



38<sup>TH</sup> ANNUAL MEETING



13<sup>TH</sup> BIENNIAL MEETING

# PROGRAM AND ABSTRACTS



Together for cure and care  
in childhood cancer



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## Welcome to (virtual) Trondheim!

Dear Nordic-Baltic NOPHO-NOBOS friends, invited speakers and sponsors!

On behalf of the organizing committee, we cordially welcome you to a joint NOPHO-NOBOS meeting! It is the 38th annual NOPHO meeting and the 13th biennial NOBOS meeting.

The original planned physical meeting in May 2020 was cancelled due to the pandemic, and thanks to acceptance from both NOBOS and NOPHO boards, and the organizing committees of the following meetings in Kuopio and Lund, we decided to organize a virtual meeting from Trondheim May 7-11 2021, instead. It has been a long journey from when we started preparation for more than three years ago, but as the meeting is right in front of us, we are proud to present a hopefully interesting scientific program, both for NOBOS and NOPHO. We are especially happy with the planned joint sessions, which include genetic predisposition to childhood cancer, ethics discussions, end-of life care, and late effects. Great clinicians and scientists have agreed to join, coming from Sydney, Colorado, Memphis, Frankfurt and Heidelberg, in addition to our own Nordic region. A lot of abstracts have been accepted for free paper presentations, which we look forward to attend.

We are very sorry that we not can meet physically! To be together and socialize has always been a cornerstone in our great Nordic collaboration. Maybe we can have a social meeting later on in Trondheim when everything is back to normal again.

Organizing a virtual conference for the first time is challenging, but with good help from *Kongress & Kultur* and *NEP*, our organizing and IT-companies, we hope that everything will go without too much trouble down the road.

The digital platform will unfortunately not allow participants to talk during the sessions, but in the Q&A parts, you will all be able to comment and ask through the chat function as much as you want, and your questions will be read out loud and hopefully answered as best as possible.

So, again, a warm welcome to *Virtual Trondheim*, and let's go

*Together for cure and care  
in childhood cancer!*

Ann-Karin and Bendik

## The local organizing committee



The local organizing committee (from left): Magnus Hjort, Ann-Karin Mosand (chair NOBOS), Solveig Solbraa, and Bendik Lund (chair NOPHO). Associated members are Siw Fossan, Ann Åsberg, Kristin Solem, Erling Moe, Eva Beate Pedersen.

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## Conference secretariat and webmasters

The conference company, Kongress & kultur ([kongress.no](http://kongress.no), e-mail: [mail@kongress.no](mailto:mail@kongress.no)), is responsible for registration, payment, and all the logistics related to the meeting.

In addition, we could not have run the streaming without our IT-company NEP.

Our two web-masters, Elisabeth Broby (NOPHO), and Gitte Petersen (NOBOS) have done all the marketing towards NOBOS and NOPHO members.

# Sponsors

## Gold Sponsors



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## Silver sponsors



## Other sponsors



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TrønderEnergi





NIDAROSDOMEN

FOTO: MYKOLA KSENOFONTOV

## Trondheim

Intimate charm in the third largest city in Norway! Since you will not be physically present in our city during the meeting, we feel that a short presentation of Trondheim can give you some ideas and inspiration to visit us another time when everything opens up.

The vibrant city of Trondheim is home to some of Trøndelag's most popular attractions, cosy shopping streets and a myriad of restaurants and bars offering local specialties.

The Nidaros Cathedral; Nidarosdomen is an impressive sight. The cathedral is the national sanctuary of Norway, built over the grave of St. Olav. Work began in 1070, but the oldest parts still in existence date from the middle of the 12th century. The Gothic Nidaros Cathedral features

### Vikings, pilgrims and computers

Trondheim was the first capital in Norway, founded by the Kong Olav Tryggvason in 997. Today, Trondheim is not a big city on a European scale, but it is the third largest city in the country with a population of 194,000. The city is still the town where new kings receive their ceremonial blessings. It has been, and still is, a popular pilgrimage site. It is a regional capital and last but not least, a city of education and research. The wide range of things to do may in part be attributed to the city's students, who number more than 30,000. Trondheim has a number of sights that each year are among the most visited in Trøndelag.



KING OLAV TRYGGVASON MONUMENT

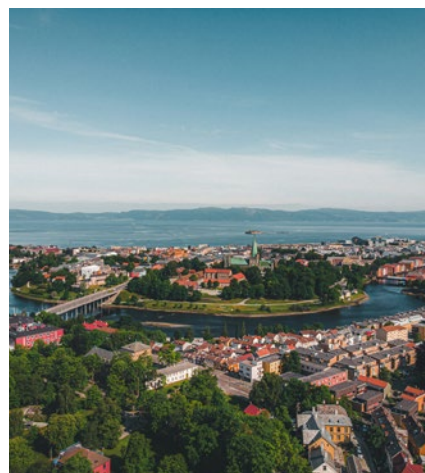




WEST FAÇADE OF NIDAROSDOMEN



BYBRUA



TRONDHEIM



BYMARKA



BAKKLANDET



LOCAL FOOD IS WORLD CLASS

an ornate rose window and a detailed west façade. It's also one of the most popular sights in Trondheim. Popular museums with exciting exhibitions include the National Museum of Decorative Arts, the Trondheim Museum of Art and the Archbishop's Palace Museum. A museum that stands in contrast to these is Rockheim, Norway's national museum of popular music.

Just a short ride from the City Centre on the world's northernmost tram, **Gråkallbanen**, you will find Bymarka. The popular recreation area is ideal for walking and jogging, with a network of marked trails crisscrossing the reserve, leading to viewpoints, rest areas and cabins selling refreshments.

The intimate City Centre combined with the exciting shops makes Trondheim a popular city for shopping. Here you can enjoy many independent shops selling clothes and accessories that you will not find everywhere. Particularly in historic **Bakklandet**, you will find several shops that make the garments they sell from scratch or by adapting old garments.

Trondheim is one of the places in Norway with the strongest focus on local food and the products are in **world-class**. Many local establishments, including pubs, cafés and restaurants, serve a wide range of excellent locally brewed beers, preferably together with food specially developed to accompany the beer.



ST. OLAVS HOSPITAL



WOMEN AND CHILDREN'S CENTRE

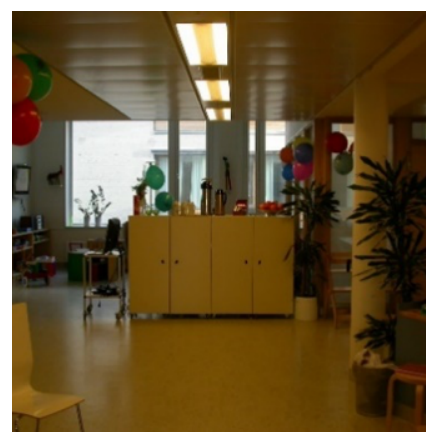
## Welcome to the childhood cancer unit!

We are proud to show you some pictures from our own department!

St. Olavs Hospital, the University Hospital in Trondheim, is one of the largest hospitals in Norway. About 11.000 people work here! The Hospital offers specialized treatment for the population, including research, education and training for patients and their relatives. It is situated by the river *Nidelven* and was built between 2005-2013.

The women and Children's Centre (*Kvinne-barn-senteret*) is like a small hospital on its own. Here we have our own pediatric units for surgery, intensive care, neo-

natology, medicine/infections/ neurology, and our own unit for cancer and blood diseases. The childhood cancer unit is a small unit with only nine beds, one daybed and an outpatient clinic. We give treatment to children and adolescents with all kinds of cancer and blood diseases, including autologous stem-cell transplantation (allo-transplant is centralized to Rikshospitalet, Oslo). Our patients come from all over the region in the middle of Norway (Midt-Norge) and many families have to travel quite far to receive their treatment.



