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**Cystic Fibrosis Foundation
Extends CF Adult Care Program**

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Describe the philosophy of why the CF Foundation is establishing adult care programs.

During the last 10 years, the number of individuals with CF 18 years old and older has nearly doubled. Assuring access to quality adult care is critical to the mission of the CF Foundation. Just 20 years ago, CF was thought of as only a pediatric disease. Now due to the success of the specialized CF care center network, as well as scientific advancements, individuals with CF are living longer and require new services from the health care system.

In the early 1980s, the CF Foundation launched a unique program to teach physicians who were already in adult pulmonary medicine about CF (i.e. internist specializing in pulmonary medicine). However with an increasing number of adult patients, the CF Foundation must intensify its efforts to ensure specialized care.

Why now when things seem to be working well with the system as it is?

Because for many years, CF was a disease seen only by pediatricians; physicians who care for adults did not learn about CF. When there were only a small number of adults at each center, the dedicated pediatricians who cared for them continued to do so. This has led to odd situations in some centers, with 40- and 50-year-olds being hospitalized with children. Also, as time unfolds, medical issues develop that are out of the sphere of pediatricians. These include: reproductive issues; gynecologic issues (including menopause (how's that for success!)); high blood pressure; osteoporosis; issues related to cancer screening (breast, prostate, GI tract, etc.); back pain; and more.

In addition, there are some CF specific problems such as diabetes and biliary tract problems, which occur with greater frequency in adults. Adult program directors can coordinate care to be sure that these issues are recognized. They can work with their subspecialist colleagues to develop expertise among the adult program's consultants in areas such as endocrinology or gastroenterology that will be important, as more and more individuals with CF age. So although the system has been a good one, we need to look to the future and in many ways, the future is now!

How do the current programs address the issue of transition between pediatric and adult care programs?

The goal of the transition program is to allow the patient to move from a pediatric program to an adult program at a high level of comfort.

Both the adult and pediatric care programs play a key role in the transitioning process. As the name suggests, we are moving patients from what they have experienced in a pediatric setting to that which is appropriate for adults. The style of adult care is quite different. Beginning in late adolescence, patients are asked to take greater responsibility their care. It has been my experience that for every patient who welcomes the change, another finds it difficult to leave the familiarity and comfort level they have enjoyed with their pediatric CF specialist.

In either case, the change must not be an abrupt one. Each CF care center as part of their accreditation evaluation by the Foundation, has been asked to design a transition program. This program can take the form of a joint clinic for teenagers where patients may see members of both teams or similar variations. (In many centers, the nutritionist, respiratory therapist and social worker may be the same for both the pediatric and adult programs.)

What are the criteria that must be met by an adult care program to be accredited by the CF Foundation?

The adult program director should be a board-certified internist or family practitioner. Subspecialty training in pulmonary medicine is desirable, but the most important characteristic is a commitment to CF care. Patient care must be provided by a multi-disciplinary team whose members are well versed in, and oriented toward, adult-care issues. When adults with CF need to be hospitalized, they should be in an age-appropriate setting. The Foundation believes that the formation of adult care programs is a major developmental step in the tradition of quality it has established over its 30-year history of accredited care centers.

How are the internists identified and recruited?

The best way is by personal contact between the center director and colleagues in the institution's Department of Medicine. The Foundation does have several fellowship training programs in place to accomplish the pulmonary training for adult medicine physicians. But the vast majority of the internists who became involved in CF do so because they have recognized the challenges and rewards of CF care. Opportunities for clinical research are equally strong motivators, as is the knowledge that CF patients need and appreciate their commitment.

What provisions are in the program for training adult care physicians?

Current adult CF care providers have formed a network to assist and guide others in the developmental stages of an adult CF program. The CF Foundation provides grants to clinicians to attend the North American CF Conference if they show significant interest in becoming involved in the adult CF care arena. The center director (who is almost always the director of the pediatric program) continues to oversee the entire center, and his or her experience in CF care can be valuable to the adult care providers

What provisions are made for education and career counseling for patients in the adult care programs?

The team approach to care involves social workers and psychologists who are trained to guide patients as they develop career and personal goals for their adult lives. The adult care team helps to address the medical needs of the patient and the rigorous demands of living full, independent lives, while adhering to a sometimes complex treatment regimen demanded by a chronic disease.

It gives me a great deal of personal satisfaction to see my patients living longer and better lives with the need to plan for college and careers. Our greatest success is that we have lots of adults with CF dealing with the ups (and downs!) of dating, marriage, and the working world.