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

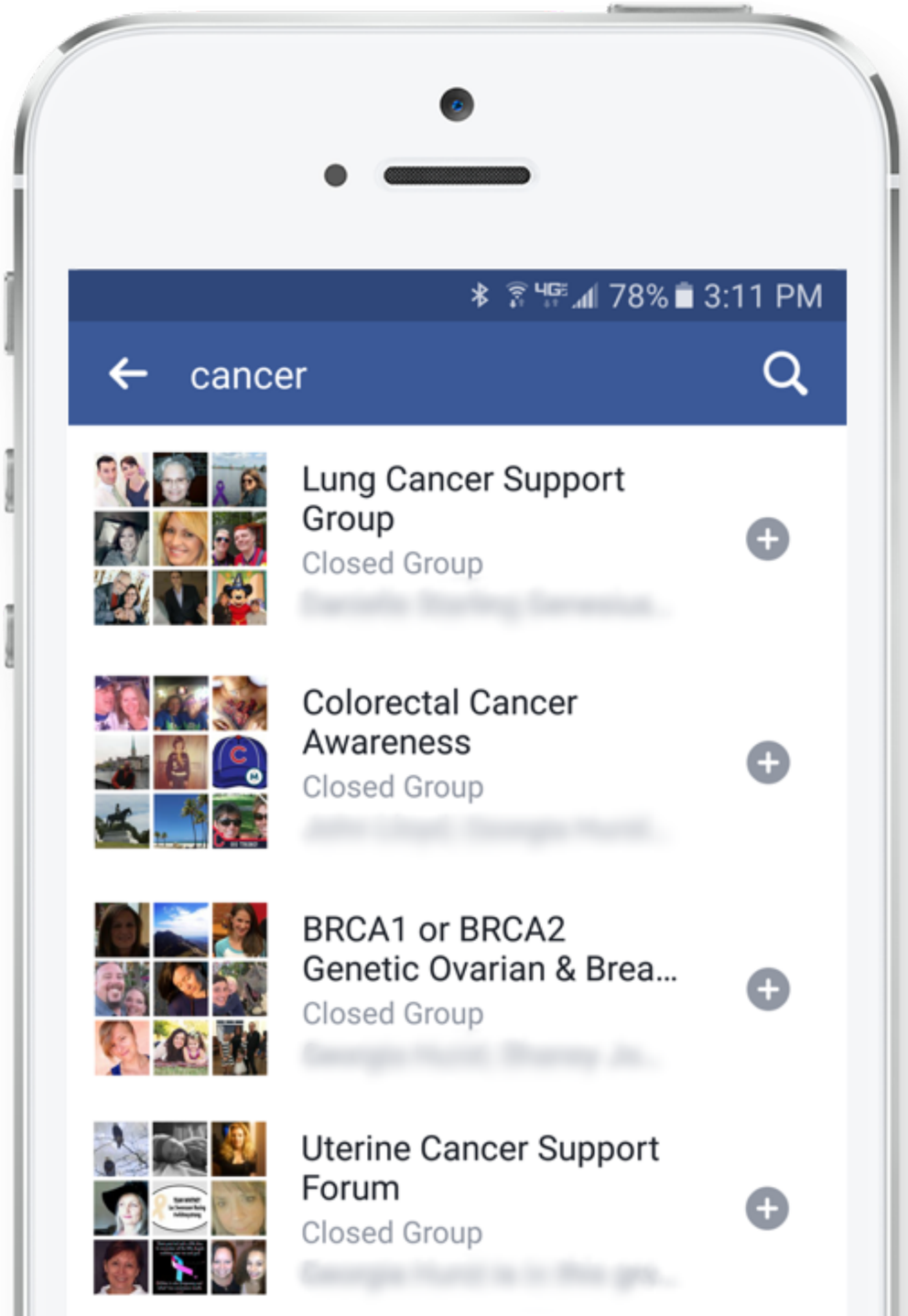
what they tell us to.

am I normal

Google Search I'm Feeling Lucky

what was this like for you?

