

The NCL Foundation

Research • Funding • Training • Fundraising



2024

annual report

Editorial



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Jan Josef Liefers,
Patron of the NCL Foundation

It is virtually impossible to imagine what the lives of a child suffering from NCL and their family are like. Anyone who does try will immediately understand how fundamentally important it is to treat childhood dementia as quickly as possible.

For more than 18 years now I have been supporting the NCL Foundation, for the last eight years as its patron, and accompanying and sharing its journey to a future without childhood dementia. This year Werner Schulze-Erdel and I once again organised the Münster Eagles Thriller Cup to raise money for the NCL Foundation. The entertaining gala evening and the golf tournament held the following day broke all records this year and I am proud to announce that, with the help of many, many donors, supporters and cooperation partners, we have been able to collect one million euros to fund research over the past 12 years.

This amount of money has made it possible to finance a large amount of research work and a lot has been achieved. For example, Prof. Monther Abu-Remaileh and his research group at Stanford University, which receives funding from the Foundation, have not only made breakthrough findings regarding decoding of the CLN5 protein's function, but have also gathered fundamental understanding of how the neurodegenerative disease mechanism works. In addition to this, they are shedding more light onto the function of the CLN3 protein, which has not been previously fully understood, opening up promising new options for the development of a treatment. This report provides more information on this and other exciting research and clinical development approaches.

My greatest wish for all those who are confronted with this disease but do not have the tools to fight it, is that there will soon be a cure, keeping alive the hope of a future without childhood dementia.

Yours
Jan Josef Liefers

Title: Top left: Jan Josef Liefers, Anna Loos and Werner Schulze-Erdel at the Thriller Cup © Joachim Busch | Top right: Student at the Gläsernes Labor lab © Gläsernes Labor | Bottom left: PhD student Katharina Hirn © private | Bottom right: Guests at the LebensKünstler art auction, from the left: Juliane Golbs, Katharina Fegebank and Jacqueline Pojer © Jan H. Winter



© Ein Herz für Kinder

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

NCL childhood dementia is what is known as a medical orphan. A rare disease resulting in death which receives too little attention from the pharmaceuticals industry and the general public. It is incredibly hard to imagine how it feels to be a parent who is told that their own child will gradually lose all their abilities – to see, to think, to walk, to speak and to live.

When faced with this desperate situation sufferers and their families often receive hope and help from charitable foundations and self-help groups who focus on rare diseases and give the sufferers a voice. These organisations can make a significant contribution to the funding of research to develop effective treatment approaches and medications for sufferers of rare diseases.

For over 22 years now the NCL Foundation has been actively supporting national and international research funding. Successful work to combat many other diseases has shown us just how much focused, cooperative and outstanding research projects can achieve.

Although the Foundation concentrates on scientific issues, we also make sure to devote time to PR work and education.

In 2024 we gave many lectures at congresses; to service organisations and at events. We had numerous dialogues and interesting discussions on the NCL disease and its progression. We went into schools and visited universities. This year our scientific education also focused on providing information to optometrists who treat children, because, together with paediatricians, ophthalmologists and school doctors, they play a key role in the early detection of NCL. So, the NCL Foundation has worked hard every day to raise society's awareness of childhood dementia.

I would like to take this opportunity to say a big thank you to everyone for their support and heartily encourage them to continue to do so. I remain confident and convinced that there is no alternative to targeted, innovative research.

Yours
Frank Husemann

DZNE/NCL symposium on neurodegeneration

Research on rare diseases is often pioneer work involving innovative therapies such as gene therapy or enzyme replacement therapy, which, as is the case for CLN2, are being tested for the first time. Correspondingly, they provide many learning opportunities. In addition to this, a deeper understanding of the cell-specific way in which the juvenile dementia disease mechanism works can contribute to the identification of new therapy target structures which are also relevant for other, frequently occurring neurodegenerative diseases suffered by adults, such as Alzheimer's dementia, Parkinson's or frontotemporal dementia. We therefore place immense value on sharing information which applies to multiple indicators.

In keeping with this, this year we partnered with the **German Centre for Neurodegenerative Disorders (DZNE)** to offer the **"Common mechanisms in childhood and adult neurodegenerative disorders"** symposium at the DZNE's centre in Bonn. The leading scientists in the field of neurodegeneration in childhood and/or adulthood who came to Bonn discussed common topics and mechanisms, such as **neuroinflammation**; the role of **microglia**; mechanisms which cause **endo-lysosomal dysfunctions** and **disruption of the lipid metabolism**.

Dr. Angela Schulz of the University Medical Centre Hamburg-Eppendorf also provided a **clinical overview** of the CLN3 disorder, the most common, juvenile form of NCL. She discussed phenotype variability in CLN3 patients, which makes it more difficult to measure efficacy in clinical studies and presented options which could make it easier to overcome this challenge in future clinical studies.

"We thank all the speakers and participants for the very exciting, fruitful discussions and are confident that they will result in new, joint project approaches," said hosts Dr. Sabina Tahirovic of the DZNE and Dr. Frank Stehr of the NCL Foundation at the end of the event.

A big thank you also goes to our sponsors the **Anna-Geissler-Stiftung foundation**, **Contactpunt NCL (BEL)**, **Stichting Beat Batten! (NL)**, the **Stiftung Bostelmann** foundation and the **Reinhard Frank-Stiftung** foundation!



The participants at the DZNE/NCL symposium on 4 June in Bonn

NCL Research Prize awarded

PD DR. GUIDO HERMEY AND DR. MARCEL KLEIN RECEIVE THE 14TH NCL RESEARCH PRIZE

Since 2008 we have been awarding the annual **NCL Research Prize**. Endowed with **EUR 50 000** it is the highest monetary award in the field of childhood dementia. Our 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.

This year's 14th NCL Research Prize went to **PD Dr. Guido Hermey** and **Dr. Marcel Klein** from the Centre for Molecular Neurobiology Hamburg (ZMNH) at the University Medical Centre Hamburg-Eppendorf for their project "**Posttranslational modifications of the CLN3 protein and their implications for CLN3 localisation and function**".

The project's goal is to shed light on the structure of the CLN3 protein, which is defective in sufferers of the juvenile NCL disease. Within the scope of their work, the scientists examined various lipid modifications which could provide information on the structure, function, regulation and localisation of the CLN3 protein. This knowledge is fundamental to understanding the function and dysfunction of the CLN3 protein and developing therapy options.

The prize money will be used to finance Marcel Klein's post-doctoral research position in Guido Hermey's working group, created to carry out the project work.

We wish our winners much success and thank the **Joachim Herz Stiftung** foundation for once again funding our research prize!



