



Health Awareness

New Survey Highlights the Challenges of People Living with Rare Cancer

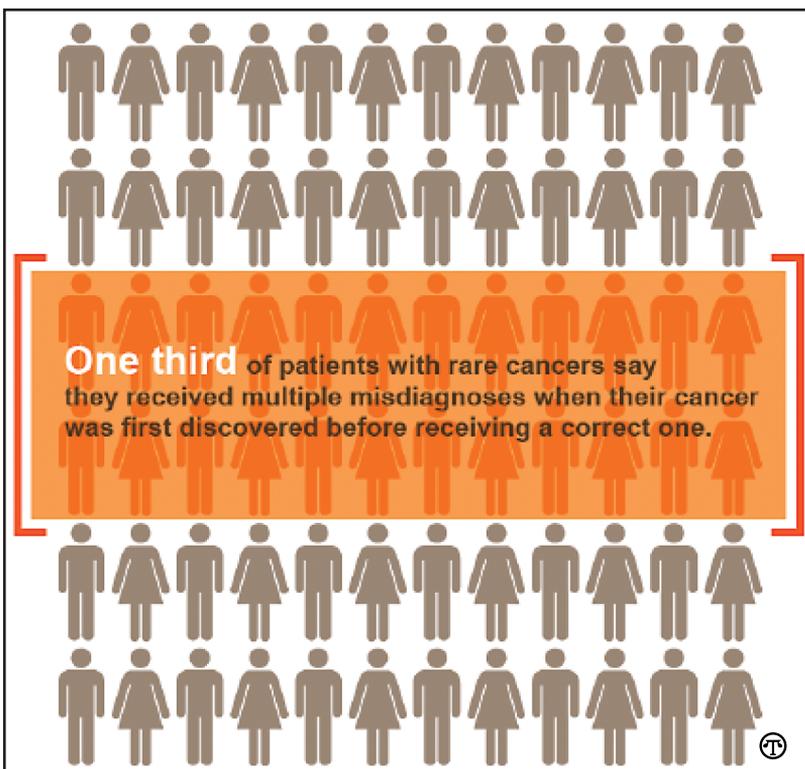
(NAPSA)—A new national survey shows that nearly one in three patients with rare cancers—twice the number as those with more common cancers—say they received multiple misdiagnoses when their cancer was first discovered. This delay in receiving a final, correct diagnosis leaves the vast majority of patients with rare cancers (75%) feeling very frustrated. The online *CURE* Rare Cancer Survey, sponsored by Novartis Oncology, was conducted independently for *CURE* magazine among 1,365 of its readers living with cancer to uncover challenges facing patients today and better identify their needs.

If you or a loved one are among the nearly 35,000 adults in the US who have a rare cancer, you are familiar with these challenges. Rare cancers are difficult to diagnose because symptoms can be absent, masked or mimic those of more common diseases, while overall awareness, research and treatment options typically lag behind those for more common cancers.

According to the survey results, patients with rare cancers are also more likely than those with more common cancers to say they lack access to credible and reliable information, causing them to feel alone in dealing with their disease. In fact, 74% believe they must be their own treatment champions. Acting as their own advocates, patients with rare cancers are two times more likely to search for disease information online than those with more common cancers.

Online resources are increasingly available for those with rare cancers. Novartis Oncology developed programs to help patients become educated on two rare cancers mentioned by survey respondents—chronic myeloid leukemia (CML) and gastrointestinal stromal tumors (GIST):

- The CML Alliance (www.CMLAlliance.com) and GIST Alliance (www.GISTAlliance.com) programs provide valuable information to people with CML and GIST, such as information about the rare cancers, treatment goals, the importance of regular testing and checkups, and patient assistance programs.
- CML Earth (www.CMLearth.com) and GIST Earth (www.GISTearth.com) are social networking communities designed to help patients feel less alone by



The *CURE* Rare Cancer Survey, sponsored by Novartis Oncology, was conducted independently for *CURE* magazine. Complete survey results are available at www.CUREToday.com, www.CMLAlliance.com and www.GISTAlliance.com.

Are You Surprised?

- Nearly one in three patients with rare cancers received multiple misdiagnoses.
- Patients with rare cancers are searching online twice as often as those patients with more common cancers.

providing a portal for them to privately share, support and connect with others like themselves. Patient discussion panels show that networking is important to patients with rare cancers who are looking to connect with people who have had similar experiences.

“These survey results show that patients with rare cancers have an urgent need for comprehensive, accurate information,” said John Hohneker, M.D., senior vice president, US Clinical Development and Medical Affairs, Novartis Oncology. “Our online resources provide patients with CML and GIST accessible, reliable and multidimensional support so they can make informed decisions about their treatment options.”

Detailed results from the *CURE* Rare Cancer Survey were published in *CURE*'s fall 2009 issue available at www.CUREToday.com. The magazine and Web site also

include the first-ever *Patient's Guide to Rare Cancers*, which is designed to address the issues raised in the survey and to help patients communicate more effectively with health care providers about their cancers.

“Surrounding patients with many levels of support can help them feel less alone in their disease management,” said Debu Tripathy, M.D., *CURE* Editor-in-chief. “Giving patients with rare cancers a better understanding of their disease can ease their frustration.”

The complete *CURE* Rare Cancer Survey report is available online at www.CMLAlliance.com, www.GISTAlliance.com and www.CUREToday.com.

Be Your Own Best Advocate

- Keep regular appointments with your medical team.
- Take your medication exactly as prescribed.
- Stay informed by visiting sites like www.CMLAlliance.com and www.GISTAlliance.com.
- Connect with other patients like yourself. Try www.CMLEarth.com and www.GISTearth.com.