## INFUSING FOR LYMIES

A step-by-step guide with money-saving tips for buying and infusing IV medications, maintaining a PICC line, minimizing the herx reaction, insurance denials, and more.

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## Infusing for Lymies

## **Table of Contents**

	Int	rod	uct	tion
• • •			GC.	

- ... Meds in a Box: Using Infusion Services
- ... When Insurance Fails: Meds on a Budget
- ... Ordering Your Medications
- ... Gathering Your Supplies
- ... Supplies on a Budget
- ... Prescription Discount Cards
- ... Getting a PICC Line: How to Avoid Freaking
  Out
- ... Protecting the PICC Line
- ... Care and Maintenance of the PICC Line and Dressing
- ... Avoiding the Itchies: Dressings for Sensitive Skin
- ... Bathing: How do I keep this thing DRY?

## Table of Contents (... continued ...)

- ... Infusions: What do I do with all this STUFF?
- ... Heading off the Dreaded HERX
- ... Clean Up Your Act: Eating to Help Your Body
  HEAL
- ... Insurance Denials: To Fight, or Not to Fight?
- ... RESOURCES: Recommended Reading, Support Groups and Forums
- ... Appendix 1: Summary of Resources in this eBook
- ... Appendix 2: Product Order Numbers for Selected Supplies
- ... Appendix 3: Supplies Order Form

#### Introduction

As lyme patients, we face a lot of challenges in getting proper care and treatment, as the result of a medical system that is just taking its baby steps into the lyme world.

One of the biggest gaps in this process is teaching patients how to handle IV medications on their own, either with the help of an infusion pharmacy and a home nursing service, or buying medications and supplies a-la-carte through pharmacies and medical supply companies and handling this solo.

This ebook was written to help fill the gap that the doctor's offices don't have the resources to handle on their own. Typically they'll hand you off to the infusion pharmacy and home nursing service and assume that all is well, instead of explaining how to obtain the needed medications and supplies, the step-by-step process of mixing medications and infusing them, as well as handling PICC lines, dressing changes, herx reactions and the switch to the dreaded so-called Lyme Diet.

Most patients will start out using an infusion pharmacy for their medications as well as a home nurse for their weekly dressing changes, but many are finding out that insurance won't cover these services for long. There is a need for affordable (and manageable) alternatives so patients can remain on their medications for as long as their doctors feel is necessary, which is where this book comes in.

While the infusion pharmacies provide convenient door-to-door service, many patients are finding that the out-of-pocket costs are just too high to manage for long. There is a need for more options, whether by using out-of-network infusion services instead of in-network, or buying the medications without the use of an infusion pharmacy.

## Introduction (... continued ...)

This ebook is not meant to replace any advice that your doctor has given you, it is meant as a resource to use in addition to the instructions that you receive from your doctor, as well as a guide to use for those times when your lyme-brain just can't remember the steps involved to do an infusion or mix your medications.

It may be a good idea to share this ebook with your doctor so he can confirm that the instructions for mixing and infusing medications are in agreement with his preferred procedures. Simply send it to your doctor in an email if you have a downloaded version, or direct him to the website where this is published online.

You may also want to share this ebook with fellow lyme patients, as they may be in the same boat as the rest of us, with limited financial resources and a need for lower-cost sources for medications as well as an easy-to-follow guide on how to handle the infusion process.

Hopefully this book will make the whole idea of IV medications, PICC lines, herxes and dietary changes less scary and more manageable for you.

Wishing you good health!

Linda

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P.S. If you found this ebook helpful, please help cover our costs of making this available to you by making a <u>small donation</u>.

## Meds in a Box: Using Infusion Services



Infusion services provide a handy one-stop-shop for all of your medications and supplies, and are great if your insurance will cover their costs, but may not be your best option otherwise.

The infusion service will ship everything to your doorstep, including your medication, infusion supplies, and dressing change supplies. It's a handy set-up, since you have everything you need in one box and only have to go as far as your front porch to get it.

Your insurance company prefers that you use in-network infusion services. It's just a dollars-and-cents decision for them, not a guarantee of coverage or of good service. You do have the option to go out-of-network for IV medications and still get insurance coverage!

Always ask the infusion service what your outof-pocket cost will be per dose. Typically the
in-network services will have a higher per-dose
cost than the out-of-network infusion services,
since their goal is to have you reach your annual out-of-pocket
maximum as quickly as possible. In insurance-speak, that's the
\$5000 or so that it's your responsibility to pay every year before
insurance will cover at 100%, which is not the same as your
deductible.

## Meds in a Box (... continued ...)

Patients have reported per-dose out-of-pocket pricing from these in-network infusion services ranging from \$45-\$85 per dose for Ceftriaxone (generic Rocephin), which is nothing short of highway robbery compared to the pricing from out-of-network services! This means that they're getting your \$85 cash PLUS whatever the insurance company pays them – yikes!

If your in-network infusion service will be charging you out-ofpocket costs for your medications and supplies, be sure to check with the out-of-network services listed below as well. We've found that out-of-network infusion services often provide lower out-of-pocket costs and better service.

Typically the out-of-network infusion services will charge \$30-\$35 per dose of Ceftriaxone, including all necessary supplies, and this may be reduced to zero if you have insurance coverage. Prices for Zithromax IV are similar, other medications may be significantly more.

When your insurance coverage for IV medications gets denied, then skip to the section 'When Insurance Fails: Meds on a Budget' for how-to's on getting medications at much more affordable rates. Notice I said 'when' and not 'if' on this? Most patients have troubles getting long-term insurance coverage for IV medications, so don't be surprised if your insurance only authorizes them for a limited period of time.

Meanwhile, continue reading for how to use the out-of-network infusion services to keep your out-of-pocket costs to a minimum, or even at ZERO, while you still have insurance coverage for your IV medications...

#### Meds in a Box (... continued ...)

#### Infusion service companies (out-of-network)

These are companies that patients have used with good success. There are other companies that provide the same services, but as of this writing these are the most reliable and lowest-cost services.

- ARC Infusion Service, La Palma, CA. (714) 522-8802
- InfuServeAmerica, St. Petersburg, FL. (800) 886-9222
- InfuSource, Rohnert Park, CA. (707) 588-8894

All of these out-of-network infusion services will bill your insurance for you. The difference is primarily in their billing practices.

Both <u>InfuServeAmerica</u> and InfuSource bill the patient up-front at their cash customer pricing of about \$30-\$35 per dose of Ceftriaxone, and then reimburse you later once insurance has paid them. ARC works differently, in that they get insurance approval prior to shipping your medications, and then they collect from the insurance company with nothing out-of-pocket from you other than what's left of your deductible. If you've already met your annual deductible, then your out-of-pocket costs with ARC will likely be ZERO for covered medications.

These infusion services are the ones that serve California customers as well as some other states. If you live outside of California, there may be other infusion services that better suit your needs.

## When Insurance Fails: Meds on a Budget



Sooner or later, your insurance company will likely declare you 'healed' and start denying coverage for your IV medications. For most this is a 'when', not an 'if'.

When this happens, you can continue as a cash customer with one of the infusion services at \$30-\$35 per dose of Ceftriaxone, or you can save \$20 per dose or more by being a smart shopper.