From the left: Dr. Frank Stehr (Managing Director of the NCL Foundation)), PD Dr. Guido Hermey, Dr. Marcel Klein, Dr. Herman van der Putten (Research Director of the NCL Foundation))

2ND NEURODEGENERATION RESEARCH AWARD

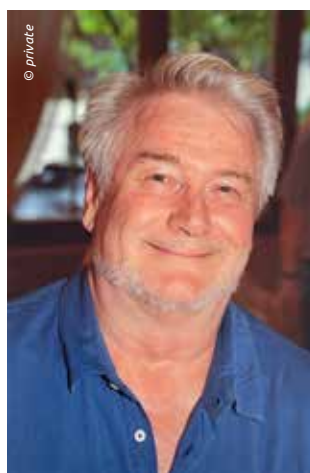
Thanks to the amazing support of the **Friedrich Flick Förderungsstiftung** foundation; the **Werner Reichenberger Stiftung** foundation; the **Gerhard Muggenburg Stiftung** foundation and the **Lübecker Bucht Lions Club** we were able to invite applications for the second NEURODEGENERATION RESEARCH AWARD, which is endowed with **EUR 100 000**.

The prize is intended to fund a post-doctoral research position and aims to promote **synergy effects** between research on childhood **CLN3 dementia** and **age-related neurodegeneration**.

Correspondingly, two cooperation partners should jointly apply for the prize, with one partner actively involved in CLN3 research and the other in research into age-related neurodegeneration.

Ideally, the work will be carried out in the labs of both partners.

We are looking forward to the applications!



Our Research Director, Dr. Herman van der Putten, reviews applications and discusses the planned research projects with the candidates.

Ground-breaking new research findings and publications in 2024

NEW RESEARCH FINDINGS...

The CLN3 form of juvenile NCL is caused by mutations of the CLN3 gene, which codes the lysosomal transmembrane protein. The loss of CLN3 results in a significant accumulation of **glycerophosphodiester (GPD)**, the end products of glycerophospholipid clearance in the lysosomes of somatic cells, as described by the working group led by **Prof. Monther Abu-Remaileh** of Stanford University, USA, in its ground-breaking 2022 publication in "Nature".

Lysosomes metabolise and recycle lipids and other biological molecules in order to maintain homeostasis (a balanced metabolism) in the body's cells.

Current work shows that, in the case of NCL, the accumulated material disrupts **lysosomal lipid homeostasis**, suggesting that GPD "clearance" could be a potential therapeutic approach.

In 2024 Monther Abu-Remaileh's group presented additional new findings which highlight the crucial role the intra-lysosomal lipid metabolism plays in neurodegeneration. This has enabled the identification of the endo-lysosome-specific lipid **bis(monoacylglycero)phosphate (BMP)** as **the key** to lysosomal lipid clearance.

BMP was long thought to be a very stable lipid inside the lysosome, however several neurodegenerative diseases, including CLN3 or CLN5, exhibit **abnormal BMP homeostasis**. Scientists therefore suspect that the loss of gene products in NCL is responsible for a lack of BMP and/or disruption of its function. The next task will be to examine the exact mechanism in more detail.

Selective modulation of BMP in NCL and other diseases could pave the way for promising new therapeutic options.



NCL researchers Uche Medoh and Prof. Monther Abu-Remaileh (r.)

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“In the past few years researchers have made huge strides in understanding how the disease mechanisms of NCL function. This opens up promising new options for the development of a treatment.”

Dr. Herman van der Putten, Research Director of the NCL Foundation

... AND A BRIEF OVERVIEW OF THE LATEST NEWS

The **BDSRA Foundation** (Batten Disease Support & Research Association, USA) announced at its annual conference that it had set up the Batten Disease Global Research Initiative. The research funding programme aims to invest in the most promising research on all forms of NCL around the world. We, as the NCL Foundation, have offered to review future joint financing options which are specifically linked to the CLN3 disease.

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CLN1 gene therapy: In February 2024 it was announced that a CLN1 patient received treatment with gene therapy candidate TSHA-118 within the scope of an investigator-initiated study (IND) at RUSH University Medical Center in Chicago, USA. The gene vector was provided by Taysha Gene Therapies.

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CLN2 enzyme replacement therapy (ERT): BioMarin announced that the FDA has now also approved BioMarin's BRINEURA® (Cerliponase alfa) ERT for use in children aged under 3 years.

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Miglustat: TheraNexus and the Beyond Batten Disease Foundation confirmed positive results of their Phase-I/II study to evaluate Batten-1 (Miglustat) in CLN3 following a 18-month treatment period. The findings indicate the decrease of a biomarker in the serum and suggest that Miglustat has therapeutic potential for treatment of the CLN3 disease.

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Within the scope of a global licensing agreement **Tern Therapeutics**, a private biotechnology company, has acquired the programmes RGX-381 and RGX-181 from REGENXBIO. TTX-381 and TTX-181 are innovative gene therapy products developed to treat manifestations of CLN2 in eyes and the central nervous system (CNS).

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CLN3 gene therapy: Amicus returned the rights to all NCL gene therapy programmes to the Abigail Wexner Research Institute at the Nationwide Children's Hospital (NCH), USA. This includes the clinical CLN3 and CLN6 programmes as well as the pre-clinical CLN8 programme. The NCH is now responsible for the development of these programmes.

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CLN3 ASO therapy: The first personalised ASO (antisense oligonucleotides) therapy using "Zebbronkysen" for two CLN3 patients, initiated by the ForeBatten Foundation, USA, has begun.



2024 publications by scientists who are funded by the NCL Foundation

Tagless LysoIP method for molecular profiling of lysosomal content in clinical samples

Daniel Saarela et al., bioRxiv 2024

Loss of CLN3 in microglia leads to impaired lipid metabolism and myelin turnover

Seda Yasa et al., bioRxiv 2024

TRPML1 activation ameliorates lysosomal phenotypes in CLN3 deficient retinal pigment epithelial cells

Daniela Wünkhaus et al., Sci Rep. 2024; 14: 17469

Glycerophosphodiesterases inhibit lysosomal phospholipid catabolism in Batten disease

Kwamina Nyame et al., Molecular Cell 2024; 84: 1354-1364

The Batten disease gene product CLN5 is the lysosomal bis(monoacylglycero)phosphate synthase

Uche N. Medoh et al., Science 2024; 381: 1182-1189

The parent and family impact of CLN3 disease: an observational survey-based study

Angela Schulz et al., Orphanet J Rare Dis. 2024; 19(1):125

The Bis(monoacylglycero)-phosphate Hypothesis: From Lysosomal Function to Therapeutic Avenues

Uche N. Medoh and **Monther Abu-Remaileh**, Annu. Rev. Biochem 2024; 93: 447-469

Loss of the lysosomal protein CLN3 modifies the lipid content of the nuclear envelope leading to DNA damage and activation of YAP1 pro-apoptotic signalling

Neuza Domingues et al., bioRxiv 2024

PLA2G15 is a Lysosomal BMP Hydrolase with Ester Position Specificity and its Targeting Ameliorates Lysosomal Disease

Kwamina Nyame et al., bioRxiv 2024



Projects currently being funded around the world

THE FOLLOWING TWO NEW RESEARCH PROJECTS ARE AMONG THOSE WHICH HAVE BEGUN.

