

The NCL Foundation

Research · Funding · Training · Fundraising



2022 annual report

Editorial



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Jan Josef Liefers,
Patron
of the NCL Foundation

The 20th anniversary of the founding of the NCL Foundation coincided with the 10th anniversary of the Eagles Thriller Cup in Münster. The Thriller Cup is one of many wonderful fundraising events held to support the NCL Foundation. Why are these events so important?

NCL is a rare disease. This means that less than 5 people in 10 000 suffer from it. In Germany there are around 700 children with NCL. To raise awareness of this disease we need a lot of people who talk about NCL childhood dementia. I am proud to be one of them - as the foundation's patron. Together with Werner Schulze-Erdel, a member of our board of trustees, this year I organised the anniversary Thriller Cup. We raised donations for NCL research and increased awareness of the disease. The more we talk about NCL; pass on information and find new supporters, the sooner we will achieve our goal of a future without childhood dementia.

Join us and give hope to the children suffering from the disease and their families.

Yours
Jan Josef Liefers



© Ein Herz für Kinder

Dr. Frank Husemann,
Founder of the NCL Founda-
tion and Chairman of
the Foundation Board

In August 2002 I set up the NCL Foundation with the aim of creating a future without childhood dementia. Back then my son, who had NCL and died this spring, was my reason for doing so. I couldn't and didn't want to simply stand by and watch my child slowly slip away - I had to do something.

For 20 years now the NCL Foundation has acted as a forum for researchers, PhD students, doctors, labs and also the families of sufferers. It facilitates the sharing of information and promotes collaborations to find a treatment to combat NCL childhood dementia, which is a terminal disease. We have made great strides along this road but we haven't reached our destination yet. Promising avenues of research have been discovered and the NCL Foundation team continues to strive to achieve their declared goal - finding a way to cure NCL.

Without our many supporters, donors, sponsors, volunteers, ambassadors and our patron these past 20 years wouldn't have been possible. I am very grateful for this and am optimistic that we can make a future without childhood dementia happen.

Yours
Frank Husemann

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2022: A milestone in NCL research!



The title and authors of the ground-breaking publication on the function of the CLN3 protein in the 21 September 2022 issue of "Nature"

IDENTIFYING THE FUNCTION OF THE CLN3 PROTEIN

The findings of the project, which we co-funded, were published in "**Nature**", one of the world's most prestigious scientific journals, in September 2022. The ground-breaking publication's title is "**CLN3 is required for the clearance of glycerophosphodiester from lysosomes**".

Background information: The loss of the CLN3 transmembrane protein causes juvenile NCL, one of the most common NCL diseases. A typical characteristic of the disease is the abnormal storage of cellular degradation products in lysosomes, cell "recycling centres". The function of CLN3 and its role in the NCL disease mechanism have not yet been determined.

The work being carried out by **Prof. Monther Abu-Remaileh**

and his research group at Stanford University, USA, is now bringing us a huge step closer to identifying the role of CLN3 in juvenile NCL. The group has been able to prove for the first time that the loss of CLN3 alters the metabolic characteristics of lysosomes in cells.

The compilation of metabolic profiles for lysosomes isolated from the brains of CLN3-deficient mice and cultivated cells revealed a massive accumulation of **glycerophos-**



Lead author Dr. Nouf N. Laqtom, Stanford University, USA

phodiester (GPDs). As a result, these recycling products, which serve as the components for the maintenance of healthy membranes, are not as readily available for the reconstruction of cell membranes, causing cells to decay.

The findings show that CLN3 is required for the lysosomal clearance of GPDs. They also characterise NCL as a neurodegenerative lysosomal storage disorder with a defect in the glycerophospholipid metabolic process.

In addition to this, the authors found increased concentrations of the **glycerophosphoinositol** metabolite in the cerebrospinal fluid of CLN3 patients, indicating that it could possibly be used as a **biomarker** for the disease.

Overall, the findings offer potential for new approaches for both treatment and also early diagnosis, forming the framework for further ground-breaking studies.

Congratulations to Monther and his group! We are so pleased with the findings!

Also a big thank you to **Stichting Beat Batten!, Bijou Brigitte Stiftung, Contactpunt NCL, the Eagles Thriller Cup, Hauschildt Stiftung** and **Joachim Herz Stiftung** for their generous funding of this breakthrough project.

Click here to see the "Nature" publication:
<https://www.nature.com/articles/s41586-022-05221-y>



Prof. Monther Abu-Remaileh (centre) with his team members Dr. Wentao Dong (L) and Uche Medoh, Stanford University, USA

Other significant publications:

Dr. Rebecca Ahrens-Nicklas, member of our Scientific Advisory Board and, together with Prof. Eric Marsh, winner of our 8th NCL Research Prize in 2018, has published new research findings. They show that the restoration of CLN3 expression only normalises the function of the neuronal network in neurons. +++ A team of scientists from Zürich and Göttingen, led by **Prof. Robert Steinfeld**, also a member of our foundation's scientific advisory board, has published a paper describing the crystalline structure of the CLN5 protein. In addition to this, the team also describes a previously unknown enzymatic function of the protein as a prototype for a new class of S-depalmitoylases. +++ The findings of a study carried out by **Prof. Christian Grimm** and his working group at LMU Munich indicate that activation of a channel type known as TPC2 could restore lysosomal function, thus offering a potential therapeutic approach for NCL and other disorders characterised by an impairment of these cell compartments. +++ The team around **Dr. Chunlei Cang** of the University of Science and Technology of China, Hefei and **Dr. Dejian Ren** of the University of Pennsylvania, USA, recently published information that the CLN7 gene, which is defective in one form of late infantile NCL, encodes a protein serving as a lysosomal chloride ion channel and regulates lysosomal ion homeostasis and function.

Viewed overall these findings open up promising new avenues for therapeutic strategies.

New research work in the field of lysosomes



© Diego Luis Medina

*NCL 2022 Research Prize winner
Prof. Diego Luis Medina, TIGEM,
Pozzuoli, Italy*

PROF. DIEGO LUIS MEDINA AWARDED THE 12TH NCL RESEARCH PRIZE

Since 2008 the NCL Foundation has been awarding the annual NCL Research Prize. Endowed with EUR 50 000 it is the highest monetary award in the field of childhood dementia. The Foundation's Scientific Advisory Board awards the prize in recognition of innovative research ideas which contribute to the development of a therapy or medication to treat NCL.

