

Living with Idiopathic Pulmonary Fibrosis

Patients living with idiopathic pulmonary fibrosis (IPF) and their families have a new resource online. The Pulmonary Fibrosis Foundation (PFF)—whose mission is to find a cure for IPF by funding research, advocating for IPF issues, promoting disease awareness, and providing a compassionate environment for supporting patients and their loved ones—launched an entirely redesigned web site (<http://www.pulmonaryfibrosis.org>) in April 2010.

The site discusses the common symptoms of IPF, options for treatment, and ways in which patients with this condition can maintain a high quality of life. One highlight of the site is the “Patient Resources” section, where visitors can join one of the pre-existing online or face-to-face support groups or they can create a new support group. This section also answers frequently asked questions, lists resources for lung transplantation, and provides information on the regional chapters of the PFF community.

The “Get Involved” section is designed to inform visitors of the events and fundraisers that the PFF is involved with each year. It also provides information on how to become an advocate for IPF, opportunities to volunteer, and the steps involved for those interested in starting a new fundraiser. The site also has the latest news articles of interest to those within the IPF community as well as videos and podcasts involving the PFF.

A unique feature of the site is the “Research” section, which enables visitors to view all of the current, active research related to IPF. Visitors of the

site can sort this research based on a variety of factors, including the specific medical condition referenced, the category of the research (for example, observational versus interventional), or the date of the research. This section also tracks the amount of funds generated by the PFF each year.

Resource for Patients with Parkinson Disease

The National Parkinson Foundation (NPF)—an organization dedicated to improving the quality of care for patients with Parkinson disease (PD) through research, education, and outreach—launched a new web site (<http://www.parkinson.org>) in March 2010. The aim of this new site is to be a comprehensive source providing the most up-to-date information for

patients with PD, their caregivers, and their families.

A large portion of the site is devoted to outlining what PD is and ways in which the disease may affect a patient’s life, including symptoms, treatment options, and ways to maintain a healthy lifestyle after diagnosis. The site also offers information for patients, caregivers, and health professionals about improving care through research, education, and outreach. The “NPF Network” lists leading allied health care professionals who are devoted to improving the quality of PD care today.

In the “Ask the Doctor” section, visitors can voice concerns or ask questions regarding PD as well as read other members’ questions and physicians’ responses. The video library features clips of medical professionals answering frequently asked questions

www.parkinson.org

about the disease. Visitors also have access to information about recently published studies involving PD as well as related news articles.

A highlight of the site is the “NPF Community,” where members can connect with each other, share personal stories, find local PD events, and donate to community fundraisers. In “Discussion Corners,” members can ask questions about PD, connect with other patients and caregivers, or simply chat and make friends with other community members.

With the “Find Local Resources” feature, visitors can locate nearby community organizations and support groups. Attention also is given to the many ways that community members can lend their support, including opportunities to volunteer.

Life Beyond Cancer

The Life Beyond Cancer Foundation (LBCF) believes that the effects of cancer do not simply end when the treatment is over; the adjustment back into everyday life can be emotionally, physically, and mentally challenging. The LBCF seeks to assist cancer patients throughout the country by working with a variety of nonprofit and community-based organizations to bring cancer prevention and early detection programs to communities nationwide. In order to help cancer patients and their families connect with support programs, learn about financial assistance, and have access to other essential resources, the LBCF has launched a new web site (<http://lifebeyondcancer.org>).

One highlight of the site is the section devoted to the various outreach and advocacy programs for cancer patients. In the Patient Financial Assistance program, the foundation works with health facilities where patients are receiving treatment in order to provide funds that cover



living expenses (such as mortgage, grocery, rental, and utility payments) for eligible patients. This section of the web site also provides information about the LBCF retreat—a four-day retreat for female cancer survivors, oncology nurses, and social workers that focuses on “the many components of wellness through and beyond the cancer experience.”

The site lists and provides links to a variety of useful cancer resources that may be of interest to site visitors. The web site also has a section focusing on news stories that provide information on recent advances in prevention and treatment of cancer.

Children’s Skin Health

The American Academy of Dermatology (AAD)—the largest, most influential, and most representative of all dermatologic associations—has created a new web site focusing on the many skin, hair, and nail conditions that affect children. The web site (<http://kidsskinhealth.org>) is unique in that it caters not only to parents looking for information for their children, but also for visitors who are children.

At the site’s homepage, visitors can choose to enter either the section

“For Kids” or the section “For Grown Ups.” The portion of the web site designed for parents is divided into three parts: (1) skin, hair, and nail care, (2) frequently asked questions, and (3) activities for parents to do with their children to teach them about different health topics.

In the skin, hair, and nail care section, parents can learn healthy habits to teach their children, such as maintaining hygiene and protecting their skin from too much sun exposure. This section also discusses the different conditions that often affect children, such as acne, lice, and ingrown toenails. Information pertaining to adults, such as aging skin, psoriasis, and hair loss, also is available in this part of the web site.

In the “For Kids” section, children can learn about their skin, nails, and hair on their own as well as play interactive games that test what they have learned. This section answers common questions and offers quick facts using child-friendly language to help children better understand the subjects. Another useful feature of the site is the “Skin Dictionary,” which defines the many different terms and conditions related to skin, hair, and nail care. ●