In addition to PD Dr. Guido Hermey and Dr. Marcel Klein's NCL Research Award-winning project, we are funding the following two new projects among others:

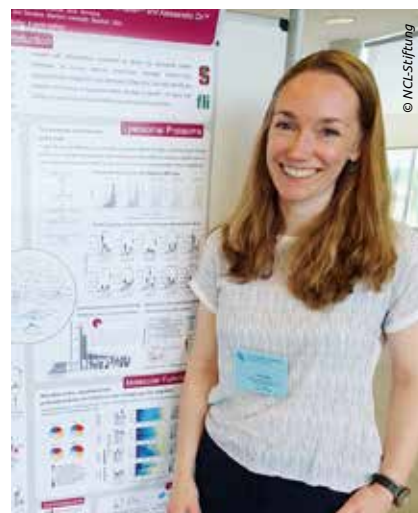
Work by **Dr. Julia Heiby** of the Leibniz Institute on Aging – Fritz Lipmann Institute in Jena.

Background information: CLN3, juvenile NCL, results in a pathological change in the protein composition, known as the proteome, of lysosomes, the "recycling centres" of somatic cells, caused by the absence of the CLN3 protein. This, in turn, alters cellular metabolic pathways and the resulting build-up of toxic clearance products kills nerve cells.

The aim of Julia's research work is to use an *in-vitro* model to analyse the proteomic changes which occur in the CLN3 disease and thus also gain a better understanding of the CLN3 protein's function. This will provide a possibility to identify new therapeutic points of attack and test potential active substances.

Together with Dr. Alessandro Ori, Julia is the winner of last year's 13th NCL Research Prize. Her work, which we are now funding, is a continuation of the award-winning project and has a term of 6 months.

The funding partner for this project is the **Bijou Brigitte Stiftung** foundation – many thanks for your support!



Dr. Julia Heiby at the Gordon Research Conference on Lysosomal Diseases, Barcelona 2023

The second research project which we have begun funding aims to identify CLN3 protein interaction partners which are connected to its protein function and could serve as target proteins for a juvenile NCL treatment. The work is being carried out by PhD student **Katharina Hirn**, a member of the working group led by **Dr. Dominic Winter** at the University of Bonn.

An essential characteristic of many proteins is their interaction with other proteins and the formation of protein complexes. These in turn create signal networks which play an important role in protein function and cellular homeostasis. To date it has only been possible to identify a very small number of potential interaction partners for the CLN3 protein.

Research is now being carried out to establish whether CLN3 forms lysosomal membrane complexes; interacts with proteins in the lysosome or plays a role in interactions with non-lysosomal proteins and to what extent changes in interaction are related to the CLN3 disease.

We are grateful to our funding partners the **Adalbert Zajadacz Stiftung** foundation, **Ernst & Young**, the **Heinz und Heide Dürr Stiftung** foundation, **IQVIA Commercial**, the **Scheck Stiftung** foundation and **Staack Pooltankstellen**!



Dr. Dominic Winter (l.), Katharina Hirn and Dr. Frank Stehr at the certificate presentation in Bonn

**Prof. Alessia Calcagni**

Project: Alessia examined the influence of so-called microglia on the pathogenesis of NCL. To do this, new CLN3 knockout mice were generated which were either missing CLN3 in all cells or only in their neurons or microglia. Within the scope of this work, lysolP and behavioural studies indicate that microglia play a role in the disease's incidence. This data is expected to be published in 2025.

Institution: Baylor College of Medicine in Houston, Texas, USA and the University of Naples "Federico II", Italy.

Funding partner: Werner Reichenberger Stiftung foundation.

**Llinos Siân Honeybun**

Project: Llinos has identified pathological changes in various CLN3-deficient cell types. These phenotypes are currently being used to search for potential active substances using high throughput screening methods.

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

Funding partner: Contactpunt NCL, Eurofins Foundation, Reinhard-Frank-Stiftung foundation.

**Masood Ahmad Wani**

Project: Masood is investigating which pathological changes affect signal transmission, both inside CLN3 neural cells and also between neural cells. He has already identified changes which could contribute to the loss of cognitive functions and epilepsy.

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

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

**Sukanya Arcot Kannabiran**

Project: Lysosomal calcium ion channels play an important role in the incidence of CLN3. Sukanya used high resolution imaging techniques to identify changes in the ion channel function at the microdomain level. Her findings could also be significant for senile dementia as they show that lysosomal ion channels have an effect on calcium homeostasis at both the microdomain and also the whole cell level.

Supervisor: Prof. Andreas Guse (University Medical Centre Hamburg-Eppendorf).

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

**Esther Sammler¹, Peter van Hasselt², Angela Schulz³**

Project: The project's objective is to analyse the lysosomal proteome and lysosomal metabolites and lipids in comparison to the whole-cell lysates of patients with CLN3 disease in order to identify disease-specific biomarkers.

Institution: University of Dundee¹, UK, Universitätsklinikum Utrecht², Netherlands, University Medical Centre Hamburg-Eppendorf³.

Funding partners: Adalbert Zajadacz Stiftung foundation, Freemasons Berlin Outpost 46/ First Berlin Foundation, Helga und Alfred Buchwald-Stiftung foundation, Stichting Beat Batten!

**Prof. Monther Abu-Remaileh**

Project: Monther and his team would like to gain a better understanding of the biochemical fundamentals of the lysosomal dysfunction; the molecular fundamentals of CLN3's neurotoxicity and the direct role of glycerophosphodiesters (GPD) in the disruption of the lysosomal phospholipid metabolism. In addition to this, the lab wishes to develop high throughput assays and new ways to reduce lysosomal GPD levels, with the goal of restoring lysosomal homeostasis as a possible new therapeutic approach to CLN3.

Institution: Stanford University, USA.

Funding partners: Bijou Brigitte Stiftung foundation, Contactpunt NCL, Stichting Beat Batten!, W. u. R. Hauschildt Stiftung foundation.

