

Executive Summary of Planned Activities

The Cystic Fibrosis Worldwide (CFW) Education Podcast Series I is based on CFW's well-established education program. Since inception in 2002, CFW has hosted a variety of conferences and workshops, which feature top medical and allied health professions who specialize in cystic fibrosis (CF).

With 67 member countries and numerous partnerships, CFW has been able to spread information to families, patients, and medical professionals. The Education Podcast Series I is designed to extend this effort by providing resources to those who may not normally have access to CFW's conferences and workshops. CFW will achieve this goal by making presentations available on the CFW website and iTunes. Many medical professionals lack the time and money needed to travel to educational conferences, but most professionals have internet access. Also, data indicates that approximately 43% of physicians own an iPod or similar mp3 device.*

In addition to increased availability due to internet access, CFW will make pertinent information about CF available to a broad audience by offering the presentations in multiple languages, English and Spanish. In the US, Hispanic patients face difficulty due to the inability to communicate effectively with medical and allied health professionals as well as the CF community. It has been found that 64% of US patients with limited English speak Spanish.** In addition, Hispanic children make up 33.1% of children living in poverty in the US, which increases the concerns for adequate health care and information. The Spanish translations will not only be available to Spanish-speaking medical and allied health professionals but also Spanish-speaking patients and families. Informed medical professionals are only half of the equation. Patients and their caregivers need to be knowledgeable of treatment options and healthy habits to improve their health.

In addition to accessibility, the Education Podcast Series I offers an innovative approach to education. The program allows medical and allied health professionals, as well as patients and families, to access quality educational materials from the comfort of their own home. Not only are participants able to access the information from a computer anywhere in the world, but they are also able to download the information and take it with them to view at their own leisure. The mp3 format allows participants to listen to the presentations without being stuck in a classroom or in front of a computer. According to The Pearson Foundation, 61% of community college students have taken an online course.*** Distance learning is in demand, and medical and allied health professionals, as well as patients and families, need access to education that fits their busy schedules and tight budgets.

The Educational Podcast Series I will feature the following presentations.

CF from Gene to Disease

Dr. Harry Heijerman - Pulmonologist, Netherlands, CFW Medical Advisor

Early Lung Disease - Diagnosis and Monitoring

Dr. Ian Balfour-Lynn - Respiratory pediatrician, Royal Brompton Hospital, London, UK

Nursing: Overview of CF

Dr. Su Madge - Consultant Nurse, Royal Brompton Hospital, London, UK, ECFS Board

CF Nursing - Hygiene and Cross Infection:

Practical management of indwelling ports and gastrostomies

Dr. Su Madge - Consultant Nurse, Royal Brompton Hospital, London, UK, ECFS Board

Inhaled Therapies (not antibiotics)

Dr. Harry Heijerman - Pulmonologist, Netherland, CFW Medical Advisor

Diagnosis and Treatment of PI

Dr. Anne Munck - Pediatrician, Paris, France, ECFS Board

European Standards of Care

Dr. Su Madge - Consultant Nurse, Royal Brompton Hospital, London, UK, ECFS Board

DIOS and Other GI Manifestations

Dr. Anne Munck - Pediatrician, Paris, France, ECFS Board

Liver Disease

Dr. Anne Munck - Pediatrician, Paris, France, ECFS Board

Nutrition from Infancy to Adulthood

Sue Wolfe - Chief Pediatric Dietitian, Leeds, UK and ECFNG

Physiotherapy - Maintaining the Airways and Keeping the Body Fit

Louise Lannefors -Physiotherapist, Lund, Sweden. IPG - CF

New Therapies

Dr. Ian Balfour-Lynn - Respiratory pediatrician, Royal Brompton Hospital, London, UK

ABPA, Wheeze, Hemoptysis, and Pneumothorax

Dr. Ian Balfour-Lynn - Respiratory pediatrician, Royal Brompton Hospital, London, UK

Other CF Complications

Dr. Harry Heijerman - Pulmonologist, Netherlands, CFW Medical Advisor

CF Related Diabetes

Dr. Harry Heijerman - Pulmonologist, Netherlands, CFW Medical Advisor

Physiotherapy/ Modern Physiotherapy

Louise Lannefors -Physiotherapist, Lund, Sweden. IPG – CF

* Pri-Med National Insights & Behaviors Study, May 2008 (N=851 PCPs)

** Virtual Mentor. April 2008, Volume 10, Number 4:211-216.

*** The Pearson Foundation Community College Student Survey, 2010