Impact of Social Media on Clinical Trial Integrity.

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WIRB-Copernicus Group
Social Media Before the Study
CREATE A PROFILE on Fox Trial Finder and you’ll:

• Receive a custom list of trials in your area
• Message anonymously and safely with trial coordinators
• Join a community of volunteers committed to driving PD research forward

www.foxtrialfinder.org

michaeljfox.org @MichaelJFoxOrg • Jun 9
Take action. Participate in our clinical trials in your area today:
#parkinsons bit.ly/1G9FxyN
Frontage In NJ has a New Study Posted...

Frontage seeks non-smoking healthy adults, between 18 and 55.

The study requires up to 12 consecutive overnight visits and 10 outpatient visits, depending on study group.

Participants must weigh 110 lbs (60kg) and have a body mass index (BMI) between 18 and 30 kg/m²

Compensation up to $2950 for completing all study procedures.

To find out if you qualify, call 877-298-9071, apply online: www.frontagelab.com/enroll-in-a-study.asp:

Or email: recruiting@frontagelab.com

Check it out on Study Scavenger now:

http://www.studyscavenger.com/Content/ViewStudy.aspx?SiteID=31d3d095-cabe-4171-a20f-0ac77d189fcbated web page..

Call Today!! 877-298-9071
Recruiting for healthy males and females 18-45. Up to $5,800. bit.ly/1zdzlD8. #CovanceEvansville.

New direct flights to Dallas being added over the next month! usat.ly/1vnEbuH Check out our current studies at bit.ly/1eHov92

Looking for Healthy Non-Smoking Women, 18-45, for research study 8298-349. Up to $6,000. bit.ly/1sJQVL1 #CovanceDallas

Healthy adults, age 18-55 needed for clinical research study 8302-509. Up to $2200 upon completion. Call 800-732-2528. #CovanceMadison
INTRODUCING THE ORBIT STUDY.
A clinical research study for people with EoE.

Welcome!
Thanks for visiting Just Another Lab Rat!, your one stop guide for learning how to volunteer for a clinical research study and the best resource for veteran volunteers.

If this is your first time here, please check out the Guide To Clinical Research
The major Phase I clinics are listed below. If you’re not healthy, there may be a patient clinic near you.
In order to sign up for a clinic, you must call or sign up through the clinic directly. This site is only a resource guide and is does not directly recruit volunteers. Please mention you found out about studies from this site! Get the Smartphone APP!

Major Phase I Clinics in the US

Got a phone? Get the Smartphone APP!
To sign up for a study, choose a clinic below and call the clinic directly using provided numbers

| AZ Tempe     | Celerion   | ND Fargo  | Novum    |
| CA Cypress   | WCCT Global| NE Lincoln| Celerion |
| CA Glendale  | Parexel    | NJ Emontown| Cliniabs |
| CT New Haven | Pfizer     | NJ Hackensack| Frontage |
| FL Daytona Beach | Covance    | NJ Marlton| PRA Health Sciences |
| FL Jacksonville| Seaview Research | NJ Neptune| Inflamx Research |
| FL Miami     | mVentiv Health | NJ Newark | Biotrial |
| FL Miami     | Seaview Research | NV Las Vegas| Novum    |
| FL Orlando   | OCRC       | NY NY City| Novum    |
| IL Graylake  | AbbVie     | OH Cincinnati| Cliniabs |
| IN Evansville| Covance    | OH Cincinnati| Medpace |
| KS Lenexa    | Analab     | OH Columbus| Ohio Clinical Trials |
| KS Lenexa    | JCTC       | TN Knoxville| NOCCCR  |
| KS Lenexa    | PRA Health Sciences | TX Austin| PBN Development |

Recently Updated Studies:
(current studies provided by clinics)
All studies are subject to capacities, change and or cancellation.
To view studies on your phone, download the APP or click here to view online.
For information on how to list your study, please click here.

Spaulding Clinical
Location: West Bend, WI
Health Condition: *Healthy Volunteers Studies

Covance Daytona Beach
Location: Daytona Beach, FL
Health Condition: Osteoarthritis

ICON Early Phase Services
Location: San Antonio, TX
Health Condition: *Healthy Volunteers Studies
J.T.
Garden Grove, CA
55 friends
9 reviews

6/13/2013
★★★★★

Only been there once and it was thanks to Nina Tran who helped me out with the process. She's a great coordinator. I hope to do business with you again.