The 12th NCL Research Prize honours the "**Lysosomal storage-associated genes in CLN3 disease**" project of **Prof. Diego Luis Medina**, Telethon Institute of Genetics and Medicine (TIGEM) in Pozzuoli, Italy. The project's objective is to identify genes and signalling pathways which influence pathological lysosomal storage in the CLN3 form of juvenile NCL with the hope of finding new ways to develop therapeutic agents.

We wish Diego much success in his endeavours and thank the **Joachim Herz Stiftung**, which has once again donated the prize money.



Healthy neural cell



Neural cell with pathological deposits

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“The mechanism behind the accumulation of pathological degradation products in cells affected by CLN3 is still largely unknown. Diego Medina's avenue of research could provide a decisive contribution to determining this, thus opening up new therapy options.”

(Dr. Frank Stehr, Managing Director of the NCL Foundation)

➤ See also P.17 “NCL research and therapy – An outlook”.

Doctoral thesis completed

DANIELA WÜNKHAUS, KATARZYNA WIĘCIÓREK-PLUCIENNIK AND EINAR KROGSAETER HAVE SUCCESSFULLY COMPLETED THEIR DOCTORAL THESES

Funding young scientists is a matter which is particularly close to our hearts. Accordingly, we award doctoral scholarships for up to three years, with candidates proposed by their supervisors. Should we decide to award a scholarship, then regular reports and lab visits are key elements of the funding programme.

In 2022 Daniela Wünkhaus, Katarzyna Więciorek-Pluciennik and Einar Krogsaeter, the three young scientists we have funded, all successfully completed their doctoral theses. Congratulations!



Daniela Wünkhaus established a new human CLN3 cell model which shows a variety of CLN3 disease-relevant changes at the organelle, protein and lipid levels. She also identified a mechanism based on lysosomal target structures to reduce pathological changes. These findings have opened up new therapeutic avenues for the treatment of NCL childhood dementia. Since completing her thesis Daniela has been working at Evotec in Hamburg.

We would like to thank **Evotec**, the **Heinrich Hartmann Stiftung** and the **Eagles Thriller Cup** for financing the project.



Einar Krogsaeter was able to show that the use of small molecules to activate the TPC2 ion channel results in an improvement of the cellular phenotypes associated with lysosomal storage diseases (LSD) such as NCL, for example lipofuscin accumulation or the formation of abnormal vacuoles. Data indicates that TPC2 is a promising target for therapies to treat various types of LSD. After completing his doctoral thesis, Einar is now working as a postdoc at the Gladstone Institute, USA.

Many thanks to our partners **IQVIA Commercial**, **Lieselotte-Paulsen-Stiftung**, **Reinhard Frank-Stiftung** and **Werner Reichenberger Stiftung**.



Katarzyna Więciorek-Pluciennik carried out differential gene expression studies in CLN3 cell models under various nutrient conditions. They indicate a variety of changes which could cause the disruption of communication between lysosomes and mitochondria. The findings point to several potential therapeutic targets and provide insights into the mechanism of NCL diseases. Katarzyna is now working for ICON plc in Langen.

Thank you to **dggroup**, **Hans Rosenthal-Ehrenpreis**, **HAORI-Stiftung Bremen**, **Heinz und Heide Dürr Stiftung**, **Julia Risel** and **von Poll Immobilien** for providing funding.

Projects currently being funded around the world

TWO NEW RESEARCH PROJECTS HAVE STARTED

We are pleased that this year two more new research projects have started in addition to Diego Medina's NCL Research Prize-winning project (cf. P. 4).

In June **Prof. Alessia Calcagni** of Baylor College of Medicine in Houston, Texas, USA began a project to explore the role played by **microglia cells** in the CLN3 disease. Both CLN3 patients and also corresponding mouse models exhibit pathological changes to their microglia cells. Microglia cells are the brain's immune cells. They play an important role in the monitoring of pathogens and neuronal homeostasis - in other words, the maintenance of a stable balance in the neural system to ensure that it is in optimum functional condition. Alessia's project focuses on establishing whether changes in the microglia are indirectly caused by neurodegeneration or are the direct result of the CLN3 protein's absence in microglia cells. Her cooperation partners are Dr. Paolo Grumati and Dr. Davide Cacchiarelli (both TIGEM, Pozzuoli, Italy) and Prof. Monther Abu-Remaileh (Stanford University, CA, USA). We thank the **Werner Reichenberger Stiftung** for funding this project!

The second new project started in July 2022 and is being led by **Prof. Christian Grimm** of the Walther Straub Institute of Pharmacology and Toxicology at the Ludwig Maximilian University of Munich (LMU). Its objective is to analyse the **neuronal lipid profile** in collaboration with **Prof. Martin Giera** at Leiden University Medical Center, NL. Lipids are the basic building blocks of all cell and organelle membranes. Their integrity and regeneration are essential for the functioning and survival of neurons. The project will investigate the long-term impact of the CLN3 dysfunction on the neuronal lipid profile's composition. A better understanding of the changes to the neuronal lipid profile could create the basis for new therapeutic approaches. We would like to thank the **Reinhard Frank-Stiftung** for funding this project!



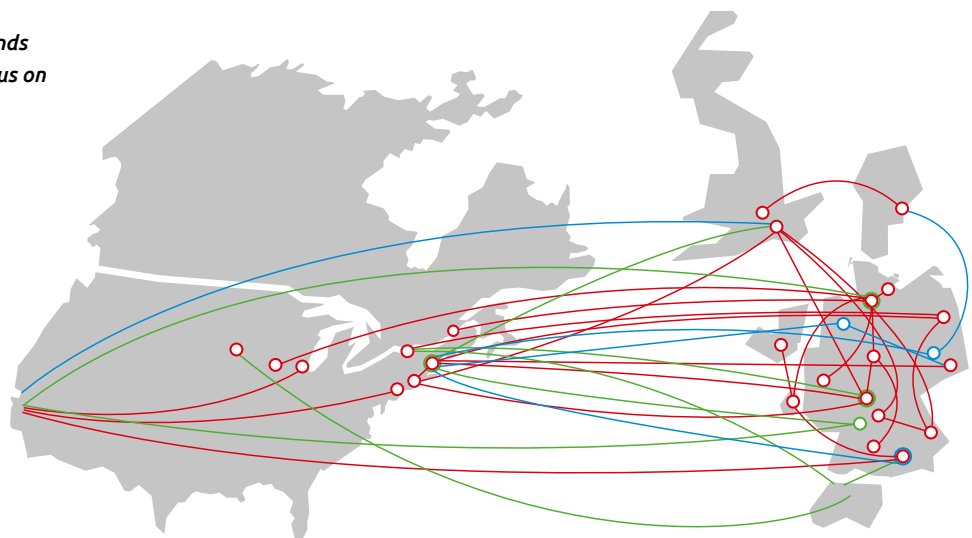
Prof. Alessia Calcagni with her team members Tuong Huynh (L.) and Niculin Joachim Herz, Baylor College of Medicine in Houston, USA



Prof. Christian Grimm, Ludwig Maximilian University, Munich

The NCL Foundation initiates and funds international cooperation with a focus on academic research groups.

