

# The NCL Foundation

Research Funding Training Fundraising



# 2023 annual report

# Editorial



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**Jan Josef Liefers,**  
Patron  
of the NCL Foundation

*In August 2023 the 11th Eagles Thriller Cup was held in Münster. A wonderful gala evening was followed by a successful golf tournament for fantastic people who have been supporting the NCL Foundation for many years now. Together we raised donations totalling more than 140 000 euros for the NCL Foundation. We would like to take this opportunity to thank all the donors again for their amazing generosity. Without this money it would not be possible to fund NCL research projects.*

*In 2022, for example, the proceeds of the Thriller Cup were used to help fund a research project headed by Professor Monther Abu-Remaileh in Stanford, USA. The NCL Foundation has been supporting his laboratory since 2018. This year Professor Abu-Remaileh published a paper on another scientific breakthrough. Researchers have finally discovered the enzyme which produces the BMP lipid in the lysosome - the CLNS5 protein. Faulty regulation of this process not only plays an important role in NCL but probably also in senile dementia. This is a groundbreaking development for research, offering promising possibilities for new therapeutic approaches to neurodegenerative diseases. Another milestone in NCL research!*

*The proceeds of the 11th Thriller Cup will also be invested in research into NCL. Because we can see that research funding is worthwhile and results in progress. That is why it continues to be so important that we collect money; make contacts; find and retain supporters and, most of all, talk about and publicise the Foundation and its work. Get involved!*

*Together we can keep working towards our goal - a future without childhood dementia!*

**Yours**

**Jan Josef Liefers**

*Titel:*

*Top left: see P.5 | Top right: Jan Josef Liefers, Anna Loos and Werner Schulze-Erdel at the Thriller Cup | Bottom left: see P.6 | Bottom right: Medal of Merit award ceremony, from the left: President Jens Niewöhner and Founding President Benedikt J. Gellrich (Schnelldorf LC), Frank Husemann and Frank Stehr (NCL Foundation). © LC Schnelldorf*



© Ein Herz für Kinder

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

*We have been on our journey for 21 years now. As the Foundation's founder I often ask myself whether we are doing enough; when we will finally reach our goal and whether we can be satisfied with what we have achieved up until now. The answers to these questions are not as clear-cut as you would think. Particularly if the person who has to give them is the father of a brave boy who lost his daily struggle against NCL last year. Tim has gone to a better place. Countless other children still have this difficult path ahead of them. A path which deserves the greatest respect, every single day. Making sure that other children don't have to travel this path is what keeps me motivated.*

*When viewed in these terms, this year has been like all the others before it - we have not achieved enough. But I too have had to learn not to measure the progress made by therapeutic research and its success by whether or not a treatment has been developed. The road we have to travel to get there is difficult, undefined and long.*

*Nevertheless, in 2023 there was some impressive progress. Not only because we made a constructive contribution towards promoting dialogue in research institutions and hospitals; were active participants at congresses and lectures; were honoured to accept awards and donations; and were able to organise a diverse range of events or be the charity which they supported. These are all things which make us proud and happy. But the best thing about 2023 was the developments which the researchers made. Special highlights were the identification of the function of an NCL protein and an improved description of the aspects which overlap with senile dementia.*

*All of this was only possible because of great team work. I would therefore like to take this opportunity to say a very special thank you to all the researchers & doctors; donors & sponsors; ambassadors & trustees; employees & volunteers; multipliers & networkers and all the other helpers for their commitment to our cause.*

*Research into childhood dementia will have a successful outcome. But to get there we must remain optimistic, motivated and have just a little bit of luck. The luckier we are, the sooner I will be able to cut my greetings down to one simple phrase: "Mission accomplished". How wonderful that would be.*

**Yours**

**Frank Husemann**

# International NCL Congress in Hamburg 2023



## 18TH INTERNATIONAL CONGRESS ON NEURONAL CEROID LIPOFUSCINOSES

SEPTEMBER 26 – 30, 2023  
HAMBURG, GERMANY

### MAJOR ADVANCES IN RESEARCH & CLINICAL DEVELOPMENT AND THE ESTABLISHMENT OF CLOSE TIES

In 2023 the focus of NCL research, clinical progress and global patient groups was on **Hamburg**.

From 26 to 30 September the **18th International NCL Congress** on Neuronal Ceroid Lipofuscinoses (NCL) was held at the Bucerius Law School in Hamburg. It was organised by Dr. Angela Schulz and her team at the University Medical Centre Hamburg-Eppendorf (UKE Hamburg). The conference covered all the forms of NCL, focusing on genetics and biology; disease models and mechanisms; biomarker discoveries and omics<sup>1</sup> approaches; and translational preclinical and clinical research.

There was a remarkably large number of lectures on **CLN3**. Two of the keynote lectures were given by researchers who are funded by the NCL Foundation. **Alessia Calcagni** demonstrated how the loss of CLN3 results in a malfunction of important proteins and disruption of autophagic lysosome reformation. **Monther Abu-Remaileh** presented another breakthrough in NCL research regarding the role played by CLN5 (see P.4).

Overall the NCL field is making fantastic progress, both in the preclinical and the clinical areas. The latest announcements regarding a Phase III study examining the efficacy of the drug **Miglustat** for the **CLN3 disease** and a **CLN5 genetic therapy study** are just two examples.

In addition to this, in cooperation with the BDSRA\* and the UKE we organised a meeting of the **NCL Global Patient Group**, with participants from NCL foundations and patient organisations

around the world. They included the BDFA\* (UK), BDSRA (USA & AU), Stichting Beat Batten! (NL), BBDF\* (USA), ForeBatten Foundation (USA), Bobby and Robine Foundation (NL), NCL Gruppe Deutschland (DE), NCL Group Finland (FI) and NCL Denmark (DK). Its purpose was to enable the participants to get to know each other and discuss options for collaboration. Following this, the directors of the patient groups took part in a round table with industry representatives (BioMarin, JCR Pharmaceuticals, Neurogene, Regenxbio, Theranexus and UT Southwestern).

The development of a **network** for all stakeholders in the NCL field is essential because we can only win the fight against childhood dementia if we work together. We were pleased that this event resulted in so many close partnerships and personal meetings!

Read about our **9th Young Scientists' Meeting** in Hamburg, held before the International NCL Congress, on P. 5.



*Participants at the NCL Global Patient Group meeting in Hamburg - from the left: Ronald Jansen, Chair of Stichting Beat Batten!, NL, Frank Stehr and Herman van der Putten of the NCL Foundation and Addy Rouwenhorst, board member of Beat Batten!*

<sup>1</sup>Technologies for integrated analysis of biological samples (e.g. genomics for the overall genome, proteomics for the complement of proteins, etc.)

\*BDSRA: Batten Disease Support and Research Association; BDFA: Batten Disease Family Association; BBDF: Beyond Batten Disease Foundation

## Function of the CLN3 protein decoded

### PROF. MONTHER ABU-REMAILEH AND HIS TEAM MAKE ANOTHER SCIENTIFIC BREAKTHROUGH!

Last year Monther Abu-Remaileh's working group at Stanford University, USA, was able to demonstrate for the first time that the **CLN3 protein** is required for the lysosomal clearance of **glycerophosphodiesterases, GPDs**, (published in a "Nature" article). This was a ground-breaking insight which helped to better understand how the juvenile NCL (CLN3) disease mechanism works.

