



princess
máxima
center
pediatric oncology

Focused and promising

The strategy of the Princess Máxima Center
for pediatric oncology for 2020-2024

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Mission: to provide a cure for every child with
cancer while maintaining an optimal quality of life

Core values: Groundbreaking and passionate

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Foreword

“Building together” was the motto of our strategy for the period 2016-2020. Central to this was the opening of the Princess Máxima Center building in May 2018. This allowed us to achieve concentration of care, research and training in pediatric oncology. We began working safely and responsibly with a brand new organization. A unique innovation in highly complex care, bringing together all expertise in pediatric oncology under one roof. There is an enormous amount of inspiration and motivation to take the next steps in finding cures and improving quality of life of children with cancer, their parents and families their parents and families. In “Focused and promising” we describe our roadmap for the coming years.

From the moment that a child gets diagnosed with cancer, the Princess Máxima Center is fully focused on the welfare of that child, her/his parents and family. We are completely committed to making the child ‘better better’: free of disease, with as little pain and stress, as few side effects and complications, and as little long-term harm as possible. All this is done with the minimum possible disturbance to the child’s development. The opinions of the child and her/his parents about the different stages of treatment count a great deal. We consider the impact on the whole family and are honest about what may happen with an intensive treatment, about the unpredictability of complications and about prognoses that are often good and hopeful, but are sometimes uncertain or poor. We deliver concrete care and attention to the consequences of cancer, its treatment or a poor outcome.

Ultimately, all this is driven by our wish to provide a cure and optimal quality of life for every child with cancer. That is our mission, which emerges from the commitment of parents, survivors, care professionals and scientists in pediatric oncology. They have joined forces to achieve quicker and greater progress in the understanding and treatment of childhood cancer. Crucial to this is

attracting and training the best professionals. We are certain that we can realize our mission, given the results of recent years in pediatric oncology, and the prospects that new scientific insights, therapies and technologies offer us. The representatives of parents and children are a reliable compass in this regard.

The Princess Máxima Center brings together the best of different worlds. First and foremost it integrates care and research. Alongside this it has a multidisciplinary approach, not only for medical, paramedical, nursing and scientific roles, but also expertise and innovations in terms of education and training, IDT (Information and Data Technology), HR, facilities management and communication. The strategic partnership with UMC Utrecht and the Wilhelmina Kinderziekenhuis (WKZ) also delivers a wealth of expertise and knowledge. Furthermore we invest in good partnerships with other stakeholders in the domains of care, science, training, service provision and funding.

Through the unique relationship with KiKa, the work of the Princess Máxima Center Foundation and the support of various other funding bodies and donors, we are supported financially and

morally by many people and organizations. They give us even more motivation to get good results in care and research to help children with cancer. We use this as a springboard to make strong connections with leading international institutes and organizations in pediatric oncology.

The founders and owners of the Princess Máxima Center are united in an overarching cooperative, consisting of the Parents, the Children and Cancer Association (Vereniging Ouders, Kinderen en Kanker, VOKK) and the Dutch Society for Pediatric Oncology (Stichting Kinderoncologie Nederland, SKION). VOKK and SKION strengthen the notion that curing children with cancer must go hand in hand with a way of working that does not harm

the surroundings, respects people’s dignity and does not overly burden them, and entails running operations in a financially healthy way.

This strategic multiannual plan “Focused and promising” describes the roadmap for progression. On our way we will fully work out our route and will seek continuous developments to keep moving forward smoothly and safely. In our strategy we have made clear choices, but of course have also left the space to be able to respond flexibly to new developments and opportunities. This is to ensure that, together with all our partners, we can achieve what we stand for: providing a cure and optimal quality of life for every child with cancer.





The Princess Máxima Center has great ambition, as expressed in our mission: **the Princess Máxima Center for pediatric oncology wants to provide a cure for every child with cancer while maintaining an optimal quality of life.**

Introduction

1 An ambitious mission

Groundbreaking and passionate

What would you do for your own child if they got cancer? This thought drives every employee at the Princess Máxima Center to give their best, every day, to help realize our mission. This is reflected by our two core values: groundbreaking and passionate. Together these core values offer the shortest possible summary of what the Princess Máxima Center stands for: we go further than others have ever gone before, and we do it with heart and soul. Innovation is the common theme in all our work. This is inevitable for a center that emerged as an innovate initiative from parents and medical professionals, that connects

care and research more than ever before, that works in a multidisciplinary way and that delivers development-focused care for children and families.

Personalized treatment with a multitude of specific expertise

Treating children and young people¹ with cancer is a long and complex process, requiring numerous domains of expertise from scientists, clinical specialists, nurses, paramedics and a range of supporting disciplines. Through multidisciplinary consultation, there is continuous alignment on precisely when and how various elements – including surgery, radiotherapy,

radiology, chemotherapy, immunotherapy, stem cell transplantation, psychosocial care, supportive care, pain specialists, and the comfort team – must be deployed. Furthermore, for the increasing number of biological subclasses of tumors, there are personalized, and usually more intensive, treatment pathways.

It is extremely challenging to quickly recognize and adequately treat rare but often life-threatening side effects of specific treatment elements and the underlying illness. What is crucial is the work of the LATER outpatient clinic, which is a center of expertise for the care of children who have been cured of cancer and adults who had cancer when they were children. Finally, optimal palliative care and support for children who will not be able to recover and who are going to die (and support for their parents and others around them) is also integral to cancer care.

A holistic approach to childhood cancer

The Princess Máxima Center delivers care to children with cancer and their families. Starting out from the basis of a child's environment, we adopt a holistic approach to child cancer. We deliver care of demonstrably excellent quality, involving the optimal use of innovative technical and organizational solutions. We have fostered a culture in which we act as much as possible from the perspective of children, their families and others around them (with consideration for all of a child's areas of development), in a transparent, honest and pleasant workplace. In this way, we strive for the highest quality standards in pediatric cancer care at the Princess Máxima Center.

Together with patients and parents

The Princess Máxima Center is an innovation in care. One reason for this is that parents and professionals are joint owners. Guided by children's development prospects, patients, parents and survivors are structural partners shaping everything that we do and develop, in terms of care, research and training. Among other things, this is achieved through the contributions of the Client Council, the Children's Advisory Board and VOKK, and via innovative types of partnerships that contribute to the emancipation of children and parents. We strive for maximum participation in the broadest sense, which means co-production and co-decision making. When it comes to decisions on treatment, we aim to achieve joint decision-making. In our everyday practice we always work from the perspective of children and parents, are always accommodating and uphold quality as our top priority.

The crucial role of research

We can only improve the care and quality of survival/life of children with cancer with innovative research, both inside our center and through national and international partnerships. By bringing together expertise in the Princess Máxima Center we create more critical mass and interaction, which increases the quality and diversity of both scientific research and care. The starting points for achieving our strategic objectives are that all patients can get the best possible treatment and can all play a role in improving therapies.

¹For readability purposes, we write "children" for the remainder of this document. With "children" we are referring to the whole primary group of patients at the Princess Máxima Center, namely patients aged 0-18, and occasionally, "young adults" who have a cancer for which most expertise exists in the domain of pediatric oncology.

What this means is that almost all treatment is part of a clinical trial. We therefore take patients and their parents on a collective journey with doctors and scientists, en route to achieving our mission.

Training and development

To realize our mission, it is essential that all our employees work in an optimal way, now and in the future. Education and training are crucial to achieve this, and so this forms the third pillar of the work of the Princess Máxima Center. Learning and development is a process that never stops, and it is supported by our HR policy and efforts from our Academy. We are perfectly positioned to train the pediatric oncology professionals of tomorrow and to provide our employees with opportunities to continually develop, both within our center and externally. Furthermore, the Academy provides a platform to reach out to the outside world. This involves organizing national and international

conferences and events, as well as our Outreach program, through which we share our knowledge and expertise and make it accessible and applicable to patients across the world. As a result, we increase our visibility and research opportunities, and strengthen our position when it comes to attracting talented professionals who are performing at the highest level.

Everyone serves the mission

An organization is only as good as its people. Everyone who works for us– in care, research, training, technology development, innovation and support services – does so with the same dedication that they would have were it their own children, and they all want to perform at the top level, professionally and personally. The Princess Máxima Center is an environment in which professionals can thrive, as part of committed teams that always give their best for the children and their families. People with the ambition and

desire to continuously improve can grow with us and get support in their career planning. Empowering employees, by allowing them to take on challenges and responsibilities, requires inspiring and facilitating leadership, which is strongly committed to a shared culture. Our culture does not emerge from a set of behavioral rules, but aligns with an intrinsic motivation that we foster and strengthen together. Our organization has a strong societal commitment and is also focused on sustainability. That entails that we always work with resources and means sustainably (in the broadest sense of the term).

