EDITORIALS

Rapid FEV1 Decline, Early COPD, and Angiotensin-Converting Enzymes? 671
Jadwiga A. Wedzicha; Gavin C. Donaldson
>> See article, page 695

The Prognostic Value of the GAP Model in Chronic Interstitial Lung Disease: The Quest for a Staging System 672
Athol U. Wells; Katerina M. Antoniou
>> See article, page 723

Primary Ciliary Dyskinesia and Cystic Fibrosis: Different Diseases Require Different Treatment 674
Jane S. Lucas; Mary Carroll
>> See article, page 738

SECOND OPINION

Quitting 677
Rob Rogers

POINT/COUNTERPOINT EDITORIALS

Point: Does the Risk of Cross Infection Warrant Exclusion of Adults With Cystic Fibrosis From Cystic Fibrosis Foundation Events? Yes 678
Manu Jain; Lisa M. Saiman; Kathy Sabadosa; John J. LiPuma

Counterpoint: Does the Risk of Cross Infection Warrant Exclusion of Adults with Cystic Fibrosis from Cystic Fibrosis Foundation Events? No 680
Steven L. Shepherd; Eric J. Goodrich; Julie Desch; Paul M. Quinton

Rebuttal From Dr Jain et al 683
Manu Jain; Lisa M. Saiman; Kathy Sabadosa; John J. LiPuma

Rebuttal From Mr Shepherd et al 684
Steven L. Shepherd; Eric J. Goodrich; Julie Desch; Paul M. Quinton

GIANTS IN CHEST MEDICINE

Giants in Chest Medicine: Marvin I. Schwarz, MD, FCCP 686
Mark Geraci

COMMENTARY

Air Travel and Pneumothorax 688
Xiaowen Hu; Clayton T. Cow; Misbah Baqir; Jay H. Ryu

ORIGINAL RESEARCH

COPD

Rapid Lung Function Decline in Smokers Is a Risk Factor for COPD and Is Attenuated by Angiotensin-Converting Enzyme Inhibitor Use 695
Hans Petersen; Akshay Sood; Paula M. Meek; Xian Shen; Yan Cheng; Steven A. Belinsky; Caroline A. Owen; George Washko; Victor Pinto-Plata; Emer Kelly; Bartolome Celli; Yohannes Tesfai
>> See editorial, page 671
In 1990, LiPuma and colleagues described person-to-person transmission of *Pseudomonas cepacia* (now *Burkholderia cepacia*) between young adults with cystic fibrosis (CF) attending an educational program. One of the newly infected individuals had been previously in good health, but deteriorated rapidly and died within several months. This tragic case highlights the potential for catastrophic consequences from person-to-person transmission of bacterial pathogens in CF. This report and others from around the world that also described person-to-person transmission of *B cepacia* associated with acceleration of pulmonary disease and death led to the recommendation that people infected with *B cepacia* not attend Cystic Fibrosis Foundation-sponsored events. Reports describing person-to-person transmission of other more prevalent CF pathogens, most notably *Pseudomonas aeruginosa*, soon followed. In response, the CF Foundation published recommendations for infection prevention and control in 2003. Over the last 10 years, accumulating evidence has described further instances of person-to-person transmission of CF pathogens as well as poor clinical outcomes associated with transmission of certain strains of *P aeruginosa*, methicillin-resistant *Staphylococcus aureus* (MRSA), and *Burkholderia*. In response, the CF Foundation commissioned an update of the guidelines and invited public comment on a draft version. The period for public comment is now closed.

The updated recommendation that has generated the greatest controversy is that only one person with CF attend an indoor CF Foundation-sponsored or CF center-sponsored event. We make the case that this recommendation is the most prudent course of action to protect the health of an individual with CF and for the CF community as a whole.

To support the recommendation that only one person with CF should attend an indoor event, we believe the following three questions can be answered in the affirmative: (1) Can cross infection occur between people with CF? (2) Can acquisition of microorganisms through person-to-person transmission lead to clinical deterioration and possibly death? (3) Can limiting exposure of individuals with CF to each other reduce the risk of cross infection?

