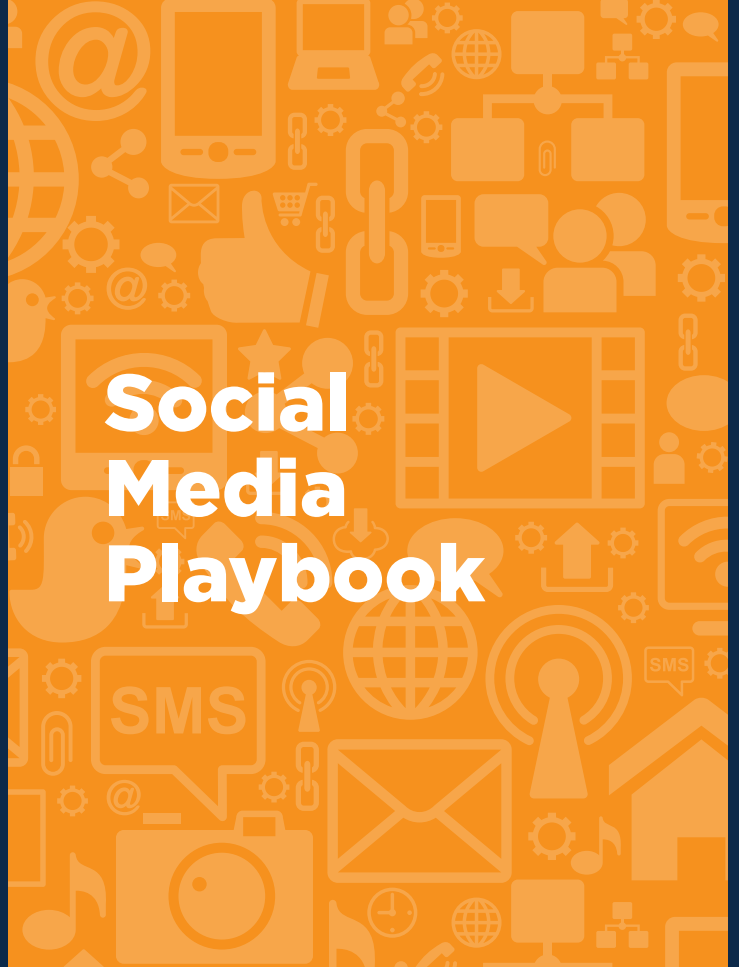




**Project LEO**  
Learn. Empower. Overcome.

# Social Media Playbook





# Welcome to the Project LEO Patient Advocate Program

Thank you for stepping forward to share your cancer survival story with others who are dealing with the same life-changing diagnosis.

As a patient advocate, you have power to influence these patients and help them select the treatment option that gives them the best chance at life. Let's make sure you have everything you need to get started.



# FPO



## About Project LEO

As the zodiac sign after Cancer, Leo is a symbol of confidence and encouragement. We strive to help newly diagnosed patients accomplish three things:

- **L**earn
- **E**mpower
- **O**vercome

Research shows that 45 percent of cancer-related discussions involve someone looking for support or advice. Up to 20 percent of these discussions refer to alternative treatments. We want to be an Internet presence that helps give patients the hope they need to explore their options and fight back.



**According to a 2011 Pew Research study, 59% of patients use online sources to seek out health information and 66% go online to find disease-specific information.**

## The goals of the program

Project LEO was created to connect newly diagnosed patients with survivors who underwent IL-2/immunotherapy, and to help them view IL-2/immunotherapy as a treatment option for metastatic renal cell carcinoma (RCC) or metastatic/stage IV melanoma.

Newly diagnosed metastatic RCC and melanoma patients turn to online communities and social media to connect with others with similar diagnoses, share support and gather information about their cancer. This program is designed for Proleukin Patient advocates to engage patients soon after their diagnosis, when they are exploring every possible option.



**This program will place demands on your time, but your support staff will work to help make performing your responsibilities as easy and efficient as possible.**

## Your role as an advocate

You know how sensitive and uncertain the patient experience can be. That's why your personal survival story can become an invaluable resource for patients who are seeking guidance.

As an advocate, you will participate in conversations regarding diagnoses and treatment options, providing a human voice and educational support. Some of your basic duties include:

- Explore new social media channels and conversations
- Use preapproved talking points and cite relevant data
- Treat community members with respect
- Respond to community members in a timely and reliable manner
- Document all activities for reporting purposes.

## How to use this playbook

This playbook is designed to keep you orientated with the online services and software you'll be using. Feel free to jump to any section you find relevant.

