPATI CH.

UPDATE FROM THE EUPATI CH SECRETARIAT

Association members

In 2020, we continued growing and count 38 members, the majority being patient representatives (58%) and academic representatives (31%), however, we also have industry representatives (11%). The members are listed on our [website](#).

Membership fees

The membership fees were agreed by the General Assembly for 2020 to be CHF 30 for individual members and at least CHF 50 for organisations as well as an additional category of “supporters” was introduced. A hardship clause, mentioned in the statutes, is available for individuals who cannot pay this amount.

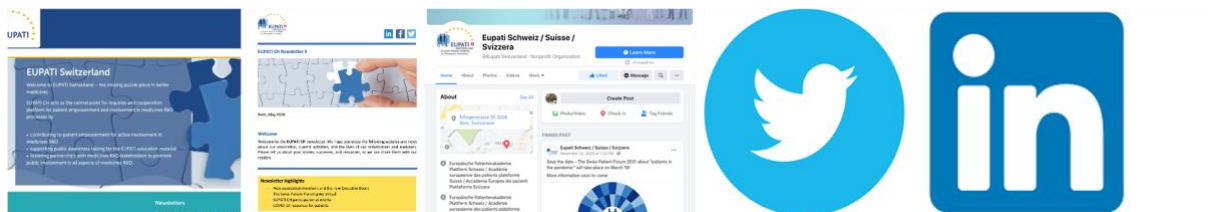
Administrative activities

The [SCTO](#) continued to support the activities of EUPATI CH at the national level by hosting and running the secretariat and fostering networking with the relevant stakeholders in Switzerland. The [Positive Council](#) Switzerland provided the president.

In 2020 too, EUPATI CH and SCTO have increasingly been involved in identifying expert patients for presentations at events, representing EUPATI CH at diverse occasions and contributing to patient advisory boards.

Communication activities

Through 2020 EUPATI CH continued to communicate through diverse channels to the members and the interested public in general. We issued two major newsletters, accessible through the new [EUPATI CH website](#). Through the social media channels we continued to actively spread news and relevant activities and events and training of interest ([Facebook](#), [twitter](#)).



The social media activities of EUPATI CH were supported by some of our members and we owe a huge thank to Steven Bourke for channelling his health communications expertise into creatively and diligently setting up and maintaining our profile on [LinkedIn](#).

EUPATI Fellows

The EUPATI Expert Training Course is an exciting and unique opportunity offering patients and patient advocates expert-level training in medicines research and development. The first editions of the course were a mixture of independent e-learning coursework and face-to-face training events over a 14-month period. Now, the complete course is offered as on-demand in the [Open Classroom](#).

The first Course cycle kicked off in October 2014 and ran until December 2015. The second course started in September 2015 and ended in November 2016. The third expert patient course with 56

participants ended in December 2018. The fourth course has started early 2020 and amongst all applicants there was only one successful Swiss candidate.

The Swiss Fellows are: Rosmarie Pfau (Lymphoma); Florian Klett (Rheumatic diseases), Peter Lack (Paediatric cancer); Hansruedi Völkle (HIV/AIDS); Malena Vetterli (Autoinflammatory diseases), Nicole Gusset (Spinal Muscular Atrophy (SMA)); Max Lippuner (Prostate cancer). They are all portrayed on our dedicated page of our [website](#).

EUPATI CH and the COVID-19 restrictions

As many other teams around the world EUPATI CH also faced major restrictions to physical activities. Our members were absorbed by the workload posed by the coronavirus crisis and thus not able to pursue EUPATI CH projects and trainings for the time being.

The academic representatives are overwhelmed by the vast and uncoordinated amount of new clinical research projects popping up and they strongly promoted the involvement of patients in such projects and undertakings. The patient organisations in turn are overrun with questions and requests from their communities and work on guidelines and tips on how to cope in the current situation, they became a main and reliable source of information.

There is a great deal of conflicting information about the virus and the actions people should take. EUPATI provides a reliable resource designed to provide evidence-based information and tools available to anyone who is interested in combatting the spread of the virus, links to the COVID-19 resources:

- European Patients' Academy ([EUPATI COVID-19 resources](#))
- European Patient Forum ([EPF resource hub](#))
- Patient focused medicine development ([PFMD resource hub](#))
- EURORDIS [COVID-19 Information resource centre](#)

EUPATI CH ACTIVITIES 2020

The "Swiss Patient Forum" 2020 was postponed to 2021



So far, EUPATI CH has been able to hold its flagship event the Swiss Patient Forum three times, twice in German and once in French language. All three events were a great success as they enabled a constructive exchange between patients, their representatives and health professionals.

