AN EXCERPT FROM
THE 2017 CHILDHOOD CANCER REPORT
ABOUT THE SWEDISH CHILDHOOD CANCER FOUNDATION’S RESEARCH INVESTMENTS
AN EXCERPT FROM
THE 2017 CHILDHOOD CANCER REPORT

Production: OTW Communication on commission of the Swedish Childhood Cancer Foundation.
Project manager and publisher of the Childhood Cancer Report: Ylva Andersson.
Editor: Synnöve Almer.
Writer: Emma Olsson.
Graphic design: Sanna Norlin.
Photographers: Karl Nordlund (4–5, 13), Amanda Lindgren/DI (10), the Malm family/private (6, 12).
Illustration: Erik Nylund (8–9).
OUR VISION: TO ERADICATE CHILDHOOD CANCER

THE SWEDISH CHILDHOOD CANCER FOUNDATION is the single largest financier of childhood cancer research in Sweden. All funding is provided exclusively through gifts from individuals, organisations and businesses. The Swedish Childhood Cancer Foundation does not receive any grants from the government, local authorities or county councils.

Since it was founded in 1982, the Swedish Childhood Cancer Foundation has approved more than SEK 2 billion in research grants. Over 80 per cent of childhood cancer patients survive these days, but in recent years development has not kept up the same pace.

THE CHILDHOOD CANCER REPORT is an annual report that highlights parts of the very latest research that the Childhood Cancer Foundation funds. It also spotlights important issues for the treatment of childhood cancer.

This year’s report focuses on the new generation of cancer treatments and how they can contribute to the breakthrough we need for more children to survive. The 2017 Childhood Cancer Report also explains why not even half of all new cancer medicines are tested on children and what is needed for a change.

Order or download the 2017 Childhood Cancer Report in Swedish (Barncancerrapporten 2017) from barncancerfonden.se.
"In the past, it was considered unethical to involve children in medical studies. With the conditions we have today, it would be unethical not to."
Clinical trials the only way forward

Today over 80% of childhood cancer patients survive. Survival rates have been at about the same level since the 1990s. This means that we’ve come as far as we can with the tools we have: chemotherapy, radiation, and surgery.

To save all children who develop cancer, we need new medicines and treatments. But progress is being made. We live in a hopeful era, in the middle of a medical revolution. Many new discoveries and technologies are opening up paths we could never have dreamt of in the past.

Today scientists know how to activate the body’s own immune system to attack cancer cells. By extracting and modifying immune cells outside the body, scientists are already creating “killer cells” that attack tumour cells.

Refined genetic analysis methods lead to more precise diagnoses, and treatments can better be adapted to each individual child. Scientists can build antibodies, doctors can repair the injuries caused by the disease and its treatment, and the healthcare system has become better at dealing with infections that were once life-threatening.

But many deathly ill children today have no access to the latest therapies. And even when they are permitted to test medicines that are under development, it is not possible to draw conclusions about what it is that works and why, because the child is not a part of a paediatric clinical trial.

Children are not small adults. Their bodies are growing, and they respond differently to treatment. To provide the most effective and safe treatment, specific paediatric trials are an absolute necessity.

Historically it was considered unethical to test medicines on children. The result was that paediatricians had to take a trial-and-error approach with adult medicines when the traditional treatment methods didn’t work. Sometimes this worked. Sometimes it didn’t.

Sometimes combining the outcomes of many trials leads to useful knowledge. But that takes far too long and the results are not scientifically verified. And in the meantime, children are dying of their cancers.

The vision of the Swedish Childhood Cancer Foundation is to eradicate childhood cancer. One of the first steps is to note that an 80% per cent survival rate is not sufficient. To increase that figure, we need international collaboration on scientific testing involving children. This is necessary in order to include more children in trials, which will lead to better conclusions about the outcomes. It will also help to secure funding for the development of advanced medicines for a small patient group.

