



Schweizerische Pädiatrische Onkologie Gruppe
Groupe d'Oncologie Pédiatrique Suisse
Gruppo d'Oncologia Pediatrica Svizzera
Swiss Paediatric Oncology Group

50 years of paediatric cancer research

1976–2026
A chronicle of hope

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Editorial

Research – giving a future to children with cancer

Dear readers,

The Swiss Paediatric Oncology Group (SPOG) is turning 50. This is a good opportunity to look back at the past and our beginnings while also looking ahead to the future – with this timeline, we attempt to combine both perspectives.

In 1976, the year SPOG was founded, very few children and adolescents survived cancer – the specialist field of paediatric and adolescent oncology was only just emerging. Similarly, international studies and treatment protocols were initially available only for individual diseases. However, the International Society of Paediatric Oncology (SIOP) had already been founded in 1969 and some Swiss doctors were among its founding members.

The founding of SPOG and its development are inextricably linked to Prof. Hans-Peter Wagner from Bern. He was the pioneer of paediatric and adolescent oncology in Switzerland. He also represented Switzerland internationally for decades and was particularly committed to supporting children and adolescents with cancer in less developed countries. He was also a mentor and guiding figure for an entire generation of paediatric oncologists in Switzerland.

Fifty years later, almost 90% of children and adolescents in Switzerland survive cancer, thus making Switzerland one of the leading countries internationally.

What does the future hold? Through comprehensive, individual tumour analyses, treatment will become even more targeted for individual patients. This will, of course, require intensified international collaboration. The development of new treatments must also be given high priority in paediatric and adolescent oncology. A further area of focus is likely to be the continued development and use of AI.

The successes of the past would not have been possible without the support of many people. I would first like to

express my sincere thanks to our patients and their families, who have placed their trust in us and continue to do so. Special thanks also go to all the staff at the SPOG Coordinating Centre (which in the early days was little more than an administrative office) and to all the staff at the nine SPOG hospitals. They work day in, day out towards our shared goal: 'Research – giving a future to children with cancer'. Without the generous support of and close collaboration with private and institutional funders as well as research partners and public authorities in Switzerland and abroad, the work of SPOG would not be possible. Many thanks for your ongoing support and cooperation.

I am looking forward to the continued journey of SPOG...

Prof. Dr med. Katrin Scheinemann, M.Sc.
President of SPOG



Prof. Dr med. Katrin Scheinemann, M.Sc.
is a specialist in paediatric and adolescent medicine working in paediatric oncology/haematology and director of the Haematology/Oncology Centre at the Children's Hospital of Eastern Switzerland. She has been President of SPOG since 2020.

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50



A chronicle of hope

Contents

Editorial

Research – giving a future to children with cancer 3

The origins of SPOG

The history of paediatric oncology 6

The founding years 10

The first funding commitment 12

Interview with Andreas Feldges, founding member 13

Key figures

Our presidents 18

Liselotte Lang – Secretary of SPOG for 20 years 20

The Scientific Meeting: Scientific exchange, a strong community 23

Medical progress

The development of treatment protocols 24

An organisation in transition

The SPOG Coordinating Centre: Rising to the challenges 29

How SPOG found its visual identity 34

What the future holds

Round-table discussion: Two generations of SPOG look to the future 36

Interview with Nicole Seiler, Chair of the SPOG Patient Advisory Board 41

50 years of research for children

42

The history of paediatric oncology

The origins of SPOG are closely linked to the history of paediatric oncology. Former SPOG President Felix Niggli describes the developments.

Paediatric oncology is a relatively recent subfield of medicine. Until the mid-20th century, malignant diseases in childhood were almost always considered fatal. There was no standardised treatment and, until the 19th century, it was almost exclusively limited to surgical procedures. Natural remedies, herbs, and other experimental methods were also used. At the beginning of the 20th century, radiotherapy was developed to locally irradiate and contain the tumour. However, it initially remained experimental and was associated with severe side effects.

In particular, acute lymphoblastic leukaemia (ALL), the most common cancer in childhood, almost always led to death within a few months. Diagnostic options were limited, and there was a lack of age-appropriate treatment options. Although surgeons and radiotherapists treated children with cancer, paediatric oncology as a distinct discipline emerged only with the introduction of systemic drug treatments that can target cancer cells dispersed throughout the body.

1947

First chemotherapy for leukaemia

An initial turning point came around 1947, when pathologist Sidney Farber first discovered the cell-inhibiting effect of a folic acid antagonist. Treatment with this substance resulted in the complete, albeit temporary, disappearance of leukaemia cells. This led to the development of methotrexate, a substance that is still regularly used to treat ALL today. This marked the beginning of the era of systemic chemotherapy. At the same time, the first leukaemia registries and treatment protocols were developed, thereby laying the foundation for structured research.

1955

First paediatric oncology study group in the US

In the US, the first collaborative paediatric oncology study group was established in 1955. This marked the beginning of coordinated clinical research in paediatric oncology. In the 1960s, combination chemotherapies using multiple agents were introduced and, for the first time, leukaemias became

treatable over the long term. From 1965 onwards, 10–15% of children with ALL were cured.

At the same time, cranial radiotherapy (radiation treatment of the skull) and supportive care medicine became established. Supportive care includes measures such as blood transfusions, antibiotics, anti-nausea medication, and nutritional therapy that reduce the short- and long-term side effects of tumour treatment.

It became apparent early on that coordinated treatment protocols markedly improved treatment outcomes. Survival rates rose – initially for leukaemias and later for solid tumours – from less than 10% to around 50% by the end of the 1970s.

In 1962, the St. Jude Children's Research Hospital in Memphis (US) became one of the first specialised paediatric oncology centres.

1965

Foundation of the Swiss Group for Clinical Cancer Research (Schweizerische Arbeitsgemeinschaft für klinische Krebsforschung SAKK)

In 1965, the first adult oncology group was founded in Switzerland: the Swiss Group for Clinical Cancer Research (SAKK).

1969

The International Society of Paediatric Oncology (Société Internationale d'Oncologie Pédiatrique SIOP) was founded in Paris with the involvement of Switzerland.

In 1967, specialists with an interest in paediatric oncology met at the Institut Gustave Roussy (IGR) in Villejuif, near Paris. Under the leadership of the French paediatrician Odile Schweisguth, they founded the International Society of Paediatric Oncology (SIOP) in 1969.

Among the 28 founding members were paediatricians from Switzerland: Edouard Gugler, Walter Hitzig, Hans Käser, Hans Jörg Plüss, and Hans-Peter Wagner. The aim was to give every child and adolescent with cancer access to appropriate treatment and care.

1976

Foundation of SPOG as the paediatric section of SAKK

About 10 years after SAKK was founded, paediatricians established a paediatric section. This ultimately gave rise to the Swiss Paediatric Oncology Group (SPOG) in 1976. At that time, the newly founded SPOG had relatively few financial resources and had to seek support from the federal government and the Cancer League.

In its early years, SPOG worked closely with the Cancer and Leukaemia Group B (CALGB) and later with the Paediatric Oncology Group (POG) in the US. Participation in these clinical trials was demanding. However, it provided most children and adolescents with cancer access to the latest cancer treatments.

Today, SPOG is the national association of the nine specialised paediatric and adolescent oncology units in Switzerland. SPOG also led to the establishment of the Swiss Childhood Cancer Registry (ChCR) and a tumour bank for biomedical research. The aim of SPOG is to enable the best possible treatment for children and adolescents with cancer or blood disorders through national and collaborative studies.

1976

Establishment of the Berlin–Frankfurt–Münster Leukaemia Study Group

In 1976, paediatricians in Germany founded the Berlin–Frankfurt–Münster (BFM) Leukaemia Study Group with the aim of collaborating in the area of ALL. In the years that followed, further collaborative study groups were established in Europe. In Germany, the Society of Paediatric Oncology and Haematology (Gesellschaft für Pädiatrische Onkologie und Hämatologie GPOH) established itself as a professional society.

International collaboration played a key role for the hospitals within SPOG. Multicentre phase II/III studies became the standard method for defining treatment regimens for leukaemias, lymphomas, and solid tumours.

While hospitals in French-speaking Switzerland cooperated with American paediatric oncology groups for a long time, from the mid-1980s onwards, paediatric oncology centres in German-speaking Switzerland increasingly aligned themselves with the BFM Study Group and GPOH in Germany. Over the past 20 years, the requirements for conducting clinical studies had increased substantially because of regulatory and ethical standards. This increased costs and made it nec-

essary for SPOG hospitals to collaborate more closely in order to implement standardised treatment protocols. At the international level, too, study groups increasingly joined forces to develop shared treatment strategies.

1980

Development of modern multimodal treatments and improved imaging

Between 1980 and 2010, modern multimodal treatments (i.e. treatments combining various therapeutic approaches) were developed. Imaging techniques such as computed tomography (CT) and magnetic resonance imaging (MRI) also improved. Paediatric oncologists increasingly used risk-adapted treatments, whereby the treatment is individually tailored to the specific risk profile of the person's disease. In addition, stem cell transplants were introduced.

From 2010 onwards

Precision medicine and immunotherapy

With the introduction of immunotherapies and the development of precision medicine, the five-year survival rate for paediatric tumours has risen to over 80%. Precision medicine is a modern treatment approach that tailors treatment specifically to the individual molecular characteristics (genetic profile) of the tumour rather than treating solely on the basis of the type and stage of the cancer. Immunotherapy uses the body's own immune system to specifically recognise and



fight cancer cells. Unlike chemotherapy, which directly kills cancer cells (but also damages healthy cells), immunotherapy activates or strengthens the body's own defence mechanisms.

Molecular diagnostics, targeted treatments, monoclonal antibodies, and CAR T-cell therapies define the current era. Monoclonal antibodies are laboratory-produced immune substances that can recognise and target cancer cells with high precision. In CAR T-cell therapies, the child's immune cells are harvested and genetically modified and multiplied in the laboratory so that, once returned to the body, they can recognise cancer cells and destroy them in a targeted manner. These improved treatments further increased the chances of a cure. Researchers have also increasingly incorporated factors such as quality of life, long-term effects, and psychosocial care into study designs.