Person-to-person transmission of species in the *B cepacia* complex, including *Burkholderia cenocepacia*, *Burkholderia multivorans*, and *Burkholderia dolosa* has been well documented. However, at most CF centers, *Burkholderia* species are detected in a small number of patients, in contrast to *P aeruginosa*, which chronically infects as many as 80% of adults with CF. Although historically it was believed that *P aeruginosa* was almost exclusively acquired from the environment, person-to-person transmission has been increasingly described. The earliest reports of cross infection involved CF camps. In one study, investigators described new *P aeruginosa* infection in eight of 10 individuals. A mucoid *P aeruginosa* strain was recovered from three of the newly infected individuals, suggesting cross infection from a chronically infected person. Another report described the acquisition of *P aeruginosa* in five previously uninfected individuals attending a week-long camp, and molecular analysis confirmed that these strains matched the *P aeruginosa* strain isolated from an attendee known to be chronically infected with *P aeruginosa*. Subsequently, investigators from the United Kingdom described recovery of the same strain of *P aeruginosa* in 55 children cared for at the Liverpool CF center. Infection with this strain, now referred to as the Liverpool Epidemic Strain, has been detected in many other centers in the United Kingdom and described in adults with CF in Ontario, Canada. We emphasize that shared strains of *P aeruginosa* can only be reliably identified by molecular testing.
With respect to other CF pathogens, epidemiologic studies have shown that individuals with CF can share *S aureus* strains, including MRSA. Most recently, two reports have described person-to-person transmission of nontuberculous mycobacteria at CF centers. Although it remains difficult to precisely quantify the risk of person-to-person transmission, it is clear that the answer to the question “Can cross infection occur between people with CF?” is an unequivocal yes.

Several studies have shown that acquisition of shared strains of *Burkholderia* can be devastating. There is also substantial evidence that transmissible strains of *Pseudomonas* are associated with clinically significant deterioration. Reports from Australia describe acquisition of mucoid, multidrug-resistant *P aeruginosa* by young children who attended CF clinic on the same day as older patients infected with the same strain. These children died before 7 years of age. Individuals with CF infected with the Liverpool Epidemic Strain are hospitalized more frequently, lose lung function at a greater rate, and are more likely to die or require lung transplantation than those infected with unique strains. During the last several years, multiple studies have found that MRSA infection is associated with faster decline in lung function and increased risk of death. Further, in a recent outbreak of *Mycobacteria abscessus* subspecies *massiliense* at a CF center in Seattle, Washington, two of four patients who had identical isolates by molecular typing to the index case died within months of acquiring the organism. These data suggest that microorganisms acquired from another individual with CF may be more virulent than those acquired from the environment, and could accelerate decline in lung function, hasten lung transplantation, and/or increase the risk of death. Thus, the answer to the question “Can acquisition of microorganisms through person-to-person transmission lead to clinical deterioration and possibly death?” is yes.

Finally, can the risk of cross infection be reduced if individuals with CF limit exposure to one another? While not advocated by the CF Foundation, many centers practice cohort segregation whereby only people infected with the same pathogens, such as MRSA or specific epidemic strains of *P aeruginosa*, attend the same clinic session. This strategy, which was supplemented by other interventions such as alternative waiting rooms and discouraging socialization between individuals with CF, has proven successful in limiting the spread of epidemic *P aeruginosa* strains and *Burkholderia* species. Similarly, interventions that limit exposure of individuals with CF to each other in clinic (eg, no shared waiting room and faster throughput of patients) have been associated with a reduced prevalence of chronic *P aeruginosa* infection. In addition, not attending CF camps is associated with a much lower risk of acquiring *B cepacia* infection, and discontinuing CF camps is associated with lower risk of cross infection with *P aeruginosa*. Two decades of compelling evidence supports the premise that limiting exposure between people with CF significantly decreases the risk of pathogen transmission. Thus, the answer to the question “Can limiting exposure of individuals with CF to each other reduce the risk of cross-infection?” is yes.