University University
 University Research institute
 University Company



**Llinos Siân Honeybun**

Project: Identification of pathological cell changes, so-called cellular "phenotypes", which in the best case also correlate with the disease stage, in order to be able to search for potential active substances using high throughput screening methods.

Supervisor: Dr. Emyr Lloyd-Evans (Cardiff University, UK).

Funding partners: Contactpnt NCL, Eurofins Foundation, Reinhard-Frank-Stiftung.

**Masood Ahmad Wani**

Project: Masood is studying which pathological changes impair the transmission of signals between neural cells in the CLN3 brain. He has already identified very early changes in the NCL model which occur before deposits are formed.

Supervisor: Dr. Benedikt Grünewald (University Medical Centre Mainz).

Funding partners: Helga und Alfred Buchwald Stiftung, Reinhard Frank-Stiftung, Scheck Stiftung, Stiftung Bostelmann, von Poll Immobilien.

**Anna Scotti Rosato**

Project: The objective of the project is to identify mitochondrial phenotypes in the wild type and in diseased cells as well as to test potential active substances to identify those which have a positive effect (see also P. 4 "Other significant publications", Prof. Christian Grimm).

Supervisor: Prof. Christian Grimm (Ludwig Maximilian University, Munich).

Funding partners: Dr. med. Carl-August Skröder Stiftung, Helga und Alfred Buchwald Stiftung, Reinhard Frank-Stiftung, Werner Reichenberger Stiftung.

**Wentao Dong**

Project: Mass spectrometry and the rapid isolation method for lysosomes developed by Abu-Remaileh and colleagues was used to identify an altered metabolite profile in the lysosome of cells, mice and samples from patients with a CLN3 defect. This CLN3 disease-specific profile is now being used as a biomarker to evaluate the efficacy of therapeutic approaches. See also P. 3, "2022: A milestone in NCL research!" – Wentao Dong is the co-author.

Supervisor: Prof. Monther Abu-Remaileh (Stanford University, USA).

Funding partners: Eagles Thriller Cup, Joachim Herz Stiftung.

**Sukanya Arcot Kannabiran**

Project: Calcium ion channels in the lysosome could be a key target structure in the CLN3 disease. Sukanya is using high resolution microscopes to examine this channel function at the microdomain level. Her findings could be important for both juvenile and adult dementia.

Supervisor: Prof. Dr. Dr. Guse (University Hospital Hamburg-Eppendorf).

Funding partners: Bijou Brigitte Stiftung, "Hand in Hand für Norddeutschland" (NDR), Peter Jensen Stiftung.

**Christoph Schwering**

Project: Christoph Schwering is a paediatric specialist and has been caring for NCL children at the Hamburg University Hospital (UKE) in Eppendorf's special consultation clinic for some years now. He has collected important quality of life data which will be key for future therapy studies. In addition to this he has established an NCL biobank at the UKE.

Supervisor: Dr. Angela Schulz (University Hospital Hamburg-Eppendorf).

Funding partner: BILD hilft – Ein Herz für Kinder e. V.



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The young scientists at the 8th JNCL Young Investigator Symposium

National NCL Congress and JNCL Young Investigator Symposium in Hamburg

STIMULATING LECTURES AND LIVELY DISCUSSIONS

Finally held as a face-to-face event again – our **19th National NCL Congress** and the **8th JNCL Young Investigator Symposium** took place as a combined gathering from 19 – 21 September 2022 in Hamburg.

The **National NCL Congress**, held annually, traditionally serves as our platform to share innovative research approaches and the latest findings. It also promotes new collaborations to close research gaps.

The aim of the **JNCL Young Investigator Symposium** is to bring together young scientists working on juvenile NCL CLN3 to promote the exchange of information and to identify where support is needed.

The title of this year's meeting was **“Break-throughs in Translational Science”**, which clearly illustrates the great strides

which NCL research has made and that it has now arrived in a clinical setting.

We heard stimulating lectures and enjoyed lively, very frank discussions. The latter is certainly not always a matter of course at such meetings of scientific experts.

Readers who are interested in finding out more about the conference can read a summary in our current research newsletter (visit the NCL Foundation Homepage / English / Research Newsletter).

A huge thank you to all the speakers and to our partners and sponsors for their support: **Stichting Beat Batten!, Contactpunt NCL, Die Hamburg-Cruiser, Else Kröner-Fresenius-Stiftung, ForeBatten Foundation, Joachim Herz Stiftung, SAP Rest-Cent Förderung, Stiftung Kindness for Kids and Theranexus.**



© Andreas Überscher

Put together an interesting programme: our research director Dr. Herman van der Putten (l.) and managing director Dr. Frank Stehr.

“Thank you so much for allowing me to be a part of this fantastic event. Every year I am very impressed with how well it is organized and am grateful for the environment you all have created. I really appreciate all that NCL-Stiftung has done in creating this symposium, sponsoring travel, and funding projects (like the FLAG mouse). There was a lot of promising work presented including exploring potential biomarkers, determining the function, and solving the protein structure. I am hopeful that one day soon there will be an effective treatment in the clinic. I appreciate all of the formal and informal discussions at this meeting and the potential foundations created for new collaborations as well as strengthening current ones. This is always one of my favourite conferences to attend.”