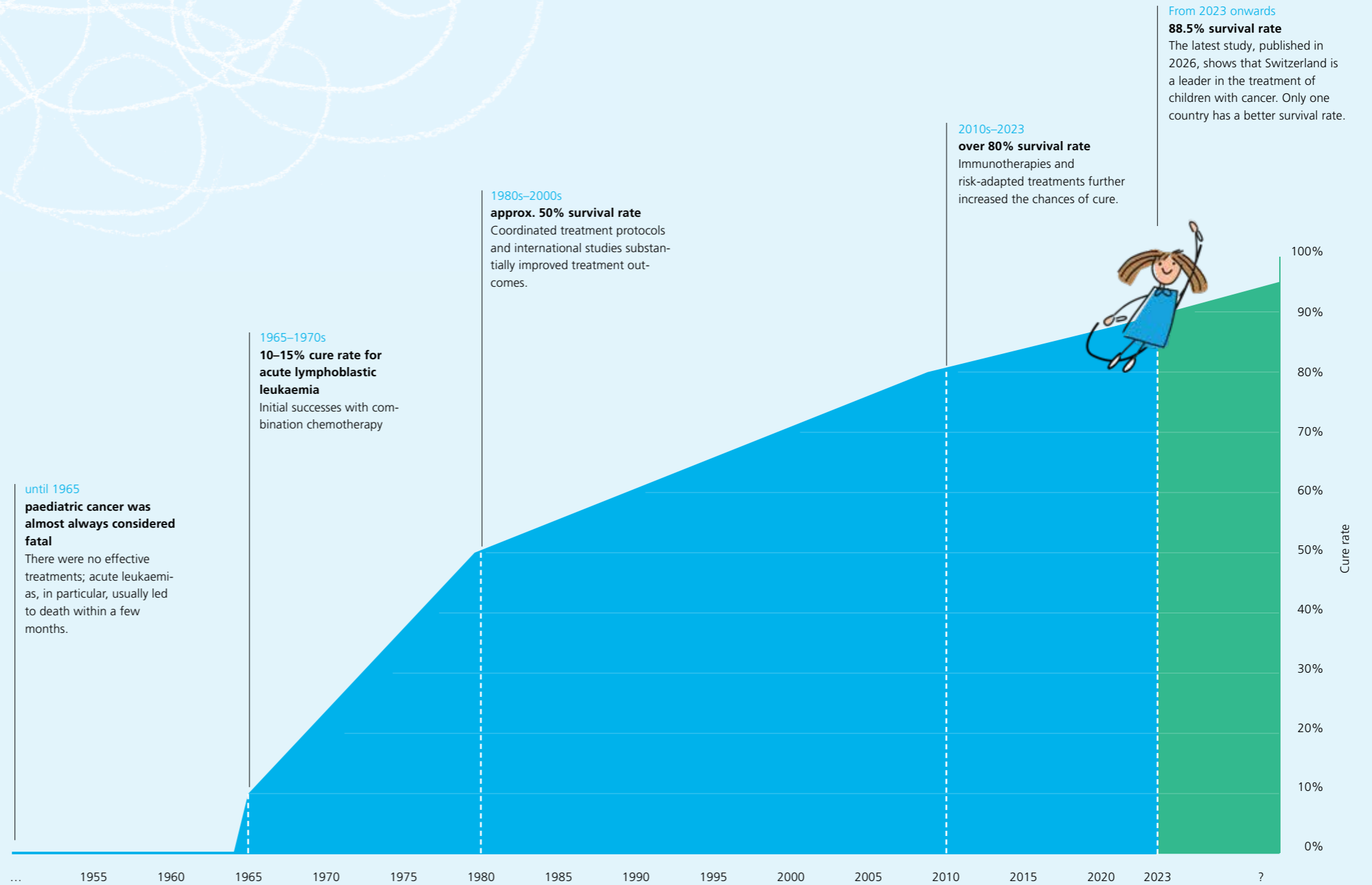
Prof. em. Dr med. Felix Niggli



headed the Paediatric Oncology Department at the University Children's Hospital Zurich from 1999 to 2020 and was President of SPOG from 2011 to 2017. Since 2022, Niggli has been a member of the Zurich Cantonal Ethics Committee.

Development in cure rates for paediatric cancer

The chances of a cure for children with cancer have improved dramatically over the past few decades. Whereas malignant diseases in childhood used to be mostly fatal, today almost 9 out of 10 affected children survive in the long term. The aim of SPOG is to cure all children and adolescents with cancer. The overview below is based on historical milestones and not on a complete statistical time series.

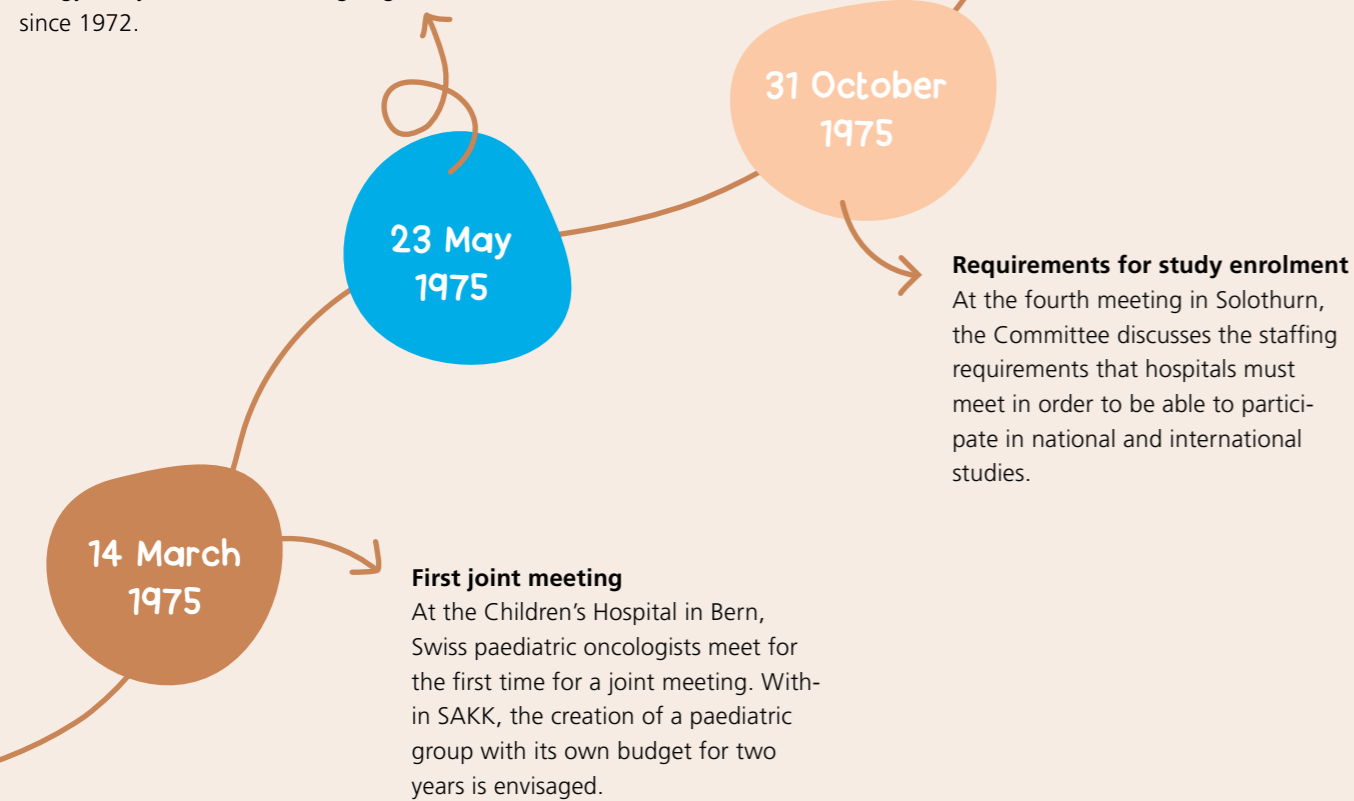


The founding years

The early development phase of SPOG can be traced using a personal account compiled by Hans-Peter Wagner, founder of SPOG, dated 5 August 2015. In the early 1970s, several Swiss paediatric hospitals began treating leukaemia according to international protocols, in particular those based on studies by the Cancer and Leukaemia Group B (CALGB) in the US. These collaborations led to the idea of nationally coordinated paediatric cancer research.

Discussion of joint projects

At the second meeting in St. Gallen, the participants discuss potential joint research projects, including a haematology study that had been ongoing since 1972.



First joint meeting

At the Children's Hospital in Bern, Swiss paediatric oncologists meet for the first time for a joint meeting. Within SAKK, the creation of a paediatric group with its own budget for two years is envisaged.

Requirements for study enrolment

At the fourth meeting in Solothurn, the Committee discusses the staffing requirements that hospitals must meet in order to be able to participate in national and international studies.

Funding application approved

Following the rejection of the proposal to integrate the group into the SAKK budget, at the fifth meeting, the application to the Federal Office of Public Health and the Cancer League, prepared by Hans-Peter Wagner, is reviewed, revised, and approved.

Funding for national research

For the first time, the Federal Office of Public Health provides CHF 250,000 for one year. These funds enable national collaboration in paediatric cancer research.

Coordination of clinical studies

The paediatric hospitals in Zurich, Basel, and St. Gallen have been participating in studies conducted by the Active Leukaemia Group B (ALGB) since as early as 1969. At its sixth meeting, a list is drawn up of ongoing studies of the Cancer and Leukaemia Group B (CALGB) in which active participation is possible.

Establishment of the organisation

Launch of collaborative paediatric tumour research in Switzerland. The collaboration between the paediatric hospitals is formalised, and the current Swiss Paediatric Oncology Group (SPOG) is established as a national research organisation.

Publication of the first activity report

At the 13th meeting held in Bern on 2 March 1977 the first activity report of the paediatric section of the SAKK, later the Swiss Paediatric Oncology Group (SPOG), is presented.

Prof. Dr med. Hans-Peter Wagner (13 November 1930 – 9 March 2022)

Hans-Peter Wagner is regarded as a pioneer of paediatric oncology in Switzerland. In the 1970s, he recognised early on that progress in the treatment of children with cancer could be achieved only through collaboration.