The group has now discovered that the previously unknown gene product **CLN5** is the lysosomal **bis(monoacylglycero) phosphate (BMP) synthase**. The CLN5 disease is a form of late infantile NCL which commences sometime between the sufferer's third and fifth birthdays. The finding was published in the prestigious journal "Science" in September 2023, with PhD student **Uche Medoh** cited as the lead author.

Background information: It is known that many so-called **lysosomal storage disorders** such as NCL are caused by a specific genetic mutation, for example in the CLN3 or CLN5 gene. This genetic information includes instructions for the production of a protein (CLN3 or CLN5 protein) which is contained in the lysosome. Scientists have not yet been able to discover what the function of this protein is in healthy people and why the mutation results in many of these disorders.

After clarifying the function of CLN3, the team has now been able to demonstrate that **CLN5** drives a key step in the synthesis of the lipid molecule bis(monoacylglycero)phosphate (BMP). BMP is an important regulator of the lysosomal function and plays a role in a series of neurodegenerative disorders in which the BMP level is disrupted. Up until now, how and where the cell produces BMP was a complete mystery. The discovery of the CLN5 protein's function has now revealed this secret.

Following the identification of the protein which creates BMP, it will now be possible for scientists to develop new types of **active agents** to boost the protein's activity, in turn increasing the level of BMP. This could have a positive impact on both **rare** and also **common neurodegenerative diseases**.

**Congratulations** to Uche Medoh, Monther Abu-Remaileh and the entire team! We are once again highly impressed by their work and are pleased to be one of Monther's funding partners.



Prof. Monther Abu-Remaileh (left) and Uche Medoh

## NCL Research Prize awarded



Dr. Alessandro Ori and Dr. Julia C. Heiby, the winners of the 13th NCL Research Prize

### DR. ALESSANDRO ORI AND DR. JULIA C. HEIBY, THE WINNERS OF THE 13TH NCL RESEARCH PRIZE

Alessandro and Julia work at the Leibniz Institute on Aging - Fritz Lipmann Institute in Jena, Germany.

The **NCL Research Prize**, which is endowed with EUR 50 000, is the highest monetary award in the field of NCL childhood dementia. By awarding this prize, our scientific advisory board is honouring an innovative research idea which contributes to a better understanding of CLN3's role and the CLN3 disease, making it possible to develop treatments.

Alessandro and Julia's prize-winning project is entitled "**Targeting alterations of**

**the lysosomal proteome in NCL**". Their objective is to reproduce lysosomal "omics" changes in a suitable *in vitro* cell model. When doing so, a particular focus will be on proteomic changes which are observed *in vivo* in CLN3 lysosomes in order to test therapeutic approaches. The prize money will help fund Julia's post-doc work within Alessandro's working group in Jena.

**Congratulations** to our winners! We wish you much success in your endeavours!

A big thank you goes to **Joachim Herz Stiftung**, which has sponsored our NCL Research Prize again.

# 9th JNCL Young Investigator Symposium in Hamburg



The participants at the 9th JNCL Young Investigator Symposium in Hamburg in 2023

## STIMULATING LECTURES AND LIVELY DISCUSSIONS

Thanks to the generous support of **sponsors** such as Stiftung Bostelmann (DE), Stichting Beat Batten! (NL), Hamburg Marriott Hotel, Theranexus (FR), ForeBatten Foundation (USA), Inner Wheel Club Tecklenburger Land (DE), Friends of Britain e.V. (DE), Lions Club Deidesheim Mittlere Weinstraße (DE), Reinhard Frank-Stiftung (DE) and Contactpunt NCL (BE) we were able to host the **9th JNCL Young Investigator Symposium**, held at the **Hamburg Marriott Hotel** on 24/25 September 2023.

At the symposium 24 young researchers presented their work, which covers a broad spectrum of **CLN3 research topics**. These include protein structure; protein-protein interactions; the function of CLN3; lysosomal metabolic defects which are associated with a CLN3 deficiency; synaptic biology; the function of microglia and the function of CLN3 in organs outside the nervous system. Other topics are zebrafish and minipig models;

the discovery of biomarkers and also phenotypical approaches to aid the discovery of new therapeutic goals as well as the use of antisense oligonucleotides to treat the CLN3 disease.

**Dominic Winter** (University of Bonn, DE) and **Rebecca Ahrens-Nicklas** (University of Pennsylvania, USA) were the plenary speakers. Dominic provided an overview of the mass spectrometry-based technologies used to characterise the lysosomal proteome, while Rebecca outlined the challenges and options associated with the development of treatments for the CLN3 disease.

In summary, it can be said that **major advances** have recently been made in understanding the fundamentals of the CLN3 disease. We are optimistic that lysosomal omics and translational approaches will provide us with better options to modify the disease and treat patients.



Lively discussions at the Young Investigator Symposium



Focused work but still lots of fun at the communal cookery event

# Projects currently being funded around the world

## THREE NEW RESEARCH PROJECTS WERE STARTED

We are pleased that this year, in addition to Alessandro Ori and Julia C. Heiby's NCL Research Prize-winning project, three more new research projects were started.

**Prof. Monther Abu-Remaileh's** new project at Stanford University, USA builds on previous discoveries and is entitled "Glycerophosphodiesterases (GPDs) in NCL: From High Throughput Detection Assays to their Role in the Pathology of Diseases". Monther and his team were the first to demonstrate that loss of CLN3 results in a massive, pathological accumulation of GPDs in the lysosome. The team would now 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 GPDs in the disruption of the lysosomal phospholipid metabolism. In addition to this, the laboratory wants to develop high throughput assays and new ways to reduce lysosomal GPD levels, with the goal of restoring lysosomal homeostasis as possible new therapeutic approach to CLN3. Thank you to our partners **Stichting Beat Batten!** in the Netherlands; **ContactPunt NCL** in Belgium and **W. u. R. Hauschildt Stiftung** and **Bijou Brigitte Stiftung** in Germany for their generous co-financing of the project.



*Prof. Monther Abu-Remaileh of Stanford University, USA. He was the winner of our 10th NCL Research Prize in 2020*

A second project is being carried out by **Prof. Diego Luis Medina** and PhD student **Dr. Claudia La Vecchia** at the Telethon Institute of Genetics and Medicine (TIGEM) in Pozzuoli, Italy. The title of the new two-year research project is "Preclinical approaches to determine efficacy of correctors of NCL". The team's objective is to investigate the efficacy of various medications at the lysosomal metabolome and proteome levels. This will hopefully enable them to provide more effective predictions regarding which therapeutic agents will, in the final instance, be most effective when treating CLN3 patients. A further focus will be on identifying suitable biomarkers to promote the clinical development of medications. A big thank you goes to our supporter **Edith Waschneck**, whose generous donation has made funding of this important project possible (see also P. 13).



*Dr. Claudia La Vecchia and Prof. Diego Luis Medina. Diego Luis Medina won our 12th NCL Research Prize last year*

The third new project which we are funding supports work by **Dr. Angela Schulz** of the University Medical Centre Hamburg-Eppendorf (UKE) in collaboration with **Dr. Esther Sammler** of the MRC Protein Phosphorylation and Ubiquitylation Unit at the University of Dundee, UK. 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 the CLN3 disease in order to identify disease-specific biomarkers. The UKE will carry out the isolation of lysosomal organelles from fresh peripheral white blood cells obtained from CLN3 patients' blood samples. The samples will then be frozen and stored at -80 Grad centigrade until they are sent to the University of Dundee. Some of the multi-omics analyses will be carried out in Dundee, while Prof. Abu-Remaileh's laboratory at Stanford University will study others. The project's funding partners are **Adalbert Zajadacz Stiftung** and **Helga und Alfred Buchwald-Stiftung**. Thank you so much!



