

# Tips for Getting a Proper Diagnosis of an Autoimmune Disease



# Welcome!

- You do not need to take notes!
- Your hosts are: Sandra Cobb, and Katie Simons of AARDA
- Thank you for joining us



The following are the notes to accompany the webinar “Tips for Getting a Proper Autoimmune Disease Diagnosis” recorded on August 28, 2019

Thank you for taking the time to watch or review the notes for this presentation.

We have received an amazing amount of interest in this topic as well as many people expressing their thanks and appreciation. On behalf of AARDA I also want to extend my gratitude to all of you for taking the time to join us. We know for people with chronic illness like autoimmune disease time is a valuable resource, and we hope that we can provide you with some knowledge and tools to save you some time in getting to a proper diagnosis

# Welcome!

## AARDA & our mission

The American Autoimmune Related Diseases Association is dedicated to the eradication of autoimmune diseases and the alleviation of suffering and the socioeconomic impact of autoimmunity through fostering and facilitating collaboration in the areas of education, public awareness, research, and patient services in an effective, ethical, and efficient manner.



At AARDA our mission is to the dedication to the eradication of autoimmune diseases and the alleviation of suffering and the socioeconomic impact of autoimmunity through fostering and facilitating collaboration in the areas of education, public awareness, research, and patient services in an effective, ethical, and efficient manner.

# Welcome!

## AARDA & our mission

- People with autoimmune disease (AD) often have a very difficult time getting a diagnosis
- The category of autoimmune disease
- Why does a “proper” diagnosis matter?



We know that people with an autoimmune disease (AD) on average spend 3 years and see an average of 4 physicians before getting a proper diagnosis, and we are working to change that.

AARDA is the only national nonprofit to focus on the entire category of AD, so we generally do not cover disease specific information. However, if you contact our office with specific questions, we always do our best to provide whatever resources or guidance we have to offer.

So why does a proper diagnosis matter anyway? Well, given that you are listening to this webinar you probably already know. Once a person gets a diagnosis, they can begin getting proper treatment, more accurate information about their prognosis, and can seek out a community for support

# Welcome!

## Listen to the experts

- Yourself!
  - Set your own goals
- Your healthcare team
  - check credentials
- Beware of Dr. Google

So, now we're on the AD journey. While on this journey, it's always a good idea to listen to the experts, and there is no better expert than you when it comes to your body. If you have been dealing with severe symptoms it may be harder to tap into that expertise, especially if you've had to ignore what's been going on in your own body in order to be a parent, spouse, caregiver, or keep you job. If that sounds familiar, it would be a good idea to take a refreshers course. Listen to your body and do your best to understand what it's saying.

Similarly, if you've been seeking a diagnosis for an extended period you've probably had your symptoms dismissed or worse. We often hear of people who have been told that they are overreacting, maybe they just need to take a break, or that it's all in your head. Well it's not. You are not overreacting, and you most certainly are not crazy.

You should also make sure to set out your own goals. Your doctors may use test results to try and get certain numbers between certain ranges, but that does not cover the whole picture. You should decide what is most important to you, and work towards achieving those goals, and not just one goal, or a goal. If you're having mobility problems, perhaps set a goal of being able to walk one block, then maybe walk a nature path, or more easily climb a flight of stairs. Be sure to share these goals with your doctor so that they know how best to help you achieve them.

Remember, you can't go it alone. You need to have your medical team on your side working with you, so that you can fight your disease together. When looking to build your team, don't be afraid to look up their credentials and ask them what kind of background and knowledge they have in autoimmune disease. Physicians will have varying degrees of understanding of AD, and it's important to find those who are experts.