Yes, it takes a little more effort to save that \$20 per dose, but isn't it worth it? If you're infusing daily, that's an extra \$600 in your pocket every month!

You can still have most of the convenience of the meds-in-a-box from the infusion service, since basically you'll be ordering all of your supplies from them, and your medications will likely come from either <u>Walgreens pharmacy</u> or <u>Costco</u>. The biggest difference is that your meds will no longer arrive pre-mixed and ready to infuse.

Don't panic, keep reading and I'll walk you through the process...

## **Ordering Your Medications**



One of the least expensive sources for Ceftriaxone (generic Rocephin) at this time is through Walgreens pharmacy at \$61.90 per 10-pack, which is about \$6.19 per vial. This pricing may be subject to change, so always verify with

your pharmacy before ordering!

⇒ See the next page for tips on ordering other medications.

There is an annual fee of \$20 for the Walgreens pharmacy card, which is required to get their lowest pricing. You must sign for this card in the store as well, you cannot do this online. Order and pick up your medication from your local store (they will not ship).

The <u>Walgreens online drug pricing tool</u> is handy, but not always accurate – check with your local pharmacist for pricing and coverage for your medications.

## Ordering info for the Walgreens pharmacy:

- Remind the pharmacist to price your medication with the Walgreens pharmacy card discount.
- If you order on Monday-Thursday, you should have your medication ready for pickup the next day.

**IMPORTANT:** The medication must be ordered through the store pharmacy, not online, or via their 800#, or via the Walgreens infusion services. This pricing may be subject to change at Walgreens.

If you're having troubles ordering from Walgreens, read on...

## Ordering Your Medications (... continued...)

If Walgreens is out of stock on the Ceftriaxone covered by their pharmacy card or is no longer offering this low price, you may be able to order Ceftriaxone at other pharmacies at a similar cost.

#### **Ordering from Other Pharmacies**

You may be able to get generic Ceftriaxone from other pharmacies at similar prices, so it may be worth checking with your local pharmacy as well. Just provide them with the NDC numbers listed here and have them check pricing for you.

We've found that <u>Costco</u> has similar pricing to <u>Walgreens</u>, but not all Costco pharmacies will order for you. If your local Costco won't order the Ceftriaxone for you, try calling one of their larger stores instead.

- Hospira brand in 10-packs: NDC 0409-7335-03
- Sagent brand in 25-packs: NDC 25021-107-20
- Other brands have them research for you!

#### Other medications

It may be less expensive for you to order other medications this way as well. For example, Zithromax IV is a relatively inexpensive medication at around \$10.00 per vial in some pharmacies.

All that you would change would be the medication, possibly the size of the syringe used for mixing, and possibly the size of the saline IV bag that is needed - all else remains the same. You'll need the same supplies, and do the same process for mixing and infusing your meds.

# **Gathering Your Supplies**



You will need supplies for each infusion, as well as supplies for your weekly dressing (bandage) changes.

It's easiest to order supplies from InfuServeAmerica, so everything will be shipped to you in a complete kit other than your vials of medication. Get a separate prescription from your doctor so you can order your supplies from InfuServeAmerica and your medication

from <u>Walgreens pharmacy</u>, <u>Costco</u>, or your local pharmacy. This means you'll have two (2) prescription forms from your doctor: #1 for the medication (i.e. Ceftriaxone or Zithromax), and #2 for your supplies.

See the next page for a complete supplies list...

## Gathering Your Supplies (... continued ...)

#### Your supplies should include the following:

	Qty Per
	Infusion
Infusion Supplies	
Saline IV Bag	1
IV Admin Set	1
Saline Flush 10ml	2
Heparin Flush 5ml	1
Svringe 20ml with 18G1 Needle	1

## **PICC Maintenance Supplies (Weekly)**

Dressing Change Kit Extension Set with Cap

StatLock

Optional: Cap Only, No Extension Set Optional: Dressing for Sensitive Skin

#### **Bulk Supplies**

Alcohol Swabs

Gloves

# Supplies on a Budget



You can save about \$80 per month or more by ordering the Saline IV Bags at a regular pharmacy like <a href="DrugsDepot">DrugsDepot</a> instead of having them shipped by <a href="InfuServeAmerica">InfuServeAmerica</a> with the rest of your supplies.

The least expensive 100ml Saline IV Bags are made by Braun:

- Purchase in 64-packs or 96packs from <u>DrugsDepot</u>.
- Curreint pricing is \$135.29 per 64-pack or \$152.40 for a 96-pack (you must order a full pack). The perbag cost is much cheaper with the 96-pack.
- Order with these product numbers for 100ml bags:
  - 64-Pack: NDC 0264-1800-32
  - 96-Pack: NDC 0338-0049-18
- Be sure to get a separate prescription from your doctor for the saline bags, and remind him to write the prescription for a case-pack of 64 or 96 instead of authorizing only enough for your month's worth of infusions.
- For those of you who are counting, that makes THREE prescription forms that you'll need to get from your doctor!
- You'll pay \$4.69 per bag at <u>InfuServeAmerica</u>, so for a little extra trouble you're saving quite a bit per dose. With the current pricing at <u>DrugsDepot</u>, each 100ml bag for a 64-pack is \$2.11 per bag, and it's only \$1.59 per bag if you buy a 96-pack.

**NOTE**: California law requires either a fax directly from your doctor's office, or an original prescription form before they can fill your order.

## **Prescription Discount Cards**

These discount cards and programs may help you to get reduced prices on covered medications. Typically these only cover generic medications, but can sometimes provide significant savings for medications that your insurance doesn't cover. Ask your pharmacist to check for you!

- <u>FamilyWize</u> (United Way)
- UnaRXCard
- YourRXCard
- <u>Doryx Discount Card</u>: Doryx is timed-release doxycycline
- <u>Costco Pharmacy</u>: Must be a Costco member for best prices. Many patients report very low prices overall from Costco pharmacies.
- Ralphs Pharmacy: \$4 prescriptions for covered medications.
- <u>Target Pharmacy</u>: \$4 prescriptions for covered medications.
- Walgreens Pharmacy: \$20 per year fee. Provides 10% off most Walgreens brand products and photo finishing as well as prescription discounts.
- Walmart Pharmacy: \$4 prescriptions for covered medications.
- <u>TogetherRXAccess</u>: Only available if you have no insurance coverage and are not Medicare eligible.

If you belong to a trade association, also check to see if they participate in a free discount prescription card program like <a href="Mediling">Mediling</a>. Other associations like the Auto Club (AAA) and AARP may have discount cards available to their members as well.

# Getting a PICC Line: How to Avoid Freaking Out



So your doctor told you, "Get yourself a PICC line!", and all you heard was "We're going to cram a big plastic tube up through your arm vein and into the vein near your heart, but not to worry, we'll just use a turkey baster and you'll be fine."

#### What to do to avoid freaking out?

Well, first of all, it's not as bad as it sounds. The part that goes inside your vein is really

really tiny, not the big fat tube you see hanging from IV poles.

The part inside your vein works like a piece of spaghetti inside a straw, it's in there, but not blocking the blood flow.

There's a part of the PICC line that goes inside your arm, and there's a part that hangs out so you can infuse your meds. The whole thing is cut to size to fit your body perfectly.

