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cancer  
fonden**

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# Childhood cancer

Every 2<sup>nd</sup> day, a child in Denmark is diagnosed with cancer





## Childhood cancer

- Most frequent medical cause of death for children above 1
- 12 different diagnoses
- 200 children diagnosed a year
- 600 children treated a year
- Mostly unknown cause
- 85 % survival (approx. 5,000 survivors)

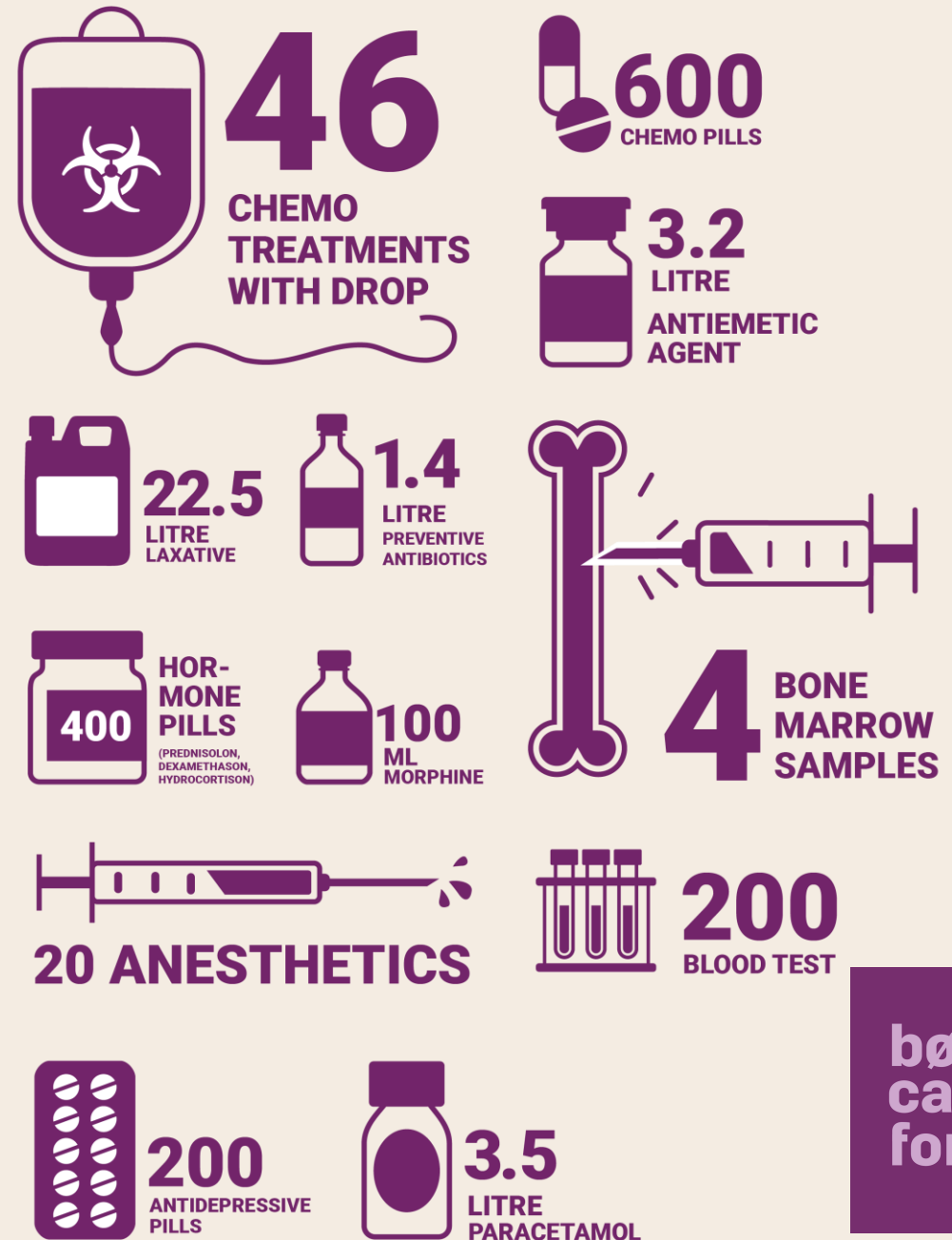
## Treatment

- Intensive
- Long
- 50 % get complications and late effects
- Affects children's quality of life in the short and the long term
- Survivors have 3 times as high risk of secondary cancer
- 30 % relapse



# Unreasonably hard treatment

Developed by the Danish Childhood Cancer Foundation, illustrating a 2.5-year leukemia treatment protocol



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# Danish Childhood Cancer Foundation

*No child should  
die of cancer*





# About us

We work exclusively for children with cancer and their families. We concentrate our efforts on three main areas:

- Research
- Family support
- Raising awareness

As a private, independent foundation, we rely 100 % on donations.



