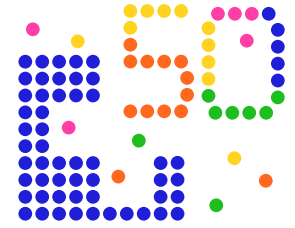


50 years of Childhood Cancer Registration

Past, Present, and Future

21. – 22. August 2026

Bern



Program

Friday, August 21

09:00 – 09:30	Registration and welcome coffee
09:30 – 09:45	Welcome and opening remarks <i>Angèle Gayet-Ageron, Director, Institute of Social and Preventive Medicine, University of Bern, Bern</i> <i>Linda Nartey, Deputy Director, Federal Office of Public Health</i> <i>Ursula Kuehnel, Executive Coordinator, Childhood Cancer Registry, Bern</i>
09:45 – 11:15	Childhood cancer registration – how it started, why we need it, what comes next? How childhood cancer registration started in Switzerland <i>Nicolas von der Weid, President Swiss Pediatrics, University Children's Hospital Basel</i> From data to impact: Opportunities in childhood cancer registration <i>Claudia Kuehni, Head, Childhood Cancer Registry, Bern</i> Incidence and survival: Is childhood cancer on the rise and how good are we at curing it? <i>Marina Haller, Childhood Cancer Registry, Bern</i> Childhood cancer incidence trends in international perspective: observations from Germany <i>Friederike Erdmann, German Childhood Cancer Registry, Mainz, Germany</i> Use of hospital & routine data for cancer epidemiology - hopping on the high-speed data train? <i>Fabiën Belle, Childhood Cancer Research Group, ISPM, Bern</i>
11:15 – 11:45	How registry data inform research, policy, care and patients: 1-minute flash talks as "appetizers" for the poster session
11:45 – 13:00	Poster session with lunch
13:00 – 14:50	In search of environmental causes of childhood cancer Research on environmental causes of childhood cancer in France: the GEOCAP research program <i>Stéphanie Goujon, French National Registry of Childhood Cancers, Inserm CRESS, Paris, France</i> Pesticides, agricultural crops, and childhood cancer risk in France <i>Aurélien Danjou, French National Registry of Childhood Cancers, Inserm CRESS, Paris, France</i> Research on environmental causes of childhood cancer in Switzerland: an overview <i>Ben Spycher, Environmental & Spatial Epidemiology Research Group, ISPM, Bern</i> New evidence on PFAS exposure and childhood cancer risk <i>Catherine Metayer, UC Berkeley School of Public Health, Berkeley, US</i>
14:50 – 15:30	Ice cream and coffee break
15:30 – 16:15	Future perspectives Quality of care and the role of the Childhood Cancer Registry <i>Katrin Scheinermann, President Swiss Pediatric Oncology Group, Children's Hospital of Eastern Switzerland, St. Gallen</i> Cancer registration – Why keep a focus on children? <i>Claudia Kuehni, Head, Childhood Cancer Registry, Bern</i> The future of cancer registration – patient and family perspective <i>Paul Castle, Patient advocate</i>
16:15 – 17:00	Panel discussion <i>Petra Baeriswyl, Federal Office of Public Health; Rhoikos Furtwängler, Inselspital Bern; Paul Castle, Patient advocate; Katrin Scheinermann, Swiss Pediatric Oncology Group; Claudia Kuehni, Childhood Cancer Registry</i>
17:00 – 18:00	Apéro riche
18:00 – 19:30	Social program

