LRAN Lupus Research Action Network

by Lupus Foundation of America

Help Us Solve
The Cruel Mystery
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September 26th , 2024

WELCOME!

Housekeeping Items:

- Please mute your audio when not speaking
- Use the Raise Hand function (found in the "Reactions" button) if you have a question or comment, we will have time for Q & A
- Chat function is open to all if you want to engage with each other during the training

Agenda

- Welcome and Introductions
- LRAN Program Updates
- RAY Updates
- LRAN in Action
- Special Topic: How to find Clinical Trials
- Evaluation/Feedback

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CEO Welcome

Lousie Vetter,
President & Chief Executive Officer

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IMPACT+ Program Updates

Stephanie Slan, MBA, ACRP-CP
IMPACT+ Project Director

Who is in LRAN?

A look at the numbers

- 86 members
  - 2 males (2.3%)
  - 84 females (97.7%)
- LRAN members are located across the country
  - Florida: 23
  - Pennsylvania – 10
  - Texas – 10
  - New Jersey – 8
  - New York – 8
  - California – 7

Who's in LRAN (cont.)

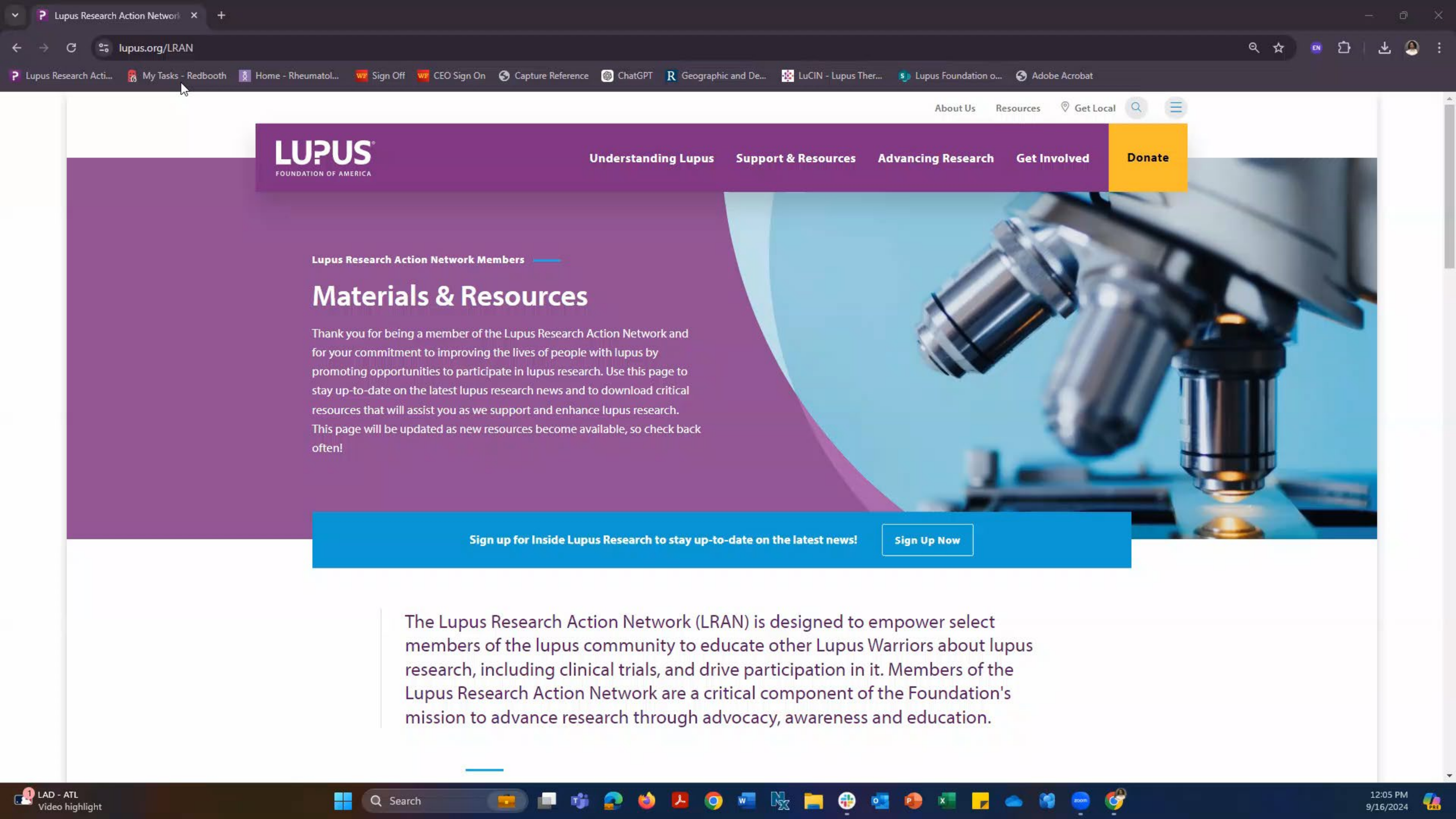
- 58 currently enrolled in RAY
  - 28 LRAN members not in RAY
- It is especially important for LRAN members to encourage and facilitate enrollment in RAY.
  - Remember, RAY is a way to begin to participate in research, allowing your voice to be heard your experiences to shape the future of lupus treatment.

