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# ‘#Better together’

A co-creating journey developing patient information and a community platform



# Declaration of conflicts of interest

**There a no conflicts of interest**



# Project ‘Better together’

Improve stroke treatment for little patients

Project duration: 3 years

Project region: Germany, nationwide

Supporting organization: German Stroke Foundation

Kick-off: First of January 2024



Funded and sponsored by:



**WIR HELFEN KINDERN**



# Project 'Better together'

## Primary goals

- \* Raising general public awareness for the rare disease pediatric stroke
- \* Raise disease awareness among pediatricians
- \* Knowledge transfer for affected families and specialist groups
- \* Providing guidance in a complex healthcare system
- \* Ease pressure for families and support the initial stabilization



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# Family matters

The many things parents do have in mind



# Kick-off phase

What was our approach?

**Basis of the survey:** 4 telephone interviews with parents

**Online survey:** As shown in poster presentation ELASF Forum 2025, Prague

**Survey scope:** 32 questions

**Anonymous online questionnaire:** Third quarter of 2024

**Families invited:** 322 from the foundation's address database

**Response rate:** 163 questionnaires / 51%

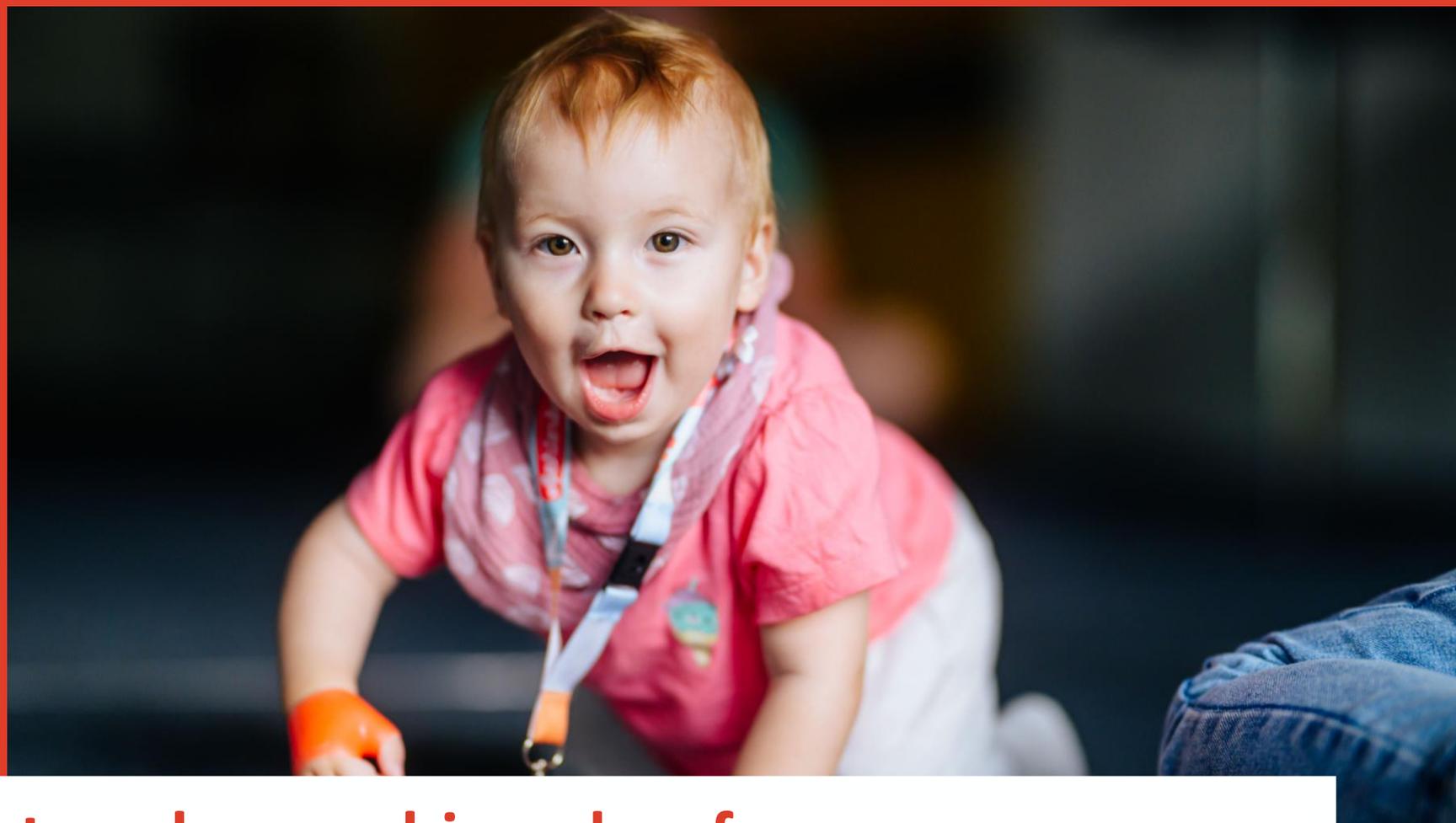


# Project 'Better together'

The three main pillars of better together:

- \* Printmaterial
- \* Video series
- \* Online Community Plattform



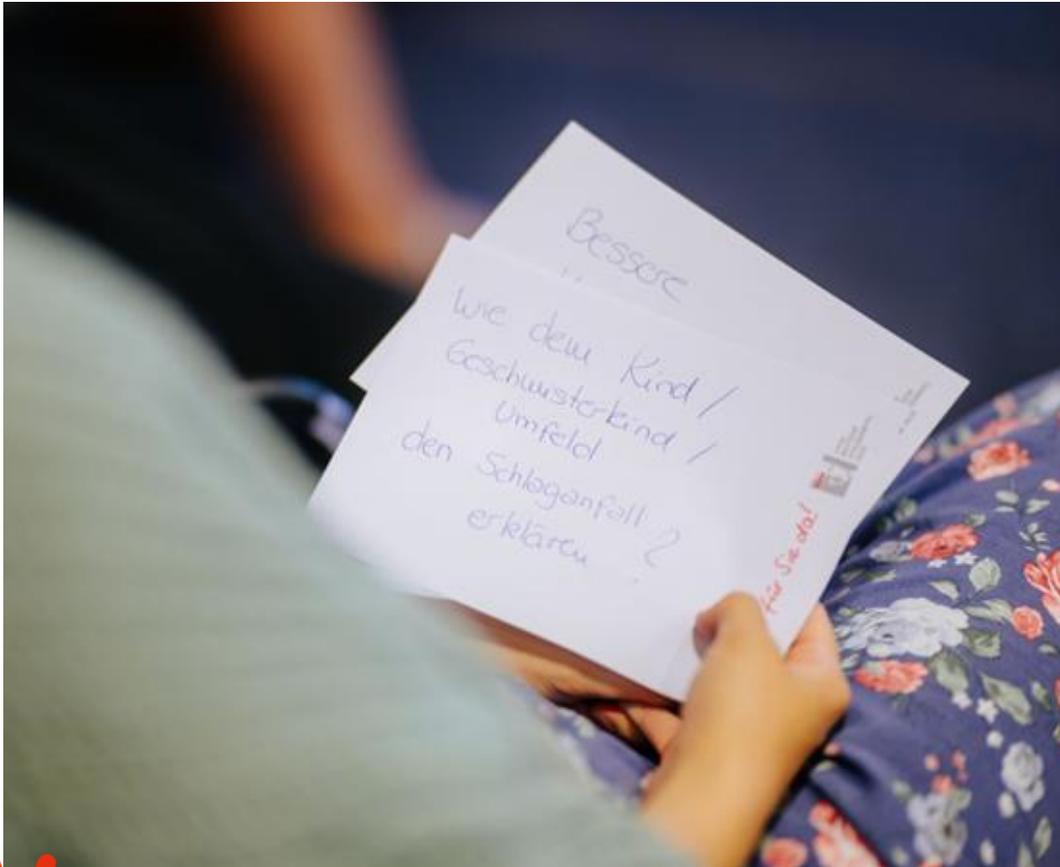


## What we have achieved so far

Project „Better together“

# Broschures and pocket card

Planned release: End of the 2nd quarter 2026



## \* **Medical aspects**

In collaboration with Dr. Nathalie Schell (Childcenter Bethel), Dr. Lucia Gerstl (iSPZ Hauner Munich) und Dr. Ronald Sträter (University Clinic Münster)

## \* **Social law**

In collaboration with childstroke navigators

## \* **Psychosocial issues affecting families**

With the help of psychologists Dr. Vathsalan Rajan, Ulrike Dickenhorst and Frauke Drews

→ **Fun fact:** Frauke Drews plays a role in one of the family portrait, as her own brother also suffered a perinatal stroke.

## \* **Pocket Cards** with information on diagnosis for pediatricians in private practice

→ Translation into other languages are planned in the future

→ All media will be written in plain and accessible language



# Community plattform

#better together – an online community is taking shape

First digital workshop on the topic of community platforms with eight affected mothers and fathers took place in September.

## Further project planning:

- \* Presentation of results and further discussion with affected families.
  - \* Round table meetings with affected parties as an initial practical test, End of March 2026
  - \* Soft kick-off / launch at the family workshop hosted by the German Stroke Foundation in June 2026
- Web- and Smartphone-Application



## Video series

Some pictures tell far more than words

- Nine videos planned in total
- Filming began in mid-June 2025. The family portraits have already been completed and approved.
- Filming was completed at the end of January 2026. The first video is scheduled for release in April / May 2026.



# Video series

Family portraits: ‘When children suffer a stroke’

- \* Family portrait 1: **‘Ida's journey with the disease’**
  - **Topics:** Path to diagnosis, development up to nursery school
- \* Family portrait 2: **‘Nela gets started’**
  - **Topics:** Everyday family life, leisure activities, choosing a school
- \* Family portrait 3: **‘Freddy's path to independence’**
  - **Topics:** Education, independent living, sibling relationships
- \* Family portrait 4: **‘Karlotta finds her way back to herself’**
  - **Topics:** the invisible consequences of stroke and the hope for a normal life



Digital movie night with all participating families  
(Planned for March / April 2026)



# Work in progress

A brief look behind the scenes



## Video series

Kurzgesagt – in a nutshell: expert voices and animated videos

- \* Expert voices 1: **‘Symptoms, causes, consequences and medical specifics’**  
An interview with Dr. Lucia Gerstl at ispZ Hauner Munich
  - \* Expert voices 2: **‘Insights into inpatient rehabilitation’**  
In collaboration with Schön-Klinik Vogtareuth
  - \* Expert voices 3: **‘Ways to find the right medical aids’**  
In collaboration with health insurance expert Bärbel Heins and the Rahm medical supply store
- 
- Animated Video 1: **‘Perinatal stroke’**
  - Animated Video 2: **‘Pediatric stroke and Be-FAST test’**



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