Saturday, August 22

08:30 – 09:00	Arrival and coffee
09:00	Welcome <i>Prof. Claudia Kuehni, Head, Childhood Cancer Registry, Bern</i>
09:00 – 10:30	What data can offer – Genetic predisposition, biobanks, omics and novel treatments Childhood Cancer Predispositions: when genes go crazy and cause cancer <i>Nicolas Waespe, Inselspital, University Children's Hospital Bern and University of Geneva</i> Multi-cancer early detection <i>Kevin Oeffinger, Duke Cancer Institute, Durham, US</i> KidsCan – a molecular cancer database, and what the registry can offer <i>Raffaele Renella, Lausanne University Hospital CHUV or Jean-Pierre Bourquin, University Children's Hospital Zurich</i> Biobanks and genetic data <i>Marc Ansari, Geneva University Hospital and CANSEARCH Research Platform, Geneva University</i>
10:30 – 11:00	Coffee and snacks
11:00 – 13:00	Life after cancer – research on long-term health The Swiss Childhood Cancer Survivor Study – from registry data to long-term health <i>Grit Sommer, Childhood Cancer Research Group, ISPM, University of Bern</i> Cardio-oncology: early screening and preventive therapy <i>Christina Schindera, University Children's Hospital Basel</i> Safeguard from further cancers: breast cancer screening in the young <i>Kevin Oeffinger, Duke Cancer Institute, Durham, US</i> Psycho-social outcomes – why it is important to address them in follow-up care <i>Gisela Michel, University of Lucerne</i> The survivor and family perspective <i>Laura Kundert and Christine Jean, Kinderkrebs Schweiz, Basel</i>
13:00	Closing remarks, followed by standing lunch <i>Prof. Claudia Kuehni</i>
14:00 – 15:30	SCCSS investigator meeting (for all investigators and those interested)

Registration:



Kinderkrebsregister
Registre du cancer de l'enfant
Registro dei tumori pediatrici
Childhood Cancer Registry

Venue:

University of Bern, von Roll Area
Fabrikstrasse 6, 3012 Bern, Room 003
/ Room 001
Bus Nr 20 from railway station
Stop "Länggasse"

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**UNIVERSITÄT
BERN**

Organizing committee:

Prof. Dr. Claudia Kuehni
Prof. Dr. Ben Spycher
PD Dr. Grit Sommer
Ursula Kuehnel, MA, HIM
PD Dr. Fabiën Belle
PD Dr. Christina Schindera
PD Dr. Nicolas Waespe

Welcome to the 50th anniversary of the Swiss Childhood Cancer Registry.

Over the past five decades, the childhood cancer registry has grown from a visionary initiative of Swiss pediatric oncologists into the first national cancer registry in Switzerland and an internationally recognized research infrastructure. By systematically collecting high-quality data on every child diagnosed with cancer in Switzerland, it has documented the burden of disease, supported clinical trials and epidemiological research, and contributed to improvements in survival and long-term outcomes.

These achievements have only been possible through the commitment of many partners: children and families who shared their data, clinicians, researchers, registry staff, public authorities, and funding organizations. Together, they have shown that routine health data are not merely administrative records—they are the foundation for better treatment, better care, and better outcomes.

This symposium brings together experts from Switzerland and abroad to reflect on five decades of progress, discuss new scientific developments, and explore how health data, genomics, environmental research, and digital innovation can further improve the lives of children with cancer and survivors. We hope these two days will inspire new ideas, strengthen collaborations, and help shape the next chapter of childhood cancer research and care.

The organizing committee

Prof. Dr. Claudia Kuehni; Prof. Dr. Ben Spycher; PD Dr. Grit Sommer; Ursula Kuehnel, MA, HIM;
PD Dr. Fabiën Belle; PD Dr. Christina Schindera and PD Dr. Nicolas Waespe



Prof. Dr. med. Nicolas von der Weid, University Children's Hospital Basel

Prof. von der Weid is a Swiss pediatric oncologist dedicated to clinical care with a research focus on long-term complications of childhood cancer and its treatment. In the early 90'ies, he was involved in the early digitalization of patients' data and so built the first steps of the Swiss Childhood Cancer Registry. Prof. von der Weid worked in different Swiss pediatric oncology units all over Switzerland, earning a broad view of the domain in our country. Between 2005 and 2011, he was the President of the Swiss Pediatric Oncology Group (SPOG). In the last 15 years, Prof. von der Weid has been the Head of the Pediatric Hematology-Oncology Division at the University Children's Hospital of Basel (UKBB) and the President of Childhood Cancer Switzerland, a national umbrella organization uniting all stakeholders in Switzerland. Since 2025, he is also the President of the Swiss Society of Pediatrics.



Prof. Dr. med. Claudia Kuehni, Childhood Cancer Registry, Bern

Claudia Kuehni, pediatrician and epidemiologist, is a Professor of Pediatric Epidemiology at the University of Bern, where she heads the Childhood Cancer Registry and the Swiss Childhood Cancer Survivor study. Since joining the Registry in 2004, she has led its development into a population-based database and a national platform for research on childhood cancer. Her work focuses on cancer epidemiology, survivorship, and the long-term health of childhood cancer survivors. She has initiated and coordinated numerous national and international studies on cancer incidence, treatment outcomes, late effects, and quality of life. Through the Registry, her research provides evidence to improve clinical care, follow-up, and health policy for children, adolescents, and adults affected by childhood cancer.

