



CHILDRENS INTERSTITIAL AND DIFFUSE LUNG DISEASE FOUNDATION

The Legacy of the Pinwheel



Alex Porta spinning a pinwheel with a puff of air from his new lungs for the St Louis Children's Hospital Transplant Center in 1999.

When Gregory “Alex” Porta was born in 1994, he struggled to breathe. Alex was oxygen-dependent and, as his unknown disease progressed, his family and physicians raced to find answers while the little boy fought to survive.

Eventually Alex’s doctors and parents were left with only one treatment option – a double lung transplant. The boy received his new lungs in 1999 at a Saint Louis, Missouri transplant center.

Alex’s quality of life improved and not long after the transplant Alex was photographed for a brochure detailing the hospital’s lung program. The photo chosen for publication showed Alex spinning a pinwheel with a puff of air from his new lungs.

But Alex’s good health didn’t last. His body began to reject the new lungs.

On June 14, 2002, Alex lost his lifelong battle with what is now identified as a form of Children’s Interstitial Lung Disease (chILD).

Two years after Alex Porta’s death, Dr. Robin Deterding, Director of Breathing Institute at The Children's Hospital and Chair, Children's Interstitial Lung Disease Research Network (chILDRN), applied for a R13 grant from the National Institute of Health (NIH) to fund the first conference for pediatric interstitial lung disease in conjunction with a Rare Lung Disease Consortium Conference. The Portas and four other families that had been significantly affected by a lung disorder were invited to share their experiences with conference attendees.

During the conference, physicians formed what is now known as the Children’s Interstitial Lung Disease Research Network (chILDRN) and approached these families, asking them to form a family foundation. The group that emerged was first known as the Pediatric Interstitial Lung Disease Foundation and later became the chILD Foundation. During the group’s first meeting, families shared similar concerns and, concluded that it was vital to connect with other parents with youngsters affected by chILD while advocating for research and seeking a cure for all children.

In the process of getting to know one another at this first parent gathering, stories were told and photos exchanged. Alex's photo inspired organizers of the fledgling foundation to unanimously settle on the pinwheel as the group's logo.

The pinwheel symbolized air flowing freely, an iconic children's toy gloriously whirling on a gust from the lungs of a child who could finally breathe.

In the years since, the legacy of the pinwheel has carried across the globe. The chILD community has expanded to touch families in 19 different countries throughout the world. New chILD organizations have formed in England, Spain and Australia, with common goals of promoting chILD awareness, supporting families and patients, increasing quality of care and, most important, raising money for research to find cures. All of the chILD foundations worldwide have adopted a pinwheel as their logo, paying tribute to the roots of the organization while adding their own contributions and meaning to the movement.

For those who knew Alex during his lifetime, who have come to know Alex's story after his death, or who know a child suffering today from a chILD disease, the pinwheel serves not only as a memorial to one child and all he endured, but as a reminder of where the chILD community began, where it is going, and the difference that one dedicated family can make in the lives of so many others.

Separately we are a few scattered families battling one of many rare diseases on our own. Together we are one family composed of many, a unified voice for Alex and other children that will not be ignored and that will someday overcome.

For all of the chILD families, the pinwheel reminds us to cherish every moment, celebrate every milestone with our children. For some families these moments may be rare or fleeting, but they fill our hearts with joy and make the difficult times easier to bear.

For the general public and the scientific community, the pinwheel serves as a reminder of the vital mission of the foundation; the importance of finding effective treatments and eventual cures for these rare and devastating diseases.

For chILD Foundations worldwide, the pinwheel is a unifying emblem; our reminder that we must continue working together to make our voices heard and to direct the medical and research communities' focus on an array of more than two dozen chILD diseases.

