

# Visionary: Silke Mader has a vision for the care of premature infants and their parents

Nov 27, 2019

For some people, experiences of profound hardship can be the beginning of the end. Others do their best to cope and move on. A small percentage of people take their difficult experience and use it to change the world. Silke Mader, Chairwoman and co-founder of the European Foundation for the Care of Newborn Infants (EFCNI), is one such person.

Twenty-two years ago, Ms. Mader gave birth to twins, a boy and a girl at only 25 weeks. Her baby girl died but her son Lukas survived, and was admitted to the neonatology intensive care unit, where he had to stay for several months. One consequence of Lukas' preterm birth was that he developed retinopathy of prematurity (ROP), a disease involving abnormal blood vessel growth that can, if not treated, lead to blindness. At that time, the only treatment available for ROP was laser therapy, a procedure that uses a beam of light to burn, then scar, the area where abnormal blood vessels have not yet reached. Additionally, the brief medical information that was shared with Ms. Mader was incomplete and there was no recognition of the need for psychological support for parents of preterm infants.

Dealing with that very difficult experience encouraged Ms. Mader to take action. In 2008, together with a father who had lost triplets born preterm, and a neonatologist, she founded the European Foundation for the Care of Newborn Infants (EFCNI) to raise the standard of care for preterm babies and to ensure that Europe—and ultimately the world—adopts and harmonizes standards of care to protect and support preterm babies as well as their families. The same year it was founded, EFCNI introduced World Prematurity Day. Today, World Prematurity Day, which takes place on 17 November, is one of the most important days in the year to raise awareness of the challenges and burden of preterm birth globally and is celebrated in more than 100 countries as a way for individuals, healthcare institutions and NGOs to join forces and commit to action to help address preterm birth.

“Preterm birth is not a marginal phenomenon; babies born too early represent up to 10% of births in Europe,” Ms. Mader said in the EFCNI press. Indeed, complications resulting from preterm birth can impact a baby's breathing, heart and brain functions, blood and metabolism, temperature control, immune system and more. “These children and their parents receive too little political support and above all, they lack the backing in society. That is something we want to change.”

Thanks to the efforts of Ms. Mader and EFCNI, parents of babies born at risk for ROP today have a very different experience than she did. (Ms. Mader's own son Lukas is doing well, studying sociology at university and managing his ROP with regular medical care.)

Watch this [video](#) of parents in a neonatology intensive care unit for a glimpse of the medical care that Ms. Mader's advocacy work has helped to achieve.

IE02/COR19-CNF042 November 2019

## List of links present in page

1. <https://prod1.novartis.com/ie-en/ie-en/stories/visionary-silke-mader-has-vision-care-premature-infants-and-their-parents>
2. <https://prod1.novartis.com/ie-en/taxonomy/term/61>
3. [https://www.youtube.com/watch?time\\_continue=12&v=4doPUyEEvio&feature=emb\\_title](https://www.youtube.com/watch?time_continue=12&v=4doPUyEEvio&feature=emb_title)