Marina Haller, Childhood Cancer Registry, Bern

Marina Haller is a statistician and research associate at the Institute of Social and Preventive Medicine (ISPM), University of Bern. She works with the Swiss Childhood Cancer Registry (ChCR) and the Environmental and Spatial Epidemiology Research Group. She holds a BSc in Statistics and an MSc in Data Science, with a particular focus on statistical modelling and visual analytics. Her research uses childhood cancer registry data to investigate trends in incidence and survival, as well as environmental, spatial, and other factors that may influence the occurrence of childhood cancer. At the Swiss Childhood Cancer Registry, she contributes to national cancer monitoring and reporting, conducts statistical analyses, and prepares findings for scientific and public-health dissemination.



PD Dr. Friederike Erdmann, German Childhood Cancer Registry, Mainz, Germany

PD Dr Friederike Erdmann is an internationally experienced childhood cancer epidemiologist with a background in public health and epidemiology. She heads the Research Group on Etiology and Inequalities in Childhood Cancer and serves as Co-Head of the Division of Childhood Cancer Epidemiology at the University Medical Center Mainz, Germany, which hosts the longstanding German Childhood Cancer Registry. Throughout her career, her research has focused on exploring the role of environmental, social and psychosocial factors across the childhood cancer continuum. She has extensive experience in establishing, leading and contributing to multidisciplinary international research consortia and has served as an invited expert for WHO, IARC and several national organizations.

PD Dr. Fabiën Belle, Childhood Cancer Research Group, ISPM, Bern

PD Dr. Fabiën Belle leads the Pediatric Hospital Routine Data research team at the Institute of Social and Preventive Medicine (ISPM) Bern. Since 2025, she is the co-PI of the Growth study, a retrospective European cohort study investigating nutritional status from birth to adulthood in childhood cancer patients and survivors by reusing routinely collected clinical data. She leads two working groups of the International Guideline Harmonization Group (IGHG) and coordinates two nested projects within SwissPedHealth, the pediatric national data stream of the Swiss Personalized Health Network (SPH). She is a nutritional epidemiologist, trained at Wageningen University, Netherlands and Fred Hutchinson Cancer Research Center, Seattle, US.



Dr. St  phanie Goujon, French National Registry of Childhood Cancers, Inserm CRESS, Paris, France

With a background in biostatistics, St  phanie Goujon joined Inserm in 2001. Holder of a PhD and a French Habilitation to Supervise Research (HDR), she conducts research on environmental risk factors for childhood cancers within the OPPaLE team (Obstetric, Perinatal, Pediatric Life course Epidemiology) at the Research Center in Epidemiology and Statistics (CRESS, UMR 1153). She also contributes to the team's leadership as Deputy Co-Director. Her research is based on the GEOCAP program ('Geolocalisation des cancers p  diatriques'), of which she is the Principal Investigator. Linked to the French National Registry of Childhood Cancers (RNCE), GEOCAP's main objective is to study the influence of environmental exposures on the risk of childhood cancers in France, using geocoded data and a Geographic Information System.

Dr. Aur  lie Danjou, French National Registry of Childhood Cancers, Inserm CRESS, Paris, France

Aur  lie Danjou is a cancer epidemiologist (PhD), specialized in the research of environmental risk factors. After her postdoctoral fellowship at the International Agency for Research on Cancer, where she notably worked on the etiology of testicular cancer in young men, she joined Inserm (CRESS UMR 1153) in 2022. Since then, she has developed research related to the assessment of GIS-based environmental exposures within the GEOCAP program and the French national registry of childhood cancers, looking at pesticides and per- and polyfluoroalkyl substances (PFAS), and their impacts on the occurrence of pediatric cancers.



Prof. Dr. Ben Spycher, PhD, Environmental & Spatial Epidemiology Research Group, ISPM, Bern

Ben Spycher is Professor of Environmental and Spatial Epidemiology at the University of Bern. His research focuses on the causes of childhood cancer, with particular emphasis on environmental risk factors, spatial epidemiology, and advanced statistical methods. Since joining the Swiss Childhood Cancer Registry more than 20 years ago, he has led studies linking registry, census, and environmental data to investigate childhood cancer risk. His work has advanced understanding of ionizing radiation, air pollution, parental occupational exposures, and geographic variation in childhood cancer. Through national and international collaborations, he contributes to methodological advances and epidemiological research that strengthen the evidence base for childhood cancer prevention.