Today we finally have the foundations for international collaboration in Sweden.

The Swedish Childhood Cancer Foundation is a co-founder of a whole new unit in Stockholm – HOPE – which links Sweden to the international Innovative Therapies for Children with Cancer (ITCC) network.

This means that Swedish children who do not respond to traditional therapies can have the opportunity to test the very latest cancer medicines.

Through testing, doctors can find out what works and doesn’t work, under safe conditions. This will eventually lead to new medicines that may become the standard therapy and save more children.

The Swedish Childhood Cancer Foundation wants to help to eliminate all the obstacles on the road towards new medicines that can cure more children with severe and rare illnesses.

For this reason, the Foundation has joined the Kids Cancer Act Now consortium, an international collaborative platform for the development of medicines for paediatric use.

But what we’re doing is still not enough. It takes commitments from the community and from pharmaceutical companies, and a healthcare system that gives doctors and nurses time and opportunity to conduct research.

In the past, it was considered unethical to involve children in medical studies. With the conditions we have today, it would be unethical not to.

The Swedish Childhood Cancer Foundation demands:

- The EU must change its pharmaceutical testing regulations to force drug companies to include the paediatric perspective when developing new medicines. Pharmaceutical companies must not be allowed to avoid testing on children, even if the diagnosis does not exist among children. Swedish and EU politicians need to work towards this goal.

- Develop alternative funding models. For example, the national government and county councils could contribute financially when pharmaceutical companies develop medicines for unusual diagnoses. This would result in cheaper medicines for the county councils.

- Both time and money must be made available to paediatric oncologists and paediatric oncological nurses to conduct research. The culture in the healthcare system must be changed. It must become easier to apply for permits for paediatric testing.

- The EU needs to develop new regulations for data storage. For research to continue at the same high level, the regulations need to allow researchers access to anonymised information, while protecting individuals’ right to privacy.

Kerstin Sollerbrant, Head of Research and Education at the Swedish Childhood Cancer Foundation, kerstin.sollerbrant@barncancerfonden.se
OPINION

CLINICAL TRIALS ON CHILDREN
NELSON, 3, DIED OF HIS TUMOUR

The future of cancer treatments creates hope – for adults. Only 4 of 10 potential therapies were required to undergo the necessary testing to be approved as a paediatric medicine – in part due to a loophole in the EU regulations. Nelson Malm, 3, was given a leading-edge therapy too late. Now his parents and the Swedish Childhood Cancer Foundation are fighting for other children to be able to participate in studies that may save their lives and countless more in the future.

NELSON MALM died at age 3. His brain tumour was aggressive and difficult to treat.

He is one of the 20 per cent – the children who do not survive their cancer. Intensive research is currently under way, and new medicines are proving effective against diseases that have traditionally had poor prognoses. Quite simply, cancer therapy is seeing a revolution.

“I think this is a whole new era,” says Arja Harila-Saari, patient flow manager at the Division of Paediatric Oncology at Karolinska University Hospital in Solna. “Our biological understanding of cancer has grown immensely in just a few years. Now we’re taking the next step. We have new weapons and new medicines that can help us to cure more people and reduce the side effects.”

The problem is that most of the new medicines under trial are reserved for adults.

Overall, childhood cancer has a high survival rate of over 80 per cent. But around 70 children in Sweden alone die of their cancer every year – from conditions like high-risk neuroblastoma, high-risk ependymoma, metastasised sarcoma, bone tumours and high-degree glioma.

The figure has remained constant since the 1990s.

“The only way we can save more children is with new medicines,” says Kerstin Sollerbrant, head of research and education at the Swedish Childhood Cancer Foundation.

“And to get new medicines, we must test them on children, because they respond completely differently than adults to treatment.”

But the majority of new cancer drugs – 60 per cent of 89 new potential therapies – never needed to be tested on children, according to the European Journal of Cancer (62, 2016). Even though the EU enacted new paediatric regulations in 2007, with the aim of stimulating research on paediatric medicines. The regulations include a requirement that pharmaceutical companies test new medicines on children.

