

Tips for Choosing a Lyme Literate Health Care Provider

©Written By Michael Parent

Here is a tips list to help you sort through the names as you choose who your new health care provider will be. Here is some advice to help narrow down the list based on my experience.

It can be an overwhelming process sorting through the care providers and researchers provided, and so this tips list is designed to help you organize the process. Begin with choosing 5 names off the list. Choose them by whatever criteria attracts you to their name. Call each one, and follow this process below:

Starting the conversation:

When you call each office, tell them you're considering becoming a new patient but that you have questions of concern before going in for a consult. (After all you don't want to waste your time or money, or the doctor's time, if you aren't sure this doctor is right for you. Be a medical consumer and an advocate for your care)

Do they meet the standards listed below. The names used below are fictional examples.

The questions to ask:

- First ask the person's name that answers the phone. When you know their name, say "Hello Jason is Dr. Richards taking new patients?" (Using the person's name helps create a connection between you and the person you're speaking to. The other person will be more receptive to your questions, and more willing to reveal information they may not usually reveal otherwise.)

Notes:

- Which insurance carriers do you accept? (if the person says none: ask how much money does the first consult, phone consults, and follow up appointments cost, and are out of office or in office tests included in that price?)

Notes:

- Tell the person you're speaking to: Jason in this example -- that you'd like to talk to the doctor yourself, or have him/her return a phone call so you can speak directly with

him/her so you can decide whether you want to invest money and driving time in a consult.

Notes:

- If the office has a policy that you can't talk to the doctor directly, then ask the office staff (Jason in this example) which words they'd use to describe the doctors level of care and would they see the doctor themselves if they or a family member were ill? At this point pay attention to tone and attitude. If they get irritable, indifferent or apathetic write a note that this is a sign of problems. If Jason does answer with positive words like compassionate, open minded, intelligent, a good listener etc. then you know this is a strong choice. Words like "fine, good, or ok or anything that seems forced or unenthusiastic tells you things aren't likely going to work.

Notes:

- Ask Jason (example name) "How would this doctor feel about dealing with a controversial or poorly understood disease?" (Let them respond for a moment) then continue and say "Like Chronic Lyme Disease." Many physicians will not tell you they accept patients with Lyme Disease by phone, as they are under scrutiny, so approach it indirectly. Once the person starts talking about it openly, then you'll be safe to tell your story briefly, that you have Lyme Disease, or other associated diseases, and need treatment as soon as possible.

Notes:

- Ask Jason if the physician treats patients who have Lyme Disease or associated infections with long term antibiotics both oral and IV beyond the conventional 6-8 week time period, if the patient requires it.

Notes:

- What laboratories are commonly used? If they don't know, ask if they can find out. If they use only Labcorp, Quest, this can be a problem. You can press further by asking if

they use specialty labs like Igenex, Medical Diagnostic Laboratories, Central Florida Research, or Fry Laboratories. If they use any of these, that's a good sign. They may use others as well, which are effective but not listed here.

Notes:

- Also ask if the doctor takes Co-infections seriously, and is he or she willing to test for these and treat these?

Notes:

- Ask Jason how long the first appointment is for most patients? If the answer is anything less than 1 hour for the first appointment, then it's unacceptable, and ask for more time. If they don't allow it, move on.

Notes:

- Ask Jason if you can fax, or e-mail a one to two page summary of your situation to the doctor once you've decided that you'll see this physician.

E-mail:

If the doctor's e-mail is included on the list you receive, then you can avoid making the phone call above all together. I personally would do both, call and write. Most Lyme specialists who have E-mail also tend to make themselves more available to their patients, which is important. Write the doctor directly. Give him/her a short bio history of who you are, what you're illness is, and symptoms, only 1 or 2 paragraphs at most, keep it concise and factual. Ask the same questions you would ask the office staff. Those questions are listed above.

Additional advice:

Try to work with a "Medical M.D" or NP (Nurse practitioner) before turning to holistic, DO, ND, or other alternative practitioners" -- I say this because, you need a diagnosis from a medical physician or NP in order to have credible records for insurance and or medical care, especially if you're disabled or may be filing for it.

Additionally, antibiotic therapy is the first line of defense and shows the greatest improvements in the average patient based on the available science, vs. these other forms of care which aren't entirely understood. However, it's also true antibiotics only get most patients so far who have chronic Lyme or its co-infections before they need to consider employing alternative practitioners who are using cutting edge techniques or herbal treatments.

In late stage cases or cases involving Bartonella or Babesia (Which are very common and must be taken seriously) the entire body is ill, requiring nutritional care, detoxification, as well as therapies aimed at killing the infection (s) and so on. The body has been exhausted so long, that the specialist also needs to be aware of those facts too and treat them. I don't discount using the other forms -- in-fact, I'm certain many of them work. If you choose to work with an M.D. and that physician likes to combine therapies such as antibiotics/antimalarial, or so on with say Samento, Cowden, Rife etc., light therapy, Infared Sauna, Photon Therapies. These can be useful in tick-borne illness. It doesn't hurt to see a DO or ND in combination with an M.D. either, since treatments can be combined and two heads are better if they specialize in Lyme.

