

# The SwiSCI Biobank – a Swiss multicenter rare disease biobank for spinal cord injury cohorts

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## INTRODUCTION

A spinal cord injury (SCI) is a rare condition with traumatic SCI incidence in Switzerland at 21.7 per 1 million population per year. It can accelerate the onset of some common multifactorial diseases.

Even with improved and earlier medical intervention, specialized rehabilitation and regular follow ups, all of which have contributed to improved survival, the longevity and quality of life of SCI individuals still remains below that of the general population.

The longitudinal multicenter Swiss SCI (SwiSCI) cohort study aims to better understand and support SCI individual's "functioning, health maintenance, and quality-of-life". Consequently, the SwiSCI Biobank launched in 2016 as a strategic supporting resource.

The SwiSCI Biobank recruits participants from specialized rehabilitation centers in Switzerland and generates high quality samples for use in both translational and clinical studies.

The biobank can be classified as a rare disease cohort, cross-sectional & longitudinal biobank. It is governance, ethics, and quality accredited and collaborates with the national Swiss Biobanking Platform.

## MULTI CENTER APPROACH

The SwiSCI biobank is established at Nottwil in the Swiss canton of Luzern. It is closely connected to the SwiSCI study center and the SwiSCI database. The first donation came from SPC, followed by Clinique Romande de Réadaptation (CRR) Sion and REHAB Basel.

Patient recruitment in SPC is undertaken by a clinical trial unit (CTU). In the other centers, research assistants are responsible for recruitment. Patients whom consent to donate biospecimens sign a specific consent with further use. This means, the processed samples can be used for SCI projects that are reviewed and approved by ethics committees beforehand.

The specimens from CRR are processed on site, frozen and shipped on dry ice, whilst the specimens from REHAB are transported to Nottwil via an express courier and processed at the SwiSCI Biobank.

Specimens from patients recruited at the SCI Center at Balgrist University Hospital in Zurich are stored in the Swiss Center for Musculoskeletal Biobanking (SCMB) at Balgrist Campus.

Further, the SwiSCI biobank is associated applicant to theNetwork (SPHN) grant proposal of the Inselspital Bern in order to establish an IT infrastructure to compare diagnostic reference values of specific patient populations in Switzerland. In addition, the head of the SwiSCI Biobank is a member of the liquid biopsy expert group of the Swiss Health Study (SHeS) launched by the Bundesamt für Gesundheit (BAG), the Swiss federal office of public health.

The Swiss Biobanking Platform (SBP) in Lausanne is the national coordinator for Swiss biobanks. They have developed the Solution for Quality Assessment and Normalization (SQAN) process. This includes an accreditation process with three different levels: VITA (law, governance & ethics), NORMA (standardized process & resource management) & OPTIMA (standardized quality assurance management). The VITA label is mandatory for all Swiss biobanks in order to be part of the SBP network.