Most hospitals use the <u>PowerPICC Solo</u>, which is the purple line pictured here. The purple and blue valve at the top left and the purple wing-nut below it are what's on the outside of your arm. The rest is a thinner line that goes inside your arm.



The purple wing-nut is an anchor that sits just below the insertion point on the outside of your arm (where the line actually goes into your arm vein), and helps to keep the PICC line from pulling out of your arm.

## Getting a PICC Line (... continued ...)



The wing-nut anchor thingy on the PICC line gets connected to a <u>StatLock®</u> or similar device that is stuck to your arm with adhesive, and helps to keep the PICC line in place (as in not falling out of your arm).

The whole area, <u>StatLock®</u>, insertion point and all, is then covered with a dressing to keep everything clean and dry.

#### The Installation Process

Your PICC line will most likely be installed in the hospital, either in an out-patient procedure room or in radiology.

You'll lie on your back with your arm extended out on a table or platform. Typically the nurse or practitioner will ultrasound your arm to determine to location of the most suitable vein and numb your arm, so you won't feel anything other than a little pressure. Once done, they may x-ray you to verify proper placement. For more details, download this pdf patient guide.

#### Reducing pain and swelling from the PICC insertion

The insertion point for the PICC line is just a small hole in your arm that should heal rapidly. You can reduce bruising and swelling by using a heating pad above the insertion point for about 20 minutes of every hour for the first few hours after you get home from the hospital.

## **Protecting the PICC Line**

The PICC line is held in place by a <u>StatLock®</u> and the insertion point is kept clean and dry with a dressing, but that won't keep it safe from catching on clothing and away from dogs and babies.

The hospital will likely send you home with an elastic stretchy open-weave tube dressing that goes over everything, PICC line, <a href="StatLock®">StatLock®</a> and dressing, and helps to keep the exterior portion of the line tight against your arm. This works fine to some extent, and you can get replacements from your infusion supply, but frankly it's itchy and not all that comfortable.

Many people will use a cut-off tube sock instead, or for a cleaner look, a cut-off dress sock or stocking. Tuck everything up under the sock, including the line and the extender (if you use one), all should be tucked in and out of sight, and therefore less likely to be tugged on by pets and children or caught on clothing.

For the ladies, there are also cute little PICC line covers that you can order online from various sources that make your PICC a lot less obvious when you're out and about. Some will come in general sizes (as in too big for small arms), and some will be made to order according to your color preference and biceps measurement.

Personally, <u>I like these the best</u>. I leave the tube sock on underneath, and just slide this over the top.

Voila, behold the secret PICC line! Very few people think to ask what you're covering when you wear one of these.



## Protecting the PICC Line (... continued ...)

#### What about sleeping with the PICC line?

Seems the safest thing to do is to have it all tucked up in the elastic thingy or under a tube sock as usual, and then sleep in a long-sleeved shirt in case it sneaks out from under the covering.

If you end up sleeping on the PICC, you may find that the area is a bit sore in the morning from the StatLock®, clamp or cap creating a pressure point. If this happens, the soreness should go away in a day or two.

#### Just for fun...

These little <u>stuffed spirochetes</u> can be a great educational tool for youngsters, or rage-busters for the rest of us. Many have mentioned using a tennis racket on them Gotcha Gopher-style to get some healthy venting in a non-destructive way. They also come in a <u>larger size</u> without the little petri dish box.



# Care and Maintenance of the PICC Line and Dressing

First and foremost: The dressing covering the PICC line MUST be kept clean and dry at all times!

If the dressing becomes wet, dirty or frayed, replace it immediately. Once wet, moisture and body heat become the ideal breeding ground for bacteria.



The dressing and StatLock® should be changed weekly using the dressing change kits provided by <a href="InfuServeAmerica">InfuServeAmerica</a>. These kits include everything you'll need to change the dressing, including a ChloraPrep swab (or similar) to disinfect the area. The StatLock® will be packaged separately.

Do not use alcohol wipes or the ChloraPrep swab on the StatLock® unless you are removing it, as the StatLock® adhesive is designed to break down with alcohol.

It's a good idea to change the cap on your PICC line weekly as well, along with the extender line (if you use one).

If you use a nursing service along with your infusion service, the nurse will take care of these bandage changes for you. Otherwise, you can have the nurse or your doctor show you (or a friend or family member) to do this on your own, or ask your doctor for assistance.

# Care and Maintenance of the PICC Line and Dressing (... continued ...)

Some doctors will do the dressing and StatLock® changes for you during your regular office visit (yay!). If your doctor agrees to do this, bring in all that he'll need, including:

- Dressing change kit
- StatLock®
- Extender line (if you use one)
- Replacement cap
- Saline flush syringes (bring 2)
- Heparin flush syringe
- Optional: Alternate bandage for sensitive skin

If you will be infusing your medications on your own, you'll probably want to connect the extender line to your PICC line. This will reach to your hand, so you'll be able to hold onto the cap while connecting the syringes and the IV admin set. You should always have a cap on the end of either the PICC line or the extender line, so make sure this is connected as well. The clamp on the PICC line (or extender) should be closed when not in use. If you're using the new <a href="PowerPICC Solo">PowerPICC Solo</a> and no extender line, then there will be no clamp to fuss with.

## **Troubleshooting PICC line issues**

If flushing is difficult, check to see that the clamps on the PICC line are released. If you are still having difficulty flushing the line, call your nurse or your doctor's office for assistance. On days that you are not using antibiotics, flush the line with saline and heparin to help prevent it from clotting.

## Avoiding the Itchies: Dressings for Sensitive Skin



Nothing is worse than itchy, inflamed skin, especially when you'll be wearing a dressing (bandage) over the same area for an extended period of time.

If your skin is sensitive to adhesives, it's possible that the Tegaderm<sup>TM</sup> dressing that comes in the standard

dressing change kit will be irritating to your skin. To avoid the risk of infection, and for your own comfort, you'll want to switch to a dressing that will be non-irritating.

#### Dressing options for sensitive skin:

#### Clear dressings:

- OpSite
- IV3000
- SorbaView



White cloth-like dressing with gauze pad (easiest on the skin):

Primapore



Order these dressings from <u>Allegro Medical</u> at about \$1-\$2 per dressing, typically sold in boxes of 20. Be sure to order a large enough size to cover the entire StatLock® (anchor) device and the insertion point for your PICC line, which for the <u>Primapore</u> would be the 6 x 3 1/8" dressing.

## Bathing: How do I keep this thing DRY?



You can use a combination of Saran Wrap and tape for showering, or purchase a PICC line protector to keep the dressing dry.

There are various types of combo PICC line and cast

covers available, just be sure to leak-test them on your opposite arm before taking a shower or bath.

One popular option is the <u>Dry Pro<sup>TM</sup> PICC</u> <u>Protector</u>, which provides waterproof protection that even allows swimming and water sports. The Dry Pro<sup>TM</sup> is a rubberized flexible sleeve that is placed over the dressing and PICC creating a water tight seal, with a bulb to suck the air out for a tighter seal.



