



# Cystic Fibrosis Research News

**Title:**

Position Paper: Models of Post-Transplant Care for Individuals with Cystic Fibrosis

**Lay Title:**

Models of Cystic Fibrosis care after lung transplant

**Authors:**

Edward McKone<sup>1</sup>, Kathleen J. Ramos<sup>2</sup>, Cecilia Chaparro<sup>3</sup>, Joshua Blatter<sup>4</sup>, Ramsey Hachem<sup>5</sup>, Michael Anstead<sup>6</sup>, Fanny Vlahos<sup>7</sup>, Abby Thaxton<sup>8</sup>, Sarah Hempstead<sup>8</sup>, Thomas Daniels<sup>9</sup>, Michelle Murray<sup>10</sup>, Amparo Sole<sup>11</sup>, Robin Vos<sup>12</sup>, Erin Tallarico<sup>8</sup>, Albert Faro<sup>8</sup>, Joseph M. Pilewski<sup>13</sup>

**Affiliations:**

1 St. Vincent's University Hospital and University College Dublin School of Medicine, Dublin, Ireland

2 Division of Pulmonary, Critical Care, and Sleep Medicine, Department of Medicine, University of Washington, Seattle, Washington, USA

3 Toronto Lung Transplant Program, Ajmera Transplant Centre, University Health Network, Toronto, Ontario, Canada. Division of Respiriology, Department of Medicine, University Health Network and University of Toronto, Toronto, Ontario, Canada

4 Washington University in St. Louis, Department of Pediatrics, St. Louis MO, USA

5 Washington University in St. Louis, Division of Pulmonary & Critical Care, St. Louis, MO, USA

6 Division of Pulmonary, Critical Care, and Sleep Medicine, Departments of Medicine and Pediatrics, University of Kentucky, Lexington, Kentucky, USA

7 Community Advisor to the Cystic Fibrosis Foundation, Bethesda, Maryland, USA

8 Cystic Fibrosis Foundation, Bethesda, Maryland, USA

9 Adult Cystic Fibrosis Physician, University Hospital Southampton, Tremona Road, Southampton, UK

10 National Lung Transplant Programme, Mater Misericordiae Hospital, University College Dublin, Ireland

11 Lung transplant and adult Cystic fibrosis unit. Hospital Universitario La Fe. Universitat de Valencia. Valencia. Spain

12 Division of Respiratory Diseases, Univ. Hospitals Leuven, Belgium and BREATHE, Dept. of CHROMETA, KU Leuven, Leuven, Belgium

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[cfresearchnews@gmail.com](mailto:cfresearchnews@gmail.com)



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13 Division of Pulmonary, Allergy, and Critical Care Medicine, Department of Medicine, University of Pittsburgh, Pittsburgh, Pennsylvania, USA

## **What was your research question?**

What are the best models for individuals with Cystic Fibrosis to manage both their transplanted lungs and the aspects of CF that remain after transplant?

## **Why is this important?**

Lung transplant is an option for many individuals with Cystic Fibrosis and progressive severe lung disease despite best available medical care. Many individuals are lost to follow-up by a CF Center after lung transplant and the expertise among lung transplant programs to manage the unique medical issues for individuals with CF varies widely. While recommendations on referral for lung transplant and communication between CF and lung transplant programs have been published, there are no recommendations for models of care for individuals with CF to manage the aspects of CF that remain after lung transplant.

## **What did you do?**

The CF Foundation virtually gathered a group of worldwide experts in CF and lung transplant care. After review of publications, and creation and review of the results of a survey, the committee proposed two models of care for individuals with CF after lung transplant.

## **What did you find?**

The committee recommended two models as good options for shared care after lung transplant: Model 1 re-engages the CF team after transplant and clarifies responsibilities for the CF and transplant teams and other providers to share care. Model 2 focuses care in one center if an institution has CF and lung transplant programs with shared providers who have expertise in both CF and lung transplant.

## **What does this mean and reasons for caution?**

Individuals with CF who undergo lung transplant should work with their CF and transplant providers to establish the optimal care for both lung transplant and CF issues, with focus on preventing complications. Clear expectations between lung transplant recipients and multi-disciplinary providers, and timely communication will be necessary. Model selection needs to be decided between the transplant and the CF center and may vary from center to center. In either model, individuals with CF who have received a transplant require a clear

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understanding of the roles and responsibilities of their providers and ways to have effective communication.

## **What's next?**

The shared care models will be communicated to the CF and transplant communities, and CF and transplant programs will develop and use quality improvement tools to improve care of all health issues after lung transplant.

## **Original manuscript citation in PubMed**

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