CHILDHOOD CANCER UNIT DURING HALLOWEEN.



# Practical information

## Registration

Registration is done at the NOPHO web:  
[www.nopho.org/welcome/frame.htm](http://www.nopho.org/welcome/frame.htm)  
or at the NOBOs web:  
[nobos.org/conferences](http://nobos.org/conferences)

## Digital participation

Everyone who is registered for the conference and has paid the participant fee will receive a link to the streaming. On Friday May 7th, you will receive an email with a link. By clicking on this link, you will get access to the streaming. No prior software downloads or login is required. You can participate via your own PC or mobile. You should access the streaming 5 – 10 minutes before the conference starts. Remember to check that you have sound. As a participant, you will not be on video or audio. You will still see both the chair and the speaker.

## Questions to the speakers

Questions can be submitted via chat on the streaming platform in the individual session.  
Write in the message which speaker the question is addressed to.

## Program

For more information and updated program  
[kongresskultur.eventsair.com/nopho-nobos](http://kongresskultur.eventsair.com/nopho-nobos)

## Posters

Posters will be available on the conference website from May 5th and throughout the conference: <https://kongresskultur.eventsair.com/nopho-nobos>. We encourage all conference participants to visit the virtual poster exhibition. Here you will also find contact information for the individual author if you have any questions.

## Recordings

Recordings will be made available everyday throughout the conference and for up to 4 weeks after the conference. The video recordings after the conference will only be available to those who are registered. You will receive a password by e-mail shortly after the end of the conference.

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### ***Young NOPHO Educational Session – Saturday May 8<sup>th</sup>, 14:00–17:30***

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To attend NOPHO Educational Session you need to Join Zoom Meeting on this link:

<https://NTNU.zoom.us/j/95891846649?pwd=R2NIW-mFEKzdrbVNsekpWdytTNGR6Zz09>

Meeting ID: 958 9184 6649

Passcode: 581555

Do not hesitate to contact Kongress & Kultur directly if you have any questions; [media@kongress.no](mailto:media@kongress.no)



# Industry satellite symposia

## CAR-T

**Sunday May 9, 15:20-15:50.** Chaired by Jochen Büchner, guest lecturer **Peter Bader** (Frankfurt) will talk about his experience from Frankfurt University Hospital where they have treated more than 40 pediatric patients with CAR-T therapies. He will trigger the discussion on how to select the right patient at the right time to optimize long-term patient outcomes.

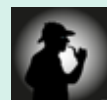
Sponsor: **Novartis**



## SHERLOCK HOLMES

**Monday May 10, 13:00-13:45.** **Henrik Hasle** (Århus), NOPHOs own detective, accompanied by co-detective **Ann Åsberg** (Trondheim), will ask the audience for advice on **how to solve the mysteries...** They will use the web-tool **MENTIMETER**. You log on to the session at [www.menti.com](http://www.menti.com) using **the special Sherlock Holmes code** given by Henrik.

Sponsor: **Sanofi GENZYME**



## NEUROBLASTOMA

**Tuesday Mai 11, 10:45-11:05.** Guest lecturer **Jesper Sune Bro** (Copenhagen) will focus on high-risk neuroblastoma and clinical perspectives included treatment related side-effects.

Sponsor: **EUSA Pharma**



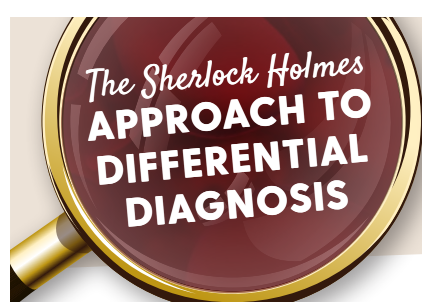
# Working groups NOPHO

Working group meetings will be arranged through **Zoom** by the WG-chairs 4–8 May.

You find detailed information in this table, **but it might be changes!** Updated schedule will always be on [www.nopho.org/welcome/frame.htm](http://www.nopho.org/welcome/frame.htm). WG-chair invites members into the meeting. Non-WG-members are free to ask chair to join a meeting.

## UPDATED APRIL 17, 2021

Day	Time	Working group	WG-Chair
<b>Tuesday 4<sup>th</sup> May</b>	15:30–17:00	Radiotherapy wg	Yasmin Lassen
<b>Thursday 6<sup>th</sup> May</b>	14:00–17:00	Solid Tumor Committee	Jukka Kanerva
	15:00–16:30	ALL Relapse wg	Petter Svenberg
	17:30–19:30 1!	Novel Therapy wg	Karsten Nysom
<b>Friday 7<sup>th</sup> May</b>	11:00–12:00	Joint Lymphoma meeting	Anna Schröder Håkansson
	12:00–17:00	LLC	Inga Rinvoll
	12:00–16:00	Brain tumor Committee	Virve Pentikainen
	16:30–18:15	Histiocytosis wg	Jan-Inge Henter
<b>Saturday 8<sup>th</sup> May</b>	08:00–12:30	NOPHO board	Trond Flægstad



*The Sherlock Holmes*  
**APPROACH TO  
DIFFERENTIAL  
DIAGNOSIS**

*Monday 10th May 13.00–13.45 direct transmission*

Welcome to **“The Sherlock Holmes symposium”**  
at NOPHO sponsored by Sanofi Genzyme

**We at Sanofi Genzyme are happy to welcome NOPHO participants with an interest in pediatric patient cases to The Sherlock Holmes Symposium with focus on rare hematological diseases.**

The Sherlock Holmes symposium approach is to differential diagnosis within hematology.

Our “diagnostic detectives” MD Henrik Hasle (DK) and MD PhD Ann Åsberg (NO) will take us through two interesting cases. You will be part of this interactive session and contribute to the diagnostic finding by answering: What are the clues, Which questions to be asked? Which diagnostic tests should be performed? Test your diagnostic and deductive skills and learn more about rare disorders in this enjoyable interactive session.

**Program**

13.00 – 13.05  
**Welcome and Introduction**  
MD Henrik Hasle

13.05 – 13.25  
**Case 1**  
MD PhD Ann Åsberg

13.25 – 13.45  
**Case 2**  
MD Henrik Hasle

**Chairperson and speaker**


MD Henrik Hasle  
Department of Pediatrics  
Aarhus University Hospital  
Denmark

**Speaker**

MD PhD Ann Åsberg  
Barn og Ungdomsklinikken,  
St. Olavs Hospital, Trondheim  
Norway

MAT-NO-2100360-v1.0-April2021

The symposium is arranged by Sanofi Genzyme.  
Should you have any questions regarding the meeting please contact [camilla.sidenius@sanofi.com](mailto:camilla.sidenius@sanofi.com)

**SANOFI GENZYME** 

# Scientific program NOPHO with joint sessions

See also: [www.nopho.org/welcome/frame.htm](http://www.nopho.org/welcome/frame.htm)