Dr. med. Catherine Metayer, UC Berkeley School of Public Health, Berkeley, US

Dr. Metayer is Professor Emerita at the University of California Berkeley, School of Public Health, Division of Epidemiology where she led the Center for Integrative Research on Childhood Leukemia and the Environment. Prior to joining UC Berkeley, Dr. Metayer was a scientist at the US National Cancer Institute, Division of Cancer Epidemiology and Genetics. She previously served as Chair of the Childhood Cancer and Leukemia International Consortium. She recently joined the University of Paris, School of Medicine as a Professor in Epidemiology and Chair in Pediatric Oncology Research at the Centre for Research in Epidemiology and Statistics. Her work primarily focuses on environmental, dietary, and genetic risk factors of childhood leukemia and testicular cancer. She collaborates with researchers at the intersection of various omics including genetics, epigenetics, and metabolomics.



Prof. Dr. med. Katrin Scheinemann, President Swiss Pediatric Oncology Group, Children's Hospital of Eastern Switzerland, St. Gallen

Prof. Dr. med. K. Scheinemann, MSc, is a board-certified pediatric oncologist/hematologist with over 25 yrs of experience in the field, who has trained and has had staff positions in Switzerland, Canada and Germany. Currently she works as the division head of pediatric oncology/hematology at the Children's Hospital in Eastern Switzerland. Her research focus is in the area of pediatric neurooncology and survivorship care as well as AYA oncology with an own research group – the LACC (Life after childhood cancer) research group. She has published over 140 peer reviewed papers and has edited two books in the field of pediatric oncology. She has/had many national and international leadership positions including president of SPOG (Swiss Pediatric Oncology Group), Vice-president of Oncosuisse, immediate past chair of PanCare and chair of the SIOPE BTG (Brain tumor group) – just to name a few.



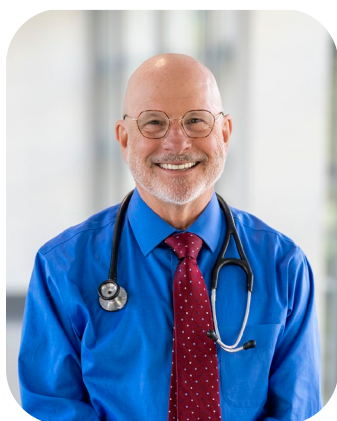
Paul Castle, Patient advocate

Queuing for lunch can have unexpected side effects. He's forgotten what he ate, but Paul Castle knows that chatting in the queue started his activities in childhood cancer. During 12 years as a Trustee of the Basel CC Foundation, he met the CC Registry team and many other wonderful allies. Paul is now on the CCR's Panel of Experts and a patient advisor. His son, who had leukemia as a teenager, is a lawyer, enjoying married life and long-distance cycling. Paul retired from a modest career in the life sciences sector in 2024. He was a rowing commentator at five Olympic Games and prefers reggae to Rachmaninoff. Food queues continue to play an important role in his life: volunteering at a food bank reminds him how fortunate he has been. Paul lives with his wife and dog near Basel. Last year, two of these three became grandparents.



PD Dr. med. Nicolas Waespe, Inselspital, University Children's Hospital Bern and University of Geneva

Nicolas Waespe, PD, MD, PhD, is a Swiss board-certified pediatric hematologist/ oncologist and senior physician at Bern University Hospital, where he leads the outpatient clinic and established the multidisciplinary pediatric cancer predispositions program. His research focuses on cancer predispositions, second neoplasms after childhood cancer, and genetic modifiers of treatment-related toxicities. He established BISKIDS, Switzerland's national germline DNA biobank for childhood cancer, and initiated the associated GECCOS study with the CANSEARCH research platform, Geneva. He set up QUOCCAS, which includes germline genetic testing for all newly diagnosed cancer patients in Bern. He chairs the SIOP Europe Host Genome Working Group and serves on the boards of the Swiss Society of Pediatric Hematology and Oncology, and Childhood Cancer Switzerland.