**Prof. Diego Luis Medina, Dr. Claudia La Vecchia**

Project: The team is investigating the efficacy of various medications at the lysosomal metabolome and proteome levels with the objective of providing more effective predictions regarding which therapeutic agents will, in the final instance, be most effective when treating CLN3 patients. A further focus is on identifying suitable biomarkers.

Institution: Telethon Institute of Genetics and Medicine (TIGEM) in Pozzuoli, Italy.

Funding partners: Edith Waschneck, Reinhard Frank-Stiftung foundation.

**Dr. Yevgeniya Atiskova**

Project: Imaging using optical coherence tomography (OCT) is of critical importance in the process to determine retinal degeneration caused by the CLN3 disease as early as possible. The Foundation is therefore funding the maintenance of an OCT device at the ophthalmology clinic.

Supervisor: Clinic und Policlinic for Ophthalmology, University Medical Centre Hamburg-Eppendorf.

Funding partner: Ernst und Elfriede Griebel's Förderungs- und Unterstützungsstiftung foundation.

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“Just like all parents of a child with NCL, I would like to find a cure for the disease, and I believe that we are now getting closer to understanding the disease's fundamentals. This makes me optimistic.”

Ronald Jansen, father of an 18-year old son suffering from NCL and Chairman of Stichting Beat Batten!, NL, a close partner of the NCL Foundation

NCL in Finland



The participants at a workshop held in cooperation with the Finnish JNCL Family Support Association

NCL ONLINE WORKSHOP TO SHARE INFORMATION

Sharing information within the international NCL community is crucial to advancing research in the field.

Correspondingly, this year, we partnered with the Finnish JNCL Family Support Association (Suomen JNCL-perheiden tukiyhdistys ry) to invite families affected by CLN3 and interested experts in Finland to attend an online workshop.

NCL experts Dr. Miriam Nickel and Dr. Angela Schulz of the UKE in Hamburg reported on the status of clinical research and provided an overview of early and pre-clinical research. In addition to this, Christian Thulfaut, Chairman of the German NCL Self-Help Group, was also on hand to speak with the families.

We would very much like to raise awareness of the NCL disease in Finland and would be happy to see Finnish working groups once again enriching the NCL research environment. Perhaps this workshop was the start of something bigger!



The Finnish "JNCL Family Support Association" provides support to families of children and adolescents suffering from NCL (website image).

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Myös NCL-lapsella ja -nuorella on oikeus elämääniloon!

NCL children and adolescents also have a right to enjoy life! (jncl.fi)

We welcome three new members to our Scientific Advisory Board

We have expanded our unsalaried **Scientific Advisory Board**, which assists us with all specialist questions regarding science and research, to include more internationally recognised scientists and CLN3 experts:

Existing members

1 Prof. Robert Steinfeld (Chair),
Charité – Universitätsmedizin Berlin,

2 Prof. Beverly L. Davidson,
The Children's Hospital of Philadelphia, USA,

3 Dr. Angela Schulz,
University Medical Centre Hamburg-Eppendorf
and

4 Prof. Beverly L. Davidson,
The Children's Hospital of Philadelphia, USA,

will now be joined by new members

5 Prof. Monther Abu-Remaileh,
Stanford University, USA,

6 Dr. An Ngoc Dang Do,
National Institutes of Health, USA, and

7 Prof. Diego Luis Medina,
University of Naples and TIGEM-Telethon
Institute of Genetics and Medicine, Italy.

All three have published ground-breaking publications on CLN3 research and are winners of our NCL Research Prize.

We are pleased to be able to draw on this body's extensive specialist knowledge; thank them and our departing member **8 Dr. Graeme Bilbe**, who has assisted us in the past years, and are very much looking forward to our collaboration!



Expanding NCL education

NEW OFFERINGS FOR DOCTORS

In addition to our two existing **training courses for doctors** on NCL, we can now offer a new certified webinar-based training course:

In the cme course offered by cme-Verlag **Dr. Angela Schulz** of the University Medical Centre Hamburg-Eppendorf outlines the **"Clinical diagnosis of neuronal ceroid lipofuscinoses (NCL)"**. When doing so she once again emphasises the importance of obtaining an early diagnosis so that the families of sufferers do not have to embark on an odyssey from one doctor to the next and, in addition to this, so that they can receive early genetic counselling as well as to ensure that clinical treatment begins as soon as possible.



The webinar is certified with **2 CME points**, held online and lasts approx. 45 minutes. Many thanks to our funding partner for this course, the **Doris Leibinger Stiftung** foundation! We would also like to thank **cme-Verlag** for their assistance in continuing to raise awareness of NCL!

We were very pleased to also be given the opportunity to raise the awareness of paediatricians in Austria regarding the NCL disease. This year, paediatric trade journal **"Arzt + Kind"**, published by the Prometheus-Verlag publishing house in **Austria**, issued a special edition on **childhood dementia** for which we had editorial responsibility and which included articles on its **pathology; diagnosis; treatment** and the **current state of research**. The authors included, among others, members of our scientific advisory board Dr. Angela Schulz and Prof. Robert Steinfeld as well as Dr. Frank Stehr and Dr. Herman van der Putten from our NCL Foundation team.



Ophthalmologists play a key role in diagnosing CLN3 childhood dementia. So we are all the more pleased that **EYEFOX**, Europe's largest ophthalmology online portal, devoted a news article to the topic as well as publicising our factsheet for **ophthalmologists** and **orthoptists**. In addition to this, EYEFOX' special newsletter covering the annual congress of the German Society of Ophthalmology included an in-depth interview with our managing director Dr. Frank Stehr on the pathology of NCL and specialist ophthalmological diagnosis.

This is of great assistance to us in our educational work and we are very grateful to you!

At this year's **annual convention of the Society for Neuro-paediatrics** in Stuttgart we were able to offer an NCL symposium on the topic of "Diagnosis and new therapy options for childhood dementia". Within the scope of this, the mother of a sufferer gave an impressive keynote speech describing her family's journey to receiving its NCL diagnosis.



NEW OFFERINGS FOR SCHOOL PUPILS AND TEACHERS

Do your own research on Rare Disease Day: Our **Hands-on Lab** at the Hamburg MINTarium was inaugurated on last year's World Alzheimer's Day. We continued the theme on this year's **Rare Disease Day**, 29 February 2024. Anyone who was interested was invited to come along to the lab and discover how to use a pipette to isolate DNA, the chain which links all life, under expert guidance. Participants also had the opportunity to find out more about "medical orphans", as rare diseases are also known. Visitors included well-known Hamburg personalities such as Lutz Marmor, Jacqueline Pojer and Marco Ostwald as well as representatives of the Town & Country Stiftung foundation, who presented a symbolic donation cheque. It was an interesting, entertaining evening and we are very grateful to the **MINTarium** for their support and hospitality!



