

**LYME  
POWER  
OFUS  
CAMPAIGN**

# **LYMEPOWEROFUS**

**the power of us to bring about change**

## **SOCIAL AMBASSADOR TOOLKIT**

[www.ilads.org](http://www.ilads.org)





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# #LYMEPOWEROFUS

ABOUT THE CAMPAIGN



# About The Campaign

## What is The LymePowerOfUs Campaign?

LymePowerOfUs' goal is to inform, inspire and motivate individuals and groups across the world to take actions that bring awareness of Lyme disease and put an end to the growing epidemic of tick-borne diseases.

The Campaign was created in honor of Dr. Nick Harris who will be awarded the 2013 Pioneer Lyme Disease Award on October 19, 2013 at the ILADS San Diego Conference.

We're working towards our vision of a world where no one is denied appropriate diagnosis and treatment of Lyme disease, where families aren't ruined financially, and where no one lives a life of suffering from chronic Lyme disease. Join Us. We need your voice.



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# JOIN THE ROAR





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# 40% relapse

Short treatment courses have resulted in upwards of a 40% relapse rate. Especially if treatment is delayed.

## About ILADS

Through Education, Awareness, and Action, ILADS promotes understanding of Lyme and its associated diseases and strongly supports physicians and other health care professionals dedicated to advancing the standard of care for Lyme and its associated diseases. By supporting ILADS you will improve physician understanding of Lyme disease and increase public awareness of the devastation Lyme causes to the lives of people worldwide.

## About ILADEF

The International Lyme and Associated Diseases Educational Foundations (ILADEF) is the educational foundational arm of the International Lyme and Associated Diseases Society (ILADS). The ILADEF mission is to advance Lyme disease care through support of programs in education and research.



### EDUCATE

London. Boston. Belgium. Toronto. Austria. San Diego. We're educating healthcare professionals in the battle against Lyme disease through our bi-annual international conferences each year.



### CREATE AWARENESS

We get the word out. In 2012, we promoted Lyme disease awareness through a message that could not be missed on the JumboTron in Times Square, at the Superbowl and Daytona 500.



### TAKE ACTION

We believe in giving back. We bring the latest in cutting-edge research to you through our Free International Streaming Events. In 2012, we had events in the United States, Europe and Australia.





click to tweet this

## Why Is The Campaign Important?

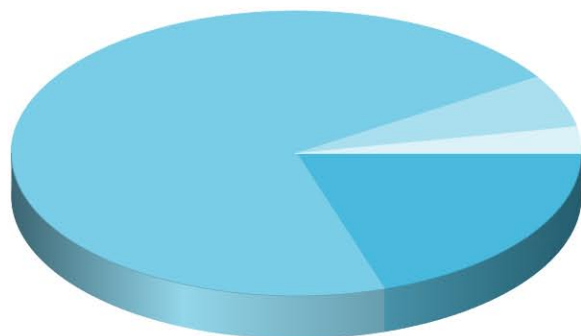
It is unclear how many cases of tick-borne diseases are properly diagnosed or reported each year. Estimates indicate that only one out of every ten cases of Lyme disease is reported and that many people are misdiagnosed and undertreated.

The CDC states the following: "Most cases of Lyme disease can be treated successfully with a few weeks of antibiotics." This is the information that is being disseminated to physicians worldwide and it strongly influences physician treatment decisions.

This misinformation is putting people at risk of developing chronic Lyme disease, creating untold suffering and making it much more difficult to cure. Education and awareness among doctors and patients, coupled with heightened attention to the appropriate diagnosis and treatment of tick-borne diseases is absolutely essential.

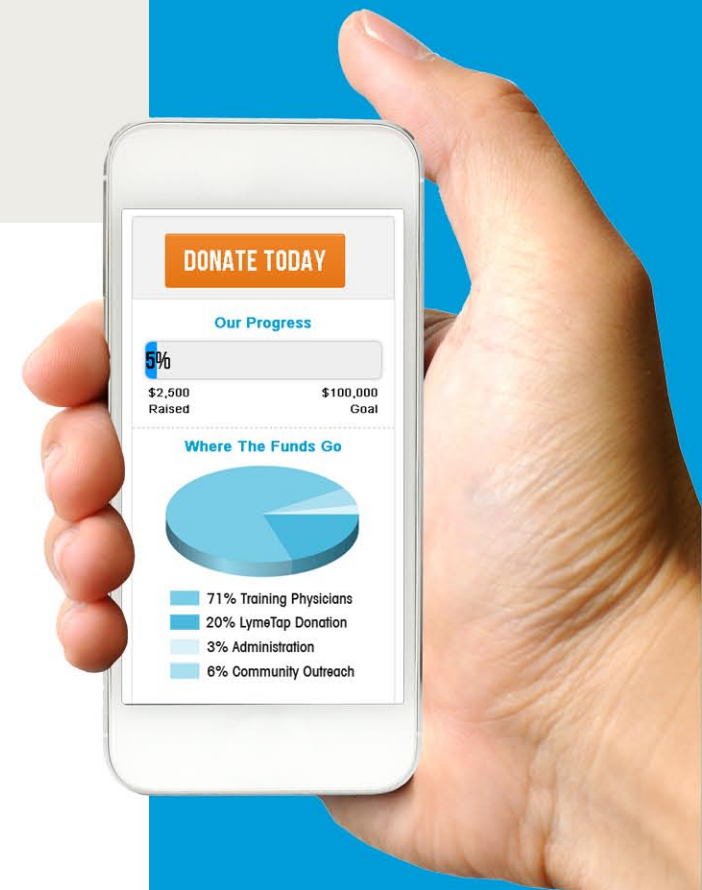
**We need your voice to make this happen.**

## Where Do The Funds Go?



### HOW FUNDS ARE USED

- 71% Training Physicians
- 20% LymeTap Donation
- 3% Administration
- 6% Community Outreach



**Together our single voice can become a roar.**





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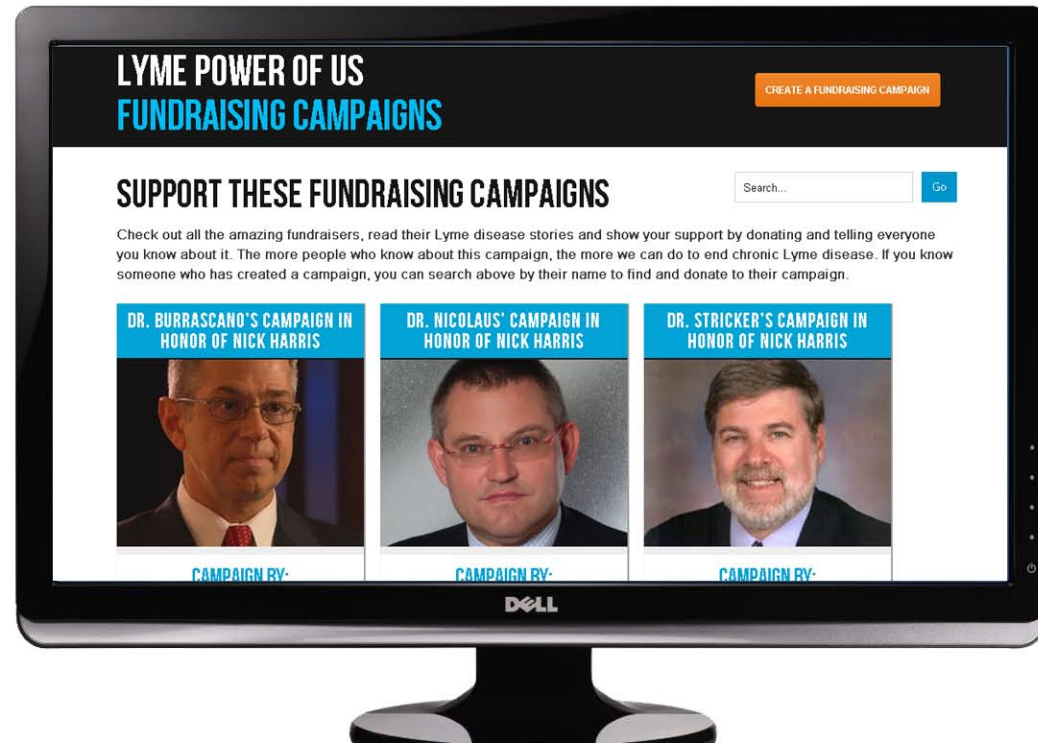
My new personalized car license plate. Thankful for my healthcare provider that was professionally trained by ILADS

