Online Communities: Examples of Research Engagement

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WELCOME
Association of Cancer Online Resources

ACOR is a unique collection of online communities designed to provide timely and accurate information in a supportive environment.

ACOR offers access to 159 mailing lists that provide support, information, and community to everyone affected by cancer and related disorders.

MAILING LISTS
- ONLINE COMMUNITIES
- SUPPORT & RESOURCES
- COPING WITH CANCER
- TYPES OF CANCER
- AN A-TO-Z LIST
- TREATMENT OPTIONS
- CURRENT TREATMENTS
- CLINICAL TRIALS
- EXPERIMENTAL TREATMENTS
- PUBLICATIONS
- CANCER-RELATED BOOKS
- PARTNERSHIPS
- ALLIANCES & FRIENDS
- HELP ACOR
- DONATIONS & VOLUNTEERS

News

VARI study could improve treatments for prostate cancer
Van Andel Research Institute scientists have determined how two proteins required for the initiation and development of prostate cancer interact ...
Apr 01, 2010
[Full Story]

What’s New

Please join us in a town-hall conversation about health care reform. With your help we’ll provide effective feedback to the new administration!

- How Cancer Survivors Provide Support on Cancer-Related Internet Mailing Lists
- ACOR Reference
Browse Alphabetically:

2 I A O R C D E F G H I J K L M N O P Q R S T U V W X Y Z

Choose Mailing Lists by Topic:

Most Common Cancers

BC-SUPPORTERS: (130 subscribers)
Support List for Partners of Breast Cancer Patients

BRCA: (334 subscribers)
Breast Cancer Electronic Support Group

BREAST-ONC: (834 subscribers)
Current Advances in Breast Cancer Treatments

CLUB-METS-BC: (213 subscribers)
Metastatic Breast Cancer Online Support Group

COLON: (824 subscribers)
Colorectal Cancer Discussion List

LUNG-NSCLC: (333 subscribers)
Non Small Cell Lung Cancer

LUNG-ONC: (250 subscribers)
The Lung Cancer Online Support Group

PROSTATE: (1258 subscribers)
The Prostate Problems Mailing List
About ACOR

Mission

ACOR is an Internet-based public charity dedicated to improve the quality of care provided to cancer patients and the quality of life of patients, survivors and their caregivers.

ACOR leverages its wide technological and biomedical resource expertise to be a reliable source of knowledge, support and community in a relentless worldwide campaign to empower those suffering from the disease.

ACOR achieves its mission by constantly investing in advanced technologies and improving them to:

- Provide uninterrupted open access to a large nexus of online peer support groups (Health eCommunities) it creates and manages,
- Host a number of exceptional patient-centered websites,
- Conduct breakthrough research.

These efforts are supported by a large team of dedicated volunteers and support staff. Thanks to them, ACOR is consistently recognized as a leader in helping cancer patients and in promoting health care quality through its Health eCommunities.

Principles
in helping cancer patients and in promoting health care quality through its Health eCommunities.

Principles

ACOR is committed to the following principles:

1. ACOR should provide free and unencumbered access to peers suffering from the same disease or treatment effects, to end the isolation suffered by many cancer patients, survivors & caregivers.

2. Informed patients and caregivers are better prepared to navigate the treatment options maze.

3. Cancer patients should have free access to accurate and timely information regarding their disease.

4. ACOR should promote universal access to the full complement of resources necessary to assess and implement treatment choices.

5. Equal access to information and support should be provided regardless of gender, race, ethnicity, nationality or economic status.

6. All cancer patients, survivors and those who care for them should be assured that empowerment through knowledge enables the following elements of quality care:
   - Finding the appropriate specialists: recommendations about initial cancer management, which are critical in determining long-term outcome, are best made by experienced professionals.
   - Gaining a real understanding of the care plan offered by the clinical team: agreement between the patients and the professional providing health care is vital in cancer care.
   - Gaining informed access to high-quality clinical trials;
   - Receiving continual psychosocial support through a large number of easily accessible specific cancer eCommunities.
7. Widespread acceptance of the use of peer to peer (p2p) eCommunities is limited by the lack of robust evaluation of their efficacy. To increase understanding of their importance, ACOR is leading the development of secure online survey tools and their use to conduct rigorous research. ACOR seeks to improve the quality of online health research by promoting systematic development of ethical research design and methodology guidelines and putting them into practice. ACOR participates in groundbreaking collaborations with premier academic research organizations. ACOR advocates for the widest possible dissemination of:
   - Robust validated instruments for online research
   - Online research guidelines
   - Results of studies using only proven research methodologies.