Participants at the Hands-On Lab: Lutz Marmor, member of the NCL Foundation Board of Trustees (l.)

The **Glass Lab at the Campus Berlin-Buch science and biotech park** has been our much appreciated students' lab partner in Berlin for some years now. It regularly offers school classes the chance to try their hands at carrying out our lab-based NCL genetic diagnosis which uses PCR. The Glass Lab marked the 25th anniversary of its inauguration this year – truly a reason to celebrate and **we offer them our warmest congratulations!** In addition to the birthday party, the event was also marked by a large **congress for teaching staff**. Under the motto "Working together to inspire students to become scientists - shaping the future together" around 150 teaching staff from all school forms came together to share information and gain inspiration from numerous educational offerings. The NCL Foundation was also represented at the "Opportunities Market" with our **A-level programme**, which includes PCR genetic diagnosis in the lab and, as a virtual offering, our talks for schools and ethics discussion. Thanks you for this opportunity! The "**Long Night of Science**" in Berlin is always an absolute highlight for us! We took up the invitation of the **Glass Lab**, our cooperation partner at the Campus Berlin-Buch science and biotech park, to inform visitors about childhood dementia at our **NCL stand**, as in the previous two years. Our offering included a knowledge quiz which asked participants to assign models of various animals' brains to matching photos. The Glass Lab also offered a lab workshop on **NCL genetic diagnostics** to provide new knowledge and a genuine "researcher feeling". This event is great fun, not least because the atmosphere is cheerful and relaxed and the numerous guests are so interested and eager to learn. Since most of them are hearing about "childhood dementia" for the first time, the opportunity to take part in the Long Night of Science is even more valuable for us and our **educational work**. A big **thank you** to the Glass Lab at Campus Berlin-Buch for the invitation and support! We look forward to joining you again next year. Many thanks also go to Dr. Anja Reichert and Christian Heimbold of Biomarin for their extremely valuable support as volunteers helping to man the stand!



Which brain belongs to which animal? A challenge for visitors to the Long Night of Science in Berlin.

Within the scope of "**Berlin Science Week**" in November our managing director **Dr. Frank Stehr** gave a lecture on the topic of "**Mysterious brains – causes of dementia in young and old**" for teaching staff and the general public at an event held in cooperation with the German Neuroscience Society and the Glass Lab. A great opportunity to make even more people aware of NCL childhood dementia!



Living with NCL: parents of sufferers work to achieve a future without childhood dementia

A CHARITY MARCH BORN FROM THE LOVE FOR A CHILD

It is a huge shock when a child is diagnosed as having a rare incurable disease which will result in death, especially for the parents. This makes the commitment of affected families to finding a wide range of ways to raise awareness of this topic even more admirable.

On Saturday, 21 September 2024, World Alzheimer's Day, Karsten Knobloch prepared to face a very special challenge in Erfurt. This afternoon, on a warm and sunny late summer day, he will be taking part in HEROS 100. The annual charity march to raise money for the NCL Foundation is organised and run by extreme sports enthusiast and Foundation ambassador Jan Hähnlein. Karsten, a notary from Weimar, is not doing the 100-kilometre hike around Erfurt because he loves extreme sports or for the challenge in itself. His motivation is an entirely different one – his daughter Frieda.

Anke and Karsten Knobloch's 10-year old daughter was given the shocking, earth-shattering diagnosis that she had childhood dementia four years ago. After an exhausting search for the best possible medical treatment Frieda was accepted as a patient at the University Medical Centre Hamburg-Eppendorf's specialist outpatient clinic. Within the scope of so-called "off-label use" she is also receiving two medications at the Vestisch Children's and Adolescents' Clinic in Datteln (Witten/Herdecke University) which are not yet approved for NCL treatment in Germany but appear to be promising options to slow down the disease's progress. A study which began in the USA confirms this effect, at least for one of the two medications.

The Knobloch family's initial feeling of helplessness has been replaced by a thirst for action and the desire to do something. In response to this they are involved in work to raise the public's awareness of childhood dementia and so advance research into NCL. Whether

finding generous sponsors for previous charity marches like the HEROS 100 and/or many other activities supported by the Knobloch family, everything helps the NCL Foundation to get closer to its goal: a future without childhood dementia. The family's relatives, friends and colleagues are also actively involved in helping Frieda and other children suffering from the disease.

Karsten Knobloch finishes the HEROS 100 in 22 hours. It goes without saying that he is proud and happy as he crosses the finishing line but his primary emotion is overwhelming gratitude to Jan Hähnlein for the many years he has devoted to working for the NCL Foundation and for the substantial amount of money which he has raised. Karsten is also highly impressed by the other 21 charity marchers who have undertaken this extreme challenge even though they are not personally affected by NCL. Instead their goal has been to give hope to all NCL families.

100% of all the proceeds of the HEROS 100 charity march go to the NCL Foundation and thus into current promising research projects. In total, all the activities have recently passed the 100 000-euro mark for donations. This is a figure which Foundation ambassador Jan Hähnlein and all the participants, sponsors and supporters can be incredibly proud of. But the proudest person of all is a small spectator at the side of the road: 10-year old Frieda Knobloch.

For more information on Jan Hähnlein's activities, click here:

www.spendenmarsch.org/heros-100/



Anke and Karsten Knobloch collecting donations



Anke and Karsten Knobloch presenting a gift to Jan Hähnlein (centre).



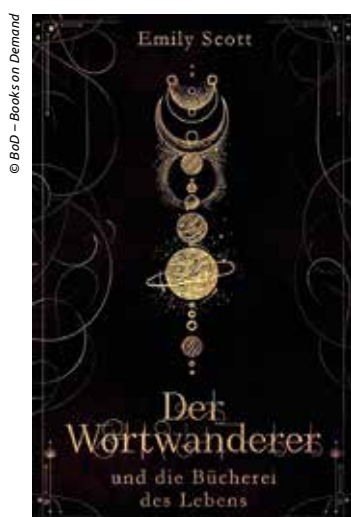
Communication and the media – an important catalyst

This year numerous media representatives and communicators have once again given us their support, for which we are very grateful. You are all an important part of our educational work. For example, the summer issue of **Chrismon** magazine included a three-page article on the christening of NCL sufferer Sarah. Special edition magazine **Our genes** invited us to present the Foundation and our research activities. This interesting magazine is distributed with the Sunday issue of the Frankfurter Allgemeine newspaper, among other publications, and also handed out at leading medical congresses. We were also guests on several podcasts, including Dr. Frank Stehr's appearance on **Profcast – the podcast on rare diseases**. Our colleague Melissa Ortiz Gómez participated in the **Weltverbesserer (Idealists) podcast**, talking about her fundraising activities. Appearances on radio and TV also raised our profile. Broadcaster ZDF's TV programme **Volle Kanne** included an item which provided a very in-depth insight into the disease and current forms of treatment, while radio station Bayern 2 provided a platform for our colleague Tiziana Sandmaier, experts from the University Medical Centre Hamburg-Eppendorf and the mother of a sufferer to talk about the disease.