Jessica Centa, USA

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Living with NCL

“DAS, WAS ICH WAR, IST NICHT GEBLIEBEN” (THERE IS NOTHING LEFT OF WHAT I ONCE WAS)

The father of Kulani, who suffers from the CLN2 disease, has written a poem about his son's illness. Most poignant of all - it is written from his child's point of view. This impressive poem is extremely touching and we are proud to be able to share it here:



Kulani

*Irgendwann muss ich es akzeptieren,
Mein Gedächtnis zu verlieren.
Schon im Kindesalter fängt es an
Und schreitet unaufhaltsam voran.*

*In meinem Kopf kommt es zu Gewittern
Und ich fange überall an zu zittern.
Es bringt mich an einen and'ren Ort
Wo ich schnell will wieder fort.*

*Hinzu kommt das Augenproblem,
Was ich nicht kann versteh'n.
Bald bin ich erblindet;
Es ist nicht das Letzte, was entschwindet.*

*Das Nächste, was wird von mir geh'n,
Ist das Laufen, Rennen, Steh'n.
Meine Hände wollen nicht mehr,
Das macht mein Leben doch sehr schwer.*

*Auch meine Stimme verlässt mich nun
Und ich kann gar nichts dagegen tun.
Schwer fällt mir auch das Schlucken
Und ich fange an zu husten und zu spucken.*

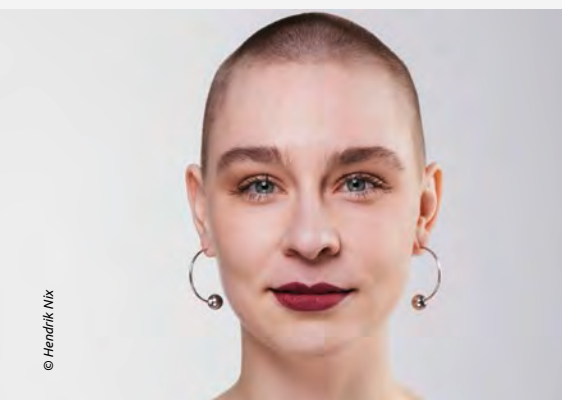
*Mit der Luft wird es bald knapp,
Denn auch meine Lunge, die macht schlapp.
Das alles macht mir Angst und Sorgen,
Denn ein Teil von mir stirbt jeden Morgen.*

*Das, was ich war, ist nicht geblieben,
Versuch' doch einfach mich zu lieben.
Und bleib bei mir, reich mir die Hand,
Denn ich möchte nicht ins and're Land.*

*Ein letzter Gast kommt auf leisen Sohlen
Um mich aus dieser Welt abzuholen.
Deinen Schmerz kann ich versteh'n,
Doch für mich war es Zeit zu geh'n.*

*Ich bin nun an einem bess'ren Ort;
Alle Qualen und Schmerzen sind hier fort.
Wenn der letzte Gast dir auch erscheint
Sind wir auch bald wieder vereint.*

Mario Villwock, father of Kulani



© Hendrik Nix

**Terminal care and grief counsellor
Johanna Klug**

READING BY JOHANNA KLUG

To mark this year's Rare Disease Day, which takes place every last day of February, we chose a topic which affects us all but which we often prefer to ignore - dying and death. In keeping with this topic we organised a virtual reading by Johanna Klug.

Johanna is a trained terminal care and grief counsellor and accompanied Sarah for a year and a half. Eleven years old at the time, Sarah suffered from childhood dementia. Johanna's book "Mehr vom Leben" (More from life), part of which she presented at the reading, documents her experiences and shares her stories about life and death. The evening was moving, thought-provoking and often also joyful.

Raising awareness of NCL

NEW OFFERINGS FOR DOCTORS

In addition to funding research, one of our key concerns is to make a contribution to significantly shortening the **diagnosis time** for NCL.

At present it still takes between two and four years to get a diagnosis - an extremely difficult time for sufferers and their families. It is also lost time, time in which sufferers could receive treatment, treatment which is most effective when given as early as possible.

In response to this we have now expanded our existing programme of doctors' courses on NCL pathology to include a **training course** devoted specifically to its diagnosis.

The speakers at the **webinar** entitled "**Clinical diagnosis of neuronal ceroid lipofuscinosis (NCL) and the use of multiomics**" are two recognised experts.

Dr. med. Angela Schulz, a paediatrician at University Hospital Hamburg-Eppendorf and director of the hospital's special NCL childhood dementia consultation clinic, explains the clinical aspects of diagnosing the disease, while **Prof. Dr. med. Peter Bauer**, Chief Genomic Officer at CENTOGENE GmbH in Rostock, explains how multiomic biomarkers are used to assist genetic diagnosis.

We are very grateful to both of them for giving their time and support and very much hope that this training course will contribute to raising awareness of, and shortening the time required to diagnose, NCL.

The certified webinar is rated with 2 CME points and is available to doctors on the MedLearning AG platform.

THANK YOU to the **Merck Family Foundation** for its generous funding and to the **MedLearning** team for their invaluable support!

Our partner **intermedix** is also supporting our important goal of shortening the time required to diagnose NCL. Working in partnership with us, intermedix has developed a variety of educational and awareness-raising measures which have been integrated into intermedix software systems for surgeries and doctors. This information is displayed whenever ophthalmologists or paediatricians enter predetermined notes or diagnoses in patient files. The doctor can then click onto more detailed information on how to diagnose NCL and on medical training courses (CME). The objective is to provide ophthalmologists and paediatricians with information at a critical moment, thus reducing the number of incorrect diagnoses. Many thanks to intermedix for their invaluable support!



This year we have focused on **school doctors**. Why? Because the most common form of NCL is juvenile NCL (given the genetic nomenclature CLN3) and its initial symptoms present in primary school children. Typically, a previously healthy child will experience problems with their eyesight around the time they start school and these problems will quickly worsen. Following this, the child will experience loss of their mental and motor abilities. School doctors thus play a key role in diagnosing the disease.



Dr. Angela Schulz, Department of Paediatrics, University Hospital Hamburg-Eppendorf



Prof. Peter Bauer, CENTOGENE GmbH

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“As an educational specialist I have personally experienced the long and painful road which families must travel before they get a diagnosis. I have also personally experienced the impact on the children of not being understood by educators, who stigmatise them as lazy, difficult or worse still. Nothing could be further from the truth. The children already had the illness and weren't to blame for their behaviour. I am glad that someone is doing everything possible to provide doctors with detailed information. It would be a blessing for all concerned.”