The Authentic



The <u>Seal-Tight</u> protector made by Brown Medical is made of TPE, high performance thermoplastic elastomer that stretches easily, folds compactly and

maintains a waterproof seal. It eliminates the need for pumps, velcro

straps and adhesive tapes that may irritate skin.

Another option is the <u>XeroSox</u> PICC line protector.

You can order all of these online at Allegro Medical.

# Infusions: What do I do with all this STUFF?



There are two ways to get your medications: From an infusion supply service pre-mixed and ready to infuse, or from Walgreens or another pharmacy (unmixed).

If you're getting your medications

pre-mixed from an infusion supply service, then skip the steps on mixing medications. Either way, you must keep everything STERILE. That means clean hands, gloves, and don't let the needle you use for mixing meds touch anything else.

#### **Getting ready to infuse: Mixing medications**

If you're getting your medications, saline bags and infusion supplies separately, then you'll need to mix what's in the vial into the saline bag before you can do your infusion.

**Step 1:** Wash your hands thoroughly with an antiseptic soap prior to handling the PICC line or supplies. Be sure to include the palms, back of hands, fingers and spaces between them and fingernails, dry them with a paper towel, and then put on some gloves.

**Step 2:** Assemble the items needed for mixing on a clean surface.

- Medication (vial of Ceftriaxone or other medication)
- Saline (sodium chloride) IV bag
- 20ml syringe with needle (10ml for mixing Zithromax)
- Alcohol wipes



#### Mixing medications

**Step 3:** Remove the blue cap from the medication vial, and the blue cap from the saline bag (if you're using the Braun saline bags).

E.minimi

**Step 4:** If the syringe and needle are in separate packages, attach the needle to

the syringe by screwing it to the end (it only takes about ½ turn). Leave the plastic cap on the needle for now.

**Step 5:** Wipe down the top of the vial and the injection port on the saline bag (the part that was covered by the blue cap for the Braun, or the yellow spongy stuff for others) with an alcohol pad.

**Step 6:** Remove the plastic cap from the needle, and insert it into the injection port on the saline bag. If you're using a 20ml syringe, remove about 18ml of saline from the bag by pulling back on the syringe plunger. Be careful not to touch the needle on anything else!

**Step 7:** Remove the needle from the saline bag, and inject the saline that is now in the syringe into the medication vial. CAUTION: This will create pressure in the vial, so be sure to hold onto the syringe tightly and keep the plunger on the syringe pushed down.



**Step 8:** Shake the vial gently to thoroughly mix the medication with the saline. Release the plunger on the syringe and allow the now-mixed medication to flow back into the syringe. You may have to pull the needle out a bit to get all of the medication out of the vial.

#### Mixing medications

**Step 9:** Insert the needle back into the saline bag, and push the mixture from the syringe into the bag. Be sure to properly dispose of the needle using a Sharps container.

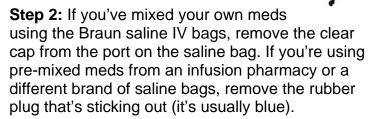
That's it – you're done mixing! Your medication is now mixed and ready to infuse.

Continue reading to learn how to set up the IV pole and the line to your arm...

#### Setting up the IV Pole and the Line to Your Arm

You'll need to hang your saline IV bag (with meds mixed in) on an IV pole or similar, since gravity is what gets this stuff to drip into your arm. A line from the saline to your arm (IV admin set) needs to be set up as well. Here's how you set things up:

**Step 1:** Hang the bag from the IV pole, and extend the pole as high as it will go.



**Step 3:** Open the IV admin set package and remove the paper wrapping.



**Step 4:** CLOSE the valve on the line so nothing can flow through it yet. If you forget to do this, you'll end up with some meds on the floor, but not to worry, it happens to everyone at least once!

**Step 5:** Remove the plastic cap from the spike end of the IV admin set, and insert that end into the open port on the saline bag. It will take a little pressure and some twisting.

**Step 6:** Squeeze the clear plastic tube on the IV admin set so a little fluid fills the bottom of it. This will allow you to see how fast it's dripping a little more easily.

#### Setting up the IV Pole and the Line to Your Arm

**Step 7:** Open the valve and let the meds flow to the end of the line, letting a couple of drops come out, then close the valve again. This primes the line.

**Step 8:** FLUSH your PICC line with 10ml of saline, using the saline flush syringes (the ones with a white cap) that are made for this purpose. Be sure to wipe the cap on your PICC line with alcohol first! The saline flush syringe connects easily with a push-and-twist motion.



**Step 9:** Connect the end of the IV admin set to your PICC line in the same way as you did the flush syringe, with a push-and-twist motion.

**Step 10:** Open the valve on the IV admin set a little at a time, until the meds are dripping at the appropriate rate. For Ceftriaxone, you'll want to infuse at a rate of 30 minutes per dose or more, and never less than 30 minutes.

Step 11: Once you're done with your infusion, disconnect the IV admin set and FLUSH your PICC line again with another 10ml saline flush syringe, and then with a heparin flush syringe (usually with a yellow cap).

Memory Tip: SASH acronym for flushing and medications The proper order for your medications and flushing the PICC line is the following:

**S**aline

**A**ntibiotics

Saline

**H**eparin

This ebook was written by a lyme patient, not a doctor, and thus is not to be considered as medical advice.

## Heading off the Dreaded HERX



We've all heard about it, the HERX from HELL that knocks you on your butt for days and makes your life miserable in the meantime...

While you likely can't avoid herx reactions completely, there are ways to help your body to detox so the herx may be minimized somewhat.

First of all: **CLEAN UP YOUR DIET.** More on that later...

# Common herx-busters and detoxifiers include the following:

- Lemon water: Juice of a fresh lemon in a glass of water, sweetened to taste with Stevia.
- Lemon and olive oil liver cleanse: Blend a small WHOLE LEMON, peel, seeds and all, with 1 tablespoon of olive oil and 8-10 ounces of water. Cut the lemon into quarters, throw it in the blender with water and olive oil, add a little Stevia to taste, and let it whirl! You won't taste the olive oil, it just turns the whole mixture into kind of a smoothie-like texture. Use organic lemons for this!
- <u>Licorice Root Extract</u>: This comes in tincture (liquid) and in capsules. Use 2-20 drops of tincture in 2-4 ounces of water, or capsules as directed. CAUTION: If you have blood sugar issues, consult your doctor before using this, as it may affect blood sugar levels.

#### Common herx-busters and detoxifiers

- St. John's Wort: This also comes in tincture (liquid) and in capsules. Use 2-20 drops of tincture in 2-4 ounces of water, or use capsules per the directions on the bottle. This stuff is a life-saver when dealing with that horrible burning nerve pain. CAUTION: If you are taking blood thinners, consult your doctor before using this.
- Alka-Seltzer GOLD: This helps to alkalize the body, and some say it offers immediate herx relief. One packet in a glass of water, and drink it down. Plop, Plop, Fizz, Fizz...
- <u>Chlorella</u>: This can help to bind and remove toxins from your body. Take per package directions.
- Modifilan: Works in a similar manner as chlorella, but is a brown seaweed extract that some say gives better results. Take per package directions.
- Activated Charcoal: This is one of the lastresort choices, as it will clear everything out of your system, including medications. If you're feeling completely crappy and just can't snap out of it, this may be worth a try.



