Using Social Media and Online Communities to Partner with Patients

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NHC Health Leadership Conference

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CEO, Smart Patients
Doctors and scientists study and learn what is the best way to keep ourselves healthy.

Our fathers and mothers learn from them and they tell us.

They know a lot more than we do, and if we are bright, we do what they tell us to.
am I normal
Clinicians and researchers sent monthly reminders — with links to Connect 2 My Act — as well as occasional educational information to each member of the Facebook group. The alerts would show up just like any other Facebook notification, making the reminders easy to access.

After 12 months, Partners Connected Health achieved 79 percent “engagement” with the approximately 125 teens in the study group, compared to the typical rate of just 18 percent, according to Kvedar. Engagement with the ACT is defined as taking the survey at least once per month for a year.
Smart Patients
An online community where patients and caregivers learn from each other.

enter your email
JOIN

Christina, smart patient

Learn from other patients.
Patients often become extraordinarily knowledgeable about their disease. You can, too.

Mike and Lisa, smart patients

Research the latest treatments.
Understand how advances in personalized medicine can mean better treatment and fewer side effects.
Goals:

1. Help patients and families learn from each other (and from their providers) in safe, high quality peer-to-peer communities.

2. Help the healthcare system learn from patients and families in order to serve them better.

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Important Aspects of Peer Support

Strong privacy

Experienced staff monitors and moderates all communities

Close collaboration with advocacy and/or medical centers to help them learn more from patients

Support for patients and caregivers

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The Neonatal Intensive Care Unit (NICU) at El Camino Hospital is proud to partner with Smart Patients, an online community for patients and caregivers to support and learn from each other. The Smart Patients NICU Community was created as a resource especially for families affected by the challenges of giving birth prematurely or needing advanced medical attention in a neonatal intensive care unit (NICU). Providing care with the warmth of a community hospital and the quality of a large academic medical center, El Camino Hospital is also developing new ways of learning from patients about what matters most to you and we’d like to invite you to be part of this effort.
Smart Patients
Lung Cancer Community

In partnership with
Bonnie J. Addario Lung Cancer Foundation

enter your email
JOIN

The Bonnie J. Addario Lung Cancer Foundation (BJALCF) is proud to partner with Smart Patients, an online community for patients and caregivers affected by lung cancer and other kinds of cancer. The online support of the Smart Patients community complements the programs of BJALCF, which include monthly in-person support group sessions (“The Living Room”) and a patient education handbook (“Navigating Lung Cancer, 360 Degrees of Hope”).

Smart Patients was designed to extend the reach of these kinds of resources to an even broader group of cancer patients who can learn from each other about treatments, the latest science, and how it all fits into the context of their experience.

Join Smart Patients, ask a question, and support others who can learn from you.
New Community Case Study

"But you don't look sick..."
Sjogren's and SEX!
Traveling Tips
First Time Doctor Visit

Absent Friend
Pregnant and dealing with Sjogrens
Sick Sjoggie Parent - Help!
“My family and husband don’t understand what I’m going through on most days...they think I’m faking my illness and have called me a drama queen. I look perfectly healthy to them.

“I’m visiting a new doctor for the first time. What should I do and/or need to know to show up the most prepared for the visit?

“It makes it harder by the fact that so often, we look fine on the outside....or at least, not as sick as we feel on the inside.

“How do you help your health care team better understand the emotional impact of illness on your life?

“Thanks so much... I love the humor!

“I found it helpful to put in a thicker eye gel and then place a sleep mask over
You are not alone

I found the simple yet profoundly uplifting gift of being understood. For 20 years I carried my TM story and my TM symptoms in secret, not because I wanted to keep the secret but because there was no one else to understand the secret. The simple truth is that no one could really tell me that one thing all people need to hear- "You are not alone". I don't have words to convey the full scope of the changes a gift like that can make in the life of a man like me.
Nervous about dad's surgery

Started by Chuck on October 14, 2016

So it looks like we're all set for dad's hip replacement next month. We have a bunch of tests and appointments but they seem reasonable. I'm more worried about what happens AFTER the surgery. Any tips on how to prepare?

tags: orthopedics, hip replacement

by Jaqueline on October 14, 2016

Thinking ahead about after the surgery is definitely smart. Two things we found especially helpful: putting everything you need on one floor of the house and get used to doing daily stretches before the surgery.
Challenges of being in the NICU

Based on your NICU experience, in which of the following areas do you think your center has the most room for improvement?

- Understanding what is being done to my child
- Being able to stay with my child overnight
- Communication about discharge from the NICU
- Training on tube feeding, O2 monitoring, etc. at home

NEXT
Search clinical trials

I am looking for trials that are recruiting in united states.
Show all treatment trials.
Show trials for any target.
Show all phases.
Show trials within 100 miles of 64101.

Show the results as a list with the most relevant first.

23 matching trials

A Study of Nivolumab in Advanced Non-Small Cell Lung Cancer (NSCLC)
Status recruiting
Conditions lung cancer, non-small cell lung cancer
Treatments alimta, avastin, carboplatin, crizotinib, docetaxel, gemcitabine, nab-paclitaxel, nivolumab, paclitaxel, tarceva
Phase phase 1/phase 2
Targets ALK, EGFR, PD-1, VEGF, c-MET, ROS1
US States Alabama, Arizona, California, and 34 other states
Closest site Topeka, KS
Tags chemotherapy, immunotherapy, targeted therapy, metastatic cancer

Dinutuximab in Combination With Sargramostim in Treating Patients With Recurrent Osteosarcoma
Status recruiting
Conditions bone sarcoma, lung cancer, osteosarcoma, sarcoma, non-small cell lung cancer
### Clinical trials for multiple myeloma

**brought to you by Smart Patients**

Trials for:
- newly diagnosed
- smoldering myeloma
- maintenance therapy
- relapse/refractory
- all

Show trials within 100 miles of

**zipcode**

*Enter a 5 digit zipcode to filter trials by distance.*

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Thank you.

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