*Dr. Esther Sammler, University of Dundee, UK (left) and Dr. Angela Schulz, Director of University Medical Centre Hamburg-Eppendorf's (UKE) special NCL consultation clinic*

In addition to this, our research work has received generous support from **IQVIA Commercial** and **Lieselotte-Paulsen-Stiftung**.



**Prof. Diego Luis Medina**

**Project:** Diego is examining the therapeutic potential of genes which could prevent the formation of pathological cell deposits in juvenile NCL sufferers and/or break down these deposits. This work has identified new, potential drug targets.

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

**Funding partner:** Joachim Herz Stiftung.



**Prof. Alessia Calcagni**

**Project:** Alessia is examining the influence of so-called microglia on the pathogenesis of NCL. She would like to clarify whether this influence plays an indirect role in neurodegeneration or the microglia actively contribute to the pathogenicity of the disease.

**Institution:** Baylor College of Medicine in Houston, Texas, USA.

**Funding partner:** Werner Reichenberger Stiftung.



**Prof. Christian Grimm**

**Project:** This project is examining the neuronal lipid profile of so-called induced pluripotent stem cells (iPSCs) which have been derived from neurons. These iPSCs contain various CLN3 mutations. The analysis is being carried out in cooperation with Prof. Martin Giera at Leiden University Medical Center, NL.

**Institution:** Ludwig-Maximilian University, Munich, Germany.

**Funding partner:** Reinhard Frank-Stiftung.



**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:** Contactpnt NCL, Eurofins Foundation, Reinhard-Frank-Stiftung.



**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 Grünwald (University Medical Centre Mainz).

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



**Sukanya Arcot Kannabiran**

**Project:** Lysosomal calcium ion channels play an important role in the incidence of CLN3. Sukanya is using high resolution imaging techniques to identify changes in the ion channel function at the microdomain level. Her findings could also be important for senile dementia.

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

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

## Other interesting conferences...

### MEETING OF NCL EXPERTS AT THE GORDON RESEARCH CONFERENCE

While attending the 2023 Gordon Research Conference on Lysosomal Storage Disorders (LSD) in Barcelona in May, our managing director **Dr. Frank Stehr** and our research director **Dr. Herman van der Putten** had discussions with NCL and LSD researchers which were aimed at strengthening the exchange of scientific information within the scope of a face-to-face meeting. The conference focused on the latest findings on the fundamental function of lysosomes and questions relating to how their function is impaired by lysosomal disorders such as NCL and how the findings can be more widely applied in biology and medicine. Frank and Herman also talked to **Dr. Ineka Whiteman**, Head of Research and Medical Affairs at the Batten Disease Support & Research Association (BDSRA), USA, and **Dr. Angela Schulz** of the UKE in Hamburg, Germany.

### DUTCH ANTISENSE THERAPEUTICS SYMPOSIUM

**Herman van der Putten** took part in the 2nd Dutch Symposium for Antisense Therapeutic Agents (DATS) in Nijmegen, which was devoted to the use of **antisense oligonucleotide (ASO) therapies** in the medical field – also a significant approach for NCL. Correspondingly, efforts to obtain further validation of ASO-based therapy approaches to CLN3 and, in the best case, to develop such approaches are continuing. This also includes the so-called “exon skipping” approach, which hopes to generate a protein which is at least partially functional and can restore the CLN3 function in the lysosome.



*Meeting of experts at the Gordon Research Conference (from the left): Dr. Herman van der Putten, Prof. Monther Abu-Ramaileh, Dr. Frank Stehr*

## ... and significant publications

### WE HAVE FUNDED THE FOLLOWING SCIENTISTS:

**Alessia Calcagni et al.** were able to demonstrate that CLN3 is a vesicular transport hub which connects the Golgi and lysosome cell compartments. +++ **An N. Dang Do et al.** used proteomic analysis of cerebrospinal fluid to identify known and unknown biomarker candidates (winner of the 11th NCL Research Prize in 2021). +++ **Daniela Wünkhaus et al.** reported that activation of the TRPML1 ion channel ameliorates certain lysosomal storage phenotypes in CLN3-deficient retinal pigment epithelial cells. +++ **Relton et al.** demonstrated that the absence of CLN3 is associated with an altered metabolic profile, reduced global translation and altered stress signalling.

### CLINICAL DEVELOPMENT HIGHLIGHTS:

**Hahn et al.** reported on an encouraging clinical compassionate trial which tested an enzyme replacement therapy on a CLN1 sufferer (see also P.9 of this annual report). +++ **Theranexus** reported encouraging preliminary 6-month results in their Phase-I/II study of Batten-1 (Miglustat). +++ The official report and outcome of the **Amicus Therapeutics** CLN3 gene therapy trial (AT-GTX-502 AAV9-gene therapy) are still awaited. +++ A Phase I/II CLN7 gene therapy trial is underway at the **University of Texas Southwestern Medical Center**. +++ **Neurogene** is collaborating with two clinical centres to enrol CLN5 patients to participate in an experimental gene therapy trial with NGN-101.



*Dr. An Dang Do with Dr. Herman van der Putten (left) and Dr. Frank Stehr at the presentation of the 11th NCL Research Prize certificate*



# Living with NCL: Johannes' story

## FIRST INDIVIDUAL CLINICAL COMPASSIONATE TRIAL FOR CLN1

**Johannes was born on 18 May 2016. He was a happy, loving child who developed quickly. At a just a few weeks old he could already hold his bottle and the family often joked that he would start talking by the time he was 6 months old. But things turned out very differently... .**

At 18 months Johannes was suddenly no longer able to stand or sit; he kept dropping things; continually rubbed his eyes and stopped laughing. The parents were very concerned, but their paediatrician kept reassuring them that everything was alright. A series of tests at a large clinic also failed to produce any results. A relief!

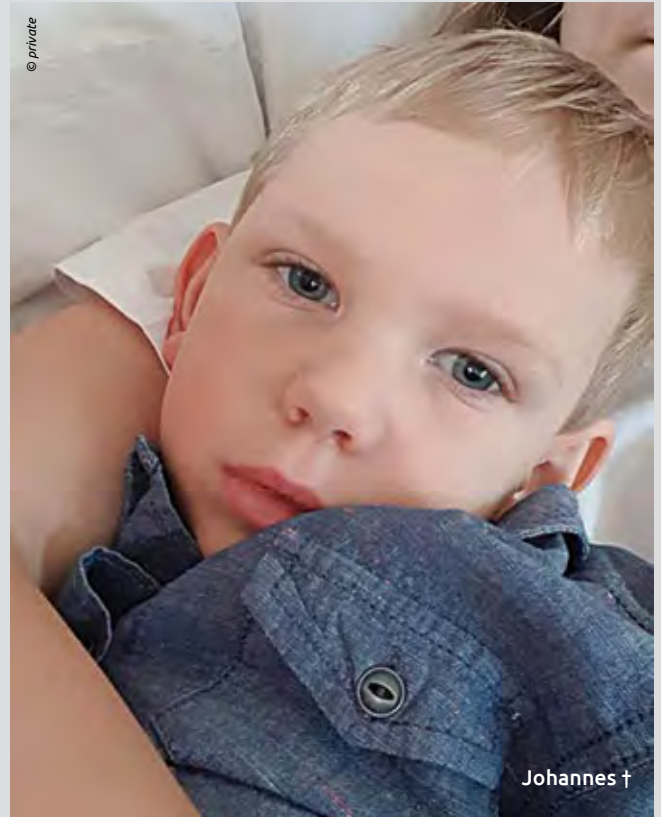
Despite receiving extensive physiotherapy, Johannes stopped developing. Six months later the entire series of tests was repeated. The findings? Atrophy of the brain, in other words, loss of brain matter. Doctors told the parents, "Take your child home. We don't know what his illness is yet, but he will die young." The diagnosis of infantile NCL, CLN1 was faxed to them on a Friday afternoon. After searching the Internet the parents knew that CLN1 was incurable, resulting in death within just a few years.