## Saturday May 8

14:00–17:30	<b>YOUNG NOPHO EDUCATIONAL SESSSION (Zoom)</b> Chair: Magnus Hjort, Simon Kranz
14:00–14:30	<b><i>Targeted therapy in paediatric cancer – what, who, when, where?</i></b> David Ziegler (Sydney)
14:30–14:35	<b>Q&amp;A</b>
14:35–15:05	<b><i>Implementing Survivorship Care in Paediatric Oncology</i></b> Richard Cohn (Sydney)
15:05–15:10	<b>Q&amp;A?</b>
15:10–15:40	<b><i>End-of-life care: Non-pain symptom management</i></b> Justin Baker (Tennessee)
15:40–15:45	<b>Q&amp;A</b>
15:45–16:15	<b><i>Lessons learned from the experience with CAR T cell therapy for childhood leukemia</i></b> Terry Fry (Colorado)
16:15–16:20	<b>Q&amp;A</b>
16:20–16:30	Coffee break
16:30–17:30	<b><i>RAPID FIRE (RF) ABSTRACTS</i></b> (3 min +1 min Q/A, online streaming) Chair: Magnus Hjort, Simon Kranz
16:35–16:40	<b>RF1: <i>Intrathecal Tobramycin and Pausing Induction Chemotherapy for Pediatric Acute Lymphoblastic Leukemia Facilitate Successful Management of Disseminated Pseudomonas Aeruginosa Infection and Meningitis.</i></b> Henri Aarnivala (FIN)
16:40–16:45	<b>RF2: <i>Has surgery for inflammatory myofibroblastic tumors in the ALK-inhibitor era become obsolete?</i></b> Maria W Gunnes (NOR)
16:45–16:50	<b>RF3: <i>DNA Methylation as a Prognostic Tool in Pediatric T-Cell Acute Lymphoblastic Leukemia.</i></b> Sofie Degerman (SWE)
16:50–16:55	<b>RF4: <i>Managing Care and Treatment of Paediatric Cancer Patients in the Setting of Coronavirus Pandemic: Experience from a Tertiary Care Centre.</i></b> Austeja Stankute-Kolosova (LIT)
17:00–17:05	<b>RF5: <i>Prognostic Factors for Peripheral Blood Stem Cell Apheresis in Children.</i></b> Kapitancuke Monika (LIT)
17:05–17:10	<b>RF6: <i>Disseminated Mucormycosis in 2 Children while treated for ALL.</i></b> Dorota Malgorzata Wojcik (NOR)
17:10–17:15	<b>RF7: <i>Chemotherapy Induced Neutropenic Fever - An International Pediatric Co-operative Prospective Project under simple Conditions in a privileged Country and South Africa.</i></b> Dorota Malgorzata Wojcik (NOR)
17:15–17:20	<b>RF8: <i>cAMP-mediated autophagy promotes cell survival via ROS-induced activation of PARP1; Implications for DNA damage-induced therapy of acute lymphoblastic leukemia.</i></b> Nina Richartz (NOR)

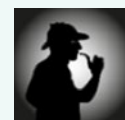
## Sunday May 9

09:00–09:30	<b>OPENING CEREMONY</b>
09:00–09:10	<b>Welcome</b> by organizing committee
09:10–09:30	<b>Glimpses of NOPHO history as seen from Trondheim</b> <b>Guest lecturer (GL):</b> Dr. Randi Nygaard (Trondheim)
09:30–11:30	<b>JOINT SESSION (1) NOPHO/NOBOS:</b> <b>Genetic predisposition to childhood cancer: clinical, biological and ethical issues</b> Chair: Bendik Lund, Kristian Juusola
09:30–09:45	<b>Cases:</b> 1) Ida Knapstad 2) Ann-Karin Mosand
09:45–10:05	<b>Genetic sequencing. GL:</b> Randi Hovland (Bergen)
10:05–10:25	<b>Genetic counselling. GL:</b> Inga Bjørnevoll (Trondheim)
10:25–11:00	<b>Genetic testing of children: When is genetic exceptionalism justified?</b> <b>GL:</b> Berge Solberg, professor in medical ethics (Trondheim)
11:00–11:10	10 min break
11:10–11:30	<b>Panel discussion.</b> Berge Solberg, Ida Knapstad, Inga Bjørnevoll, Randi Hovland
11:30–12:25	<b>LUNCH. Abstract view</b>
12:25–12:30	<b>Movie: Pediatric Cancer Unit invaded by Star Wars</b>
12:30–13:10	<b>THE NOPHO LECTURE :</b> <b>Fertility after childhood cancer. GL:</b> Kirsi Jahnukainen (Stockholm, Helsinki) Chair : Trond Flægstad (NOPHO GS), Bendik Lund
13:10–13:20	<b>Q&amp;A</b>
13:20–13:30	Coffee break
13:30–15:10	<b>NOPHO session: CAR T.</b> Chair: Kjeld Schmiegelow, Bendik Lund
13:30–14:15	<b>Addressing the limitations of CAR T cell therapies. GL:</b> Terry Fry (Colorado)
14:15–15:00	<b>CAR T in NOPHO: lessons from ELIANA and current status. GL:</b> Jochen Büchner (Oslo)
15:00–15:10	<b>Q&amp;A</b>
15:10–15:20	Coffee break
15:20–15:50	<b>SYMPOSIUM (1): CAR-T.</b> Chair: Jochen Büchner
15:20–15:45	<b>Real World Data – How to Optimize Patient Outcome with CAR-T Therapies in Pediatric Patients? GL:</b> Peter Bader (Frankfurt am Main) <b>Sponsor: Novartis</b>
15:45–15:50	<b>Q&amp;A</b>
15:50–16:00	Short break
16:00–17:15	<b>NOPHO Free paper session (1)</b> Chair: Ann Åsberg, Inga M. Johansdottir. (10 min, prerecorded, +2 min Q/A live)
16:00–16:13	OP1: <b>M-ficolin: a valuable biomarker to identify leukemia from juvenile idiopathic arthritis.</b> Ninna Brix
16:13–16:26	OP2: <b>Patient-Tailored Measurable Residual Disease Monitoring in Peripheral Blood Using Deep Sequencing and Droplet Digital PCR for Early Detection of Relapse in Childhood Acute Myeloid Leukemia: A NOPHO-DBH Collaborative Study.</b> Anne-Sofie Skou
16:26–16:39	OP3: <b>Asparaginase Enzyme Activity Levels and Risk of Toxicity in Childhood Acute Lymphoblastic Leukemia - a NOPHO ALL2008 study.</b> Line Stensig Lynggaard
16:39–16:52	OP4: <b>NOR-GRASPALL 2016 (NCT03267030): Asparaginase Encapsulated in Erythrocytes (eryaspase) – A Promising Alternative to PEG-asparaginase in case of Hypersensitivity for Patients with Acute Lymphoblastic Leukemia.</b> Line Stensig Lynggaard
16:52–17:05	OP5: <b>Pharmacokinetics and Immunogenicity of the First Doses of PEG-Asparaginase – an ALLTogether Pilot Study.</b> Merete Dam