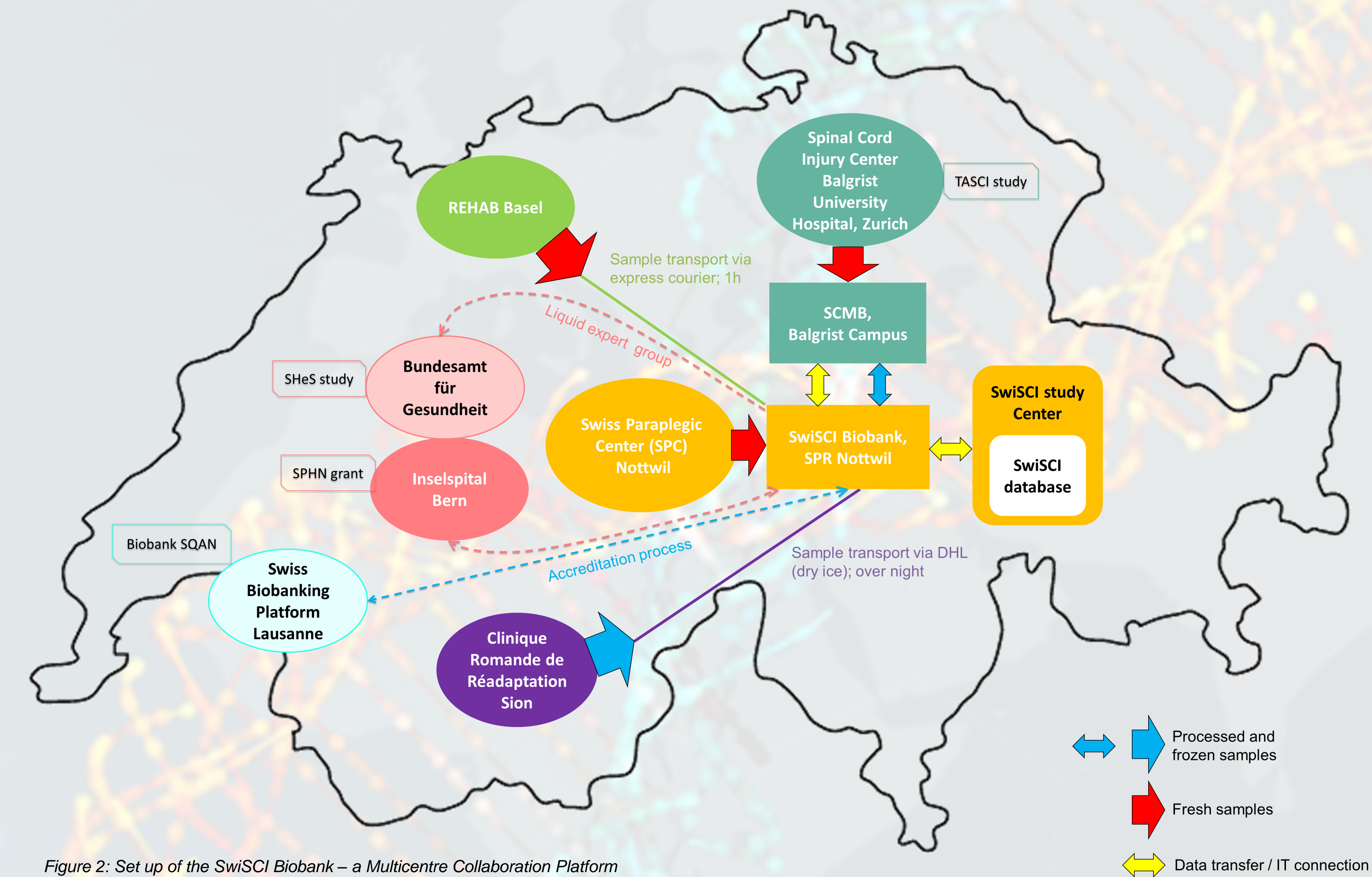


Figure 2: Set up of the SwiSCI Biobank – a Multicentre Collaboration Platform

## METHODS

Primary biospecimens are blood and urine. Biospecimens are processed and stored according to validated SOPs derived from CEN/TS (EU) and ISO standards.