They went into shock. Johannes' mother, herself from the scientific field, resigned from her job to devote herself exclusively to her child and his CLN1 disease. What she did:

- Founded a CLN1 Facebook group (currently with 114 members worldwide)
- Researched specialist literature, compiled lists of all CLN1 studies and publications
- Established contacts with all researchers and companies
- Attended the 2018 International NCL Congress in London and had numerous meetings and discussions. What did she learn? That there an active substance which was a candidate for an enzyme therapy existed and was being stored at sub-zero temperatures by an American pharmaceuticals company.

After many phases of despair and fear for Johannes' life, for the first time the parents had a sliver of hope.

Months of negotiations and legal clarification began. Then the decision. The active substance candidate would be made available for a clinical compassionate trial if a doctor could be found to conduct it. The family contacted 900 addresses, at locations from Israel to Hawaii. Clinics in many countries gave them appointments for an examination and they received hundreds of rejections.



But finally the mother found someone. Professor Andreas Hahn at Gießen University Medical Centre, Germany was willing to carry out the clinical compassionate trial. The infusion therapies commenced in mid-2019. Johannes' condition stabilised.

In February 2023 Prof. Hahn presented the promising results of the treatment at the congress for lysosomal storage diseases in Orlando. Parallel to this, the mother was able to obtain research funding for further development. Another major step.

Two weeks later, on 10 March 2023, Johannes passed away from the effects of severe influenza.

His mother is continuing to devote all her energy to further development of this promising medication. For the other children who are suffering from CLN1 and also so that Johannes and his achievements will not be forgotten.

Scan the QR code to read the publication by Professor Andreas Hahn et al. Hahn A. et al. Treatment of CLN1 disease with a blood-brain barrier penetrating lysosomal enzyme. Mol Genet Metab Rep. 2022 Oct 26;33:100930.



# Expanding education on NCL

## NEW OFFERINGS FOR DOCTORS

In addition to our existing **training courses for doctors** on NCL pathology and NCL diagnosis, we are now also able to offer a further webinar-based course for doctors and medical professionals.

It takes the form of a short, compact lecture including presentation slides which give an update on NCL pathology in just a few minutes. The webinar is entitled “**SummedUp**” and can be accessed by registered users, also in Austria and Switzerland, on demand in the media library of the FOMF (Forum für medizinische Fortbildung).

Our managing director, Dr. Frank Stehr, is the course instructor. His presentation provides a summary of NCL pathology; explains the clinical symptoms and provides information on the diagnosis and treatment of the illness.

His **take home message** for doctors?

“If at least two of the following symptoms present together, then please consider the possibility of an NCL disorder:

- Loss of vision,
- Delayed speech development,
- Developmental regression (incl. dementia),
- Epilepsy.”

Many thanks to the **FOMF** for giving us the opportunity to continue expanding education on NCL!



This year we also expanded education on NCL for **school doctors** because the initial symptoms of the most common form of the NCL disorder, juvenile NCL (CLN3), present in primary school children. We were thus able to distribute our **NCL factsheet** for school doctors at the annual congress of the German Association of Public Health Service Doctors, which took place in Potsdam in April and had over 700 delegates. Furthermore, we also contacted over 80% of all German public health authorities and sent them information material.

We are also pleased that our managing director, Dr. Frank Stehr, had the opportunity to present the pathology of NCL juvenile dementia at this year’s **annual convention of the North German Society for Paediatrics (NDGKJ)** in Cottbus in June. The convention’s practically oriented programme is aimed at doctors working in surgeries and hospitals; further training assistants and therapists & nursing personnel – all important target groups for us. The lecture “NCL juvenile dementia – a genetic lysosomal storage disease” focused on diagnostic opportunities.

In November we also offered a series of lectures on NCL given by recognised experts at the **annual convention of the Society for Neuropaediatrics** in Dortmund, which were well attended.



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We have also continued to provide doctors’ offices and clinics with children’s books by authors **Heiko Baumann** (“Hummel Holly”) and **Jando** (“Sternenreiter”).

**A big thank you to our sponsors for the funding which they gave:**

amedes  
 Böttcher-Stiftung  
 Fresenius Kabi  
 Herbert Feuchte Stiftungsverbund  
 intermedix  
 Lions Club Gladbeck  
 Lions Club Grevenbroich  
 Rentschler Biopharma  
 Rotary Club Ganderkesee  
 Staack Pooltankstellen  
 Town & Country Stiftung  
 Werner Tiernahrung

*“I would like to tell you how grateful I am. Years ago my school, Matthias-Claudius-Gymnasium, had a learning partnership with your foundation. It reinforced my decision to go to university and become a researcher. I am now in Finland, where I am working on my master’s thesis in a work group which focuses on paediatric neurology. One of the projects which I am currently involved with includes the characterisation of a mouse model for an NCL subtype. So I have come full circle. Once again, many thanks!”*

*Jessica M.*

### NEW OFFERINGS FOR SCHOOL PUPILS AND TEACHERS

We also continued to make offerings for **schools** and the **general public** and were able to expand these activities. For example, for the first time we awarded our **Special Prize for Rare Diseases** at the Hamburg-Eppendorf regional heat of the **Jugend forscht** (Young researchers) national competition. The winner was 18-year old **Julia Chen**, a student at Helene-Lange-Gymnasium school in Hamburg. Her project involved testing options for an alternative treatment approach to skin disorders, which could also be relevant for rare diseases. Congratulations, Julia!

We are also very delighted that, in addition to the MINTarium in Hamburg and the Glass Lab in Berlin, our **PCR genetic diagnosis course** is now available at a further students’ lab. As of this school year (2023/2024), it is now also included in the programme offered by the **B!Lab, the biology lab in Brakel**, North Rhine-Westphalia. A big thank you to the lab’s director, Petra Schröder, for her support!

In addition to this, we were able to offer a **teachers’ training course** on PCR genetic diagnosis. Our lecturer Stine Behrmann ran the course at the Berlin/Brandenburg Regional Convention for MINT teachers and took this opportunity to promote our comprehensive programme for schools.