Was this review ...?
Useful
Funny
Cool

Annette T.
Irvine, CA
15 friends
12 reviews

6/13/2013
★★★★★

Staff was very friendly and professional. Howard was very helpful with the process.

Was this review ...?
Useful
Funny
Cool

William K.
Diamond Bar, CA
112 friends
8 reviews

6/13/2013
★★★★★

I was a research patient and I wanted to give a quick review of my experience. The staff was very professional and courteous. One of the staff that stood out above the rest was Inho Lee. I enjoyed the entertainment rooms with the big screen tv and Netflix. I was completely comfortable. I will definitely do another study with them.

Was this review ...?
Useful
Funny
Cool

Sam H.
Phoenix, AZ
0 friends
2 reviews

1/27/2014
★★★★★

First to Review

I signed up for one of their clinical trials. I was told I would be there for about 2 hours, but I ended up being there for 4. they asked me about my sexual history(no joke) out loud and in front of other patients, and asked what kind of birth control I would use, and their phlebotomist was grossly impatient, and under-qualified. I wanted to call in to file a complaint, but the extensions to their phone number were all in spanish.

Was this review ...?
Useful
Funny
Cool

Henry L.
Lake Elsinore, CA
0 friends
8 reviews

8/1/2014
★★★★★

I was a research patient and I wanted to give a quick review of my experience. The staff was very professional and courteous. One of the staff that stood out above the rest was Inho Lee. I enjoyed the entertainment rooms with the big screen tv and Netflix. I was completely comfortable. I will definitely do another study with them.

Was this review ...?
Useful
Funny
Cool

This place is just foul. I responded to a Craigslist ad for a study. After showing up and spending over 2 hours at the clinic; giving blood and other test I was told that if I passed the first phase I would be call to start the second phase. This was supposed to happen in the next 2 weeks. After waiting and receiving no call back I assumed my test results came back negative thus I was not going to proceed to the next phase.

I was ok with this but then today I received a call from 714-399-3897. The lady said since I did not show up to the 2nd phase trial that I could participate on another. I told her wait a minute, I was not told that I had passed to the second phase. She said that someone should have called me and let me know, but maybe I needed to check my voicemail. This really got me upset because I always answer my phone and if I'm unable to answer I check my voicemail constantly. I NEVER RECEIVED ANY CALL OR TEXT.

AFCR October 2017
"It's kinda like a cargo cult, if they pretend they're doing science then they can pretend their results are pristine."

well that's the game, we pretend to be pristine so they can pretend to be doing science. The less you lie, the less work you will get. It's an elaborate farce, and you have to know your lines, which are usually "no" and sometimes "yes."

If the study coordinator was reading what they wrote, because sometimes they do. The official answer: if you have taken a medication within 30 days of the study period, bring the medication and show it to staff so they can determine if you are still ok for the study. Less official: people do studies for various reasons, sometimes out of economic desperation, and do what they need to do to get in. Generally, the less you tell them, the better your chances. Some people feel that since the clinics will lie to you (and they do) it's ok to lie to them. That's an individual decision that's up to you. For me, it's partly a question of when they ask. On an initial phone screening, I'm pretty candid. I want to know if the study is a good fit for me and me for them. But once I've set aside a week to go screen, driven hundreds of miles, perhaps turned down other screenings, maybe spent money on a hotel room, I'm less likely to volunteer info that is likely to get me excluded. So I get really annoyed at places that won't email the consent in advance, or play hide the
Social Media During the Study
I am starting cycle 12. They have added some side effects to the list. Edema and fatigue are most common, along with something else which I can't remember... And nausea, diarrhea, constipation are less common. No mention of the acne like skin or hair loss.
My nurse today was distracted by having to fill the pump. So distracted that I didn't notice she forgot my labs!! lol
And I have the beginnings of a UTI so I'm on Cipro. So in 2 months my meds have doubled! We talked about the edema and the fact that I can't seem to take a day off: the swelling comes right back, not that it goes away completely. But kidneys look good so I will keep taking it.
Scan yesterday shows nothing new. And stability. So I'm happy there. CA19-9 is up a bit to 39. Guess I gotta lay off the meat for a bit.
All in all, a good day!