# Our Board



**Christina E. Høi-Hansen**  
Professor, DMSc  
(Chairwoman)



**Thomas Leth Frandsen**  
Senior Medical Project Manager,  
PhD



**Søren Rittig**  
Professor, DMSc



**Anja Pinborg**  
Professor, DMSc



**Claus Sixtus**  
Associate Professor  
and Clinical Nurse Specialist



**Jens Bjørn Andersen**  
Professional Board Member  
and Investor



**Jesper Buchardt**  
Parent Representative



**Morten Stadil**  
Attorney

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# Our Scientific Committee



**Cai Grau**  
Professor,  
Head of Research



**Linda Holmfeldt**  
Associate Professor, PhD



**Ulrik Lassen**  
Professor, PhD



**Henrik Frederiksen**  
Professor, PhD



**Monica Cheng Munthe-Kaas,**  
MD, PhD

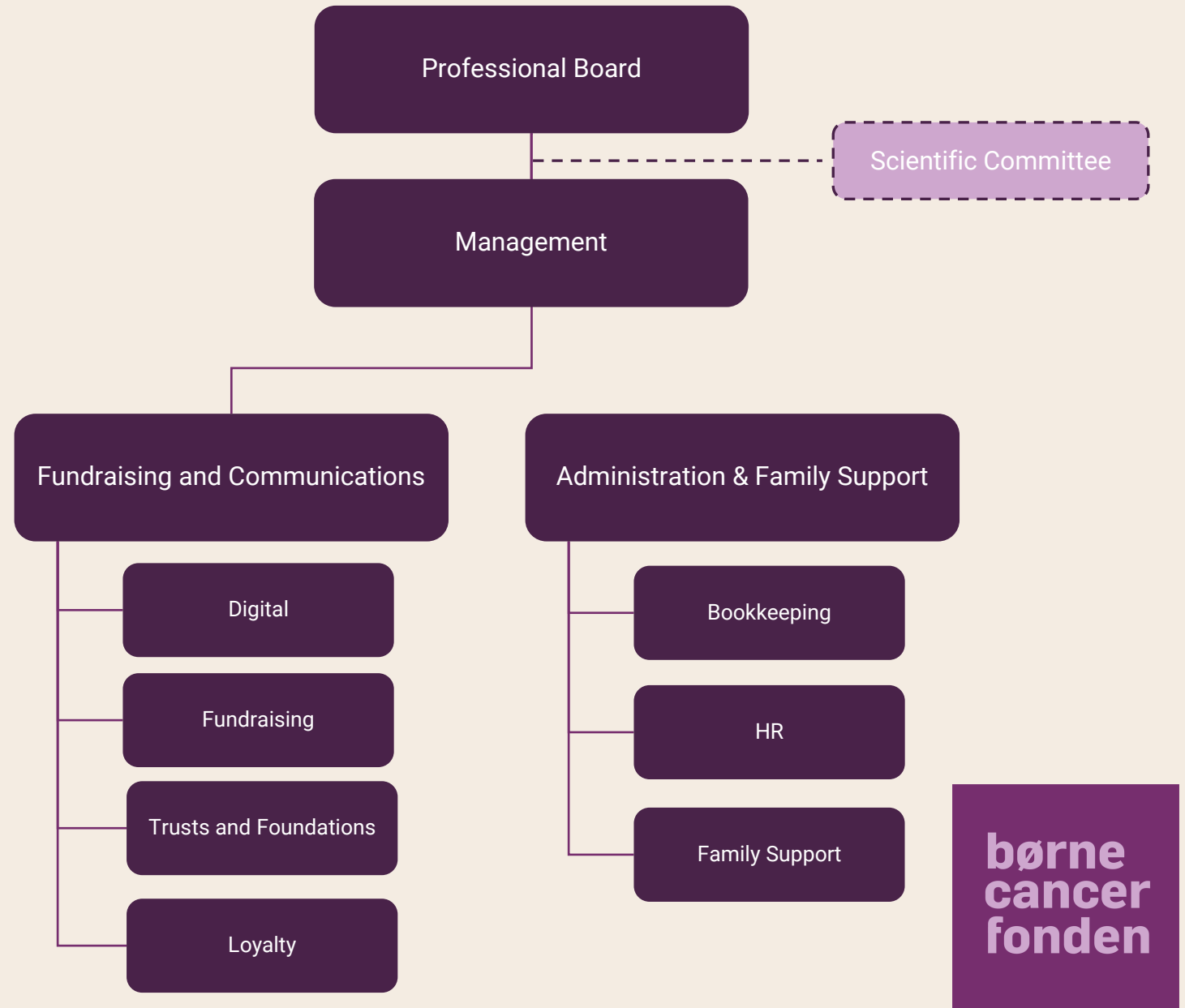
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# Organisation