Google Search I'm Feeling Lucky


78% 3:11 PM
cancer
Lung Cancer Support Group
Closed Group
Colorectal Cancer Awareness
Closed Group
BRCA1 or BRCA2 Genetic Ovarian & Brea...
Closed Group
Uterine Cancer Support Forum
Closed Group

HEALTH IT, PATIENT ENGAGEMENT

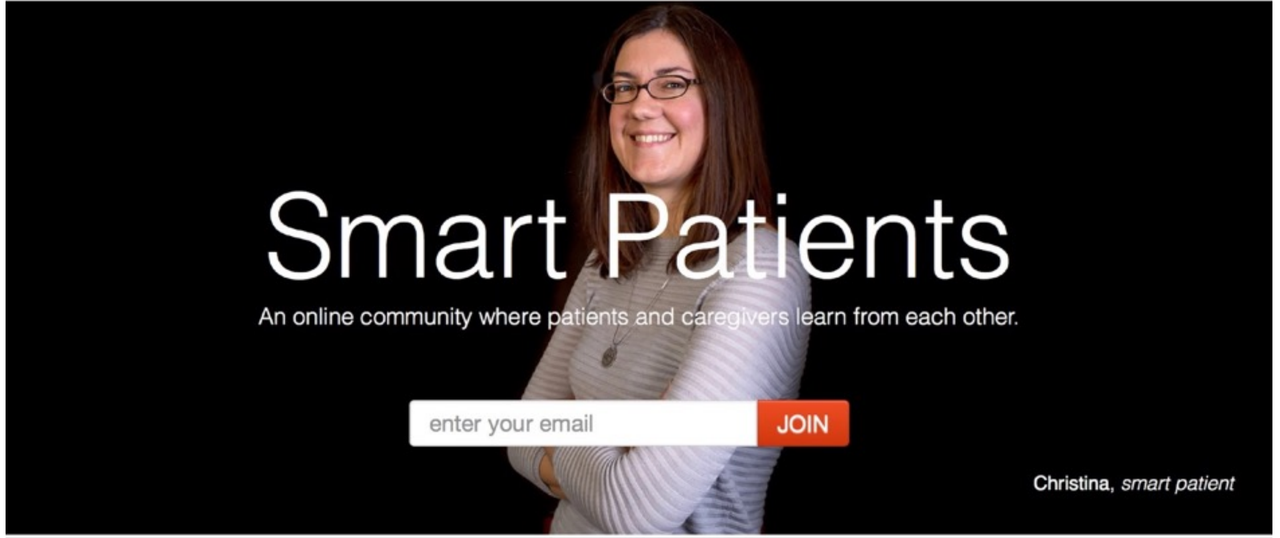
Facebook reminders help teens control asthma