ACOR reserves the right to limit access to its p2p eCommunities only to research projects that promote and employ this rigorous philosophy.

8. ACOR does not, at present, have its own institutional review board (IRB). According, ACOR will partner with organizations whose IRBs understand and support the special needs of online researchers and cancer families.

9. Health eCommunities focused on a rare disease can become significant players in basic and clinical research by acting as the online information and recruitment center for all the projects related to the disease.
www.liferaft.org

LIFE RAFT GROUP
Welcome to the Life Raft Group

The Life Raft Group (LRG) is a 501 (c)(3) non-profit organization providing support, through information, education, and innovative research to patients with a rare cancer called GIST (Gastrointestinal Stromal Tumor). Since we received our non-profit status in June 2002, we have expanded our outreach efforts to many thousands of patients and their doctors. Local chapters have formed in a growing number of cities throughout the world. To learn more about the history of the Life Raft Group, click here.

Membership in the LRG is free as is access to our newsletter, webcasts and our other office-based assistance programs.

Applications for membership can be found on our website, or obtained by contacting our office at 973.837.9092.

Donations are tax deductible in the United States.
Join the LRG

The Life Raft Group is open to all GIST patients, their caregivers and family members. Please fill out one of the following Application Forms to join.

All information is confidential.
All information provided will be kept strictly confidential and is for the internal use of the Life Raft Group only. We are committed to protecting the privacy of our members. Any data or information that we share in any way is always cleansed of any identifying information in order to protect confidentiality.

If you fax the form, make sure that your contact information (phone or email) is on the first page you send. Several people have sent failed faxes with no way to contact them.

If you have any problems sending us your application, please contact us at liferaft@liferaftgroup.org or (973) 837-9099.

On-line application - Due to the sensitivity of this page, please do not use special characters (e.g., parentheses, commas, hyphens).

Download Microsoft Word Document
Download PDF Document
Seat at the table

Because we are dying too fast for the traditional cancer research process, the Life Raft Group has decided to carve out a seat for itself at the cancer research decision making table. Traditionally most cancer research decisions are made by three key players, those representing the Pharmaceutical Industry, the Clinical Researchers and the Government. Although the decisions are made about patients and although patient representatives are sometimes given token roles, particularly by the government, we submit that patients not only do not play a critical role in the cancer research decision making process but that they are generally totally excluded. What’s wrong with this process?

There is a general injustice in one group of adults making life altering decisions about another group without their knowledge or consent. On top of this, the current situation is generally not focused primarily upon finding the drug or the combination of drugs that the cancer patients in mind need.

The pharmaceutical representative understandably must focus upon finding drugs that can be brought to market and that can earn a profit. That makes trials with drugs made by multiple pharmaceutical companies very difficult to bring about. The clinical researcher must be cognizant of choosing a particular clinical trial that is different though not necessarily better than that which is being done by a colleague and must choose which trial to process first if he/she has more than one. Whether that decision is influenced by any financial benefit provided by the pharmaceutical company is always an open issue. Finally the government must judge the merits of the research in question based upon the narrow protocol it approved in the first place, not against any strategic plan to treat and cure the cancer in question. Only the patient has as their primary focus the issue of the likelihood that a particular research will contribute to the survival and well being of the patients and the sense of urgency to accomplish that.

The rationale for our approach is based upon the tremendous respect we have for our colleagues in the pharmaceutical, clinical research and government worlds. We believe that putting patients at the cancer research decision making table, if not at the head, will help all three of these disciplines from the market place and cultural restrictions that limit their effectiveness in carrying out critical cancer research.
GIST Collaborative Tissue Bank

ADULT AND PEDIATRIC GIST PARAFFIN BLOCK TISSUE BANK

Help researchers find a cure for GIST

Put valuable tissue in the hands of the world’s leading researchers with one donation

Why a GIST Collaborative Tissue Bank?

How is the GIST Collaborative Tissue Bank different?

Who can participate in the GIST Collaborative Tissue Bank project?

How will participants benefit?

What am I being asked to do?

How did the Collaborative Tissue Bank project develop?

What is a Paraffin Tissue Block and how is this different from frozen tissue?

Who is studying my tissue?

How long will the study last?

Will I be able to see the research results?

I have already donated my tissue to a research facility. Will this overlap other studies that are going on?

How will my personal information be protected?

Will it cost me anything to participate in the study?
www.armyofwomen.org

LOVE/AVON ARMY OF WOMEN
Register as a volunteer with the Love/Avon Army of Women. By registering, you are indicating your interest in learning about active research studies in need of volunteers.