Dr. Kevin Oeffinger, Duke Cancer Institute, Durham, US

Dr. Kevin Oeffinger is the Director of the Duke Cancer Institute (DCI) Center for Onco-Primary Care and Professor of Medicine with Tenure at Duke University. He has a long track record of studying the late effects of childhood cancer therapy and conducting intervention studies aimed at improving the long-term outcomes of cancer survivors.

Prof. Dr med. Dr. phil. Raffaele Renella, Lausanne University Hospital CHUV

Prof. Dr med. Dr. phil. Raffaele Renella, FRCPCH, is Head of the Pediatric Hematology-Oncology Unit at the Centre Hospitalier Universitaire Vaudois (CHUV), and Associate Professor at the University Lausanne, Switzerland. Since 2026, he is the Co-Director of the National Center of Competence in Research (NCCR) entitled "Children & Cancer", a national effort supported by the Federal Department of Economic Affairs, Education and Research and the Swiss National Research Fund, and co-lead by the Universities of Zurich and Lausanne. His research spans the molecular pathogenesis and therapy of childhood cancers incl. neuroblastoma, and rare blood disorders, including bone marrow failure syndromes and myelodysplasia.



Prof. Dr. med. Dr. sc. nat. Jean-Pierre Bourquin, University Children's Hospital Zurich

Jean-Pierre Bourquin is Professor of Pediatric Oncology at the University of Zurich and Head of the Department of Oncology, Hematology, Immunology, Stem Cell Transplantation and Somatic Gene Therapy at the University Children's Hospital Zurich. Trained in Zurich (MD-PhD) and at the Dana-Farber Cancer Institute, he leads a translational program on treatment resistance in childhood acute leukemia. His group combines patient-derived xenograft models, functional genomics and single-cell drug response profiling to identify actionable dependencies of oncogenic fusion transcription factors and of the resistant leukemia niche. He chairs the Resistant Disease Committee of the I-BFM Study Group. Since 2026 he directs the NCCR Children and Cancer, which sets national priorities for childhood cancer research from fundamental biology to clinical translation, toward a national institute for childhood cancer research.

Prof. Dr. med. Marc Ansari, Geneva University Hospital and CANSEARCH Research Platform, Geneva University

Prof. Marc Ansari is a Swiss physician with more than 25 years experience in the medical field and specifically in the fields of pediatric hematology, oncology, and precision medicine (genetics). He studied in both Switzerland and Scotland and has worked in hospitals in France, Switzerland and Canada. In 2012, Prof. Ansari was appointed to become the head of the pediatric hematology-oncology unit of the Geneva University Hospital (HUG). In 2011, he created the first pediatric hematology and oncology research platform at the Geneva Medical School (CANSEARCH research platform). To stabilize this research activity he created the CANSEARCH foundation for children suffering from cancer. Currently, Prof. Ansari is head of the hematology-oncology unit of the Geneva University Hospital and director of the CANSEARCH research laboratory at the University of Geneva.



Dr. med. Lara Chavaz, Geneva University Hospital and CANSEARCH Research Platform, Geneva University

Lara Chavaz is an MD-PhD student at the CANSEARCH Research Platform (HUG, Geneva), under the supervision of Prof. Marc Ansari. Her work focuses on platinum-induced ototoxicity in childhood cancer survivors, combining a clinical and genomic approach (GECCOS cohort) with in vitro mechanistic studies on auditory cell models. She is a member of the international SILENCED consortium and collaborates notably with Inserm, Institut Gustave Roussy, and the Princess Máxima Center Utrecht.

PD Dr. Grit Sommer, Childhood Cancer Research Group, ISPM, University of Bern

Grit Sommer leads the Data Request Unit at the Swiss Childhood Cancer Registry (SCCR) and heads the research team of the Swiss Childhood Cancer Survivor Study (SCCSS). She holds a PhD in biochemistry from the University of Leipzig, Germany, and completed postgraduate training in statistics at the University of Bern. Since 2010, her research has focused on childhood cancer epidemiology, particularly long-term outcomes. Her current work investigates longitudinal trajectories in survivor quality of life to detect early declines, supporting timely intervention within medical and psychosocial survivorship care. She is involved in international research collaborations through the PanCare network and the International Guideline Harmonization Group and contributes registry data to global initiatives including CONCORD 4, CRICCS, and ENCR.



