My journey as a mother of a child with PAH

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Medical history of my son

2010: Born with the heart defect “transposition of the great arteries”

Open-heart surgery to correct the arteries

Good life expectancy after surgery

2012: Pulmonary arterial hypertension (PAH)

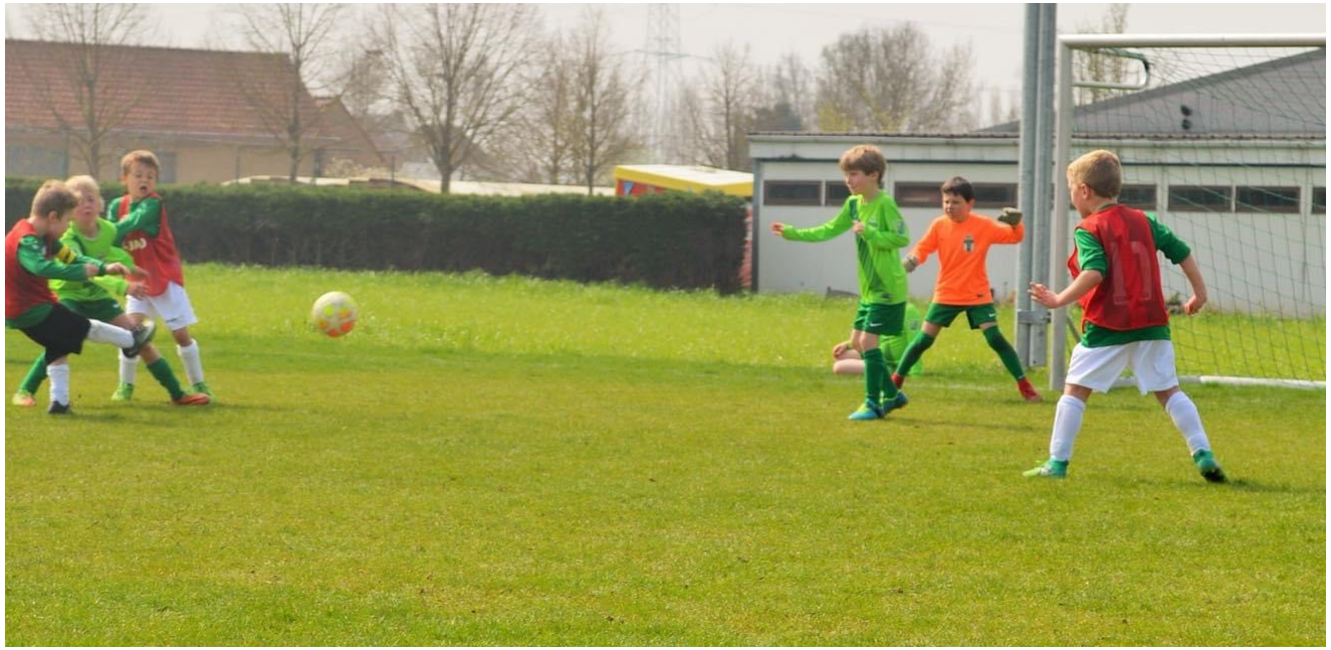
An ultrasound showed enlargement of the right ventricle at a six-month follow-up.