TEN YEARS AGO, there was no way to predict the current development in cancer research, and an exception was added to the regulation: Medicines that are developed to treat a diagnosis that does not exist in children, do not need to be tested on children.

These regulations were written before all the advances in immunotherapy and targeted therapies. The legislation does not take into account the fact that a medicine intended for lung or prostate cancer may also be effective for a paediatric diagnosis. The same genetic mechanisms may be at the root of both diseases, meaning that a medicine that targets that specific genetic anomaly may well be effective for both diagnoses.
AN EXCERPT FROM THE 2017 CHILDHOOD CANCER REPORT

CLINICAL TRIALS ON CHILDREN

From lab to approved therapy

New pharmaceuticals start out with laboratory studies in test tubes. This is followed by animal testing to see if the therapy is safe and effective. Only after that can clinical trials occur. These trials encompass three phases and determine whether or not a specific drug therapy works and is safe and effective on humans. The researcher/pharmaceutical company arranges funding and applies for permits from the ethical committee and the European Medicines Agency’s Paediatric Committee.

Phase I

Tests that involve a small patient group, often those who have not responded to established cancer therapies. The focus is on how the pharmaceutical is metabolised in the body, dosage, side effects and efficacy. The patient may benefit from the treatment, but the primary focus of the trial is not to cure.

Phase II

If the Phase I test shows that the treatment is feasible and does not lead to excessively severe side effects, the trial goes into Phase II. This is where the researchers study what proportion of people who receive the treatment get better. Phase II trials have more patients, but not as many as Phase III. For medicines to treat childhood cancer, Phase I and Phase II are often combined.

Phase III

In this phase, the trial is conducted with a larger number of patients at multiple clinics. Often the intended therapy is compared with the standard treatment, usually in randomised, double-blind trials. The patients are randomly sorted into one of two (or sometimes more) groups.

Paediatric trials

When children are included in a clinical trial, the number of interventions must be minimised as much as possible without jeopardising the results. There must also be staff who are accustomed to working with children. A special permit is required from the European Medicines Agency’s Paediatric Committee. The researcher must also motivate why children should be included in the trial.
“We need to be involved in the development of new medicines, and offer Swedish children the opportunity to test targeted medicines under controlled circumstances. Without clinical pharmaceutical trials, we won’t advance.”

Ingrid Øra, Paediatric Oncologist and Researcher

Up to now, pharmaceutical companies that have applied for an exemption from testing their medicines on children have had their request granted. This means that the very sickest children do not get access to the latest in cancer therapies. For this reason, the Swedish Childhood Cancer Foundation and several other players are demanding changes in the legislation.

“Now that new medicines are being developed, we want them to be developed for children,” Sollerbrant says, “but the EU’s exception is a problem. Clinical trials should be assessed by molecular properties, not by diagnosis.”

And the healthcare system agrees. “We don’t want to let the pharmaceutical companies get out of paediatric clinical trials based on diagnosis, only based on biological effects,” says Arja Harila-Saari.

But the European Federation of Pharmaceutical Industries and Associations (EFPIA) says that the European regulations requiring paediatric testing have had an effect, despite the loophole. According to the organisation’s figures, the proportion of clinical trials involving children has gone from 8 to 18 per cent since the regulation was enacted in 2007. During this time, 238 medicines and indications (areas of use for medicines) have been developed and approved for paediatric use.

“It takes time to develop a new medicine, and we will see more benefits from the Paediatric Regulation in the future. We look forward to working with all stakeholders in the field,” writes Magda Chlebus, Science Policy Director at EFPIA, in an e-mail reply to the Childhood Cancer Report’s questions.

But Harila-Saari doesn’t think those results are impressive.

“It’s not hard to double the number of paediatric tests when the baseline was practically zero,” she says.