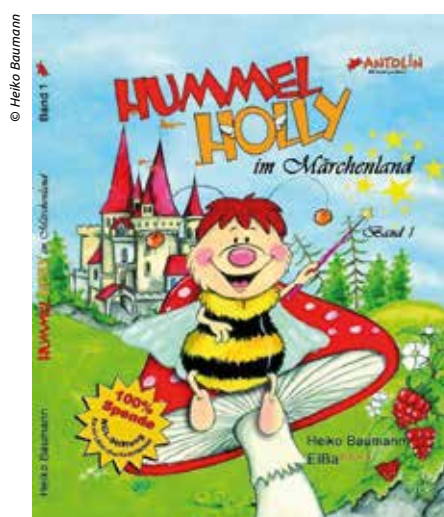
Instagram influencers such as **mothers_ad**, **von_tisch_zu_tisch**, **aboutpatricia**, **mrs.tollpatschig** and many others have also made a major contribution to our PR work this year, drawing a lot of attention to NCL. Many thanks to all of you!

A number of books dealing with NCL childhood dementia have also been published this year, with proceeds going to support our work. **Wortwanderer**, published in June by BoD Norderstedt, is 17-year old author Emily Scott's second book. Emily's story deals with the childhood dementia disease, so she decided to donate some of the proceeds it generated to our foundation.

Author Heiko Baumann's tiny heroine Hummel Holly and the book devoted to her, **Holly Hummel im Märchenland**, aims to raise the public's awareness of the Foundation and the NCL disease. With the help of numerous sponsors, since 2018 a total of 4400 Hummel Holly books have been given to ophthalmologists and children's hospitals; doctor's offices; speech therapists and school medical boards (public health authorities) in Germany and Austria. **Author Jando** has also allowed us to use his modern fairy tales for our charitable work.



© BoD – Books on Demand



© Heiko Baumann



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Our 2024 highlights

We can look back on an exciting year, full of successful events and larger and small(er) activities, some of a sporting nature, some artistic, but all important. We thank all our helpers from the bottom of our hearts for their tireless support. We are grateful and happy to provide an overview of our 2024 fundraising year on this and the following pages.

JANUARY

The Foundation's fundraising year began with a musical event: a New Year's concert at Wittgenstein Palace, organised by the **Lions Club Düsseldorf-Königsallee** to raise money on our behalf.

FEBRUARY

Club **SV Erika/Altenberge** organised an **indoor football charity tournament** given the name **"Budenzauber"** (Shindig) and chose us to be their charity partner. The focus was on raising awareness and education, as well as collecting donations. **1** *An athletic cheque presentation in Altenberge*

This year's NCL **LebensKünstler** art auction, held at JENSENS Lagerhaus, was a great success again! Almost 200 guests showed their interest in art, bidding for a total of 30 art objects, which included pieces by Udo Lindenberg and Otto Waalkes among others. Board of trustees member **Birgit Saatrübe** acted as the mistress of ceremonies, while **Eva-Maria Uebach-Kendzia** presented the art objects to the buyers. The team at the **Hamburger Marriott Hotel** provided us with culinary delights. All the artists donated their work for free, enabling us to collect 36 100 euros to go towards **funding research**. **2** *Dr. Frank Stehr presents Deputy Mayor Katharina Fegebank (patron of the charity art auction) with the piece by Armin Mueller-Stahl which she bought.*

MARCH

A new episode of newspaper **Hamburger Abendblatt's** podcast **"Becker am Morgen – Alles was Hamburg bewegt"** (Things that get Hamburg going) came out. It included an appearance by our managing director Dr. Frank Stehr, who talked about the NCL disease; its symptoms and our Foundation.

APRIL

The **DAS!** chat show, broadcast by **NDR**, devoted a programme to the topic of Alzheimer's dementia. An item about NCL childhood dementia was also included, introducing 16-year old sufferer Sarah and her family, with whom we have been closely connected for many years.

By **bike** from **Hamburg** to the island of **Sylt** in five days, playing one round each at ten **golf courses** along the way. Over 315 kilometres cycled; 167 fairways played and over 77 km walked. Golf enthusiast **Dirk Beyer** came up with yet another exciting event to raise money for the NCL Foundation. **3** *Dirk Beyer with his bike and golf bag*

We were able to take part in health and beauty retailer **Budni's Godparent Day** and had a small stand to present the Foundation's work.

Whiskey tasting to raise money for charity. As part of the **2024 Rarities for Charity** event at the **"Whisky Fair Limburg"**, **Gérard Hofmann** collected donations for the Foundation.

Cheque presentation in Frankfurt. This year **von Poll Immobilien GmbH** once again provided generous support for our research work.

4 *Sigrid Bauschert and Beata von Poll at the cheque presentation*

The Association of German Dance Instructors (**ADTV**) and the Commercial Association of German Dancing Schools (**WDTU**) initiated a major fundraising campaign to mark the **2024 International Dance Day** on 29 April. The associations asked social media users to upload a video – **AhSi-Levantando las Manos** – and include a request for donations to the NCL Foundation in their post. The campaign ran until 3 November. Numerous dancing schools took part, raising a significant amount of money. **5** *Melissa Ortiz Gomés with lots of enthusiastic dancers*

MAY

850 highly motivated heroes and heroines responded to **Jan Hähnlein's** call for action and took part in the **5th HEROS charity march** in aid of the **NCL Foundation** in Frömmstedt, Thuringia at the end of May. They completed the 8-, 25- or 50-kilometre distances with flying colours and the atmosphere was fantastic. The youngest marcher was just 10 weeks old – what an amazing level of commitment! Thanks to the numerous marchers and sponsors a large number of donations were collected! **6** *Ambassador Jan Hähnlein at the charity march*
7 *The Knobloch family, themselves affected by NCL, thank all the participants*



The weather for the traditional Hamburg spring get-together of the **Round Table 169** was great. Everyone enjoyed a good chat and BBQ and the tombola raised 2 000 euros in donations.