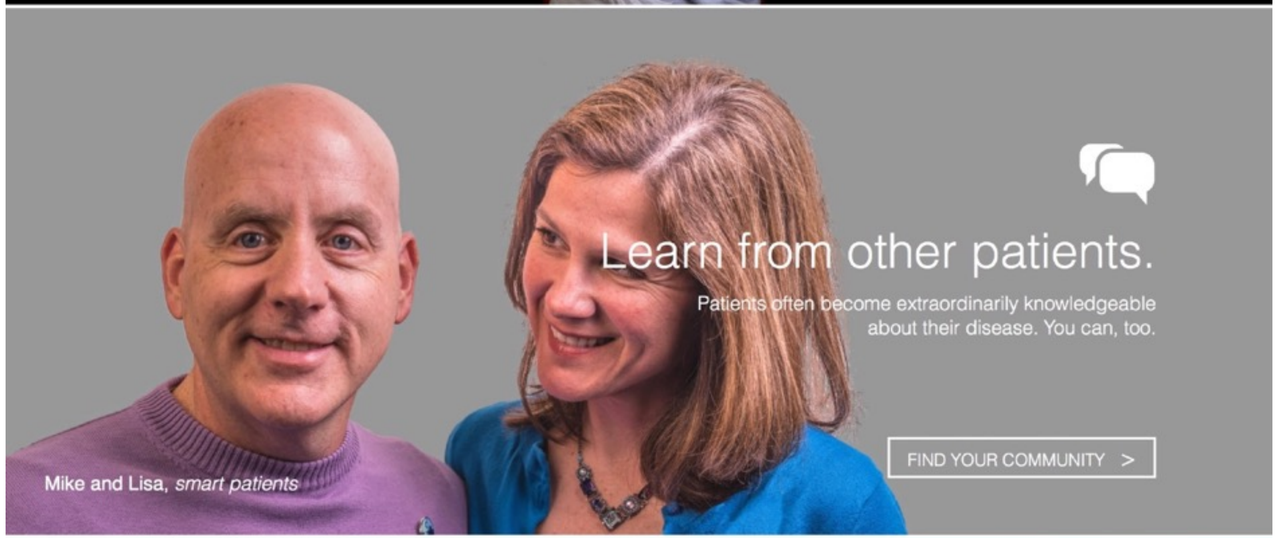
By NEIL VERSEL

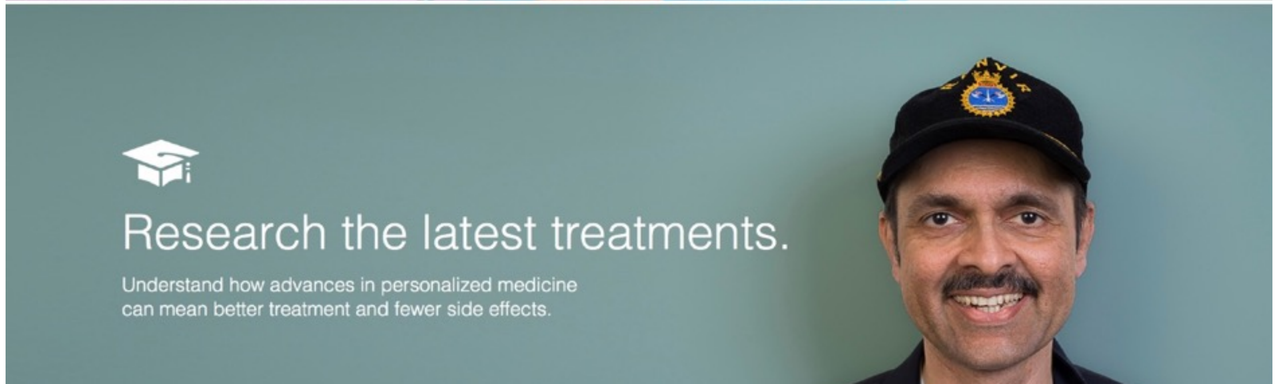
Post a comment / 427 Shares / Jul 22, 2015 at 7:16 PM

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.
FIND YOUR COMMUNITY >
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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Smart Patients
NICU Community

In partnership with

El Camino Hospital

enter your email JOIN

El Camino Hospital®
THE HOSPITAL OF SILICON VALLEY

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

BONNIE J. ADDARIO
LUNG CANCER
FOUNDATION

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 Sj grens

Sick Sjoggie Parent - Help!