## The diagnosis journey: a starting point

- Your family's medical history,
- “Know your AQ”

**Do you know your family AQ?**

*The following article is an AARDA press release designed to spread autoimmune awareness. This information forms the basis for a PSA featuring Kellie Martin, AARDA's spokesperson, which has been picked up by TV stations across the country. Watch for it!*

The American Autoimmune Related Diseases Association (AARDA) wants to help you learn your family's AQ. AQ is a play on IQ that stands for **Autoimmune Quotient**. It's about knowing how likely you or a loved one is to develop an autoimmune disease, based on the prevalence of these diseases and your family history.



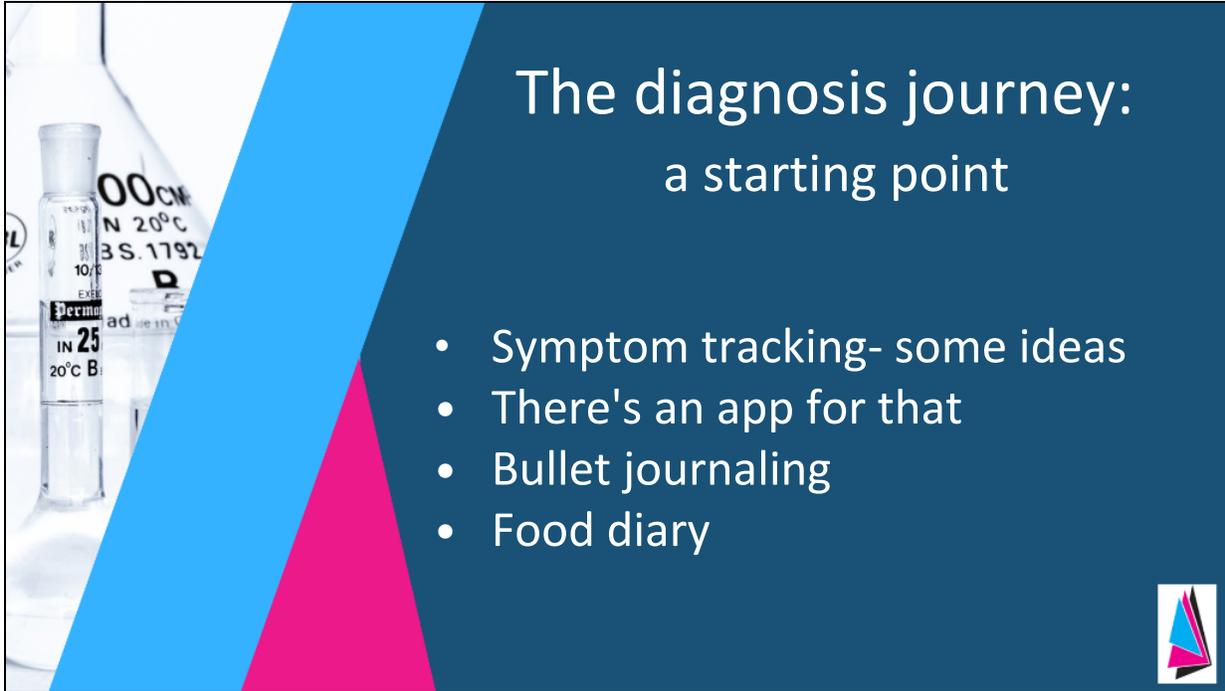


So where to begin? As we mentioned, getting a diagnosis can take several years, and it's often the start of a journey filled with plenty of exciting twists and turns.

Start with your family. AD does run in families, so we do recommend that you “Know Your AQ” or your autoimmune quotient, that is how much does AD run in your family? Please note, that if AD does run in your family, it does not mean that that your children will automatically inherit an AD. To complicate matters there are well over one hundred AD, so it can be difficult to know what to include. We do have a list on our website that you can check to see if a condition is an AD, or a related disease. And while it may be difficult, it is important to talk about this with your family. It could be likely that a family member maybe seeking a diagnosis as well or may not even know that what they have is considered an AD.

