



Lung Cancer Alliance

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NO MORE EXCUSES. **NO MORE LUNG CANCER.**

65 year old female lung cancer survivor Member since February 2007



February 24, 2007:

I've been on this site for a month or so, finding great courage, comfort and optimism in the shared stories of survivors and their caregivers.

Now, where do I begin to start my own message, and ask for input to a situation I haven't seen addressed on this site. I'm sure it's not unique, I just haven't run across it. Last Tuesday my husband was told his CT shows what appears to be very early stage lung cancer, too.

(6 replies)



May 27, 2008

The tumor in my brain has shrunk and there are no new ones. Other than that one tumor, which appears to be dead and disappearing, my oncologist could find "No Evidence of Disease" at this time.

I am scheduled for another brain scan and full body CT. But, I refuse to give in to anxiety until the week between the actual scans and the report.

For those who prayed and sent kind thoughts, thank you so much. The brain MET was round two of this disease and I'm still on my feet.

(20 replies)

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Wife of stage IB patient
Member since December 2006



January 2007:

...we have told no one. We haven't told our friends, our neighbors, our relatives, our colleagues...no one knows the real truth....keeping this secret is so isolating but that's my husband's way of coping.

(31 replies)



May 2008:

I logged on to check on the health of my friends...I was overwhelmed by the kindness of so many posters on our site. The afflicted and the worried post questions about nutrition, procedures, calcium, you name it, and more than a handful of respondents are quick to answer with their personal experiences, advice, compassion, concern. We are lucky to have each other... many of us speak from the heart as well as from the mind, very naked in the street. I admire the heartfelt kindness of the many layers of connection.

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Lung Cancer Alliance



- **Established in 1996, headquartered in Washington, DC**
- **Only national non-profit organization solely dedicated to providing patient support and advocacy for those living with or at risk for lung cancer**
- **Mission: to lead the movement to reverse decades of stigma and neglect by empowering those with or at risk for the disease, elevating awareness, and changing health policy.**

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Empowerment



2006 Key Patient Support Services

- **Toll Free Information Line**
 - 9 a.m. to 5 p.m. Monday through Friday
- **Phone Buddy Program**
 - 1:1 peer to peer support by telephone
- **Clinical Trials Matching Service**

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Specific Challenges



- **Lack of support services and barriers to using those that exist**
 - Late stage diagnosis, low survival rates
 - Issues around stigma and blame
- **Limited resources**

LCA's Goals



- **24/7 support option**
- **Connect patients and loved ones**
- **Forum for information, encouragement, support**

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Solution



- ***Survivors for Lung Cancer Awareness & Support*** (Estrea Janoson and Dave Grant)
- **Inspire (then ClinicaHealth)**
 - Personal attention
 - Sensitivity to concerns

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Implementation



- **Organizing meeting June 21, 2006**
- **Site went live July 31, 2006**
- **Used existing moderators + Inspire MoM**
- **Required existing members to re-register**
- **Immediate and vocal response from users**

Lessons Learned



- **Our approach**
- **Active participation is helpful=rapid response**
- **Online communication is different and unique**
- **People don't like change**
- **Good communication, flexibility, and adaptability are the keys**

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The Community Today



Me Messages Friends My groups Sign out Inspire

Lung Cancer Alliance Survivors
Support Community

Home New Recommended Discussions Journals Members About Join Search

The Lung Cancer Alliance Survivors Support Community connects patients, families, friends and caregivers for support and inspiration...
[More about this group](#)

All new and active discussions & journals

Another Diagnosis
By [mekbride](#) · New reply 11:14 am
Discussion in [Non-small cell lung cancer - General](#) · 10 replies
Hello everyone. After 2 1/2 years since surgery (upper left lobe removed) and 2 years since chemo, they've detected nodules, am going to undergo a PET to see the extent. Question. I have been working ...

13 transfusions in less than a week!!!!
By [lllsister](#) · New reply 11:12 am
Discussion in [Small cell lung cancer](#) · 5 replies
Ok is this normal? My Dad's platelets are really low and dont seem to be getting any better! In the mornings he is feeling good by lunch he is dalusional and everyone is trying to kill him. He has had ...

Paul Newman has lung cancer
By [kimb](#) · New reply 11:08 am
Discussion in [Non-small cell lung cancer - Stage IV](#) · 11 replies
Sad news but I am hoping his having this dreadful disease will help make the public more aware ...

Thank you for the knowledge and support!
By [Kross18](#) · New reply 11:08 am
Discussion in [Non-small cell lung cancer - Stage IV](#) · 9 replies
Yesterday I watched my best friend, La 28, diagnosed stage IV in February, die yesterday in Hospice. It was an awful day that none of us want to experience. However, it was a beautiful day to see her ...

My Brother

New members

[Cindy3998](#) [strummed_our](#) [Colin5398](#) [28forest](#) [Sunbare](#)
[More members](#)

Discussion topics

- [Non-small cell lung cancer - General](#)
- [Non-small cell lung cancer - Stage I](#)
- [Non-small cell lung cancer - Stage II](#)
- [Non-small cell lung cancer - Stage III](#)
- [Non-small cell lung cancer - Stage IV](#)
- [Small cell lung cancer](#)
- [Family members and caregivers](#)
- [Treatment options](#)
- [Good news](#)
- [What, me worry?](#)
- [Survivor stories](#)
- [Nutrition](#)
- [Lung cancer in the news](#)
- [Help desk](#)

You

[Start a discussion](#)

[Post a journal entry](#)

Internet 100%

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The community today



- **Registered users**
 - Nearly 3000 currently
 - Nearly 50 countries and all US states except Alaska
 - 60% of users are 45 and older
- **Hits per month average over 2+ M**

Benefits



- **Connects those dealing with lung cancer**
- **Beyond support, an avenue to educate and inform**
- **Allows LCA to engage our constituency**
 - Couples and communication survey
 - Advocacy and calls to action
 - Endless possibilities

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“There are realities we all share, regardless of our nationality, language, or individual tastes. As we need food, so do we need emotional nourishment: love, kindness, appreciation, and support from others.”

–J. Donald Walters

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