RAY
LUPUS RESEARCH
ACCELERATED
by YOU
Lupus Foundation of America

What's New?

Your LRAN Member Website

- https://www.lupus.org/LRAN
- You will find access to
  - recordings of LRAN classes and continuing education sessions
  - access LRAN Toolkit materials
  - general clinical trials information
  - sign up for latest research news
  - Enroll in RAY
  - download a presentation for a speaking engagement
  - report a speaking engagement
  - connect with other LRAN members



Lupus Research Action Network Members

Materials & Resources

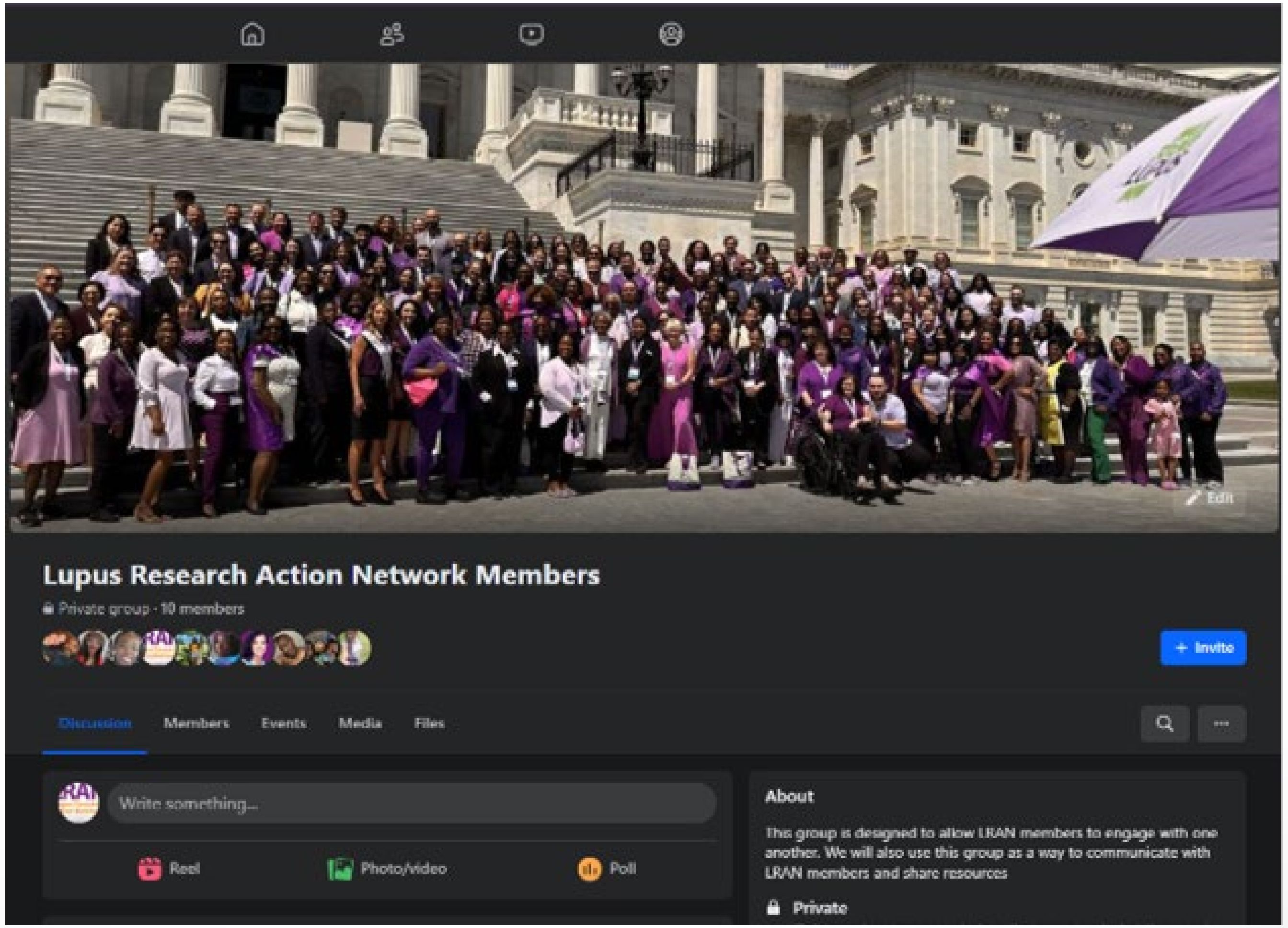
Thank you for being a member of the Lupus Research Action Network and for your commitment to improving the lives of people with lupus by promoting opportunities to participate in lupus research. Use this page to stay up-to-date on the latest lupus research news and to download critical resources that will assist you as we support and enhance lupus research. This page will be updated as new resources become available, so check back often!