## What do we hope to achieve?

While our goal may seem lofty, it is our mission: A Lyme Specialist in every Country, State/Region, and HomeTown. We believe attaining this goal will go a long way to eliminating Chronic Lyme Disease.

The ILADEF Physician Training Program, a groundbreaking project vital to fostering excellence in care for Lyme disease patients, directly addresses challenges in properly diagnosing and treating Lyme and other tick-borne diseases. The Training Program provides physicians the opportunity to study with Lyme-literate physicians and allows them to go back to their communities and offer appropriate treatment to people with Lyme disease.

This campaign also is focused on giving back to the people who are affected the most. Those are the people suffering from Lyme disease. 20% of the funds raised through the LymePowerofUs Campaign will be donated to LymeTap in Dr. Nick Harris' name to provide assistance for initial Lyme-related lab tests to patients who demonstrate financial need.



# #LYMEPOWEROFUS

## LYME DISEASE QUICK FACTS



# LYME DISEASE QUICK FACTS

## NO ACCURATE TESTS

THERE ARE NO TESTS AVAILABLE TO PROVE THAT THE ORGANISM IS ERADICATED OR THAT THE PATIENT IS CURED.



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**50%**

**FEWER THAN 50% OF PATIENTS WITH LYME DISEASE RECALL A TICK BITE.**

In some studies this number is as low as 15% in culture-proven infection with the Lyme spirochete.

**50%**

**FEWER THAN 50% OF PATIENTS WITH LYME DISEASE RECALL ANY RASH.**

The “bull’s-eye” rash is not the most common dermatologic manifestation of early Lyme infection.

**40%**

**SHORT TREATMENT COURSES HAVE RESULTED IN UPWARDS OF A 40% RELAPSE RATE, ESPECIALLY IF TREATMENT IS DELAYED.**

There has never been a study demonstrating that 30 days of antibiotic treatment cures chronic Lyme disease. However there is much documentation demonstrating that short courses of antibiotic treatment fail to eradicate the Lyme spirochete.

**40%**

**40% OF LYME PATIENTS END UP WITH LONG TERM HEALTH PROBLEMS.**

The average patient sees 5 doctors over nearly 2 years before being diagnosed.



# LYME DISEASE QUICK FACTS



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## FASTEST GROWING

ACCORDING TO THE CDC, LYME DISEASE IS THE FASTEST GROWING VECTOR-BORNE, INFECTIOUS DISEASE IN THE UNITED STATES.

300

**THERE ARE 5 SUBSPECIES OF BORRELIA BURGDORFERI, OVER 100 STRAINS IN THE US, AND 300 STRAINS WORLDWIDE.**

This diversity is thought to contribute to its ability to evade the immune system and antibiotic therapy, leading to chronic infection.

25x

**THE NUMBER OF CASES REPORTED ANNUALLY HAS INCREASED NEARLY 25-FOLD SINCE NATIONAL SURVEILLANCE BEGAN IN 1982.**

200,000

**MANY EXPERTS BELIEVE 200,000 PEOPLE PER YEAR ARE BEING INFECTED WITH THIS DISEASE.**

The CDC reports 24,364 confirmed cases and 8,733 probable cases of Lyme disease in 2011 in the US, but acknowledges the actual number may be far higher due to underreporting. Everyone agrees there are no tests to accurately determine the real number.

50%

**UP TO FIFTY PERCENT OF TICKS IN LYME-ENDEMIC AREAS ARE INFECTED.**

The onset of Lyme disease symptoms can be easily mistaken for other illnesses. Once symptoms are more evident the disease may have already entered the central nervous system, and could be hard to cure.

35%

**THE ELISA SCREENING TEST IS UNRELIABLE.**

The common Elisa test you receive at your doctor's office misses 35% of culture proven Lyme disease. Some studies indicate up to 50% of the patients tested for Lyme disease receive false negative results.