Governance around children with cancer

The Princess Máxima Center is founded on the importance of children and their families. The Cooperative of the Princess Máxima Center, set up by VOKK and SKION, owns the operational private limited liability company (BV) and ensures that the mission is carried out. We are a learning organization, and continually work on quality using the plan-do-check-act cycle. We are resilient and agile and work with minimal overheads. We always employ co-creation and partnership. On the basis of the Care Governance Code (Governancecode Zorg) we apply a transparent and solid governance structure with a clearly demarcated division of roles between management bodies. The governance model comprises three bodies: the Board of Directors,

the Supervisory Board and the General Meeting of Shareholders (Algemene Vergadering van Aandeelhouders). The General Meeting consists of the umbrella cooperative as owner of all normal shares and UMC Utrecht as the owner of a priority share. Stakeholder participation is ensured through the contributions of the Client Council, the Works Council and the Children’s Advisory Board, and via the Medical Advisory Board (MAR) and the Nursing and Paramedic Advisory Board (VAR). For fundraising there are two separate foundations: the Princess Máxima Center Foundation and World Child Cancer NL. They each have their own management that make autonomous decisions about the allocation of funds raised and supervise the spending thereof.

Making the difference in treating childhood cancer

Based on the core values of ‘groundbreaking’ and ‘passionate’, the Princess Máxima Center will progress in the coming years in order to realize the strategic objectives as described in “Focused and promising”. Our commitment: to substantially improve and innovate care for children with cancer and those around them by integrating this care with research and training. We will do this together with top international pediatric oncology institutes, strategic partners and various stakeholders. This is how we will make the difference in the treatment of childhood cancer.



Childhood cancer in the Netherlands

In the Netherlands, around 600 children (aged 0-18 years old) are diagnosed with cancer every year. The peak for most forms of childhood cancer is around the age of 4. Furthermore, each year, approximately 150 children have a relapse of their cancer. With children there is a great range of diagnoses, and all forms of childhood cancer are rare, with most affecting only 5 to 25 children per year. The underlying biology of tumors in children differs from that of adult cancers. In childhood cancers, different anomalies in the DNA play a role and the mechanisms that lead to DNA damage also differ. Childhood cancer often develops in other

cells of the body compared to cancer in adults. The treatment of the two also differs. For most forms of childhood cancer, chemotherapy plays an important role. Generally speaking, this chemotherapy is longer and more intensive. On the other hand, children cope with chemotherapy better than adults. The pattern and seriousness of the side effects of the therapy differ, as in children organs that are still developing are exposed to the treatment. During a child’s treatment, it is not only the child who plays an essential role, but also the child’s parents and other relatives.



2

Key strategic objectives for 2020-2024

With “Focused and promising”, the Princess Máxima Center wants to achieve outcomes in the two main components of its mission: fewer deaths (i.e. greater survival rates) through more effective treatment, and a better quality of survival/life, with fewer side effects, complications and late effects, as a result of less damaging treatments. Besides this, our aim is that children and their parents have a positive experience of the care provision and processes.

Through six key objectives the Princess Máxima Center expresses its clear commitment to new developments that we currently consider the most promising in terms of realizing our mission².

² The choice of the key objectives does not detract from all the other activities and rolling programs at the Princess Máxima Center that strengthen the basis for our work and continually improve the quality of our care and service provision. In the first phase, much of our energy was directed to opening the center in a safe and responsible way. Now we are doing state-of-the-art work on many fronts, also viewed from an international perspective.

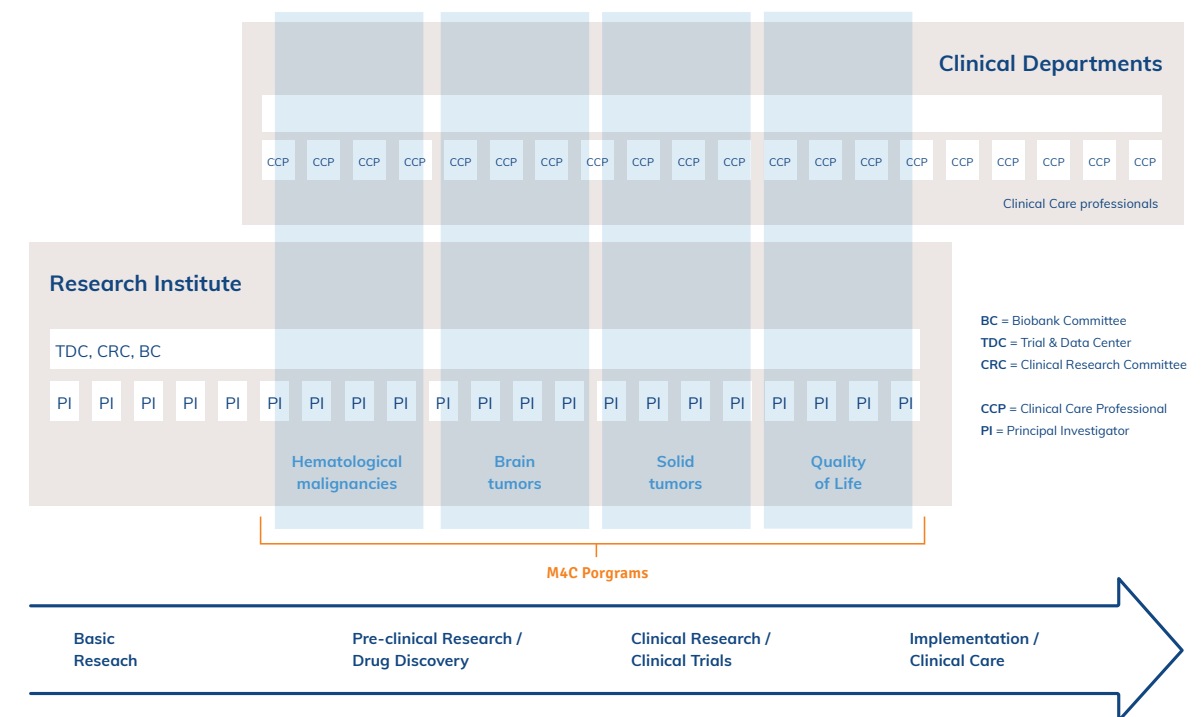


Key strategic objective 1:

The Máxima Comprehensive Childhood Cancer Center (M4C)

The Princess Máxima Center accelerates the translation of fundamental, preclinical and clinical research into clinical practices, and encourages the generation of ideas for patient care from this research.

Máxima Comprehensive Childhood Cancer Center (M4C)



Our current situation:

For a number of cancers, the interaction between research and patient care is optimally designed. We want to apply this methodology across the whole spectrum of childhood cancers and further optimize it.

For the coming years, the overarching ambition of the Princess Máxima Center is to develop and implement innovations in care and (clinical) research. The center wants to be a research hospital in which patient care and research go hand in hand, combined with training the most talented professionals to ensure that this connection pays dividends. We want to optimally integrate scientific research into our clinical programs and to foster innovation.

The structure within which we do this is the 'Máxima Comprehensive Childhood Cancer Center' (M4C). The M4C forms the biotope for clinical

scientists, pediatric oncologists and other clinical specialists who are engaged in research. These professionals work continually on new treatment protocols and methods based on the latest studies and techniques. The partnership between scientific researchers and clinical specialists will inspire progress in the domains of largest clinical need and will stimulate advances in translational research.

Parallel to the four clinical departments of the Princess Máxima Center, the M4C has four main programs: hemato-oncology, neuro-oncology, solid tumors and quality of life. So-called "cross-cutting

horizon themes" strengthen the connection between care and research. The goal of the M4C programs is to allow (pre)clinical researchers and care professionals – doctors, nurses, paramedics and psychosocial staff – to work together intensively, so that we shape the most important translational themes in the Princess Máxima Center. The M4C aims to simplify and accelerate the translation of fundamental, preclinical and clinical research, carried out by ourselves and by others, to clinical practice, while this research generates ideas from patient care.

This involves:

- integrating research into our daily clinical programs
- defining the most important clinical and translational research challenges, aligning care and research
- working together with 'connecting researchers' and clinical care professionals in research
- investing in new areas of clinical innovation
- continuous training and development of the best people.

An important part of the M4C is the trial & data center, including the supporting facilities in terms of methodology and statistics. The M4C works with overarching research programs that are aligned with the clinical directors. These programs anchor scientific research in our clinical programs. The research programs and the multidisciplinary disease-specific groups are intended to:

- embed existing disease committees in the Princess Máxima Center and the respective clinical departments
- define the most important clinical and translational challenges for the various forms of cancer
- connect researchers and professionals in clinical care
- set up better clinical trials
- foster a strong international position in terms of substantive work and implementation in pediatric oncology.

For each main program, the multidisciplinary programs are as follows:

1. Hemato-oncology

The hemato-oncology program comprises five multidisciplinary programs:

- Acute Lymphatic Leukemia (ALL)
- Lymphomas
- Acute Myeloid Leukemia (AML)
- Myelodysplastic syndrome/bone marrow failure
- Allogeneic stem cell therapy (SCT)

2. Neuro-oncology

The neuro-oncology program comprises three multidisciplinary programs:

- Gliomas
- Embryonal tumors
- Craniopharyngiomas

3. Solid tumors

The solid tumor program comprises six multidisciplinary programs:

- Neuroblastomas
- Soft tissue and bone tumors
- Kidney tumors
- Germ cell tumors
- Liver tumors
- 'Rare' tumors

4. Quality of life

The quality of life program comprises three multidisciplinary programs:

- Supportive care
- Psychosocial care
- Late effects

Through transparency – primarily as recognized by children and parents – and internationally corroborated standards, the Princess Máxima Center aims to show that it is a center of excellence for pediatric oncology care, research, training and innovation. Determining and safeguarding standards is integral to the implementation of the M4C in the coming years.