Three-year-old Nelson’s parents say there was hope in the form of a new drug being tested in Canada, but which wasn’t available on the market yet. Finding the medicine and obtaining all the permits took too long. The medicine was introduced in Nelson’s last days of life.

40 per cent of potential cancer-inhibiting drugs were covered by the requirement for paediatric clinical testing.

60 per cent of potential cancer-inhibiting drugs were not covered by the requirement for paediatric clinical testing.

89 potential cancer-inhibiting medicines have been developed since 2007, when new regulations for paediatric testing were implemented.

30,000 Number of children in Europe living with cancer.

300 A bit more children than this are diagnosed with cancer each year in Sweden. 20 per cent of them die of the disease.

60–70 Percentage of childhood cancer survivors who develop late complications.

89 Number of potential cancer-inhibiting medicines that have been developed since 2007, when new regulations for paediatric testing were implemented. 60 per cent of them were not delivered by the requirement for paediatric clinical testing.

15 million Estimated cost in SEK of running the new clinical paediatric testing unit HOPE until it becomes self-supporting.

237.6 Amount in SEK millions that the Swedish Childhood Cancer Foundation allocated to research and training in 2016.
“We’re ashamed that society isn’t doing more.”

JOHANNA AND FREDRIK MALM, FOUNDERS OF ENTREPRENEURS FOR GOOD AND PARENTS OF NELSON
“Entrepreneurs for Good developed out of what we went through with Nelson, when the pain of his death sank in. We felt that we can’t just do nothing, now that we know and have experienced the shortcomings of the healthcare system.”

JOHANNA MALM, FOUNDER OF ENTREPRENEURS FOR GOOD AND MOTHER OF NELSON

“It was completely meaningless to introduce the medicine by then, in a little boy with cancer everywhere,” says Fredrik Malm. “The doctors should have known about the medicine earlier. But they don’t have time to keep track of everything going on in their own house, or what their neighbour is doing, or what’s happening in the rest of the world.”

Nelson died in 2013, after ten months’ extremely harsh therapy.

“Sometimes we buy medicines that have been effective on children with similar progressions, which we’ve read about in case descriptions,” Arja Harila-Saari says. “Sometimes we’re grasping at straws. But without trials, we can’t know what works and what doesn’t.”

Fredrik and Johanna Malm decided to start the foundation Entrepreneurs for Good, to ensure that children receiving care in Sweden can have access to the very best medicines available.

“The foundation developed out of what we went through with Nelson, when the pain of his death sank in,” Johanna Malm says. “We felt that we can’t just do nothing, now that we know and have experienced the shortcomings of the healthcare system.”

ENTREPRENEURS FOR GOOD, the Swedish Childhood Cancer Foundation and Karolinska Fundraising have teamed up to fight to ensure that the new cancer medicines are also developed for paediatric use.

“There are a lot of us who think we need to do this much better,” Kerstin Sollerbrant says. “The healthcare system is not good at being proactive. The staff are struggling to manage their daily activities, and what falls by the wayside is time for new development.”

The result of this collaboration is HOPE (which stands for the Swedish words Haematological and Oncological Testing Unit), which is physically located at Karolinska University Hospital.

Ingrid Øra is one of two doctors on staff at the unit. She is an experienced paediatric oncologist, who divides her time between HOPE in Stockholm and the paediatric oncology ward at Skåne University Hospital in Lund. She and Arja Harila-Saari are developing the HOPE unit.

“We need to be involved in the development of new medicines, and offer Swedish children the opportunity to test targeted medicines under controlled circumstances,” Øra says. “Without clinical pharmaceutical trials, we won’t advance. This is the only way for us to be able to cure more people in the future than we do today, and hopefully in a way that’s gentler on the body.”

There are also ethical aspects to clinical trials on children. Doctors do not expect to cure many of the children who come to HOPE. But they will cure some, and the knowledge they gain about the therapies will give children in the future a much greater chance at surviving their cancer.