“Know your AQ” [https://aarda.org/wp-content/uploads/2016/12/AARDA-Do\\_you\\_know\\_your\\_family\\_AQ-DoubleSided.pdf](https://aarda.org/wp-content/uploads/2016/12/AARDA-Do_you_know_your_family_AQ-DoubleSided.pdf)

List of autoimmune and related diseases <https://www.aarda.org/diseaselist/>



## The diagnosis journey: a starting point

- Symptom tracking- some ideas
- There's an app for that
- Bullet journaling
- Food diary

Where to focus next? We recommend keeping track of your symptoms. This can be an invaluable resource. And something you can and should review with your doctor. It provides data to help clarify what you're going through. For instance, a doctor can dismiss someone saying that they are tired, but by keeping track of your symptoms, you can show that it is much more, that the fatigue you're dealing with has occurred every day for weeks, or that you've missed x amount of days at work because of this symptom

Tracking can also help with determining how well a treatment is working, highlight any side effects or improvements; whatever they are.

For how and what to track, refer to your own expertise. Will a digital option like downloading an app on your phone work best, or perhaps a bullet journal style tracker? What symptoms are the most problematic for you, and which concern you the most? Don't forget to also track your goals in relation to your symptoms. Maybe you want to keep track of any additional pain killers you've taken or how often you've used a topical cream.

You may also find it helpful to start a food diary alongside your tracker. Many people with AD find that they are sensitive to gluten and some other foods.

Don't worry if it takes some trial and error to figure out what works best for you and don't let tracking become a burden. Tracking should be a helpful resource for you and, hopefully, it will become a moment to look forward to as you get better and can see the progress you've made and how far you've come.

## The diagnosis journey: a starting point

- Symptom tracking apps

FD

Person icon

Child icon

Red heart icon

WebMD

A quick search yields a lot of results for app to track symptoms **AARDA is not affiliated with any of these apps**, but we are including them just so that you can get a look at what's out there and available to you. There is “flare down” “pain scale” “iBeat Pain for teens” offered through the mayo clinic, “simple symptom tracker”, and “WebMD mobile pain coach”

Some things to be aware of, is the cost, make sure to read the reviews, understand the permissions, and terms of service, especially if you are concerned about your privacy and the app company, and finally look for apps from trusted sources, like the mayo clinic or WebMD

# The diagnosis journey: a starting point

- Symptom tracking

**Symptom Tracker**

Print out this sheet to keep track of all your symptoms - or simply what's happening when you don't feel your best. Your doctor can use this information to help establish a diagnosis or learn to identify conditions or prescribe the best medication for you. This information will also show an insurance company how long you have been managing a health issue, how severe it is, and how you and your doctor have been working to treat it.

| DATE AND TIME | WHAT DID YOU EXPERIENCE? | HOW LONG HAVE YOU BEEN EXPERIENCING THIS SYMPTOM? | OTHER DETAILS: HOW DID IT FEEL? HOW PAINFUL WAS IT? ANYTHING YOU WANT TO MENTION LATER? |
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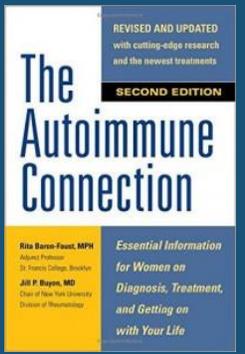
Additionally, there are many resources online if you prefer a paper or a physical option. We do have a symptom tracker template on the Let My Doctors Decide website. and if you prefer the journal method, you can also include other things beside symptoms, such as starting a food diary, or include other goals, ideas, inspirational quotes. Some AD patients find this a good way to practice self-care and to wind down at the end of the day.