To achieve this objective, we are utilizing the following strengths:

- Care and research are in a single location in the largest childhood cancer center in Europe.
- For a number of malignancies we have top scientists and clinicians who are internationally recognized.

We are working on strengthening the following weaknesses:

- Care staff are sometimes insufficiently involved in research, meaning that inclusion is suboptimal.
- For a number of malignancies we do not have any clinicians or scientists of top international standing.

We are capitalizing on the following opportunities:

- The international development of the use of clinical scientists.
- Transformation of disease committees, currently largely made up of clinicians, through the addition of diagnostic and research experts.
- The stable financial position of KiKa.

...and we are able to avert the following threats:

- Researchers or clinicians acting in isolation from the outside world.
- Insufficient 'earmarked' time to do research within clinical practice.
- Insufficient support from (potential) funders and donors.



Key strategic objective 2:

Innovative diagnostics and treatment

The Princess Máxima Center is a leader in the development of innovative diagnostics and treatment for better chances of recovery, with two clear focus areas.

Our current situation:

In the partnership between UMC Utrecht and the Princess Máxima Center, the first steps have already been taken in the fields of radiology, nuclear medicine and radiotherapy, to facilitate new analyses and therapies for patients in our center. This sets an example and provides a driving force for further innovative diagnostics and treatment.

Through the intensive partnership between research and care around specific diseases, and through new insights from pharmacology and applications with new technologies, the Princess Máxima Center has created new (combinations of) medicines, therapies and treatment methods. This means that we can more effectively treat children with cancer, with less damaging side effects and fewer complications.

We are strongly focused on precision medicine: targeted tumor imaging and therapy on the basis of tumor characteristics, such as specific proteins or abnormalities in the genetic material of the tumor cells. We want to be international leaders

in pharmacological and early phase (phases I/ II) clinical studies. We have set up a diagnostic platform for genetic tumor sequencing and molecular diagnostics, and a preclinical platform for organoid cultures from tissues and tumors, 3D modeling of tumors and PDX mouse models. Thus we have created a 'diagnostic treatment pathway': from molecular characterization of tumor tissue to a corresponding specific treatment. Within this we have left space for fundamental research that could deliver unforeseen innovations.

For fundamental and translational research – primarily in the domain of neuro-oncology – the Deutsches Krebsforschungszentrum/Nationales

Centrum für Tumorerkrankungen (DKFZ/NCT) in Heidelberg is an important partner. We are aware of the importance of basic research, without detracting from the aims of concrete impact and implementing the insights of research. For studies for which we have too few patients, we admit specific groups of patients from abroad, as long as we have sufficient capacity in our center. Furthermore we can see opportunities to roll out studies abroad.

Within key strategic objective 2, the Princess Máxima Center has two focus areas: immuno-oncology and neuro-oncology. These are explained separately in more detail below (see 2a and 2b). The choice of immuno-oncology is based on the diverse and very promising current developments for adults in this domain, and the recent positive and very promising results of the treatment of children with what are known as CAR T-cells. Immuno-oncology is a fourth treatment option alongside surgery, radiotherapy and chemotherapy.

The choice of neuro-oncology has been prompted by the need to deliver an extra contribution to the development of effective treatments for children with certain types of brain tumors, who currently have little or no prospect of recovery. Compared to hemato-oncology and solid tumors, the application of new biological insights to neuro-oncology treatment has proven to be a bit more difficult.

In the coming years our priorities are:

- Early drug trials, primarily combination therapy involving multiple drugs:
 - a trial pharmacy and drug laboratory for pharmacogenetics, phramocodynamics, pharmacokinetics and determining drug levels
 - molecular diagnostics and tumor models for drug screening
 - expanding the trial & data center for early drug studies with patients, developing a specific policy for treating patients from abroad.
- Theranostics: image-guided therapy for metastases or resistant tumors on the basis of tumor characteristics (personalized precision medicine involving specific targeted therapy, based on the previous use of diagnostics with the same starting point):
 - innovations in image-guided therapy
 - setting up a radiochemistry research lab in partnership with UMC Utrecht.
- Perioperative imaging:
 - intraoperative MR imaging
 - intraoperative visualization of tumor expansion using tumor identification (fluorescence)
 - visualization with the help of diagnostic radiopharmaceuticals.

To achieve our objective, we are utilizing the following strengths:

- Our focus is on childhood cancer. We have specialist internal knowledge as well as a lot of equipment, clinical data, and details about outcomes and biomarkers.
- We have our own, well functioning trial & data center.

We are working on strengthening the following weaknesses:

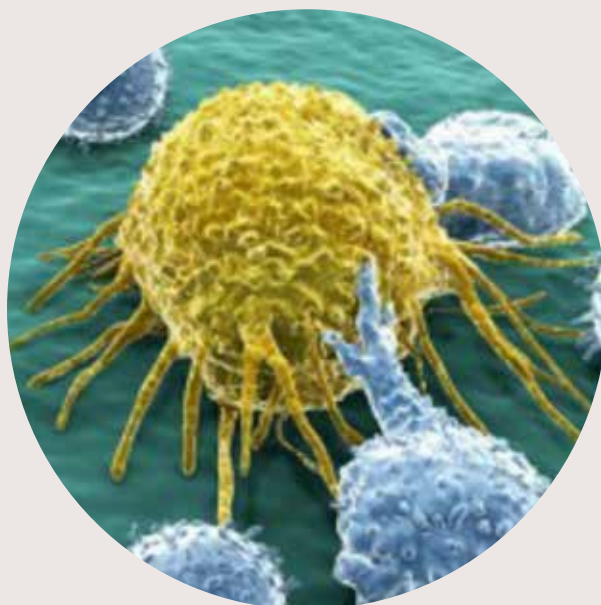
- The inclusion of patients in studies is still insufficient. This calls for better communication with parents about the importance of studies, good information for clinicians about ongoing and upcoming studies, and an active attitude from all clinicians.
- Clinical data is not yet clearly recorded and the infrastructure for structured data has not yet been organized.
- Some essential facilities are not present or are of an insufficient size, in particular a cellular therapy facility, a drugs laboratory, a trial pharmacy, a radiochemistry laboratory, and an intraoperative MRI/neuro-OncoSuite.

We are capitalizing on the following opportunities:

- Our position as a large center, which makes us an attractive partner for the pharmaceutical industry for clinical trials and drug research.
- Our ability to apply new insights and use facilities together with UMC Utrecht and other partners.
- Attractiveness to (inter)national partners and scientific talent.

...and we are able to avert the following threats:

- Too large a burden on children and families through participation in studies.
- Decision-making and priority setting at organizations we work with that are too slow for the development of our center.
- Insufficient support from (potential) funders and donors.



Key strategic objective 2a:

Focus on innovation: immuno-oncology

For innovative diagnostics and treatment, the Princess Máxima Center has a specific focus on immuno-oncology.

Our current situation:

For a number of years, antibody therapy has been used to treat children with neuroblastomas, lymphomas and leukemia. Alongside this, we recently started the first approved application of cell therapy (CAR-T). The results are encouraging. This cell therapy, coupled with what are known as checkpoint inhibitors, offers the best chance of further progress.

The immune system and the microenvironment of the tumor cell are very promising elements for more effective therapies against cancer. For various types of cancer, there is a lot of development in terms of immunology. In hemato-oncology and with solid tumors, we have already seen treatment applications that have given some children a second chance. For neuro-oncology, there are challenging opportunities for immunological targeting on the horizon.

There is also a lot of work to be done to make the leap from preclinical scientific research to clinical research and then treatment. That is why we are investing in setting up new research groups for fundamental and translational immuno-oncology research. We are also looking for renowned international partners, such as the Children's Hospital of Philadelphia (CHOP) and the Gustave Roussy Institute in Paris.

In the coming years our priorities are:

- The development and implementation of innovative therapies:
 - immunological techniques for cell therapies, in particular CAR-T (chimeric antigen receptor T cells) and TIL (tumor infiltrating lymphocytes)
 - in partnership with UMC Utrecht, realizing a well-functioning cell therapy facility to implement these techniques.
- Attracting and collaborating with top (inter) national experts in the application of immuno-oncology and researching its effects.

To achieve this objective, we are utilizing the following strengths:

- We are the largest pediatric oncology center in Europe and have the possibility of carrying out clinical trials with many patients.
- We have everything under one roof, with a clear organization, and can form a loop from (translational) research to (research or non-research related) treatment, and vice versa.