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# #LYMEPOWEROFUS

## SOCIAL AMBASSADOR GUIDE

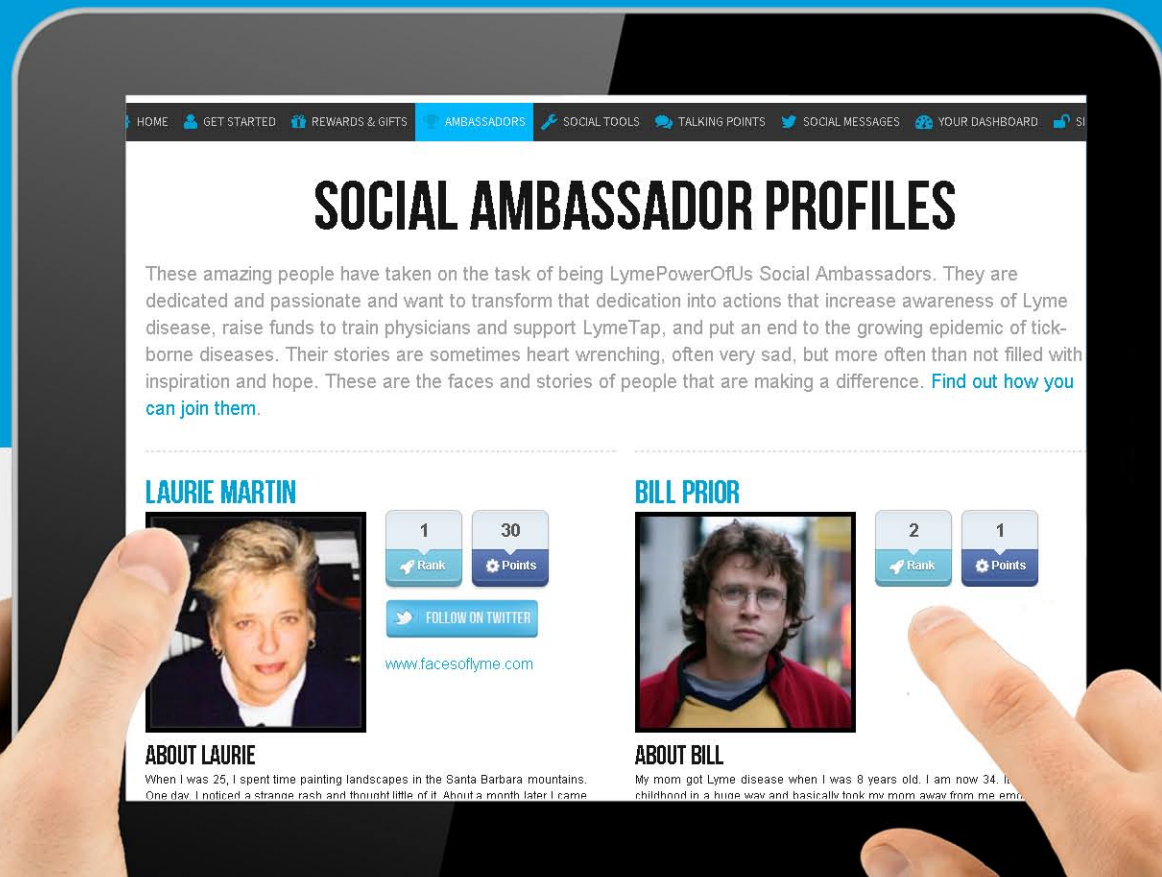


# ABOUT SOCIAL AMBASSADORS

Harness the power of social media by reaching out to people like you; passionate and committed to Lyme disease awareness, and make it easier to bring our voices together and make a difference.

*It's simple – as individuals, our ability to impact people suffering from Lyme disease globally is limited; together it's extremely powerful.*

*We're working for a world where no one is denied appropriate diagnosis and treatment of Lyme disease.*





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49%

49% of U.S. internet users say friends and family are their top sources of brand awareness.

## Social Ambassador Program

### What Is The Social Ambassador Program?

Lyme disease is the fastest growing vector-borne disease worldwide but it can be stopped, if we all speak out and raise our voices. Together our single voice can become a roar. Too many people are becoming debilitated from this disease, some are dying and many are being financially devastated.

That's where you come in. The Social Ambassador Program is a key part of the LymePowerOfUs campaign, to bring our voices together collectively in getting the word out and increasing awareness of the Lyme disease epidemic and how important it is to treat this disease early. Together our voice is louder and our impact greater!

Social media is completely transforming our ability to create change. It's now possible to harness the power of social media and educate people about Lyme disease worldwide. It's simple – as individuals, our ability to impact people suffering from Lyme disease globally is limited; together it's extremely powerful – powerful enough to change the face of Lyme disease.

We want to harness this power by reaching out to people like you; passionate and committed to Lyme disease awareness, and make it easier through the tools we've created to bring our voices together and make a difference.

The benefits of helping our community come together under a common theme and set of messages, we believe will lead to increased awareness, education, prevention and training in the appropriate diagnosis and treatment of Lyme disease. This is the #LymePowerOf Us Social Ambassador Campaign's goal.

**We're working towards our vision of a world where no one is denied appropriate diagnosis and treatment of Lyme disease, where families aren't ruined financially, and where no one lives a life of suffering from chronic Lyme disease. Join Us. We need your voice.**





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## What do we offer our Ambassadors?

We offer our Ambassadors a simple guide to using social media and innovative marketing to inspire and motivate others to support and raise funds for the cause that matters so much to all of us. We make this easy by providing online tools to manage your social outreach with tracking tools and statistics, personal referral links, social widgets, profile management and an email form to send messages to your family and friends.

## Who can serve as an Ambassador?

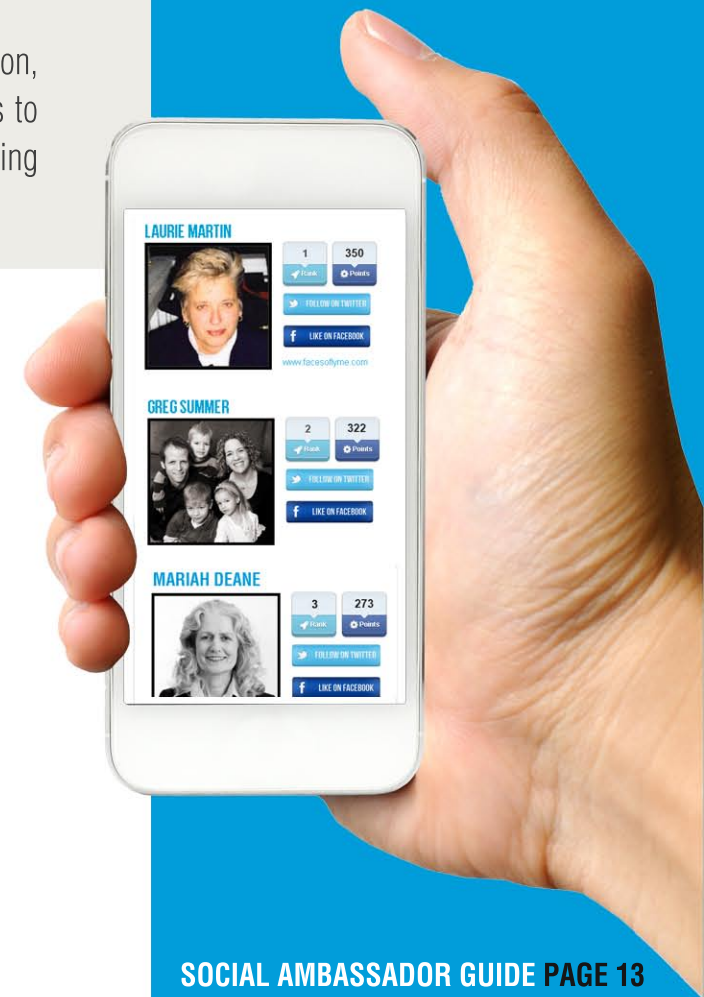
Many of you were invited because you reached out to us and asked to help. We created this campaign because we've received so many messages worldwide from people who wanted to make a difference. You are our core ambassadors and we are lucky to have you.

#LymePowerOfUs Social Ambassadors are dedicated and passionate about Lyme disease education, training and action and want to transform that dedication into spreading the Campaign's messages to others through social media. If you have these qualities, we welcome you and look forward to you adding your voice to the roar that will change lives.

## What is the role of an Ambassador?

#LymePowerOfUs Ambassadors are a unique groups of individual that are deeply committed to changing the face of Lyme disease. Ambassadors will help to:

- ◆ Build awareness about #LymePowerOfUs in order to further expand and deepen its reach and impact.
- ◆ Actively promote and share with their network about what #LymePowerOfUs does and its contribution to ending the Lyme disease epidemic.
- ◆ Introduce their network to the various ways to contribute and donate to the campaign.
- ◆ Encourage people to participate in spreading the message to their networks by becoming Ambassadors themselves.
- ◆ Encourage people to tell their story on the Lyme Wall.
- ◆ Encourage their family and friends to join the Thunderclap Campaign.







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## What rewards and gifts do you receive?

We appreciate you and know that your voice makes all the difference. So we would like to show our appreciation to you for all of your hard work.

When you earn 50 points, you will receive the following gifts:

- ◆ LymePowerOfUs Tee Shirt
- ◆ LymePowerOfUs Car Sticker
- ◆ LymePowerOfUs Wrist Band

Rewards will be given in the following manner:

- ◆ Recognition on our website of all Social Ambassadors.
- ◆ Video Bundle of your choice for all Social Ambassadors that earn over 150 points.
- ◆ Recognition in our newsletter of all Social Ambassadors that earn over 150 points.
- ◆ Top 3 Social Ambassadors will receive tickets to the ILADS San Diego Lyme Disease Conference from Oct. 18-20, 2013 and a ticket to the Gala Awards Dinner where you will be seated in a place of honor and thanked publicly for your hard work.
- ◆ The Social Ambassador with the most points accrued from click referrals and donations will be recognized and awarded "The Social Ambassador Star Award" at this year's Gala Awards Dinner.