Let My Doctors Decide Trackers: <https://letmydoctorsdecide.org/trackers>



## The diagnosis journey: selecting a path

- Finding the right doctor for you
  - Doctor referrals
- Clinical exams and testing
  - 586-776-3900,  
aarda@aarda.org
  - “The Autoimmune Connection”



You absolutely need the right people on your side. As we mentioned earlier, not every doctor has a background tailored to treatment AD, and unfortunately, there is currently no specialist for auto-immunology. But the silver lining is that AARDA does provide doctor referrals. If you contact our office with the type of specialist you're seeking or your major symptoms along with your address, we can see what is available in your area. You can call our office at 586-776-3900 or by email at [aarda@aarda.org](mailto:aarda@aarda.org)

If you are looking for information on AD themselves and the exams and diagnostic testing, we recommend reading “The Autoimmune Connection” by Rita Baron Faust. It is an excellent book, and while it is packed with scientific information, it is readable and understandable to the average person. You can also purchase that book on AARDA’s website.

To purchase “The Autoimmune Connection” <https://www.aarda.org/autoimmune-connection-announcement-2-2/>



## The diagnosis journey: getting going

- Importance of fighting together
- Questions to ask
  - When to get a second opinion



Once again we stress the importance of the doctor patient relationship. Like any other relationship, much depends on communication and respect. Patients often become experts in their conditions out of necessity and doctors may be short on time and patience, but both sides need to be respected in order to be productive. You should try to give it some time to be able to develop a relationship with your doctor, but never be afraid or hesitant to initiate the breakup or to see other people, by which we mean seek out a second, third, or however many other options it takes before you are satisfied

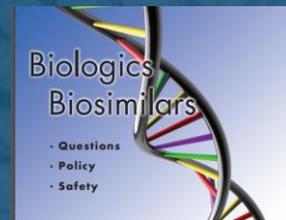
For a more in-depth look at this topic we recommend viewing one of our previous webinars entitled “The Doctor-Patient Relationship”, with featured speaker doctor Santos who talked about the best way to prepare for your appointments, why doctors have such limited time to spend in person with their patients, along with information on how to work best with your doctor.

“The Doctor-Patient Relationship” <https://www.youtube.com/watch?v=VyIGhT8xPIE&t=869s>

AARDA Tube <https://www.youtube.com/user/AARDATube/videos>

## After a diagnosis: treatment

- Timing
- Quick considerations
- Understanding your options
- Biologics vs Biosimilars
- Coordinating Care



The journey doesn't end when you finally get that diagnosis. When you begin treatment, you will want to balance quick intervention so that your condition comes under control, but you should also make sure that you are comfortable with your treatment plan. It's your body and your choice, so if you do not fully agree or are comfortable with a treatment plan it is okay to investigate other options. However, it is important to act as quickly as possible.

It is common for AD patients to have biologics or biosimilars included into their treatment plan. But you may not know the difference between the two. AARDA has an informational booklet, but here are the simple definitions:

[From Wikipedia,] A biopharmaceutical, also known as a biologic medical product, or biologic, is any pharmaceutical drug product manufactured in, extracted from, or semi-synthesized from biological sources. Biosimilars are officially approved versions of original "innovator" products and can be manufactured when the original product's patent expires

When you are seeing multiple specialists, it becomes crucial that you work to coordinate your care. How you do that depends greatly on your own circumstances but if possible the specialist you see the most frequently, or the specialist who is treating your most significant diagnosis. You want to make sure that your doctors are in contact with each other and agree on a treatment plan, so they know the full picture of your health beyond what their own specialty is when they are treating and evaluating you.

Biologics biosimilars <https://www.aarda.org/wp-content/uploads/2019/02/Biologics-Biosimilars-BookletFINAL.pdf>

## After a diagnosis: beyond a prescription

- Your support network & caregiving
- Diet & nutrition
- Stress management
- Self-care strategies