We also have a brand new offering for **primary schools**. They can borrow one of our so-called **inclusion boxes** which aim to educate younger children about rare diseases, such as NCL. Among other things, the boxes include books, information and illustrative material, with the opportunity for the students to try out things for themselves. The boxes are available from our foundation office in Hamburg as well as at ten further locations in Germany and two locations in Austria. The inclusion boxes were the idea of the Syngap Elternhilfe e. V. charity. A wide range of associations and organisations which are active in the field of rare diseases, are involved in this activity.

In June we again participated in the **Long Night of Science** in Berlin with an information stand and a quiz. In addition to this, our cooperation partner, the Glass Lab at the Campus Berlin-Buch science and biotech park, offered workshops on the topic “How is a rare genetic disorder diagnosed?”, at which we were able to tell participants about NCL childhood dementia. Throughout the event, all the “knowledge stations” had a large number of visitors, who were very interested in our work for a future without childhood dementia!

To mark this year’s **World Alzheimer’s Day**, 21 September, we opened our new **Hands-on Lab** at the Hamburg MINTarium. We invited 15 well-known Hamburg personalities who are associated with the foundation and support our vision of a future without childhood dementia to spend two hours carrying out experiments at the lab and get a feel for how science works. A special highlight was the presence of Hamburg’s State Councillor for the Ministry of Science, Research, Equality and the Districts of the City of Hamburg, Dr. Eva Gumbel, who gave a welcoming speech. In future we plan to offer a hands-on lab for interested members of the public several times a year.



*Julia Chen, winner of the NCL Special Prize at Jugend forscht in Hamburg*



*Greeted guests at the new NCL Hands-On lab at the MINTarium Hamburg: Heidi Schäfer (left), MINTarium, Dr. Eva Gumbel, State Councillor for the Ministry of Science, Research, Equality and Districts of the City of Hamburg, and Dr. Frank Stehr, managing director of the NCL Foundation*

# Our 2023 highlights



We had an eventful year, with many diverse, large and small events; cheque presentations; awards and more fantastic activities organised by active supporters who helped us. We are pleased to be able to provide this overview of our fundraising year 2023.

## JANUARY

The Foundation's new year got off to a good start and we were visited by the President of **Lions Club Großhansdorf**, who gave us a donation cheque.

## FEBRUARY

We were presented with a cheque for 2 000 euros at the **International School of Hamburg's** morning assembly. **1 Student Anna-Mara hands over the cheque to Dr. Frank Stehr**

On 28 February, **Rare Disease Day**, we launched our **2 "Selten im Blick" (Rarely seen) social media campaign**. Among other things, we gave information about the Foundation, research and how NCL is diagnosed. In addition to this, we again also auctioned off a whole load of amazing items via the **United Charity** portal.

## MARCH

Following the end of the pandemic, the **Lions Club Kassel-Brüder Grimm** booster club relaunched its charity dinner, the Brothers Grimm Meal. This wonderful evening was attended by 120 guests and generated a total of 10 000 euros in donations for us.

At the 4th **R+V ESports Support Marathon #Assists4Charity** players won 2 500 euros for us. Participants playing the League of Legends game had to collect as many assists as possible.

## APRIL

This year our **ambassador Jan Hähnlein** once again set records to raise money for us, even achieving two in one weekend! He was awarded the first world record for **"The greatest distance cycled on a bike roller in 24 hours using a 20 inch folding bike"**. Jan achieved an impressive 374.4 kilometres. The second was for **"The longest row of MIFA GDR folding bikes"**. Comprising 368 people and bikes, the line up of folding bikes was incredibly long. These activities raised a total of EUR 6 548.80 for the Foundation. **3 From the left World record holder Jan Hähnlein with mascot and former centre manager Agâh Schaumburg**

As part of the **2023 Rarities for Charity** event at the **"Whisky Fair Limburg"**, **Gérad Hofmann** organised a whisky tasting to raise money for the Foundation.

Employees at the **DAK-Gesundheit** health insurance company donated the spare cents after the decimal point of their monthly salaries to us. The **"Nullkommaviel – Spende deinen Cent" spare cents fund-raising campaign** generated EUR 2 187.09.

## MAY

As was also the case in previous years, we were given the opportunity to organise a tombola at the **Round Table 169 Hamburg-Hafen spring party** while also enjoying a wonderful evening by the Alster lake.

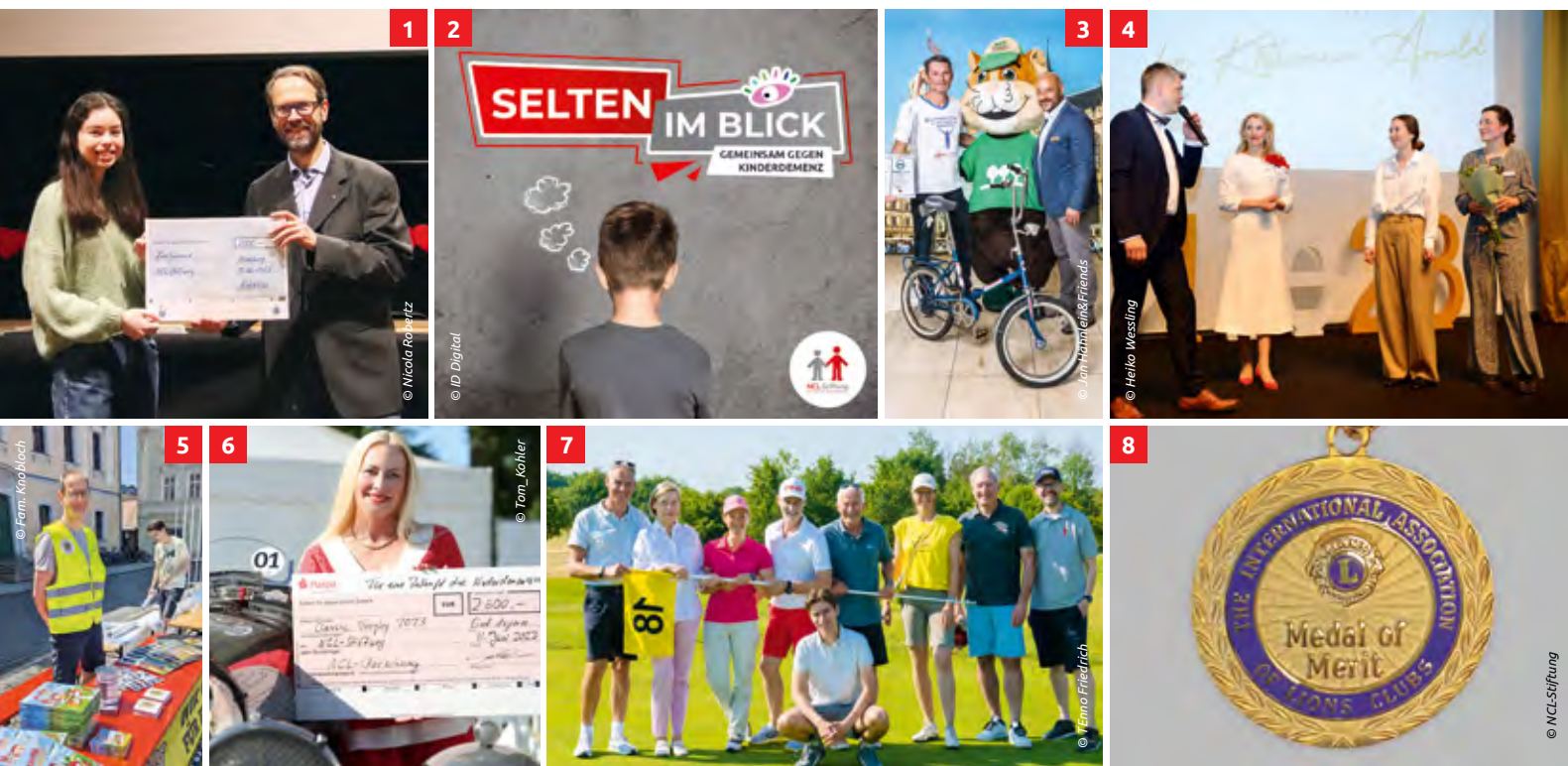
**Katharina Arnold** organised the **Inspire23 networking event** in Hamburg. It was attended by 150 businesswomen who enjoyed interesting talks, top-class fashion shows and inspirational dancing. We ran a tombola and received a cheque for over EUR 2 400. **4 On the Inspire23 stage, from the left Prof. Dr. Stephan Buchhester, Katharina Arnold, Carolin Kirchmann and Eva Wolfram**