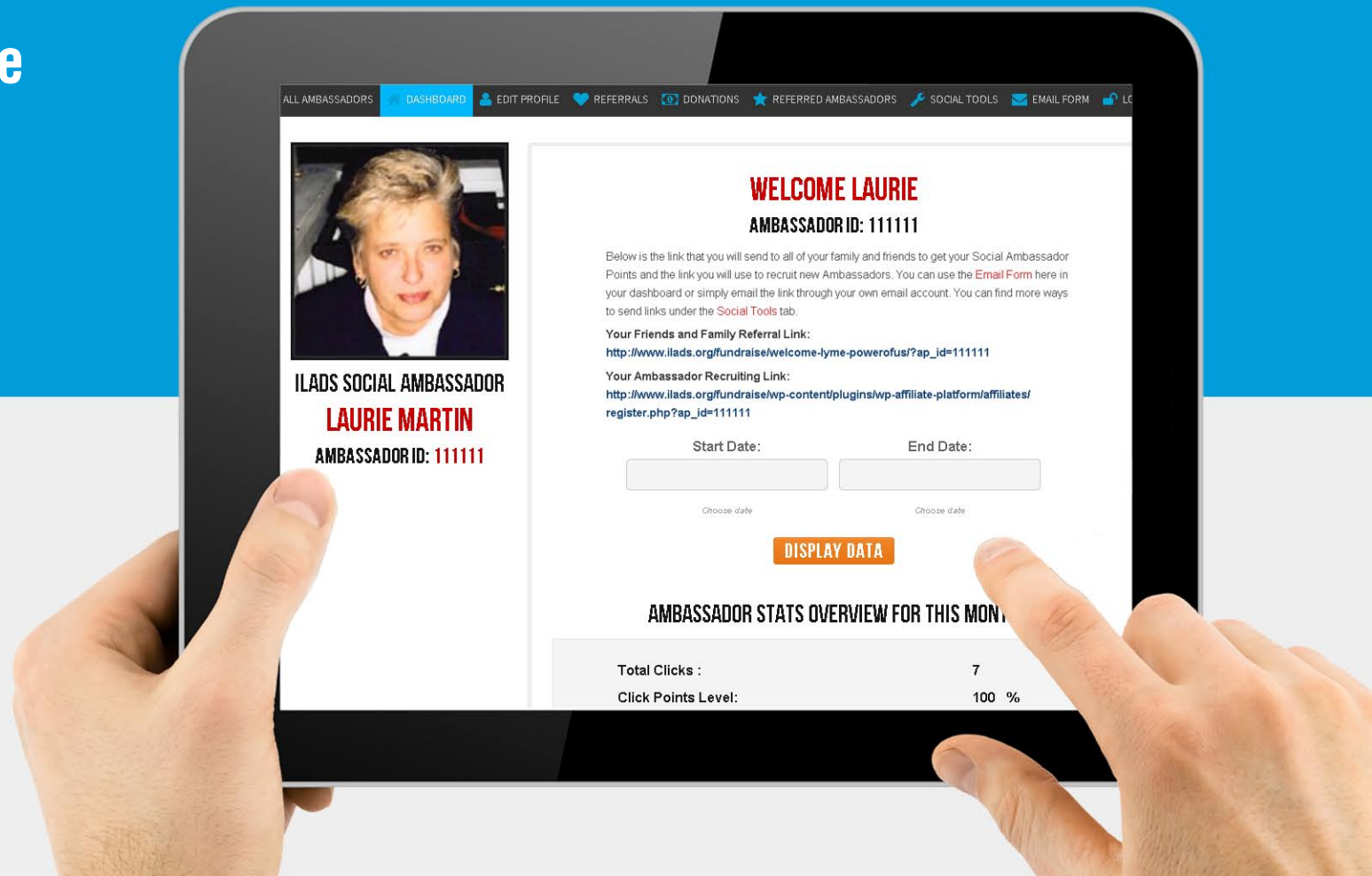


# SOCIAL AMBASSADOR TOOLKIT

Tools to help you  
get started and  
get the word out  
through your online  
Ambassador  
Dashboard.

*Ambassadors are the most efficient way that we can spread awareness about the Lyme disease epidemic and educate people about proper diagnosis and treatment.*

*We're working for a world where no one is denied appropriate diagnosis and treatment of Lyme disease.*



ALL AMBASSADORS DASHBOARD EDIT PROFILE REFERRALS DONATIONS REFERRED AMBASSADORS SOCIAL TOOLS EMAIL FORM LC



ILADS SOCIAL AMBASSADOR

**LAURIE MARTIN**

AMBASSADOR ID: 111111

**WELCOME LAURIE**

AMBASSADOR ID: 111111

Below is the link that you will send to all of your family and friends to get your Social Ambassador Points and the link you will use to recruit new Ambassadors. You can use the **Email Form** here in your dashboard or simply email the link through your own email account. You can find more ways to send links under the **Social Tools** tab.

Your Friends and Family Referral Link:

[http://www.ilads.org/fundraise/welcome-lyme-powerofus/?ap\\_id=111111](http://www.ilads.org/fundraise/welcome-lyme-powerofus/?ap_id=111111)

Your Ambassador Recruiting Link:

[http://www.ilads.org/fundraise/wp-content/plugins/wp-affiliate-platform/affiliates/register.php?ap\\_id=111111](http://www.ilads.org/fundraise/wp-content/plugins/wp-affiliate-platform/affiliates/register.php?ap_id=111111)

Start Date:

Choose date

End Date:

Choose date

**DISPLAY DATA**

**AMBASSADOR STATS OVERVIEW FOR THIS MONTH**

Total Clicks :	7
Click Points Level:	100 %



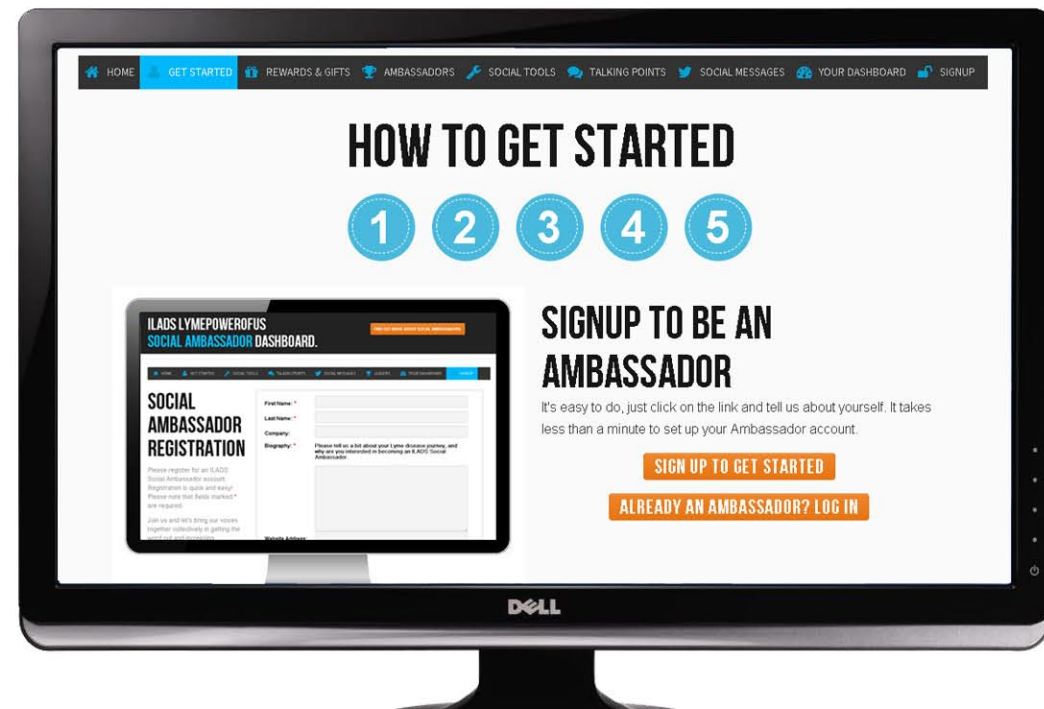
fill out feedback  
form online

# About The Ambassador Toolkit

The Ambassador Toolkit provides tips, resources, and materials designed to help you spread the word about the #LymePowerOfUs Campaign. We have provided sample activities on the following pages to give you a roadmap, but we encourage you to also come up with your own activities. We would love it, if you gave us feedback online about how this program works for you and how we could make it better.

We hope you find these materials helpful as you motivate others to support the cause that matters so much to all of us. In this toolkit you will find:

- ◆ Steps to Getting Started as an Ambassador
- ◆ #LymePowerOfUs Key Messages
- ◆ #LymePowerOfUs action plan ideas
- ◆ Social media guide with sample tweets and Facebook status updates
- ◆ Sample outreach email to share with your networks



# How to Get Started

Signing up to be an #LymePowerOfUs Ambassador is easy to do. The process takes a few minutes and gives you powerful tools to manage your account and send out links to your family and friends so that you can start earning points right away.

## 1 Register as an Ambassador

Click on the link and tell us about yourself. You will be asked for basic contact information, and why you would like to be a #LymePowerOfUs Social Ambassador. We also would love to hear a bit about your experience with Lyme disease.

## 2 Your Profile has been Created

Once you've completed your registration, you will receive an email with a link to your private Dashboard. Keep this email. We will review your application quickly, and once the review is complete you will receive an email letting you know your Ambassador Profile and Dashboard are live, where you can start spreading the word. You can update your profile page, download your Ambassador Business Card, view your stats for points received from referrals and donations, start recruiting other Ambassadors, get Widgets for your website, and lots more.

## 3 Start Getting Points

On your dashboard home page, you will find three links. The first one is the link you will use to send to your family and friends for referrals. When they click on this link, a click referral is registered and you get 1 point. Donations are even better, anytime your friend or family clicks on the second link and donates, you get 50% of the donation in points. So if your friend donates \$100, you get 50 points. But there is one more step that really starts bringing in the points. The third link on your Dashboard, is the link you will send out to recruit Ambassadors. If a person signs up as an Ambassador from the link you sent them, you will now get points every time someone donates on that Ambassador's account. So, if your recruited Ambassador gets a donation of \$100, they get 50 points, but so do you. You can see how this can rack up the points very quickly.



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## How to Get Started

### 4

#### **More Ways To Get Referrals**

The Social Tools Tab in your Dashboard takes you to a page where you have a number of different ways to promote your campaign. The Download Tools tab gives you marketing materials that will assist you. The Widgets and Text Link tabs have more links that you can copy and paste into your emails, website, blogs with custom LymePowerOfUs Widgets. These widgets have your personal link embedded so that anytime someone clicks on these widgets you will earn a point, and if they donate when they visit #LymePowerOfUs website, you will receive 50% of the donation in points.

### 5

#### **It's easy to see where you rank**


You can view your total points in your personal dashboard or you can view your points on the Social Ambassador Profiles Page. Your rank will be shown along with all the other Ambassadors on the profile page giving you a clear picture of where you are in the pack. So if you are competitive and want to win the coveted "Social Ambassador Star" Award, check often to see how you're doing.















# What kind of committment?

Ambassadors are asked to make a commitment until the ILADS Gala Awards Dinner on October 19, 2013. Points will be counted on Oct 1st for all rewards.

Of course, we would love it if you continued working for the Campaign after the event. We will have other reward programs throughout the year and will let you know about them.

How much work you put into the campaign will depend on how proactive you are in seeking opportunities to promote #LymePowerOfUs and how passionate you are about getting the message out. The more you reach out, the bigger difference you will make in the lives of people with Lyme disease.

As part of the commitment to be an ambassador, we ask that you do the following: (Of course, none of this is required, but the more you do, the more you will create the change you want to see.) A number of these actions are explained in further detail in the upcoming pages.  Indicates link to website.

- ◆ Download The Social Ambassador Kit and review it.
- ◆ Become Familiar With Basic Lyme Disease Facts. 
- ◆ Tell your story and join The Lyme Wall. 
- ◆ Send Social Messages as often as you can. 
- ◆ Start your own Fundraising Campaign. 
- ◆ Join The Thunderclap Campaign. 
- ◆ Write A Tribute To Dr. Nick Harris. 
- ◆ Wear Your LymePowerOfUs Tee Shirt and Wrist Band 
- ◆ Download and Print Out Flyers and put them everywhere. 
- ◆ Download and Print Out Poster and place it in a visible area. 
- ◆ Place The LymePowerOfUs Widgets on your Emails and Website. 
- ◆ Put the LymePowerOfUs Car Sticker on your bumper. 
- ◆ Print out your business card and hand it out when introducing yourself. 
- ◆ Place the #LymePowerOfUs Email Signature on all of your outgoing emails. 
- ◆ Send Emails to your friends and family. 



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# Social Actions

## Your Ambassador Activities

There are many ways you can generate awareness about #LymePowerOfUs — from simply mentioning your role as an Ambassador to displaying a poster in your office or as involved as creating a full on social media campaign. The goal of all of your actions is the same: Get the word out about our message: *A world where no one is denied appropriate diagnosis and treatment of Lyme disease, where families aren't ruined financially, and where no one lives a life of suffering from chronic Lyme disease.*

### 1 Let People know You Are an Ambassador

Increase awareness of #LymePowerOfUs by making sure people know you are a #LymePowerOfUs Ambassador. Tell your friends, colleagues, acquaintances and family. Download your business card from your Dashboard and hand it out as often as you can. Send an email about your role, including a link to the #LymePowerOfUs' Web site (email sample included in this kit). Ask them to forward the link to anybody who may be interested and anybody they know that may have an unexplained illness.

### 2 Update Your Email Signature

Add #LymePowerOfUs to your email signature so that everyone is reminded of #LymePowerOfUs and what you do.

#### Example:

Laurie Martin  
#LymePowerOfUs Ambassador  
[www.ilads.org/lyme-powerofus.php](http://www.ilads.org/lyme-powerofus.php)

*#LymePowerOfUs' is working towards our vision of a world where no one is denied appropriate diagnosis and treatment of Lyme disease, where families aren't ruined financially, and where no one lives a life of suffering from chronic Lyme disease.*

# Social Actions

## Your Ambassador Activities

### 3 Network with other Ambassadors

On the Ambassador Profile Page, you will see links to your Ambassador peers with their twitter, facebook and websites contact information. Introduce yourself to other Ambassadors. This will help build a network and facilitate collaboration in the future.