**10 Self-care ideas for Autoimmune Warriors**

- 1 Hydrate**  
Drink more water, try new teas or other drinks, maybe even go wine tasting with friends (if your meds allow it).
- 2 Move**  
Stretch (it shouldn't be painful), walk, even dance it out to your favorite music!
- 3 Pause**  
Take deep slow breaths, try mindfulness or guided meditation. There are many options & resources online.
- 4 Create**  
Art, crafts, a new routine, an organization system, journaling, recipes, blogs, music, travel plans, anything you want.
- 5 Kindness**  
Be kind to yourself, be kind to other, practice and inspire others to commit random acts of kindness.
- 6 Community**  
Engage in an autoimmune-related community, share, listen, learn, be heard, and support each other.
- 7 Treat Yourself**  
Indulge, or invest in items to make life easier. Try exploring a new park, borrowing something from your library, or a night in with friends.
- 8 Laugh**  
Watch a funny movie, tv show, or videos. Follow social media profiles that make you laugh.
- 9 Nature**  
Try growing a garden of herbs for your cooking, succulents, or a traditional garden. Go outside and explore your neighborhood, a park, or arboretum.
- 10 Celebrate**  
Big wins or small victories celebrate the joy in your life. From having a great day or simply getting through the day, it's all worthy of recognition.

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

Don't hesitate to rely on your support network, bring people to appointments if needed or wanted because they can be very helpful to take notes, ask questions you may not think of, or for moral support. Like with the other relationships keep up a good communication make sure you are clear with what you need/can do.

Good nutrition always helps, but everything with AD is individual. Even within single diseases what works for one person could harm another. If you are using your diet as a means of treatment or for symptom relief, you need to be discussing that with your doctor. This is important with supplements as well, because they can cause interaction with medications, or your immune system in general.

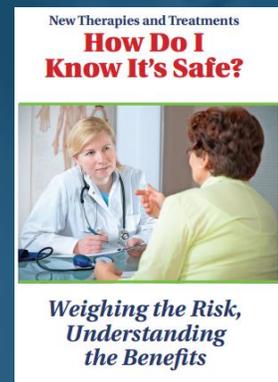
You should be taking care of yourself. Chronic disease can take its toll on your mental health, and stress is known to trigger flares. Again, consult the experts, YOU. Figure out what helps you to relax- hot cup of tea, funny videos, scented candle, a walk in a park, whatever fits your needs. If you are past the point of self-care being enough, find a good therapist or counselor because your mental health is just as important, and just as important to find the best treatment that works for you. In today's world counseling services are offered online and through text as options, but again sure the services are properly credentialed.

Self-Care for Autoimmune Disease <https://www.aarda.org/self-care/>

Crisis Text Line: Text "HOME" to 741741 (USA) <https://www.crisistextline.org/>

Still  
seeking  
answers:

- Additional AD
- Clusters
- Treatment side effects
- “Risks & Benefits”
- Misdiagnosis
- Rare disease



If you are still seeking answers, you know that there aren't always simple solutions. However, knowledge is power, so there is something that you should be aware of to be able to talk about them with your doctor in making diagnosis and treatment plans.

First, is the clustering effect. Not only does AD run in and cluster in families, but they cluster in people too. The biggest indicator that you will develop an AD is already having one. So, it can be difficult to tell what symptoms are caused by one AD or possibly an additional condition.

Another complication is that some symptoms could be side effects and not part of any disease or condition. This can get very murky and is why we strongly advocate for you to keep track of your symptoms and work with your doctor. Also, in terms of side effects, know and determine for yourself what you are willing to deal with in terms of those impacts. Another one of AARDA's brochures is our "Weighing the Risk, Understanding the Benefits" that can guide you through that decision-making process.

There is also the possibility of being misdiagnosed, which can happen when you have a rare disease that may seem like another condition or two. If you think you've been given a misdiagnosis, listen to yourself, remember that you are your own expert, keep asking questions or write them down as they occur to you. Keep tracking your symptoms and their severity, and ask for the results from all your tests and any other medical records to show when getting another opinion.