## JUNE

The **Knobloch family** manned our information stand at the **19th Rainbow Tour** and advertised the charity march. Tour participants cycled from Gotha to Weimar via Erfurt. **5 Dr. Karsten Knobloch at the NCL information stand**

The **Classic Trophy** included a visit to a polo tournament at Gut Aspern. Our **ambassador Jacqueline Pojer** kept the trophy company over the weekend and we ran a tombola stand. We also admired the gleaming classic cars and cheered on the polo players. **6 Jaqueline Pojer at the Classic Trophy**

In June our **17th NCL Golf Trophy** tournament was held at the beautiful **Castanea Golf Resort** in Adendorf. Over 100 golf enthusiasts and prominent guests came together on the greens. The sold-out tombola and a number of cheque presentations ensured that we collected a record-breaking amount of donations. **7 From the left Dr. Frank Husemann, Marion groß Osterhues, Anjorka Strechel, Simon Licht, Gerry Hungbauer, Katrin Wrobel, Dr. Martin Wilhelm, Dr. Frank Stehr, in the front: Leopold Hungbauer**



**Lions Club Schnelldorf** honoured our Foundation founder **Dr. Frank Husemann** and the **NCL Foundation** with the **“Medal of Merit”** **8**. The “Medal of Merit” is the highest award which the Lions Club International can give to non-members. It recognises outstanding work in the humanitarian field and exemplary public conduct.

The **2023 HEROS charity march** in Frömmstedt, Thuringia, organised by our **ambassador Jan Hähnlein** and numerous supporters, was another great success! With **750 registrations**, this year’s march set a new record. Both the 8-km and 25-km distances were sold out and there were also plenty of participants for the 50 km distance. **9** *The team of helpers did a fantastic job!*

The **CRIF GmbH summer party**, held at Hamburg Beach Club, included a tombola to raise money for our Foundation. Around 230 employees from all over Germany enjoyed the event.

Within the scope of our cooperation with **Gymnasium Corveystraße** in Hamburg, students in Carsten Altmann’s biology class organised a **flea market**. The items sold plus donations raised a total of EUR 325.45.

**Dirk Beyer** set another **golfing world record** at Weidenhof Golf Club in Pinneberg. He played **716 holes** on the short course; walked 83 kilometres while doing so and collected over EUR 7 800 in donations. **10** *Dirk Beyer with his world record certificate*

**JULY**

For many years now, we have been the “Spirit to Serve” partner of the **Hamburg Marriott Hotel**. This year the hotel once again organised the Hamburg Marriott DOM fair. We had another tombola at this event and enjoyed a wonderful evening at the hotel.

The **“Sunshine Band” at Gymnasium Hochrad** in Hamburg collected EUR 288.50 in donations for us on their tour to the island of Föhr.

During their project week, students on the **Biology A-Level course at Walddorfer Gymnasium school** in Hamburg initiated numerous amazing activities connected to NCL, while also raising donations at the same time.

Our supporter **Edith Waschneck** heard about NCL while watching TV and presented us with a cheque for 100 000 euros. This enabled us to start a **new research project**. **11** *From the left Dr. Frank Stehr, Edith Waschneck and Michael Schneider*

Following our **lecture at Lions Club Pfaffenhofen/Hallertau** we were presented with a donation of 11 111 euros. It also included contributions from the **three Lions Clubs in Ingolstadt**; the **Lions District** and **Rotary Club Pfaffenhofen**. In addition to this, we were also incorporated into the “Seltene Erkrankungen Bayern” (Rare Diseases in Bavaria) campaign. **12** *From the left Marcus Krauß (LC Ingolstadt & representative of the Lions Zone), Johannes Hofner (LC Pfaffenhofen/Hallertau), Tiziana Sandmaier (NCL Foundation), Nicola Struck (RC Pfaffenhofen), Verena Gutsche (LC Ingolstadt Hohe Schule ) and Uli Resch (LC Ingolstadt Auf der Schanz)*

**AUGUST**

At the end of his **“Sternenreiter” summer reading tour Jando** made a guest appearance at Wannsee lake in Berlin, giving a reading together with voice actor **Christopher Groß**. This wonderful evening was organised by presenter **Chrissy Schulz**, who also arranged an entertaining supporting programme with numerous well-known guests. **13** *From the left Alexandra Beyer, author Jando, Chrissy Schulz, Henriette Schneider, Christopher Groß*

For the **11th time** now, our **patron Jan Josef Liefers** and our **board of trustees member Werner Schulze-Erdel** issued a joint invitation to the **Münster Eagles Thriller Cup**. 250 guests attended the gala evening, which included a great entertainment programme; top-class auctions and a large tombola. The next day, 160 keen golfers teed off, enjoying an active day on the course. The total sum of donations was an amazing 140 000 euros - a new record! **14** *From the left Dr. Frank Husemann, Werner Schulze-Erdel and Jan Josef Liefers talking about NCL*

Real estate company **von Poll Immobilien GmbH** continued to provide generous support for our research work. **15** *Beata von Poll and Dr. Frank Stehr at the cheque presentation*

Our **ambassador Thorsten Schröder** was a contestant on the TV game show **“Gefragt - Gejagt”** and won some money for us.



**SEPTEMBER**

**Melissa Ortiz Gomez** organised another **charity event in Hamburg**, this time at a location by the Elbe river. It was presented by **Martin Rütter**, who also publicised the Foundation in a podcast. TV station RTL Nord accompanied the evening. The lively evening, which included entertainment interludes and a tombola, also provided us with an opportunity to tell the audience about the Foundation's work.

**16** Dr. Frank Stehr with Melissa Ortiz Gomez and Martin Rütter (right) at the charity event

We were the main charity partner of **Friends of Britain** at this year's **British Flair** fair at Gut Basthorst. We spent three exciting days surrounded by shiny classic cars; British lifestyle and a large tombola stand.

**17** *Bagpipe players*  
At the **6th KultVögel Ostalgietreffen**, a retro event dedicated to all things related to the former East Germany in Germendorf near Berlin, our Foundation was represented by a cheerful **Katrin Wrobel**, who accepted a cheque for 2 033 euros on our behalf.