Sign up for Inside Lupus Research to stay up-to-date on the latest news!

> The Lupus Research Action Network (LRAN) is designed to empower select members of the lupus community to educate other Lupus Warriors about lupus research, including clinical trials, and drive participation in it. Members of the Lupus Research Action Network are a critical component of the Foundation's mission to advance research through advocacy, awareness and education.

Join Our Facebook Group

www.facebook.com/groups/lupusresearchactionnetwork/



Lupus Research Action Network Members

Private group · 10 members

About

This group is designed to allow LRAN members to engage with one another. We will also use this group as a way to communicate with LRAN members and share resources

Private

Interested in Contributing?

- Would you like to help facilitate engagement between your fellow LRAN members?
- Would you like to lend your voice to the continuous improvement of lupus research?
- Reach out to Stephanie Slan at: slan@lupus.org to volunteer to be a Facebook moderator.

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Research Accelerated by You Update

Safoah Agyemang, MS

Health Outcomes and Research Manager, LFA

Enrollment Update

Total Number of RAY Participants	**4024**/3500
Participants added since Oct. 2023	**1272**
Participants added since June 2024	**733**

Current RAY Demographic Breakdown

Race/ Ethnicity

- **69%** White
- **16%** Black
- **5%** Asian
- **6%** Other/Not Specified
- **4%** Native American/ Alaskan
- **<1%** Hawaiian/ Pacific Islander
- **13%** Hispanic/ Latino origin

Nationally, Black/African Americans comprise

30-43% of the lupus population

Current

632

Black/African Americans
In RAY

15.7%

→

Goal

1,500 – 2,150

Total Black/African American Participants Needed in RAY by end of FY25

30-43%

Add at minimum

+868

New Black/African American Participants in RAY!

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How Can LRAN Help?

86

LRAN Members

Each LRAN Member should aim to get...

10+

Black/African Americans living with lupus to enroll in RAY!

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For resources:

Registrycoordinator@lupus.org

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LRAN in Action

Salathiel DeLoach

Warrior & Advocate

Salathiel DeLoach

LRAN Member

- Agenda:
  - My journey with the Lupus Research Action Network
  - Why I chose to join LRAN
  - Latest Events & A Story that moved me

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My Journey with the Lupus Research Action Network

Who is Salathiel?	Benefits of being part of LRAN	Personal role and contributions

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Why I Chose to Join LRAN

It’s personal

Warrior

Together WE can

Community

Family

I am my sister’s keeper

Shape the WORLD

Impact

- Diagnosed 2001
- Karell Coppock 2009, Sharee Coppock 2010, Monique Johnson 2017, Omega DeLoach 2017
- Lack of resources, awareness, support advancing research… CURE
- Be the change that will affect the world far beyond the surface

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Latest Events & a Story That Moved Me

- Juneteenth Festival most recent event (8/24/2024)
- Key takeaways, tips, and success of the event
- I won't be silent… I'm all in!!!