 Green Clay: Similar to activated charcoal, this is a binder and detoxifier that will remove all toxins and medications from your system. If you're taking it on a regular basis, take it away from all medications.

#### Common herx-busters and detoxifiers

- <u>Burbur</u>: Herbal tincture designed to help detoxify. 10-20 drops in 2-4 ounces of water, can be taken every 15 minutes if having a bad herx reaction.
- Avea: This is a RAGE BUSTER. When you're feeling that dark cloud of rage that just won't leave, 10-15 drops of this in 2-4 ounces of water just may evaporate that anger in a flash.

**Baths:** You can do regular baths or foot baths, both have great benefits. Dry brushing your body before a bath can help the process as well. Use a natural bristle brush for this!

If you have heart issues, kidney or liver disease, seizures or dizziness, then don't do full baths without your doctor's permission, and make sure there's someone nearby to help out if you get in trouble. You may want to try these recipes as foot baths instead.

- Epsom salts. 3-4 cups of Epsom salts in a warm tub. Some will add 32 ounces of hydrogen peroxide (the cheap stuff at the drug store) and/or 1 cup of baking soda to this. For a foot bath, you'd use ½ cup of Epsom salts, 1 cup of hydrogen peroxide and 1 tablespoon of baking soda. You can add a couple drops of a good-quality essential oil to the bath for extra healing benefits, and to make it smell nice.
- **Apple Cider Vinegar.** You can add 3-4 cups of this to a warm bath, or ½ cup or so to a foot bath. Not my favorite smell, but it does seem to help!

#### More Baths:

- Sea Salt or <u>Himalayan Salt</u>. 3-4 cups for a regular bath, ½ cup or so for a foot bath. As with the Epsom salts bath, you can add a couple drops of essential oils to the bath water.
- Mustard foot bath. Said to help raise the core body temp. 1 tablespoon of mustard powder and 1 teaspoon of cayenne pepper added to a foot bath.
- Ginger. You can add fresh crushed ginger to the Epsom salts and sea salts baths. Place it in a tea ball or bath ball, or in a little muslin sack before dropping it into the bath water.
- Opaline Dry Oxy. This is supposed to assist in removing hazardous materials such as carbon monoxide, carbon dioxide, advanced nano materials and other similar chemical toxins from the skin. Add 3 tiny scoops of the Dry Oxy powder plus 2 capfuls of Willard's Water to a bath.
- Magnesium flakes. I actually like these better than the Epsom salts. It helps to replace magnesium in your body, and makes your skin SOFT.

#### More herx-busters and detoxifiers:

- Colon Hydrotherapy: Yep, it sounds gross, but there's a lot of stuff that can build up in there, and some of that stuff can keep you sick by polluting your system with old waste. A good colon hydrotherapy center will actually make this a relaxing experience.
- <u>Coffee Enemas</u>: Another way to cleanse the colon, as well as detoxifying the liver and gallbladder. This can make the liver and gallbladder purge, thus preventing the buildup of excess bile and even gallstones. <u>Instructions and a special coffee</u> for this make it easy to do. Never thought you'd be taking coffee up the wrong way, did you? All kidding aside, this is one low-cost thing you can do at home that really helps to clean up your system.
- <u>lonic foot baths</u>: These are a bit controversial. Some people swear by them, and some say they are total bunk. If you have the opportunity to try these out, you may want to see if they seem to help you at all.
- <u>Detox foot pads</u>: Another controversial item, but again, some say that these help. Generally you put these on at bedtime and let them do their thing while you sleep.
- Far Infrared (FIR) Saunas: These help to detox by helping you to sweat out the toxins. Best to dry brush your body before getting in! You can get inexpensive plastic tent-like ones or small one-person wooden ones, or splurge for the full-size full-featured sauna, depending on your budget. If you get the plastic tent-like ones, be sure to let it run for a while outside to off-gas the fumes before your first use.

#### More herx-busters and detoxifiers

- <u>Rebounders</u>: Bouncing gently on a rebounder helps to stimulate lymphatic drainage. Or as an alternative, you can sit on an exercise ball and bounce a bit. Best to get a rebounder with a handle to hold on to! Try to bounce for 5-10 minutes per day.
- Probiotics: Yes, probiotics can help with herxes and detox as well as providing good stuff for your gut. Many will recommend that you increase your dosage of probiotics when you're not feeling well, which would include a herx. Personally, I prefer the Dr. Ohhira brand of live probiotics instead of the freeze-dried Sea Monkey type of probiotics, but ask your doctor if there is a special brand or formula that he or she recommends.
- Earthing: Our bodies are electrical the heart, brain, muscles, cells and all body systems function electrically. Today we live totally insulated from earth and our bodies become electrically stressed and charged with inflammation and chronic pain, which is a very unnatural state. The effect of Earthing is that it discharges electrical stress and restores the body's natural and stable electrical state. Earthing products are designed to help you get grounded while indoors.
- WATER: Last, but not least! Drinking plenty of plain, filtered water will help your body to flush out the toxins that can cause a herx. Guidelines are your weight divided by two in ounces of water per day. So if you're 150 pounds, you'll need to drink 75 ounces of water per day.

#### MONEY AND TIME SAVING TIP:

If you're not able to get to the store easily for your bath and detox supplies (like when you're feeling like crap from a herx), much can be found on <a href="mailto:Amazon.com">Amazon.com</a> and shipped to your door, usually arriving in about 2 days.

They have items like bath and body products, supplements, syringes, batteries, and other health and household items that you can get shipped free of charge.

Joining their <u>Amazon Prime</u> program gives you free shipping for an entire year, no matter how much you order, with an annual fee of \$79. If you want next-day shipping, it's an extra \$3.99 per item. Just look for the <u>Amazon Prime logo</u> on items that you order for the free shipping!

# Clean Up Your Act: Eating to Help Your Body HEAL



Alright, here it is, the dreaded DIET section.

In reality, it's not a diet, it's a lifestyle change. CHOOSE to be healthy and to feed your body the fuel that it needs to function properly and to heal the best that it can. The end result should be to eliminate or greatly reduce sugars, gluten and processed foods from your diet.

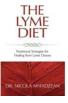
You wouldn't fuel a high-end performance car with that junkgas from the corner no-name gas station, would you? Then why do you feed your body that way??? So... here we go, and I'll make this as painless as possible...

**Step 1:** Start to eliminate JUNK FOOD from your diet. This doesn't mean you can't eat out, it just means that you have to THINK before you EAT. This isn't a Cold-Turkey thing, you can phase out your favorite junk foods, and we'll cover some replacements for these later to make the transition easier.

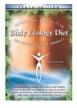
**Step 2:** Start reading labels on the prepared foods that you buy. Do they contain hidden sugars (high fructose corn syrup, corn sugar, fructose, etc), preservatives, and stuff you wouldn't even feed your dog? If so, it's time to find replacements for those foods. Also, beware the gluten-free foods! They often contain ingredients that are worse than the gluten, so most gluten-free cookies, crackers and cereals should be avoided.