In summary, (1) pathogen transmission can occur between people with CF; (2) such transmission may involve especially virulent strains, worsening clinical outcomes and resulting in premature death; and (3) infection prevention and control measures have proven effective in halting the transmission of specific pathogens. While it seems intuitive that the risk of transmission is likely greater with closer contact between individuals with CF, the precise risk cannot be quantified. More importantly, it is impossible to exclude with confidence which individuals may be harboring virulent, transmissible strains since acquisition of new pathogens is most often “silent” (ie, not initially marked by obvious clinical signs or symptoms) and new potentially virulent pathogens continually emerge. For the safety and well-being of all individuals with CF, the most prudent course of action to reduce the risk of person-to-person transmission is to limit exposure. It is unfortunate that this recommendation adds to the burden of disease as the value of the psychosocial support provided by participation in CF community activities cannot be overstated. Adults with CF are particularly affected as their contact with one another in camps and educational retreats has ended and in clinical settings has become more and more restricted. These previous actions reflected growing knowledge of the routes and risks of transmission, and in the updated guidelines, new knowledge has led to the current recommendation to restrict attendance at indoor events. To enable individuals with CF to connect with each other and the community, we urge the CF Foundation and centers to use readily available online and video communication technologies. We also emphasize that other recommendations regarding the potential risks associated with leisure activities in the updated guidelines are intended to help individuals with CF make informed choices. We believe that as a community, we need to continue to be extremely mindful of how to live safely with CF, for ourselves, for family members, and for everyone around us who share in the hope that one day there will be a cure.

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Financial/Nonfinancial Disclosures: The authors have reported to CHEST the following conflicts of interest: Dr Saiman receives funding from the CF Foundation to provide expertise in infectious diseases and microbiology. Ms Salvador is a full-time, 10-year employee of the Cystic Fibrosis Foundation. Drs Jain and LiPuma have reported to CHEST that no potential conflicts of interest exist with any companies/organizations whose products or services may be discussed in this article.

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DOI: 10.1378/chest.13-2404

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Counterpoint: Does the Risk of Cross Infection Warrant Exclusion of Adults with Cystic Fibrosis from Cystic Fibrosis Foundation Events? No

In 2011, the Cystic Fibrosis Foundation (CF Foundation) assembled an infection prevention and control committee to update the CF Foundation’s 2003 Infection Control Recommendations for Patients with Cystic Fibrosis. In March 2013, acting on a recommendation made orally by committee members and included in the written draft guideline circulated later (Infection Prevention and Control Committee,
CF Foundation, written communication, May 19, 2013), the CF Foundation announced a new policy2:

At any CF Foundation-sponsored indoor event, meeting or office, including gatherings such as Foundation chapter committee meetings, only one person with CF may be present. This person will be designated by the Foundation…? [emphases in original]

The four of us have cystic fibrosis (CF). We all have attended CF Foundation events and believe we should have the continued right to do so. But other reasons lead us to judge the CF Foundation’s new policy as unfounded, misguided, unnecessary, and harmful.

UNFOUNDED

Months after its adoption, the CF Foundation issued a list of 16 papers offering its scientific rationale for the ban.3 The CF Foundation advocates “evidence-based” recommendations.1 So what in these papers supports a ban on the presence of two or more people with CF in public and professional settings where adults behave with constraint?

Along with a great body of other work, the CF Foundation’s 16 listed papers document the person-to-person transmission among people with CF of genetically distinct, difficult-to-treat pathogens, including strains of Pseudomonas aeruginosa and species of Burkholderia.5 The papers also show significant associations between the presence of these organisms and increased risks of morbidity and mortality.

Several of the papers address possible modes of transmission. They show that viable pathogens can be recovered from the hands, bed linens, and clothes of hospitalized patients with CF; from room air hours after a patient with CF has left; and from dry surfaces 2 days after deposition. None of these studies shows actual patient-to-patient transmission, and all include statements similar to that of Festini et al,3 who noted that while the transmission of P aeruginosa as far as 2 m by coughing or speaking was possible, “its probability is low.”

