

# Colloquium

Institute for Regenerative Medicine (IREM) in collaboration with  
Wyss Translational Center Zurich (Wyss Zurich), Regenerative  
Medicine Technologies Platform

## Interdisciplinary Colloquium Regenerative Medicine I

**Tuesday, 29<sup>th</sup> August 2017 at 12:30 – 1:30 pm,  
Kleiner Hörsaal OST,  
University Hospital Zurich**

**Prof. Ernst Hafen**

**Institute of Molecular Systems Biology, ETH Zurich**

### Data to the People – MIDATA Personal Data Cooperatives

Health data are stored and controlled by physicians, clinics, hospitals, labs, pharmacies, insurance companies and government agencies in innumerable, incompatible data silos. The quantity and complexity of these data is rapidly expanding, from innovations such as mobile apps, sensor and tracking devices, and affordable genome sequencing. Citizens (individuals with medical needs and healthy persons) lack access and control over their own data. This dysfunctional – and unsustainable – data model substantially increases the cost and reduces the quality and effectiveness of healthcare globally. Moreover, personal data fuel a rapidly expanding data economy and thereby augment the socio-economic asymmetries and digital dependencies from multinational companies. For a fair and sustainable data economy it is vital that citizens gain control over the use of their personal data. Such a control is also prerequisite for personalized healthcare that requires large complex datasets from millions of people. To regain digital self determination, citizens need a constitutional right to a digital copy of all their personal data. Furthermore, they need a trust-promoting framework to actively share their personal data for research, personal services and the common good. We posit that such a framework consists of a secure cloud-based open source platform that is governed by citizen-owned not-for-profit MIDATA cooperatives. On such a platform citizens store, manage and fully control access to their individually encrypted data sets. The revenues from citizen-controlled data sharing are invested in platform maintenance, data services and projects the serve the common good. Data sharing use cases (e.g. patient follow-ups, drug safety studies, wellness, and rehabilitation services) are build around dedicated smartphone apps with which citizens/patients can collect and share data. These apps can be developed by third parties with for-profit-business models. The first MIDATA cooperative and its data platform are operational in Switzerland and currently tested with patient-outcome studies. Plans to build MIDATA cooperatives in Germany, The Netherlands, UK, Ethiopia and Vietnam are currently being developed. Through a network of linked MIDATA personal data cooperatives citizens and patients are empowered to manage and share their own data and contribute to the democratization of the personal data economy.

**Organiser:** Prof. Dr. Dr. Simon P. Hoerstrup

**Execution/Chair:** Dr. Steffen M. Zeisberger

IREM & Wyss Zurich, Univ. of Zurich and ETH Zurich