(Nina S., Foundation follower)

In 2022 we began to run and offer special training courses for school doctors and the staff of municipal public health services. In addition to this we have produced a **factsheet** aimed specifically at this target group. It can be downloaded from our homepage (<https://www.ncl-stiftung.de/was-wir-machen/aufklaerungsarbeit/mediziner/>) and requested as a flyer. Thank you to **Mercedes-Benz AG**, the **Peter Jensen Stiftung**, **Roche Pharma AG** and **Staac Pooltankstellen**.

NEW OFFERINGS FOR SCHOOL PUPILS AND TEACHERS

As already reported, we have entered into a wide-ranging learning partnership with the **Glass Lab** in Berlin, one of Germany's largest and most successful students' labs. This year 20 school classes – both A-level and Year 10 students – were able to carry out **PCR genetic diagnosis** of NCL at the lab.

In addition to this, we participated in the **teachers' congress** organised by chemical industry association “Bildung Nordostchemie” for the Berlin/Brandenburg region. We were able to present our wide-ranging offering for schools during a lecture and at workshops. We also premiered our new **“NCL macht Schule!”** (NCL at school!) factsheet for teachers, which provides information on our overall programme for schools. The factsheet is also available on our homepage at <https://www.ncl-stiftung.de/was-wir-machen/aufklaerungsarbeit/schueler/>.

One of the highlights of 2022 was undoubtedly our shared participation in the **“Long Night of Science”** in Berlin. The Glass Lab at the Campus Berlin-Buch science and biotech park offered a lab course on our PCR genetic diagnosis programme to interested visitors, while we were able to inform them about childhood dementia at our NCL stand in the foyer. Over 1 300 science-loving guests at the campus took the opportunity to chat and experience science and research up close.

Most of the visitors to our stand had never heard of “childhood dementia” and were not even aware that such a disease existed. Even more valuable for us and our educational work is having the chance to participate in events such as the Long Night in Berlin.

A big thank you to the **Glass Lab** and to our sponsor, **Berliner Sparkassenstiftung Medizin!**



Our factsheets for school doctors and teachers can be requested by post or accessed on our website.



Alexandra Beyer (l.) and Frank Stehr (r.), NCL Foundation, and Ulrike Mittmann, Glass Lab (2nd from left) with guests at the NCL stand.



Dr. Frank Stehr, Managing Director of the NCL Foundation, with Ines Fasting, Chairwoman of the Board of the Berliner Sparkassenstiftung Medizin foundation.

The highlights of our anniversary year 2022

We are pleased and grateful that events such as our LebensKünstler art auction could take place face-to-face again. As well as our traditional events we were also lucky enough to have many new supporters who helped us in our anniversary year. Our warmest thanks to all our sponsors and partners for their work, ideas and amazing commitment!

JANUARY

A colourful heart **1** for the NCL Foundation. Initiated by our ambassador Jacqueline Pojer, artist **Harriet Oberländer** designed colourful hearts. Our foundation will receive part of the proceeds from their sale. A great idea!

FEBRUARY

An exhibition by **Emmi Lou!** **2** Emmi Lou suffers from CLN3 and has lost her sight. She presented her work at an exhibition entitled "Farbe spüren" (Feeling colours) in Lemgo and used the show as another opportunity to collect donations for our foundation. "I don't paint with my eyes, I paint with heart," she says. Fantastic, dear Emmi Lou!

"Dwarfs against forgetting" **3** was the title of an unusual event organised by Thomas Böttcher, journalist, presenter and actor. He auctioned off garden dwarfs which he had repaired and painted to raise money for us.

MARCH

In March the **Lions Clubs Düsseldorf Königsallee** charity concert finally took place, after having to be postponed last December due

to COVID-19. The "Arriaga Nova Quartett" string quartet performed works by Haydn and Borodin. It was a fantastic evening!

The **Lions Club Wiesmoor/Ostfriesland** installed donation boxes in two supermarkets/ beverage markets and put up posters asking shoppers to donate their refund receipts for deposit bottles to our NCL Foundation. Many shoppers did just that and the Lions Club was generous enough to match these donations like for like. What a wonderful idea!

APRIL

betterplace.org came up with a second fundraising activity this year. During its "Matching Wednesday" promotion betterplace added an extra 10% to every donation for a maximum sum of 200 euros made to a social project. The money which this generated will help us to distribute even more of our "Hummel Holly" books to children's institutions and doctors' surgeries!

MAY

Bethmann Bank **4** invited golfers to compete in its first charity tournament for a future without childhood dementia, held at Dortmund

Golf Club. The event was a huge success. We will use the proceeds to fund urgently required research. (Pictured: Frank Husemann's flight with Dr. Jens Hauptmann and others).

Hamburg charitable organisation **Round Table 169** held a spring party with a BBQ buffet and exclusive tombola to raise funds for us. We had lots of fun!

JUNE

In June we were able to welcome keen golfers, numerous celebrities and other guests to our **16th NCL Golf Trophy** **5** held in the beautiful surroundings of the Castanea Resort Adendorf in Lower Saxony. An all-round success! (Photo, from left to right: Gerry Hungbauer, Frank Stehr, Anjorka Stachel, Marion groß Osterhues, Dr. Martin Wilhelmi).

This year Beata von Poll, management board member of **von Poll Immobilien** **6**, once again presented a generous donation to our managing director Frank Stehr. We are very grateful for this loyal support!



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© Harriet Oberländer

© IMMOBILIENBLAUME-ART

© Thomas Meyer

© von Poll Immobilien GmbH

© Enno Friedrich

© Conventium Hoesch School, Hamburg



300 km from the Ruhr region to the North Sea by bike and for a good cause – the **Ruhr2Northsea Challenge 2022** **7**. The Pilgrims, parents of two children with NCL, took up the challenge, collecting money for our foundation from sponsors along the way. Above and beyond!

For the first time we were the charity partner of the **Classic Trophy Hamburg**, held by Thiesen car dealership and Bentley Hamburg. Numerous supporters and a fantastic tombola ensured that the event raised money for us!

In addition to its traditional 50 and 25 km routes, this year the **HEROS charity march** **8** organised by our ambassador Jan Hähnlein (pictured) and his supporters in Frömmstedt, also offered its first 8 km Kids Run. An unforgettable experience for all concerned!