# Monday May 10

09:00–10:30	<b>JOINT SESSION (2) NOPHO/NOBOS:</b> <b>End-of-life care.</b> Chair: Anja Lee, Margareta af Sandeberg
09:00–09:30	<b>Preparation for Imminent Death. GL:</b> Justin Baker (Tennessee)
09:30–10:00	<b>Paediatric Palliative Psychosocial Oncology Research in the Nordic Countries</b> <b>GL:</b> Ulrika Kreicbergs (Stockholm)
10:00–10:20	<b>Establishing Pediatric Palliative Care Teams in Norway - Initial Experiences</b> <b>GL:</b> Anja Lee (Oslo)
10:20–10:30	<b>Q&amp;A, discussion</b>
10:30–10:45	Coffee break
10:45–12:00	<b>NOPHO Free paper session (2)</b> (10 min, prerecorded, +2 min Q/A live) Chair: Trond Flægstad, Bendik Lund
10:45–10:57	OP6: <b>Inter-Observer Variations in Target Delineation for Radiotherapy in Pediatric Ependymoma.</b> Laura Toussaint
10:57–11:10	OP7: <b>Incidence and Survival of Childhood Central Nervous System Tumors in Denmark from 1997-2019.</b> Anne Sophie Lind Helligsoe
11:11–11:23	OP8: <b>Postoperative speech impairment and surgical approach to posterior fossa tumours in children: a prospective European multicentre study.</b> Jonathan Grønbaek
11:23–11:35	OP9: <b>Home-Based Cross-Sectoral End-of-Life Care for Children and Adolescents with Cancer: A Qualitative Study of Bereaved Family Members and Involved Professionals.</b> Nanna Maria Hammer
11:36–11:48	OP10: <b>Emicizumab for the Management of Children with Severe Hemophilia A: Experience from Hemophilia Centres in Lithuania.</b> Sonata Saulyte Trakymiene
11:48–12:00	OP11: <b>Outcomes of Acquired Severe Aplastic Anemia in Children.</b> Asta Kolomenskyte
12:00–13:00	Lunch
13:00–13:45	<b>SYMPOSIUM (2):</b> <b>Sherlock Holmes interactive!</b> <b>Case 1.</b> Henrik Hasle (Denmark) <b>Case 2.</b> Ann Åsberg (Trondheim) <b>Sponsor: Sanofi Genzyme</b>
13:45–15:00	<b>MARY BÉVE SYMPOSIUM:</b> <b>Targeted therapy.</b> Chair: Monica Cheng-Munthe Kaas, Maria W. Gunnes <b>Mary Béves Stiftelse för Barncancerforskning</b>
13:45–14:15	<b>From Poison to Precision. GL:</b> David Ziegler (Sydney).
14:15–14:45	<b>INFORM-study. GL:</b> Stefan Pfister (Heidelberg)
14:45–15:00	<b>Q&amp;A, discussion</b>
15:00–15:10	Coffee break
15:10–15:55	<b>NOPHO Free paper session (3)</b> (10 min talk, prerecorded, +2 min Q/A live) Chair: Bem Zeller, Magnus Hjort
15:10–15:23	OP12: <b>Flow Cytometry of Cerebrospinal Fluid for Detection of Central Nervous System Involvement in Childhood Non-Hodgkin Lymphoma.</b> Maria Thastrup
15:23–15:36	OP13: <b>Pediatric Metastatic Melanoma in Congenital Melanocytic Nevus – diagnostic and treatment challenges.</b> Kapitancuke Monika
15:36–15:49	OP14: <b>Effect of Previous Chemotherapy and Leukemia on Ovarian Tissues from Pre-pubertal and Adolescents after Xenografting.</b> Babak Asadi-Azarbaijani
15:50–16:00	Coffee break
16:00–18:00	<b>NOPHO GENERAL ASSEMBLY (Zoom).</b> Organized by Trond Flægstad (SG) Link to meeting will be at the conference web page and sent by mail to NOPHO members.



## Tuesday May 11

08:30-10:30	<b>JOINT SESSION (3) NOPHO/NOBOS:</b> <b>Late Effects.</b> Chair: Ellen Ruud, Maria Olsson
08:30-09:00	<b>Implementing Survivorship Care in Paediatric Oncology</b> <b>GL: Richard Cohn (Sydney)</b>
09:00-09:30	<b>"The cancer treatment was only half the work" - childhood cancer survivor's challenges after cancer treatment and principals for rehabilitation</b> <b>GL: May Hauken (Bergen)</b>
09:30-10:00	<b>Providing information about late effects: What, how and when?</b> <b>GL: Hanne Cathrine Lie (Oslo)</b>
10:00-10:30	Q&A, discussion
10:30-10:45	Coffee break. Poster view.
10:45-11:05	<b>SYMPOSIUM (3): Neuroblastoma</b> <b>High-risk neuroblastoma; introduction, overview and treatment related side-effects - a clinical perspective.</b> <b>GL: Jesper Sune Brok (Copenhagen)</b> <b>Sponsor: EUSA Pharma</b>
11:10-11:45	<b>NOPHO presentation: HD-MTX and pharmacokinetics prediction tool</b> <b>GL: Jesper Heldrup (Lund), Laura B. Ramsey (Ohio)</b> Chair: Tove Nystad, Ingrid K. Torsvik
11:50-12:50	<b>NOPHO Free paper session (4)</b> (10 min talk, prerecorded, +2 min Q/A live). Chair: Tove Nystad, Ingrid K. Torsvik
11:50-12:03	OP15: <b>Executive Functions in Survivors of Pediatric Brain Tumor and Consequences for Societal Participation.</b> Anita Pühr
12:03-12:16	OP16: <b>Objectively Measured Physical Activity in Pediatric Childhood Cancer Survivors Compared to Healthy Controls: A Report from the Physical Activity of Childhood Cancer Study (PACCS).</b> Sabine Kristin Brüggemann-Pieper
12:16-12:29	OP17: <b>Continuous Infusion of Piperacillin-tazobactam in Children with Cancer and Fever: Target Attainment and Dosing Strategy.</b> Sabine Frølich Maarbjerg
12:29-12:42	OP18: <b>Bone Mineral Density is Reduced in Long-Term Survivors of Childhood Medulloblastoma or CNS-PNET.</b> Janne Anita Kvammen
12:42-12:55	OP19: <b>Quality of Life in Mothers and Fathers of Children with Acute Lymphoblastic Leukemia in Sweden, Finland and Denmark.</b> Ella Saaranen
12:55-13:00	Short break
13:00-13:30	<b>CLOSING CEREMONY</b> Chair: local committee  <b>Award ceremony NOPHO</b> <ul style="list-style-type: none"><li>Nikolas Herold, NOPHO Scientific committee</li></ul> Presentation of next meetings <ul style="list-style-type: none"><li>NOPHO, Kuopio 2022 (Kaisa Vepsäläinen)</li><li>NOPHO NOBOS, Lund 2023 (Anders Castor)</li></ul> <b>Closing remarks</b>

# Scientific program NOBOS with joint sessions

See also: [nobos.org/conferences](https://nobos.org/conferences)