Such a format of event as face to face was not possible this year because of COVID-19. It should take place again next year, on March 19, 2021, however, this time in virtual form via an internet platform. We will debate on a very topical issue, namely «Patients in a pandemic situation». It will again consist of a workshop reserved for patients and their representatives, as well as a plenary session open to the public where an exchange with health professionals will take place. Further information will be available on our [website](#).

EUPATI CH participation and contribution activities in 2020

The year 2020 brought an abundance of opportunities to participate, contribute, and share EUPATI CH members expertise and experiences, most of them were reported in our newsletters and through the social media. Here we report some highlights.

EUPATI CH through its Executive Board was represented in diverse boards and councils such as in a Roche Advisory Board, SAKK Patientenrat, cancerscreening, SPITEX study and eHealth Suisse working group.

eHealth Suisse working group “patient organisations and health leagues”

In collaboration with patient organisations, health leagues and other non-profit organisations in the health sector, as well as the cantons, [eHealth Suisse](#) has developed an implementation guide for the nationwide electronic patient dossier (EPD). This is intended to support the aforementioned organisations in launching measures with the aim of making the population of the EPD competent. EUPATI CH is represented and actively contributing to this working group through its member Hansruedi Völkle.

The implementation guide considers three target groups for empowerment, for each of which different implementation organisations are suitable and different measures taken: healthy population, patients and vulnerable persons. For the implementation of these measures, the implementation guide contains a list of specific tools, some of which are already available and some of which are recommended for creation.

DayOne Health Hack 2020

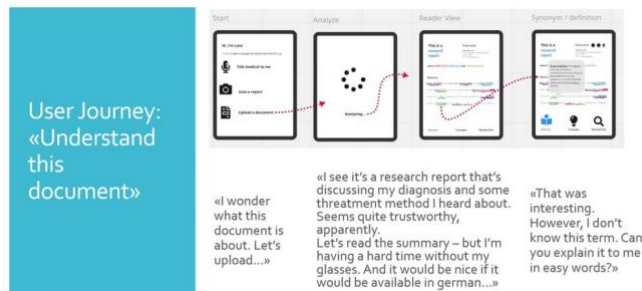
In October and November 2020, the [DayOne Health Hack 2020](#) was successfully implemented as the first patient centric innovation Hackathon in Switzerland organised by the the healthcare Innovation initiative managed by Basel Area Business & Innovation.

Led by patronage partner EUPATI CH and supported by consortia representing all stakeholders of the healthcare ecosystem, patient champions were invited to join teams and to assume an active role in finding new, digital driven solutions and improving healthcare for the better. EUPATI CH member Steven Bourke helped to organise this Hackathon event.

EUPATI CH board member Larisa Aragon participated as a patient champion in an interdisciplinary Hackathon team, the MedJargonBuster team. As one of the winning projects of the DayOne Health Hack they qualified to compete with more than 100 startups to be accepted in the Basel Accelerator Programme for health startups. Their project was selected as one of the six winning teams for a six months programme. The Basel Accelerator Programme offers life sciences ventures a platform to further develop their ideas into sustainable and investible business.

Their innovative project “[WhachaCallitMed](#)” helps patients to better understand their own health situation.

Larisa Aragon summarises the value of their digital solution for patients:



“Our software solution [MedJargonBuster](#) transforms complex medical information (e.g., personal health reports, scientific research studies) into clear and simple words using natural language processing and machine learning algorithms, which are automatically translated into any foreign language.

Thus, our mission is to empower patients and their families with easy to understand medical knowledge so that they can take better decisions together with their care teams.”.

If you are interested in MedJargonBuster, please get in contact with [Larisa](#).

EUPATI CH stakeholder analysis and networking / collaboration with other organisations

EUPATI CH has initiated a stakeholder analysis to better understand the expectations and needs of our stakeholders and to be able to design targeted activities. The stakeholder analysis was performed by our Executive Board member Dr Cristiana Sessa in the frame of her ECPM master thesis. The diverse stakeholders were asked about their views and perceptions on the role of EUPATI CH in an online survey and later in face-to-face interviews.

Clearly, the stakeholders agree that patient involvement requires more and better empowerment of patients and the public in order to establish a constructive interaction, mutual trust and better understanding of clinical research results that matter for patients and the public. As diverse as the stakeholders were, so were their expectations of EUPATI CH, which certainly cannot all be met. However, some of the recommendations for EUPATI CH are taken seriously and implemented such as clear communication on the mission, structure, financial support and relationship with pharmaceutical industry.