We are working on strengthening the following weaknesses:

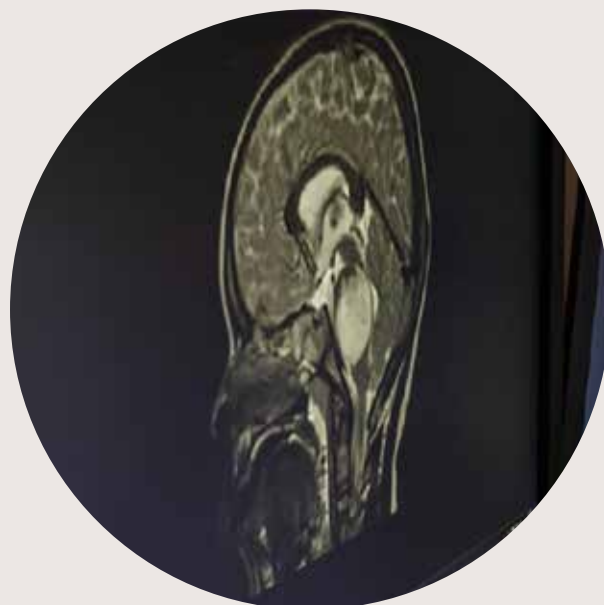
- We do not yet have a clinical reputation for cellular immunotherapies.
- In terms of research and care, we still have relatively limited internal expertise in immuno-oncology.
- As yet, lab facilities are not (optimally) available.

We are capitalizing on the following opportunities:

- A further intensification of the partnership in immuno-oncology with UMC Utrecht Cancer Center, the WKZ and international partners.
- Attractiveness for (inter)national partners and scientific talent.
- Strong international scientific competition.

...and we are able to avert the following threats:

- Competition for recruiting the top clinicians and researchers in immuno-oncology.
- Delays in access to new and improved cell immunotherapies for Dutch patients.



Key strategic objective 2b:

Focus on innovation: neuro-oncology

For innovative diagnostics and treatment, the Princess Máxima Center has a specific focus on neuro-oncology.

In the coming years our priorities are:

- Initiating and implementing clinical trials:
 - carrying out phase III studies
 - setting up phase I/II studies.
- The development and implementation of innovative technologies:
 - intraoperative MRI for brain tumor operations, with innovations in terms of MRI sequences and workflow
 - use of intraoperative visualization of tumor tissue with markers (5-ALA)
 - opening blood-brain barrier
 - with HIFU (High Frequency Ultrasound)
 - CED (Convection Enhanced Delivery): administering medication directly to a brain tumor via a catheter.
- The further development of neuropsychological care:
 - diagnostics to assess the damaging effects of tumors and treatments
 - effective interventions to treat these effects promptly.
- Attracting and collaborating with top (inter) national experts in neuro-oncological research and care.

Our current situation:

Both nationally and internationally, the treatment of neuro-oncology diseases in children is a very tough and complex challenge. As a new center, the Princess Máxima Center is able to play a leading role in looking for solutions. The preparations for using new image-guided techniques and ultrasound are already at an advanced stage, and concrete steps for using them can be made in the coming years.

For various types of brain tumors, such as DIPG (diffuse intrinsic pontine glioma) and high-grade glioma, there are no effective curative therapies. The children affected, and their parents, desperately need some prospects of recovery. Investments in neuro-oncology are vital to be able to make progress toward higher survival rates, as well as a better quality of life/survival. This is all the more so because children with tumors in the central nervous system are very vulnerable in terms of brain development. Both the tumor and the treatment cause harm, often with lasting consequences.

This terrain is also relatively unexplored on an international level. New developments, such as around immuno-oncology, mean challenging opportunities for neuro-oncology in terms of research and experimental treatments. The relative deficit in this area means there is a chance to quickly make a difference. Our focus is on aggressive gliomas and embryonal tumors. We will form strategic partnerships within (pediatric) neuro-oncology, such as with UMC Utrecht and international centers like the DKFZ/NCT.

To achieve this objective, we are utilizing the following strengths:

- We are the biggest center for pediatric oncology in Europe and are a strong draw when it comes to conducting clinical studies.

We are working on strengthening the following weaknesses:

- There is still insufficient critical mass in the field of neuro-oncology research.
- In comparison with other areas of pediatric oncology, participation of neuro-oncology patients in clinical trials remains insufficient.
- Internationally, in the neuro-oncology field, there is still not enough attention to either the clinical domain or research.
- The added value of new technologies is not sufficiently apparent for children and parents.

We are capitalizing on the following opportunities:

- Our attractiveness as a large pediatric oncology center for (inter)national partners and scientific talent.
- Collaboration with other institutes, in particular the DKFZ/NCT and UMC Utrecht, on the surgical neuro-OncoSuite.
- Development of phase I/II/III studies in neuro-oncology, which are still relatively scarce on an international level.

...and we are able to avert the following threats:

- Strong (inter)national competition for recruiting top talent.
- Too-high expectations for short-term outcomes.
- Limited willingness to invest given the relatively low number of patients.



Key strategic objective 3:

Quality of life

The Princess Máxima Center improves the quality of life of patients during and after treatment.

Our current situation:

The Princess Máxima Center's LATER outpatient clinic is one of the best in the world, and clinical research and care are well integrated there. Yet in terms of studies of and concrete interventions in supportive care, many structural improvements still need to be made. To determine quality of life objectively, we can see great added value in determining indicators, together with patients and parents, around the results or outcomes of treatment. These value-driven indicators – which are not yet available – are about outcomes rather than processes.

For our patients it is not only important that they can survive the disease, but also that their recovery involves maintaining an optimal quality of life. Furthermore there must be good prospects of them being able to participate as valued and resilient members of a rapidly changing and demanding society, even if their treatment means they have a lasting disability. Elaborating on this commitment to quality of life adds new dimensions to our activities, such as taking structural inventories of the results and experiences of children, their parents and other loved ones, or the development of interventions and effective support. The Princess Máxima Center always focuses on children's development. This means that we pay systematic attention to physical, social,

emotional, cognitive and spiritual domains, not only during treatment, but also in follow-up and the subsequent phases of life (late effects). We support children and young adults who are recovering from cancer to optimally participate in society. Psychosocial support, physical exercise and in particular supportive care – including pain, fear and stress reduction, as well as palliative care – and help for survivors, are all essential elements of this. We also support parents and families who lose a child – sometimes unexpectedly, for example through sudden complications.

The Quality of Life Department ensures the continuous improvement of all this care, in conjunction with the rest of the organization.

Nurses and paramedics play a proactive role in research in this field. To allow parents and children to understand the impact of childhood cancer on their lives as best as possible, we are realizing ever-improving coordination (including meetings, planning and provision of desired information).

In the coming years our priorities are:

- Standardization and monitoring of outcomes, together with patients, survivors and parents, to identify best practices in the quality of care and quality of life:
 - development of value-driven outcome indicators, starting from the formula 'surviving relevant side effects'³.
- Implementing best practices in the domain of quality of life and reducing late effects:
- monitoring the effects of treatment on quality of life
- interventions targeted at improving quality of life
- evidence-based supportive therapies during and after treatment.
- Empowering children and families:
 - monitoring care processes on the basis of children's and parents' experiences
 - fixed case managers for each child and family for optimum coordination and customization
 - care close to home when possible, in collaboration with our networks (diagnostics, monitoring, therapy)
 - reliable and comprehensible patient information, drawn up in consultation with parents and children.

³The character and impact of the side effects are determined through the assessment of children and parents (in close alignment with the Client Council), concretely identified per disease/patient group, monitored through internal improvements in care quality, and compared via benchmarking with the results of other centers across the world.

To achieve this objective, we are utilizing the following strengths:

- Based on our holistic approach, we pay a lot of attention to empowering children and families.
- We have strong internal knowledge and expertise around the many factors that play a role in improving quality of life.
- We have a very large LATER outpatient clinic (also large in international terms).
- We have a strong position in the domain of research into late effects.

We are working on strengthening the following weaknesses:

- Quality of life is a very broad concept and for parents it is not clear what the boundaries of custom work are.
- There is still no complete toolbox to measure value-driven outcome indicators and the experiences of children and families.

We are capitalizing on the following opportunities:

- Collaborating with good (potential) partners with a lot of experience and expertise in improving the quality of life.
- Committing to care close by, thus strengthening the continuity of regional collaboration.
- The international position of our center offers the chance to develop outcome indicators.
- Developing studies for interventions to improve quality of life.

...and we are able to avert the following threats:

- Underestimation or undervaluation of the importance of a specialized approach for this part of care.



Key strategic objective 4:

State-of-the-art data provision

The Princess Máxima Center has integrated data provision capacity for innovations in research, diagnostics and treatment.

In the coming years our priorities are:

- Setting up and continued development of an integrated data facility:
 - primarily aimed at efficient daily use by researchers and clinicians, to ensure optimal analyses
 - optimal conditions for the secure and reliable processing of big data (data science)
 - a strong IDT architecture, equipped with a flexible infrastructure, that moves in accordance with the
 - changing requirements of research and care, and with high quality digital workplaces for top experts.
- The elaboration of suitable data governance:
 - rules and agreements for a data strategy, ownership of and responsibility for data and algorithms, quality requirements and data authorization and use patterns
 - aligning with national (sharing) standards for care and international standards for global research projects.
- Building up knowledge and skills in the fields of:
 - machine learning capabilities
 - artificial intelligence (AI).

Our current situation:

Over the years, SKION has built up a wealth of experience in measuring and recording diagnostic parameters, treatment outcomes and potential side effects for a number of cancers. We see a lot of potential in expanding this across the full range of childhood cancers, starting with structured recording at the source (including in HiX).