Sunday May 9	
09:00-09:30	<b>OPENING CEREMONY</b>
09:00-09:10	<b>Welcome by Organizing Committee</b>
09:10-09:30	<b><i>Glimpses of NOPHO history as seen from Trondheim.</i></b> <b>GL:</b> Dr Randi Nygaard (Trondheim)
09:30-11:30	<b>JOINT SESSION (1) NOPHO/NOBOS:</b> <b><i>Genetic predisposition to childhood cancer: clinical, biological and ethical issues</i></b>
09:30-09:45	<b>Case 1:</b> Ida Knapstad <b>Case 2:</b> Ann-Karin Mosand
09:45-10:05	<b>Genetic sequencing</b> <b>GL:</b> Randi Hovland (Bergen)
10:05-10:25	<b>Genetic counselling</b> <b>GL:</b> Inga Bjørnevoll (Trondheim)
10:25-11:00	<b>Genetic testing of children: When is genetic exceptionalism justified?</b> <b>GL:</b> Berge Solberg, professor in medical ethics (Trondheim)
11:00-11:10	Short break
11:10-11:30	<b>Panel discussion</b> Berge Solberg, Ida Knapstad, Inga Bjørnevoll, Randi Hovland <b>Chair:</b> Bendik Lund, Kristian Juusola
11:30-13:00	<b>Lunch and poster view</b>
13:00-13:55	<b>Education session NOBOS</b>
13:00-13:05	<b>Short presentation</b>
13:05-13:25	<b><i>Oral Care for Children with Cancer.</i></b> <b>GL:</b> Monica Barr Agholme, (Sweden)
13:25-13:45	<b><i>Nutrition for Children with Cancer.</i></b> <b>GL:</b> Janne Anita Kvammen, (Oslo)
13:45-13:55	<b>Q&amp;A</b> <b>Chair:</b> Siw Fossan, Ann-Karin Mosand
13:55-14:40	Break and poster view
14:40- 16:25	<b>NOBOS Free Paper Session 1</b> (15 min talk prerecorded, 5 min Q&A live)
14:40-14:45	<b>Short presentation</b>
14:45-15:05	S01-0: <b><i>Participating in a clinical phase 1-2 trial from A to Z.</i></b> Luise Thellesen
15:05-15:25	S01-1: <b><i>More complex and intensive treatment regimes in children with cancer increases nursing care needs.</i></b> Eva Helena Hansson
15:25-15:45	S01-2: <b><i>Carrying us through the unbearable; Parents experiences of palliative care at home for children with cancer at the end of life.</i></b> Eva Helena Hansson
15:45-16:05	S01-3: <b><i>Health care providers' perceptions of follow-up care of paediatric brain tumour survivors: Need for a new approach?</i></b> Anette Ålykkja
16:05-16:25	S01-4: <b><i>Establishment of consensus on content and learning objectives for an inter-professional educating in childhood cancer: A Delphi study</i></b> Martha Krogh Topperzer. <b>Chair:</b> Gitte Petersen, Solveig Solbraa

## Monday May 10

09:00–10:30	<b>JOINT SESSION (2) NOPHO/NOBOS:</b> <i>End-of-life care</i>
09:00–09:30	<b>Preparation for Imminent Death. GL:</b> Justin Baker (USA)
09:30–10:00	<b>Paediatric Palliative Psychosocial Oncology Research in the Nordic Countries. GL:</b> Ulrika Kreicbergs (Sweden)
10:00–10:20	<b>Establishing Paediatric Palliative Care Teams in Norway – Initial Experiences GL:</b> Anja Lee (Oslo)
10:20–10:30	<b>Q&amp;A, discussion. Chair:</b> Anja Lee, Margareta af Sandeberg
10:30–11:00	<b>Short break</b>
11:00–11:45	<b>NOBOS Key Note speaker</b>
11:00–11:40	<b>Resilience. A health-promoting factor in supporting children and adolescents with cancer. GL:</b> Mary Elizabeth Bradley Eilertsen (Trondheim)
11:40–11:45	<b>Q&amp;A. Chair:</b> Helle Borg Christensen, Solveig Solbraa
11:45–12:00	<b>Short break</b>
12:00– 13:25	<b>NOBOS Free paper session 2</b> (15 min talk prerecorded, 5 min Q&A live)
12:00–12:05	<b>Short presentation</b>
12:05– 12:25	<b>S02-1: Childhood cancer/stemcell transplantation and the mealtime with a gastronomy tube.</b> Ulrika Mårtensson
12:25–12:45	<b>S02-2: Feasibility of outpatient intravenous antibiotic therapy to children with cancer by a portable pump at home.</b> Rikke Thenning Michelsen
12:45– 13:05	<b>S02-3: Transitioning to survivorship. Healthcare professionals views on the Off treatment transition for adolescents with cancer.</b> Elna Hamilton Larsen
13:05–13:25	<b>S02-4: “I have to do things differently now, but I make it work.” Young childhood cancer survivors experience of self-management in everyday living</b> Marie Hamilton Larsen. <b>Chair:</b> Anne Rajatammi, Ann-Karin Mosand
13:25–14:00	<b>Break and poster view</b>
14:00–14:30	<b>NOBOS General Assembly</b> Organized by Kristian Juusola (Teams) Link to the meeting and agenda are sent out to NOBOS members
14:30–15:00	<b>Break and poster view</b>
15:00–16:25	<b>NOBOS Free paper session 3</b> (15 min talk prerecorded, 5 min Q&A live)
15:00–15:05	<b>Short presentation</b>
15:05– 15:25	<b>S03-1: Childhood cancer patients social baseline as a determining factor for self-reported impact of person based exclusion.</b> Line Thoft Carlsen
15:25– 15:45	<b>S03-2: Adaption strategies used by siblings childhood cancer patients.</b> Line Thoft Carlsen
15:45– 16:05	<b>S03-3: Feasible evaluation of children’s self-reported participation in paediatric care.</b> Britt- Mari Gilljam
16:05–16:25	<b>S03-4: The moderating role of resilience on long term quality of life in cancer bereaved parents: Communication with healthcare professionals</b> Omid Rasouli. <b>Chair:</b> Vigdis Hrönn Viggðsdóttir, Solveig Solbraa



## Tuesday May 11

08:30–10:30	<b>JOINT SESSION (3) NOPHO/NOBOS: <i>Late Effects.</i></b>
08:30–09:00	<b><i>Implementing Survivorship Care in Paediatric Oncology</i></b> <b>GL:</b> Richard Cohn (Sydney)
09:00–09:30	<b><i>“The cancer treatment was only half the work” - childhood cancer survivor’s challenges after cancer treatment and principals for rehabilitation.</i></b> <b>GL:</b> May Aasebø Hauken (Bergen)
09:30–10:00	<b><i>Providing information about late effects: What, how and when?</i></b> <b>GL:</b> Hanne Cathrine Lie (Oslo)
10:00–10:30	<b>Q&amp;A, discussion</b> <b>Chair:</b> Ellen Ruud, Maria Olsson
10:30–11:00	Break
11:00–11:45	<b>NOBOS Key Note speaker</b>
11:00–11:35	<b><i>Caring for Adolescents and young adults with cancer. A challenge or a privilege?</i></b> <b>GL:</b> Maria Olsson (Sweden)
11:35–11:45	<b>Q&amp;A</b>
	<b>Chair:</b> Britt Ingunn Sævig, Tonje Randisdatter Tunstad
11:45–13:00	Break
13:00–13:30	<b>CLOSING CEREMONY</b>  <b>Award ceremony</b> <b>RF/OP/poster prizes</b> (Nikolas Herold, NOPHO Scientific Committee)  <b>Presentation of next meetings</b> <b>NOPHO, Kuopio 2022</b> (Kaisa Vepsäläinen) <b>NOPHO NOBOS, Lund 2023</b> Chair: Local committee  <b>Closing remarks</b>

# Guest lecturers NOPHO

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## **Randi Nygaard**

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09:10-09:30 Sunday May 9  
***Glimpses of NOPHO history as seen from Trondheim***



MD, PhD. Born 1945. Completed medical school at University of Oslo 1970. Specialized in pediatrics in Wisconsin, USA and at University Hospital of Bergen, Norway, where she also worked in the department of radiation therapy. Since 1979 until retirement in 2013 she held various positions at the University of Trondheim and in the Dept of Pediatrics, St Olav's Hospital. Consultant in pediatric hematology and oncology since 1984. She served on the board for the National advisory unit on solid tumours in childhood and was member of the National interdisciplinary expert group for tumours of the CNS. She belongs to the first generation of NOPHO members and has held several positions of trust in the organization as well as in SIOP. She was among the organizers of the Nordic meeting at Røros 1982 (when it was decided that NOPHO should be established) as well as SIOP 1988 and NOPHO 2001 in Trondheim.