Thank you!

Salathiel DeLoach
(912) 231-4880

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Finding Clinical Trials

Your Guide to Exploring Treatment Options for Lupus

Why Clinical Trials are Important

- Help advance lupus research and discover new treatments
- Gain access to new therapies before they are widely available
- Contribute to the future of lupus treatment
- Receive expert care and monitoring

What to Know Before Searching

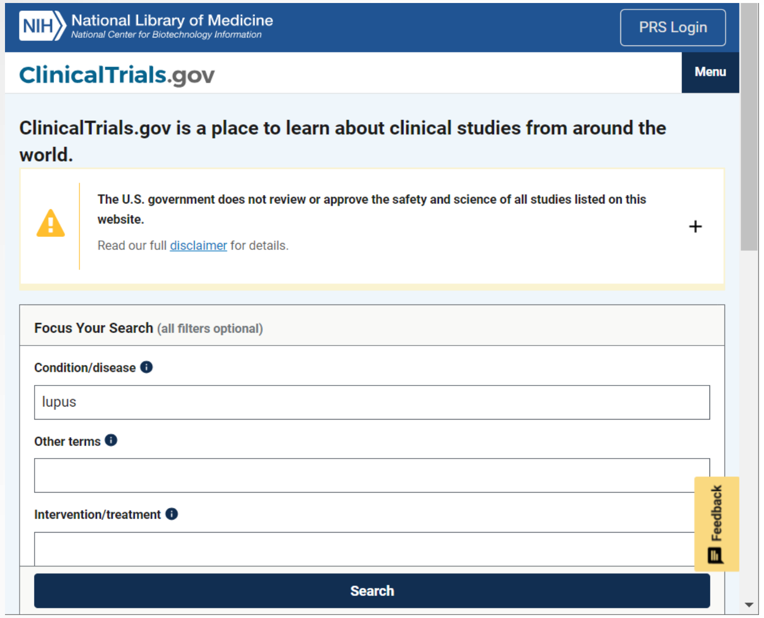
- Know your lupus diagnosis, symptoms, and current treatments
- Understand the phases of clinical trials (Phase I, II, III, IV)
- Talk with your doctor(s) to ensure clinical trials are suitable for you
- Be aware of potential risks and benefits

Clinical Trial Phases

- **Phase 1**: Assess **safety** and **dosage** *(20-100 participants)*
- **Phase 2**: Evaluate **effectiveness** and further assess safety *(100-300 participants)*
- **Phase 3**: **Confirm** effectiveness, monitor **side effects**, and **compare standard treatments** *(300-3,000 participants)*
- **Phase 4**: Post-approval monitoring or **long-term effects** *(3,000-10,000+ participants)*

Where to Search for Clinical Trials

1. The Lupus Foundation of America
   - **Research Accelerated by You (RAY)**
   - Local advocacy groups
2. ClinicalTrials.gov
   - Largest database for ongoing clinical trials
   - Filter by condition (lupus), location, and status
3. Antidote Match (antidote.me)
   - User-friendly interface for finding trials by condition and location
4. CenterWatch.com
   - Lists trials across various conditions including lupus
5. Local Hospitals



ClinicalTrials.gov is a place to learn about clinical studies from around the world.

The U.S. government does not review or approve the safety and science of all studies listed on this website.