Our Board consists of high-profile experts within medical science, law, and corporate affairs.

Once a year, our Board allocates funds to state-of-the-art research and development projects within childhood cancer. Our affiliated Scientific Committee assesses all research applications.

We have two primary business areas: Fundraising and Family Support.



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# Research gives hope

The majority of our funds  
are allocated to research



# Front runners in childhood cancer research

- €30m allocated to research in the past 5 years alone.
- The single organisation that has funded most research projects within childhood cancer in Denmark.
- 6 professorships dedicated to research in childhood cancer.
- €2.4m for strategic research within brain tumours and immunotherapy.



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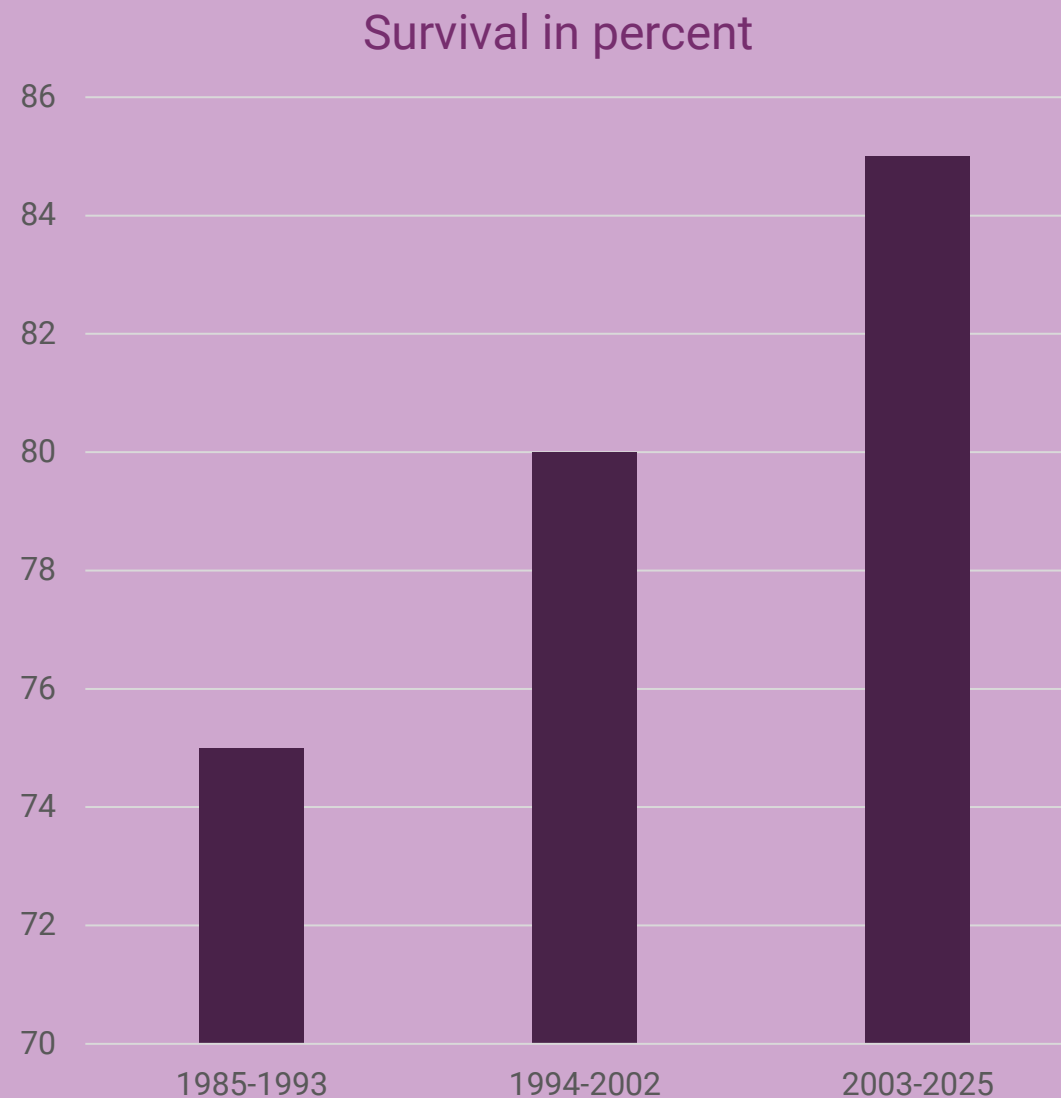