## **Randi Hovland**

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09:45-10:05 Sunday May 9  
***Genetic sequencing***



Randi Hovland, Bergen Norway. Is a clinical laboratory geneticist with speciality within cancer genetics of hematological malignancies. She has a member of the NOPHO cytogenetic working group since 2002 and the Norwegian childhood leukaemia group since 2006. From 1999 to 2020 she worked at Department of Medical Genetics at Haukeland University Hospital. She is now head of the newly established Section of cancer genomics at the same hospital. Recent years her research focus had been within precision medicine and liquid biopsies.

## **Inga Bjørnevoll**

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10:05-10:25 Sunday May 9  
***Genetic counselling***



Inga Bjørnevoll is registered nurse in 1985. MSc in Genetic Counselling 2003. Worked at Medical Genetics at St. Olavs Hospital since 2001, with Hereditary Diseases and Conditions such as; Cancer and Neurological Diseases, Sudden Death and Prenatal Diagnosis.

## **Berge Solberg**

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10:25-11:00 Sunday May 9  
***Genetic testing of children: When is genetic exceptionalism justified?***



Berge Solberg is a professor in medical ethics and head of the teaching in medical ethics in the medical school at the Norwegian University of Science and Technology (NTNU). He is the deputy leader of the National Committee for Medical and Health Research Ethics (NEM), and he is the secretary of the Clinical ethics committee at St. Olav's Hospital. Between 2004 and 2013 he was a member of The Norwegian Advisory Board on Biotechnology, and thereby worked intensively with policy issues regarding prenatal diagnosis, assisted reproduction and genetic testing in Norway. Solberg wrote his PhD on the ethics of prenatal diagnosis. Recent years, much of his focus has been on the research ethical questions regarding biobanks and the development of large scale biobank infrastructures as well as the use of next generation sequencing technology.

## **Kirsi Jahnukainen**

12:30-13:10 Sunday May 9

### **THE NOPHO LECTURE**

#### **Fertility after childhood cancer**



Kirsi Jahnukainen is a visiting Professor of Pediatric Oncology at the Department of Women's and Children's Health, Karolinska Institutet and a professor in pediatrics at the Department of Pediatrics, University of Helsinki, Finland. She graduated from medical school at the University of Turku in 1992 and presented her doctoral thesis entitled "Leukemia in the testis" in 1995 at the Department of Anatomy at the same university. She did postdoc at the Karolinska Institutet 1998-1999 and at the University of Pittsburgh 2005-2006. She finished her education in pediatric hematology and oncology in 2006 at Children's Hospital, Helsinki and worked in the Units of Pediatric Oncology in Turku and Helsinki. In parallel, she held a 50 % research position with the Swedish Childhood Cancer Foundation from 2009 to 2016. She was appointed adjunct professor of pediatrics at the Karolinska Institutet in 2002, adjunct professor of pediatric hematology and oncology at the University of Helsinki in 2012 and full professor of pediatrics at the University of Helsinki in 2020. The main focus of her research has been on late adverse effects among adult survivors of childhood cancer and pediatric hematopoietic stem cell transplantation. She and her colleagues have shown that survivors after pediatric hematopoietic stem cell transplantation are at risk of early gonadal, skeletal and vascular aging and frailty. Her research group is exploring methods to predict and prevent gonadal late effects after childhood cancer. The clinical aim is to establish robust, large-scale quality testing methods for cryopreserved immature ovarian and testicular tissue and to take the next steps towards effective clinical applications utilising these tissues to restore fertility.

## **Terry Fry**

15:45-16:15 Saturday May 8

### **Lessons learned from the experience with CAR T cell therapy for childhood leukemia**

13:30-14:15 Sunday May 9

#### **Addressing the limitations of CAR T cell therapies**



Dr. Fry obtained his MD from Georgetown University followed by a pediatric residency and chief residency at Georgetown University Hospital. He subsequently completed pediatric hematology and oncology fellowship training at Johns Hopkins

University. Dr. Fry began his research training in T cell homeostasis and cancer immunotherapy as a post-doctoral fellow in laboratory of Dr. Crystal Mackall at the National Cancer Institute. After leading the Hematopoietic Stem Cell Transplantation Program at Children's National Medical Center Dr. Fry returned to the National Cancer Institute where he now leads the Hematologic Malignancies Section (HMS) in the Pediatric Oncology Branch and directs a translational research program focused on development of novel immunotherapeutics for pediatric leukemia. He has conducted seminal mechanistic studies of immune reconstitution and graft versus leukemia effects following HSCT. More recently, his research program has an increase focus on the use of cell-based immunotherapy for pediatric leukemia. He is principal investigator on a first-in human clinical trial using a novel CD22-targeted chimeric antigen receptor that has induced remissions in 75% of patients with refractory acute lymphoblastic leukemia (ALL). His laboratory has developed two novel CAR constructs that will soon enter clinical trials including a CD19/CD22 bispecific CAR as well as a CAR targeting TSLPR, an oncogene in B cell-ALL.

## **Jochen Büchner**

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14:15-15:00 Sunday May 9

***CAR T in NOPHO: lessons from ELIANA and current status***



Dr. Jochen Büchner is a Clinician Scientist in Pediatric Hematology/Oncology. He graduated from University Medical School in Freiburg, Germany, MD in 2000. Residency at the Children's University Hospital Freiburg, with research interests in leukemias and myelodysplastic syndromes in childhood (EWOG-MDS). From 2004-2012, fellow/consultant at the Children's University Hospital of Northern Norway, Tromsø; research on miRNAs in neuroblastoma, PhD in 2011. Since 2012, Senior Consultant at the Department of Pediatric Hematology and Oncology, Oslo University Hospital and since 2014 Head of the national Pediatric Stem Cell Transplantation Program. Current research is focused on SCT and other cellular and immunotherapies, including early phase clinical trials and engineered T cells. Since 2015, Principle Investigator on several multicenter CART cell trials in pediatric ALL/lymphoma and in charge of the pediatric CART cell program in Oslo.

## **Peter Bader**

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15:20-15:45 Sunday May 9

***Real World Data – How to Optimize Patient Outcome with CAR-T Therapies in Pediatric Patients?***

***Sponsor: Novartis***



Peter Bader, MD is Professor of Paediatrics at the Johann Wolfgang Goethe University in Frankfurt a. M., Germany. He received his medical degree from the Eberhard-Karls-University in Tübingen. Since October 2004 he is Head of the Division for Stem Cell Transplantation and Immunology and Vice Director of the University Children's Hospital in Frankfurt a. M., Germany. From 2014 to 2018 Prof. Bader was chairman of the Pediatric Diseases Working Party (PDWP) of the European Society for Blood and Marrow Transplantation (EBMT). In March 2019 he was Co-Pres-

ident of the 45th Annual EBMT Meeting in Frankfurt. His research is focused in particular on pre-emptive strategies to prevent relapse after allogeneic stem cell transplantation in children and adolescence with malignant diseases as well as the development and application of innovative cell therapy.