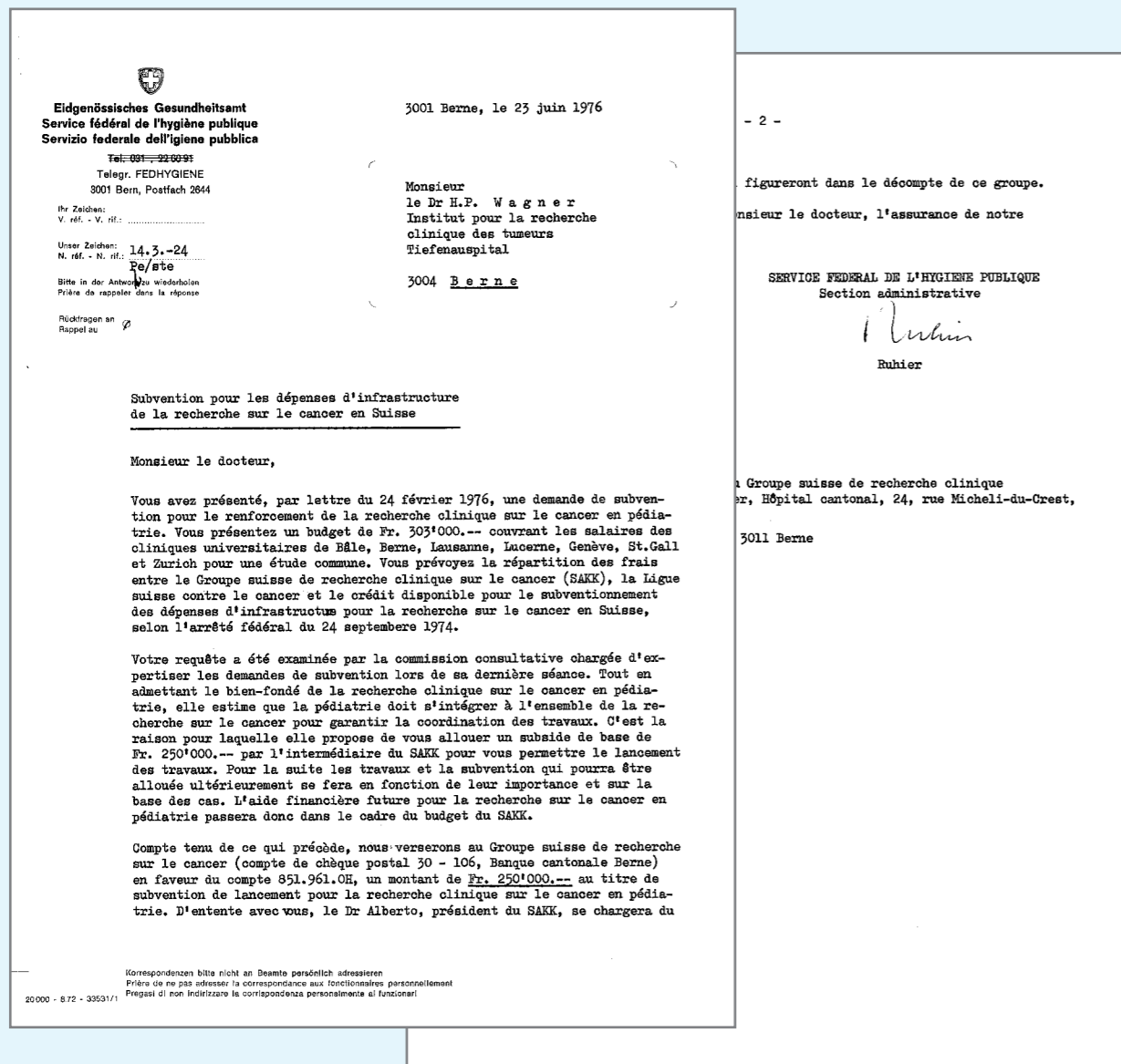
At Inselspital Bern, he established one of the first specialised units for children with cancer and actively advocated for participation in international studies. In 1976, he initiated the establishment of the Swiss Paediatric Oncology Group (SPOG), thereby laying the foundation for the national coordination of paediatric cancer research. In 1969, he was also one of the co-founders of SIOP, which was established in close collaboration with experts from Europe and the US.

His commitment shaped the development of the field for decades – in Switzerland and beyond. ♦



The first funding commitment

On 23 June 1976, the Federal Office of Public Health sends a letter to Dr med. H. P. Wagner at the Tiefenaospital in Bern. The letter announces that a start-up grant of CHF 250,000 is being awarded for a joint clinical study on cancer research in paediatrics. The funds are channelled through SAKK. There is one condition: paediatrics should be integrated into cancer research across Switzerland in order to ensure the coordination of work. SPOG was established on the basis of this initial funding commitment. •



«Collaboration in paediatric oncology was strong from the very beginning.»

St. Gallen paediatric oncologist **Andreas Feldges** is one of the founding members of SPOG. In late autumn 2025, President **Katrin Scheinemann** and Managing Director **Isabelle Lamontagne-Müller** met with him. The meeting resulted in a conversation about the origins of SPOG, the visions held at the time, and what has been achieved.

We owe this major development within SPOG primarily to our founder, Hans-Peter Wagner. He was also our first President and played a key role in the successful development of SPOG.

What visions did you have as founding members?
 The vision was to develop basic research in addition to improving the chances of a cure for cancer in children and adolescents.

What treatment options were available for children and adolescents with cancer before SPOG existed?
 Andreas Feldges: Before the founding of SPOG in 1976, there were already oncology clinics at centres in Geneva, Lausanne, Bern, Basel, Zurich, and St. Gallen. These clinics were run by oncology specialists. These specialists had received their training at specialised paediatric oncology centres in the US. In Basel, Zurich, and St. Gallen, children with acute lymphoblastic leukaemia were already being treated according to an American protocol from the Cancer and Leukaemia Group B several years before SPOG was founded. However, Wilms' tumours, rhabdomyosarcomas, and Ewing's sarcomas were also treated according to a multicentre, collaborative treatment trial in the US.

«The **vision** was to develop basic research in addition to improving the chances of a cure for cancer in children and adolescents.»

How were paediatric oncologists connected at that time?
 There was already strong collaboration, with oncologists meeting to discuss patients. Collaboration in paediatric oncology was strong from the very beginning.

What form was this new organisation to take?
 The organisation took the form of a research council. Within this structure, the elected members of the individual centres held seats, like in an association. Twice a year, there was a Research Council meeting during which activities were discussed. Once a year, a scientific conference was held. International experts were invited to share their knowledge with us.

SPOG was founded in 1976. What was the reason behind separating paediatric oncology from SAKK, the Swiss Group for Clinical Cancer Research?
 By establishing an independent association, the aim was to differentiate ourselves from oncologists working with adults. As early as the 1960s, with the founding of SAKK, these oncologists had already developed prospective studies aimed at improving the chances of cure for cancer patients. The founding members of SPOG also shared this goal.

What challenges did SPOG aim to address?
 The aim was to develop multinational, interdisciplinary studies for the treatment of paediatric cancer. In the late 1970s, SPOG approved Swiss treatment protocols for acute lymphoblastic leukaemia, Hodgkin's disease, and histiocytosis X.





Were there any critical moments in the early days?

In the early days, we had to cope with the deaths of two members. These were founding member Jörg Sartorius of Basel University Hospital, who died in 1979, and President Daniel Beck of Lausanne University Hospital, who died in 1995. These were two major losses for SPOG. Our colleagues Annette Lüthy in Basel and Maja Beck in Lausanne filled the gaps left at their centres with great dedication. And for that we remain grateful to them to this day.

How was SPOG financed in its early years?

SPOG received financial support from the federal government in the form of a core grant. This money was used to fund the salary of a secretary at the SPOG secretariat in Bern and the salaries of data managers at the respective centres.

What particular experiences from the early days have stayed with you?

In the early days of SPOG, members of the Research Council also went on private trips, including after attending continuing education conferences in California and Florida. The first trip was a wine tasting in Napa Valley. The second, an excursion to the Everglades wetlands in Florida, was particularly impressive. Marinette Wyss, a paediatric oncologist at Geneva University Hospital, in particular, had a major fright when a crocodile emerged from a river and approached us. Fortunately, a ranger managed to drive the crocodile back into the river.



What milestones did SPOG achieve in its early years?

One milestone was becoming a member of the Paediatric Oncology Group (POG) in the US. The centres in Bern, Lausanne, and Geneva treated children with acute lymphoblastic leukaemia in accordance with a Cancer and Leukaemia Group B protocol.

Another milestone was the inclusion of the centres in Basel, Aarau, Lucerne, Zurich, and St. Gallen in the Berlin–Frankfurt–Münster (BFM) Leukaemia Study Group. This enabled them to treat paediatric patients with new protocols for acute lymphoblastic and acute myeloid leukaemia.

What were the key changes within the organisation?

A major milestone for SPOG was the establishment of the Childhood Cancer Registry, which originated from SPOG under the leadership of Claudia Kühni in Bern. This made it possible to systematically collect data on the incidence of cancer in children and adolescents.

Another change that I consider important was that, after 22 years, the Research Council was restructured to include a President, a Secretary, and representatives of the centres.

What was the most meaningful moment in your work with the organisation?

The collaboration with paediatric haemato-oncologists from Germany was particularly meaningful. They had also developed the treatment optimisation protocols that we subsequently adopted. After I retired, the protocols became established across all institutions in Switzerland. There was a follow-up protocol for acute lymphoblastic and myeloid leukaemia. There were also protocols for bone sarcomas, Wilms' tumour, rhabdomyosarcoma, and Langerhans cell histiocytosis.

« The Latin expression 'vivat, crescat et floreat' - meaning 'may it live, may it grow, may it flourish' - is my heartfelt wish for SPOG.»

Andreas Feldges
Founding member



International collaboration played an important role.

Together with Hansjörg Senn [oncologist and chief physician at St. Gallen Cantonal Hospital, editor's note], we also established contacts with the German Democratic Republic (GDR). Through a colleague, we invited paediatric oncologists from the GDR and presented our developments. This led to contact with paediatrician Wolfgang Dörfel in Berlin. That eventually developed into a friendship. Similar to Hans-Peter Wagner, he was the principal investigator of the Hodgkin study. We were grateful to be able to share something with the GDR.

So you brought valuable knowledge back to Switzerland through your time abroad at St. Jude and at other institutions, and passed on your experience.

Yes, we really did have that spirit. The nurses also initiated a project of their own. In St. Gallen, we had introduced the Port-a-Cath system for children. We already had a connection with the Paediatric Oncology Centre in Minsk, which was headed by Olga Aleinikova at the time. We were able to organise an exchange, travelled to Minsk with paediatric surgeon Dr Leuthard, and introduced them to the Port-a-Cath system. They then also started using it.

Looking back at the history of SPOG, what do you think the association has achieved?

The establishment of centres of excellence in Switzerland. Specifically, centres of excellence where young paediatricians can obtain a specialist qualification in haematology–oncology. This is also possible at smaller centres – not just at university centres.

We are also pleased to see the establishment of laboratories at university centres such as the Children's Hospital in Zurich. These enable genetic and molecular diagnostics of leukaemia in children.

Do you have any wishes?

Yes, I do. I hope that SPOG will be able to raise funds to recruit researchers who specialise in translational medicine. Transferring insights from basic research into clinical practice is the future of medicine.