We have provided a number of supplemental references to aid your personal training:

- Best practices
- Orientation with selected social media sites, software and their features
- When and how to respond to questions and comments
- Legal and regulatory issues
- How to access and use FDA-approved content
- And an engagement calendar with recommendations on timing of messaging

## Other advocate sources

You will be provided with a variety of additional resources and support to help make your efforts as positive and effective as possible.

### **LEAD DEVELOPMENT**

Your support staff will monitor the various sites and channels targeted during this campaign and will alert you to opportunities for engagement.

### **WEEKLY CONFERENCE CALLS**

In order to coordinate efforts, address contingencies and provide ongoing support, advocates will be asked to participate in a weekly conference call.

### **ACCESSING AND USING APPROVED CONTENT**

Due to FDA-regulations, it is absolutely critical that you only use the reviewed and approved content. Your support staff will collaborate with you to develop and review content prior to the launch of the program.

### **DEVELOPING NEW CONTENT**

Naturally, there will be unforeseen circumstances and unique situations that you will experience and that will need to be addressed. Your support staff will work with you to develop the material you need to be successful.



**Remember that if you ever have any questions these pages can't answer, do not hesitate to contact your support staff.**

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## Using approved content (cont.)

With that in mind, we have to be very cautious about what our advocates post on our behalf. That is why **all Project LEO advocates must only post content concerning Proleukin, IL-2 or immunotherapy that has been pre-approved by both Prometheus and the FDA.**

We know that you may find this policy discouraging, since you might want to share your own thoughts freely. Please understand that this approach ensures that the program can continue without unnecessary complications.

However, we would encourage you not to limit your online conversations to Proleukin and your treatment, but to extend your involvement to sharing your perspective and insight on all aspects of dealing with your diagnosis, fortifying yourself for your fight, and moving on to fully live your life. When it comes to those aspects of your story, we encourage you to post about them freely and frequently.

Having a more rounded presence within a community will help lend credibility and genuineness to your Project LEO efforts. If you ever have any question about what you should or shouldn't say, please consult your support staff before proceeding.

With time, your deliberation and feedback will allow us to develop and improve our content strategy.



If you have any questions or issues regarding posts or approved content, please contact your support staff.



SECTION 2:

## **Best Practices**

Building a presence  
and establishing  
credibility

All the first-hand knowledge  
and scientific evidence in  
the world won't have any  
effect if no one listens to it.  
That's why credibility is so  
crucial in message boards,  
online forums and other  
social media.

## SENIORITY

Users with older registration dates and more posts are held in high regard. Some communities limit the accounts of new users, even preventing them from posting during a probationary period following their initial registration.

If you have an existing account and have been active, that is a tremendous advantage. If you haven't, it is critical that you start by developing a compelling profile.

## A SOLID PROFILE

A good profile can help you establish credibility among the rest of the community. Provide a detailed description of your experience, adding personal information to humanize your profile. Information like your hobbies and interests are a great way to increase your appeal. Just remember that as a general rule, political or religious beliefs can be distracting. It is also critical that your profile includes contact information so other users can get in touch with you directly, outside of the forum, if that is how they feel most comfortable communicating with you.

## MAKE A GOOD FIRST IMPRESSION

Just as in all other facets of life, your first impression to an online community is critical. Extending from your profile, your introductory post should include a brief description of your expertise and an explanation of why you joined the forum. Let the other users know that your main goal is to contribute to and learn from the community.

## START SLOWLY

While Proleukin sponsors Project LEO, we don't want you to feel like your job is to sell or market our product. Instead, we want you to share your story with newly diagnosed patients and help them discover the options and possibilities for themselves.

Avoid including a link to branded content in your early posts, and keep them limited even after you have established yourself. You have a great deal of informative content at your disposal and we want you to share it, but do so subtly or in response to a specific query. Ask yourself: *If I read this, would I think it was spam?*



**Talking about other aspects of your experience not related to Proleukin is a great way to help build your online identity and to establish yourself as a trustworthy member of a community.**

# The art of listening before you post

When it comes to existing online communities, you should strongly resist the urge to start posting right away. Our purpose is to observe, engage and educate our fellow patients, in that order.

## **GET FAMILIAR FIRST**

Message boards and online forums are extremely tight-knit communities, and long-time users can be leery of newcomers who overstep their bounds.

Start off by spending a substantial amount of time *reading* the forum to get a sense of the community's special quirks and cultural norms. Figure out who the most influential users are and note which topics generate the most discussion, both positively and negatively.

Take notice of how newly diagnosed patients introduce themselves to the forum, what kind of questions they ask, and how and when other forum members respond. Learning this information will help you fit in more quickly, and will give more credence to your contributions.

## **JOINING THE CONVERSATION**

Even after you have become integrated in the community, it is important that you take the time to reflect upon posts from others before responding. Always add value to the conversation. If you can't add value, think about whether a response is truly needed.