Now Ingrid Øra and the rest of the staff at HOPE aim to open as many relevant pharmaceutical trials as possible. It takes between three and five months to open a trial, and many trials are needed so alternatives can be offered to the sickest patients. But much of their work is also about obtaining funding.

“We’re not self-sufficient yet, we need more resources,” Øra says.

Just under SEK 10 million has been raised, but it will take another SEK 15 million in the next few years to keep pursuing the operations. Money is a big obstacle to children receiving the newest, most effective medicines.

“We need financial support because we in paediatric oncology just aren’t as interesting to the drug companies,” Harila-Saari says.

Her medical revolution is stuck in first gear due to lack of funds.

“The problem is funding pharmaceutical research for a narrow patient category,” says Mats Heyman, paediatric oncologist and researcher at Karolinska Institutet. “There is good research, but there has to be someone who is willing to produce and test the medicines.”

THROUGH HOPE, Sweden finally got its membership in ITCC, Innovative Therapies for Children with Cancer. It is a union of European paediatric oncology centres and laboratories that started in 2011 at the European Medicines Agency (EnprEMA) and that collaborates with the pharmaceutical industry to test new therapies for children. This kind of collaboration is especially important in paediatric oncology because the patient groups in each country are so small. After HOPE came the Pediatric Clinical Research Center, PCRC, a corresponding unit in Gothenburg.

The requirements for joining include having a quality-assured testing unit with staff, well-established routines and collaboration with other units.

“Only through international collaboration, research and well-planned studies can we learn and develop healthcare in an ethically sustainable way. That’s the only way,” Harila-Saari says.

Thanks to ITCC and HOPE, children who do not respond to treatment, who develop a resistance to chemotherapy or whose cancer recurs – 60 to 70 children a year – will be able to participate in international studies.

How new therapies can be made available to children

Patients can get access to medicines that have not yet been approved, either by participating in a clinical trial, by their doctor applying for a licence to prescribe the substance, or through what’s called compassionate use – for humanitarian reasons.

Rules for testing on children

When children are included in a clinical trial, the number of interventions must be minimised as much as possible without jeopardising the results. There must also be staff who are accustomed to working with children. A special permit is required from the European Medicines Agency’s Paediatric Committee. The researcher must also motivate why children should be included in the trial.

SOURCE: SWEDISH MEDICAL PRODUCTS AGENCY

AN EXCERPT FROM THE 2017 CHILDHOOD CANCER REPORT 11
CUP
Sweden has been affiliated with the EU’s Compassionate Use Programme (CUP) since 2012. The aim of CUP is to give more patients access to pharmaceuticals that are not on the market yet, through a standardised EU procedure. The medicine must either be a part of a clinical trial within or outside the EU, or be in the process of approval. The patient must have a severely impairing illness, a chronic illness or a disease that is life threatening and cannot be satisfactorily treated with existing medicines. The patient may not be a part of a trial. But in contrast to the patients in clinical trials, CUP does not result in knowledge that can help future children. CUP must not be used in research.

Source: Swedish Medical Products Agency

PCRC
The Pediatric Clinical Research Center, PCRC, is a research unit that works similarly to HOPE and is located at the Queen Silvia Children’s Hospital in Gothenburg. The centre is funded by Gothia Forum, which in turn is funded by Region Vastra Gotaland. But in contrast to HOPE, PCRC’s funding is secure. PCRC’s team consists of a unit manager, doctors and paediatric nurses with extensive experience of clinical trials. The unit is linked to the European organisation ITCC, Innovative Therapies for Children with Cancer.

Such a study might have made a difference for a child like Nelson Malm. “I don’t think about what life would have been like if he had survived,” Johanna says. “It’s impossible to imagine what might have been.” “It was a whole lifetime for us, that period,” Fredrik adds. “Imagining that we could relive it and that everything would be okay is completely foreign to us.”