The Latin expression 'vivat, crescat et floreat' – meaning 'may it live, may it grow, may it flourish' – is my heartfelt wish for SPOG. ♦



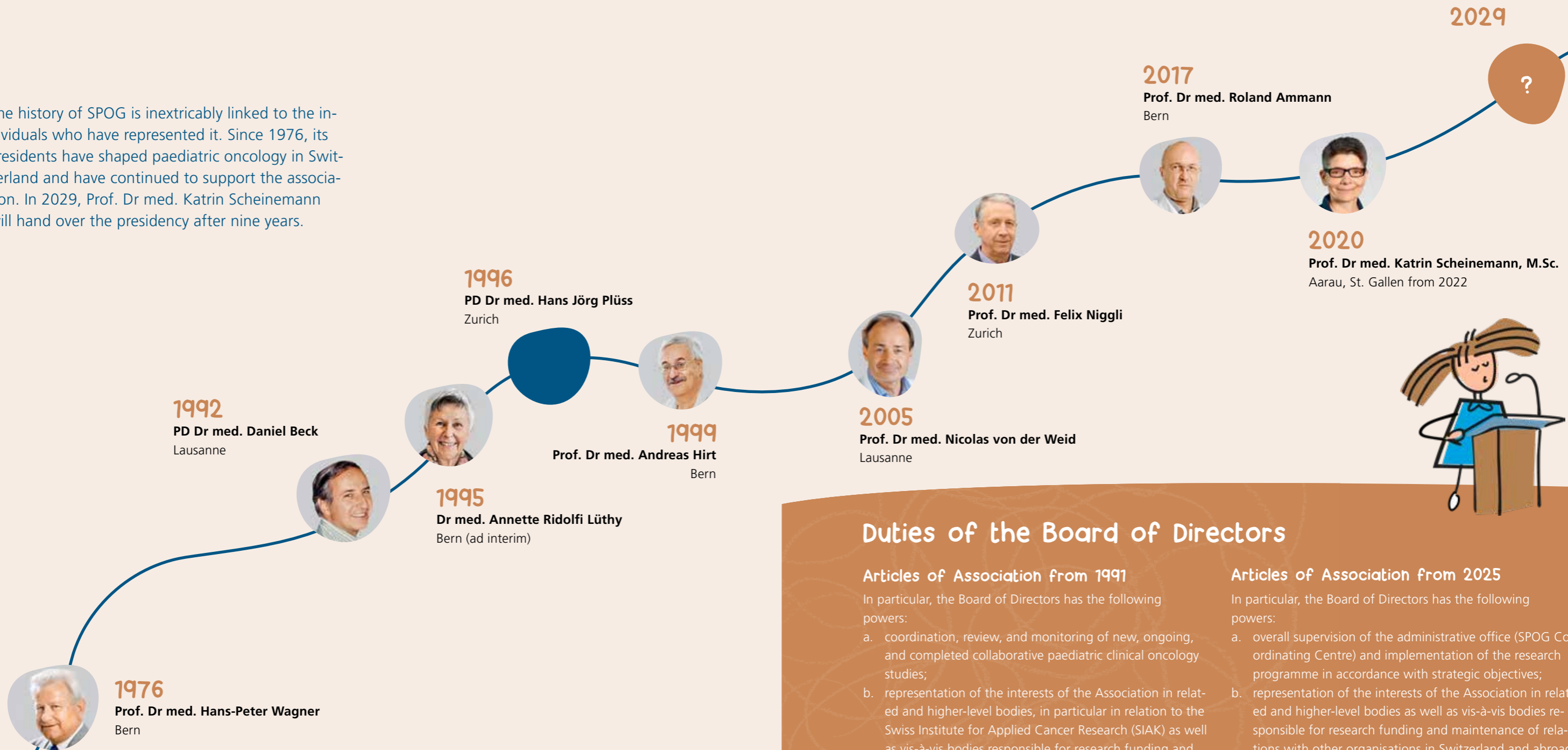
Dr med. Andreas Feldges

From 1974 to 2001, Dr med. Andreas Feldges headed the Paediatric Oncology Department at the Children's Hospital of Eastern Switzerland in St. Gallen. In this role, he was one of the founding members of SPOG.



Our presidents

The history of SPOG is inextricably linked to the individuals who have represented it. Since 1976, its Presidents have shaped paediatric oncology in Switzerland and have continued to support the association. In 2029, Prof. Dr med. Katrin Scheinemann will hand over the presidency after nine years.



Duties of the Board of Directors

Articles of Association from 1991

In particular, the Board of Directors has the following powers:

- a. coordination, review, and monitoring of new, ongoing, and completed collaborative paediatric clinical oncology studies;
- b. representation of the interests of the Association in related and higher-level bodies, in particular in relation to the Swiss Institute for Applied Cancer Research (SIAC) as well as vis-à-vis bodies responsible for research funding and maintaining relations with other organisations in Switzerland and abroad that pursue the same or similar objectives;
- c. preparation and convening of the Research Council as well as the submission of motions relating to matters to be decided;
- d. supervision and management of day-to-day business;
- e. establishment or dissolution of standing or ad hoc committees.

The Board of Directors shall adopt the regulations required for this purpose.

Articles of Association from 2025

In particular, the Board of Directors has the following powers:

- a. overall supervision of the administrative office (SPOG Coordinating Centre) and implementation of the research programme in accordance with strategic objectives;
- b. representation of the interests of the Association in related and higher-level bodies as well as vis-à-vis bodies responsible for research funding and maintenance of relations with other organisations in Switzerland and abroad that pursue the same or similar objectives;
- c. preparation and convening of the General Assembly and submission of motions relating to matters to be decided;
- d. election of the Managing Director;
- e. supervision and management of day-to-day business as well as the establishment or dissolution of standing and ad hoc committees, including the election or appointment of their members.

The Board of Directors shall adopt the regulations required for these purposes. If the content of these regulations falls within the responsibilities of the General Assembly, they must be approved by the General Assembly. •

Liselotte Lang - Secretary of SPOG for 20 years

In 1987, Professor Hans-Peter Wagner, one of the founders of SPOG and its first President, hired Liselotte Lang as a part-time secretary. She worked for SPOG until 2007. During a visit to the SPOG Coordinating Centre in Bern, she shared her memories.

"I initially worked at the former Tumour Institute, a barracks-like building next to the Tiefenau Hospital in Bern. Hans-Peter Wagner also had an office there. I took over the responsibilities of my predecessor, Marianne Bischoff, who had worked as the first secretary of SPOG for 10 years.



Liselotte Lang in conversation with Isabelle Lamontagne-Müller, Managing Director of SPOG.

My job was to enter new cases of illness (study patients) registered in a Paediatric Oncology Group (POG) study into the relevant lists. In doing so, I recorded the cases from the university hospitals and top-tier hospitals with a paediatric oncology department that collaborated with POG. I also had to collect the copies of these patients' treatment flow sheets and place them in boxes. These were completed at the centres and sent to the secretariat; the originals went directly to the US. At the larger centres, dedicated data managers were appointed for this task; at the smaller centres, doctors car-

ried out this work in addition to their clinical duties and were often overworked as a result.

Every six months, I had to check whether the flow sheets had arrived from all the centres. If any were missing, I had to follow up with the relevant centre. At the secretariat, I also received the 'notices of patients' deaths' and placed them in boxes labelled with the illnesses of the patients. I also received the data of patients not included in studies.

This data collection was the real beginning of the Childhood Cancer Registry. Later, my successor Barbara Kindler handed over all these data in a paper bag to Claudia Kühni, the first head of the Childhood Cancer Registry.

The SPOG secretariat also received the medication for the study patients by post from the study headquarters in the US. I had to manage these and forward them to the hospitals as required. The secretariat also received new amendments to the protocols from the US. I made copies of these and forwarded them to the member hospitals.

In total, I worked with five presidents. SPOG meetings were held three to four times a year. At that time, Hans-Peter Wagner took the minutes himself. His successor, Daniel Beck, wanted me to take the minutes. He and the subsequent presidents would then correct them, particularly with regard to the medical aspects.

At first, I typed the minutes and correspondence on an IBM Selectric typewriter. Later, the secretariat was equipped with an Olivetti automatic typewriter that was able to save typed text. As computers became more common, I took courses to learn how to use them. One major advantage was the ability to sort patient lists alphabetically. This made work much easier because we used to have to go through the entire list to find a patient.

At the end of 1988, the SPOG secretariat had to relocate to the Children's Hospital at the Inselspital in Bern, and Hans-Peter Wagner, together with his son, carried out the entire move, including all the boxes and cupboards. I was given a space in an open-plan office and later a private office in the management wing. In 1996, the office moved to the premises of the Cancer League; this was initially known as the 'Haus des Krebses'. In this new environment away from the hospital setting, I felt a bit isolated at first. I also attended the two-day twice-yearly meetings in Ticino.

On Friday afternoon and Saturday morning, the scientific conference – today's 'Scientific Meeting' – took place. I would listen to the presentations. This was followed by the SPOG meeting for which I took the minutes. At the conference, I also got to know the data managers in person.

The secretariat had nothing to do with the finances; these were handled by the SAKK Treasurer. For a short time, I helped prepare submissions for the ethics committees. I also occasionally wrote English surgical reports for a doctor based on recordings of his spoken notes." •



From index boxes to electronic study documentation

The organisation of the SPOG office has changed considerably over the years. In the early years, day-to-day work in the secretariat relied on typewriters, handwritten lists, and archived paper files. Later, typewriters and computers made the work easier. This transformation has continued to this day: In 2025, the Coordinating Centre introduced fully electronic study documentation. As a result, processes have become more efficient and can be traced without gaps.



Liselotte Lang

Liselotte Lang completed her training at the Wirtschaftsmittelschule der Stadt Bern (WMB), the predecessor of the current school. After working as a secretary in Geneva and Bern, she spent several extended periods abroad in England, Denmark, and the US before taking up her position at SPOG in 1987.



2008 Locarno



2013 Lugano



2014 Lugano



2016 Bern



2017 Lugano



2018 Lugano



2019 Lugano



2020 Lugano



2023 Bern



2024 Bern



2026 Lugano

Key figures

The Scientific Meeting: Scientific exchange, a strong community

Over several decades, the Scientific Meeting has grown alongside SPOG. It brings together the people behind the research, strengthens the bonds between the centres, and highlights what has set SPOG apart to this day: scientific excellence in the spirit of a strong community.

What is now an established institution originated from a simple need – the desire to share knowledge – as well as from the courage of a generation of doctors who took on a seemingly insurmountable challenge.

From the very beginning, scientific exchange has been one of the defining elements of collaboration within SPOG. In the early years, there were hardly any proven treatments for children with cancer. Anyone wishing to provide treatment in Switzerland first had to acquire the necessary knowledge abroad. The pioneers of paediatric oncology in Switzerland therefore undertook further training at specialised centres in the US. They brought their knowledge back to Switzerland and passed it on. They also invited international specialists to share their experience with the growing Swiss community.