### 4 Leverage Social Media

If you use online social networks such as Facebook, Twitter, or LinkedIn, announce your role as an Ambassador through your status messages and include a link to the #LymePowerOfUs Web site: [www.ilads.org/lyme-powerofus.php](http://www.ilads.org/lyme-powerofus.php). In addition, show your connection to #LmePowerOfUs by becoming a fan of the ILADS Facebook page. Read the Social Media Guide in the following pages and review our sample tweets and posts for more information about using online networks to generate awareness of #LymePowerOfUs

### 5 Use Web Sites

Post a link to #LymePowerOfUs on your website and include details about how to contact you for additional information. Widgets are available in your Dashboard to make this easy.

### 6 Make it Easy for People to Find You

Display #LymePowerOfUs posters and flyers around your office or in an appropriate location at your workplace where people will see them. Also, consider hanging posters in doctors' offices, hospitals, and community health centers.

### 7 Twitter Background Image

Download the Twitter backgrounds from your Dashboard and upload to Twitter.



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signup online

GET YOUR  
TWITTER  
BACKGROUND







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signup online

## Social Actions

### Your Ambassador Activities

#### 8 Listen To People's Stories

Peoples' journey through Lyme disease is heart-wrenching. Many need to be heard. Give back by taking the time to listen and encourage them to tell their story on the LymeWall.

#### 9 Get out the Facts

Download Lyme fact sheets from the website and hand them out to raise awareness about Lyme disease and spark conversation. Keep several in your office and have them on hand to share with people that show an interest.

#### 10 Wear It, Drive It

Wear your #LymePowerOfUs teeshirt and wrist band. Place the car sticker on your bumper. Make sure to have flyers and Lyme facts in your car so if someone is interested, its easy to give them the information.

#### 11 Promote The Roar

Thunderclap can help LymePowerOfUs amplify our message on a big scale! It takes just a second to signup. Tell everyone you know to pledge a tweet.

#### 12 Create Your Own Fundraising Campaign

Create your own campaign page, tell your story and ask friends and family to donate.

#### 13 Donate

Make a donation to #LymePowerOfUs so others are inspired to make contributions.



# Key Messages

## The Importance of Key Messages

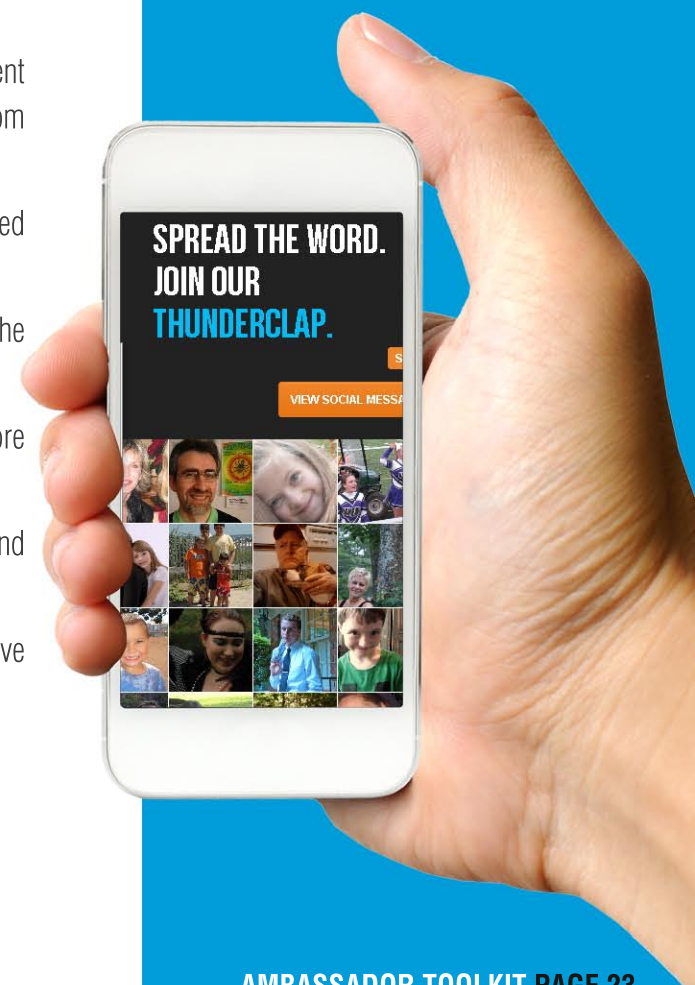
#LymePowerOfUs' key messages are what we want an individual to remember and react to. These messages are essential to informing others to take action if they have been bitten by a tick or have an unexplained illness and motivating people to support the campaign to end the Lyme disease epidemic.

As our campaign Ambassador, you will be talking with people that you may or may not know. You could be at work, out shopping, at a café. You might have 5 minutes or longer to talk. Regardless of the circumstances or how you say it, make sure that you deliver these key messages:

- 1** We're working towards our vision of a world where no one is denied appropriate diagnosis and treatment of Lyme disease, where families aren't ruined financially, and where no one lives a life of suffering from chronic Lyme disease.
- 2** According to the CDC, Lyme disease is the fastest growing vector-borne, infectious disease in the United States.
- 3** The common test you receive at your doctor's office misses 35-50% of Lyme disease. You may leave the doctor's office thinking you do not have Lyme disease. This may not be true.
- 4** Early diagnosis and appropriate treatment of Lyme disease means people will less likely get ill and more likely will quickly return to their former lives.
- 5** The ILADEF Training Program provides physicians the opportunity to study with Lyme-literate physicians and allows them to go back to their communities and offer appropriate treatment to people with Lyme disease.
- 6** #LymePowerOfUs mission: A Lyme Specialist in every Country, State/Region, and HomeTown. We believe attaining this goal will go along way to eliminating Chronic Lyme Disease.
- 7** 40% of Lyme patients end up with long term health problems if not diagnosed and treated early. The average patient sees 5 doctors over nearly 2 years before being diagnosed.
- 8** Short treatment courses have resulted in upwards of a 40% relapse rate, especially if treatment is delayed.



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# #LYMEPOWEROFUS

## SOCIAL MEDIA GUIDE







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# Social Media Guide

## What is Social Media?

Social media describes the powerful ways individuals are engaging with content on the Internet. At its essence, Social media is the collective of online sites dedicated to community-based input, interaction, content-sharing and collaboration.

Think of regular media as a one-way street where you can read a newspaper or listen to a report on television, but you have very limited ability to give your thoughts on the matter.

Social media, on the other hand, is a two-way street that gives you the ability to communicate too.

## Why is Social Media important for #LymePowerOfUs?

No organization or person can end the Lyme disease epidemic alone, the fight requires the support of the entire community. This is why Social media is important. We consider every fan and follower a warrior in the fight to end this epidemic. Through you, we can fulfill our mission of raising awareness and educating more people about Lyme disease and training physician worldwide in the appropriate diagnosis and treatment of Lyme.

Taking social actions takes minimum effort, but it can have a major impact and make a big difference in the lives of people with Lyme disease. By using social media to spread the word, you as an Ambassador will “Lead The Roar”.