2023: start-up Veletri via Hickman catheter

2024: Preparation of a transplant plan

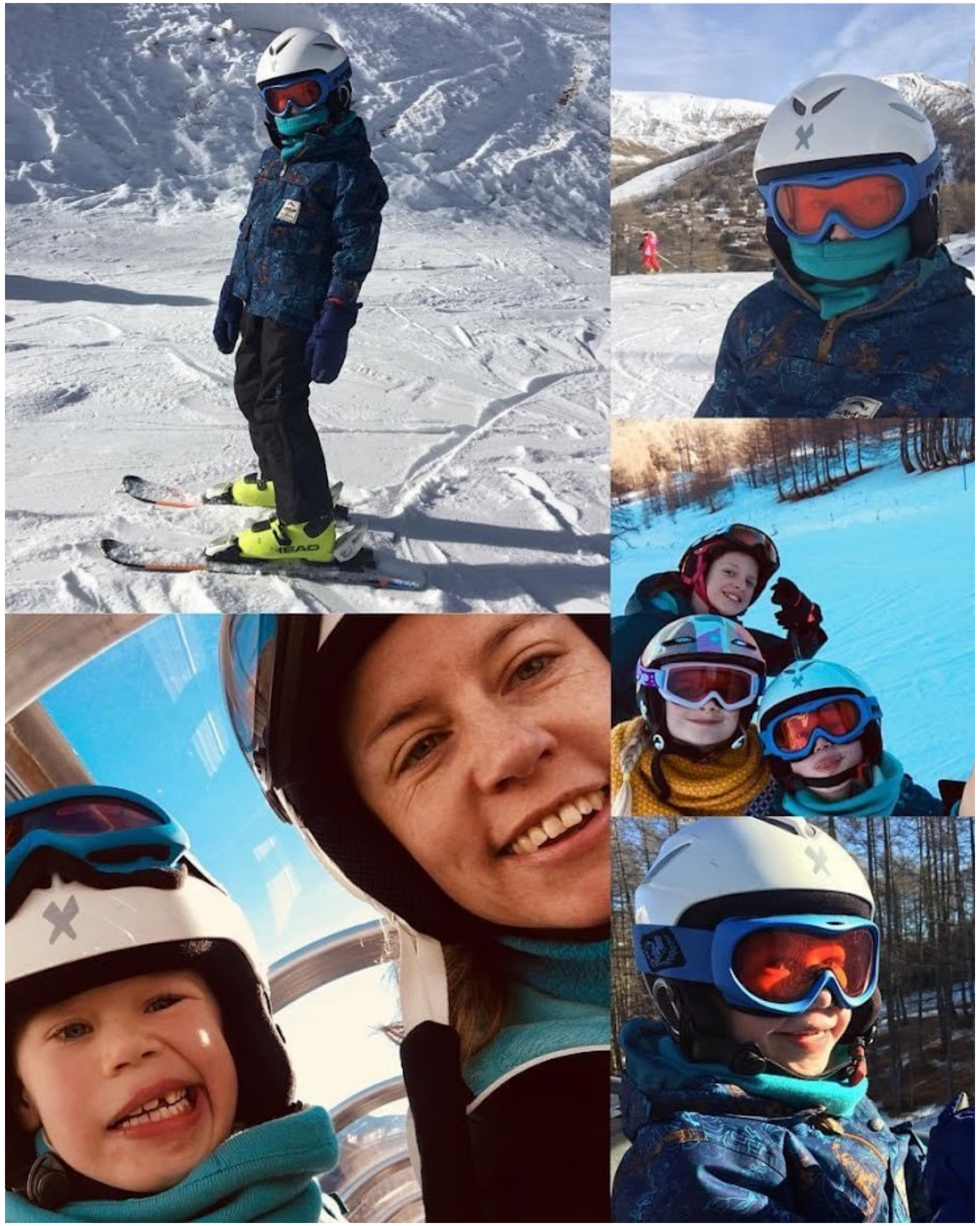
We can't take away his disease, but we can do everything we can to give him the best life possible".

Our motto is "Let him live, explore and have fun".



No sooner said than done

- Although we knew his soccer career would be tough and short, we didn't hesitate to let him join a soccer club at the age of five. At eight, he made the brave but difficult decision to stop playing soccer because it was too physically demanding.
- Go skiing - Because of his illness, he couldn't ski himself, but we skied down the mountain together.
- Despite the many limitations, always try to find solutions to do as much as possible.



What are the conflicting areas for parents and young PH patients?

- A lack of treatment leading to a decrease in quality of life and life expectancy
- Difficulties with social and educational integration and independence
- Difficulties in finding fellow patients for support and to decrease isolation
- Difficulties in carrying out research and studies due to difficulties in recruitment of patients and groups of patients because of the scarcity of the disease
- Less medication available than for adults
- Mean, stupid and harsh comments
- Significant impact on the family
- Every person with PH, or the parent of a person with PH, deals with chronic grief during the battle with PH, mourning a loss that never ends. You must constantly adapt to significant life changes.

What is important in my opinion?

- Don't withhold information from your child and explain disease risks
- Communicate openly
- Do not postpone – life is now, later it may be too late
- Give them a voice in their treatment – it’s their life and body
- Be an advocate for them in difficult conversations with their doctors and fight for their quality of life.
- If they are having a bad day, let them stay home from school.
- As a parent, don't be too hard on yourself; give yourself a break as well.

Have a good laugh and most of all, have fun!