As a result, the need for a dedicated forum for professional exchange arose at an early stage. Liselotte Lang, long-serving secretary of SPOG, recalls two-day, twice-yearly meetings in Ticino. On Friday afternoon and Saturday morning, the scientific conference took place. This was followed by meetings to plan and coordinate clinical studies. This marked the beginning of the annual SPOG Scientific Meeting.

People listened to presentations, exchanged ideas, and spent the evenings together. Colleagues soon became friends. In conversations with long-standing SPOG members as well as the younger generation, it becomes clear how formative this exchange has remained to this day. This sense of community has long been one of SPOG's greatest strengths. Shared challenges forge connections that often last a lifetime.

In the 1980s and 1990s, these gatherings evolved into regular scientific conferences attended by representatives from all SPOG centres as well as by international experts. These conferences provided a forum for presenting the latest studies, sharing treatment experiences, and jointly developing new

research questions. They also strengthened cooperation between the centres and promoted joint projects.

To this day, the Scientific Meeting remains indispensable for the exchange of ideas between paediatric oncology centres in Switzerland. It is also a place of community, where long-standing members are celebrated and bid farewell. For example, at the 2024 Scientific Meeting, SPOG paid tribute to Professor Maja Beck Popovic, who had helped shape the scientific programme over the course of decades. At the 2026 Scientific Meeting, once again held in Lugano, Professor Nicolas von der Weid was honoured as he stepped down after a long career closely linked to SPOG far beyond his years as President.

The Scientific Meeting also welcomes new members. Katrin Scheinmann, the current President of SPOG, attended the Scientific Meeting for the first time in 2001 and was "quickly made to feel very welcome" by the community.

Today, the Scientific Meeting is an important opportunity, particularly for younger doctors and researchers, to present their own projects and to network within the national professional community. The winners of the SPOG Young Investigator Grants each present the results of their first independent research project at the Scientific Meeting. It thus also becomes a place where experience is passed on, the next generation is supported, and the future of SPOG is actively shaped. •

The development of treatment protocols

From the first clinical trial on paediatric cancer in Europe in 1971 to cure rates of over 80%: the successes achieved in paediatric oncology are based on close international collaboration and a wide range of clinical trials. As early as 1995, Hans-Peter Wagner, founder of SPOG, demonstrated that patients enrolled in trials had better survival rates.

Modern paediatric oncology began with the pioneering work of two researchers, Sidney Farber from Boston and Odile Schweiguth from Paris. In the early 1960s, Sidney Farber was the first to introduce chemotherapy for the treatment of leukaemia in children and later for Wilms' tumours. Odile Schweiguth, who founded the first paediatric oncology centre in Europe in 1952, recognised early on the importance of combination chemotherapy for treating paediatric cancer. She also emphasised the need for collaboration between paediatric oncologists and various other specialists.

First collaborative clinical trials in Europe

In 1969, Schweiguth provided the impetus for the founding of SIOP, thereby paving the way for the development of

collaborative clinical trials. The first international randomised clinical study in Europe, SIOP-1 for Wilms' tumour, was launched in 1971; this was followed by MMT-1 for malignant mesenchymal tumours in 1975.

In the following years, national paediatric oncology groups were established across Europe, starting with the Berlin–Frankfurt–Münster (BFM) group in Germany for the treatment of leukaemia and lymphoma, the most common childhood cancers. This was followed by national groups in France, the UK, the Netherlands, and Italy. SPOG was established in Switzerland in 1976.

Significantly improved patient survival rates in studies

Two insights characterise the further development of the clinical studies of SPOG.

First, for rare diseases such as paediatric cancer, which have small numbers of cases at the national level, international collaboration is a fundamental requirement in order to improve treatments and survival rates and to reduce side effects. To this end, the enrolment of patients in clinical trials is essential.

Hans-Peter Wagner, the founder of SPOG, demonstrated this convincingly in a 1995 publication. He conducted a retrospective analysis of 162 children with non-Hodgkin lymphoma who had been enrolled on a SPOG or POG study protocol between 1976 and 1991. A comparison between 120

study patients enrolled in a protocol and 42 non-study patients who were treated according to the protocol but were not formally enrolled revealed that the registered study patients had considerably better survival rates: 76% (older SPOG protocol) and 93% (newer POG protocol) vs 52% for the non-study patients. Enrolling patients in clinical trials includes quality control and improves the prospects of cure; this explains the important role of these trials in paediatric oncology.

Over the years, this insight led to close collaboration with international study groups. This collaboration continues to this day. Swiss centres participated in American clinical trials within POG/COG (Paediatric Oncology Group, later Children's Oncology Group) or in German BFM-GPOH trials.

Treatment protocols for almost every oncological condition thanks to collaboration

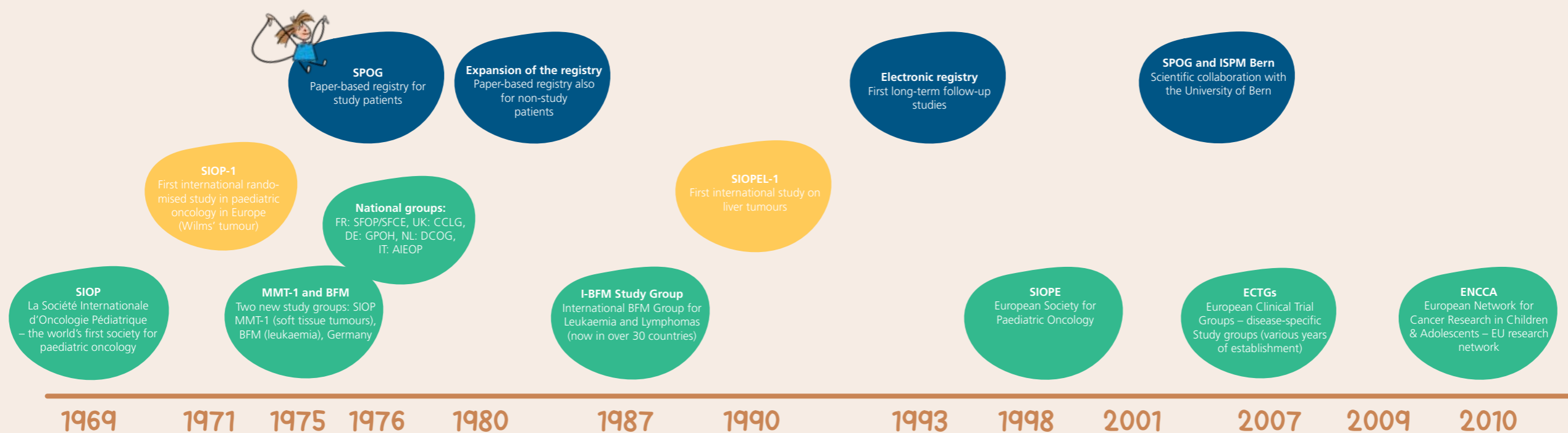
At the European level, paediatric oncology became progressively more organised through the establishment of SIOPE (the European branch of SIOP) in 1998, the harmonisation of clinical research based on European regulatory legislation in 2001, and the formation of European Clinical Trial Groups in 2007. The number of European international protocols increased and gradually covered all oncological diseases. SPOG also increasingly participated in standardised clinical trials run by the European Clinical Trial Groups (ECTGs). Today,

SPOG centres are active members of these European research groups. SPOG doctors lead international and national studies, head working groups within SIOPE, chair European Clinical Trial Groups (ECTGs), serve on the SIOPE Board, and represent Switzerland on other European bodies.

Cancer registry enables long-term follow-up studies

The second insight concerns the important role of a cancer registry. The first step was taken as early as 1976 with the founding of SPOG and the introduction of a hospital-based, paper-based registry; this was initially only for study patients but also included non-study patients from 1981. In 1992, the transition to a digital format made it possible to centralise the data and develop long-term follow-up studies. Collaboration with the Institute of Social and Preventive Medicine in Bern expanded the database and the scope for research projects.

Between 2010 and 2015, an average cure rate of 80% for paediatric cancers was achieved worldwide. This improved survival rate raised new questions regarding long-term effects, follow-up care for survivors, and personalised disease- and treatment-related recommendations. New systems for long-term care and for the early detection of long-term effects became necessary. A personal 'passport' was developed to support individualised care for patients who had been cured.



The intensive research activity of SPOG within the cancer registry is reflected in numerous publications on various aspects of organ- or system-specific long-term effects. Research has also been conducted on psychological, family-related, and education-related issues. Further attention has been paid to interventions such as exercise during and after treatment aimed at minimising long-term effects.

Fifty years of SPOG have brought many advances in the treatment of cancer in children and adolescents as well as international recognition for the quality of its collaboration and initiatives in various fields of paediatric oncology. •



Prof. em. Dr med. Maja Beck Popovic



headed the Paediatric Department of Oncology and Haematology at the University Hospital of Lausanne from 1995 to 2023. From 2011 to 2022, she served on the Board of Directors of SPOG. At the international level, she served as President of SIOP Europe Neuroblastoma (SIOPEN) and the European Retinoblastoma Group (EuRbG).



«No single country would have been able to increase the cure rate to 80% on its own. International collaboration was - and remains - a fundamental requirement in order to give children with cancer better chances of survival.»

Maja Beck Popovic

Former head of unit at Lausanne University Hospital



An organisation in transition

The SPOG Coordinating Centre: Rising to the challenges

Over the past 50 years, paediatric cancer research has brought about impressive medical advances. Over the same period, there was a marked increase in legal requirements for human research; these were aimed at protecting patients and ensuring the integrity of the data collected. To meet these increased requirements, the Coordinating Centre has been further developed and structurally adapted, particularly since 2008.

Ultimately, both the challenges and opportunities faced by SPOG over the past 50 years have contributed to remarkable advances in medical science. Achieving this required key structural developments that provided the foundation for the functional development of the organisation, enabling it to address regulatory and financial challenges, support the scientific network, and make the most of research opportunities for the benefit of patients.

At the time SPOG was founded, fundamental international ethical guidelines for research involving human subjects were already in place: the Nuremberg Code, adopted in 1947, was drawn up as a result of the Nuremberg Medical Trials, during which doctors were convicted of conducting unethical human experiments in the Second World War. The Declaration of Helsinki, which was drawn up by the World Medical Association (WMA) in 1964, established ethical standards in research and continues to serve as a fundamental reference.

In Switzerland, the Swiss Academy of Medical Sciences (SAMW) published its first 'Guidelines for Research Studies in Human Subjects' in 1970. These were based on the Declaration of Helsinki. These guidelines included the following passage: *"It is recommended that consultative bodies to which the medical and ethical aspects of a proposed research study can be submitted be established."*

Today, these bodies are known as ethics committees, and submission is no longer optional but rather a legal requirement.