# Survival since 1985

**1985-1993** – 3 out of 4 children survived

**1994-2002** – 4 out of 5 children survived

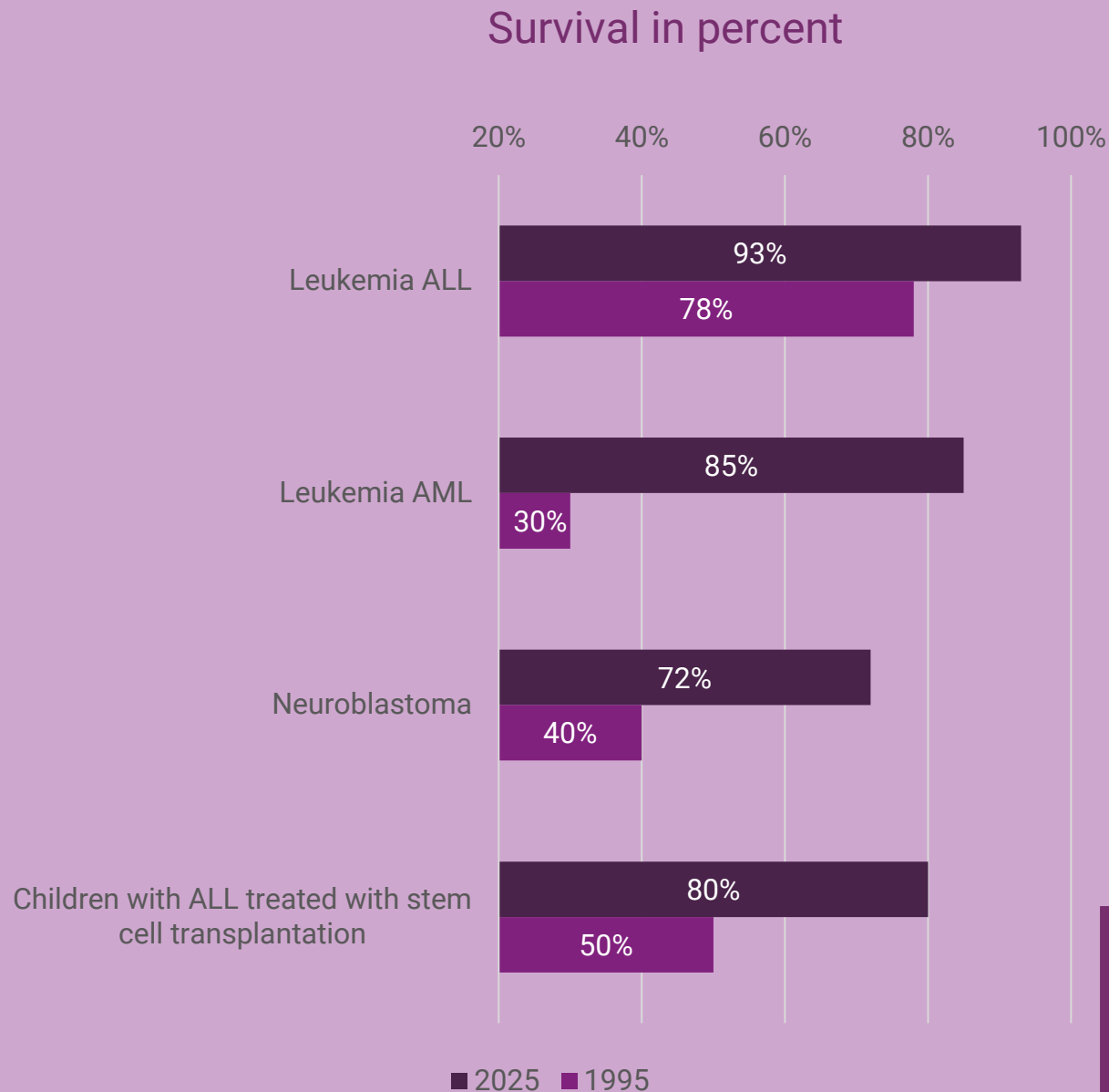
**2003-2025** – 6 out of 7 children survive



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# Research improves survival

New medicine and radically different treatments are needed to ensure that no child dies of cancer – and that children survive cancer with no og minimal late effects.