Without funding from government grants or pharmaceutical companies, test centres like HOPE are dependent on private initiatives, like Johanna and Fredrik Malm’s foundation.

“An analysis of potential other funding models should be done, models in which pharmaceutical companies get help in funding paediatric trials,” says Sollerbrant. “Perhaps the county councils could contribute to paying for the pharmaceuticals if they got better prices on the finished medicine.”

There are already international examples of alternative methods of funding paediatric pharmaceutical trials. The Swedish Childhood Cancer Foundation has joined an international non-profit initiative, Kids Cancer Act Now, started by Cesare Spadoni.

Spadoni, who lost his daughter to cancer in 2006, is a cellular biologist and has many years of experience with the pharmaceutical industry. His vision is to fill up the “Valley of Death” – the gap between research and industry in which research findings do not lead to new medicines. Development simply dies out because it is too expensive to act on the research findings.

Spadoni’s solution is to unite charity organisations like the Swedish Childhood Cancer Foundation to jointly invest in converting research findings into real therapies. “There are thousands of charity organisations with the same goal,” he says. “Why shouldn’t we work together? We’re all motivated by the patients’ needs.”

With the amount of money an international collaboration could raise, it would be possible to pursue pharmaceutical development in partnership with pharmaceutical companies. “We still need to generate scientific results,” he points out. “But we have to be strategic and work together.”

Another example is the Acceleration Initiative, which was launched in 2013 by the non-profit organisation Cure-Search. The initiative allocates grants to international leading-edge research. The goal is also for the new medicines to give survivors a better life after their illness.

Somewhere between 60 and 70 per cent of those treated for childhood cancer will develop some kind of late complications, and one third of those will live with potentially life-threatening injuries. “We’re in a situation today where we know that more aggressive treatment will not be enough, we also need new medicines,” says Karin Mellgren, senior consultant in paediatric oncology at the Queen Silvia Children’s Hospital. “This is an era where so much is happening, and we have hopes of being able to replace chemotherapy with other medicines with fewer side effects.”

But to help the next Nelson, one more thing is needed, besides new laws and more money. Time.

The people in charge of Sweden’s six childhood cancer centres state that doctors sometimes have no time to devote to research due to a lack of staff. At two of the centres it happens every month, and another two state that it happens every six months, according to a survey in the 2016 Childhood Cancer Report.

“The employers at university hospitals must ensure that there is time and money for research and trend monitoring,” Sollerbrant says. “Ultimately, it’s about giving children with cancer access to the latest medicines, just as we do with adult cancer patients.”
CHILDREN ARE NOT small adults. Their bodies are not done growing, their hormones and metabolism are different. When the new generation of pharmaceuticals can potentially represent a cure, we need clinical trials on children.

“Most of the medicines, which save 80 per cent of children with cancer today, were not tested on children,” Sollerbrant says. “They are adapted to them based on the experience doctors have developed over time. But clinical trials are vital if more are to survive and if we are to minimise late complications. Children have a much longer remaining life expectancy than adults.”

Now there are two Swedish testing centres linked to ITCC (Innovative Therapies for Children with Cancer), an international network that collaborates on paediatric clinical trials of new medicines.

This means that Swedish children will be able to gain access to the very latest research.

There are several reasons why this is not currently the case. It is harder to get ethical approval, because the requirements are higher on tests involving children.

At the same time, childhood cancer is an unusual disease. This means that pharmaceutical companies have less financial incentive to develop medicines for it. Pharmaceutical development is costly.

Because the disease is unusual, testing requires international collaboration to include enough individuals of the same age and diagnosis.

There are also challenges in the hospital setting. Paediatric oncologists simply do not have the time it takes to pursue research and monitor trends.

To increase survival rates for childhood cancer, new treatments are required – which children are not getting access to today. The head of research at the Swedish Childhood Cancer Foundation, Kerstin Sollerbrant, explains what it will take to ensure that more children survive.