The **Kids4Kids** umbrella organisation of the **International School of Hamburg** supported us again, presenting us with a cheque at a morning assembly. **8** *Dr. Frank Stehr with International School of Hamburg students*

Networking event at the Hanse Lounge. Board of trustees member **Birgit Saatrübe** and businesswoman **Nathalie Vladi** invited other women to attend a **Ladies Breakfast**. NCL managing director Dr. Frank Stehr was on hand to provide information about childhood dementia.

JUNE

This year, **Katharina Arnold** again organised the **Inspire24 networking event** in Hamburg. 150 businesswomen were inspired by interesting lectures and enjoyed an exquisite fashion show and impressive dance performance. We ran a tombola, enabling us to raise a significant amount of money. **9** *Katharina Arnold at the charity fashion show*

The 18th **NCL Golf Trophy in Adendorf** took place under the patronage of **Daniela Behrens** (Lower Saxony's Minister for Internal Affairs and Sport) and **Thomas Maack** (Mayor of the municipality of Adendorf). Although the event was still a huge success. 75 golfers played rounds to raise money for charity. The proceeds amounted to a substantial 21 500 euros, made up of the proceeds of a tombola; the golfers' entry fees and sponsors' donations. In addition to this, **Castanea Golf Resorts** generously increased the amount to a round number.

10 *From the left: Sebastian Deyle, Gerry Hungbauer, Hinnerk Baumgarten, Lea Husemann, Melissa Ortiz Gómez, Marion groß Osterhues, Dr. Frank Stehr, Dr. Frank Husemann*

Runner **Alexander Voß** participated in the Hella Half-Marathon in Hamburg to support the Foundation. With the help of his sponsors, Alexander run, which he called **"Schwitzen mit Herz"** (Sweating for a good cause), raised an amazing amount of money which will go towards NCL research. **11** *Alexander Voß and Dr. Frank Stehr at the cheque presentation*

The organisers of the **BDN summer party**, held in the beer garden of Kassel's Schlosshotel, collected a generous amount of donations.

Spectacular folding bike event in Erfurt. NCL ambassador **Jan Hähnlein** invited owners of MIFA GDR folding bikes to join him to form the "world's longest line of folding bikes" and beat his existing record. Although the group wasn't able to win a new world record, the line up of folding bikes, comprising 289 people and bikes was incredibly long. **12** *Participants at the folding bike event*

This year students in the biology class at **Gymnasium Corveystraße** school in Hamburg held another **flea market** to raise money for the NCL Foundation. The items sold plus donations raised a total of EUR 310.50. **13** *Charity flea market*

Company **CP Tech** put its old work uniforms up for sale to raise money for us and added an additional donation.

Inspiration and networking. Our ambassador Edgar Itt presented the **X-Chance** – an important event organised by **Mission Female** – and we were there! This event encourages people to take action and make

changes, motivating them to play an active role in transforming our society. **14** *Melissa Ortiz Gómez (Fundraising) and Nadja Bachmann (Communications) with ambassador Edgar Itt*

JULY

In early July the CEO and two representatives of the general works council of company **DB Schenker** visited our managing director Dr. Frank Stehr to present a donation cheque to support our research projects. **15** *Cheque presentation at our Foundation offices*

For the first time we were the charity partner of this year's **IDEE German Derby Meeting** at Hamburg Horn race course. We had a great time over the five days of flat racing despite the mixed weather and some heavy rain; selling tickets for the charity tombola; educating interested visitors to our stand about **childhood dementia** and watching the exciting horse races with our prominent supporters and guests such as singer Volkan Baydar, ambassador Jacqueline Pojer, TV presenter Hinnerk Baumgarten and board of trustees member and former NDR director-general Lutz Marmor. The event enabled us to collect donations to help fund international research projects and gave us the opportunity to have many conversations about NCL. **16** *Volkan Baydar came to the derby with his wife Lisa.*

Following our **lecture** on childhood dementia at **Ingolstadt Lions Club** we were presented with a large donation. Other service clubs such as the Round Table and Rotary were also present at the event. **17** *Our staff member Tiziana Sandmaier with Marcus Krauß at the cheque presentation*



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© Gymnasium Corveystraße



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AUGUST

For the 12th time, **Werner Schulze-Erdel** and **Jan Josef Liefers**, supported by the **Volksbank im Münsterland** bank, extended an invitation to the **Münster Eagles Thriller Cup**. Around 250 guests attended a fabulous gala evening, which, thanks to many live appearances, including Jan Josef Liefers, was an unforgettable experience. The following day, guests were able to enjoy an exciting golf tournament. Among the celebrity competitors were **Otto Waalkes**, **Stefanie Hertel** and many others. Over the years this event has raised donations amounting to 1 million euros! **18** *Dietmar Dertwinkel of the Volksbank bank with Jan Josef Liefers (r.).* **19** *Comedian Otto Waalkes with our patron Jan Josef Liefers at the golf tournament*

SEPTEMBER

For the 10th time big and small visitors to **Randel Park** were able to admire classic cars and try their luck at the tombola. Breakfast TV show **Frühcafé's** presenter **Marco Ostwald** took us through the warm and sunny afternoon, while the **OT300** sold food and drinks. **20** *There were also lots of classic cars to inspect.*

The **OT215** and **RT115** organised a race with 20 giant inflatable ducks which were steered by members of the Lünen Canoeing and Skiing Club. The ducks were sponsored by companies and businesses in the region, with the net proceeds of the race going to three charity partners, which included the NCL Foundation. **21** *20 giant ducks race for the NCL Foundation*

For the first time we were the charity partner of the **Rhein-Main-Klassik** a three-day car rally organised by **B&M Marketing**. Some 70 vehicles participated, covering a total of around 500 kilometres. The gala evening at Hofgut Laubenheimer Höhe estate near Mainz was a highlight of the competition and we were there with a tombola. **22** *Dr. Frank Stehr on the Rhein-Main-Klassik stage*

"Demenz - Gemeinsam. Mutig. Leben." (Dementia - Together. Courageous. Life) was

the motto of this year's German Dementia Week. We were among the participants in this event and our goal was to raise awareness that children can also fall ill with dementia. Correspondingly, our managing director Dr. Frank Stehr took the opportunity to talk about NCL childhood dementia on the **Frühcafé** breakfast TV show of broadcaster **Hamburg 1**. In addition to this, we received a lot of support from prominent, committed people who used the campaign week to publicise the NCL disease and our work on their social media channels.