Do you have an appropriate response that shares valuable information? Are you repeating yourself or echoing what someone else has said without contributing new ideas or a different perspective? Is the tone or direction of the discussion becoming disorderly or even belligerent?

Try to avoid baited posts. If you find yourself working to defend your position, take a step back.

## **WHEN IN DOUBT, *DON'T POST***

As an advocate, you are responsible for your words and actions. When interacting with patients in such a serious situation, you must ensure that your posts are completely accurate and not misleading.

In any circumstance in which you are uncertain about how to respond to a post, consult with the support staff.

## Making social media a habit

While your work as an advocate is incredibly important, there is no reason it can't be fun as well. Enthusiasm in Project LEO not only allows you to connect with people across the country, but also helps spread valuable information about treatment options.

Your support staff will be assisting you on identifying certain online communities and specific conversations where your narrative might be most effective. Still, it's important that you frequent these sites on a daily basis to stay abreast of issues and trends.

### **STAYING MOTIVATED**

If you are new to social media, it might be helpful to consider these sites along the lines of the morning television news, a daily newspaper or a late-night talk show that you incorporate into your daily life. Set aside time each day to browse your news feed, check your messages, and respond as appropriate.

Social media is fast-paced medium, and while we don't want to miss opportunities to engage with patients, we also don't want you to feel overwhelmed. If there are certain mediums you feel more comfortable with — say you prefer Facebook to Twitter — let the support staff know. We want to play to your strengths however we can.

If you ever feel like you are being stretched too thin, there might be other ways we can refine your focus to better your experience.

### **SOCIAL MEDIA AGGREGATORS**

One way to maximize your social media time is through a social media aggregator, which is usually a web service or application that can organize your various social media accounts into one location.

These services allow a number of additional ways to manage multiple social media accounts, such as scheduling/automating posts in advance, publishing one post to multiple networks, or simply viewing all of your activity in one glance.

## POPULAR AGGREGATORS



### **Hootsuite**

HootSuite is a free service for individuals that allows you to view multiple social media streams at once, including Twitter, Facebook and WordPress. HootSuite tools allow you to reply, schedule updates, and read full conversation threads. It can be used through its online site or its mobile app, which is free to download.



### **TweetDeck**

A service that was recently acquired by Twitter, TweetDeck gives a clear “dashboard” look to your various social media accounts — including Twitter and Facebook — so you can monitor, filter and schedule tweets, comments and posts. It is free as both a mobile and desktop application for Windows and Mac.



### **Digsby**

Digsby combines various chats and conversations into one window, including Facebook, Twitter, Gmail and AIM.

## Getting visual

Social media often requires sifting through a great deal of information, so users are naturally drawn to the content that gets the message across quickly.

Images break through the clutter and quickly communicate messages, which is why social media has developed a more visual focus with Pinterest, Instagram, Vine and an ever-growing list of new photo- and video-sharing products.

Given these considerations, it is important that you incorporate visual elements whenever possible. Your support staff will help you develop an image library to pull from, and recommend what messages these assets might best reinforce.

If you have ideas for additional images, please share them. Do you have any photos that help to share your story? Is there a video that helps make your message easier to understand? These additions can help your audience relate to you as a person.



- **The most shared and clicked-on links on Twitter are images**
- **Images on Facebook generate more reach, views, and interactions**
- **Blog posts with images generate more traffic**
- **Recruiters judge your LinkedIn profile more by the photo than the content**

## Recording and reporting activities and interactions

Social media is an ever-evolving environment, so we plan for this program to evolve along with it. To do this, we'll need to track and measure our progress to see what is working and what isn't.

In addition to engaging patients as advocates, this campaign will rely on you actively monitoring the online communities we are reaching out to.

**If you come across positive or negative remarks about immunotherapy, IL-2, Proleukin or Prometheus Laboratories, please share them with the support staff.**

Because online conversations are often fleeting, it is important for you to keep track of them. Keep records of any online dialogue pertaining to the campaign and send a copy to the support staff.

When you come across disparaging comments, beyond reporting these situations, avoid the temptation to react yourself. Reacting emotionally can lead to things quickly getting out of control. Your support staff will assess the situation and determine the best response, developing materials specific to the situation as appropriate.



SECTION 3:

# Orientation to Social Media Networks

## The social networks

While you may already use one or several of these social networks for personal use, this section can provide you with supplemental understanding of each network's strengths and how you can use each to their full potential.

# WordPress

WordPress is a popular a blog-publishing service that gives you an online space for collecting and sharing thoughts, news, links and other content. Think of it as a diary or newsletter you can update and share with the world at large.