## **Justin Baker**

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15:10-15:40 Saturday May 8

***End-of-life care: Non-pain symptom management***

09:00-09:30 Monday May 10

***Preparation for Imminent Death***



As a pediatric oncologist, palliative care physician, vice-chair of the ethics committee and patient-reported outcomes and Phase I and end-of-life care clinical investigator at St. Jude Children's Research Hospital, I am intimately aware of the distress experienced by children with advanced cancer and the ethical and end-of-life/bereavement issues surrounding their disease progression. I have the training, expertise, and leadership to mentor Dr. Jennifer Snaman in her current project outlined in her NIH LRP grant proposal. I currently serve as the Chief of the Division of Quality of Life and Palliative Care at St. Jude as well as the medical director of our Quality of Life for All (QOLA) Service – the St. Jude palliative care team. I also serve as the Director of our large Pediatric Hematology/Oncology fellowship program. My research interests include ethical considerations surrounding enrollment in Phase I clinical trials, AYA palliative oncology care, end-of-life decision making, integrating palliative care into the ongoing care of children with cancer as well as patient-reported outcomes and pain and symptom control in the context of pediatric oncology care. I have received significant extramural funding for my research and I have participated in >30 studies related to pediatric palliative care. I have authored >100 academic works on palliative care subjects within the context of pediatric oncology. In sum, I am a recognized international expert and leader in the field of Pediatric Palliative Oncology.



## Anja Lee

10:00-10:20 Monday May 10

**Establishing Pediatric Palliative Care Teams in Norway  
- Initial Experiences**



Anja Lee, MD PhD, has been working as a pediatrician since 2000. She has formal training in palliative care from Germany (Dattelner Curriculum). Since 2015, she has been working full time in adult and pediatric palliative care, and since 2019, she has been the coordinator of the first Norwegian regional pediatric palliative care team, located at Oslo university hospital. Anja is the leader of the Palliative care special interest group of the Norwegian Society of Pediatricians.

## Henrik Hasle and Ann Åsberg

13:00-13:45 Monday May 10



**SYMPOSIUM (2):**

**Sherlock Holmes interactive!**

**Case 1. Henrik Hasle (Denmark)**

**Case 2. Ann Åsberg (Trondheim)**

**Sponsor: Sanofi Genzyme**



Henrik Hasle is professor in pediatric hematology/oncology at the department of Pediatrics, Aarhus University Hospital, Denmark. Henrik Hasle is the author or co-author of more than 280 peer reviewed journal articles mainly dealing with myeloid leukemia in children, genetic predisposition to cancer, and late effects after cancer therapy.



Ann E. Åsberg, MD, PhD, is a pediatric hematologist and oncologist. She has participated in earlier NOPHO ALL protocols. Her special interests are immune dysregulation, childhood leukemia and inflammatory reactions during extracorporeal circulation.

## David Ziegler

14:00-14:30 Saturday May 8

**Targeted therapy in paediatric cancer  
- what, who, when, where?**

13:45-14:15 Monday May 10

**From Poison to Precision**



Prof David Ziegler trained as a Fulbright Scholar at Harvard Medical School, and is now a paediatric oncologist at the Kids Cancer Centre, Sydney Children's Hospital, Randwick. He treats children with all types of cancer and is Head of the brain tumour program and the clinical trials program. He is the Group Leader of Brain Tumour Group at the Children's Cancer Institute, Australia, focusing on development of novel targeted therapies for childhood brain cancers. He leads the national childhood cancer personalized medicine trial.

## Stefan Pfister

14:15-14:45 Monday May 10

**INFORM-study**



(CV) Stefan Pfister serves as Director of the Preclinical Research Program of the new Hopp Children's Cancer Center Heidelberg, a joint venture between the German Cancer Research Center (DKFZ) and Heidelberg University Hospital. He is heading the Division Pediatric Neurooncology at the German Cancer Research Center (DKFZ) since 2012. Being a pediatrician by training, Pfister received his MD from Tübingen University, and his clinical education at Mannheim and Heidelberg University Hospitals. As a physician-scientist, he completed postdoctoral fellowships with Christopher Rudd at the Dana-Faber Cancer Institute/Harvard Medical School, and with Peter Lichter at the German Cancer Research Center, Division of Molecular Genetics. Pfister's research focuses on the genetic and epigenetic characterization of childhood brain tumors by applying next-generation profiling methods, the development of faithful models and functional validation of findings, and the preclinical testing of

new treatment options using these models. In all his activities, translating novel findings into a clinical context is of highest priority. For his translational neurooncology projects, Pfister received amongst others the German Cancer Award in 2012. In 2020 he became member of the National Academy of Sciences Leopoldina.

### **Richard Cohn**

**14:35-15:05 Saturday May 8**

**Implementing Survivorship Care in Paediatric Oncology**

**08:30-09:00 Tuesday May 11**

**Implementing Survivorship Care in Paediatric Oncology**



Professor Cohn is a Senior Paediatric Haematologist and Oncologist in the Kids Cancer Centre at Sydney Children's Hospital, Randwick, and has a senior management role as the Clinical Program Director of Medicine and Diagnostics in the

Sydney Children's Hospital Network. He has a senior teaching and research role as a Conjoint Professor in the School of Women's and Children's Health, UNSW Medicine. He is Director of the Long-term Follow-up Program at the Sydney Children's Hospital. Professor Cohn has published over 250 peer reviewed papers (145 in last 5 years), in the highest ranking journals and 3 book chapters. He is a clinician researcher whose research has changed practice in all domains of paediatric haematology and oncology care, from diagnosis to cure and beyond. In collaboration with basic scientists, he has been an investigator on projects which have improved molecular understanding of disease mechanisms. He is an author on landmark publications on the location of the Fanconi Anaemia complementation group A gene (Nature Genetics) and the Fanconi Anaemia Group C gene (Human Mutation) and the molecular subgroups of Medulloblastoma (Nature 2012), knowledge which is now used to progress personalized medicine. His clinical research reflects a dedication to evidence-based practices and has substantially contributed nationally and internationally to areas such as treatment safety and efficacy, multidisciplinary team

development, models of long-term follow-up care of cancer survivors, innovative health service delivery, and psychosocial issues from diagnosis and cure to long-term survivorship and bereavement.

### **Hanne Cathrine Lie**

**09:30-10:00 Tuesday May 11**

**Providing information about late effects:**

**What, how and when?**



Hanne is a psychologist educated in Australia with her PhD from School of Psychology/ School of Animal Biology, University of Western Australia (UWA), Perth, Australia. She currently holds a position of Associate Professor and Head of

Studies, Department of Behavioural Sciences in Medicine, Institute of Basic Medical Sciences, Faculty of Medicine, University of Oslo, Norway. Over the past 10 years, the main focus of her research has been on childhood cancer survivors and late effects, with a special emphasis on the patient perspectives on unmet needs, physical activity and fitness in survivors, potential for improvement in follow-up care, and communication about emotional concerns and late effects with adolescent survivors. She has received several grants and awards for her work and participates in supervision and teaching.

11:10-11:45 Tuesday May 11

### HD-MTX and pharmacokinetics prediction tool



Senior Pediatric Oncologist, Childhood Cancer and Research Unit, University Children's Hospital, SE-221 85 Lund, Sweden.

[Jesper.Heldrup@skane.se](mailto:Jesper.Heldrup@skane.se)

Jesper Heldrup is an internationally recognized Paediatric oncologist

with extensive experience in the treatment of acute lymphoblastic leukemia with High dose Methotrexate in children and young adults. Has practiced as a senior Oncologist at Childhood Cancer and Research Unit, University Children's Hospital in Lund. Has since 1992 focused his research on early recognition of signs of delayed methotrexate clearance and methotrexate induced nephrotoxicity (acute kidney injury) and the treatment of the condition. He has for many years been the principal investigator of NOPHO's High dose Methotrexate initiative including glucarpidase treatments and written the NOPHO and ALLTogether Glucarpidase guidelines and the Acute Guidelines for Intrathecal Administration of Glucarpidase that could be found on [www.NOPHO.org](http://www.NOPHO.org) under Emergency. He has been an active force in the international initiative for the "Consensus Guideline for Use of Glucarpidase in Patients with High-Dose Methotrexate Induced Acute Kidney Injury and Delayed Methotrexate Clearance" *Oncologist* 2018; 23:52–61. And in the international work of The EXtracorporeal TReatments In Poisoning (EXTRIP) workgroup for not using extracorporeal treatment at High dose Methotrexate induced nephrotoxicity "Extracorporeal treatment for methotrexate poisoning : Systematic review and recommendations from the EXTRIP workgroup" *Clinical Toxicology*, 2021.