Any advice or comments I give are based on personal experiences and knowledge and are my opinions only. They are not to be substituted for professional medical advice. Please seek professional advice from a qualified doctor or medical professional.
Jeri Burtchell @FingoHead • Nov 7

Back where it all began. #clinicaltrial checkup for extension of Gilenya study. Leaving with 6 mo. of pills.
“…And my pills are very bitter and nasty tasting. I’ve also cross referenced my taste experiences with others who I know are getting the (study drug) and we all agree on the flavor…”

“…If you can suck it without gagging and it tastes vaguely neutral then it’s the placebo.”

“…can you describe your pills in more detail? Like a more complete description of what they look like, how they react when they get wet, what their texture is, how long do they last in the mouth after being swished around, and a more complete description of the taste.”

The placebos were sweetish to neutral tasting. That's how all placebo people interpreted their pills. Nearly everyone who was later actually proven to be getting VX950 described it as a gagging bitter taste. But Vertex has been monitoring our chats here all along (including placebo detection), so they may have wised up by now and bittered their placebos. However, I can't believe they're still testing a group that does not get ribavirin? I'd look into that carefully, I seriously doubt they are dumb enough to keep doing that. That would be a waste of money and also be horribly unethical based on what happened to the others here already. But against all odds, if they are including a ribaless group - I wouldn't enroll in the trial if I were you.
One could conceivably get a viral load outside of the trial, (at their own cost), at about the 2 week mark and see if their viral load had gone just about undetected (if not undetected) and be able to tell in that way. A previous non-responder is not going to clear the virus on standard SOC in 2 weeks time.

I did not go outside of my trial because I knew right from the beginning that I was actually getting Telaprevir, because Group C was the only group in Prove 3, that did not receive RIBA...., Group C got Telaprevir and Pegasys, Period, end of story, no placebo for Group C. This was the group I got randomized into. At week 5, after my week 4 blood draw results came back, they called me up and told me that I would not be allowed to continue because I had rebound on my
Parents on private Facebook groups, ask for copies of test results/ imaging and post for discussion

- Obtain MRI of quadriceps, post for evaluation of the degree and progression of fibrosis to decide whether on active drug
- Obtain urinalysis, protein spilling is associated with active drug

Patricia Furlong, Parents Project Muscular Dystrophy, Presentation on September 16, 2017
“... The (study drug) is causing the [side effect] ... and it must be removed ... (1) Stop the (study drug) and get it out of your system; (2) Go to a dermatologist ... (3) Get them to start you on a prednisolone taper starting at 40 mg first day, then 30mg for 4 days, then 20mg for 4 days and then 15mg for one day. ... 

[if that is not successful] try 125mg iv of Solu-Medrol. ... don’t let some jive-talking doctor try and tell you it’s the same thing... I’m the resident expert on the subject at this point. So yeah, I’m gonna ... assert you should stop the (study drug)! And no I’m not a doctor...”
Patients posting structured data on efficacy & safety on investigational drug to public / social sites
Keeping Participants Engaged

- Interactive social media
  - Subjects often want to be able to discuss their experiences
  - Makes subjects feel like they are part of a community and their contributions are recognized: “We were looking for others to understand what we were going through. A trial is an isolating experience. We formed a bond” (Jeri Burtchell, 2014).
Are There Downsides?

- Increasing recent attention on the potential complications
  - How to get around eligibility criteria
  - Breaking the blind
  - Sharing AE information, encouraging/discouraging AE reporting
  - Premature efficacy assumptions
  - “Group mentality” about which trials are acceptable for participation
  - Misinformation
Communication Between Subjects

- Financial analysts were publishing conclusions about results while the study was still ongoing (e.g., “10/20 subjects report online that they have responded, we predict response rate will be 50%...”)

- “On Sept. 12, ...tweeted “Dropped max at school. This morning just max no wheelchair.” Volume in Sarepta stock soared...On Oct. 31...posted a video of Max walking in a Halloween parade. Shares jumped 10% the next day
THE POTENTIAL INFLUENCE OF INTERNET-BASED SOCIAL NETWORKING ON THE CONDUCT OF CLINICAL RESEARCH STUDIES

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Received: April 4, 2011; revised: October 10, 2011

The rapid growth of Internet usage has led to an explosion of social networking sites geared towards discussion of health issues. The sites are increasingly used to recruit subjects to clinical trials and provide a forum for subjects to communicate with one another during the course of the study. Although these sites are an important resource for patients, the information shared between subjects during the course of a clinical trial has the potential to influence the outcome of the study. In this article we provide an overview of the role of social networking Internet sites in clinical research, provide specific examples of how information posted in social networking could affect the integrity of ongoing clinical trials, and discuss key challenges this phenomenon presents for research subjects, investigators, research sponsors, and regulatory agencies.