The main mission of EUPATI is to train patients to empower them for participation.

As a consequence, and also in view of targeted fundraising, EUPATI CH has established a working group to further determine the main stakeholders. The focus will be on fundraising with an objective to secure financial resources for specific projects but also to provide a continuous and sustainable back-office support. We need to focus on our needs and at the same time be realistic with the currently available resources to perform a professional networking and fundraising.

Swiss training module

EUPATI CH has initiated with a small working group the development of a Swiss module to educate patients in clinical research with a focus on Swiss specific aspects. A concept was developed and approved by the Executive Board. As a next step, potential collaboration partners will be contacted to plan the development and roll-out of the Swiss Module which is based on the available [EUPATI training material](#).

EUPATI INTERNATIONAL ACTIVITIES IN 2020

EUPATI turned into a foundation

EUPATI has become a foundation under Dutch law, the “Stichting EUPATI Foundation”, and has published its business model as well as the new governance structure and associated strategy and workplan.

The national platforms are [members](#) in the Foundation and the first General Assembly was held on September 17, 2020. Each national platform has delegated three representatives to attend. Working together, national platforms raise awareness about the important role of patients, and members identify challenges and opportunities for joint action.

New EUPATI website and Open Classroom training

EUPATI has redesigned its website to accommodate the integration of the EUPATI website with the diverse trainings, the toolbox and the national platforms' websites into one site. The look comes clean and fresh, have a peak at the [EUPATI website](#).

The EUPATI Patient Expert Programme has been transformed into an online, on-demand learning opportunity on the [EUPATI Open Classroom](#) platform. The EUPATI Open Classroom is freely accessible and can be explored and browsed for the content without registering.

OUTLOOK

In 2021, EUPATI CH will continue raising awareness, including for the education material, and to promote training of patient representatives to empower them for active engagements.

EUPATI CH will work on the stakeholder networking and targeted fundraising for a sustainable financing of its back office and its activities.

EUPATI CH will develop and deliver a Swiss training module.

At the same time, we strive to maintain the level and quality of the communications activities and expect that a continuing sponsoring can be secured.

Also, in 2021, EUPATI CH will hold the Swiss Patient Forum in Q1.

In addition, we want to build on the commitment, knowledge, and experience of our fellows and association members and propose ways for them to get more involved and support the Executive Board and secretariat.

On an international level we will continue the collaboration and contribution to the EUPATI Foundation and regional group activities (German and French speaking platforms' activities) which will not only strengthen the network of the national platforms, but also provide us with a unique opportunity to learn and profit from others.

FINANCIAL REPORT 2020

EUPATI CH annual financial report 2020

Accounts 01.01.2020 - 31.12.2020

Balance sheet 10.03.2020

1. Income	2019	2020
Membership fees	1'230.00	1'452.47
Sponsoring Swiss Patient Forum	6'000.00	6'000.00
Sponsoring Communication	10'000.00	0.00
Donation (Roche)	850.00	0.00
Sponsoring Stakeholder analysis	0.00	0.00
<i>Total income</i>	18'080.00	7'452.47
2. Expenses		
The Swiss Patient Forum (excl. Overheads)	12'347.75	0.00
Communications activities (excl. Overheads)	4'547.60	3'372.20
Stakeholder analysis (excl. Overheads)	0.00	1'667.00
Overheads use EUPATI CH (travel, fees, rent, meetings)	6'389.08	520.85
<i>Total expenses</i>	23'284.43	5'560.05
Total income	18'080.00	7'452.47
Total expenses	23'284.43	5'560.05
<i>Total profit margin/ loss of profits:</i>	-5'204.43	1'892.42

Balance as per 31.12.2020

Account balance PC 89-565298-4	14'746.24
Deferred charges to income	
Deferred charges to expenses	6'199.40
Capital of the association	
	8'546.84

4. Association assets	CHF
Asset as per 30.12.2019	13'488.81
Asset as per 30.12.2020	8'546.84
<i>profit margin / loss of profits :</i>	-4'941.97

AUDITOR'S REPORT 2020

I hereby confirm, to the best of my knowledge, that the 2020 annual financial statements accurately reflect the EUPATI CH account at PostFinance and its bookkeeping.

The Auditor proposes the discharge of the members of the Executive Board and the secretary of EUPATI CH for their activities during the association and financial year 2020.

Date: 15th March 2021

Brigitte Franke-Bray
Treasurer IFAPP