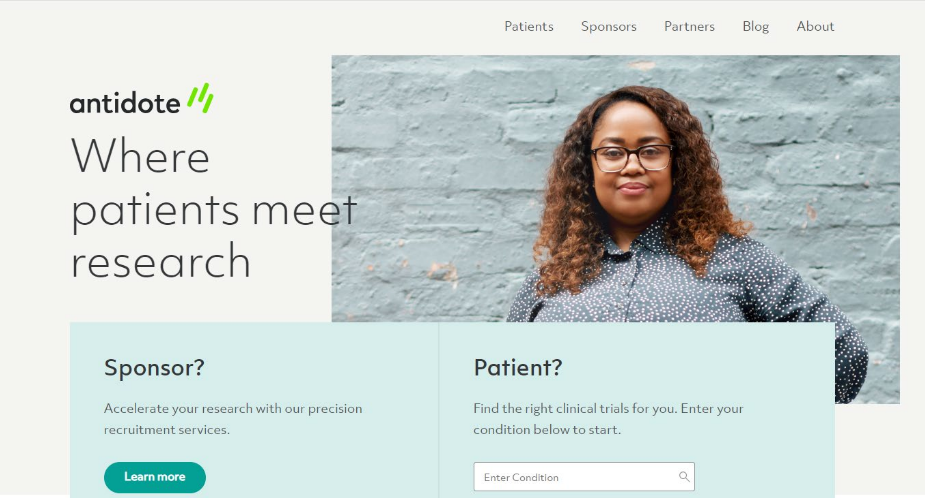
Read our full disclaimer for details.

Focus Your Search (all filters optional)

Condition/disease: lupus

Other terms:

Intervention/treatment:



Sponsor?

Accelerate your research with our precision recruitment services.

Patient?

Find the right clinical trials for you. Enter your condition below to start.

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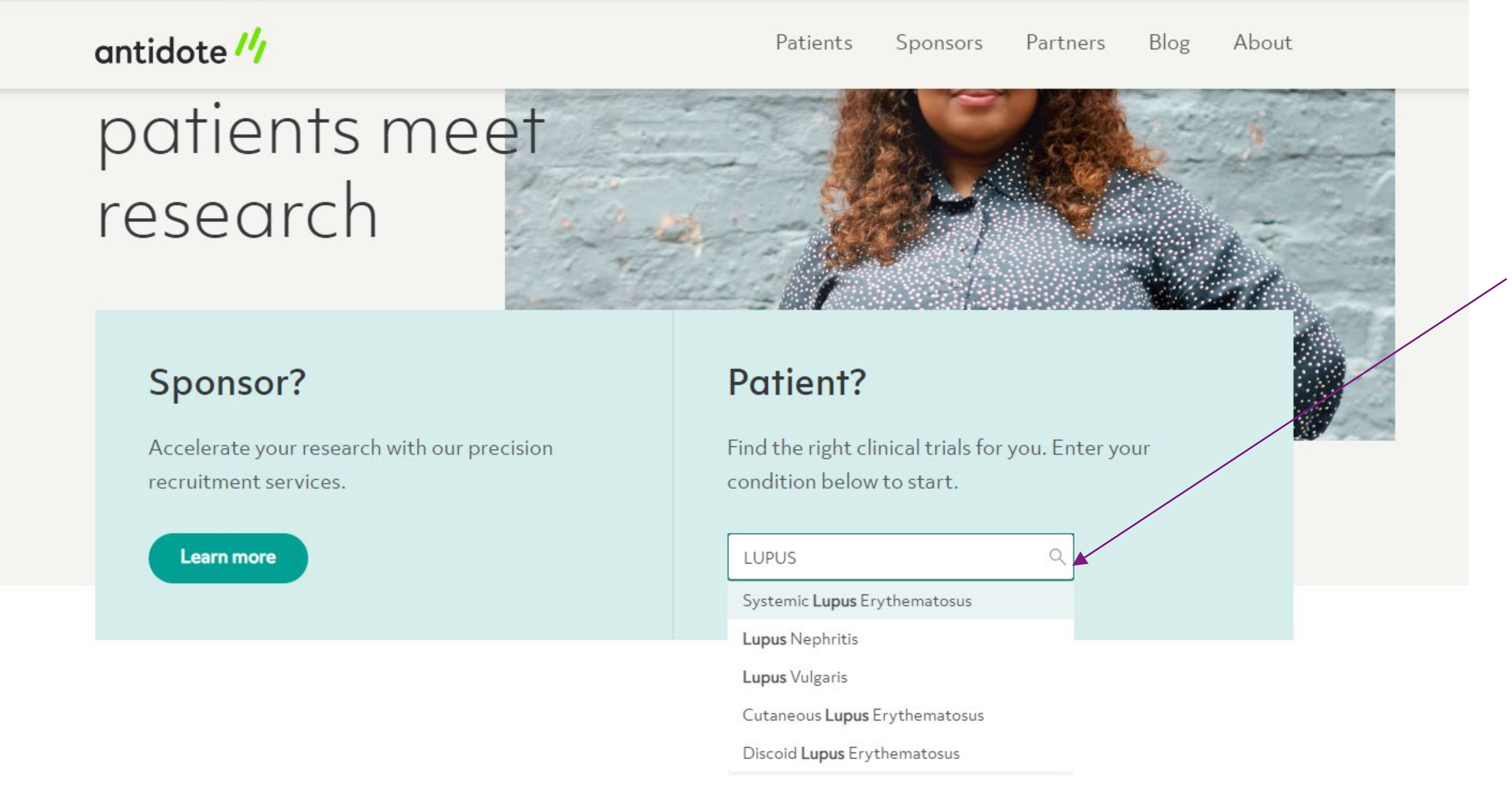
Finding a Clinical Trial