JULY

The fundraising campaign run by **Aumüller Automatic GmbH** to mark its 50th company anniversary allowed us to further invest in our school project, which aims to raise school pupils' awareness of NCL childhood dementia. Something which is close to our hearts!

The **"Sunshineband"** **9** at Gymnasium Hochrad School in Hamburg went on tour to the island of Föhr to raise donations for us. A fabulous idea!

The **Jänicke family** is collecting refund receipts for deposit bottles at their EDEKA Jänicke supermarket in Adendorf to raise money for us and has already gathered a significant sum. These kinds of activities are a big help!

AUGUST

An atmospheric gala evening; a spirited golf tournament and record donations – the **10th Eagles Thriller Cup** **10** in brief. It takes place in Münster and is traditionally organised by actor Jan Josef Liefers, our patron, and presenter Werner Schulze-Erdel. We are so pleased to have such dependable partners at our side!

26 hours of continuous play – and the **world record for a golf marathon** was broken! Passionate golfer Dirk Beyer **11** thought up this spectacular event to raise money for our NCL Foundation. Our greatest respect and congratulations!

There is a new **charity wine** **12** for our benefit. The "Child of God Charity to NCL-Stiftung" pinot gris produced by the Becker winery is the brainchild of Thomas Lange and available from dealers Kocher. The bottle label has been lovingly designed by the mother of child suffering from the disease. What a lovely joint fundraiser!

Christian Liese (l. in photo) of the **Round Table 70 Lüneburg** **13** handed over yet another generous donation to our managing director Dr. Frank Stehr. We are grateful for so many years of loyal support and voluntary work!

Our ambassador **Juliane Golbs** took advantage of her show at Hamburg's Barlach Hall K to further publicise the work of our foundation and gather donations for us. Thank you so much for your tireless support!

Company **nexperia** collected electrical scrap to raise money for us before ensuring that it was disposed of properly. An excellent idea!

Gourmet chef Christian Lohse **14** raised donations for us in the last episode of the summer special of VOX series "Grill den Hensler". A great event!



SEPTEMBER

Following the traditional HEROS charity march in June, our tireless supporter Jan Hähnlein and his team went on to organise the **HEROS 100 15** event. What was it? A 100-kilometer hike in 24 hours. Our greatest respect for all participants!

After taking an enforced one-year break due to COVID-19, our **LebensKünstler art auction 16** finally took place live again, as always at JENSENs Lagerhaus in Hamburg. Auctioneer Eva-Maria Uebach-Kendzia and host Birgit Saatrübe-Möllers guided us through the event. We are already looking forward to next year! Pictured: our board of trustees members Lutz Marmor and Birgit Saatrübe-Möllers.

We were invited to hold a tombola at the **13th OT300 Classic Car Festival** at Randel Park. We were very pleased to be part of this fun family event!

Dancer **Melissa Ortiz Gomez 17**, one of our dedicated supporters, invited guests to attend a fundraising celebration with a large tombola to mark her 40th birthday. A wonderful party!

This year we were once again among the charities benefitting from the traditional **Lüner "Big Duck Race" 18**, organised by the OT215 and RT115. Thank you so much for this!

OCTOBER

Our long-standing supporter Gérard Hofmann organised a **whisky tasting event** with dinner at Massen Shopping Centre to raise money for the NCL Foundation. An unusual idea!

Company **Fresenius** ran an employee fundraising campaign to collect money for us – a commendable display of support!

Company **Rentschler Biopharma** celebrated the 150th anniversary of its founding with the decision to support our educational work to raise awareness of NCL. We are pleased to be embarking on this new partnership!

This season the **players in one of the SG Hamburg Nord girls handball teams 19** will be wearing our NCL Foundation logo on their shirts. We are very pleased about this and hope that they will have a successful season!

NOVEMBER

From 21 November to 12 December our big **anniversary auction 20** was held on the **"United Charity"** platform. Numerous prominent and dedicated supporters donated diverse items to be auctioned off to raise money for us. They included concert tickets and signed pieces of art, sports jerseys and books. A worthy end to our anniversary year!

Staff at **DHL IT EXPRESS Deutschland 21** held an auction to collect money for us as their charity partner. A great pleasure!

In the last quarter of the year **mobile GARTIE Deutschland GmbH** made a donation to us for each dealer guarantee it sold – we appreciated this fundraising activity!

MAD About Juice and its managing director Jan Jucknat **22** (l. in photo) started a sales promotion for a charity juice which customers could buy to support our foundation. The promotion start was marked by the unveiling of a corresponding piece of art by our ambassador Juliane Golbs in the presence of Frank Stehr. Fantastic!

DECEMBER

Together with our patron Jan Josef Liefers we will once again be showcased during the national **"Ein Herz für Kinder"** telethon. An incredible opportunity to raise awareness of NCL, for which we are extremely grateful.

Thanks to our sponsors amedes, Budnianer Hilfe, Feuerbestattungen Verden, Rentschler Biopharma and Town & Country Stiftung we were able to send out more copies of Heiko Baumann's **"Hummel Holly" 23** charity book to numerous specialist institutions, such as children's or eye clinics. This is amazing!

Among the supporters who provide us with a great deal of assistance are the **Hamburg Marriott Hotel**, which has, for example, sponsored the catering at our art auctions, and **Dental21 GmbH**, whose surgeries collect old dental gold for our benefit. Both are extremely valuable partnerships!





We remember Tim Husemann

Tim, the son of Frank Husemann, founder of our foundation, passed away in 2022 from the effects of his NCL disease at the age of 27.

He was diagnosed in 2001, one year before the foundation was set up. His father's greatest desire was to use the Foundation as a vehicle to channel all his strength into NCL research, in the hope of finding an active substance to combat the terminal metabolic disorder.

It is too late to help Tim now. But we will continue to strive to ensure that one day there is a cure for other children affected by the disease. We have already journeyed a good way along this road.

We will never forget Tim.



20 Jahre NCL-Stiftung

Für eine Zukunft ohne Kinderdemenz

The NCL Foundation turns 20 – Looking back at the past

Our 20th anniversary is a good reason to look back at the past. What have we achieved? We have approached this question by compiling some figures which we would like to share with you here.