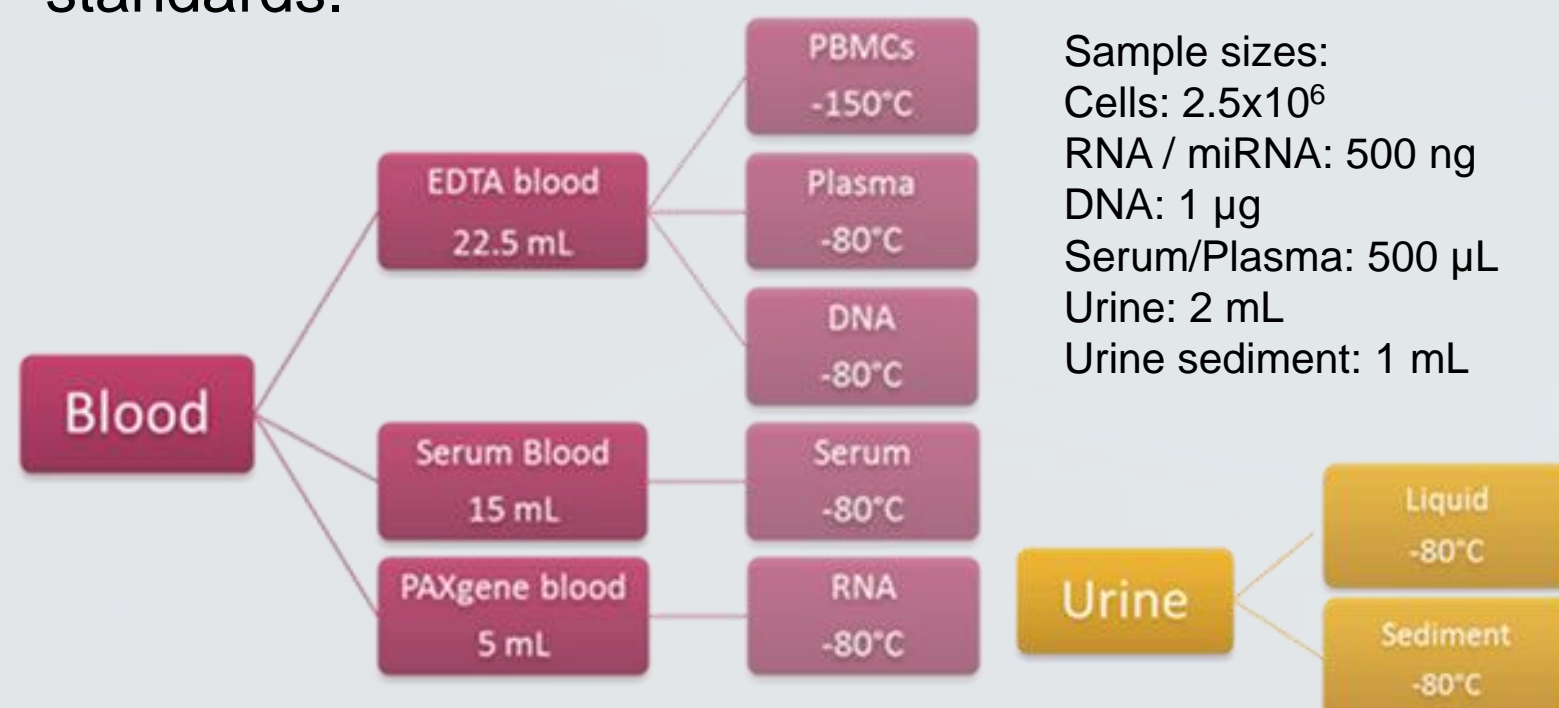


Figure 1: Biobank Processing Workflows

Quality management: Needle to freezer tracing, use of standards, quality control of RNA, DNA, immune cells (PBMC).

Research data derived from samples is linked to SwiSCI panel data, and in the future, to clinical databases.

## MILESTONES

- 1<sup>st</sup> specimen collection: SPZ – Jun 2016; CRR Sion – Aug 2018; REHAB Basel – Jan 2019.
- Accreditation: VITA – Feb 2019; NORMA – Jan 2020

	SCI Donors (27 <sup>th</sup> Oct '20)	Start of Rehab	End of Rehab
<b>Total</b>	<b>148</b>	<b>134</b>	<b>99</b>
SPC	91	85	68
CRR	32	27	19
REHAB	21	21	11