This must be done

- Change EU regulations for pharmaceutical testing. Pharmaceutical companies need to consider the paediatric perspective when developing new medicines. Pharmaceutical companies must not be allowed to avoid testing on children, even if the diagnosis does not exist among children. Instead, the tests should be based on the molecular profile, as the same anomalies may be highly significant for curing both adult and paediatric diagnoses.
- Facilitate international collaboration. To draw valid conclusions from a trial, many children of the same age and diagnosis must participate. Patient groups in Sweden are too small. Researchers from several countries must therefore work together to search for new treatment methods.
- It is expensive to develop new medicines for unusual diseases. This means that alternative models for funding are needed. For example, the national government and county councils could contribute financially when pharmaceutical companies develop medicines for unusual diagnoses. This could result in cheaper medicines for the county councils.
- Starting a new trial takes time. It is important to facilitate the process for submitting research proposals, without sacrificing safety. It must be easier to apply for permits.
- Employers in the healthcare industry must understand that doctors and nurses need to have time to participate in research and trend monitoring.
- New technology gives researchers access to detailed information, which can be sensitive. The new patient data laws must protect patients’ right to privacy while meeting the needs of research for data.
- The government must take greater financial responsibility for the research infrastructure. Otherwise, the opportunities for international collaboration will be limited.
Childhood cancer is not adult cancer

When an adult gets cancer, it is not unusual that it is related to lifestyle or external factors, but that is not the case for childhood cancer, which differs from adult cancer in several ways. In children, the disease often develops extremely rapidly and there is no known external factor that is significant to its development.

CHILDHOOD CANCER IS THE most common cause of death among children aged 1-14 in Sweden. Every year, just over 300 children and teens in Sweden are diagnosed with cancer. The growth in population and the proportion of new immigrants will not affect the national averages for many years.

Most childhood cancer patients are small children between the ages of two and six, although children of all ages can get cancer. Childhood cancer is slightly more common in boys than girls.

LIFESTYLE DOES NOT AFFECT CHILDHOOD CANCER Childhooed cancers amount to 2 per cent of all cancers, but they differ in many ways from cancers that affect adults. The most important difference is that cancers affecting adults are continuously increasing - the number of cases has doubled since 1970. Currently the figure is over 60,000 cases per year.

One reason for this increase is that lifestyle affects the risk of developing cancer as an adult. This is not the case for childhood cancers. Research has shown that lifestyle and other environmental factors do not affect the risk of developing childhood cancer. This makes the disease more difficult to prevent.

CHILDHOOD CANCER DIAGNOSES Children and teens also develop different types of cancers. While the most common cancer forms in adults are prostate and breast cancer, in children the most common form is acute lymphoblastic leukaemia (ALL).

About one third of all children with cancer have some form of leukaemia; just under a third have brain tumours and the final third have a variety of cancers, such as lymphoma - also called lymphatic cancer - or tumours in the kidneys, bones or other parts of the body.

TREATMENTS ARE NOT THE SAME AS FOR ADULTS The treatment of childhood and adult cancers differs. Children do not handle radiation well. Their bodies are growing and their brains are still developing. Radiation can damage healthy tissue in the brain, bones, metabolic system (endocrine system and metabolism) and organs that are not fully developed. Even a small radiation dose can cause great damage in a child’s growing body.

However, as children usually have an otherwise healthy body, they often tolerate chemotherapy better than adults. In general, they can tolerate larger doses of chemotherapy drugs than adults, and can therefore receive stronger and more effective chemotherapy treatment.

At the same time, however, doctors must consider the fact that a child’s body is smaller than an adult’s and has a different distribution of fat and water, as well as less bone mass. Children who are cured of cancer will also live longer with any potential consequences of the disease and its treatment.