Many of you are probably already adept at using social media – however the following pages will give people new to social media a guide to using it to promote LymePowerOfUs’ key messages. Also available are email templates you can use to promote your Campaign.





# Social Media Guide

## What Is Facebook?

Facebook is the world's most popular social networking website. It makes it easy for you to connect with your family and friends online and share messages, photos, links and other information.

## Why Facebook?

The breadth of Facebook's network is staggering - there are more than 1.11 billion active users and approximately 50% of active users log on to Facebook on any given day.

Creating a Facebook Profile Page to raise awareness for Lyme disease is the first step in getting social.

*A Facebook Profile allows you to:*

- ◆ Create a basic profile describing your role as an Ambassador for #LymePowerOfUs.
- ◆ Make your community aware that you are a LymePowerOfUs Social Ambassdor.
- ◆ Post your Ambassador Link so its easy for people to click on the link, which of course allows you to earn more points. You can find this link in your Dashboard.
- ◆ Easily click on the Social Messages of the LymePowerOfUs website and share key messages.
- ◆ Alert supporters to LymePowerOfUs advocacy efforts.
- ◆ Encourage dialogue through wall posts, status updates and newsfeeds.
- ◆ Share photos, videos and links.



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# Social Media Guide

## Getting Started on Facebook

Go to [www.facebook.com](http://www.facebook.com) and register a Facebook account. Under the words “Sign Up” on the homepage, put your first name in the first box and your last name in the second box. Next enter a valid email address and re-enter that email in the box below. This is so that Facebook can contact you for confirmation of your registration and in future send you updates from your profile. Next enter a password of your choice, your sex, and your birthday. Then hit the Sign Up button at the bottom of the page. That’s it. Its easy to do.

Once you’ve created a page, you may want to check out the LymePowerOfUs Social messages by visiting <http://www.ilads.org/campaign/lyme-disease-social-ambassador-messages.php>. We’ve made it really easy. Just click on the Facebook icon, and click on a the Facebook share button to post the LymePowerOfUs Key Messages.

Take a look to see the kinds of posts, events or links that are shared on the ILADS Facebook Page at: <https://www.facebook.com/pages/ILADS-Lyme-Society/120608014816>. Notice that fans will often engage each other, exchanging links to related information or sharing their personal experience in response to a particular news article. By networking with each other, they are helping to spread the word about LymePowerOfUs within Facebook and ultimately, beyond the internet. Providing an interesting variety of posts will keep fans engaged and returning to your profile for more information.



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## Sample Facebook Posts

These can be posted to Facebook on the LymePowerOfUs website with a simple click at:

<http://www.ilads.org/campaign/lyme-disease-social-ambassador-messages.php>

- ◆ Join the #LymePowerOfUs movement to put an end to the Lyme disease epidemic! Join us. We need your voice! <http://ow.ly/maFM3>
- ◆ Personal stories are powerful and can help bring about real change. The LymeWall brings Lyme disease into peoples' homes and makes it real. You are the face of this disease and you have a unique perspective and passion to share with the world, and that is a powerful thing. <http://ow.ly/m2uCn>
- ◆ Help end the Lyme disease epidemic. Donate to #LymePowerOfUs. Without the support of people like you, the number of those suffering with undiagnosed Lyme disease will continue to grow. Small or Large Donations, every bit helps. With you we can change the face of Lyme disease. <http://ow.ly/mX6qq>
- ◆ #LymePowerOfUs: a world where no one is denied appropriate diagnosis and treatment of Lyme disease, where families aren't ruined financially, and where no one lives a life of suffering from chronic Lyme disease. <http://ow.ly/maFM3>
- ◆ Join the Roar on Thunderclap and take actions that increase awareness of Lyme disease. Pledge a tweet to the LymePowerOfUs Campaign and once enough tweets have been stockpiled, they are unleashed simultaneously. <http://ow.ly/m2usf>
- ◆ Lead The Roar! Become A Social Ambassador for the LymePowerOfUs Campaign. Become A Social Ambassador and make our vision come true: A world where no one is denied appropriate diagnosis and treatment of Lyme disease, where families aren't ruined financially, and where no one lives a life of suffering from chronic Lyme disease. <http://ow.ly/m2tym>
- ◆ Wear It, Shout It Out! Get The LymePowerOfUs Campaign Tools. Join The Roar. The more people that get the message that there is a Lyme disease epidemic, the more people will be helped. Put flyers on cars, wear the message, put the stickers everywhere, post the widgets on your emails, blogs...You get the idea. <http://ow.ly/mX6xV>
- ◆ Join #LymePowerOfUs and become part of the team that uses Social Actions to end the Lyme disease epidemic. <http://ow.ly/maFM3>



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## What is Twitter?

Twitter is a real-time information network that connects you to the latest stories, ideas, opinions and news about what you find interesting. At the heart of Twitter are small bursts of information called Tweets. Each Tweet is 140 characters long.

Total number of active registered Twitter users: **554,750,000**

Number of new Twitter users signing up everyday: **135,000**

Average number of tweets per day: **58 million**

Number of tweets that happen every second: **9,100**

## Getting Started on Twitter

It's very easy to do. You just sign up (free registration), pick a user name (your site or profile web page will be 'http://twitter.com/your name here'), and you can 'design' your Twitter home page by uploading an image or choosing web colors.

Using Twitter is as easy way to engage with individuals and other organizations interested in Lyme disease. You can share your Ambassador link, post LymePowerOfUs key messages, and share in conversations about Lyme disease awareness. Tweets can help educate people globally about the Lyme disease epidemic and what we can do to put an end to it.





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## Twitter Basics

It's simple really. When you follow someone on Twitter any updates that this person posts will appear on your Twitter feed. Anytime you post, these will appear on all of your followers' Twitter feed. To address another Twitterer, post the username preceded by an "@". Example: @ilads\_lyme (this is ILADS twitter username)

Ideally, your followers will spread your messages by retweeting, which means that a follower will take your tweet and rebroadcast it to their own followers. You can also retweet messages by others to help strengthen your relationships with peer groups, expand your Twitter presence and bolster Twitter's dialogue on Lyme disease. The ripple effect can help your message reach individuals and organizations beyond your current reach.

## Direct Messaging

Direct Messages are private tweets (to other twitter user) that are exchanged between two users that follow each other. You cannot direct message someone that does not follow you and vice versa. Direct messages are the only private way to converse on twitter. "DM's" are basically like emails that are limited to 140 characters per exchange. They are unsearchable on twitter.

## Retweeting

Retweeting or "RT"ing is used when you want to forward along a tweet that someone else said to your followers. One of the most common ways to RT is to copy the full tweet including the person's username and put "RT" before it. Your followers then know that whatever comes next was said by that user.

## Hashtags

Hashtags are a way to label tweets so that other users can see tweets on the same topic. Hashtags contain no spaces or punctuation and begin with a "#" symbol. Whenever you are posting about LymePowerOfUs, be sure to include the hashtag: #LymePowerOfUs.