Five of the papers report the use of epidemiologic or genomic methods to demonstrate person-to-person transmission and to investigate its setting. Each of these studies found that transmission most likely occurred as the result of nosocomial exposure, and none found evidence of transmission due to social contact outside the medical setting. Aaron et al.7 for instance, studied transmissible P aeruginosa and identified seven new cases over a 3-year period, yielding an incidence of 7.0 per 1,000 person-years (a rate the authors termed “relatively low”). The only risk factor shared by the seven patients was prior hospitalization or attendance at a CF clinic, and all seven “denied social contact with any other patients with CF.”

That the greatest risk of transmission comes from nosocomial exposure is consistent with earlier work.1,5 With some very specific exceptions, so too is the failure to find evidence of transmission by social contact outside the medical setting. The first of these exceptions comprises evidence of person-to-person transmission at CF summer camps held under conditions that prevailed in the last century. In the most influential of the many camp studies, the campers were almost all children; slept together in close quarters for weeks at a time; performed chest physiotherapy on each other; were often known beforehand to harbor the pathogens in question; shared dining and personal care items; kissed, hugged, and danced together; and only infrequently washed their hands.5,9 Under these circumstances, transmission occurred and was significantly associated with the conditions and behaviors described. But these conditions and behaviors do not pertain in the settings encompassed by the CF Foundation ban.

The second exception derives from studies in the early 1990s. LiPuma et al10,11 showed transmission among participants in a 4-week educational program in which young adults were together for seminar sessions, meals, recreational activities, a 7-h bus ride, twice-daily car rides of 45 min each, and long evenings in the same apartment. Govan et al12 showed transmission among a group of adults that included sexual partners, siblings, camp attendees, hospitalized patients kissing under the mistletoe, close friends with “protracted social contact,” and nine patients who regularly exercised together in a small space. Neither research group mentioned any effort to mitigate risk. These works are repeatedly cited as evidence of transmission by social contact.1,5,7-9 But, again, the conditions and behaviors they describe have no bearing on the CF Foundation ban.

So on what grounds did the infection prevention and control committee recommend the ban? In their draft guideline, the committee offers this rationale (Infection Prevention and Control Committee, CF Foundation, written communication, May 19, 2013):

**CF indoor events**

Given the risks of person-to-person spread of CF pathogens within healthcare and non-healthcare settings, it is felt that there are also risks of transmission of CF pathogens between people with CF who attend indoor events at the same time.

They had a feeling.

MISGUIDED AND UNNECESSARY

The preceding passage goes on to note that the risk the committee sought to address “cannot be quantified.” Whether the risk is greater than the risk one might incur from driving to such an event, they do not
know. The evidence indicates the risk is low. But to focus only on risk—to note only that something is possible and to ignore the opportunities for mitigation and the possible benefits for which one takes a risk—is to present a one-sided equation. We do not make decisions based on risk alone. And in truth, the size of the risk is irrelevant.

In the United States, an 18-year-old can choose to join the military and go to war. War is risky. But adults in our society have the right to take this risk, and some, weighing the relevant factors, will choose to do exactly that. Others, weighing the same factors, will decide otherwise. In either case, the decision is theirs.

In contrast, parents make their children’s decisions. Founded by parents in 1955, when there essentially were no adults with CF, the CF Foundation could only have begun as an organization accustomed to making decisions for others. As the CF population continued for decades to consist overwhelmingly of children, it remained understandable that the CF Foundation would grow comfortable in the habit of making decisions for others. But the demographics of CF are changing. Adults now or soon will comprise one-half or more of the CF population in the United States. The CF Foundation says its ban “was created in the best interest” of people with CF. But for one-half of that population, the decision as to what is in their “best interest” belongs not to the CF Foundation but to the individuals themselves. There are no defensible grounds for the CF Foundation to take for itself a competent adult’s right to assess the potential risks and benefits of attending an event at which other people with CF may be present and to act accordingly, and to maintain otherwise can best be characterized as misguided.

Moreover, the combined use of such practices as prescreening, implementation of better hand and respiratory hygiene, and the maintenance of safe distances can render safe even settings as putatively dangerous as camps. Other CF-related organizations have managed to incorporate practices like these into policies for meetings and conferences that enable safe attendance by adults with CF, and the CF Foundation’s failure to do likewise means only that the CF Foundation failed, not that a ban was necessary.