Dr. Laura Ramsey completed her undergraduate work in 2004, receiving her Bachelor of Science Degree in Chemistry at the University of Northern Iowa in Cedar Falls, Iowa. She then joined the Molecular, Cellular, Developmental Biology & Ge-

netics Program at the University of Minnesota in Minneapolis, MN, where she studied the role of B-cell receptor signaling in autoimmunity and leukemia. After receiving her Ph.D. in 2009, Dr. Ramsey began her postdoctoral training with Dr. Mary Relling at St. Jude Children's Research Hospital in Memphis, Tennessee. There she studied pharmacogenomics, and identified genetic variants associated with clearance of the drug methotrexate. She joined the faculty of Cincinnati Children's Hospital Medical Center in 2015. Dr. Ramsey's lab is interested in all aspects of pharmacogenetics, from basic research to implementation in patient care, across many types of medications for different diseases. One medication she is particularly interested in is methotrexate – used in high doses for treating cancer and low doses for treating autoimmune diseases. She created a free webtool, used worldwide, for helping clinicians understand and predict how methotrexate leaves the blood, [MTXPK.org](http://MTXPK.org). Another focus of her group is the study of pharmacogenetics of antidepressants (sertraline, citalopram and escitalopram) in children. The Genetic Pharmacology Service is a multidisciplinary team she co-directs to develop, interpret and implement pharmacogenetic tests in the electronic medical record. She also educates doctors, pharmacists, genetic counselors and nurses on when and how to use the tests in the clinic.



# Guest lecturers NOBOS

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## **Monica Barr Agholme**

13:00-13:55 Sunday May 9

**Education session**

13:05-13.25

**Oral Care for Children with Cancer**



Monica Barr Agholme, D.D.S., Ph.D. She is present academic rank and senior consultant at Division Pediatric Dentistry, Department of Dental Medicine, Karolinska Institutet, Stockholm, Sweden. Barr Agholme graduated as a doctor of dental surgery in 1977 at Karolinska Institutet. In 1984 she got her specialist certificate in paediatric dentistry and in 1999 she got her Ph.D at Karolinska Institutet. Monica Barr Agholme has several publications the last ten years on oral health. At the NOBOS Education Session she will talk about oral care for children with cancer.

## **Janne Anita Kvammen**

13:00-13:55 Sunday May 9

**Education session NOBOS**

13.25-13.45

**Nutrition for Children with Cancer**



Janne is a Pediatric Dietitian. She finished her Master of Science in Clinical Nutrition at the University of Oslo in 2000. Since then, she has worked at the Department of Pediatric medicine at Oslo University Hospital Ullevål and Rikshospitalet.

Currently, she is working as a PhD at the Department of Nutrition at the University of Oslo. She studies nutrition in survivors of childhood brain tumors, in children undergoing allogeneic stem cell transplantation, and in children receiving home parenteral nutrition. Previously, she has researched the nutrition of hospitalized

children and the nutrition of children with milk allergies. She participated in developing the last Norwegian national guideline on infant nutrition, and she has written books about nutrition; "Bare Barnemat! Riktig kosthold for gravide, ammende, barn og ungdom", and «Håndbok i klinisk ernæring».

## **Ulrika Kreicbergs**

09:30-10:00 Monday May 10

**Paediatric Palliative Psychosocial Oncology Research in the Nordic Countries.**



RN, PhD, holds a professorship, funded by Gålö Foundation, in palliative care for children and youth at Ersta Sköndal Bräcke University College, Dept. of Health Care Sciences, Palliative Research Cen-

tre and is also associated to Karolinska Institutet, Dept. of Women and Children's health, Stockholm, Sweden. Her research on families affected by cancer has been acknowledged worldwide. She received the prestigious Schweisguth Prize – SIOP, the International Society of Paediatric Oncology in 2004. Dr Kreicbergs did her postdoc at Dana Farber Cancer Institute and Boston Children's Hospital in Boston, USA. Dr Kreicbergs has continued her research on the child and family in palliative care. Her work is focused on factors in the health care that can be modified or avoided to reduce suffering and thereby enhance quality of life for the child and their families.

## Mary Elizabeth Bradley Eilertsen

11:00-11:45 Monday May 10

**NOBOS Key Note speaker**

11:00-11:40

**Resilience. A health-promoting factor in supporting Children and adolescents with cancer**



**Associate Professor Mary-Elizabeth Bradley Eilertsen** is employed at NTNU, Faculty of Medicine and Health, Department of Public Health and Nursing.

Her research interests are mainly mental health, quality of life, psychosocial health, resilience and palliation in children and adolescents at risk. This research has focused primarily on the role of health promoting resources to children and adolescents that survive cancer, as well as siblings and parents that have a child with cancer or had a child that died of cancer.

In addition, Eilertsen focuses professionally on the advantages of collegial supervision. She has also established research collaboration with Professor Ulrika Kreichbergs and her research team at Karolinska Inst., Stockholm, Sweden.

## May Hauken

09:00-09:30 Tuesday May 11

**"The cancer treatment was only half the work" - childhood cancer survivor's challenges after cancer treatment and principals for rehabilitation".**



May Aasebø Hauken has a basis education as a nurse and has extensive clinical experience within cancer care from hospital- and primary healthcare and the Norwegian Cancer Society. She graduated as can. polit from University of Bergen

in 1998 within the subject of nursing science and pedagogic. From 2005 – 2010 Hauken was the head of Institute of further education at Betanien Deaconal University College. She defended her PhD in 2015 at Hemil, University of Bergen with the thesis «'The cancer treatment was only half the work' – A mixed method study of rehabilitation of young adult cancer survivors.». Then, she was employed at center for Crisis Psychology AS, leading the RCT study "Optimizing social network support for families living with parental cancer". After this, she worked on her postdoc "'The cancer changed my life' – psychosocial challenges for young adult cancer patients from diagnosis to rehabilitation». In 2019, Hauken was employed as a professor in health promotion and health psychology at Center for crisis psychology (CCP) at the Faculty of psychology, University of Bergen. Here, she is the head of the CCP's research group, and is in charge of several research projects related to cancer rehabilitation, health promotion and psychosocial challenges for cancer patients and their families – with a special focus on children/young adults. May Hauken has published a number of scientific and popular scientific paper within her field, and is an active lecturer and supervisor for students at different levels in their career. Hauken has an extensive project portfolio, and published a book in project development in 2019. In recent years, Hauken has cooperated with the Norwegian Child Cancer Society as a member in their Research Committee for research funding as well as lectured at a range of courses and seminars.

## **Maria Olsson**

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11:00-11:45 Tuesday May 11

**NOBOS Key Note speaker**

11:00-11:35

***Caring for Adolescents and young adults with cancer.  
A challenge or a privilege?***



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**Caring for Adolescent and young adults with cancer – a challenge or a privilege!**

Being diagnosed with cancer as an adolescent or young adult (AYA) can be a big disruption in life. How can we as health care professionals meet the special needs for the AYA cancer patients? This talk will focus on physical, psychological and social development during adolescence and young adulthood. Furthermore, describe the experiences and needs expressed by AYA cancer patients