Saturday, 21 September, World Alzheimer's Day, was a highlight of the week, as it was the day on which the 100-km **"HEROS 100"** charity march took place in Thuringia. The march was organised by our tireless supporter **Jan Hähnlein**. The march was extra special because one of the participants marching to raise money for the fight against childhood dementia is himself the father of child with NCL (see also Page 14). Impressive and moving! **23** *This is what winners look like! 21 participants after the march*

Spades, clubs, diamonds and lots of hearts: the **Deutsch-Amerikanische Frauen-Club Hamburg e.V.** organised a **charity bridge tournament** at Falkenstein Golf Club and gave us the opportunity to present the topic of childhood dementia.

OCTOBER

A combined art experience and fundraising event. Artist and NCL ambassador **Juliane Golbs** organised a week-long art exhibition at Hamburg's Alstertal shopping centre in aid of the NCL Foundation. The week ended with a live painting event by the artist, at which the public were able to buy small personalised mini artworks in return for a donation to the Foundation. **24** *Artist and ambassador Juliane Golbs*

NOVEMBER

Going once, going twice, yours! At the **"Auktion der schönen Dinge"** (Beautiful Objects

Auction), initiated by the **Old Tablers 1648 Münster** bidders were able to purchase special events, activities and objects which are not generally for sale. Art gallery **Galerie Mensing** donated selected pieces for the auction, while our patron Jan Josef Liefers provided a hand-signed lab coat from his TV show as a unique lot.

This year we premiered a very special fundraising event, an **NCL Christmas market** organised by the Foundation in the heart of Hamburg's Stadtpark city park. All Hamburg citizens and Foundation supporters were invited to attend this spectacular Advent experience. Visitors were able to enjoy tasty crêpes; warm mulled wine and entertaining stage events plus a tombola at the **Sierichs Winterzauber** event, where we collected donations for new research projects. A great success!

Oldenburg-based primary and special school teacher and stationery retailer **Martina Bromberg** supported us with her annual **"Achtsamer Advent"** (Mindful Advent) passion project. She offered her mindfulness/advent calendar as a free download in return for a betterplace donation, helping us to fund more projects.

DECEMBER

Board of Trustees member and harbour launch businessman **Hubert Neubacher** supported the Foundation: at the annual **DinGeLing!** event, held on a launch on the Elbe river, guests were able to make donations in a festive atmosphere.

NCL Foundation meets gaming: The major 24-hour online game and streaming event **Friendly Fire** took place for the **tenth time!** This year we were able to participate as one of seven charity partners and, thanks to the numerous donations, were able to expand relevant research activities. **25** *One of the participants: live streamer Gronkh*

Our warmest thanks to everyone who was involved for their work, ideas and amazing commitment! THANK YOU! We are looking forward to an eventful 2025.



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The NCL Foundation team



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FOUNDATION OFFICE (bottom, from the left): Melissa Ortiz Gómez* (Fundraising), Nadja Bachmann* (Communications & Marketing). Top left: Dr. Frank Stehr (Managing Director), Annemie Lüthje* (Project Management), Carolin Kirchmann (Fundraising), Dr. Herman van der Putten* (Research). Not pictured: Dr. Birgit Faßbender* (Scientific Communication, Training), Tiziana Sandmaier* (Training, Fundraising), Christina Jädke* (Administration)

*part-time



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



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UNSALARIED SCIENTIFIC ADVISORY BOARD (FROM THE LEFT): Prof. Beverly Davidson, Prof. Robert Steinfeld, Dr. Angela Schulz, Dr. Rebecca Ahrens-Nicklas, Prof. Diego Luis Medina, Dr. An Ngoc Dang Do, Prof. Monther Abu-Remaileh



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UNSALARIED BOARD OF TRUSTEES (from the left): Ralf Sigrist, Hubert Neubacher, Birgit Saatrübe, Lutz Marmor, Sigrid Bauschert, Olaf Rotax, Werner Schulze-Erdel

The NCL Foundation is a member of the Association of German Foundations and of Achse e. V. and works closely with other NCL institutions – such as the NCL Group Germany.



As of 2023 we are now a member of the German "National Dementia Strategy" network. Within the scope of this body the German national government works together with over 70 organisations to improve the lives of dementia sufferers and their families.

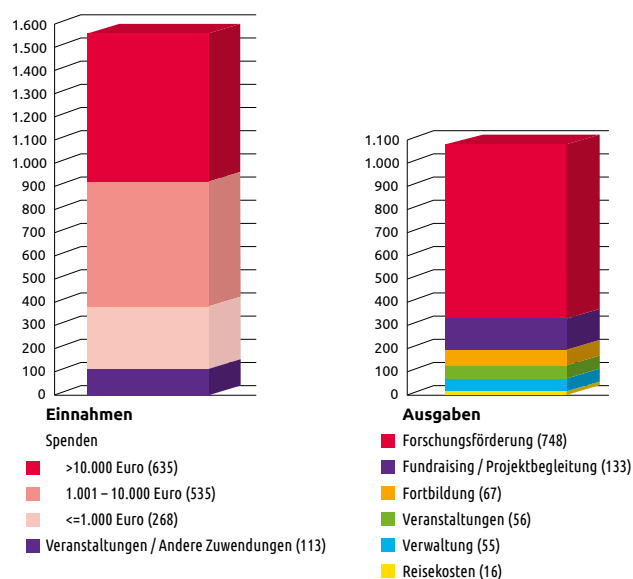


The NCL Foundation has held the DZI donation seal of approval since 2006. It is the seal of approval for legitimate charity organisations. We undertake to meet DZI standards, thus fulfilling the highest quality requirements.



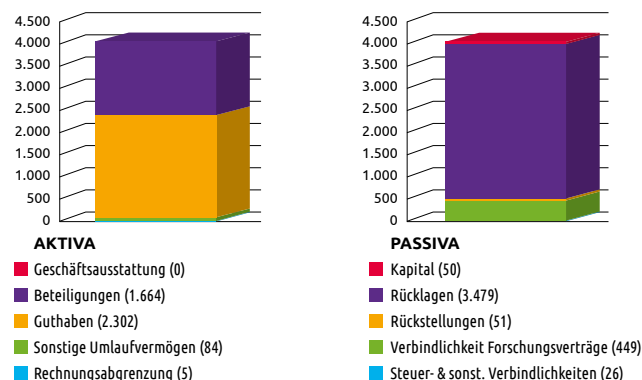
EINNAHMEN UND AUSGABEN 2023

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in Tsd.-Euro



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!

This year we have once again received fantastic support from so many people, organisations and companies. **THANK YOU** to all the donors, supporters and volunteers who make our work possible. You achieve so much good with your help! The following are just a few of them:



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Juliane Golbs, Jan Hähnlein, Edgar Itt, Jacqueline Pojer, Zodia Selele, Joss Stone, Jörg Vanden Berge: Thank you so much for your advocacy and tireless support!

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