National Jewish Health
Breathing Science is Life.

Coalition for Pulmonary Fibrosis and NJ Collaborate

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DENVER , CO —

Genetic Counseling, Medical Information, and Support Program First of its Kind in U.S.

The Coalition for Pulmonary Fibrosis (CPF) and National Jewish Medical and Research Center today announced the launch of the first genetic counseling program for patients and families affected by familial pulmonary fibrosis. The telephonic counseling program will be operated by National Jewish and is funded by CPF.

Pulmonary fibrosis is a disease characterized by progressive scarring of the lungs, which robs patients of the ability to breathe. Most cases are of unknown cause, and are called Idiopathic Pulmonary Fibrosis or IPF. IPF affects an estimated 128,000 patients in the United States with about 48,000 new cases diagnosed each year. There is no approved treatment for IPF and it is ultimately fatal.

An estimated 10-15 percent of IPF patients, have a form of the disease that runs in families. Recent research has identified two genetic mutations that are associated with familial pulmonary fibrosis, and tests for those mutations have recently become available to the public.

The genetic counseling program will provide a qualified genetic counselor, who has expertise in familial pulmonary fibrosis, to discuss by phone various issues surrounding familial pulmonary fibrosis. These can include preparation for and interpretation of genetic tests, and various life decisions, such as having children and planning for the future. Experts recommend talking to a counselor prior to having any genetic tests, so that people are prepared to learn the results.

“With a disease that has no FDA approved treatment and no cure, it is incredibly difficult for patients to deal with the diagnosis. When entire families are threatened by the disease, it is an even more devastating experience,” said Mishka Michon, Chief Executive Officer for the CPF. “This counseling program will help patients and families to better understand what is known about familial pulmonary fibrosis and to make informed decisions for themselves and their family members with regards to their overall care, including genetic testing. We are pleased to support this important service.”

“This is a groundbreaking program in pulmonary fibrosis, and we are so pleased to be working with the CPF on it,” said Kevin K. Brown , MD, Vice Chair of Medicine at National Jewish. “Genetic counseling is often important for patients and families at risk for pulmonary fibrosis. Right now, there are few known genetic mutations that may cause familial pulmonary fibrosis, but in the future, more of these mutations will be identified. A genetic counseling program is a critical resource that will help patients and families now and into the future.”

For further information on the Familial Pulmonary Fibrosis Genetic Counseling Program or to speak with a genetic counselor, call 1-800-423-8891, ext. 1022.

About the Coalition for Pulmonary Fibrosis

The Coalition for Pulmonary Fibrosis (CPF) is a 501(c)(3) nonprofit organization, founded in 2001 to accelerate research efforts leading to a cure for idiopathic pulmonary fibrosis (IPF), while educating, supporting, and advocating for the community of patients, families, and medical professionals fighting this disease. The CPF funds promising research into new approaches to treat and cure pulmonary fibrosis; provides patients and families with comprehensive education materials, resources, and hope; serves as a voice for national advocacy of IPF issues; and works to improve awareness of IPF in the medical community as well as the general public. The CPF's nonprofit partners include many of the most respected medical centers and healthcare organizations in the U.S. With more than 15,000 members nationwide, the CPF is the largest nonprofit organization in the U.S. dedicated to advocating for those with pulmonary fibrosis. For more information please visit www.coalitionforpf.org or call (888) 222-8541.

About National Jewish Medical and Research Center

National Jewish Medical and Research Center is a global leader in the research and treatment of respiratory, immune and related diseases. Since 1899, the mission of National Jewish Medical and Research Center has been to heal, to discover, and to educate as a preeminent healthcare institution. National Jewish serves by providing the best integrated and innovative care for patients and their families; by understanding and finding cures for the diseases we research; and by educating and training the next generation of healthcare professionals to be leaders in medicine and science.

Today, National Jewish is pioneering individualized medicine programs, which embrace the paradigm shift from reactive medicine to proactive, personalized healthcare. These programs enable us to integrate the provision of outstanding patient care, the conduct of novel basic, translational, and clinical research, and the education of healthcare and research professionals. Through our efforts, we seek to achieve cures for patients who seek treatment and to bring new knowledge and discoveries to help people worldwide. For more information, visit www.nationaljewish.org or call (800) 222-LUNG.

National Jewish Health is the leading respiratory hospital in the nation. Founded 125 years ago as a nonprofit hospital, National Jewish Health today is the only facility in the world dedicated exclusively to groundbreaking medical research and treatment of children and adults with respiratory, cardiac, immune and related disorders. Patients and families come to National Jewish Health from around the world to receive cutting-edge, comprehensive, coordinated care. To learn more, visit the media resources page.

Media Resources

We have many faculty members, from bench scientists to clinicians, who can speak on almost any aspect of respiratory, immune, cardiac and gastrointestinal disease as well as lung cancer and basic immunology.

- Accomplishments & Awards
- Annual Report
- Financials

Media Contacts

Our team is available to arrange interviews, discuss events and story ideas.

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