The cornerstones for the intended developments in pediatric oncology are our data and the high-value way this will be structured, securely saved and accessible. Our data is a source of innovation and progress in both care and research. The Princess Máxima Center is using data science as a resource for care, research and training. With the new insights in this domain, we want to structurally record—close to the source and without greater recording burdens—all relevant data from care in terms of diagnostics, treatments and outcomes, and integrate this together with data from preclinical and clinical research into a single data facility. Within the organization we have a good

idea of our specific wishes and the opportunities around the design of this facility.

We will use this integrated data facility for various types of reports on care, for research and to show progression in our work. Such a facility is also a prerequisite for 'clinical decision support' in care, elaborated in conjunction with research for the development of algorithms. By equipping the data facility with 'machine learning capabilities', it can also be used for continuous improvements of care and research and for artificial intelligence (AI) applications.

To achieve this objective, we are utilizing the following strengths:

- We already have a lot of data available and within the organization there is high engagement around using this data.
- We are small and dynamic and so can also innovate quickly.
- There is a lot of knowledge, skills and experience at the trial & data center and at SKION around clinical data and information science research.

We are working on strengthening the following weaknesses:

- We still lack internal expertise on data science and data technology.
- There are a multitude of data sources that remain insufficiently linked to each other.
- The organization's power of transformation could be improved.

We are capitalizing on the following opportunities:

- Good insights into the use of data from close collaboration between care and research.
- There is still no practice-oriented standard for recording and using data ('green field').

...and we are able to avert the following threats:

- Lack of availability of people on the market.
- Too-great external recording requirements.
- Insufficient funding and support from funders.



Key strategic objective 5:

Recruit, train and retain top experts

The Princess Máxima Center recruits and connects talented professionals and encourages the permanent development of its employees.

Our current situation:

In a number of fields we already have top international experts in both clinical and research areas. We certainly want, and are able to, expand on these numbers, focusing on specific positions such as clinical scientists and case managers. We also see the possibility for professional and functional development through the increasing experience of our nurses, such as has already proven successful with a relatively small group of specialist nurses and research nurses. Furthermore, we can be an attractive employer for bioinformatic scientists and data scientists, because we offer the prospect of working with medical specialists.

People determine the success of our mission. Driven professionals in many fields relevant to progress in pediatric oncology form the backbone of our organization. We wish to maintain and further build on this strength. The Princess Máxima Center wants to be attractive and to remain a leading pediatric oncology center, by being the preferred location for top research and innovative diagnostics and treatment, by delivering excellent education and training through our Academy, and by offering a unifying working environment that encourages all employees to grow and to enjoy their job.

We stimulate diversity and inclusivity, and are committed to fostering an open, safe and transparent culture. An additional challenge for us is that a lot of research has a natural cut-off point, because it involves working on delineated projects for a certain number of years. This means that once the research has ended, the researchers may go and work somewhere else.

As our center is increasingly active on the international stage, it makes sense to recruit on the international labor market. HR can widen the pool of potential employees by delivering proactive,

creative, service-oriented and customized work to attract and retain top international talent.

As a top international center we attract professionals who are active across the globe, who engage in a lot of (knowledge) exchange and who want to continuously develop, whether within or outside of the Princess Máxima Center. It is logical for us to continue running campaigns targeting specific groups of potential employees, alongside our commitment to delivering continuous training and development opportunities to all our current members of staff.

Furthermore, we ensure good working conditions, with sufficient time for clinical and translational research. And we pay continuous attention to the impact that working with seriously ill children, and interacting with the families who are finding it difficult to cope, has on (care) professionals, especially if the children die. In the future, various categories of employees will be able to postpone and change tasks. This also applies to the division of tasks between doctors and nurses, for example, as pediatric oncology nurses are better equipped to do certain care tasks than doctors. This not only

gives nurses new career options and improved future job prospects, but it delivers our patients a better quality of care.

In the coming years our priorities are:

- Recruiting and retaining⁴ talented professionals, with a focus on:
 - clinical scientists: clinical specialists who deliver trendsetting care and research and develop into the future leaders of pediatric oncology
 - top researchers
 - professional and functional development of (experienced) nurses
 - specialists in data science and technology.
- Commitment to continuous development:
 - excellent education and training for all employees
 - sharing knowledge nationally and internationally (including via Outreach)
 - an ambitious working environment that stimulates and rewards performance, development, reflection and knowledge sharing.

⁴ Amongst other things, this is done by strengthening our image, brand recognition and working conditions, including optimal facilities for new employees from the Netherlands and abroad.

To achieve this objective, we are utilizing the following strengths:

- We have our own Academy, so can deliver customized training.
- Our center is highly attractive, both in national and international terms, to ambitious professionals and scientists in all disciplines.

We are working on strengthening the following weaknesses:

- Strategic personnel planning is still insufficiently developed.
- Lack of experience among some of our care professionals.
- The rapid growth of our center means there is insufficient workspace for employees.

We are capitalizing on the following opportunities:

- Possibilities of actively recruiting people from other pools (universities, etc.). Our international position in the domain of pediatric oncology attracts ambitious people.
- Prospects for professional and functional development, such as for nurses.
- Changes of roles for various professionals, which can lead to better care.

...and we are able to avert the following threats:

- Unclear policy on training pediatricians in pediatric oncology.
- Shortages in the labor market.
- Difficulty to get to Utrecht Science Park.



Key strategic objective 6:

Internationalization

The Princess Máxima Center optimally leverages its position as a top pediatric oncology center on an international level.

Our current situation:

Our center attracts great interest internationally, and institutions want to work with us. We have made a good start in this regard, with leading centers such as St. Jude Children's Research Hospital, CHOP and the DKFZ/NCT, and will build on this position.

Through the opening of our new building, the Princess Máxima Centrum became the biggest pediatric oncology center in Europe. That was not an objective as such, but it has increased our ability to attract researchers, clinical specialists and talented people in other relevant domains, as well as stakeholders who can play a role in the progression of pediatric oncology.

This also puts our own experts more into the spotlight. We want to strengthen this strong international position, or at least clarify it, including through the potential treatment of patients from abroad and the significance that this can have for particular studies.

In the coming years our priorities are:

- Developing policy around patients from abroad:
 - clinical trials for patients from abroad
 - this means not competing with the regular care for Dutch patients and endeavoring to avoid (unnecessary) extra pressure at work
 - separately financed and separate responsibility (transparency).
- The strengthening of our international position:
 - proving our top position in Europe
 - working together with top international centers such as St. Jude Children's Research Hospital, CHOP, DKFZ/NCT, Hopp-Kindertumorzentrum Heidelberg (KITZ) and the Gustave Roussy Institute
 - taking up a leading role in collaborative international arenas such as the International Society of Paediatric Oncology (SIOP) and the Innovative Therapies for Children with Cancer in Europe (ITCC) consortium.

To achieve this objective, we are utilizing the following strengths:

- Care and research are at one location, in Europe's largest center for children with cancer.
- Both nationally and internationally, our center is highly attractive to ambitious professionals and scientists in all disciplines.
- We are an attractive partner for other top international centers for pediatric oncology and for centers which have knowledge relevant to our mission.
- Good infrastructure for phase I/II studies.

We are working on strengthening the following weaknesses:

- Some of our nurses are relatively inexperienced.

- There is still insufficient nursing expertise to expand our care provision to patients from abroad.
- A lack or insufficient levels of funding to deliver care to patients from abroad.

We are capitalizing on the following opportunities:

- Possibilities for a targeted expansion of phase I/II studies.
- The ever-stronger positioning of our professionals in international arenas.

...and we are able to avert the following threats:

- The miscomprehension that we have no limits.
- The possibility of attracting patients from abroad being to the detriment of 'regular' care.

3 Finance and funding

As the first step towards achieving its mission, the Princess Máxima Center has put a lot of energy into setting up the center in recent years. In this period, a strong financial foundation has been laid for the following years. This includes long-term loans from Rabobank and BNG at relatively low interest rates, core funding from KiKa, the award of an Academic Care Availability Contribution (BBAZ: beschikbaarheidsbijdrage academische zorg), and training subsidies for training and development in quality of care. In 2019, it was difficult to make sufficient agreements with health insurers. Now, in 2020, the aim is to come to some long-term (multiannual) arrangements.

The great ambitions of the Princess Máxima Center for the coming years make it necessary to further strengthen our financial foundation, while respecting the established framework. Our center must remain in good financial health and build up sufficient resilience. This means that we must spend the available money wisely. An important opportunity is to leverage the mission of the Princess Máxima Center to attract potential donors. Hereby a threat is the growth rate of our activities. Can the organization remain (financially) in control? It is essential to be transparent and retain good relations with health insurers, government organizations, banks and other funders (e.g. research grants). Various developments make this especially challenging, including the increasing pressure on care procurement through health insurers, the internationalization of money streams in scientific research, and a critical attitude from the public related to the impact of fundraising organizations.

The various standards for compliance and good governance in care and research and from fundraising institutions make high demands on the financial functioning of the Princess Máxima Center. The necessary complexity of the management organization – which serves the mission – requires highly qualified financial employees that can work with sufficient detail and in sufficient depth, and can handle the complexity within and outside of the organization.