You will receive email updates from the Love/Avon Army of Women announcing new research studies looking for volunteers just like you. The email will detail the research project and who and what the researchers need. If you fit the criteria and you'd like to participate, all you need to do is click “Yes Sign Me Up”, this lets us know you’ve accepted our “Call to Action”. From there, you will be asked to log-in to your account and then directed to the next steps.

If you accept the Call to Action by clicking “Yes, Sign Me Up”, you will be asked a couple of screening questions to make sure you qualify for the study. Once we confirm your qualification for the specific study, your information will be given to the researcher conducting the study and you will be contacted by the researcher for a secondary screening to make sure you meet the study criteria and answer any questions you might have about study participation. You will never be pressured to take part in any study. The decision to take part is yours — and yours alone.

If you meet the study criteria as determined by the researcher and are interested in taking part, the study researcher will let you know what you need to do next.
FOR RESEARCHERS

The Army of Women is dedicated to accelerating research into the cause and prevention of breast cancer. Our goal is to form partnerships between women and scientists. The Army of Women volunteers are eager to work with any researcher who is involved in or contemplating research in understanding the cause and prevention of breast cancer.

All researchers must register with the Army of Women before they submit a project proposal. We look forward to aiding in your partnership with women to move beyond a cure and eradicate breast cancer once and for all.

REGISTER NOW!
HEALTH OF WOMEN STUDY

In December of 2009, the Dr. Susan Love Research Foundation in collaboration with the Beckman Research Institute, City of Hope and the National Cancer Institute’s (NCI) Cancer Biomedical Informatics Grid (caBIG) launched the Health of Women Study (HOW) of the Army of Women.

We launched the HOW Study for YOU.

We know that many of our Army of Women members have been disappointed that they haven't received a Call-to-Action for a study that was the right fit for them. Well, instead of waiting for someone else to come up with just the right study, we thought it was time for us all to roll up our sleeves and push the research forward ourselves! We are inviting everyone to join us in a new approach to research that may tell us HOW breast cancer starts and HOW to prevent it—the Health of Women Study (HOW)! EVERY WOMAN and man can take part in the HOW Study regardless of whether or not they have had breast cancer. You don't even have to leave your house to participate! The HOW Study is an on-line study.

Our hope is to enroll at least one million women and a few good men in the HOW Study.

The HOW Study is the first ever online "cohort" study of an anticipated one million women. A "cohort" is a study that looks at a group of people over time, collecting data that can be analyzed to find the common risk factors or characteristics. The HOW Study will be looking at breast cancer risk factors in order to understand the cause of the disease and ways to prevent it. The goal of the HOW Study is to follow all of you over time so that we get a better picture of what causes breast cancer. In order to do this, we need to compare those who have been diagnosed with breast cancer to those who have not. The HOW Study
Find Patients Just Like You

Do you have a life-changing condition? Learn from the real-world experiences of other patients like you.

Join Now! (It’s free!)

Current Disease Communities

- Prevalent Diseases
- ALS/MND
- Epilepsy
- Fibromyalgia
- Chronic Fatigue Syndrome/ME

See how PatientsLikeMe can help you take control of your health:

"When I read a posting, even questions, I find it very helpful to look at the poster’s profile... it boosts my confidence in what I’m reading when I see how long they have been at it, what they have tried, what else they have said."

—Parkinson’s Disease Community Member
Our Philosophy

Openness is a good thing.

Most healthcare websites have a Privacy Policy. Naturally, we do too. But at PatientsLikeMe, we’re more excited about our Openness Philosophy. It may sound counterintuitive, but it’s what drives our groundbreaking concept.

You see, we believe sharing your healthcare experiences and outcomes is good. Why? Because when patients share real-world data, collaboration on a global scale becomes possible. New treatments become possible. Most importantly, change becomes possible. At PatientsLikeMe, we are passionate about bringing people together for a greater purpose: speeding up the pace of research and fixing a broken healthcare system.

Currently, most healthcare data is inaccessible due to privacy regulations or proprietary tactics. As a result, research is slowed, and the development of breakthrough treatments takes decades. Patients also can’t get the information they need to make important treatment decisions. But it doesn’t have to be that way. When you and thousands like you share your data, you open up the healthcare system. You learn what’s working for others. You improve your dialogue with your doctors. Best of all, you help bring better treatments to market in record time.