**18** *Katrin Wrobel at the Ostalgietreffen event*  
A further highlight was the **14th Classic Car Festival**, organised by the **Old Table 300** in Hamburg's Randel Park. This was another chance to admire classic cars and buy tombola tickets. Our **board of trustees member Birgit Saatrübe** made an appearance on the stage for us, while **Marco Ostwald** was an excellent master of ceremonies for the day.

**19** *Impressive cars were on show at the Classic Car Festival*  
This year's Lünen **20 duck race**, run by the **Old Table 215**, was a great success again.

In Germany, 18 - 22 September was **Dementia Action Week**. Company **Wall GmbH** and bank **Sparda-Bank Hamburg** supported us with a **poster campaign** in Lübeck.

We took part in the **#bademantelchallenge** to raise awareness of dementia.

In addition to this, our **managing director Dr. Frank Stehr** attended the **Businessstalk am Ku'damm** event in Berlin, where the charming **Chrissy Schulz** did a long interview with him.

**21** *Dr. Frank Stehr (left), Chrissy Schulz and Johann Sternberg at the Businessstalk studio*  
The **Tech@Speed Charity Bike Tour** route took participants from **Munich to Lake Garda**. Six members of **Ernst & Young's Technology Consulting department** cycled 440 kilometres in 5 days, choosing us as their partner for donations.

**22** *The Tech@Speed Team with our volunteer supporter Benedikt Pfander*  
Following 8, 25 and 50 kilometre marches in June, in September the **HEROS 100** set off on their **charity march**. 22 participants tackled the 100 kilometres, once again raising many donations. **Jan Hähnlein** and his partner **Nicole** were among the successful finishers again! Respect! **23** *All the finishers were given a giant heart biscuit by Dr. Karsten Knobloch*

**OCTOBER**

Magazine "**Alnatura Magazin**" featured our foundation in its October edition, letting readers know that they could donate their **PAYBACK loyalty points** to us or give money via **betterplace.org**.

**NOVEMBER**

Hairdressing trade journal "**New Clips**" published an article about our **donations box** at **Olaf Köhler's salon** in Lüneburg.

**24** *Olaf Köhler collects donations for us at his salon*  
The creative minds at the **Jung von Matt Academy** put their heads together for us. The results should be on show next year.

Presenter and actor **Thomas Böttcher** welcomed our ambassador Jan Hähnlein to bakery chain **Ottendorfer Mühlenbäcker's** stollen cake festival.

Schlager music singer **Stefanie Hertel** asked for donations at the **Stage Entertainment** musical MAMMA MIA!

At the benefit sports quiz gala organised by **Right To Play** and **FC Bayern Basketball** Jan Josef Liefers autographed a lab coat which was later auctioned off to raise money for us.

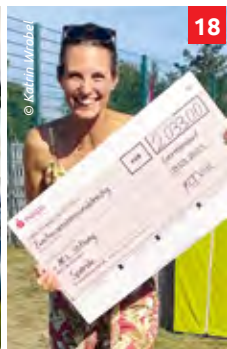
**DECEMBER**

Book store **Buchhandlung Stojan** in Großhansdorf and **Hubertus Meyer-Burckhardt** organised a **charity reading** to raise money for us. Cultural organisation **Kulturring Großhansdorf** and the **Lions Club Großhansdorf** also supported the event.

For the second year we were able to get involved with the fantastic **Christmas singing event in Jena** by running a tombola. The festive event was organised by **EAS Betriebsgesellschaft mbH**. A lovely way to end our year.

**26**  
Christmas is coming - board of trustees member **Hubert Neubacher** once again asked the audience at his **DinGeLing!** Christmas singing event to make donations.

**27**  
The supporters who provide us with a great deal of assistance include **Dental21 GmbH**, many of whose dental surgeries collect old dental gold for our benefit; our loyal partner the **Hamburg Marriot Hotel**, and the **EDEKA Jens Jänecke** supermarket in Adendorf, which has collected numerous refund receipts for deposit bottles to raise money for us. We are very grateful to you!



# The NCL Foundation team



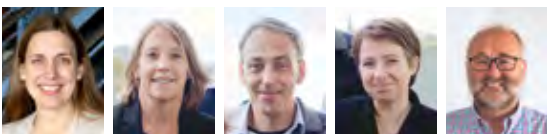
© Thomas Meyer

**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)



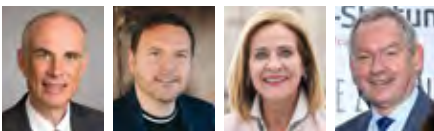
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**HONORARY FOUNDATION COUNCIL** (from the left): Dr. Frank Husemann (Chairman), Martin Hartleif (Finance), Alexander Rößler (Legal), Dr. Rainer Kuhn (Research)

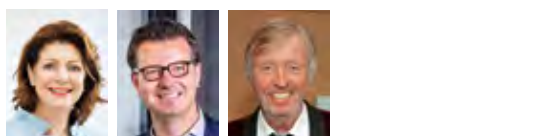


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**HONORARY SCIENTIFIC ADVISORY BOARD** (FROM THE LEFT): Dr. Rebecca Ahrens-Nicklas, Prof. Beverly Davidson, Prof. Robert Steinfeld, Dr. Angela Schulz, Dr. Graeme Bilbe



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

As of this year we are now a member of the German "National Dementia strategy" network. The organisation bundles the knowledge of numerous experts, bringing together many stakeholders in the field of dementia. Its goal is to improve the care given to dementia sufferers and their families, thus improving their quality of life.



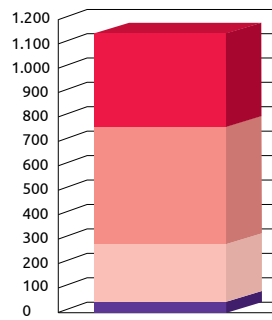
The NCL Foundation has held the DZI donation seal of approval since 2006. It is the seal of approval for legitimate charity organisations. It confirms that organisations handle the money entrusted to them carefully and responsibly.



Organisations with the seal voluntarily undertake to meet DZI standards, thus fulfilling the highest quality requirements.

## 2022 INCOME AND EXPENDITURE

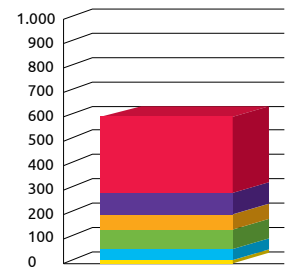
in '000 euros



### Income

#### Donations

- >EUR 10.000 (381)
- EUR 1.001 - 10.000 (480)
- <=EUR 1.000 (237)
- Events / Other donations (47)

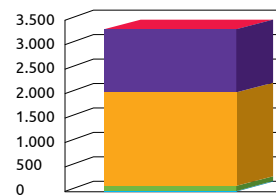


### Expenditure

- Research expenditure (311)
- Fundraising / Project management (88)
- Training (62)
- Events (80)
- Administration (45)
- Travel expenses (14)

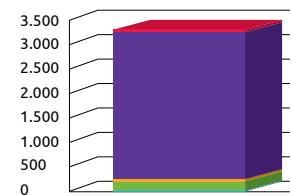
## 2022 BALANCE SHEET

in Tsd.-Euro



### ASSETS

- Office equipment (1)
- Bonds (1.289)
- Credit balance (1.914)
- Other current assets (108)
- Accruals and deferrals (5)



### LIABILITIES

- Capital (50)
- Contingencies (3.002)
- Reserves (50)
- Liabilities, research contracts (191)
- Tax liabilities (24)

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/](http://www.ncl-stiftung.de/wer-wir-sind/vertrauen/).

