

## Press release

Zurich, February 22nd 2013, 6 pm

### An End to the Odyssey

University Children's Hospital Zurich, University of Zurich, and University Hospital Zurich joining efforts in the fight against rare diseases

*A new clinical research priority program of the University of Zurich was launched today at the Children's Hospital Zurich: radiz – the Rare Disease Initiative Zürich. radiz is led by Prof. Matthias Baumgartner from the division of metabolic diseases of the Children's Hospital Zurich under the auspices of the Children's Research Center. radiz aims to bridge the gap between basic and clinical research by building a strong interdisciplinary network of researchers and clinicians focused on rare diseases in Zurich.*

A disease is considered rare when fewer than one in 2'000 persons is affected. Today, more than 7'000 rare diseases are known. Approximately five to eight percent of the global population are affected, usually already in childhood. In Switzerland, an estimated half million patients suffer from rare diseases – the equivalent of approximately the entire population of the cities of Zurich and Winterthur combined. Rare diseases often lead to a grave impairment of health and are very difficult to diagnose. Patients and their families often embark on a medical odyssey until they finally receive a correct diagnosis. For many rare diseases, there are still no treatments. radiz's partners, the University Children's Hospital Zurich, the University of Zurich and the University Hospital Zurich, will bring together their existing clinical and scientific expertise in rare diseases. The kick-off event on February 22<sup>nd</sup> 2013 provided an interesting insight into the work of scientists and doctors joining in the fight against rare diseases. The various speakers made it clear why initiatives such as radiz are needed to improve the prospects for patients with rare diseases.

#### Core sentences

**“radiz wants to become a leading center of reference for rare diseases. Our interdisciplinary research projects all have the same long-term goal: better care for patients with rare diseases.”**

*Prof. Matthias Baumgartner, lead radiz – Rare Disease Initiative Zurich*

Rare diseases are not as rare as one might like to think. The speakers invited by Prof. Matthias Baumgartner to the Children's Hospital Zurich that afternoon made this point very clear. For the leader of radiz, a strong national and international collaboration across disciplines is vitally important in the fight against rare diseases.

**“The study of rare processes leads to scientific discoveries. I believe that radiz will increase Zurich's attractiveness as a leading center of research.”**

*Prof. Daniel Wyler, Vice President for Medicine and Science, University of Zurich*

In his opening speech, Prof. Daniel Wyler explained why the University of Zurich chose to support the clinical research priority program for rare diseases. The Vice President for Medicine and Science made it clear that there is a great need for further research in the field of rare diseases. The University of Zurich believes that radiz will further clinical research, and thanked the Kinderspital for its dedication to its young patients.

**“radiz will catalyze patient care and research for pediatric and adult patients with rare diseases and will deliver momentum to the research at the Children’s Hospital and its Children’s Research Center.”**

*Prof. David Nadal, Children’s Research Center, University Children’s Hospital Zurich*

Rare diseases mainly manifest themselves in childhood. In the area of rare diseases, patient care and research present unique challenges, which have traditionally been an essential part of the Kinderspital’s focus, Switzerland’s largest children’s hospital. The Children’s Hospital with its Children’s Research Center is committed to facing this challenge with even more force. radiz, under the lead of our division of metabolic diseases, will help focus the research activities in Zurich.

**“We asked ourselves: in which area can we support beacon projects which will have a big impact despite limited funds?”**

*Rudolf Marty, President Gebert Rűf Stiftung*

radiz in Zurich will lead to the formation of the first center of excellence for rare diseases in Switzerland, which will have a sustained impact on research and which will be to the long-term benefit of the patients, said Rudolf Marty, President of the Gebert Rűf Stiftung. For the foundation, established in 1997, the creation of a network of education, basic research, and clinical application is unique and necessary.

**“Switzerland is still a ‘developing country’ as far as rare diseases and the creation of patient registries are concerned. There is a need for more national and international exchange of data and access to data. This may not be hampered by legal and economical hurdles.”**

*Prof. Felix H. Sennhauser, Medical Director, Children’s Hospital Zurich*

During his closing remarks, Prof. Felix H. Sennhauser pointed out that 30-50% of the long-term / serious hospitalizations at the Children’s Hospital are due to rare diseases. radiz shall become a beacon for clinical and academic medicine at the University of Zurich and the Children’s Hospital. The medical director called on society and medicine to establish a dialogue – a dialogue that will allow the gap between expectation and fulfillment to slowly but surely close.

radiz is closely collaborating with existing national and international organizations. For example, radiz was involved in this year’s international Rare Disease Day, which was organized together with ProRaris, Rare Disease Alliance – Switzerland at the University of Zurich on February 23<sup>rd</sup> 2013.

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