Cost Of Testing

The Rotary Club of Ferndale Foundation and the Humboldt Lyme Awareness Group have teamed up to help provide financial assistance to those needing Lyme-related lab tests.

The Lyme Test Access Program is a nationwide program offered to provide reimbursement assistance of initial medical tests needed for Lyme-related conditions for those patients needing assistance, according to a press release. Humboldt Lyme Awareness Group volunteer Sylviane Schwarz said since the groups kicked off the program in November, the application has been downloaded 500 times from their site, <http://www.lymetap.com/> and she has been answering questions on the application process. You may also contact Turn The Corner Foundation

You can use ratemd.com to look up each doctor as well. Some will be listed, some won't. The page allows you to see what other patients thought about the doctor's level of care. If the doctor has less than 4 stars I wouldn't bother seeing them. (Again just my opinion)

Other Sources To Find Appropriate Healthcare provider for Lyme And Associated Illness:

Turn The Corner Foundation as well as The Lyme Disease Association both run programs in which they will assist patients in finding health care providers to treat their Lyme Disease and associated infections. You may wish to compare and contrast the information we provide here. To get information from Turn The Corner Foundation: E-mail them at:

medicalinfo@turnthecorner.org For Information From the LDA, go here:
lymediseaseassociation.org and then choose the Dr. Referral tab.

Make The Most Of Your Appointment With Your New Specialist:

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1. Arrive prepared and on time. Do your research ahead of time and educate yourself on possible treatment options. Be aware of your limited time. Write down your questions before each visit. Make a reasonably brief list of the topics that you wish to cover. 1 to 3 pages is acceptable to provide "Important Updates (Including medication changes made by other providers as well as why it's changed), Allergies, Lifestyle: Current Dietary or changes, Current exercise as well as changes, Relationships and Work: How they're going, are they stable? Have they been stressful lately? Symptoms as well as changes, Appointments with other physicians, and what took place (Include their name and phone number), as well as a section for questions for your physician, and finally a summary including any ideas you have regarding which direction you think might be useful in your treatment. Give this to the physician and tell them to read it right when the physician sits down to begin. This will answer many of their questions saving precious time.

2. Provide copies of your health records, including pictures of any unusual rashes that you have had and the results of any laboratory tests from other health care providers. Bring any important abstracts, medical papers, etc. which support your specific requests. Summarizing the facts of your medical records can be especially useful for any physician you see. Example: I was recently tested for Lyme Disease by Dr. John Doe (His specialty, and phone number) and I had a Positive IgM Western Blot for Lyme Disease: Band 41, 39, 30, 31, 83. The laboratory was Igenex. I was tested by Dr. Richard Rich (Specialty and phone) and had a Positive IGG EBV Virus 1.49 Reference 1.0<lt;) from Quest Laboratory.

3. There will be a great deal discussed, so most of us can benefit by having a family member or friend accompany us to the appointment. They can serve as an extra set of ears. If this isn't possible, consider taking a tape recorder along. Be sure to ask the physician if it is acceptable to record prior to the start of the appointment.

4. Always discuss your most important current and past symptoms. Have this typed out in your 1-3 page report (as mentioned earlier). Keeping a copy for yourself and one to leave with your doctor for your file is useful. This is an important base for future comparison. Keep a weekly medical log in which to graph your symptom progress: type of symptoms, intensity (Scale of 1-10 works) and dates of all medications taken (When started, When ended, as well as interruptions in the treatment) and be sure to include any other pertinent health related issues.

5. Ask for some basic parameters as far as what to expect from your physician. Ask them what they expect from you. Questions you may consider are: When will your test results be available? What are the signs that things are getting better, worse, or not changing? How long should you

expect to stay on this protocol? Who should you contact should an emergency arise? Is the Doctor available for phone consultations? When should your next appointment be? Will he consult with your regular physician?

6. Be sure you have your prescriptions in hand and understand completely the recommended protocol. Make certain that you have all of your questions answered now while you have the doctor's attention. Don't be afraid to ask for clarification as many times as it takes to be clear to you. Ask that they write it down legibly for your consideration (Many physicians have sloppy writing).

7. Before you leave, be sure to sign for release of all office records for yourself and your regular physician. Although it is important to have a home based physician (Primary care provider in your local area (1-20 mile radius), do not be surprised if they leave your treatment for Tick Borne Diseases to your specialist. It is however, important that you build a team effort approach to your healthcare early, so be certain that each physician is aware of any health issues and keep them updated on "all" of the information and changes by also giving them written/typed summaries to keep them connected. Most physicians will not consult with each other even when asked to do so by the patient.

8. Set up your next appointment now. It's possible to setup monthly, bi monthly or even longer at any appointment. Setting up appointments in advance allows you to solidify your position. It's not easy to always get appointments when you want, and this puts the power in your hands.