1. Collect information about your lupus
2. Find clinical trials
    - **Research Accelerated by You (RAY®)**
    - Lupus.org
    - ClinicalTrials.gov
    - Antidote.me
3. Review the trials that interest you
    - Inclusion/exclusion criteria
    - Trial design, study visits
    - Benefits vs. Risks

Finding a Clinical Trial

4. Contact the study team to learn more
5. Ask questions
    - Talk to your doctor/care team
    - Discuss with family
6. Make an appointment

How to Use Antidote.me



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Patients Sponsors Partners Blog About

patients meet research

Sponsor?

Accelerate your research with our precision recruitment services.

Learn more

Patient?

Find the right clinical trials for you. Enter your condition below to start.

LUPUS

Systemic **Lupus** Erythematosus
Lupus Nephritis
Lupus Vulgaris
Cutaneous **Lupus** Erythematosus
Discoid **Lupus** Erythematosus

- Visit www.antidote.me
- Under the "Patient" section, type in your diagnosis and select from the drop-down list.

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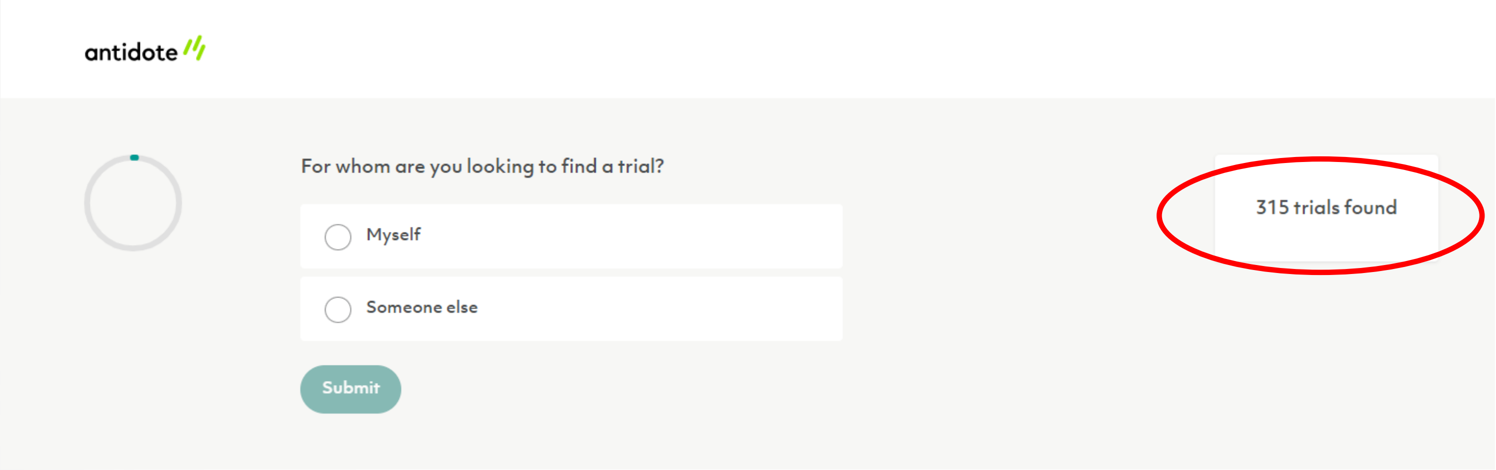

For whom are you looking to find a trial?