GENERAL

- Since 31.05.2006 holder of the **DZI donation seal of approval**
- The first foundation member of **ACHSE e. V.**, the Alliance for Chronic Rare Diseases (member since 2006)
- **Personal advocates:** including Jan Josef Liefers (patron), Eva Luise Köhler (greetings), Joss Stone (internat. ambassador), Lutz Marmor, Thorsten Schröder, BA Dr. Herlind Gundelach, BA Alexandra Dinges-Dierig, Dagmar Berghoff, Ralf Zacherl, Berti Vogts, Zodwa Selele, Werner Schulze-Erdel and many others.
- 80 regularly active **volunteers**
- The NCL Foundation has coined and shaped the term **“childhood dementia”**

TRAINING & EDUCATION

- Over 6 700 school pupils at 235 **schools** have been reached
- 2 virtual **NCL training courses** for doctors have been produced and certified (each gain 2 CME points)
- 75 eye clinics have been provided with **differential diagnostic posters**
- 35 000 **factsheets** have been distributed to doctors
- 6 230 ophthalmologists and paediatricians have been reached via **lectures** and **(online) training courses**

RESEARCH FUNDING

- 12 **NCL Research Prizes** have been awarded (highest monetary award in this research field, EUR 50 000) plus the **“Neurodegeneration Research Award”** (EUR 100 000)
- **52 research projects** have been funded and **EUR 6.5 m** has been put into research (direct and indirect funding)
- The world’s largest single NGO sponsor of **JNCL doctoral scholarships**
- 43 **young scientists** in 6 countries (UK, USA, Israel, Luxembourg, Italy and Germany) have been funded
- 12 new **NCL research sites** have been set up

RESEARCH NETWORKS & ADVICE

- 21 **NCL congresses** and (virtual) workshops with international speakers have been held
- 8 international **JNCL Young Scientist Symposia** have been organised
- Catalyst: approx. 65 new **research collaborations** have been initiated
- Global **advisor** to other foundations
- Around 63 **specialist publications** on the research projects have been initiated plus “special issues” of journals (BBA, Der Ophthalmologe)
- **Current:** ground-breaking **“Nature” publication** has been issued! (see P. 3)

Promote **research**; provide doctors and other specialists with **further training**; raise the public's **awareness**. These are key priorities when it comes to the rare disease NCL childhood dementia. We believe that we have made a substantial contribution to all of the above.

AWARDS

- 2006 Honouring of Dr. Frank Husemann as the **"Hamburg Citizen of the Year"**
- 2012 NCL Foundation comes 2nd for the **Hamburg Foundation Prize**
- 2015 The schools project is awarded 2nd place for the **Aspirin Social Prize**
- 2015 Honouring of Dr. Frank Husemann with the **Order of Merit of the Federal Republic of Germany**
- 2016 Winner of the **Google Impact Challenge** (local projects)
- 2017 The schools project is awarded the **Hertie Prize**
- 2017 **HanseMercur Recognition Prize** for success in the field of research
- 2017 German Medical Award in the category **"Medical Charity"**
- 2018 Jan Josef Liefers is honoured with the **Hans-Rosenthal Honorary Award**
- 2022 Honouring of Dr. Frank Husemann with the **Karl-Joachim Dreyer Prize**



Awarding of the Order of Merit of the Federal Republic of Germany to Dr. Frank Husemann (r.). On the left: Joachim Gauck, Federal President of Germany at that time

We are pleased that research has picked up speed, particularly in recent years, and that we are currently experiencing a very exciting phase. We will continue to give our all to play a role in scientific advances in the coming years. We look forward to this!

NCL research and therapy – An outlook

Experts expect that in the next few years we will gain decisive insights into the **function of proteins** in neurons and other types of cell. They also expect that we will be able to determine which cellular **signalling paths** are affected by the disease.

New experimental models should cast further light onto the specific contributions of the differing **CNS cell populations** in the various forms of NCL while simultaneously providing information on which types of cell should be key targets for gene technologies and other approaches.

The affected genes in each type of NCL can be expressed in **multiple cell and tissues types** and undergo a variety of pathological processes. This makes it unlikely that one single form of treatment will be able to achieve significant therapeutic outcomes.

In the final analysis, a **combined therapy** based on complementary modes of action appears to offer the best option for effective treatment of the disease.

In addition to this, the findings of a number of studies indicate that therapeutic strategies must target not only the **brain** and **spinal cord**, but also the **retina** and possibly **peripheral organs** such as the heart.

We are encouraged to see that collaboration between **academic** and **industrial** researchers working in the field of NCL diseases is on the up. This will make a decisive contribution to the advancement of new therapeutic developments, particularly at the clinical testing phase.

Furthermore, in recent years a European/US consortium has set up the international NCL register **DEM-CHILD**. Its purpose is to continuously further develop and refine patient assessment instruments as well as also to track the occurrence of all forms of NCL diseases. Further detailed studies on the natural course of the disease should be carried out to link information regarding genetic mutations to clinical data.

More highlights of our anniversary year



WINNING THE KARL-JOACHIM DREYER PRIZE

We are very pleased to have been awarded the Haspa Hamburg Stiftung's **Karl-Joachim Dreyer Prize!**

The prize, given in honour of the Haspa bank's former board spokesman, recognises the outstanding social contributions of charitable

foundations. Our foundation founder, **Dr. Frank Husemann**, accepted the prize at this year's Haspa Hamburg Stiftung foundation members' meeting, 20 years after setting up the NCL Foundation.

NEW AMBASSADORS FOR THE FOUNDATION

In addition to being able to welcome new members to our board of trustees we are also pleased to be able to greet two new ambassadors in our anniversary year.

Artist **Juliane Golbs**, based in Hamburg, has been supporting us for many years now, regularly using her exhibitions to draw attention to our work and donating some of the proceeds of sales of her art to us.

Hamburg businesswoman **Jacqueline Pojer** has over 25 years' experience in a variety of industries, advising and guiding companies from many fields within the scope of her work as a strategy and marketing expert.

THANK YOU for your support!



Lutz Marmor | Werner Schulze-Erdel | Juliane Golbs | Jacqueline Pojer

NEW MEMBERS APPOINTED TO THE BOARD OF TRUSTEES

We are pleased to welcome two new members to our foundation board of trustees in our anniversary year!