In 1971, the 'Inter-cantonal Agreement on the Control of Therapeutic Products' came into force. Based on this agreement, the Intercantonal Control Agency (Interkantonale Kon-

trollstelle IKS) for therapeutic products was established. Thus, at the outset of SPOG's research activities, medical-ethical guidelines were already known, but they did not yet have a legal status.

A high level of medical commitment and little administration

In the 1970s, in order to set up clinical research projects, doctors in various countries formed study committees based on the medical needs of their patients, developed research questions, and designed treatment protocols used to treat patients in clinical studies. These protocols set out in detail which data were to be collected and how the results were to be analysed. Ultimately, the findings were published in medical journals and incorporated into the treatment of patients worldwide.

In the early decades of SPOG, these processes relied largely on the personal commitment of doctors, who were supported by a very lean administrative and coordination structure that mainly handled organisational tasks. However, after a few years, the volume of data generated increased, and it became necessary to appoint dedicated data managers, who collected and recorded the data gathered at the individual hospitals as well as at the central coordinating office.

New regulations

In the mid-1990s, a regulatory development began in Switzerland. This would subsequently pose a number of challenges for this extremely lean structure.

In 1995, the IKS brought into force regulations on therapeutic products used in clinical trials. In 1996, the Good Clinical Practice (GCP) guidelines were published by the International Council for Harmonisation (ICH) with the aim of establishing a uniform global standard for the conduct of clinical trials.

A revised version of the 1997 SAMW medical-ethical guidelines for research involving human subjects states, among other things: *"In general, it is evident that public opinion is calling for tighter controls and closer monitoring to protect healthy volunteer research participants or patients. This goal can be achieved only through more stringent regulation."*

On 1 January 2002, the Federal Act on Medicinal Products and Medical Devices (Therapeutic Products Act TPA) came into force, and the national agency for therapeutic products, Swissmedic, was established through the merger of the IKS

The development of regulations in medical research

- 1947 Nuremberg Code
- 1964 Declaration of Helsinki
- 1970 SAMW Guidelines for Research Studies in Human Subjects
- 1971 Inter-cantonal Agreement on the Control of Therapeutic Products and Establishment of the IKS
- 1988 First cantonal Ethics Committee in the Canton of Thurgau
- 1995 IKS Regulations on Therapeutic Products in Clinical Trials
- 1996 ICH GCP Guidelines
- 2002 Therapeutic Products Act (TPA) and establishment of Swissmedic
- 2014 Human Research Act



and the Therapeutic Products Division of the Federal Office of Public Health (FOPH).

The TPA stipulates that favourable conditions should be in place for research and development in therapeutic products. It established the principle that any clinical trial of therapeutic products involving human subjects must be conducted according to the recognised principles of good clinical practice (GCP). This included the regulation of ethics committees and the precise definition of responsibilities within a defined clinical trial. The Human Research Act (HRA), which came into force in 2014, extended the applicability of GCP beyond the field of therapeutic products to all human research projects, including those not related to the investigation of therapeutic products.

From 2002 onwards, clinical research was no longer just a matter between patients and doctors. As a result of the new legislation, not only were new authorities and ethics committees introduced but also a new role: the sponsor in accordance with GCP rules. In this context, the sponsor is not a funder as the term is commonly used. In accordance with GCP rules, the sponsor is the person, company, or entity responsible for a particular study. This responsibility extends to all aspects of studies and does not cease entirely even if certain tasks of the conduct of the study are delegated to third parties.

New processes and requirements

As a result, the way studies are conducted has changed considerably.

- Today, patients and their families are informed according to clearly defined procedures and provide written consent to participate in clinical studies or research projects. They may withdraw this consent at any time without giving reasons.
- In addition to their medical training, doctors who wish to conduct clinical research are required to undergo further training in clinical research. In this context, the well-being of the individual patient is just as central as the conduct of studies in accordance with the protocol.
- National and international research collaborations must now be precisely documented, and responsibilities must be set out in a contract.
- Study protocols must be drafted in such a way that the study is conducted in compliance with the regulations.
- Before a clinical study can be opened for patient participa-

tion, the investigators must prepare a study dossier in compliance with the regulations and submit it to Swissmedic and the Ethics Committees for authorisation. Swissmedic also has the authority to conduct inspections – and does so regularly.

- Today, sponsors are required to implement quality management in accordance with GCP.

In short: conducting a study has become much more complex and resource-intensive.

Management and central study coordination: New roles in paediatric cancer research

Today, principal investigators have an extensive list of responsibilities that can hardly be fulfilled by a single doctor. In addition to medical expertise, a range of other skills is required to efficiently and effectively conduct a clinical study while giving equal consideration to the well-being of each patient and adherence to the study protocol.

To manage this complexity, SPOG established a management team in 2008. The team then expanded this central office into a management and study coordination office by 2026. This office ensures that the responsibilities of the sponsor or sponsor representative are fulfilled in compliance with the law and acts as a service centre for the member institutions. Therefore, it is no longer solely the affected children and adolescents, their families, and their treating physicians who are involved in achieving the objectives of SPOG.

Study coordinators now work at the member institutions to assist medical staff in recording and submitting study data. Care staff must be familiar with and comply with study protocol requirements, particularly in areas such as medication administration. This also applies to professionals involved in patient care from other specialist fields such as radiology and surgery.

The central coordination office employs specialists such as Clinical Project Managers and Quality Managers with specific expertise in regulatory affairs and quality management. The conduct of studies at the hospitals is reviewed by monitors from the Coordinating Centre using a risk-based approach. Specialists in fundraising and communication work with federal agencies, grant-making foundations, partner organisations, and private donors to ensure that the necessary funding is secured. In close collaboration with the Board of

Directors and the President, the Executive Management Team manages and oversees the activities of the organisation in accordance with the Articles of Association and the strategy.

A stable research programme but higher expenditure

Despite marked regulatory changes, it has been possible to maintain a stable research programme over the years; around 30 studies remain ongoing and able to enrol new patients.

However, regulation has also led to a massive increase in costs. The annual costs of SPOG increased more than sixfold between 2008 and 2025.

Expenditure in 2008:	CHF 539,818
Expenditure in 2025:	CHF 3,276,516

To a large extent, the increase in costs reflects the necessary further development of the Coordinating Centre as well as the growing expenditure on clinical project management, contracting, quality management, monitoring, and fundraising. However, the central office, which is continually adapted and optimised, provides the necessary foundation to support the core mission of SPOG: in 2025, 203 children and adolescents in Switzerland participated in a study for the first time; without this infrastructure, such studies would not be accessible to Swiss patients.

Over time, the continued development of the structures of SPOG has repeatedly convinced the Swiss Science Council. This assessment forms the basis for recognition of SPOG as a research institution of national importance. This, in turn, is why SPOG has been able to rely on substantial federal funding for more than 30 years; this funding now accounts for 32% of the required resources.

Collaboration as the key and a system in motion

There are many points of contact and many perspectives depending on the role that individual participants play in a clinical study. All of this results in high demands on communication between the individual people responsible for carrying out defined tasks within the framework of clinical studies.

We need a strong network with components that are structurally aligned with the legally defined lines of responsibility. A high degree of cooperation between the key personnel

involved is essential for effective functioning. Long-standing, reliable, and strong relationships are extremely valuable – both within the national and international research network and with authorities and funding partners. The SPOG Coordinating Centre has been deliberately structured and staffed in such a way that it can fulfil this responsibility.

It should also be recognised that optimal functioning is, to some extent, always a moving target and that these structures require continuous review, optimisation, and meaningful further development over time.

Although the complexity of conducting clinical research has increased considerably over the past 50 years, the person who ultimately matters – namely the child with cancer – and the objectives of SPOG have remained the same.

The funds available are limited. Time does not stand still. For children currently undergoing cancer treatment, we want to enable participation in studies that maximise their chances of recovery. And for children who develop cancer in the future, we would ideally like the results of today's studies to already be available.



Isabelle Lamontagne-Müller



has been managing the operational activities of SPOG since 2008. Initially supported by an administrator, she now leads a team of 18 employees.

SPOG plays an important role in combating cancer in children and adolescents, as it gives them access to innovative treatments. As a result, their chances of survival and their quality of life are improved in the long term. Through the newly established Patient Advisory Board, SPOG also gives patients and their families a greater voice in research. For paediatric cancer research, it is crucial that both public and private sources co-finance such studies. The federal government has been funding SPOG for over 30 years and thus contributes to the stability and further development of its important work.

Dr Nicole Schaad,

Deputy Head of the National Research and Innovation Division, State Secretariat for Education, Research and Innovation (SERI)



For 50 years, SPOG has been a truly remarkable success story. Thanks to participation in international clinical trials, the cure rate for children and adolescents with cancer in Switzerland is one of the highest in the world.

The geographical distribution of SPOG centres makes it possible to offer excellent care while keeping treatment close to home.

Prof. em. Dr med. Nicolas von der Weid,
President of SPOG from 2005 to 2011



I have a long history with paediatric oncology in Switzerland. My first contact with it was in the 1970s, when I had to give my first lecture in English and, as a young paediatrician at the time, was quite worried about whether everything would go well. Since then, I have always maintained close ties with paediatric oncology in Switzerland, in particular with SPOG, where I was a member of the Scientific Advisory Board for around 10 years. I had a close relationship with Hans-Peter Wagner through our joint activities within SIOP. I would like to congratulate SPOG on its 50th anniversary.

Prof. em. Dr med. Dr h.c. Günter Henze,
Former Head of the Department of Paediatric Oncology and Haematology, Charité CVK, Universitätsmedizin Berlin



SPOG is important because behind every milestone in research there is a child who gets the chance to grow up. Fifty years of collaboration, science, and compassion have transformed once fatal diagnoses into stories of survival and hope. As a patient representative, I see every day what this means for families.

Nicole Scobie,

Mother of a child affected by cancer, member of the SPOG Patient Advisory Board

How SPOG found its visual identity

What began in 1981 as a simple letterhead has evolved into a distinctive visual identity. The visual identity of SPOG is also the story of an organisation that has learned to make its work visible without ever losing sight of what is most important.

The child at the centre

In the 1980s, as SPOG became increasingly institutionalised, it developed a visual identity – initially in collaboration with SAKK. Documents from this period featured a graphically designed letterhead with a logo and the name of the organisation in German and English. An early example of this first ‘logo’ can be found in the SPOG annual report for 1981.



From the outset, SPOG placed children at the heart of its identity – as reflected in the child’s head in its early visual identity.

Even this early design included a child’s head – an indication that, from the very beginning, SPOG placed children at the heart of its identity. Over the years, this child’s face has appeared alongside a wide range of organisational designations.

