artistsinlabs.ch

Zürcher Hochschule der Künste
Institute for Cultural Studies in the Arts

Universität Zürich
Institut für Biomedizinische Ethik und Medizingeschichte

Institute for Regenerative Medicine • IREM

CALL FOR PROJECT SUBMISSIONS for a
artists-in-labs residency in 2019 / 2020
on the topic:
THE PERSISTENCE OF MEMORY – DEMENTIA AND DIGITAL AID TOOLS FOR DECISION-MAKING
at the
Institute of Biomedical Ethics and History of Medicine IBME (University of Zurich)
and the
Institute for Regenerative Medicine IREM (University of Zurich)

Sophie Calle, *Last Seen*, 1991

The artists-in-labs program offers a 6-months residency at the intersection of art, medicine and the humanities

Applications for this Residency are open for:

- artists from all disciplines, from Switzerland and worldwide. The application may be written in German or English.

RESIDENCY PERIOD: November 2019 – April 2020
The exact dates can be defined in consultation with the team of the artists-in-labs program.

APPLICATION DEADLINE: 25th of August 2019

PLEASE SEND YOUR APPLICATIONS INKL. PORTFOLIO (MAX. 8 MB) TO: ail.program@zhdk.ch (or via wetransfer.com)

If you have any questions, you are welcome to contact the AIL-team via **ail.program@zhdk.ch**

Supported by VELUX STIFTUNG

The art-science residency *The Persistence of Memory – Dementia and Digital Aid Tools for Decision-Making* offers the unique opportunity for artists of all disciplines to exchange and work for 6 months with researchers of the Institute of Biomedical Ethics and History of Medicine (IBME, UZH) in Zurich as well as medicines, researchers and patients at the Institute of Regenerative Medicine (IREM, UZH) in Schlieren and to develop an artistic project.

- The residency's unique setting opens up the possibility for a transdisciplinary dialogue that is brought about by juxtaposing concepts and procedures, cultural knowledge and backgrounds
- The residency offers significant time and space to reflect upon ideas and to explore a range of scientific topics, methods and technologies in a broad field of medical disciplines and medical humanities
- During the residency the artist will be immersed in the research and working alongside scientists from IBME and the IREM
- There will also be a coordinator at both IBME and IREM available to the artist for more general issues

On the subject of residency

Dementia is one of Switzerland's major social, cultural and health policy challenges. Today, 148,000 people with Alzheimer's disease or another form of dementia live in Switzerland. The ageing of the population will lead to a sharp increase in the number of people suffering from dementia in the coming decades. The experiences of other people with the same diagnoses, treatments or decisions have always been a valuable source of information for people facing a new diagnosis or a health-related decision. Digital media as sources of information create new opportunities and approaches to generate and harness knowledge, ideas and resources.

Researchers at the **Institute of Biomedical Ethics and History of Medicine (IBME)** at the University of Zurich are investigating the possibilities and consequences of digitalization and other issues related to dementia. A current project at IBME is the Swiss database DIPEx for patient narratives, which will serve as a basis for so-called digital decision-making aids in the future. The new database offers a systematic collection of interviews with female patients and to be made available to the public via video and/or audio sequences on the Internet in the near future. The patients' reflections on their everyday lives in connection with health and illness are collected in narrative interviews and made available via established methods of qualitative social research.

At the **Institute for Regenerative Medicine (IREM)** – also part of the University of Zurich - the focus lies on “advancing molecular life sciences into next generation bio-inspired therapies at the interface of degeneration and regeneration with a major focus on the most relevant human diseases, including neuro-degeneration and cardiovascular disease.”

In an exchange with researchers, doctors and patients, the artist will deal with the various aspects of the research and treatment as well as patient narratives. As a team member, he/she observes, thinks along, exchanges, questions and critically examines the contents of the research from the perspective of his/her own artistic practice and develops an artistic project from this.

Background - The artists-in-labs program

This art-science residency is conducted and monitored by the **artists-in-labs program (AIL)** research group at the Zurich University of the Arts (ZHdK). The ZHdK is the leading institution for this project and responsible for its **conception, curation and management**.

- Since 2003, the AIL has been facilitating artistic research by way of long-term residencies for 54 artists in 21 scientific laboratories and research institutes in Switzerland and worldwide (as of 2019)
- It is part of the Zurich University of the Arts (ZHdK) and promotes sustainable transdisciplinary and cross-border collaborations as well as the development of new knowledge by providing artists with an opportunity to critically engage with the sciences and their experimental and aesthetic dimensions
- This includes explorations of the site of the laboratory, as well as a range of scientific topics, methods and technologies. Publications and short documentary films record the processes and results of these collaborations and offer reflections on them
- All the collaborations the AIL produces are presented at various national and international exhibitions, symposia and workshops, making it possible to share findings and ideas, and to provide accessible discussions and aesthetic experiences to our students, peers and to the public.

The AIL will coordinate and document the residency. As case studies and part of their own research, the AIL will monitor and evaluate the experiences of the artist and scientists through interviews and will compare procedures, processes and methodologies of the projects. Towards the end of the residency period a video documentary of each residency will be produced including interviews with the artist and the scientists at the laboratory.

www.artistsinlabs.ch/en

www.zhdk.ch

The artists-in-labs residency “The Persistence of Memory – Dementia and Digital Aid Tools for Decision-Making” is supported by the Velux Stiftung.