HARMFUL

With the closing of the CF camps, the implementation of ever more rigorous and visible infection control measures, and an endless barrage of CF Foundation literature, patients with CF and their families have been made aware of cross-infection risks to the point of being terrified. The ban now compounds that fear. By conveying to people with CF that they are unfit to be around people like themselves, that they are a source of contagion, and that they are a danger to others, the ban damages what for many patients is an already fragile sense of self-worth. For adults, the ban carries the additional message that they are incompetent to make their own decisions. And all this, it does publicly.

Nor is the ban’s potential for harm limited to patients. Since its inception, the CF Foundation has done incalculable good for people with CF and in the process inspired for itself vast amounts of good will. To now invoke a policy that declares as personae non gratae the very people on whose behalf the CF Foundation claims to advocate creates a paradox that can be lost on few. Awareness of this irony will eventually spread and thereby do we fear that the ban puts at risk the CF Foundation’s hard-won reputation and its own well-being.

WHAT WE RECOMMEND

We recommend that the CF Foundation revoke its ban. In its place, we recommend development of a new policy that better balances possible benefit against probable harm, and that for models the CF Foundation— together with a diverse group of adults with CF—look to those organizations that now facilitate attendance at their events by people with CF.

For people with CF, the policy we envision will embrace a balance between safety and the opportunity to participate in CF Foundation events. For the CF Foundation, work toward such a policy offers the opportunity to remind itself of the greater goal for which the CF Foundation was built. That goal is not just to add to an accountant’s tally of tomorrows. Rather, the goal is to help young people with CF use their tomorrows to become healthy, functioning adults and to achieve what all parents aspire to for their children: to go responsibly and productively into the world, making choices, accepting challenges, and treating others with respect and dignity.

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Financial/nonfinancial disclosures: The authors have reported to CHEST the following conflicts of interest: Dr Quinton’s laboratory research is supported by grant funds from Cystic Fibrosis based non-profit organizations. Mr Shepherd and Drs Goodrich and Desch have reported that no potential conflicts of interest exist with any companies/organizations whose products or services may be discussed in this article.
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Rebuttal From Dr Jain et al

Authors on both sides of this debate agree that evidence exists for person-to-person transmission of virulent pathogens between individuals with cystic fibrosis (CF) in non-health-care settings that has resulted in worsened outcomes.1,2 Our disagreement stems from each side’s perspective on the relevance of that evidence to the recommendation that only one individual with CF be allowed to attend Cystic Fibrosis Foundation (CF Foundation)- or CF center-sponsored indoor events.

Mr Shepherd and colleagues3 argue that pathogen transmission has been demonstrated only in social settings under conditions that are not relevant to “public and professional settings where adults behave with constraint.” They further state that the risk, however great, is irrelevant, using the analogy of an 18-year-old making a choice to go to war. Fighting in a war may be an unfortunate metaphor for attending a CF Foundation-sponsored indoor event, but Mr Shepherd and colleagues,3 perhaps unwittingly, highlight the potential life-threatening risk that informs the CF Foundation’s policy.

The CF Foundation has a low tolerance for risk and is unwilling to host indoor events wherein two or more individuals with CF can potentially transmit a virulent pathogen. This perspective is shared by The United Kingdom Cystic Fibrosis Trust and Cystic Fibrosis Canada; both organizations make similar recommendations.4,5 Like these peer organizations, the CF Foundation is committed to pursuing opportunities to help people with CF participate in events and activities electronically, conveying voices and images, but leaving unintended touches and coughs out of the risk calculation.

We agree that individuals with CF should decide what is in their own best interest. However, individuals with CF and their families are variably informed about infection risk,5,6 have different levels of tolerance for...
such risk, and are likely to view the new guidelines differently. The Guidelines Committee included an adult with CF and three parents of children with CF, one of whom is an author of this commentary. During the public comment period, many individuals with CF and their families voiced support for the recommendation currently being debated.