Blogs create a community where you can connect with people who share similar interests and messages. While the blog is predominantly your personal narrative, readers can comment on your posts with their own questions or thoughts, making it a perfect vehicle for online discussion.

## STATS

- Out of “top 1 million” websites, 14.7% are powered by WordPress, with over 25 million users across the globe.

## COMMON TERMS

- **Comments** — Comments let others leave feedback on your posts, and allow you to leave feedback on others’ posts, creating a two-way dialog. The decision to allow Comments can be made on a post-by-post basis, and you can delete Comments that are offensive or disruptive.
- **Profile** — Profiles are where people share their pursuits and pastimes. They can help you find people who share your interests, and your profile, lets people find you.

## WORDPRESS FEATURES

- WordPress allows private or multi-user blogs with time-stamped entries.
- The Access Control plugin allows you to have a group blog with multiple authors.
- WordPress automatically provides useful statistics such as how many views your blog has received, when they were viewed, etc.

## POSTING TO THE PROJECT LEO WORDPRESS SITE

Advocates are encouraged to add content to the Project LEO WordPress site on a continual basis. While the central theme of our site focuses on immunotherapy, we support any content that helps build the Project LEO community and gives hope to the patients and caregivers who visit. This includes independent projects, events and sites that are not tied to Project LEO, but still relates to our message: Learn, Empower, Overcome.

## HOW TO WRITE A POST

1. Visit the [Project LEO WordPress site](#) and log in with your username and password. Once logged in, you will see the WordPress dashboard.
2. In the dashboard, select *Posts* in the menu to the left
3. Select *Add New*.
4. From here, you may type your content and create your post.
  - a. You can also save your post as a draft to work on later, or preview it to see how it will look once published.
5. While you will not be able to post a photo directly, we do encourage you to submit your ideas for accompanying visuals to your support staff.
6. Once your post is complete, select the *Submit for review* button for it to be reviewed and published by your support staff.
  - a. Your post will be published as soon as possible.
  - b. If there is an issue with your post, someone from your support staff will contact you.



## Forums (message boards, bulletin boards)

Forums, message boards and bulletin board systems are text-based online communities, generally focused on a specific topic, where users can pose questions or share information, and enjoy a sense of community that comes when people of similar interests congregate.

Beyond text-based ideas and messages, forums and message boards can be used to share files and links. While many of these functions are now handled through newer social media services, forums, message boards and bulletin board systems still exist and have a very dedicated following.

### **STATS**

- Research on social media and the banking industry revealed that 90% of all online conversations about banks and their products occurred on forums and message boards.
- Survey results indicate that more Americans age 12 and older read message boards each week (62 percent) than read blogs (54 percent).
- Nearly two-thirds of respondents indicated they read online message boards each week.

### **WHAT MAKES FORUMS UNIQUE**

- Forums and message boards are sometimes compared to chat rooms, but these systems were not meant to be in real time. Instead, users log in, see what has been posted since they were last there and reply as they please.
- Forums have a large number of people, concentrated in one place, who all have the same common interests.
- Forum users are often influential bloggers and active social media experts in the specific topics covered by the forum. Making a good impression in front of this audience can help your message spread well beyond your own direct audience.

Facebook (coming soon)



Twitter (coming soon)



## Social Media Glossary: common abbreviations

**B4** - before

**b/c, bc** - because

**BRB** - be right back

**BTW** - by the way

**CC** - carbon copy, works the same way as in an email

**DM** - direct message, a private message via Twitter

**EM, EML** - email

**FB** - Facebook

**FF** - follow friday (#followfriday) is a way that people promote other Twitter users to their specific interests

**HT** - Hat Tip or Heard Through, an alteration of RT (retweet)

**HTH** - happy to help

**IDC** - I don't care

**IDK** - I don't know

**IM** - instant message

**IMO** - In My Opinion

**JK, J/K** - just kidding

**L8** - late

**LI** - LinkedIn

**LMAO** - laugh my a\*\* off

**LMK** - let me know

**LOL** - laugh out loud

**MT** - modified tweet (like a retweet, but with slight changes to the original message)

**NSFW** - not safe for work

**OH** - overheard

**OMG** - oh my God

**OMW** - on my way

**ONLY** - oh really?!

**ROFL** - rolling on the floor laughing

**RT** - retweet

**SMH** - shake my head

**Thx, tx** - thanks

**TMI** - too much information

**TL;DR** - too long, didn't read

**TT** - trending topic

**TTYL** - talk to you later

**TTYU** - talk to you soon

**TY** - thank you

**UGC** - user generated content

**YT** - YouTube

**YW** - you're welcome



## **FORWARD-LOOKING STATEMENTS**

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