Based on the strategic themes for 2020-2024, and taking into consideration the aforementioned opportunities and threats, we have formulated the following strategic financial objectives:

- The Princess Máxima Center has a strategy for asset management and financing to realize its ambitions and keeps the center financially healthy.
- Finance & Risk has the (financial) expertise to ensure the organization can make the correct decisions, and offers solicited and unsolicited advice about the course of the organization in relation to the available means.
- The Princess Máxima Center has a financial organization that complies with laws and regulations and responds to the organization's requirements.
- The Princess Máxima Center has structured its in-house information provision in such a way that it aligns with the organization's requirements in terms of management and responsibility.
- The Princess Máxima Center has excellent relationships with relevant external stakeholders.

Financial policy in 2020-2024

A healthy financial foundation is necessary to be able to invest sustainably in care, research, education, IDT and building facilities. This strong basis is also needed to be able to deal with the significant external financial risks. To ensure that the Princess Máxima Center stays profitable in the coming years, with a responsible financial policy, we commit to healthy business operation, the further improvement of solvency and the realization of a good cash flow.

The Princess Máxima Center is increasing its focus on efficiency and quality through continual benchmarking, both nationally and internationally. We stimulate the control of (financial) business operations through the implementation of a dashboard with control information for management at all levels. All this plays a part in ensuring that the Princess Máxima Center remains a reliable party that is attractive to external funders.

Internal control

Within the Princess Máxima Center, responsibilities are as low down in the organization as possible. Line managers manage costs within established frameworks in relation to the amount of care and research activities delivered. The management and control system is anchored in the planning & control cycle. In this cycle the strategy of the Princess Máxima Center is transformed into comprehensive annual and multiannual plans and budgets for each department.

The feasibility of the plans and the necessary investments are carefully assessed beforehand. Part of this assessment and subsequent decision-making involves working with scenarios and risk analysis. The limits of the available resources mean it is necessary to make choices that could temper ambitions. That is why the Princess Máxima Center – partly via the Foundation – is always looking for additional funding.



The further professionalization of our Foundation is therefore of great importance (see textbox on pages 34-35).

Risks

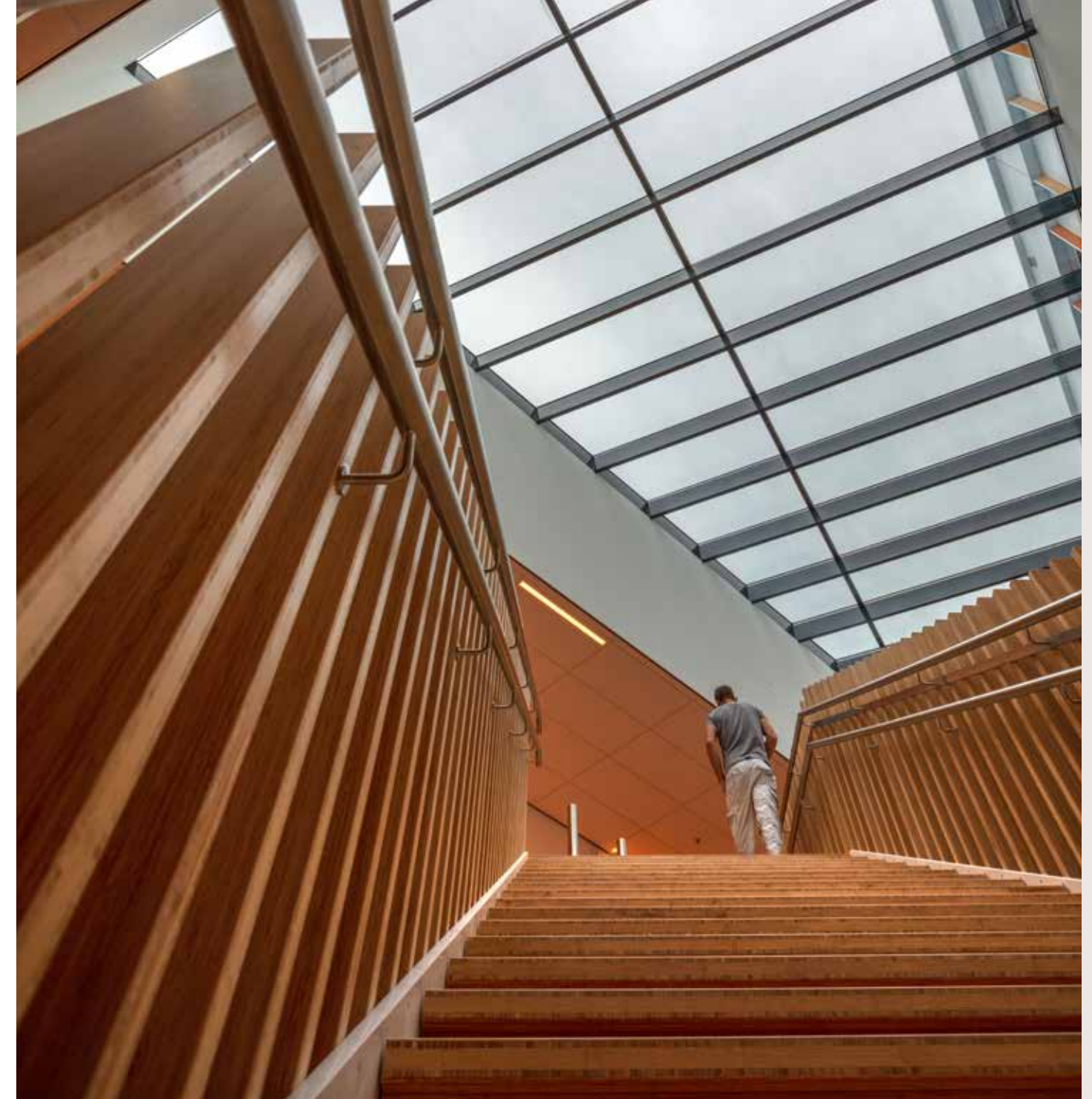
The most significant risks that the Princess Máxima Center faces are as follows:

- **Reputation:** to achieve its mission, the Princess Máxima Centrum is reliant not only on public funds but also, to a large (and growing) extent, private funds. This requires the center to have an outstanding reputation for care, research and transparent business operation.
- **Income from remunerations from health insurers:** remunerations from health insurers are crucial to carry out the diagnostics and treatments that our patients require. In society, the pressure on the use of public funds (premiums) is increasing. This means that our organization must demonstrably spend the available funds in correct and efficient ways. Moreover it is important to make timely, good (long-term) agreements about remuneration of treatments and (expensive) drugs. Managing this risk is vital for the continuity of care and treatment, as our patients have nowhere else to go.
- **Taking on SKION tasks without the related means:** SKION is the organization that represents healthcare professionals in pediatric oncology, and through the cooperative is the majority shareholder of the Princess Máxima Centrum. In the future, some of SKION's activities will take place in our center, while others need to remain independent. As it stands, SKION is separately financed by health insurers. There is, however, uncertainty about the structural character and size of financing in the future.
- **Availability and operation of IDT systems:** without optimally working IDT systems, the Princess Máxima Center cannot achieve its strategic objectives, or show what results we have achieved en route to achieving our mission. In relation to these systems, there must be adequate and demonstrable compliance with laws and regulations regarding data, privacy and security.

- **Availability of qualified employees:** our employees are our human capital. To achieve our mission we need the best people, with the right qualifications, in all parts of our organization. What is crucial here is not only recruitment, but also retention, development and promotion opportunities.
- **Culture and collaboration:** it is a fact that every top organization can only flourish with an open and transparent culture in which people respect each other's expertise and, on the basis of internal and external collaboration, bring out the best in themselves and others in order to achieve the organization's mission together. The Princess Máxima Center views culture and collaboration as two of the most important foundations for success. The first steps have been taken in this regard with the leadership development program. In the coming years, this program will be expanded to the rest of the organization in the guise of specific programs and processes.

Multiannual budget 2020-2024

In "Focused and promising" we sketch the outline of the financial policy that supports our strategy. Making this more specific, in terms of concrete activities and figures, is part of drawing up the multiannual budget and the annual plans. From the global estimates drawn up with this strategy, it appears that we can carry out large parts of the plans within the current multiannual budget, but some parts require extra funding. Effective fundraising is therefore an important factor in the success of our multiannual strategy.



Investments in our building

The great ambitions set out in the six key strategic objectives of "Focused and promising" mean it will be necessary to literally create more space for work in the Princess Máxima Center. By adding a sixth and seventh floor to the existing research building, we can realize new facilities and provide workspace (labs and offices) to a growing group of researchers.

A business case has been prepared for the required investment. Partly thanks to KiKa's willingness to increase its core funding, there is full financial coverage for this expansion in the multiannual budget. The expansion will make further integration of care and research possible and will support our drive for innovation.

The contribution of the Princess Máxima Center Foundation

The Princess Máxima Center Foundation plays a crucial role in giving an impulse to our center's mission. Alongside the core funding from the KiKa Foundation for the research department, the remuneration of diagnosis and treatment by health insurers and the money from BBAZ, additional funding from the Princess Máxima Center Foundation is vital to the center.