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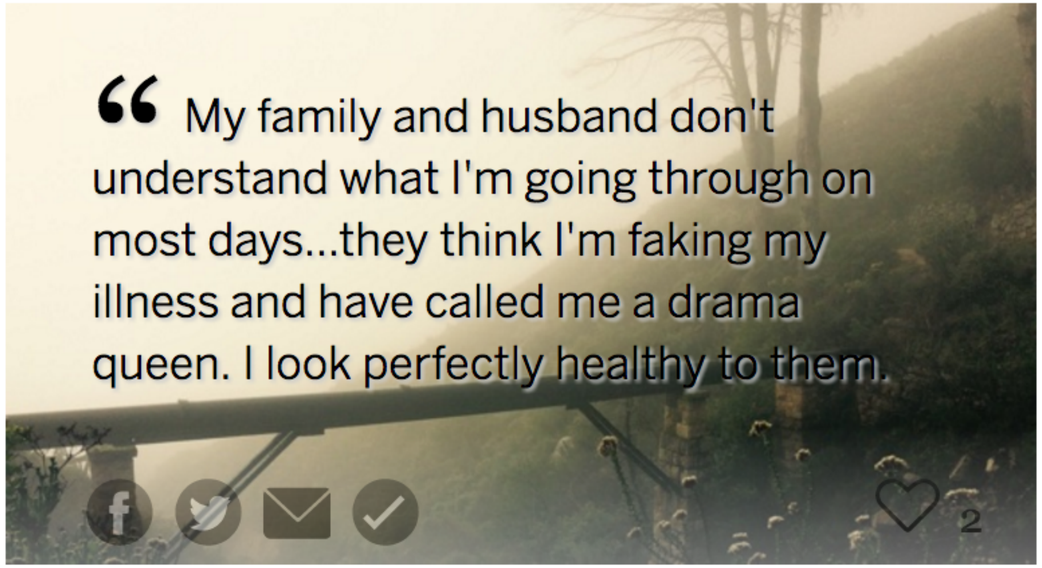
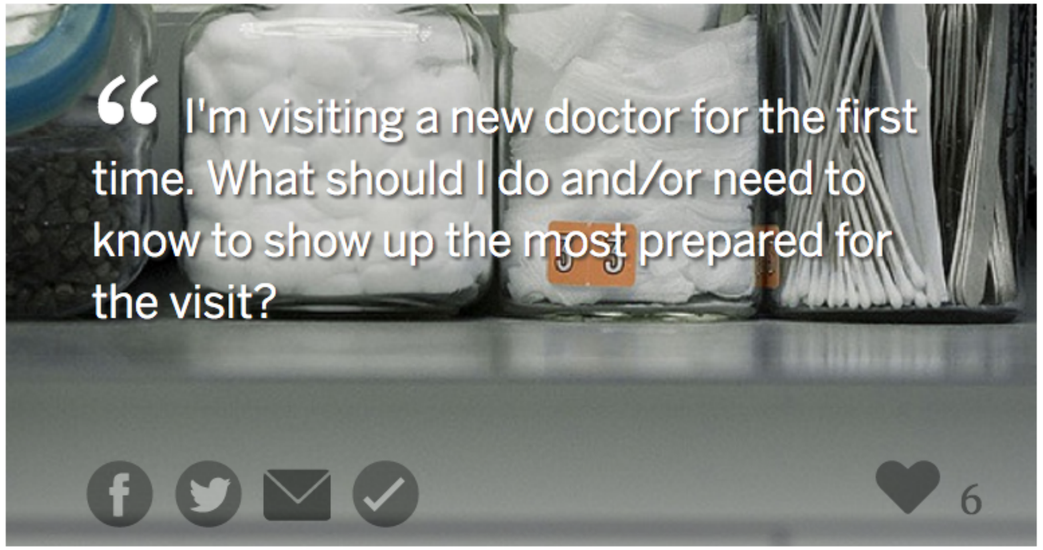
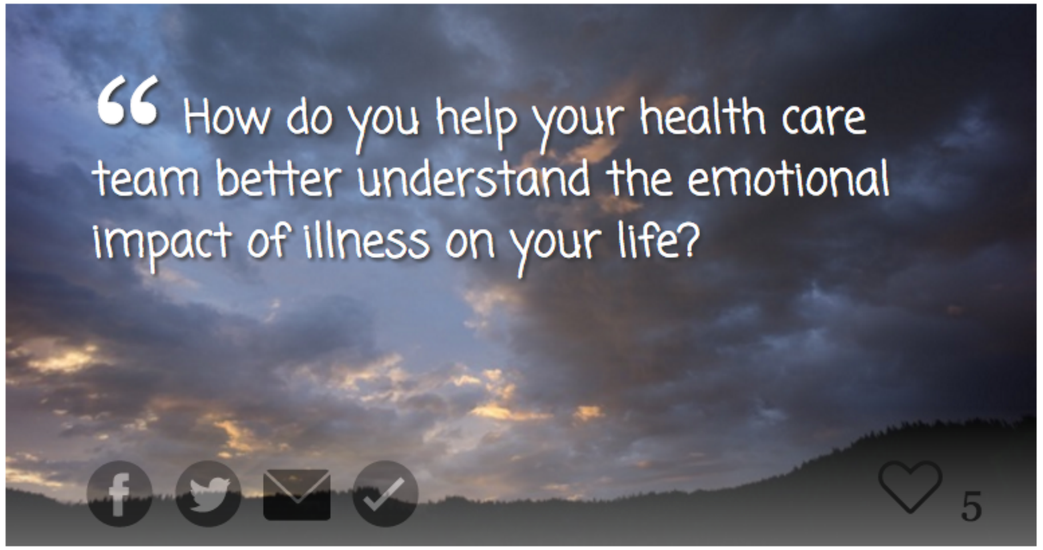
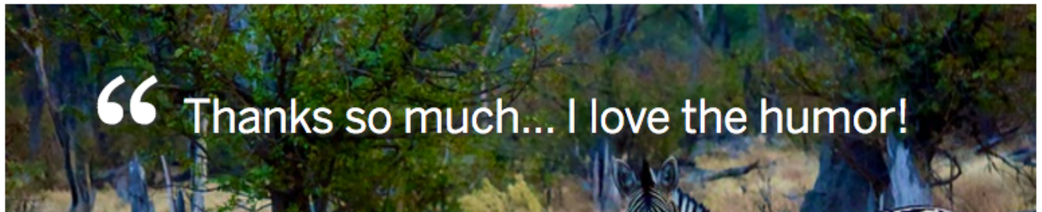
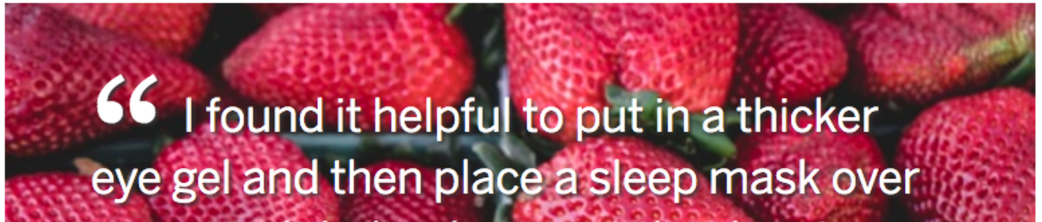