Step 3: EDUCATE YOURSELF. There are plenty of books that teach you how to eat healthy and still enjoy your food. I'm not advocating any particular diet program here, I think many of them offer some excellent suggestions, and you can pick and choose which of those will fit best into your lifestyle as well as satisfying your taste buds. Here are some books for starters:

> The Lyme Diet: Nutritional Strategies for Healing from Lyme Disease. An easy read with some good tips on nutrition and specific food recommendations to support the immune system and to detox, as well as what to eat (and avoid) with certain medications.



The Body Ecology Diet: Recovering Your Health and Rebuilding Your Immunity. Discusses dietary changes to improve intestinal health and to support the immune system.



Wild Fermentation: The Flavor, **Nutrition, and Craft of Live-Culture** Foods. This book builds on the theme in Body Ecology Diet, where fermented foods support the digestive and immune systems better than any packaged probiotics can. It even has recipes for making beer and wine!

- Heinerman's Encyclopedia of Healing Juices. Has a chapter on each type of fresh fruit and vegetable juice and their therapeutic benefits.
- HEINERMAN'S

  HEALING

  JUIGES

  JOHN HEINERMAN

  JOHN HEINERMAN
- Recipes for Repair: A Lyme Disease
   Cookbook. Eliminates the most common
   food contributors to chronic inflammation,
   then gradually reintroduces foods to
   establish a broad yet healthy diet.

The Fourfold Path to Healing:



- GAPS Guide (Simple Steps to Heal Bowels, Body and Brain). This book presents the "how to" of the Gut and Psychology Syndrome (GAPS) program in an easy to read format. Reviewed and approved by Dr. Natasha Campbell-McBride, author of the book Gut and Psychology Syndrome.
- Working with the Laws of Nutrition,
  Therapeutics, Movement and
  Meditation in the Art of Medicine.
  The Fourfold Path to Healing merges
  the wisdom of traditional societies, the
  most modern findings of western
  medicine and the esoteric teaching of the ancients.
  The fourfold approach includes: Nutrition using
  nutrient-dense traditional foods; therapeutics through
  a wide range of nontoxic remedies; Movement to
  heal and strengthen the emotions; and meditation to
  develop your powers of objective thought.

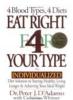
- Living Gluten-Free For Dummies. If you have a wheat allergy, gluten intolerance, celiac disease, or you just want to enjoy the benefits of a diet free of wheat, barley, and rye, then this guide is for you. Author Danna Korn explains the medical problems associated with gluten and shows you step by step how to make the transition to a gluten-free lifestyle and love it! (Also check out their online <a href="#">Cheat Sheet</a> for more tips on a gluten-free diet.)
- Cuisine. Following a vegan, raw foods diet does not mean you have to give up your favorite delicacies or condemn yourself to a life of celery and carrot sticks. From imaginative new dishes such as cactus salad, onion bread, and spirulina pie, to tantalizing variations on everything from pizza, tacos, and cookies, to the signature "Big Matt with Cheese," these mouthwatering recipes feature soups, sauces, salads, appetizers, entrees, and even desserts.

People. After spending ten minutes whipping up your own almond butter, you'll never pay outrageous prices for it again, and the Not Meat Balls will ban cravings for the processed faux-meat varieties. Innovative techniques such as replacing eggs with avocado in mousse and marinating broccoli so that it tastes cooked are also included here.

**The Primal Blueprint Cookbook:** PRIMAL Primal, Low Carb, Paleo, Grain-Free, COOKBOOK Dairy-Free and Gluten-Free. The popularity of the low carb/paleo/Primal way of eating has exploded, as people discover an appealing and sustainable alternative to the restrictive diets and flawed conventional wisdom that lead to burnout and failed weight loss efforts. You won't even miss the bland, boring, low-fat foods that previously were the central focus of your diet. How can you argue with a menu that includes Roasted Leg of Lamb with Herbs and Garlic. Salmon Chowder with Coconut Milk. Tomatoes Stuffed with Ground Bison and Eggs, and **Baked Chocolate Custard?** 

**Step 4:** Start working healthier foods into your diet as replacements for your favorite foods. For example, you can replace regular pasta with brown rice pasta and still have the same taste and texture, but without the gluten. Or replace that burger-on-a-bun with a protein-style burger (burger sans the bun and with lettuce leaves wrapped around it instead). Have the restaurant hold the bread basket and the croutons on your salad. Order from the gluten-free menu at restaurants like <a href="Claim Jumper">Claim Jumper</a> and <a href="Olive Garden">Olive Garden</a>. Skip the sodas and ask for a glass of ice water and a plateful of lemons, and bring powdered Stevia packets along to make your own fresh lemonade. See, it's not that hard!!!

**Step 5:** Consider integrating portions of the Blood Type Diet. This program shows which foods are easy for your body to digest and process, and which ones aren't, which can help your body to heal. Just follow the basics here for starters, eat more of the 'beneficial' foods and eat the 'avoid' foods as little as possible.



**Step 6:** Continue to replace high-sugar, high-gluten and high-trans-fat foods with healthier alternatives. Healthy fats are fine, and in fact they're mandatory if you're taking Mepron as part of your treatment protocol. You may not need to switch to non-fat or low-fat dairy, just stay off the bad fats in fried and processed foods. However, some diet protocols will say that dairy should be avoided completely, so pay attention to how you feel after eating it, and eliminate dairy from your diet if it makes you feel bad. If you choose to eat dairy, eat organic dairy products as much as possible to avoid the hormones and other chemicals that are often found in regular dairy products.

That's it from the diet standpoint, by now you should have a good idea of how to transition to a healthier diet, and how to eat foods that support your digestive and immune systems. A natural by-product of this will be that you'll likely get closer to your ideal weight if you're carrying a few extra pounds. If you're already underweight or borderline underweight, then be sure to eat enough variety to maintain your weight.

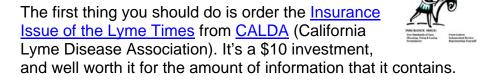
## Insurance Denials: To Fight, or Not to Fight?



Sooner or later, you'll likely come up against a brick wall with your insurance company, where they'll say that you must be 'cured' because you've been on the IV medications for long enough according to the IDSA guidelines.

This is not an easy battle for most people, but it does help to be

somewhat organized before you start the fight.



Follow the 'Game Plan' in the <u>Insurance Issue of the Lyme Times</u>, and it will walk you through the steps needed to start the appeals process. This issue also provides tips on how to fight the continued denials from your insurance company. There are charts, form letters, all that you need to start and continue the battle with your insurance company. The information that you'll be requesting from your insurance company includes a LOT of paperwork, including copies of all records, correspondence, phone calls, notes, reviews, credentials of reviewers, and reports.

**Remember this:** The insurance companies issue denials based on guidelines that were set either by themselves or by the IDSA. These are just supposed to be guidelines, not fact.

## Insurance Denials: To Fight, or Not to Fight? (... continued ...)

In a recent Reuters article, <u>Medical "best practice" often no more than opinion</u>, researchers found that only 1 in 7 treatment protocols recommended by the IDSA were based on high-quality data from clinical trials.

More than half of the recommendations relied solely on expert opinion or anecdotal evidence! The researchers analyzed 4,200 recommendations made by IDSA between 1994 and 2010, so this wasn't just a small sample study. Here's a quote from the Reuters article:

"In the absence of evidence, the [IDSA] recommendations end up depending largely on who's on the guideline-drafting panel and any assumptions or opinions they may bring to the process."

