



UNIVERSITÀ DEGLI STUDI DI MILANO

Milan March 27, 2024

**To :** European Cystic Fibrosis Society

**Re:** Prof. Pierre-Régis BURGEL

To Whom it may concern,

I had the opportunity to start working with Pierre-Régis Burgel since 2013 given my role of President of European Respiratory Society and co-Chair of the ERS/ECFS Task Force on Provision of Care for Adults with Cystic Fibrosis in Europe.

I was immediately struck by Pierre-Régis's strong personality and avid interest in different fields of Respiratory diseases with a focus on Cystic Fibrosis management. Since then, I have had numerous occasions to appreciate his scientific attitude which has brought him to cover an outstanding position in the international panorama of respiratory medicine and Cystic Fibrosis.

Pierre-Régis work in the field of Cystic Fibrosis proposed a novel approach to Cystic Fibrosis that is now internationally recognised as the current management gold standard. As a result, Pierre-Régis Burgel has received international scientific prestige and is among the leading experts worldwide in Cystic Fibrosis.

I had the opportunity of implementing several projects with him related to scientific dissemination and clinical research.



Pierre-Regis was really instrumental in shaping new approaches to Cystic Fibrosis with a great level of innovativeness.

Prof. Burgel has a very high academic profile as Professor of Respiratory Medicine at the Université Paris Cité and Cochin Hospital-Assistance Publique Hôpitaux de Paris, Paris, France, Senior Consultant and Director of the Adult Cystic Fibrosis Centre, Cochin Hospital-Assistance Publique Hôpitaux de Paris, Paris, France. He is National Coordinator of the French Rare Disease Network for Cystic Fibrosis and President of French Cystic Fibrosis Society.

I have witnessed Pierre-Regis as a speaker in international congresses and invariably find him an exhaustive and enthusiastic orator with great teaching capacities.

On the basis of my personal experience and international consensus, I believe Pierre-Régis Burgel is one of leading personality in the field of Cystic Fibrosis and an outstanding candidate as a member of the board of the European Cystic Fibrosis Society.

Prof. Francesco Blasi

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March 29, 2024

Dear ECFS Board Members:

**Re: Dr. Pierre-Régis Burgel**

I am thrilled to write a letter of recommendation for Dr. Burgel in support of his application to become a member of the board of the European Cystic Fibrosis Society.

I am a Respiriologist and Clinician Scientist within the Department of Medicine at St. Michael Hospital in Toronto, Canada and an Associate Professor at the University of Toronto. My clinical and research areas of expertise involve clinical epidemiology with a focus on cystic fibrosis (CF). Since 2017, I have collaborated with Dr. Burgel on multiple CF-related research projects and I feel I can comment on his commitment to the care of individuals living with CF as well as his contribution to CF research.

Dr. Burgel asks important questions facing individuals living with CF, many of which have implications in terms of advocacy to help improve the quality of life for people with CF and address inequities that exist in this population. The first time that I heard Dr. Burgel present at an international CF conference, I was impressed with his focus on advocacy. His research showed that 50% of individuals with CF followed in the French CF Registry died without a lung transplant and only 19% of those people were listed for transplant. This, of course, raised the question of why this life saving therapy was not being offered or available to so many individuals with end-stage lung disease. Following this presentation, I went back to the Canadian CF Registry data and realized that a similar pattern was seen in our patients which spawned future work to ensure that all eligible people are at least considered for lung transplantation. This is just one example of how his work has had an international impact on individuals with CF.

Since that initial interaction, I have had the opportunity to collaborate with Dr. Burgel on multiple international research projects and we are co-authors on 8 published manuscripts to date. These include comparing post-transplant survival outcomes between Canada and France, comparing survival between Canada/France/Australia/New Zealand, validating prior prediction models developed by Dr. Burgel's group, and more recently collaborating with our international colleagues on multi-country projects on the impact of COVID-19 in CF and the prevalence of CFTR variants across the globe. Throughout all my interactions, Dr. Burgel has been collaborative and supportive, always making time to join calls (despite significant time differences) and sharing his ideas. His commitment to all of these projects is shown by his availability, his engagement providing constructive comments, and his creative ideas for projects. Several of our earlier collaborations were projects conducted by my Post-doctoral fellow. Pierre-regis secured funding to expand this work and he always took the time to teach during our conference calls which significantly improved the experience of the Post-doctoral fellow involved in this project.

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Most recently I have been working closely with Dr. Burgel on a global project to quantify the prevalence of *CFTR* variants in an effort to show how expanding the indication label of elexacaftor-tezacaftor-ivacaftor would allow more individuals with CF be eligible for this transformative medication. This is yet another project that has the potential to be an important tool for advocacy efforts, which could have a direct impact on the lives of individuals living with CF around the world. Dr. Burgel was already conducting this research using the ECFS Patient data registry however when it was suggested that we expand the project to include a truly global perspective, Dr. Burgel immediately saw the value of this and was enthusiastic to include as many countries as possible in this project. Although the timelines were tight for completion of this work, Dr. Burgel made sure that any country that was able to provide data was included, even if it meant revisions to the manuscript at the 11<sup>th</sup> hour. He is hard-working, collaborative, and genuine in his interactions with others and works well with colleagues to successfully achieve common goals.

In summary, I have worked closely with Dr. Burgel over the past several years and I have found him to be professional, responsible and extremely committed to bettering the lives of people with CF not just locally in his country, but globally. His work has shone a spotlight on the global disparities in care of people affected by CF which has the potential to change practice and improve lives. I strongly feel that he will be a valued member of the board of the ECFS and I would highly recommend him for this role.

Sincerely,



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