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## Twitter Tips

- ◆ **Your Profile.** Set up your profile so people can understand what you care about and decide if they would like to follow you. Upload a photo of yourself. Post your Ambassador Link in your Bio and explain why you have become a #LymePowerOfUs Ambassador. Or if you don't have a website you can post your Ambassador Link in the website field, allowing people to click on the link and be taken directly to the #LymePowerOfUs website, and of course you will receive a point each time someone visits.
- ◆ **Follow lots of other people first.** Like-minded people will usually follow you back. Search on hashtags such as #lymedisease, #tick-borne diseases, #lymepowerofus, for tweets on those topics. Follow the people that posted them. Whenever you find a website you like, look for a Twitter button. Follow the people your favorite Twitterer is following, and then follow those who are following them.
- ◆ **Tweet the LymePowerOfUs key messages** and of course your own that you think will help increase Lyme disease awareness.
- ◆ **Retweet a lot.** Sharing and promoting what others have to say (if you like it) is what it's all about. Watch how other people retweet for the best ways to format your RTs.
- ◆ **Do not tweet a lot all at the same time.** This is seen as spam. Tweet frequently, but don't act like a spammer. Make sure you have something of value to tweet about and space your tweets out.
- ◆ **Thank people who retweet you.** You can use Twitter direct message to do this, but a public thank you is nice and you can do more than one at the same time. Probably the most effective thank you is a public tweet that uses a person's first name. Example: "@LaurieMiller Thanks so much for the RT, Laurie."

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## A Few Good Tweets

These can be posted to Twitter on the #LymePowerOfUs website with a simple click at:

<http://www.ilads.org/campaign/lyme-disease-social-ambassador-messages.php>

- ◆ Join our global #LymePowerOfUs campaign and help us end the Lyme disease epidemic. Here's how: <http://ow.ly/maFM3>
- ◆ Lyme Disease is the fastest growing vector-borne infectious disease globally. We need your voice. <http://ow.ly/maFM3> - #LymePowerOfUs
- ◆ Stop CDC from spreading WRONG treatment guidelines for Lyme disease. Get treated correctly. <http://ow.ly/maFM3> - #LymePowerOfUs
- ◆ Tell Your Lyme Disease Story. Be Heard. Be Seen. Speak out on the ILADS Lyme Wall. #LymePowerOfUs <http://ow.ly/m2uCn> @ilads\_lyme
- ◆ Say It Together And Be Heard. Join the Lyme Disease Awareness Roar on Thunderclap. RT. #LymePowerOfUs <http://ow.ly/m2usf> @ilads\_lyme
- ◆ Sign up #LymePowerOfUs Social Ambassador. Spread Awareness, Change the lives of people with Lyme. <http://ow.ly/m2tym> @ilads\_lyme
- ◆ ILADEF Training provides physicians opportunity to learn Lyme disease correct diagnosis and treatment. #LymePowerOfUs <http://ow.ly/mOv7m>
- ◆ The common test you receive at your doctor's office misses 35-50% Lyme disease. See a Lyme doctor. #LymePowerOfUs <http://ow.ly/mOzeK>
- ◆ Short treatment for Lyme results in 40 percent relapse rate, especially if treatment is delayed. #LymePowerOfUs <http://ow.ly/maFM3>
- ◆ Early diagnosis and correct treatment of Lyme means people will less likely develop Chronic Lyme disease. #LymePowerOfUs <http://ow.ly/maFM3>
- ◆ Improve physician understanding of Lyme disease and spread awareness of devastation to people's lives. #LymePowerOfUs <http://ow.ly/maFM3>



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# Social Media Guide

## Sample Outreach Email

The following email templates offer ideas and language you can use as part of your outreach for #LymePowerOfUs. Feel free to copy or update as you see fit for your networks as you share your involvement with #LymePowerOfUs. Using these messages as often as possible will help increase your traffic to your Ambassador links, which means more points, exposure and donations! The yellow highlighted areas are what you need to change. Your ambassador links can be found in your Dashboard.

### Sample 1: Donation Email Template

#### Subject: LymePowerOfUs: Help me end the Lyme disease epidemic

Dear Friend,

ILADEF (the educational arm of ILADS) is making a difference in ending the Lyme disease epidemic through the #LymePowerOfUs Campaign. The Goal: End The Lyme Disease Epidemic.

Join us and help make our vision come true: A world where no one is denied appropriate diagnosis and treatment of Lyme disease, where families aren't ruined financially, and where no one lives a life of suffering from chronic Lyme disease.

Your donation of (XX amount of money), can help immensely in ending the Lyme disease epidemic. We are counting on you! Please help us by spreading the word and pledging to make a donation at <http://www.ilads.org/fundraise/donate-iladef/>(your ambassador link).

With your support, we hope to raise \$100,000 by October 1, 2013.

Sincerely,

(Name)

(Title )

(Insert a link to your Facebook page)

(Insert a link to your Twitter page)

My Ambassador Profile: <http://www.ilads.org/campaign/lyme-disease-social-ambassador-leaders.php>



# Social Media Guide

## Sample Outreach Email

### Sample 2: Referral Email Template

**Subject: LymePowerOfUs: Help me end the Lyme disease epidemic**

Dear Friend,

I am part of a call to action and global campaign that will transform how people think about and talk about Lyme disease and I am asking you to add your voice to the roar.

Lyme Disease is the fastest growing vector-borne infectious disease globally but it can be stopped, if we all speak out and raise our voices. Together our single voice can become a roar. ILADS is spearheading this campaign through their educational arm - ILADEF, but no organization can make this happen alone, which is why I am asking you to empower this campaign by taking action.

There are many ways you can help. Your voice, your story, your actions; all are important. Please take a minute and do what you can to help us educate people worldwide through easy to use online tools.

Please visit <http://www.ilads.org/fundraise/welcome-lyme-powerofus/>(your ambassador link).

Sincerely,

(Name)

(Title )

(Insert a link to your Facebook page)

(Insert a link to your Twitter page)

My Ambassador Profile: <http://www.ilads.org/campaign/lyme-disease-social-ambassador-leaders.php>



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# Social Media Guide

## Sample Outreach Email

### Sample 3: Ambassador Referral Email Template

#### **Subject: LymePowerOfUs: Lead the roar to end the Lyme disease epidemic**

Dear Friend,

I am an Ambassador for the LymePowerOfUs Campaign that will transform how people think about and talk about Lyme disease and I am asking you to lead the roar with me. Because of your passion and commitment to ending this epidemic, I think you would be the perfect person to become an Ambassador for the campaign as well.

Lyme Disease is the fastest growing vector-borne infectious disease globally but it can be stopped, if we all speak out and raise our voices. Together our single voice can become a roar. ILADS is spearheading this campaign through their educational arm - ILADEF, but no organization can make this happen alone, which is why I am asking you to empower this campaign by taking action.

It's very easy to do. You get a personal dashboard with tons of online tools to make your campaign successful. Let's end this epidemic together.

To register as a #LymePowerOfUs Ambassador, please visit:

<http://www.ilads.org/fundraise/wp-content/plugins/wp-affiliate-platform/affiliates/register.php> (your ambassador link).

Sincerely,

(Name)

(Title )

(Insert a link to your Facebook page)

(Insert a link to your Twitter page)

My Ambassador Profile: <http://www.ilads.org/campaign/lyme-disease-social-ambassador-leaders.php>

# QUESTIONS?

Contact one of our  
team members.

lymepowerofus@ilads.org

rjones@ilads.org

lmartin@ilads.org

*Because of you, passionate and committed to spreading awareness of Lyme disease, we can end this epidemic and change the lives of people suffering needlessly.*

*We're working for a world where no one is denied appropriate diagnosis and treatment of Lyme disease.*