○ Myself

○ Someone else

315 trials found

- Select who you are looking for a trial for (either yourself or someone else)
- Click submit

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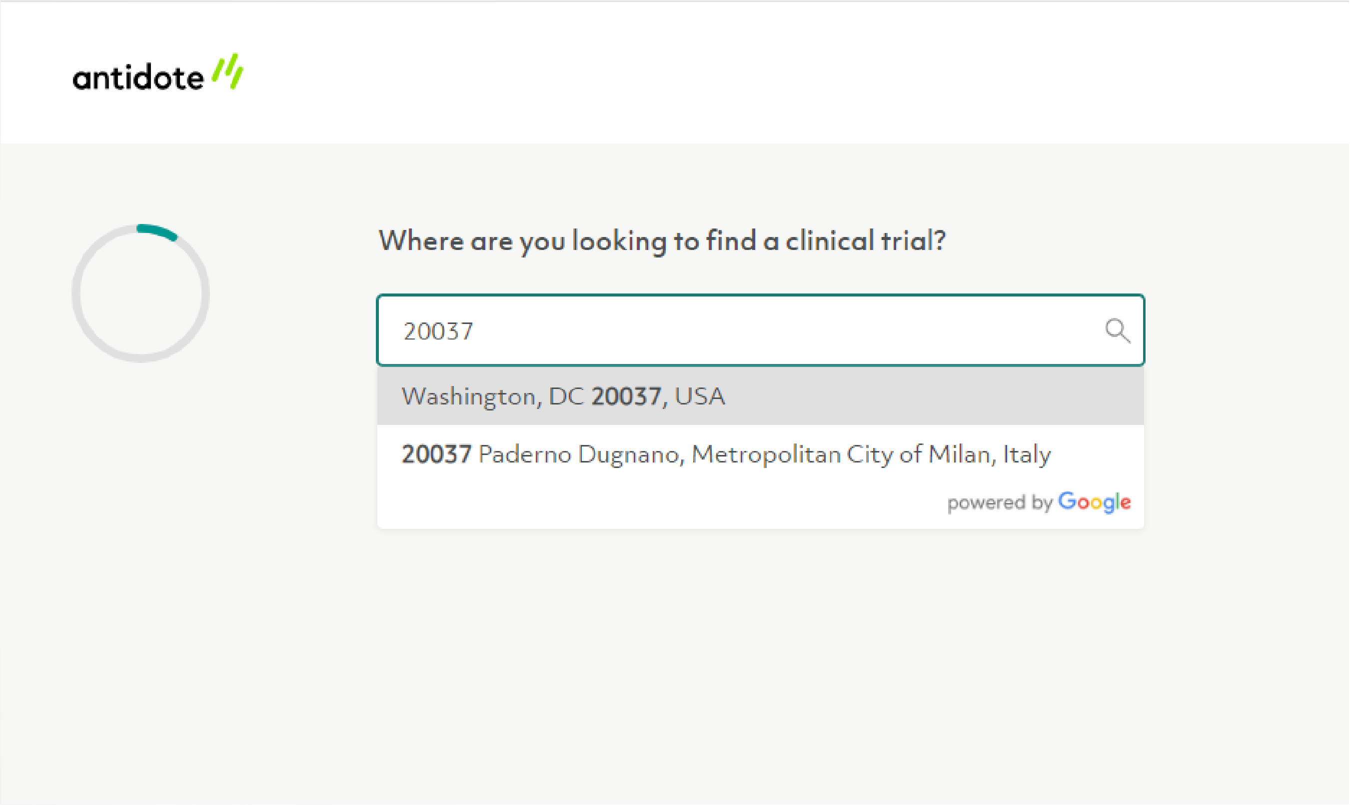

Where are you looking to find a clinical trial?