PatientsLikeMe enables you to effect a sea change in the healthcare system. We believe that the Internet can democratize patient data and accelerate research like never before. Furthermore, we believe data belongs to you the patient to share with other patients, caregivers, physicians, researchers, pharmaceutical and medical device companies, and anyone else that can help make patients’ lives better.

Will you add to our collective knowledge… and help change the course of healthcare?
Epilepsy is a condition characterized by recurrent seizures, which are brief periods of synchronized electrical impulses in the brain that cause temporary changes in thinking, behavior, and consciousness. Seizures can interfere with patients' daily lives so medications are used to help patients become seizure-free and symptom-free. Imagine knowing what treatments work for people just like you — and having the ability to easily connect with those people. That's what makes PatientsLikeMe different. By sharing your symptoms, treatments and more, you can gain insight into what affects your condition while helping others learn from your experiences. Together along with our strategic partner UCB, we can achieve more. Begin making a difference today!

**Who Will You Find?**

1,195 total patients
99 Profiles updated this week
371 New patients this month

**What Are Patients Sharing?**

Real-World Data
Real-World Experiences

**What Can You Learn?**

**Your Health Profile**

By creating and sharing your health profile with the community, you can learn more about how your condition affects you and help others learn from your experience.
What Are Patients Sharing?

### Real-World Data

<table>
<thead>
<tr>
<th>Top Treatments</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Levetiracetam (Keppra, Keppra XR)</td>
<td>187</td>
</tr>
<tr>
<td>Lamotrigine (Epitec, Lamictal Blue...)</td>
<td>161</td>
</tr>
<tr>
<td>Topiramate (Topamax, Topamax Sprinkle)</td>
<td>98</td>
</tr>
<tr>
<td>Carbamazepine (Carbagene, Equetro...)</td>
<td>63</td>
</tr>
<tr>
<td>Divalproex sodium (Depakote ER, Epival...)</td>
<td>43</td>
</tr>
</tbody>
</table>

### Top Symptoms

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory problems</td>
<td>575</td>
</tr>
<tr>
<td>Problems concentrating</td>
<td>565</td>
</tr>
<tr>
<td>Fatigue</td>
<td>532</td>
</tr>
<tr>
<td>Excessive daytime sleepiness (somnolence)</td>
<td>484</td>
</tr>
<tr>
<td>Depression</td>
<td>482</td>
</tr>
</tbody>
</table>

Patient Forum

- New Medication that seems to be helping me
- **117 new posts in the forum this week**

PatientsLikeMe Blog: The Value of Openness

- PatientsLikeMe - Out & About and OnCall
  - April 2, 2010
- Where are the Cures? An interview with Myelin Repair Foundation
  - February 24, 2010

More...
### Find Patients

**Quick searches**

#### Newest patients

#### 3 Star patients

**Filter patients by**

#### Disease Information

**Epilepsy Type**
- Any

**Years since Epilepsy Diagnosis**
- 2
- 5
- 8
- 11
- 14
- 17
- 20
- 23

**Causative Comorbidities**
- Any or None

**Non-causative Comorbidities**
- Any or None

**Seizure Type**
- Any

#### Treatments

**Type a treatment**

### Showing 1 to 15 of 155 public patients

1077 members have decided to share their profiles only with other members of the PatientsLikeMe Epilepsy Community.

To see these profiles matching your search criteria, **Join now**!

**Sort by:** Newest patients

<table>
<thead>
<tr>
<th>Status</th>
<th>Updates</th>
<th>Profile</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image" alt="SarahW" /></td>
<td>outcomes updated (less than 1 day ago)</td>
<td>onset: 06/96 Dx: 01/98</td>
</tr>
<tr>
<td><img src="image" alt="Dazed&amp;Confused" /></td>
<td>side effects updated (less than 1 day ago)</td>
<td>onset: 12/81 Dx: 01/98</td>
</tr>
<tr>
<td><img src="image" alt="hunter/jumper88" /></td>
<td>outcomes updated (less than 1 day ago)</td>
<td>onset: 06/02 Dx: 11/02</td>
</tr>
<tr>
<td><img src="image" alt="Blueeyedgoddezz" /></td>
<td>outcomes updated (less than 1 day ago)</td>
<td>onset: 04/85 Dx: 05/85</td>
</tr>
<tr>
<td><img src="image" alt="MikeCatrina" /></td>
<td>symptoms updated (less than 1 day ago)</td>
<td>onset: 04/59 Dx: 04/59</td>
</tr>
</tbody>
</table>
Community Reports

Where do you fit in? To help you get a better understanding of where you are relative to the rest of the community we periodically generate reports that will give you an overview of who is here; where they’re from their demographics and their experience of their condition. Take a look and connect with other “patients like you!”