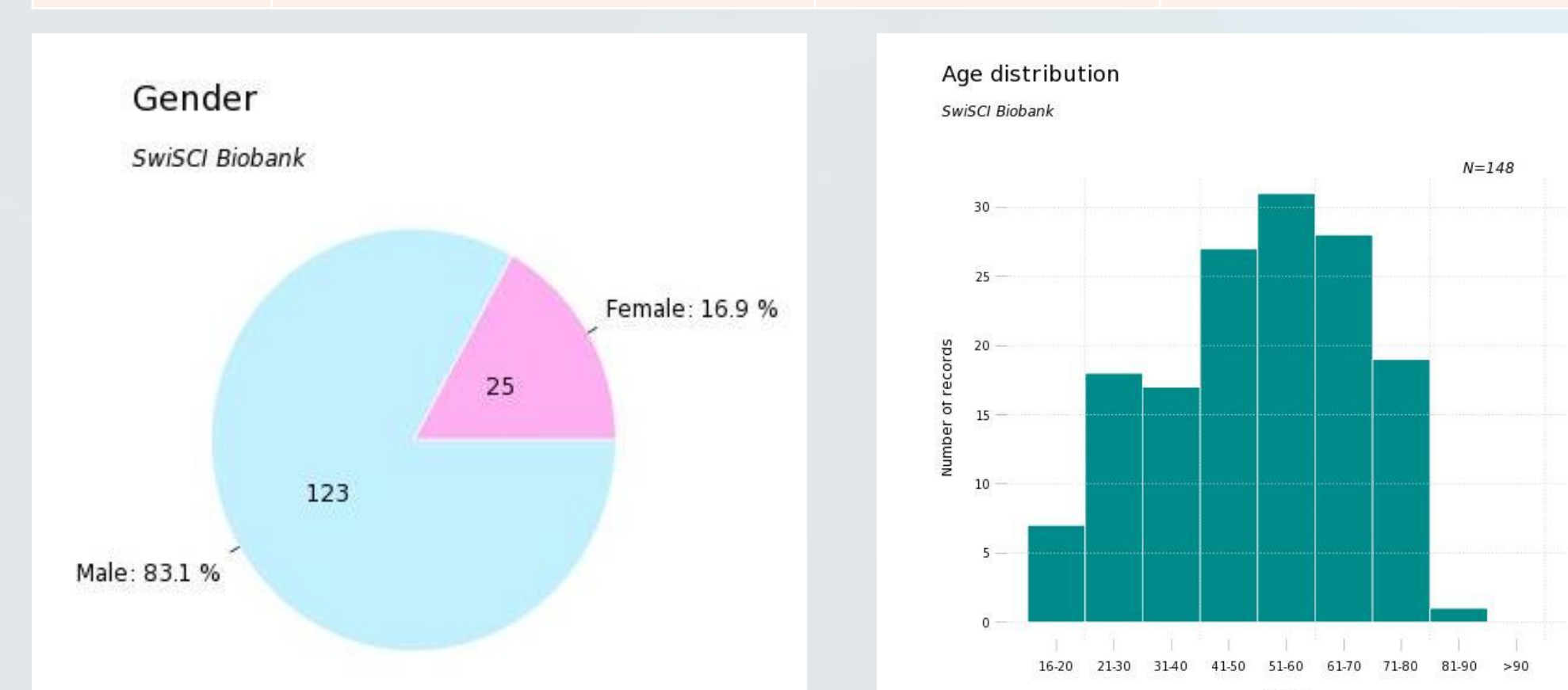


Table 1 & Figure 3: SwiSCI Biobank Donor Characteristics

## CURRENT PROJECTS

- 1) Uro-Vaxom RCT against SCI urinary tract infections (UTI).**
  - A study on the efficacy of a vaccine intervention to reduce UTI risk.
- 2) The "transcutaneous tibial nerve stimulation in acute SCI" (TASCI), RCT for the prevention of bladder dysfunction.**
  - A SCI increases the risk of bladder dysfunction, which often worsens over time and is associated with risk to kidney function and quality of life. This study investigates the effect of early TTNS on bladder dysfunction after acute SCI.
- 3) Biomarkers of aging & stress: linking the body and the mind.**
  - The high prevalence of chronic psychological stress may be correlated to reduced longevity and increased risk of early age related co-morbidity onset. Psychological stress will be longitudinally correlated to biomarkers of stress & aging.
- 4) Evaluation of incidence and predictors for the development of pain following SCI.**
  - Neuropathic pain is often a outcome of a SCI. This study will longitudinally model self reported pain, quantitative sensory testing, laser evoked potentials and putative biomarkers of pain.

## OUTLOOK

Planned projects include:

- 1) Formal accreditation as biobank infrastructure to support 3<sup>rd</sup> party SCI projects
- 2) Determining SCI clinical reference values as part of the Swiss Personalized Healthcare Network (SPHN) collaboration.
- 3) Observing and correlating testosterone and several other sex hormones over time against SCI patient characteristics

## CONTACT & ACKNOWLEDGMENTS

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