We know this policy comes at a cost. Many years ago, it was difficult for the CF Foundation to exclude individuals infected with *Burkholderia cepacia* from CF Foundation- and CF center-sponsored events, although this policy was met with relief by many individuals with CF. We now face the difficult task of expanding this policy to everyone with CF regardless of pathogen status. Mr Shepherd and colleagues’ object to this policy as paternalistic overreaching by the CF Foundation. Yet their belief that such a policy will necessarily damage the “already fragile sense of self-worth” of individuals with CF is no less patronizing. One’s sense of self-worth is neither defined by nor equated with one’s tolerance for risk.

We understand that the new recommendation will be an adjustment for individuals with CF who have participated for years at CF Foundation- or center-sponsored family nights, education days, and benefit events. However, we emphasize that the CF Foundation’s policy is informed by peer-reviewed data and represents the organization’s commitment to responsibly promote the health and well-being of people with CF.

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**Financial/nonfinancial disclosures:** The authors have reported to CHEST the following conflicts of interest: Dr Saiman receives funding from the CF Foundation to provide expertise in infectious diseases and microbiology. Ms Sabadosa is a full-time, 10-year employee of the Cystic Fibrosis Foundation. Drs Jain and LiPuma have reported to CHEST that no potential conflicts of interest exist with any companies/organizations whose products or services may be discussed in this article.

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**References**


**Rebuttal From Mr Shepherd et al**

This debate concerns a policy of the Cystic Fibrosis Foundation (CF Foundation) and the science that supports it—or does not—and we thank Dr Jain and colleagues for their willingness to address this issue. First, some clarification. Dr Jain and colleagues speak of “recommendations.” Dr Jain and his colleagues all served on the committee that recommended updates (Infection Prevention and Control Committee, CF Foundation, written communication, May 19, 2013) to the CF Foundation’s guidelines. But with respect to the recommendation that led to the ban, it was the CF Foundation that made it into policy. Dr Jain and colleagues are responsible for their recommendations; the CF Foundation is responsible for its policy.

The authors also state that the CF Foundation invited public comment on their recommendations. In January 2013, the committee forwarded 98 recommendations to the CF Foundation. In May 2013, these recommendations were distributed to cystic fibrosis (CF) center personnel and others for public comment. But the CF Foundation announced its ban on March 14, 2013, 2 months before public comment began. The ban was put in place without public comment, and the CF Foundation has refused opportunities to discuss it ever since.

Finally, the authors speak of new knowledge that now warrants the ban. Presumably they are referring to findings in the 16 papers compiled by the CF Foundation to support the ban. As we discussed in our
Counterpoint Editorial, none of these papers shows person-to-person transmission in settings of the sort covered by the ban. The remainder of the Point Editorial relies on old knowledge about transmission in CF camps, in clinics and hospitals, and among adults using no protective behavior and in repeated, sustained, close-quarter contact—none of which describes the contemporary public and professional settings to which the CF Foundation’s ban applies.

In their argument, Jain et al posit three questions, answer yes to all (as do we), and conclude the CF Foundation’s policy is, therefore, warranted. We conclude otherwise. Stopping with these three questions falls woefully short of an analysis sufficient to support the CF Foundation’s policy. Virtually every action in life carries some degree of risk for something. Yet we generally proceed—else we would never drive a car—by extending the risk analysis to include an assessment of likelihood, of steps that can be taken to reduce the risk, and the benefits to be gained by accepting the risk. Leaving out these steps may have produced a course of action Jain et al (and the CF Foundation) consider the most prudent, but it also yields the most simplistic, constricted, and damaging of the many options one might otherwise envision.

Salt Lake City’s Salt Palace Convention Center, site of the 2013 North American CF Conference, encompasses 675,000 square feet. Because of an unquantified risk, the CF Foundation refused to allow us or any two adults with CF in that building at the same time. Lacking even a ballpark estimate, some new knowledge the CF Foundation might usefully pursue is to actually quantify that risk. We suspect it would be tiny. If not, the CF Foundation would have evidence to warrant its ban. Until then, the ban is causing more harm than good and should be revoked.

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DOI: 10.1378/chest.13-2407

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