PD Dr. med. Christina Schindera, University Children's Hospital Basel

Christina Schindera is a pediatric hematologist and oncologist at the University Children's Hospital Basel and a research group leader at the Institute of Social and Preventive Medicine. She completed her training in pediatrics and pediatric hematology/oncology in Bern and Basel and completed clinical and research fellowships at The Hospital for Sick Children in Toronto, Canada, and Duke University Medical Center in Durham, North Carolina, USA. During her PhD at ISPM, she established the CardioOnco Study, a prospective multicenter cohort study conducted in six university and cantonal hospitals in Switzerland. Her research focuses on the long-term cardiovascular health of childhood cancer survivors, focusing on prevention and early detection of treatment-related cardiovascular disease.

Dr. med. Severin Fankhauser, Childhood Cancer Research Group, ISPM, University of Bern

Severin Fankhauser is an MD-PhD student at the Institute of Social and Preventive Medicine (ISPM), University of Bern, under the supervision of PD Dr. Christina Schindera. His research focuses on cardiovascular health in childhood cancer survivors, with a particular interest in the early detection of cardiac dysfunction and determinants of long-term cardiovascular health. He is part of the Swiss CardioOnCo study, a prospective multicenter cohort investigating cardiovascular late effects in adult survivors of childhood cancer.



Prof. Dr. Gisela Michel, Faculty of Health Sciences and Medicine, University of Lucerne

Gisela Michel holds a PhD in psychology. In 2003, she spent one year as a visiting scholar at the New York University, USA, before starting to work in the Swiss Childhood Cancer Registry. From 2007 to 2009, she spent two years as a post-doctoral research fellow at the University of Sheffield, UK, and then returned to the Institute of Social and Preventive Medicine at the University of Bern with an Ambizione Grant of the Swiss National Science Foundation. Since 2013, she is a professor and since 2024 the Vice President for Teaching and International Relations at the University of Lucerne. Her research is focused on psychosocial aspects of childhood cancer, including mental health in survivors, organisation of follow-up care or development of evidence-based guidelines for follow-up care. In addition, she addressed how the families of children with cancer are affected by the disease.



Christine Jean, Kinderkrebs Schweiz, Basel

Christine Jean leads the Support Service for Parents of Survivors at Childhood Cancer Switzerland. As the mother of a daughter who was diagnosed with a brain tumor over twenty years ago and continues to live with late effects, Christine understands the long-term impact of childhood cancer from personal experience. Alongside this lived expertise, she brings many years of professional experience in the field, having previously served as Executive Director of Kinderkrebshilfe Schweiz, a member organization of Childhood Cancer Switzerland. She is passionate about supporting parents with empathy, understanding and practical guidance as they navigate life after treatment. Her goal is to ensure that no parent feels alone in the survivorship experience and that every family has access to expert, family-centered support when they need it most.



Laura Kundert, Kinderkrebs Schweiz, Basel

Laura Kundert leads Public Affairs & Communications at Childhood Cancer Switzerland, where she amplifies the voices of children and adolescents affected by cancer, Survivors, and their families. With a background in political science and health policy, she combines strategic communication, public affairs and advocacy to raise awareness of childhood cancer and improve support for those living with and beyond the disease. Her work spans media relations, stakeholder engagement, social media, and multilingual content development, translating complex medical and policy topics into accessible, human-centered stories. She collaborates closely with healthcare professionals, policymakers, patient organizations and international partners to strengthen the voice of the childhood cancer community. Her goal is to ensure that no child, Survivor or family feels unseen or unheard throughout treatment and in life after childhood cancer.





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Social Program

After a stimulating day of science and discussion, we invite you to join us for an informal evening in Bern.

City walk through Bern

Discover the historic center of Bern on a relaxed guided walk. Explore the city's landmarks, charming streets, and unique atmosphere while enjoying the evening with fellow symposium participants.

Aare River Swimming

For excellent swimmers only. Experience one of Bern's most iconic summer traditions and take a refreshing swim in the Aare River.

Please note that swimming in the Aare requires strong swimming skills and familiarity with river conditions. In case of strong currents, this event will be cancelled or held elsewhere.

When: From 18.00 after the apéro riche

Meeting point: Catering area

Organizing committee:

Prof. Dr. Claudia Kuehni

Prof. Dr. Ben Spycher

PD Dr. Grit Sommer

Ursula Kuehnel, MA, HIM

PD Dr. Fabien Belle

PD Dr. Christina Schindera

PD Dr. Nicolas Waespe