Through gifts from (charitable) funds, foundations and other external donors, the Foundation finances projects that directly and indirectly contribute to the care and quality of life of children with cancer and their families. Since our opening the Foundation has focused on raising awareness of the fact that the Princess Máxima Center continuously requires a lot of money. This requires durable engagement.

The Foundation does not focus on the public domain – where KiKa does its work– but raises money, on a project basis, from wealthy individuals, funding bodies, charitable foundations and companies. This mostly concerns already earmarked money for complementary and more in-depth projects that are directly related to the objectives of the multiannual strategy. In consultation with the Princess Máxima Center, the Foundation raises contributions for projects focused on attracting top talent or accelerating the realization of the mission for example, or for smart hospital applications or psychosocial-related projects.

There have been major changes in the way people donate money to good causes. Increasingly, people prefer to take action themselves than to donate anonymously. This provides opportunities for the Foundation that call for creativity, agility and an entrepreneurial spirit. Organizing (fundraising) events in the new auditorium – where (potential) donors, care professionals and researchers can meet each other and donors can experience first hand what their contributions achieve – is invaluable. 'Third-party actions', where companies, institutions and for example rotary clubs collect funds under the supervision of the Foundation, are also becoming more and more important.



It is precisely for this reason that every year, on International Childhood Cancer Day (February 15th), the Foundation organizes what it terms an 'update'. This is a meeting in which we provide a large group of important donors with information, show accountability and underline how crucial their continued support is.

While the Princess Máxima Center revolves around children and parents, the Foundation is all about donors. But as 'the' donor does not exist, it is increasingly important to use market research, marketing and relevant media to target promising potential donors. In the coming years, the Foundation wants to take the next step by using media and marketing to connect our center with the commercial market, entering into partnerships that structurally deliver funds.

The Foundation's strategy is based on personal relationships with donors. That is where the Foundation makes a difference, in combination with specific projects that are directly connected to the realization of the center's mission.

World Child Cancer NL



The goal of the World Child Cancer NL charitable foundation is to support Outreach activities (see also chapter 5). The emphasis lies on good diagnosis and treatment, and everything that can stimulate quality in these two elements. An important part of this is what are termed twinning programs between hospitals in rich countries and partner hospitals in low- and middle-income countries. The initiatives that the Princess Máxima Center develops in this regard are a significant–though not the only–beneficiary of World Child Cancer NL. Fundraising efforts are primarily focused on equity funds and charitable foundations (both in the Netherlands and internationally), wealthy individuals (big donors) and companies, as well as acquiring subsidies from (semi-)public bodies.

Partnership with KiKa



Without KiKa, the Princess Máxima Center would never be in the position it is now. Firstly, KiKa was responsible for the 'Draag je steentje bij' fundraising drive in 2013, which allowed the center to be built. Secondly, the charitable foundation provides the core funding for our research. This means that, every year, KiKa donates a structural sum to our research organization. Alongside this KiKa ensures funding for various project studies, where research proposals are assessed and judged by an independent scientific committee.

It is anticipated that both of these funding streams will be continued in the coming years. The agreements that guarantee the position of KiKa are set out in the partnership agreement with the Princess Máxima Center. KiKa, like the Prinses Máxima Centrum Foundation, has established fundraising objectives. It specifically focuses on (structural) support for research.



4 Partners and stakeholders

To realize our mission, the concrete input and opinions of the many concerned parties in society are very important. The Princess Máxima Center sees great value in maintaining constructive and structural relationships with its partners, stakeholders and target groups. By ensuring that we uphold structural relations with significant (political) influencers and decision-makers, we can carry out discussions around issues of importance for pediatric oncology care, research and training at the right times.

The careful and systematic management of contacts with stakeholders helps to ensure that they receive good and timely information on developments that are relevant to them. Furthermore, it fosters a positive climate and broad support for the center. By properly informing and updating our stakeholders, and maintaining the relationships in a structured and systematic way, we aim to optimally serve mutual interests.

Specific attention is given to the following partners and stakeholders:

1. Strategic collaborative partners (in alphabetic order)

- Children's Hospital of Philadelphia (CHOP)
- Deutsches Krebsforschungszentrum/ Nationales Centrum für Tumorerkrankungen (DKFZ/NCT)
- Hopp-Kindertumorzentrum Heidelberg (KiTZ)
- Hubrecht Institute
- Gustave Roussy Institute
- KiKa
- Nederlands Kanker Instituut (NKI)/ Antoni van Leeuwenhoek
- shared care hospitals
- St. Jude Children's Research Hospital
- UMC Utrecht/ UMC Utrecht Cancer Center/ WKZ
- Utrecht University

2. Stakeholders

- Banks (Rabobank and BNG)
- Dutch Healthcare Authority (NZa)
- Health insurers
- Health and Youth Care Inspectorate (IGJ)
- Ministry of Education, Culture and Science (OCW)
- Ministry of Health, Welfare and Sport (VWS)
- Zorgverzekeraars Nederland

Synergy with UMC Utrecht and WKZ

As a strategic partner, UMC Utrecht is heavily involved in the Princess Máxima Center. By utilizing the knowledge and quality of UMC Utrecht, we can effectively integrate care and research. We also make use of (expensive) facilities at this academic hospital.

Alongside this, close cooperation with the WKZ offers outstanding possibilities for sharing expertise around pediatric specialisms, which further improves the quality of both pediatric oncology and care at the WKZ. The specialisms present in the WKZ are of great value to the functioning of the Princess Máxima Center, as the partnership gives us access to general pediatric knowledge and skills. These relationships can in no sense be seen as without obligation. In fact, they require continued commitment from and maintenance by all levels of our organization.

A major collaborative theme is our contribution to improving the treatment of specific patient groups, such as Adolescents and Young Adults (AYAs). The Princess Máxima Center wants to participate in a national partnership for optimal care of this group. AYAs often have specific forms of cancer for which the expertise of both pediatric oncologists and medical oncologists is important. Intensive collaboration between pediatric and adult oncology ensures care continuity and is thus vital for our mission.

We work closely with medical oncology centers, and in particular UMC Utrecht, to ensure optimal care for this group of patients. This collaboration is crucial for our role in improving treatment for adults with a 'child tumor', and adolescents with an 'adult-type' tumor, who can benefit more from developments in adult oncology.

Partnership with shared care hospitals

For patient care we work together with academic and general hospitals in shared care partnerships. The diagnosis and complex parts of the treatment take place in the Princess Máxima Center, while the less complex treatment elements are done in a shared care hospital in the patient's own region. From the beginning, such collaboration has been an essential part of pediatric oncology, with the motto 'do locally where possible, and only centrally where unavoidable'. In the interests of the children, we invest in partnerships with shared care hospitals, which allows us to deliver optimal care.

5 What kind of organization do we want to be?

Working in a very demanding context

There are few centers where the mission is as clear, the history tells such a clear story and where the employees are as engaged as the Princess Máxima Center. At the same time, our ambitious mission demands a great deal from the organization, from managers, and from employees. Working as if it were your own child, taking responsibility and always wanting to be the best: this is what characterizes all of us, from receptionists to specialist nurses, from clinical information scientists to research physicians, and from data analysts to paramedics. We ask a lot of our people, and they work in a place where on average two to three children die per week, which is hard. The Princess Máxima Center wants to motivate employees to be groundbreaking and passionate and at the same time know how to maintain their own boundaries. The organization is there for its employees, helping them to remain vibrant and 'whole' in a tough, demanding context.

Cultural values, competencies and leadership

The Princess Máxima Center is characterized by a positive culture and the strength of its employees. Our center can only be successful by doing excellent work at all levels, with the best people, the best research questions, the best protocols, the best technology, the best data insights, and an unwavering desire to keep improving. We create an inspiring working environment that not only stimulates people to deliver top performances, but also ensures that we attract the dedicated professionals we wish to recruit. An entrepreneurial spirit and a culture focused on continued improvement are important principles for us.

Our managers must be able to deal with the dynamics and the discomfort that are coupled with change, collaboration, complexity and dilemmas. The HR department supports the development of leadership behavior, including through the use of mentors and coaches, as well as team development, master classes and intervention. A core concept in this approach is 'standard-setting': managers not only ensure cohesion and collaboration in an organization in which people feel safe and understood, but also set the standard through their own persona, convictions, competencies and (exemplary) conduct.

Committed to development and mobility

In our vision, leadership is not reserved for managers, but applies to every employee. We work on the basis of 'personal leadership', which means we continuously stimulate employees to take ownership and to develop themselves and thus, from their own role and position, make a proactive contribution to our mission. We expect our employees to be motivated to respond to new developments, even if that means that their own role completely changes or even disappears, which is a natural consequence of aiming to deliver groundbreaking work. Here, mutual appreciation, trust and recognition of each other's contributions to the center's objectives are vital. We are committed to a culture of reflection and dialogue, in which mistakes can be made and successes celebrated. The children and their parents are also sensitive to the context that we forge together, and they benefit from the way we interact.

Corporate social responsibility

When the Princess Máxima Center was set up, the principle of Corporate Social Responsibility (CSR) was upheld as a prerequisite, and was applied as much as possible to the construction and organization of the center. CSR is about creating value in society (People), environment (Planet) and economy (Prosperity). These three P's – the core concepts in CSR thinking – interact with each other.

