THE ASSOCIATION

Founded in 2002 by two patients with PCD, the PCD Association is run on a voluntary basis by patients who are not doctors. Among other things, it provides psychological support to its members, patients and their families.

Our mission:

- Information on the PCD
- Advice (medical pathways and medical and social support)
- Support and networking opportunities for members Support for research

CONTACT US!

secretaire@asso-dcp.org

www.adcp.asso.fr

Association Dyskinésie CIliaire Primitive

assoadcp

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RespiRare – Maladies respiratoires rares de l'enfant

RespiFIL – Filière Maladies Respiratoires Rares

ELF

BEAT-PCD – Better experimental approaches to treat PCD

association dcp

dyskinésie ciliaire primitive

Let's join forces and pool our ideas.
Let's forge a strong bond to support the medical community and break out of our isolation!

I SUPPORT THE CHARITY:

Scan me!

To join

To make a donation:

Donations are tax-deductible.
We will send you a tax receipt.
Charity registered under the 1901 Act

Association DCP

Dyskinésie Ciliaire Primitive

TESTIMONIALS

"My name is Aline, I'm 38 years old, and I have primary ciliary dyskinesia. I was diagnosed when I was 11. As a child, I coped well with it. Things became more difficult during my teenage years, and my health deteriorated rapidly.
I've settled into a new way of life: daily respiratory physiotherapy, nebuliser treatments five times a day, monthly hospital visits...
Today, I have a daughter, conceived through IVF! I don't think I can say I've come to terms with the illness, but I'm doing everything I can to fight it."

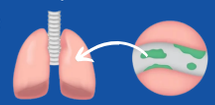

Albane, 9 ans

"My name is Albane, I'm 9 years old and I have Kartagener syndrome.
I have to undergo treatment every day: respiratory physiotherapy sessions, nasal irrigation, clearing my airways with a spirometer ...
I don't really like my respiratory physiotherapy sessions because during the exercises my throat burns and I feel dizzy...
I go to school like everyone else, and I cough a lot. It makes me feel self-conscious around my classmates... but they're used to it and understand my condition. It helps me a lot to have their support."

THE DISEASE

The airways are lined with cilia that prevent viruses, bacteria and dust from entering the body. The mucus that forms in the lungs, sinuses and behind the eardrums is then expelled by these same cilia.

Patients suffer from a dysfunction of the ciliary system, leading to increased mucus production and making them more susceptible to respiratory infections: sinusitis, rhinitis, bronchitis...



Primary ciliary dyskinesia (PCD) is a rare genetic disorder, affecting one in 7,500 births. In 50% of cases, it is associated with organ inversion (Kartagener syndrome).

As a result of the condition, patients often experience reduced fertility; they sometimes turn to assisted reproductive technology (ART) in order to have children.

Treatment consists of:
- respiratory physiotherapy sessions;
- inhaled bronchodilators;
- and antibiotics if an infection is present.

As the disease progresses, it leads to a decline in respiratory function, which can be stabilised with appropriate treatment. In addition to oxygen therapy, the most severe cases may require a lung transplant.

THE DAILY

Ciliary dysplasia is present from birth and has different effects from person to person.

In addition to medical treatments (physiotherapy, bronchodilators, inhalers, etc.), daily exercise is essential as it helps clear mucus during physical activity.

Strict hygiene measures are required.

Patients' daily lives are therefore punctuated by medical appointments (with a pulmonologist, ENT specialist, physiotherapist, etc.)