

When Disease Hits Home, Internet Provides Information And Community

(NAPSA)—When disease strikes, it affects not only the patient, but family and friends, too. Overwhelmed with concern and fear, loved-ones look to do anything that can help those who are ill not only survive, but get better and thrive.

With well-known diseases, such as cancer or AIDS, helpful information about the disease and available treatments is often readily available from physicians, as are local support groups. But for rare diseases, like the lung disease pulmonary hypertension (PH), learning about the disease and finding support from others who are battling the same illness can be a challenge.

Fortunately, in the past several years the Internet has grown into a seemingly endless source of information on sickness and disease—in the form of medical Web sites, such as WebMD.com and drkoop.com, as well as disease-specific organizations and support groups.

When looking to understand and combat a rare disease, disease-specific associations can be the best information source—and offer so much more. Often non-profit, these Web sites/organizations can provide relevant disease news and information, such as detailed explanations of the disease, advances in treatments and cautionary advice.

Such Web sites often enable patients and families to connect with others who are going through a similar experience. Many sites offer chat rooms, where patients can hear first-hand about others' treatments, learn about physician specialists and simply find others who will listen and talk.



Patients and parents can now learn more about medical treatments for rare diseases on the Internet.

“When faced with a rare disease—whether you’re a patient or a parent—it means a lot to know you’re not alone,” says Brenda Fracker, a member of the Pulmonary Hypertension Association (www.phassociation.org). Brenda’s son, Jared, was diagnosed as an infant with PH, a rare, life-threatening lung disease that can cause extreme shortness of breath, chronic fatigue and chest pain during physical activity. With more than 80,000 Web site visitors monthly, the PH Association has helped Fracker better understand the disease and connected her with other parents.

Says Fracker: “The site has provided invaluable information and helped us learn about a new treatment when it became available.” Now age eight, Jared is taking Tracleer™, the first pill treatment for PH, which has helped him not only play sports, but excel at them.

“I know a lot of people use the Internet for fun, business or shopping, but for anyone involved in a battle with disease, it can truly be a lifesaver.”