Focus on collaboration within the network

In the 1996 annual report, the original image of the child was omitted for the first time; instead, the logo of the Swiss Institute for Applied Cancer Research (SIAC) appeared; this was accompanied by the name SPOG in the four national languages. From 2006 to 2009, a combination of the SIAC visual element and the abbreviation SPOG was used as the figurative mark.

The first dedicated logo

From 2010, a new figure was added to the SPOG logo. At that time, it was still nameless and served no other purpose. This logo is still in use today. Over the years, further distinctive features such as a colour scheme and the slogan ‘So that children with cancer also have a future!’ were added to the logo.

New visual identity with its own colour scheme

In 2021, SPOG decided to overhaul its entire visual identity. The background to this was the growing importance of the organisation being recognised by the general public coupled with the strategic decision to diversify its fundraising activi-

ties to include private donations. Without a strong brand recognition, neither of these would be possible. The logo remained unchanged, the colour scheme was developed based on the child figure featured in the logo, and the slogan was further developed to read ‘Research – giving a future to children with cancer’.

In 2022, the annual report was published for the first time with the new design, and in 2023, the website was re-launched.

SPOG always places children and their needs at the heart of its work. That is why it does not show any identifiable children’s faces in its communications. However, in fundraising in particular, conveying emotions is crucial. Over time, therefore, the idea of bringing the figure from the logo to life emerged.

Spogli helps us to convey emotions

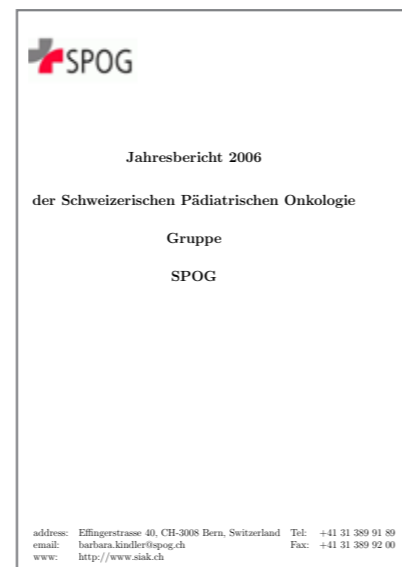
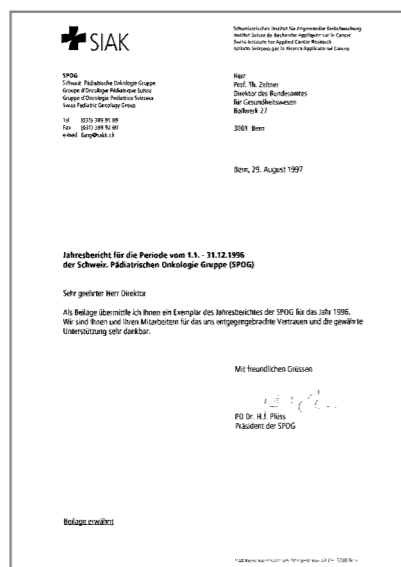
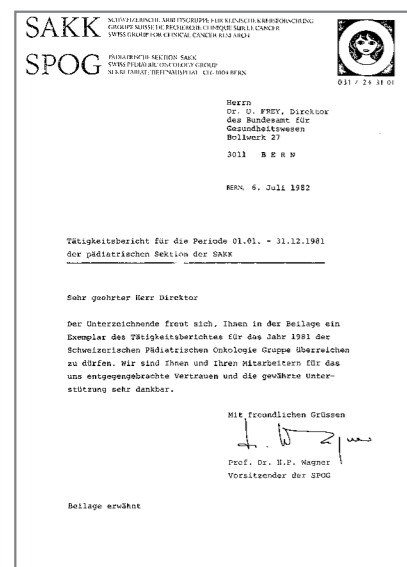
The character – later named Spogli – made its first major appearance in the explanatory video launched in 2023. Spogli is a gender-neutral character and has since helped SPOG explain its work and connect with people emotionally. Spogli has evolved from a communication tool into a symbol of hope.

Hello, I'm Spogli

At the hospital, I am always there when children with cancer are receiving treatment. My greatest wish is for every child and adolescent to get well again. That's why I help the doctors.

I am very curious and carefully write down what we learn about cancer. I observe how the treatments work and what helps the children. This helps us learn how we can treat cancer even more effectively together. Fortunately, cancer in children is rare. But there are over 250 different types – that's quite a lot! We still have a lot to learn before we can cure all children and adolescents one day.

Your Spogli



Round-table discussion: Two generations of SPOG look to the future

How is paediatric cancer research evolving, and what challenges lie ahead for SPOG? In this round-table discussion, the President and Managing Director of SPOG speak with two early-career researchers about new research topics, SPOG as a potential study sponsor, regulatory issues, and support for the next generation.

The main focus of paediatric cancer research used to be improving survival. Thanks to research, mortality rates have fallen dramatically. What are the key themes in research today?

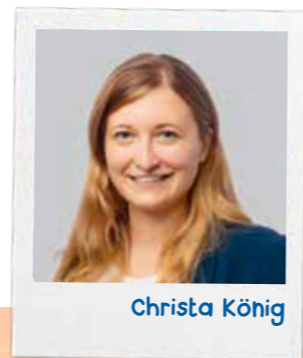
Katrin Scheinemann: We are working to gain a much better understanding of tumour biology. Before treatment, we carry out numerous analyses and investigations in order to personalise the subsequent treatment as much as possible. Here, the key term is 'personalised medicine', which refers to tailoring treatment to risk. Today, the focus is no longer on whether a child survives but rather on how they survive – ideally with a quality of life and the same opportunities as if they had never had cancer. Today, the issue of follow-up care influences treatment from day one.

Christa, what are you researching?

Christa König: I work in two different research areas. One is febrile neutropenia (supportive care). Here, too, the focus is moving towards personalised treatment. The other is renal tumours. As a Young Investigator in an international study group, I can learn from pioneers in renal tumour treatment. Although these two topics may sound quite different, the fundamental goal is the same: to provide treatment in a way that maintains the best possible quality of life.

Maria, your research topic didn't use to play any role at all.

Maria Otth: Exactly. My focus is on follow-up care. I work in an international group in which we develop guidelines on how to detect long-term effects in former paediatric cancer patients at an early stage. In Switzerland, we have also established a register in which the health status of survivors is documented annually in a standardised format.



Christa König

Dr med. Christa König, PhD

is currently a Clinical Fellow at Great Ormond Street Hospital for Children, London and a post-doctoral researcher in paediatric oncology/haematology at the Inselspital Bern. She wanted a career in which she could fully commit herself with passion. She found this in paediatric oncology. She got into research more 'by chance'. She is now convinced that, without research, there would be no paediatric oncology.

What themes will research be dealing with in the future?

Maria Otth: In follow-up care, it will be extremely important to investigate the long-term effects of new medications. For older medications and radiation, we already know a great deal about possible long-term effects. When it comes to new medications, immunotherapeutics, and targeted treatments, we do not yet know whether they will have any long-term effects at all.

Katrin Scheinemann: Another area is intervention studies. We don't just observe in order to detect and treat late effects at an early stage; we may also be able to prevent or minimise late effects through interventions. Exercise plays a major role here, as do medications given during treatment to reduce side effects.

A second major area for the future is what is known as 'Liquid Biopsy'. This technique enables tumours to be detected in a minimally invasive manner. Perhaps in 10 years we will

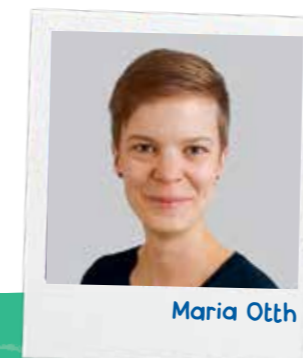
no longer even need to operate on a brain tumour unless there are problems with the build-up of cerebrospinal fluid (CSF). Instead, we will be able to determine precisely what type of tumour it is – either from the CSF or from the blood – and start treatment immediately.

Christa König: I would like to add nutrition. A Swiss study on neuroblastoma has recently been published. Depending on what we eat, a medication can have different effects. We will be able to make improvements in this area.

Digitalisation will play an increasing role in research. In the future, even greater efforts will be made to collect and share data internationally.

Can you give us some specific examples of this?

Christa König: For example, I am thinking of the European 'UNCAN' project as part of which large data platforms are being developed. The idea behind it is: Where can data be



Maria Otth

Dr med. Maria Otth, PhD

is a Senior Consultant in Oncology and Haematology at the Children's Hospital of Eastern Switzerland and a Senior Consultant in Oncology and Haematology at the University Children's Hospital Zurich. She discovered paediatric oncology in her final year of studies at the Inselspital in Bern. When she wrote her first review on brain tumour follow-up care, she realised that she enjoyed research. She is also convinced that paediatric oncology requires research.

securely stored internationally so that researchers worldwide can use it and the greatest possible benefit can be achieved? If Switzerland takes part in something like this, particularly in childhood cancer, it will likely need an organisation like SPOG to provide overall coordination.

What technologies are shaping research today? And which ones will be important in the future?

Katrin Scheinemann: Research into tumour biology – the genetic characteristics of the various tumours and tumour subtypes – is an enormous field. In the case of brain tumours, countless new groups have been identified as a result. Thanks to new technologies, we will be able to characterise tumours even more effectively. What this ultimately means for treatment is another matter.

Christa König: I would add AI. Artificial intelligence is advancing, and from the perspective of paediatric oncology, it is important not to fall behind.

Maria Otth: AI models need to be trained specifically for paediatric oncology.

Does this give rise to a new requirement for SPOG?

Isabelle Lamontagne-Müller: When it comes to AI, I also think that, to some extent, it should be child-specific. In our exchanges with adult oncology, for example with Oncosuisse, I have also observed that the rare disease issue we see in children and adolescents is becoming more relevant there because AI can help us identify new subtypes of known cancers. In that case, it may be important to consider where we should work together and where it is more effective to take a child-specific approach.

It will also be interesting to see how the regulatory environment deals with this. The Human Research Act is being revised. In my view, it is important to consider how parts of it can be redesigned in a forward-looking and meaningful way and whether outdated aspects of the regulation could be omitted.

Looking at these developments, will SPOG soon need more specialists?

Isabelle Lamontagne-Müller: Here, too, it depends on the direction SPOG takes. If it moves towards conducting its own studies, it will need data specialists, statisticians, and AI experts. Our budget for external consultancy, including legal advice and IT, is growing steadily from year to year.

Could SPOG soon have its own in-house lawyer?

Isabelle Lamontagne-Müller: I'm sceptical about that because needs are constantly changing. For a small organisation like the Coordinating Centre, it has proven useful to always carefully consider: Where do we have consistency? In these areas, we need our own staff who understand SPOG and can build relationships with the member hospitals, thereby making their work much more efficient. And where does it make more sense to rely on external support? I think at the moment we have a workable solution, but it needs to be continually adapted and optimised where necessary.