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# International research collaboration is crucial

Access to the best  
treatment for all patients



# Why international research?

- Although 400,000 children worldwide are diagnosed with cancer every year, childhood cancer is a rare disease.
- International collaboration is crucial to ensure a sufficiently large patient base for research.
- Strong national research environments and international collaboration ensure access to the best treatment for all patients.



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# The role of Danish research internationally

- Denmark is world-leading in treatment and research within childhood cancer, especially childhood leukemia. This is the result of cross-border research and international treatment protocols.
- International collaboration gives patients around the world access to the latest expertise from Denmark – and vice versa.
- Danish researchers play an active role in international research networks, and joint PhDs across Danish and international research groups are common.



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# **Selected international research programmes**

We prioritise projects  
with international reach



# International brain tumour consortium (5C)

- Central nervous system (CNS) tumours – or brain tumours – account for  $\approx 25\%$  of all childhood cancers.
- Survival is still below the average for all childhood cancers, and survivors have the highest burden of long-term side effects.
- International collaboration is necessary to make advances.
- 5C is a long-term strategic research program, aiming at obtaining excellence at the highest international level.
- International Advisory Board from Sweden, Canada, and Germany.
- Close collaboration with 5 other children's cancer centres in Europe.
- €1.6m from Børnecancerfonden.



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# ALLTogether – Improving survival of childhood leukemia

- Acute lymphocytic leukemia (ALL) is the most common childhood cancer, accounting for 25 % of all cancer cases in children.
- 16 European countries have joined forces and established the ALLTogether consortium.
- The consortium is the largest in Europe, and it covers a background population of more than 200 million individuals.
- The vision is to improve survival of ALL, minimise acute and long-term side effects as well as create the basis for future research.
- €800,000 from Børnecancerfonden.



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# Continued research is needed

Focus areas in the coming years



- **Brain tumours** – especially brain tumours with very poor prognoses. Expansion of 5C Consortium internationally to improve prognoses.
- **Sarcomas** – 5-year overall survival of 60 %, with no virtual improvement over the last 20 years in Denmark. Focus on national and international sarcoma networks to improve survival.
- **Genetic research** – key to increase understanding of why some children get cancer and how treatment can be targeted to the individual patient.
- **New treatment methods** – immunotherapy has revolutionised cancer treatment of children and adults. Future research is needed to expand treatment to more and broader patient groups.
- **Late effects** – more than 50 % of childhood cancer survivors get long-term side effects. Focus on reducing late complications to a minimum.

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# Family support

A cornerstone of our work



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# We bring support and care to families

When a child is diagnosed with cancer, life is turned upside down for the entire family.

As survival improves, it becomes increasingly important to focus on the long-term life of survivors. Therefore, early rehabilitation is a key focus area for us.

We offer:

- **Psychological counselling**
- **RESPECT – Research-based rehabilitation**
- **Rehabilitation camps**
- **Grants**
- **SuperSnøren – ‘Beads of Courage’**

We also fund various development projects within family support at the four specialist children’s cancer centres in Denmark.



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# RESPECT – Research-based rehabilitation for children with cancer

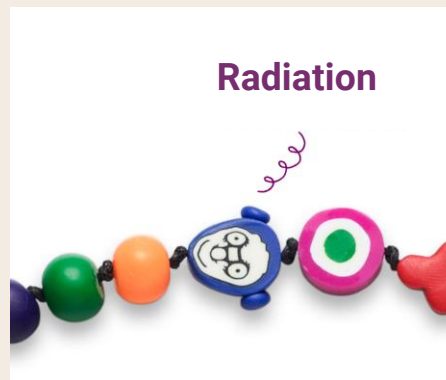
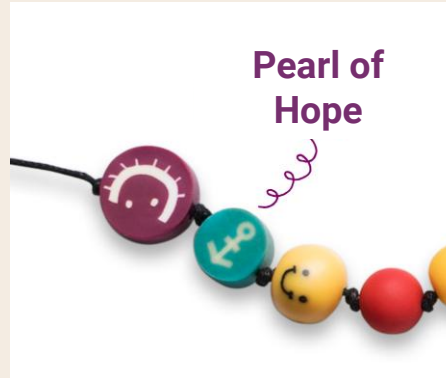
- 50 % of children with cancer experience social difficulties following treatment.
- RESPECT is a rehabilitation programme where two classmates are appointed ambassadors for their friend with cancer.
- A dedicated project nurse teaches the entire school class about childhood cancer.
- RESPECT is based on 10 years' research and has demonstrated profound results in children's life quality and well-being.
- In 2023, RESPECT became one of our permanent rehabilitation programmes for children and adolescents with cancer.



