



## AMERICAN COLLEGE OF GASTROENTEROLOGY

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### **Social Media Has Role in Delivery of Healthcare but Patients Should Proceed With Caution** *Esophageal Cancer Survivors Benefit From Facebook Group, IBD Patients at Risk of Misinformation on YouTube*

**Washington, DC (October 31, 2011)** – Social networking sites like Facebook and YouTube can be powerful platforms to deliver and receive healthcare information, especially for patients and caregivers who are increasingly going online to connect and share experiences with others with similar medical issues or concerns. However, these sites may lack patient-centered information and can also be sources of misleading information that could potentially do more harm than good, according to the results of two separate social media-related studies unveiled today at the American College of Gastroenterology's (ACG) 76th Annual Scientific meeting in Washington, DC.

In the first study, ***"Social Media for Esophageal Cancer Survivors,"*** researchers from the Mayo Clinic in Florida found that social media is an important resource for patients and their caregivers who are facing important treatment decisions after being diagnosed with esophageal cancer and managing difficult nutritional and lifestyle issues after esophageal surgery. "We have successfully worked with a highly motivated group of 65 patients who have been diagnosed with and treated for esophageal cancer and Barrett's high grade dysplasia," said researcher Herbert Wolfsen, MD.

Few patient-centered resources are available for families and caregivers facing important treatment decisions after being diagnosed with esophageal cancer, according to Dr. Wolfsen. He said that the project goal was to establish an online community through a Facebook group to assist patients and

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families anticipate—and cope with—surgical and post-operative challenges after being diagnosed with esophageal cancer. The group also helps promote disease awareness and esophageal cancer research advocacy in the community.

“Connections facilitated through this group have often lead to more contact offline to share their personal experiences and information regarding diagnosis and treatment from the perspective of the patient and their family.”

Since 2008 Dr. Wolfsen and his team recruited patients and their families to join and participate in the Mayo Clinic’s interactive Facebook group, which was created to bring together a geographically diverse group of esophageal cancer survivors. “Many of these patients do not live close enough to attend the quarterly support group meetings held at Mayo in Jacksonville, so the online group has allowed patients who may otherwise not have the support they need to connect with others who share their medical concerns,” said Dr. Wolfsen.

Much of the discussion and support revolves around strategies for coping with post-operative changes, especially with daily activities such as diet, nutrition, and swallowing and regurgitation problems, according to the study’s findings. The group also provides members with many resources including access to new medical information via text postings and links to video content on the Mayo Clinic YouTube channel, schedules of group meetings, treatment options and advice and support for patients, family and caregivers during recovery.

In a second study, ***“YouTube: A Friend or Foe When You Are Taking Care of IBD Patients,”*** researchers at the Cleveland Clinic Foundation analyzed the top 100 most viewed IBD-related videos for content, popularity and as a source of patient education information. They found that while YouTube can be a powerful tool for patient education and support, overall Inflammatory Bowel Disease (IBD) content posted on YouTube was poor. “Clinicians and their patients need to be aware of misleading information posted by patients or particularly by pharmaceutical companies who often post videos to make it seem like they are coming from a patient when in actuality it is a company advertisement,” said researcher Saurabh Mukewar, MD. “These sources are not transparent.”

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Crohn's disease and ulcerative colitis are the most common forms of IBD, which affect more than 1.4 million Americans. Both conditions inflame the intestines, leading to bouts of watery diarrhea, rectal bleeding, abdominal cramps and pain, fever, and weight loss. Crohn's disease can occur anywhere in the digestive tract, often spreading deep into the layers of the affected bowel wall. Ulcerative colitis usually affects only the innermost lining of the large intestine and rectum.

Patients with IBD respond differently to various treatments and inflammatory bowel diseases are life-long disorders, so from a healthcare standpoint, disease management is often challenging, according to Dr. Mukewar, who says many patients are constantly searching for new information and seek out the support of others with IBD—and want the kind of first-hand patient experience information that their doctors cannot provide.

“Recent reports state that 55 percent of IBD patients are not satisfied with the information provided at time of their disease diagnosis and more than 50 percent of IBD patients turn to the Internet as a source of information for IBD,” said Dr. Mukewar.

Both Dr. Wolfsen and Dr. Mukewar agree that Internet and social media can benefit patients and enhance their care. But Dr. Mukewar said his findings are concerning to him since IBD patients may get misleading information via YouTube® that could be harmful to their health.

“The success of Mayo's Esophageal Cancer Survivor Facebook group clearly demonstrates how social media can assist healthcare providers in providing patients with a way to connect and get the support they need that physicians cannot provide because we have not experienced the disease first hand,” said Dr. Wolfsen. “We are also able to provide the latest Barrett's disease and esophageal cancer research information and emphasize high quality sources of online information such as the Mayo Clinic YouTube channel.”

According to Dr. Mukewar, “one of the best resources for patients ideally would be physicians who also have health conditions and who can post a personal experience video on *YouTube*®, for instance, that would not only be medically correct, credible and trustful but would also contain that first-hand experience that patients with a disease like IBD really crave and search for online.”

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“The Internet and social media are not going away—YouTube is a powerful platform to deliver and receive healthcare information,” said Dr. Mukewar. “But healthcare providers and professional societies need to provide more educational and efficient materials using this powerful tool to counteract misleading information.”

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**About the American College of Gastroenterology**

Founded in 1932, the American College of Gastroenterology (ACG) is an organization with an international membership of more than 12,000 individuals from 80 countries. The College is committed to serving the clinically oriented digestive disease specialist through its emphasis on scholarly practice, teaching and research. The mission of the College is to serve the evolving needs of physicians in the delivery of high quality, scientifically sound, humanistic, ethical, and cost-effective health care to gastroenterology patients. [www.acg.gi.org](http://www.acg.gi.org) View releases on other research breaking at the ACG meeting at [www.acg.gi.org/media/press.asp](http://www.acg.gi.org/media/press.asp) [Follow ACG on Twitter](#)