PCH-Familie e.V.

Cruise4Life

Who are we?

We are a 13-year old **parent initiative for families with PCH-kids**. One out of 100.000 children is born with **pontocerebellar Hypoplasia Type 2 (PCH)**. PCH is a rare neurodegenerative disorder. Children with this congenital disease are severely disabled, need a high level of care and only 50% of the children survive to see their 10th birthday. Due to PCH being considered a rare disease the amount of research for a cure and/or treatment has been limited.

In the last 10 years, a better understanding of the manifold problems of PCH has been reached together with physicians, researchers and other specialists based on our parent initiative. With this knowledge, parents with newly diagnosed children have now a much better starting point and are able to benefit from the gathered knowledge. There are **family meet-ups every other year together with international experts** in one of the German children`s hospice. Unfortunately, due to limited spaces and nursing capacities, only a fraction of families could attend these meetings.

What are our goals?

To have our next PCH Meeting with at least **25 families** in **August 2020** on a **cruise ship**, where all the families who are able to join can attend. Our goals of this **#Cruise4Life** are:

1 We are a part of society!

We believe that even if **children who are severely handicapped in multiple ways can participate in every aspect of life** and that their families are an **important part of society**. With a diagnosis like PCH, **life is not over**, but it will be different and more intense than planned. We and other affected families will not hide. These children want experiences and **be part of a "normal" life**.

2 We want to say „Thank you“!

Years of intensive care for PCH children need a lot of **support and help** from many sides. Often these are the grandparents or other relatives, friends, nurses, teachers or doctors. Each family should be able **to invite 2 people to this cruise, in order to say "thank you"** to people that helped them.

3 We advance therapy development!

Based on our expert meetings and scientific work in the last 10 years, there are now tangible efforts in Germany to develop therapies for PCH children. Our goal is to **improve the quality of life for children living with this disease**, but most of all to **find a cure for PCH until 2025!** We are intensely supporting this research and collaborate closely with the scientists.

How are we going to do this?

To reach these goals and bring our message across, **we`re asking for your support**. Our **"Cruise4Life - Intense and inclusive special moments on the Baltic Sea"** is going to be **loud** and **big**! "Loud" because we want the public and media to participate and "big" because we plan this event for **250 people**: PCH families with their nurses for the child, some families with angel children, "Thank you" guests and a lot of international experts. We aim to **fund the whole project by donations**. This will give PCH families including their supporters **strength for the future**. Please join us in making this trip a reality for the families, every Euro or every Dollar counts.

Information

www.cruise4life.de
www.facebook.com/PCHFamilie
www.instagram.com/pchfamilie
E-Mail: kontakt@pch-familie.de

Donations

Bank Account:
PCH-Familie e.V.
Sparkasse Bremen
IBAN: DE54 2905 0101 0082 5458 72
Keyword: Cruise4Life
Paypal:
www.paypal.me/pchfamilie

Support us!

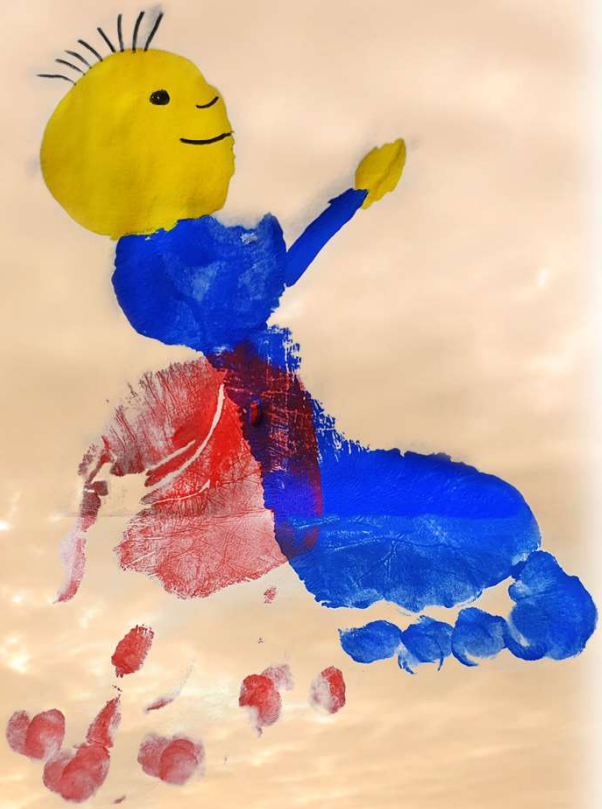
Everyone said:

This is not possible!

Then someone came along,

who didn`t know -

and just did it!



Thank you!

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Cruise 4 life