The study portfolio of SPOG comprises primarily international studies. One question remained unanswered: Should SPOG also conduct national and international protocols itself as a sponsor?

Katrin Scheinemann: Well, in principle, the answer is yes. However, this must be developed rather carefully because it requires a completely different framework from that used when we act solely as the International Sponsor Representative. We also need to find a suitable research gap; the major tumour groups are already well covered by our partners abroad.

Would an international Swiss study be appealing to you, Maria?

Maria Otth: Yes, absolutely. But, of course, an international study is a pretty big undertaking, and you really have to factor in dedicated time for it.

And for you, Christa?

Christa König: I find it particularly appealing when SPOG conducts national studies. When it comes to international studies, you have to weigh things up carefully because the main responsibility of SPOG should not be compromised: these international clinical trials are opened in Switzerland so that all patients can participate in them.

Isabelle, would SPOG be ready for that?

Isabelle Lamontagne-Müller: We're not ready yet, but we're now learning from the example of the KidsCan-01 study. For me, long-term viability is important. The advantage of joining international studies is that we can enable many children to participate in the study at a relatively low cost. At the moment, this is also what is really convincing the authorities and the federal government, which funds one third of our



Isabelle Lamontagne-Müller

studied pharmacy but soon became more interested in medicine and management. She worked in fundraising for a breast cancer organisation and had her office next to that of the then SPOG Secretary. When a Managing Director was needed, her 'unconventional' background made her the perfect fit.

work. If we were to conduct our own national – and especially international – studies, the cost equation would, of course, be quite different.

I believe that, under certain conditions, we could conduct our own national and potentially international studies. However, this will not happen overnight. First comes the concept followed by the necessary financial resources and finally implementation.

Christa, what makes your research easier for you today, and what makes it more difficult?

Christa König: For me, research becomes difficult when clinical work takes up most of my time. Patients always come first. Research then has to be accommodated alongside everything else, and striking that balance is perhaps the most difficult part.

Grants really help. They make it possible to set aside time exclusively for research. I was able to benefit from the SPOG

Young Investigator Grant and have also received other grants. Having more time for research is, in my view, the most beneficial thing.

Maria, what is going well in your day-to-day research work, and where is there still room for improvement?

Maria Otth: Christa has mentioned the most important points. One clear obstacle is time. I currently have one research day set aside, but clinical work takes priority on that day as well.

What definitely makes things easier is having a network. This develops over time once you are involved in research. Then you can network with people who have interests in the same field, and it becomes easier to launch projects.



Prof. Dr med. Katrin Scheinemann, M.Sc.

attended the SPOG Scientific Meeting for the first time in 2001 and was "quickly made to feel very welcome" by the community. Therefore, when younger staff were needed, she had no hesitation in getting involved. She was elected President of SPOG in 2020.

When it comes to regulations, there has been a considerable increase in requirements and laws over the past 50 years. How do you experience this in your day-to-day research work?

Maria Otth: My main point of contact with the regulations is the application to the Ethics Committee. To be honest, it's not a major hurdle because it's very clear what is required. We want a large number of children and adolescents to participate in the studies, and their data and information must be protected in the best possible way. This is ensured by the medical ethics committee.

Christa König: I see it in a similar way to Maria. However, clinical studies already require a great deal of effort; it is not just about patient data. It's also about the investigator; you have to have the GCP documents and keep a delegation log. All these things are related to ethics but are fairly time-consuming.

Do regulations delay research?

Katrin Scheinemann: I don't think so – at least not in Switzerland because we have good systems in place and maintain an active dialogue with the ethics committees and Swissmedic. We experience considerably more delays with contractual partners abroad or with foreign Ethics Committees.

Christa König: I agree with that. I am also in contact with researchers from other countries, and they face much greater difficulties than we do in launching clinical trials.

Have we reached the peak in terms of regulations?

Isabelle Lamontagne-Müller: I don't think the fundamental principles of GCP will change. The aim is to protect patients and their rights as well as to collect data in a way that ensures the data and analyses are reliable.

However, regulations do affect how research is conducted. Research will not remain the same over the next few decades, and the regulations will have to address how to deal with these changes. In this respect, the small size of Switzerland is advantageous. We are in dialogue with the authorities and can find solutions together.

Christa, Maria, what would you like SPOG to do to enable you to conduct good research in the future?

Christa König: All the work that SPOG is doing provides us with a great deal of support. If I imagine that SPOG didn't exist and that, as a hospital, we had to do all this work ourselves in order to be able to include patients in the studies,

none of us would have the capacity to conduct research.

Maria Otth: For young researchers, it is important to first understand what SPOG is and what it does. A national study would be interesting. At its core, SPOG should remain as it is while continuing to embrace new developments.

Katrin Scheinemann: How else could we support you, or how can we encourage you to become National Study Chairs (NSCs) or Vice-NSCs or to get involved on the SPOG Board? You are the future generation that will be able to carry SPOG forward.

Christa König: One important aspect is mentoring. There are mentoring programmes in international study groups. Personally, I found this to be particularly helpful and useful. When I felt overwhelmed by something, I was able to watch first and then gradually take on tasks. It's a win-win situation because younger colleagues gradually take on more responsibilities, thereby easing the workload of more experienced staff. Perhaps this would be something that SPOG could adopt.

Maria Otth: It should also be one of the responsibilities of the SPOG hospital heads to support younger researchers. Perhaps it could become standard practice for a young person to become Vice-NSC. I think many young researchers hesitate because they do not really know what the role involves.

Women are playing an increasingly important role in the future of paediatric cancer research. Is it a coincidence that there are four women sitting at this table?

Isabelle Lamontagne-Müller: In the research protocols from the founding years of SPOG, a Ms Wyss is mentioned. It took me a while to realise that she was a doctor. That means a woman was involved when the organisation was founded.

Christa König: It's a great development – I have a family and I can work in clinical practice and do research. A few generations ago, it was either unthinkable or such a major hurdle that many women did not take it on.

Katrin Scheinemann: I think we are pioneers. At all SPOG member hospitals, we have a large number of senior doctors who work part-time or who, in some cases, worked part-time during their training. This is not something that can be taken for granted. When I started, it was 100% or nothing. For me, as a department head, it is absolutely clear that part-time work must be made available to all employees – not only women but also men.

And finally: What is the value of SPOG? And what should its role be in the future?

Katrin Scheinemann: SPOG ensures equity of access. Every child in Switzerland under the age of 18 who has an oncological disease has access to the best treatment available at the current time. This is a distinguishing feature – especially when compared to our adult patients for whom this is not the case.

We have a lean, efficient structure that enables us to quickly open studies. This benefit is extremely high, and there are not many European countries with such an efficient system.

Isabelle Lamontagne-Müller: At the SPOG Coordinating Centre, we aim to provide a platform that allows paediatric oncologists to focus on their medical and research responsibilities. We have specialists who coordinate the supporting tasks; because this work is centralised, we don't have to reinvent the wheel for every trial.

Christa König: As someone somewhat more on the outside, I am perhaps best placed to add that the SPOG provides social and economic benefits. We treat children as effectively as possible so that their quality of life improves and healthcare costs are reduced in the long term. •

The questions for the online round-table discussion on 11 November 2025 were asked by Brigitte Casanova, Communications Officer at SPOG.

«The goal is to conduct research with the patients and their families – not just about them.»

In spring 2025, SPOG established a Patient Advisory Board. Since then, patients and their families have been able to formally express their views and concerns regarding paediatric cancer research. We asked Nicole Seiler, Chair of the SPOG Patient Advisory Board (SPAB), four questions about the future.



1. What does the establishment of SPAB mean for childhood cancer survivors and their families?

Nicole Seiler: Survivors and their families are given a voice in paediatric cancer research. Figuratively speaking, they are involved when important decisions are made. The aim is to ensure that their perspectives are represented as fully as possible through the members of SPAB.

2. What issues can the Patient Advisory Board typically contribute to?

The current areas of focus are access to treatment, patient-centred information and communication, and data management. In principle, the Advisory Board can express its views on any issues concerning patients, their relatives, and survivors.

3. How should the role of former patients and their families in paediatric cancer research evolve in the future?

Their role should evolve from being mere research subjects to becoming active participants. The goal is to conduct research with the patients and their families – not just about them.

4. As a patient representative, what wishes do you have for SPOG in the future?

More wide-ranging research with a greater focus on long-term effects would be desirable. In addition, collaboration between the various sites should be further strengthened in order to ensure that patients receive the best possible care. •



Nicole Seiler

Nicole Seiler

has been Chair of the SPOG Patient Advisory Board since 2025. As a survivor, Seiler advocates for the concerns of young cancer patients. She herself was diagnosed with a kidney tumour at the age of four. Today, she works as a registered nurse at Inselspital Bern.



**50 YEARS
RESEARCH
FOR KIDS
SPOG.CH**



«Every clinical study brings hope. Hope for improvement. And, during treatment, parents can do nothing more than hope.»

Paul Castle

Father of a child affected by cancer and founding member of the SPOG Patient Advisory Board

“A chronicle of hope” is part of the activities marking the 50th anniversary of SPOG.

In 2026, the Swiss Paediatric Oncology Group (SPOG) will be looking back on 50 years of paediatric cancer research in Switzerland. What began in 1976 as a coordinated network of paediatric oncology hospitals has developed into a nationally and internationally connected research organisation with a clear goal: to give children and adolescents with cancer better chances of cure and to minimise long-term effects.

This anniversary year provides an opportunity to make this commitment visible. Through concerts, a symposium, a movement campaign, and numerous initiatives at its member hospitals, SPOG is raising public awareness of its work. This chronicle is another part of that effort: it documents what has been achieved over five decades and makes clear why paediatric cancer research will continue to rely on support. •



Anniversary T-shirt



Symposium



Charity concert



Video & chronicle



Spogli courage beads



Movement campaign



Dear SPOG community,

On behalf of the children and adolescents, I would like to express my sincere thanks. You have been helping them and their families for half a century now. With extensive knowledge, experience, dedication and heart, you are committed to ensuring that they receive the best possible treatment.

You have built and learned a great deal and have continually sought out new ways to help. In this way, you have steadily improved the treatment of cancer in children and adolescents in Switzerland.

You are continuing to do so today. You conduct research, support families, and give hope. This is very important. That's because when a child is diagnosed with cancer, they and their families need not only medicine but also people who are there for them.

Thanks to you, many children and adolescents receive help, courage, and hope. And thanks to you, many of them are able to recover and look to the future with hope.

On behalf of the children and adolescents, I would like to say: **Thank you** for everything.

Your Spogli



www.spog.ch

Click here to watch a video
about SPOG.