When a child has survived cancer, several problems may come to light later in life - after 10 or 20 years or even more. Secondary cancer, growth problems, infertility and neurological difficulties are some examples, and these difficulties may lead to a risk of an early death.

Why some people do not develop any complications at all, researchers believe, is likely due to genetic differences between individuals. Researchers are constantly working to develop gentler treatments that do not result in serious injuries, what are called late complications.
A paradigm shift is necessary to eradicate childhood cancer

To save more children, we need new medicines that are adapted to children’s needs. This requires paediatric clinical testing to ensure the best, safest possible treatment, say the researchers who were interviewed for this year’s Childhood Cancer Report.

**TODAY OVER** 80 per cent of childhood cancer patients survive. This means that around 70 children die of cancer each year. This figure has remained fairly stable in the past few decades, as the figure above shows. The greatest challenge for childhood cancer treatment is thus to significantly increase survival rates again.

Klas Blomgren, professor of paediatrics and medical expert at the Swedish Childhood Cancer Foundation, predicts progress in the near future.

“I believe we will see a paradigm shift in childhood cancer research within a few years,” he says. “By which I mean a specific discovery in one field that can lead to major progress in entirely different areas. But this requires extensive resources, skills and time. I think we may well stumble onto something, find new tools and keys that will lead to major progress.”

But in order to go a step further and help more children, we need clinical trials, like those taking place at the new HOPE unit at Karolinska Hospital. Above all, we need to generate more knowledge about future therapies, but the trials may also save individual children.

Through HOPE, doctors may be able to test medicines on children who have certain specific genetic anomalies in the DNA of their cancer cells.

**FOR SOME CHILDREN** with cancer, these therapies represent hope for a cure, but to become a true path to the future, the researchers must also identify more genetic anomalies in tumour DNA.

“The challenges we face are time, skills and money,” Blomgren says. “Money is a huge obstacle.”

Blomgren is in the process of signing up Swedish children for a French trial with the goal of curing some of the children suffering from pontine glioma, an incurable brain tumour. For those children, their only hope is that certain subgroups of tumours will have specific genetic traits for which we have treatments today.

Collaboration is a vital factor if we are to cure more children.

“We cannot build up the studies ourselves in Sweden, we don’t have enough patients for that. We need to get other countries to work with us.”

One example of such a collaboration is the new treatment protocol against ALL (acute lymphoblastic leukaemia), which Swedish researchers are developing in collaboration with colleagues from other countries.

**IN ADDITION TO MONEY,** researchers also need material to study. Biobanks and quality databases are vital parts of the infrastructure that is necessary for research. The Swedish Childhood Cancer Foundation funds the Swedish Childhood Cancer Database and the National Paediatric Tumor Biobank, as two examples.

“Biobanks are extremely important sources of material, and we must not forget to manage them properly and encourage the clinics to continue sending in samples,” Blomgren says.

Centralising certain parts of childhood cancer treatment can also be an alternative for bringing together patients, research and skills under one roof. The Netherlands did this a year ago, and the results are promising.

“We would benefit from centralising certain things, not everything, in one or a handful of centres,” Blomgren says. “We can achieve a lot by email and telephone, but surgeons, for example, need volume training to maintain their skills.”
Since the 1970s, survival rates for childhood cancer have increased dramatically. These days around 80 per cent of childhood cancer patients survive, but in recent years development has not kept up the same pace. 80 per cent is not enough. No child should die of cancer.

And there is hope. The 2017 Childhood Cancer Report focuses on the new generation of cancer treatments and how they can contribute to the breakthrough we need for more children to survive.

This is only possible if researchers are given the funding and time they need to conduct research – and also if the discoveries made in laboratories are clinically tested on children in order to eventually become new therapies. The 2017 Childhood Cancer Report also explains why the majority of new cancer medicines are not tested on children and what is needed for a change.

Order or download the 2017 Childhood Cancer Report in Swedish ( Barncancer-rapporten 2017) from barncancerfonden.se.