Lutz Marmor is the former Director General of the ARD public-service broadcasting organisation and was Chairman of public broadcaster ARD for twelve years before retiring in 2020. He says, "Children with dementia and their families need all the help they can get. The NCL Foundation works to support research into this awful rare disease and may one day also be involved in finding a cure. It also helps ensure that sufferers and their difficult lot are not forgotten. I am very happy to be part of this work."

Actor and presenter **Werner Schulze-Erdel** has supported us for over ten years now. Together with our patron Jan Josef Liefers he set up the Thriller Cup golf tournament in Münster, which is now one of our most important fundraising events. "The Foundation's goals fascinate me and I would like to help turn the spotlight on young people who do not currently have their own lobby as well as raise doctors' awareness of NCL," he says when explaining why he supports us.

We are pleased and grateful to be able to include our new board members among our supporters and look forward to working with them!

ZDF TV FILM FOCUSES ON NCL CHILDHOOD DEMENTIA

In February 2022 a remarkable production entitled "**Eine riskante Entscheidung**" (A risky decision) was broadcast as TV channel ZDF's movie of the week. It focused on the family of child suffering from **juvenile NCL (CLN3)** and the managing director of a pharmaceuticals company carrying out clinical development of a medication against CLN3.

We think the film is remarkable not only because it **draws attention to** the rare disease NCL childhood dementia, which is largely unknown, but also because it explores the dilemma associated with decisions to allow "**compassionate use**" of non-approved medication, thus encouraging viewers to think about a topic which is not a focus of public attention.

It also puts out another **positive message**: There are companies who have set themselves the task of carrying out research into medication for rare diseases and developing them for use.

Here at the NCL Foundation we are doing everything we can to advance research in the field of childhood dementia and to show that it is possible to develop treatments and worthwhile investing in this work.

Staying with TV, our foundation founder **Dr. Frank Husemann** was a guest on **NDR DAS! talk show's** red sofa. He talked about what happened to his son Tim, whose NCL diagnosis was his reason for setting up the NCL Foundation. Many viewers were touched by Frank's story and we received a lot of positive feedback. This has in turn resulted in very joyous new contacts. We are extremely grateful for this.

The NCL Foundation team



© Thomas Meyer

FOUNDATION OFFICE (from the left): Christina Jädke (Administration), Dr. Herman van der Putten (Research), Carolin Kirchmann (Fundraising), Dr. Frank Stehr (Managing Director). Not pictured: Alexandra Beyer (Communication & Marketing), Dr. Birgit Faßbender (Scientific Communication), Tiziana Sandmaier (Training, Fundraising)



© Andreas Überschar Fotografie

HONORARY FOUNDATION COUNCIL (from the left): Dr. Frank Husemann (Chairman), Martin Hartleif (Finance), Alexander Rößler (Legal), Dr. Rainer Kuhn (Research)



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HONORARY SCIENTIFIC ADVISORY BOARD (from the left): Prof. Beverly Davidson, Prof. Robert Steinfeld, Dr. Angela Schulz. Inset photo: Dr. Rebecca Ahrens-Nicklas, Dr. Graeme Bilbe



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HONORARY BOARD OF TRUSTEES (from the left): Ralf Sigrist, Hubert Neubacher, Birgit Saatrübe, Lutz Marmor, Sigrid Bauschert, Olaf Rotax. Not pictured: Werner Schulze-Erdel

+++ DONATION SEAL OF APPROVAL +++

The NCL Foundation has held the DZI donation seal of approval since 2006. It is the seal of approval for legitimate charity organisations. It confirms that organisations handle the money entrusted to them carefully and responsibly.

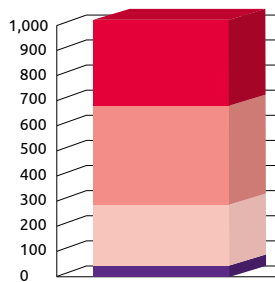


Deutsches Zentralinstitut für soziale Fragen (DZI)
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Organisations with the seal voluntarily undertake to meet DZI standards, thus fulfilling the highest quality requirements.

2021 INCOME AND EXPENDITURE

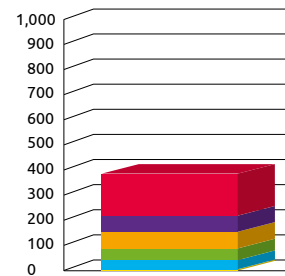
in '000 euros



Income

Donations

- >EUR 10 000 (361)
- EUR 1 001 – 10 000 (416)
- <= EUR 1 000 (256)
- Events / Other donations (48)

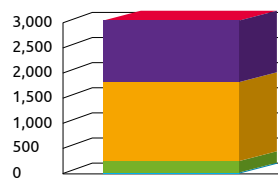


Expenditure

- Research expenditure (161)
- Fundraising / Project management (62)
- Training (64)
- Events (45)
- Administration (35)
- Travel expenses (5)

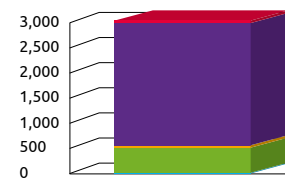
2021 BALANCE SHEET

in '000 euros



ASSETS

- Office equipment (1)
- Bonds (1 238)
- Credit balance (1,589)
- Other current assets (230)
- Accruals and deferrals (7)



LIABILITIES

- Capital (50)
- Contingencies (2 457)
- Reserves (49)
- Liabilities, research contracts (504)
- Tax liabilities (5)

The majority of donations were invested in research. Sponsoring services, unsalaried assistance and indirect research funding are not shown. For data protection regulation-related reasons the overall annual remunerations for permanently employed staff have not been disclosed. For more information visit our homepage www.ncl-stiftung.de/wer-wir-sind/vertrauen/.

Thank you!

And to conclude, we would like to say **THANK YOU!** Thank you to all our supporters - to the people who make donations; to our personal advocates and to the many volunteers and helpers without whom our work would not be possible or so enjoyable. Stay with us on our journey! The following are just a few of them:



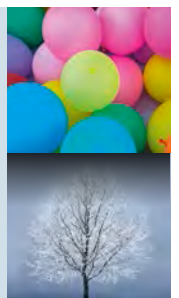
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Many thanks to Niels Faassen and printing company
Siemen for designing and printing our 2022
annual report for free!

nielsfaassen

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We would like to thank everyone who asked for donations to the NCL instead of birthday presents – and all the bereaved families who thought of us even in their darkest hour, asking for donations instead of flowers.



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