

# Together until the end

Ensuring access to specialized palliative care for children in the Zurich canton

A **UBS Optimus Foundation** Health program

## Summary

The focus of this program is to ease the suffering of terminally ill children and their families in the Canton of Zurich and to increase the access to a quality Paediatric Palliative Care (PPC) service that has been developed by the University Children's Hospital Zurich. Many children still suffer from incurable, life-limiting diseases. These children and their families have special needs which are not met with the current care provided in the given structures of children's hospitals and applied services. PPC offers innovative, needs-oriented care with high continuity and flexibility. This care makes a big difference for many families.

## The problem

Specialized services for terminally ill children are scarce. Caring for a severely ill child poses significant organizational, financial, emotional, and physical health challenges for the whole family.

Following recent medical advances, the number of children and adolescents living with life-limiting conditions is increasing. In Switzerland, it's estimated that there are 5,000 children living with a life-limiting condition and potentially in need of specialized pediatric palliative care. Yet a recent national survey showed that access to specialized palliative care for children was limited and available at only three locations.

In the Canton of Zurich, it's estimated that 400 children are eligible for such care yet only 25% of these children access quality care.

## The partner

The University Children's Hospital Zurich has developed the first center of excellence for PPC in German-speaking Switzerland and has more than doubled the number of children receiving its services during its collaboration with UBS Optimus Foundation. Its interprofessional and interdisciplinary approach is unprecedented in Switzerland. Eva Bergsträsser, the program lead, is internationally and locally recognized for her work in palliative care and is being recognized with the Swiss National Award for Palliative Care in the summer of 2018.

## The philanthropic solution

Having continuous and needs-based access to specialized palliative care allows a severely ill child to stay in the place where they feel the most comfortable, allows parents and siblings to be with the child without worrying about medical and nursing care and reduces fears of how to carry on with life after the child's death. Such a service is available for increasing numbers of children in the region of Zurich, but still many children miss this individualized and highly professional care.

The core aim of this project is to further increase the number of children receiving specialized PPC and to increase the number of children and families who receive care and support at home.

If there are additional funds secured, there is the possibility to allow for an interdisciplinary education program and cross-fertilization of interested institutions in Switzerland to build a robust community of practice and policy on PPC.

## The evidence

Results from the recent national PELICAN study (Paediatric End-of-Life CAre Needs in Switzerland, 2012-2015) showed that access to specialised palliative and end-of-life care services, including the capacity of community healthcare services was limited and available at only three places in Switzerland. Many children experienced high-intensity care with invasive interventions, high medication counts and high symptom prevalence. Only 17% of all children died at home; however, a high percentage of children died on intensive care units. Even if this study focused mainly on the end-of-life period, it underlines that in terms of palliative care for children, there is an underserved need in Switzerland.

## The impact

This funding will lead to:

- Increased access to PPC for more children
- Expanded capacity for home visits
- Quality certification label by *qualité palliative*

This program is a **"much needed, unique trailblazer project for PPC in Switzerland"** -- Prof Claus Jacobs of the KPM Center for Public Management at University of Bern.



Location	Zurich Canton, Switzerland
Target group	120 terminally ill children and 360 family members
Grant total	CHF 400,000
Duration	18 months

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The UBS Optimus Foundation is unique as the only foundation linked to a global wealth manager staffed with philanthropy experts. With an approach that takes advantage of our unique network, we're taking a leading role in driving impactful philanthropy that delivers breakthrough solutions to pressing social issues. But we know that solving social problems requires collaborative initiatives that make real impact on a large scale. So, we're taking smart risks on evidence-based, scalable solutions with diverse partners, improving health, education and child protection systems – as this is the best path to solving a wide range of the world's most pressing social issues.

Philanthropists choose to work with us because we take their passions personally, providing a variety of giving options and taking that journey with them. And they know that because of our expertise, innovation and network, we're successfully finding bold solutions to social issues, giving them the powerful impact they want.

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