# Thank you!

We have received fantastic support from so many people, organisations and companies. We say **THANK YOU!** Thank you to all our **supporters, donors** and personal **advocates**. Thank you to everyone who does **volunteer work** for us! Without you our work would not be possible! Stay with us on our journey! For a future without childhood dementia! The following are just a few of them:



A.Behrens & G.Felsch | Abt Print & Medien | Ad Alliance | affinis | Akira Mmxx | Alarmzentrale Hamburg | Aldiana | Alex Diamond | Alison Fry | Alnatura Magazin | Alsterarkaden Apotheke | Andreas Überschär | Andreas Weische | Anja Reichert | Argentum | Art 28 | Art Consulting | ASB Sömmerda | Atelier Quer | Auktionshaus Kendzia | Bäckerei Bergmann & Sohn | Barkassen Meyer | BDN | Beate Döring | Benjamin Fazio | Benjamin Pichelmann | Benni Stark | Bentley Hamburg | Bernd Husemann | Bestattungen Spannuth | Beyond Knots | BMP Foliendesign | Body & Mind | Bohlsener Mühle | Bohrtechnik Schulze | BUDNI Filiale Dammtor | Bunny GmbH | Caffè Chicco d'Oro | Carlos Fernández Laser | Carsten Boerma | CCS Charity Conception Saatrübe | Christian Lohse | ChrisTine Urspruch | Claudia Beutner | clubtags | Comedia. IT | Constance Renken | Corvey Gymnasium | Christine Lieberknecht | Culture City Weimar | Dental21 | Der Bäcker Lampe | DesignQuartier Brandenburg | Deutsche Vermögensberatung Thomas Eggers | dlution | Dr. Hans-Georg Timmler | Dr. Katrin Schneider | Dr. Miriam Nickel | Dr. Natalie Vladi Achouri | EDEKA Jens Jänecke | EDEKA Struve | Edgar Itt | Eichhorn Solutions | Ellen Dinges-Dierig | Emotion Events | Ersä-Bau | Esther Lange | F1online digitale Bildagentur | Faktor Mensch | FC Augsburg 1907 | FC Carl Zeiss Jena | Feuerbestattungen Quedlinburg | Feuerbestattungen Stade | Fiete Deichgraph | Fit4fam | Foondiart | Formidable Hamburg | Freaks 4U Gaming | Freche Freunde | Fritz Vornbäumen | Fuchs Rohr Stiftung | Galerie Mensing | Gewohl | Gerhard Muggenburg Stiftung | Golf 1 Jan Götting | Golf Club Bad Saarow | GolfHouse | Golfino | Grafikwerkstatt | Greubener Salami | GSK Stockmann | Gymnasium Süderelbe | Hamburg Airport | Hannover Airport | Hartleif-Kimenkowski Steuerberater | Heidi Kronsbein | Heikotel | Helen und Lukas | Herzenssache | Hofsommer Berufsbekleidung | Hogan Lovells | holznamen Schild.de | iD Digital | IKK classic | Innenministerin Daniela Behrens | International Intax | Janbo Nörskau | Janine Reichert Weinberatung | Jens Binek | Jens-Christian Wittig | Jimdo | Jörg Vanden Berge | Jörg Zimmerling | Joss Stone Foundation | Jute statt Plastik | Kalfany Süße Werbung | Kappich und Piel | Kirsten Köhler | Klaus Tschira Stiftung | Kocher Großhandel Gissibl | Kosmetik am Theater | Krematorium Wiesbaden am Südfriedhof | Krischan Kuberzig | Kruse Der Lecker Bäcker | LC München Heinrich der Löwe | LC Olpe-Kurköln | LC Villingen-Schwenningen Mitte | LC Wermelskirchen-Wipperfürth | Le Carrousel Hamburg | Lifepoints | Lindner Hotel am Michel | Lisa Maria Potthoff | Lieselotte-Paulsen-Stiftung | Loni Baur Editions | Love it Pure Skintech | Lufthansa | Lukas Göschl | Luther Rechtsanwälte | Management Circle | Manuela Rathje | Maria Scharpff | Markus Büchs | Matthias Bergmann | Maximilian Schwarzmann | MAXX SOLAR & ENERGIE | MCA Cleaning | MedLearning | Mehr! Theater am Großmarkt | Melina und Martin Sommer | Merck Family Foundation | MOBILE GARANTIE DEUTSCHLAND | MÖHRLE HAPP LUTHER Wirtschaftsprüfungsgesellschaft | Montblanc | N&L Kinderfreuden und Ferienfreizeit | nexperia | Nicole Schmitz | Nobel Golf | NTC | Olli Dittrich | Otto Waalkes | P. + R. Struve | Peter Möhrle Stiftung | Peter Suhren | Philipp | Phoenix Reisen | PING | Plotterfarm.de | Promenadenhof Weißensee | R+v Versicherung | Rainer Abicht Reederei | Ramona Kühne | Rapidmail | Rautenherz | RC Adenau-Nürburgring | RC Aller-Leine-Tal Schwarmstedt | RC Bad Reichenhall-Berchtesgaden | RC Bad Tölz | RC Emden | RC Gelsenkirchen | RC Gelsenkirchen-Schloss | RC Gütersloh | RC Haldensleben | RC Helmstedt | RC Husum | RC Oldenburg/Holstein | RC Trier-Hochwald | RC Wörthsee | REHA-OT Lüneburg | Reineke und Partner | Rindchens | Rita Starck-Saumann | Rotaract Lüneburg | Round Table Deutschland | RT 70 Lüneburg | Run4kids Sömmerda | S+K Autohaus | Sendmoments | SmartChecker | Smile&fly | Sobotta IT | Springer Bio-Backwerk | Stadthotel Münster | Stiftung It's for Kids | Studio 52, T.M. Fotografie | Susanne Colo | Susanne Schellenbach-Andres | Sven Evers und PEGASUS Event Marketing | Tango - Das Magazin | TEAG Gruppe | Team Uckermark | Telefónica | TEREK | The EAGLES Charity Golf Club | Thiesen Hamburg | Thilo Raisch (HiO Club) | Thomas Brockmann | Thomas Claussen | Thomas Maack | Thomas Willkoweit | twice MICE | Udo Lindenberg | Ulrich Kresse | unizell Medicare | Ute Reimers Floristic Art | VB Select | VBank | Verein zur Unterstützung benachteiligter Kinder | vinchoc | Vladi Private Islands | Volkan Baydar | Volksbank Münsterland Nord | Walentowski Galerien | Walter Burmester | WeCooperative | Weingut Freiherr von Gleichenstein | Werner Pawlok | Yasemin und Frank Aicher | Yesterday | Zwergenwiese

Many thanks to Niels Faassen and printing company Siemen for designing and printing our 2023 annual report for free!

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## HONORARY AMBASSADORS

Juliane Golbs, Jan Hähnlein, Jacqueline Pojer, Thorsten Schröder, Zodwa Selele, Joss Stone: Thank you so much for your advocacy and tireless support!



Make a  
donation now

## CONTACT

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[www.ncl-stiftung.de](http://www.ncl-stiftung.de)  
[www.ncl-foundation.com](http://www.ncl-foundation.com)

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Hamburger Sparkasse

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