Since the mid-1990s, the Internet has had a growing influence on the daily lives of people worldwide. According to a recent report from the Nielsen Company (2011) more than 80% of Americans now have a computer in their homes, and of those, almost 92% have Internet access, according to a detailed study on home
Researchers Fret as Social Media Lift Veil on Drug Trials
Online Chatter Could Unravel Carefully Built Construct of 'Blind' Clinical Trials

By AMY DOCKER MARCUS  CONNECT
July 29, 2014 10:30 p.m. ET
Engage with research participants about social media

Craig H Lipset

Published online 04 March 2014

A growing number of participants in clinical trials are sharing information about their health online. It's time that the drug development community starts to examine how this social media use might compromise the integrity of research studies and how it might also offer new opportunities.

Not long ago, the likelihood of clinical trial participants socializing and sharing information was limited to the clinic waiting room. As such, the risk of conversations among patients leading to the unblinding of experimental treatments in...
Which studies are at risk for bias?

Population factors

- Strong patient advocacy community
  - Organized online community/communications
  - Small number of locations for communication (centralized)
- High unmet medical need and a lot of interest
  - Rare disease community
  - Development of orphan drugs

Study factors

- Subjective study endpoints
Manage Communications?

- Set up chat rooms, discussion boards, interest groups for trial participants
  - PatientsLikeMe and other online patient communities are now managing study-specific fora
- Have a moderator
  - Participants may take discussion to private group
- Consider eliminating synchronous communications so a moderator can preview before posting
- Provide examples of appropriate and inappropriate messages (Bookbinder, 2014)
Participant Education?

- Make sure PIs talk to participants about where they are getting information.
- Educate/inform participants in the informed consent process?
- General education for all actual and potential participants
  - CISCRP
Six Ways Social Media Affects Your Clinical Trial (whether you like it or not)

Thursday, October 2, 2014

Melissa Hogan
RDR Contributor

It's an understatement to say that social media has made an impact on almost every aspect of rare disease. From patients being able to find each other quickly, to their ability to promote fundraising and advocacy campaigns, social media has opened doors that heretofore did not exist. For pharmaceutical companies, it poses a unique opportunity to listen and understand their patient communities better, but it also causes trepidation in some circles with respect to how it impacts their clinical development programs.

Rare disease patients involved in clinical trials do not suddenly sever their social media connections nor carve that clinical part of their lives out of conversations. Because so many rare diseases are lifelong, debilitating - and often in children, conditions that take up a substantial part of the patient's or caregiver's life - social media is used for support, information sharing, fundraising, and a sense of community. In fact, being involved in a trial, in some cases, heightens a patient or caregiver's involvement in social media because of the extensive or unique demands of a trial (creating a need for a subset of community support), their community's desire for information about new potentially lifesaving treatments, and the desire for increased activism to move research forward at a faster pace.
“Rare disease clinical trial participants will share information with one another and their disease community. In many cases, they will unblind trials, especially if their lives or the lives of their children hang in the balance of a drug development program. To expect otherwise is either patronistic, naïve, or both. As someone said recently at the Global Genes Patient Advocacy Summit, “some may look at trials as experiments, but patients look at them as treatment options.” So as long as sponsors anticipate this occurring, they can at least consider how this might impact their program.”

— Melissa Hogan, Patient Advocate and Blogger
Addition to Consent Form

“In all clinical studies, it is important that the people participating in the study (doctors, nurses and subjects) do not make any conclusions about what the results of the study might be, until all the data has been collected and reviewed. If there are rumors about how many subjects have side effects, or about whether the drug is working or not working, it may affect the study. If the data from the study might be affected by early conclusions, it could cause the study to have to be repeated.

......
Addition to Consent Form

….If you participate in this clinical study, you should feel free to discuss the study with your family and with other people who are close to you. You should also tell any health care providers who treat you that you are in the study. However, to help make sure that the data from the study is as accurate and reliable as possible, please do not discuss information about the study in public places while the study is in progress. Public places may be situations like support groups, or may be places like internet message boards. If you have questions about side effects, please talk to your study nurse or study doctor.”
Questions