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# Super-Snøren

‘Beads of courage’ help children with cancer and their families during and after treatment



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# Raising awareness

Information and guidance to families



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# Which treatment is our child facing? ... What side effects can we expect?

When a child is diagnosed with cancer, a thousand questions arise. Life is turned upside down for the entire family.

We help families with information on their child's specific cancer diagnosis as well as guidance on how to navigate through the treatment process.

We give families access to:

- **search through our knowledge base.**
- **order pamphlets and literature on childhood cancer.**
- **download our information app.**

In addition, we annually fund various awareness projects carried out by Danish experts in childhood cancer.

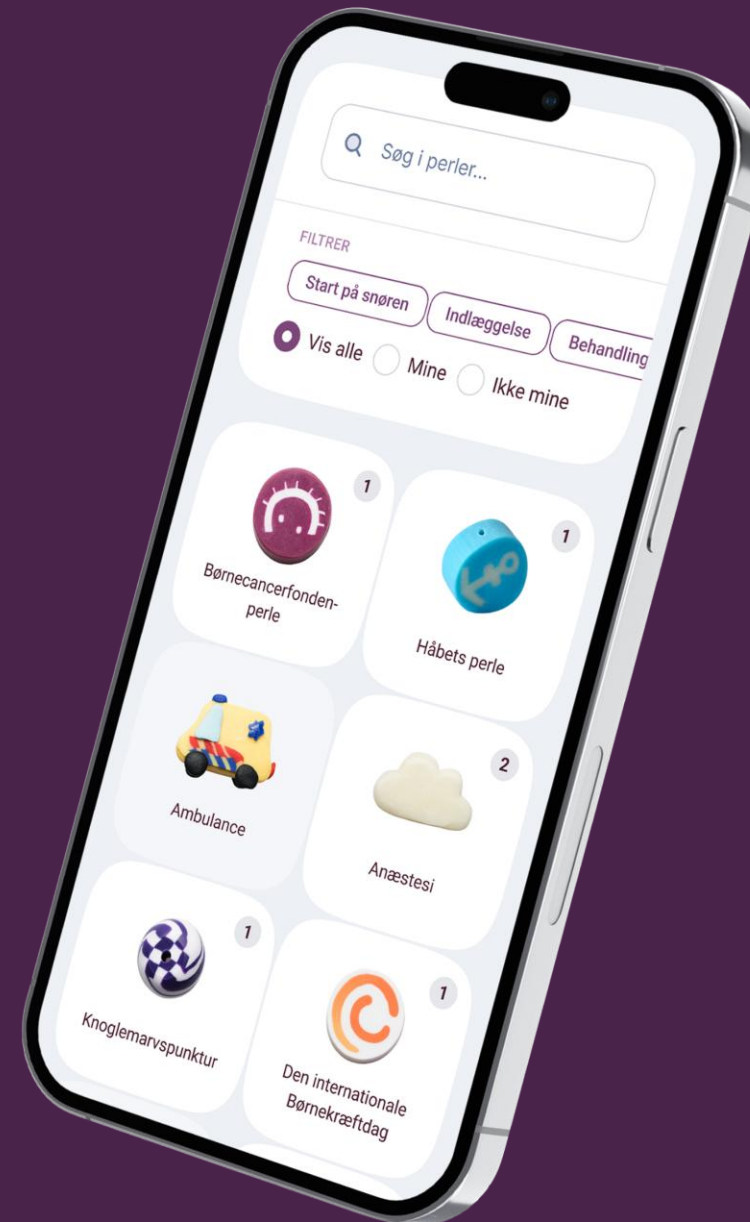


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# A digital guide to childhood cancer

In close collaboration with Danish experts in childhood cancer, we have developed a mobile app for families of children with cancer.

The app gives families flexible and quick access to guidance and information on their child's treatment process.



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**Thank you!**

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