Dec 01, 2008

2008 PatientsLikeMe HIV Community Report: Embracing the Positive

Mar 17, 2008

It’s been two years!! ALS Community Report

Jan 09, 2008

Community Report: The composition and experience of the Multiple Sclerosis community

Publications that feature PatientsLikeMe

Jun 26, 2009

Google Scholar

PatientsLikeMe is frequently cited by other publications in fields as diverse as Law, Sociology, and Medicine. See our current listing on Google Scholar.

R&D Policy

Jul 16, 2009

R&D Policy

This FAQ document contains details of our policies for all activities with regards to research and development. For further information please visit our website.
Research Tools

ALS Genetics Search Engine
Search for ALS patients on a variety of parameters including known disease-causing genetic mutations (e.g. SOD1, ALS2, VAPB). Over time we will show patients with the inherited familial form of ALS (FALS) more information about their likely progression rates and publish our findings to the scientific field.

See how ALS patients taking an experimental treatment, lithium, are doing in real-time
View FRS scores before and after starting lithium, easily compare individual dosages and blood levels, and filter results by a rich set of patient characteristics.

Clinical Trial Awareness

Eli Lilly & Company
Lilly, a leading innovation-driven corporation, is developing a growing portfolio of pharmaceutical products by applying the latest research from its own worldwide laboratories and from collaborations with premier scientific organizations.

PatientsLikeMe Research

In collaborations with patients, academics and industry leaders, the research team designs and runs studies that contribute to the understanding of each of the conditions we serve and the evolution of the site itself. The new research tab will be where we will collect and present our patient tools and research findings. If you would like to contribute ideas about the design of the site or this page please let us know through the suggestions box or to send the research team an email.

Meet the Research Team

The research team brings a variety of expertise to the design of PatientsLikeMe and the study of the data collected here. Our team's specialties include genetics, sociology, psychology, nursing, drug discovery, predictive modeling and user behavior.

Richard Bradley
Pharmacovigilance Manager
www.curetogether.com

CURE TOGETHER
manage your (own) health
so you can feel better, faster.

Check Your Symptoms
Easily enter data. See which conditions best match your symptoms. Explore what might be making your symptoms worse. Find out what makes you different.

Choose Treatments
See everything people are using to treat your condition. Discover which treatments are most popular, and which work best for people like you.

Track Your Progress
Learn how to run experiments on yourself. See exactly what effect new treatments or dietary changes are having on your body. Optimize your health with better data.

Connect With Peers
Find people who share multiple conditions with you. Learn from those who have been there. Leverage the experience of others to make better decisions for yourself.

It's anonymous and free.
To join, just enter your email: [Enter]  Go
Anyone with enough science knowledge and computational power now has the ability to contribute to research advances, outside of any institution. Examples of such citizen science have historically been popular in the fields of bird counting, water monitoring, and astronomy applications like searching for interstellar dust. Citizen health research is still in its infancy, with "experimental man" David Ewing Duncan and parents like Hugh Rienhoff pioneering first attempts.

The Open Source Health Research Plan

Step 1: Define the “source”

The openly accessible source for health research can be made up of:

- survey questions/instruments/assessments
- ideas for new treatments or treatment protocols
- health data
- algorithms to find patterns
- patterns found in data
- user interface designs

Step 2: Apply the elements

Openness

Opening up the health data part of this source to any interested person will have to be done in an aggregate, anonymized way to protect the privacy and security of individuals who have contributed sensitive health and medical information.

Collaboration and Community

Collaboration, community, and recognition can be achieved through open forums and a social network of international researchers, where anyone can classify as a researcher and be rated.
Just Released – The CureTogether Guide to Anxiety

March 24th, 2010 Alexandra Carmichael Posted in Condition Awareness, Research Findings No Comments »

You are a part of this.

It’s a new kind of health book that puts real-world data before authority, and teaches you how to make better decisions for your health.

Inside, you’ll find 7 insight-filled sections to help you navigate your way through Anxiety.

Download your copy here, or read on for the juicy details.

The Story

Health books are usually written by experts who offer authoritative information about conditions, symptoms and treatments – people who usually don’t live with the condition themselves, but nevertheless tell you what you should do because they know best.

This book is different. It’s based on the real-world experiences of patients. Our approach is not to tell you what to do, but to give you the hard data and the education to help you make your own decisions — to manage your own health. It’s not about doing it alone. It’s about taking control of the process and becoming the primary decision maker when it comes to your health.