VELUX STIFTUNG

Research at the INSTITUTE OF BIOMEDICAL ETHICS AND HISTORY OF MEDICINE (IBME), University of Zurich

www.ibme.uzh.ch

Statement from Prof. Dr. Med. Dr. phil. Nikola Biller-Andorno, head of IBME:

With an ever-growing range of medical and biotechnological possibilities offered to us, there is a need to critically reflect on past developments, current options and future visions in medicine and health care from an ethical and historical perspective. This is what our Institute is dedicated to.

The results of our research and analyses are not only made accessible in academic journals. We also see it as our task to foster public discourse and engage in policy-making. As a WHO Collaborating Center, the IBME is also concerned with health ethics issues at a global level.

Another core task of our team is teaching, mainly in the medical school. We aim to provide our students with the knowledge and skills they need as future physicians and health care professionals. We are also involved in continuous medical education and postgraduate training. Since 2009, the IBME hosts the medical track of the interfaculty PhD program "Biomedical Ethics and Law".

Finally, we also offer advice when ethical questions arise at the University or the University Hospital and are regularly involved in the ethics review of research proposals.

At our Institute, we work as an interdisciplinary group at the interface of health care, science and society. The Center for Medical Humanities, a platform that was established at the IBME in 2014, provides space for an exchange on health care from broader perspectives from social sciences, humanities, and the arts.

Patients' and Family Caregivers' Illness Experience of Alzheimer's: A Narrative Approach

Summary of the project (10/2018 – 9/2020)

Understanding how patients and family caregivers are impacted by Alzheimers disease (AD), and how they perceive care management models can provide a basis for developing more appropriate clinical interventions. Therefore, the purpose of this module is to build an archive of individuals' experience of living with Alzheimer's or caring for a loved one who has AD. To do this, it is necessary to ascertain the views of the various stakeholders in contact with AD. This study will explore, in-depth, the perspective of patients and family caregivers regarding AD; the barriers and challenges in managing caregiving tasks, their views on the support provided to family caregivers, and depressive symptoms of caregivers.

Therefore, this study combines a systematic collection and analysis of interviews with patients and family caregivers about their experience of AD and/or dementia. Our Swiss Database of Individual Patients' Experience of illness (DIPEx) will provide a methodologically rigorous collection of interviews about patients' and family caregivers' real-life experiences and presents them as video- and/or audio-sequences on an online portal open to the public. Patients' recollections of their lives regarding health and illness and family caregivers' experiences with caregiving tasks are collected through narrative interviews. These are subsequently evaluated according to an established method of qualitative social research and prepared for dissemination to the public by means of an online patient narratives platform.

Basic research questions from IBME for the artists-in-labs residency “The Persistence of Memory”:

- How can patients’ and relatives’ narrations (available as video, audio and text in German, French and Italian) best be used to support important decisions Alzheimer patients and their families have to make (e.g. regarding care at home vs. nursing home or the content of an advance directive)?

- How can we use digitalization and artificial intelligence to produce the most useful tools for patients, surrogate decision-makers and providers (e.g. by predicting treatment preferences at the end of life)?

- How can we use the narrative materials to inform policy makers and the broader public about issues that Alzheimer patients and their families encounter?

- How can we produce educational materials that foster empathy and understanding of Alzheimer patients (e.g. simulators)?

Project leader

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Gesundheitserfahrungen

alzheimer
Schweiz Suisse Svizzera

Research at the INSTITUTE FOR REGENERATIVE MEDICINE (IREM), University of Zurich

www.irem.uzh.ch

The Institute of Regenerative Medicine (IREM) has the mission to advance molecular life sciences into next generation bio-inspired therapies at the interface of degeneration and regeneration with a major focus on the most relevant human diseases, including neurodegeneration and cardiovascular disease.

One part of the institute is the clinical Center for Prevention and Dementia Therapy, which is a cooperation between the Institute for Regenerative Medicine and the Psychiatric Hospital of the University of Zurich. Here we conduct clinical trials in Alzheimer’s disease and long-term prospective cohort studies to identify factors that contribute to cognitively healthy aging. Furthermore, we offer a diagnostic workup and treatment of neurocognitive disorders with a strong focus on Alzheimer’s disease. Alzheimer’s disease is now seen as a disease in which pathology accumulates over decades before the first clinical symptoms occur. The first clinical symptoms are usually problems in recollecting recent events. In the course of the disease, these problems become more severe and a variety of additional symptoms occur, finally leading to dependence on care in many important aspects of everyday life. The disease has a profound impact on the life of the patients and their relatives who face constant challenges of adapting to changes in cognition, behavior, abilities, activities and relationships. Creating something that resists these changes or facilitates the adaptions may be vital for the patients and their relatives.

In collaboration with the Institute of Biomedical Ethics and History of Medicine, we conduct research on relevant ethical questions that go along with our work: What motivates our study participants to support research? What aspects of our studies matter the most to their decision to participate in our studies? How may the attitude and reactions of relatives and Health Care Professionals affect experiences of dignity among patients with early diagnosis of neurocognitive disorder? How precisely does a surrogate decision maker estimate what a patient would want?

With respect to the project “Persistence of Memory”, we would be very interested in artistic projects

- that help in providing opportunities to sustain important memories for the person that suffers from a progressive neurocognitive disorder as for relatives and friends.
- that try to make the loss of memory and the connected feelings artistically accessible to healthy relatives, carers and society in order of better understanding the patient’s situation.
- that reach out for new models of expression and communication between patients, families and HCPs.

Dr. Anton Gietl, Chief of Service and Leader Clinical Studies, Dr. Ute Hock, Research Associate