Most patients will accept a denial as a fact of life and not fight it, which is what the insurance companies hope for. From the insurance company's standpoint, it's a numbers game, so issuing denials and hoping that the patients don't appeal probably adds quite a bit to their bottom line.

There's a lot of smoke-and-mirrors in dealing with the insurance companies. It takes a lot of follow-up phone calls to the insurance company, and requests to talk with supervisors, to get things moving on their end. Sure, they'll send you a short form letter restating your denial and quoting some provisions from your policy, but getting copies of the rest of the documentation supporting their denial is another story.

## Insurance Denials: To Fight, or Not to Fight? (... continued ...)

While there's no guarantee that you'll get the insurance denial reversed, I *can* guarantee you that it won't get reversed if you don't continue to hound the insurance company for copies of all documentation regarding your denial, and then take the time to submit (and fight for) a new appeal based on that information.

What do you have to lose? Copy the form letters from the <a href="Insurance Issue of the Lyme Times">Insurance Issue of the Lyme Times</a>, modify as needed with your info, mail them off, and do some follow-up phone calls. Could be that you'll be one of the lucky ones who gets their denial reversed!

# RESOURCES: Recommended Reading, Support Groups and Forums

**TIP:** Our doctors will do the best they can to help us, but they cannot know everything, especially with diseases as complicated as lyme. It's up to us as patients to do our own research, and present new info for our doctors to consider if we want to get better.

Many doctors will appreciate any new info that you can provide, as long as it's presented in a cooperative manner. Don't berate your doctor for not knowing everything, nobody is capable of that. Just help them to help you get better!

### **Recommended Reading**

There are a lot of books on lyme, and a lot of books on natural healing. Many of these will be helpful in figuring out the best treatment protocol for your situation.

The Lyme Disease Solution: This is a comprehensive guide to the diagnosis and treatment of Lyme disease and other tick borne infections. The author, Dr. Kenneth Singleton, is a board certified specialist in Internal Medicine who himself struggled with severe symptoms of Lyme disease for 8 years prior to being correctly diagnosed and treated.



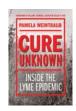


Healing Lyme: Natural Healing And
Prevention of Lyme Borreliosis And Its
Coinfections: This book by Stephen Buhner
examines the leading scientific research on
Lyme infection, its tests and treatments, and
outlines the most potent herbal medicines and

supplements that offer help—either alone or in combination with antibiotics—for preventing and healing the disease.

#### **Recommended Reading**

Cure Unknown: Inside the Lyme Epidemic: Author Pamela Weintraub turns a tragic yet eye-opening experience into a shocking exposure of what can happen when egos, greed, and peer pressure supercede objective evidence, allowing patients to suffer chronic, disabling illness.





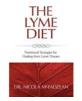
Insights Into Lyme Disease Treatment: 13
Lyme-Literate Health Care Practitioners Share
Their Healing Strategies: Author Connie
Strasheim conducted intensive interviews with
thirteen of the world's most competent Lyme
disease healers, asking them thoughtful,

important questions, and then spent months compiling their information into organized, user-friendly chapters that contain the core principles upon which they base their medical treatment of chronic Lyme disease. The specific practitioners interviewed represent a variety of medical disciplines, including allopathic, naturopathic, complementary, chiropractic, homeopathic, and energy medicine.

The Top 10 Lyme Disease Treatments: Defeat
Lyme Disease with the Best of Conventional and
Alternative Medicine: The book identifies ten
conventional and alternative treatments and gives
practical guidance on integrating them into a
comprehensive treatment plan that maximizes
therapeutic benefit while minimizing side effects. This book
covers Core Treatment Protocols: The Antibiotic Rotation
Protocol, The Marshall Protocol, The Salt / Vitamin C Protocol,
Detoxification, and Electromedicine (Rife Machine Therapy) as
well as some supplement protocols.

#### **Recommended Reading**

Healing Lyme Disease Naturally: History,
Analysis, and Treatments: Anthropologist Wolf D.
Storl shares his own success in overcoming a difficult, sometimes deadly disease that is reaching epidemic proportions. When he was diagnosed, Dr.
Storl refused standard treatments because of antibiotic intolerance. Instead, he researched healing systems of various cultures including Traditional Chinese Medicine,
American Indian healing practices, homeopathy, and traditional Western herbal lore and discovered the teasel root.



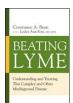
The Lyme Diet: Nutritional Strategies for Healing from Lyme Disease: Good nutrition is such a crucial part of any treatment regimen that it is well worth addressing. Food sustains us, nourishes us, and can heal us. Food is medicine. The Lyme Diet contains a wealth of

information about why dietary choices are critical for minimizing inflammation, optimizing immune function, promoting healthy digestion and gut flora, balancing hormones, and detoxifying the body.

### Making Sense Of It All: At War With Lyme

<u>Disease</u>: A poignant story of a family's journey into the perils of chronic lyme disease. This compelling book will shock, distress, and eventually inspire the reader. Encompassing revealing medical data, gripping photographs, inspirational quotes, pertinent nutritional information, and even recipes, this little book is a powerhouse of a read.

#### **Recommended Reading**



Beating Lyme: Understanding and Treating This Complex and Often Misdiagnosed Disease: The complete story of Lyme disease, a resilient and difficult-to-treat disease transmitted by deer ticks: its identification in 1975, the two-decade increase in reported cases (it's now "the fastest-growing")

infectious disease in America"), symptoms (which can be "arthritic, neurological, behavioral, cardiac, dermatological, muscular, or otherwise"), diagnosis and, most disturbingly, the disconnect between two powerful groups of physicians regarding its treatment.

Chronic Lyme Disease - Ways to Outsmart a Smart Disease: Are you discouraged by antibiotics' results, have tried naturopathy with limited success, and are losing confidence in your doctors? If knowing everything there is to know about Lyme isn't getting you anywhere, "Outsmart



Lyme" will show you how to expedite a therapeutic program that has been tried and true by the author's family members, friends, and clients. This compact and resourceful book puts you in the driver's seat of the patient's healing process.

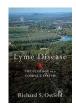


"It's All In Your Head," Patient Stories From the Front Lines: Intimate Aspects of Chronic and Neuropsychiatric Lyme Disease: The History of Lyme disease, tick-borne illnesses, testing, and the politics and personal stories as told by Lyme

patients.

#### **Recommended Reading**

Lyme Disease: The Ecology of a Complex System: This controversial book is a comprehensive, synthetic review of research on the ecology of Lyme disease in North America. It describes how humans get sick, why some years and places are so risky and others not.





When Antibiotics Fail: Lyme Disease and Rife Machines, with Critical Evaluation of Leading Alternative Therapies: This book is about how experimental frequency devices known as "rife machines" have been used for over 15 years in private homes to successfully

fight Lyme Disease.

Disease and Other Tick-Borne Disorders: As the president and founder of the Lyme Disease Foundation and the mother of a child who died of Lyme Disease, Author Vanderhoof-Forschner has the knowledge to make this book comprehensive and the personal experience to make it compelling. She discusses the status of Lyme disease as a public health threat, the nature and characteristics of ticks; the history of Lyme disease; its symptoms, diagnosis, and treatment; and the search for vaccines.