"Weighing the Risk, Understanding the Benefits" [https://aarda.org/wp-content/uploads/2017/04/aarda\\_risk\\_benefit\\_brochure.pdf](https://aarda.org/wp-content/uploads/2017/04/aarda_risk_benefit_brochure.pdf)

# Questions

- For medical advice consult medical experts
- The latest in research
- Diet & nutrition



Many of the questions we get are often disease specific and very individualized. We do try our best to answer those questions, or at least provide guidance and assistance. We ask that you contact our office either by calling 586-776-3900 or emailing us at [aarda@aarda.org](mailto:aarda@aarda.org)

If you are looking for the latest in research and specific research in single disease, you can check out publication by the association relating to the specialists you see. For instance, if you see a rheumatologist, you can check out the American College of Rheumatology, or industry journals such as from the National Institutes of Health, or the National Library of Medicine. You can also follow AARDA on Facebook or check our research round-up blog posts on our website.

Another frequently asked about topic is diet and nutrition. As we mentioned earlier, good nutrition is always a good idea, but if you are implementing a diet as part of a treatment plan or as a method of symptom relief you need to consult your physician.

# Questions

- Prevention, screening, and genetics in AD
- The doctor-patient relationship



We've gotten a few questions about preventing and screening for AD, particularly for people who have an AD and for their children. Unfortunately, this is an area that we do not have a lot of information. There is no current way to prevent the onset of an AD, similarly there are not a lot of screenings that doctors will do for those at risk unless they are actively showing symptoms. Our best advice is to keep track of symptoms, and if you are worried about your children developing an AD, just be aware of their health and understand that they may not be able to communicate or describe their symptoms the same way an adult can.

A few people have asked what they can do if the doctor they are seeing is not taking their symptoms seriously or not running the tests they are requesting. We do strongly encourage a healthy doctor patient relationship; however, we have heard that people in unproductive relationships find it useful to insist that the doctor includes in the patients' medical records what procedures were not done. People have found when insisting on that exclusion being noted, doctors will go ahead and run those tests to be safe.

One person asked what to do if their doctor is a bully. Please report them to your local medical board. You should never have to be put in that situation, and it is likely you are not the only person experiencing that negative treatment.

## More resources

- The Common Thread
- Lab Tests Online
- Inspire
- Clara Health
- The Autoimmunity Institute
- NCAPG



Even more resources!

- The Common Thread- a booklet written by Dr. Noel Rose, who is the father of autoimmunology and provides a great overview and background of AD.
  - <https://www.aarda.org/who-we-help/patients/common-thread/>
  - Q&A with Dr. Rose, the "Father of Autoimmunology"  
<https://www.youtube.com/watch?v=vRsvjyDvAWQ>
- Lab Tests Online-Lab Tests Online- an award-winning health information web resource designed to help patients and caregivers understand the many lab tests that are a vital part of medical care.
  - <https://labtestsonline.org/#>
- Inspire-Inspire connects patients, families, friends, caregivers and health professionals for health and wellness support.
  - <https://www.inspire.com/>
- Clara Health-Clara is a fast, simple, most patient friendly way to connect autoimmune diseases patients to the newest treatment options.
  - <https://clarahealth.com/>
- The Autoimmunity Institute- is a world-class, first-of-its-kind facility with patient centered coordinated care. They are working on some amazing things in the autoimmune disease community.
  - <https://www.ahn.org/medicine/autoimmunity-institute>

- NCAPG- the NCAPG is the national coalition of autoimmune patient groups, founded by AARDA, with a mission is to amplify the voice of autoimmune disease patients and to promote increased education, awareness, and research into all aspects of autoimmune diseases through a collaborative approach. AARDA often works with the coalition on advocacy efforts, and we refer people to our coalition members if they are looking for disease specific information
  - <https://www.aarda.org/who-we-are/ncapg/>

All these resources and links can be found on our website, plus more information!

<https://www.aarda.org/resources/>

**American Autoimmune**  
Related Diseases Association, Inc.  
586-776-3900 | [www.aarda.org](http://www.aarda.org)

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**Thank you for attending, be sure to stay in touch!**

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