My family and husband don't understand what I'm going through on most days...they think I'm faking my illness and have called me a drama queen. I look perfectly healthy to them.
2


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?
6

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.
1


How do you help your health care team better understand the emotional impact of illness on your life?
5


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.

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Nervous about dad's surgery

START A CONVERSATION

orthopedics

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

REPLY

orthopedics

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.

Rachel

0 0

Recent Updates
conversations

Before Your Hip Surgery

If you have any questions about about your "pre-habilitation" exercises or your upcoming hip surgery, let us know! You can always check your to-do list here.

Challenges of being in the NICU

START A CONVERSATION

Smart Patients Team

Started by Roni Z 2 hours ago

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
- [x] Communication about discharge from the NICU
- [ ] Training on tube feeding, O2 monitoring, etc. at home

NEXT

Search clinical trials

lung cancer SEARCH

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 send feedback

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.

multiple myeloma **treatments**	**5** **phase 1**	**12** **phase 2**	**6** **phase 3**	**1** **other***
targeted therapy				
carfilzomib (Kyprolis) *proteasome*	3	3	1	0
ixazomib (Ninlaro) *proteasome*	0	1	1	0
ONC201 *AKT, ERK*	1	0	0	0
bortezomib (Velcade) *proteasome*	1	2	3	0

Thank you.

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