#### **Recommended Reading**



<u>Created Witches and Changed History</u>: This work began as a history of Lyme disease. Looking in the historical records for places where this disease might have occurred in the past, the author kept finding descriptions of witchcraft afflictions. Was there a

connection between Lyme disease and the European concept of the witch?

Coping with Lyme Disease: A Practical Guide to Dealing with Diagnosis and Treatment: This comprehensive guide includes - basic prevention tips - a detailed catalog of the physical and psychological symptoms to look for - a complete look at the medical and home care options and insurance policies available to patients.



policies available to patients - a special discussion of Lyme's effects on women, children, and the elderly - an expanded resource guide, with listings of news publications, state-by-state support groups, and special family services.

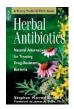


The Lyme Disease Survival Guide: Physical, Lifestyle, and Emotional Strategies for Healing: Author Connie Strasheim combines sharp knowledge of the nuts and bolts of a Lyme disease treatment campaign with a witty style and piercing

insight into the real life struggles Lyme sufferers encounter daily.

### **Recommended Reading**

The Book of Herbal Wisdom: Using Plants as Medicines: Drawing on the healing traditions of Native Americans, Quakers, and the English, as well as botanical literature and his own observations, the author explains the medicinal uses of thirty-six herbs for alleviating a variety of ailments. [This book is by Michael Wood, who teaches how to use teasel root for lyme disease.]



Herbal Antibiotics: Natural Alternatives for Treating Drug-Resistant Bacteria: Stephen Buhner offers conclusive evidence that plant medicines, with their complex mix of multiple antibiotic compounds, are remarkably effective against drug-resistant bacteria. You'll learn how antibiotic herbs such as

aloe, garlic, and grapefruit seed extract represent our best defense against bacteria such as Staphylococcus aureus, E. coli, and Salmonella -- and how their use will ensure that, in the future, antibiotic drugs will still be there when we really need them.

#### Online Forums and Websites

There are a lot of online forums and websites related to lyme. Some have more information than others, and some have more activity than others. It helps to check in with some of these once in a while for updates on new studies and new therapies. Fellow forum members can also help you with finding needed resources, like doctors and support groups in your area.

**NOTE:** This is a partial list of online resources to get you started. New online resources are popping up every day, and often will be mentioned on either the Yahoo Groups or the other Forums.

Yahoo Groups (partial list, search for more groups via Yahoo)

- California Lyme
- [Tip: For other states, replace California with your state name in the link.]
- Bartonella
- Buhner Lyme-Aid
- Lyme-Aid

#### **Forums**

- MD Junction Lyme Forum
- Win the Lyme War
- Healing Well
- LymeNet

#### **Blogs**

- Dr Jernigan
- Lyme MD
- Die Tick Die

#### Online Forums and Websites

#### Websites

- California Lyme Disease Association (CALDA)
- Lyme Disease Association
- International Lyme And Associated Diseases Society (ILADS)
- Canadian Lyme Disease Foundation
- Choosing Foods by Blood Type: University of Oregon
- Body Ecology Diet: fermented and cultured foods
- GAPS Diet: natural digestive healing
- Low Dose Naltrexone Therapy
- Gluten Free for Dummies Cheat Sheet

#### Free Email Newsletters

- Beat Lyme
- Lyme Hope
- Goodbye Lyme

## Appendix 1: Summary of Resources in This eBook

#### Infusion Pharmacies:

- ARC Infusion Service, La Palma, CA. (714) 522-8802
- InfuServeAmerica, St. Petersburg, FL. (800) 886-9222
- InfuSource, Rohnert Park, CA. (707) 588-8894

#### Other Pharmacies:

- <u>DrugsDepot</u>, San Diego, CA
- Walgreens

#### **Supplements and Herbs:**

- <u>iHerb</u> supplements and herbs at a discount (\$5 off for new customers with this link)
- Amazon surprisingly low prices on many supplements

#### **Products to Fight the Herx**

- <u>iHerb</u> supplements and herbs at a discount
- Amazon supplements and herbs, bath salts, magnesium bath products, FAR infrared saunas at a discount
- <u>Burbur</u> herx fighter
- Avea rage buster

### Infusion Supplies, Waterproof PICC Protectors, Syringes:

- <u>Allegro Medical</u> dressings, syringes, PICC protectors, infusion supplies
- Amazon syringes

### Books: Lyme Books, Cookbooks, Herbal Wisdom, Diet

- Amazon
- Eat Right for Your Type

### **CALDA (California Lyme Disease Association) resources:**

Insurance Issue of the Lyme Times

## Appendix 2: Product Order Numbers for Selected Supplies

Some insurance companies will require you to purchase all of your medications and supplies from a regular in-network pharmacy that has never handled infusion supplies before. This list is meant to help with this process by providing product numbers of each supply item for them to use as a reference.

Dressing Change Kit (Prep Tray)
Churchill Medical Systems #AMS-8180-3CP

IV Administration Set (line from the IV bag to your arm)
Churchill Medical Systems
#AMS-295-1 with roller clamp
#AMS-122-1 with flow regulator

Extension Set (extends PICC line to your hand)
Churchill Medical Systems #AMS-395-1

Ultrasite Needleless Connector (cap at end of PICC line) Churchill Medical Systems #CMS-5000

Dressings for Sensitive Skin (all from Smith & Nephew)

Primapore 6" x 3 1/8"

IV3000 4" x 5 ½"

OpSite 4" x 5 ½"

OpSite Flexigrid 4" x 4 ¾"

Saline Flush Syringes, 10ml in a 10ml syringe Vycon 30-pack #NDC 63807-016011

Heparin Flush Syringes, 5ml in a 10ml syringe Vycon 30-pack #NDC 63807-066051

StatLock® PICC Plus (Bard)

### **Appendix 3: Supplies Order Form**

If you want to order your supplies from <a href="InfuServeAmerica">InfuServeAmerica</a>, you'll need a list of what you need, as well as a prescription form from your doctor.

This form is made to be easy to copy over to your doctor's letterhead for this purpose.

NAME:	DATE: _	·
# OF IV's PER DAY	15 🗆 6	
# OF DAYS PER WEEK	Qty Per IV	Qty Per Week
Infusion Supplies Sodium Chloride IV 100 / 250 / 500 ml IV Admin Set Saline Flush 10ml Heparin Flush 5ml Syringe 20ml with 18G1 Needle	<ul><li>1</li><li>1</li><li>2</li><li>1</li><li>1</li></ul>	
PICC Maintenance Supplies Dressing Change Kit Extension Set with Cap StatLock Optional: Cap Only, No Extension Set Optional: Dressing for Sensitive Skin		1 1 1 1
Bulk Supplies (per order) Alcohol Swabs Gloves	<u> </u>	
Refills: □ 1 □ 2 □ 3 □ 4 □ 5		

This ebook was written by a lyme patient, not a doctor, and thus is not to be considered as medical advice.

May we all be able to joke about having lime green hair for Halloween, rather than being caught up in the lyme war.



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