The first P is about people in all their diversity: the children, their parents, brothers and sisters and all the other important people around them. And it is also about employees showing leadership, and a culture in which people get the space to develop.

The second P is about physical surroundings. This concerns the use of materials, products, technologies and processes that have positive consequences – or at least as few negative consequences as possible – for the environment

and the health of people and animals. Alongside concrete measures such as solar panels on our roof, this is also about measures to encourage employees to cycle to work, and fully reimbursing public transport costs. We want to create an environment that is good for children and families, as well as for employees, structured in the most sustainable way possible, for example through food concepts and gardens.

The third P is connected to our drive for financially healthy operation, with just one objective: to deploy as much of the available means as possible in the interests of our mission. Alongside this, a crucial CSR aspect is what is termed 'inclusive thinking', which means people considering what they are able to do, rather than what they are not. Children who are cured of cancer may have a lasting disability and in this context must forge a place for themselves in society. The Princess Máxima Center wants to support them to do this.



Working together on sustainability with UMC Utrecht

In the coming years, the Princess Máxima Center wants to work closely with UMC Utrecht on sustainability. Corporate social responsibility is a leading principle in both partners' business operations. Curing and promoting quality of life go hand in hand with a drive toward sustainable deployment of our own employees, and reducing the negative impact on the environment. The knowledge and practical insights of UMC Utrecht can contribute to a good mix of realism, sharpness and creativity in developing a future-proof framework for efforts in this domain.

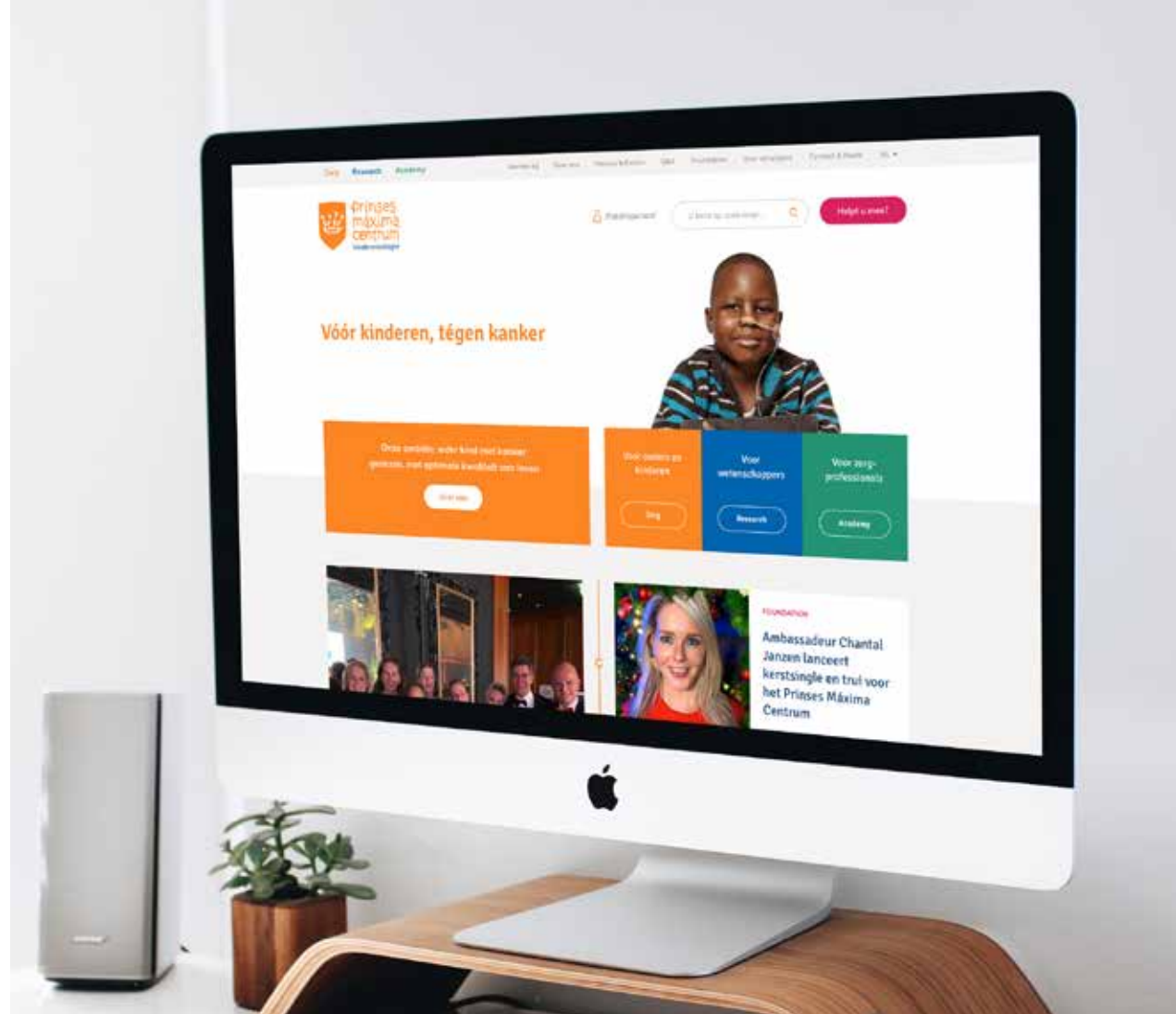
Collaboration can also reap rewards in regards to the following:

- energy use: energy saving, alternative energy sources and carbon-neutral buildings
- waste processing: limiting the environmental impact of wastewater discharge, and recycling waste streams
- sustainable procurement: considering sustainability when entering into or extending procurement contracts
- mobility and accessibility: continuing to join forces within Better Accessible Utrecht East (Beter Bereikbaar Utrecht Oost).

Global responsibility

With the Outreach program, the Princess Máxima Center takes responsibility for the situation of children with cancer in low- and middle-income countries, where children have a much lower chance of being cured. In these countries, we have set up high-value, high-quality twinning programs with a number of specific partner hospitals.

The research outcomes from international research projects as part of these programs benefit children with cancer not only in the countries concerned, but also in the Netherlands and the rest of the world. A significant part of the Outreach activities are financed by subsidies from Foundation World Child Cancer NL.



Usefulness and necessity of using media and communication

Those who do not communicate do not exist. No matter how groundbreaking the latest research results are, or how passionate the employees are, without communication there will be no awareness of this. Therefore it is a strategic necessity to have proactive, clear internal and external communication to highlight what the Princess Máxima Center does, based on the following principle: first facts, and then opinions. This requires the innovative use of diverse media platforms.

In the Princess Máxima Center, communication is about much more than sending out (corporate) messages. The department follows the policy and advises on it, making it an integral part of the organization. All communication is aimed at substantively strengthening the primary processes and in particular connecting them with each other. Good provision of information, both internally and externally, is the cement between the stones of the primary processes. This is the collective responsibility of all employees, with no exceptions.

Communication is about content. In this, the Princess Máxima Center is factual, clear and trustworthy. Our tone of voice is engaged and respectful. We have an overarching narrative, so each employee can proudly convey what the center stands for. We opt for (digital) storytelling on all possible podiums, discussing what happens in terms of care and research and at the Academy, as well as what contributes to our mission. We show accountability for the results and set great store behind reliable information for children and their parents. We send, but we also receive, as we want to continually learn what could be better.

With our digital platform (our website and social media) we aim to set a high-quality example for centers elsewhere in Europe. This platform is a substantive one: the stories that we tell underpin our reputation – among parents, children, professionals and scientists as well as the general public – and show what progress we have made, in a realistic and fair manner. Our (interactive) communication is a prerequisite for (international) fundraising, commitment to us among the general public, and the recruitment and retention of talented professionals.

Epilogue

The Princess Máxima Center is much more than an innovation in care. It is a unique and lively aggregation of strengths around children with cancer and their families. The vulnerability of a child with this life-threatening disease, the sadness of the parents and the fear of losing that child, are the intrinsic motivators for everyone who works at our center.

We all experience the motivation and necessity to provide a child with cancer with new opportunities for a normal and fulfilling life. The vitality of children, even when they are sick, is about their development, and the future. And this is what we want to offer these children and the people around them.

We aim to push the boundaries of knowledge around childhood cancer and the treatment options for our patients. The developments are boundless, as is our passion for making a difference. Completing the mission of the Princess Máxima Center will require a great deal of time and effort. Slowly but surely, we will make progress in the years to come.

In “Focused and promising”, our strategy for the period 2020-2024, we have described the next steps we need to take. We are on this journey together with our current patients, and their parents and loved ones. We work for them and for the children and families we will support in the future. Our focus is our shared goal: providing a cure and optimal quality of life to every child with cancer.

Colophon

“Focused and promising” is the strategic multiannual plan of the Princess Máxima Center for 2020-2024. It describes the insights, principles and objectives that the Board of Directors will apply in the coming years to the management and operation of the Princess Máxima Center. Of course, our overarching ambition remains the realization of our mission.

This document is the result of an intensive process involving key players from our own organization and employee participatory bodies. In it we have taken external developments into account, partly based on assessments of our current strengths and weaknesses.

Utrecht, The Netherlands, December 2019