20037

Washington, DC **20037**, USA

20037 Paderno Dugnano, Metropolitan City of Milan, Italy

- Enter your ZIP code and select from the drop down list
- Click submit

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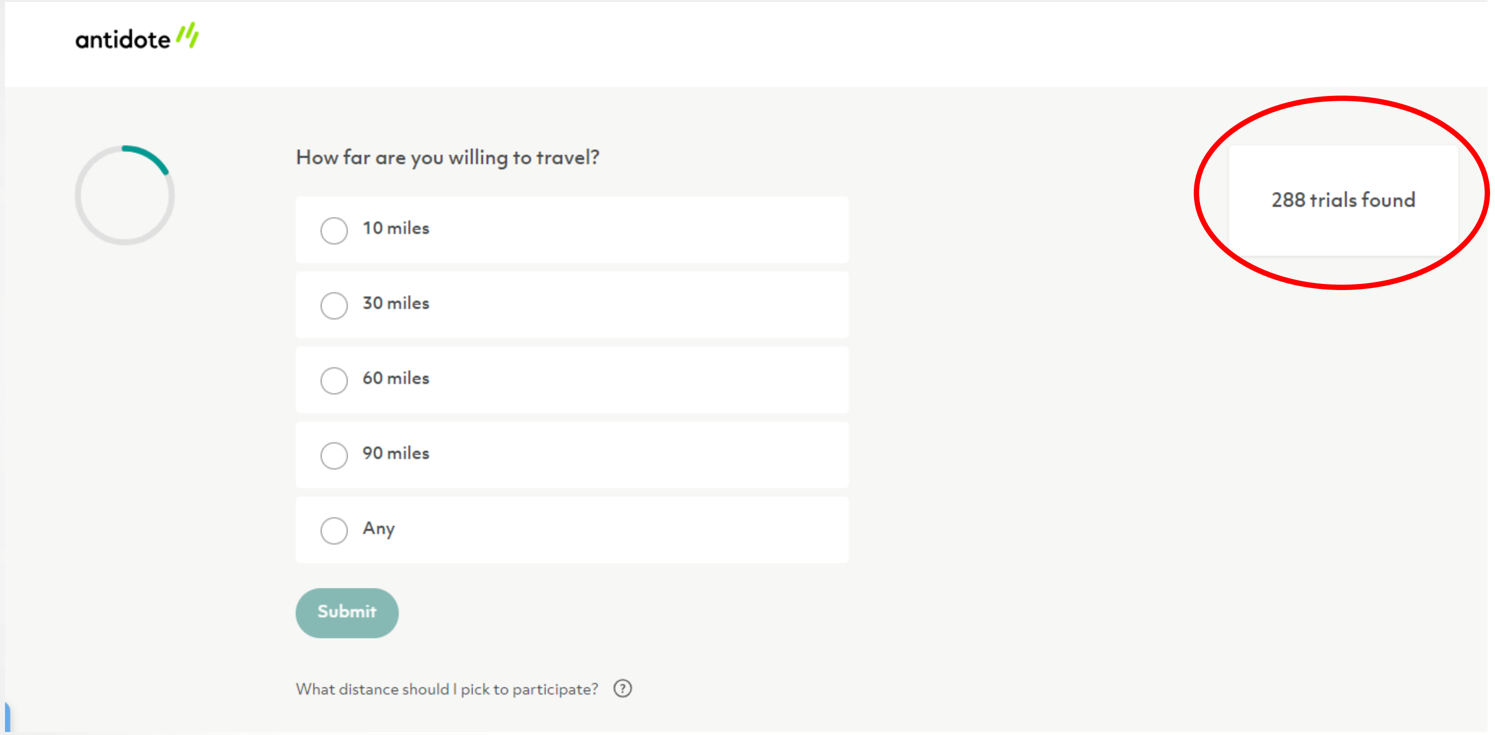

antidote

How far are you willing to travel?

○ 10 miles

○ 30 miles

○ 60 miles

○ 90 miles

○ Any

What distance should I pick to participate?

288 trials found

- Select the distance you are willing to travel to a trial site
- Click submit

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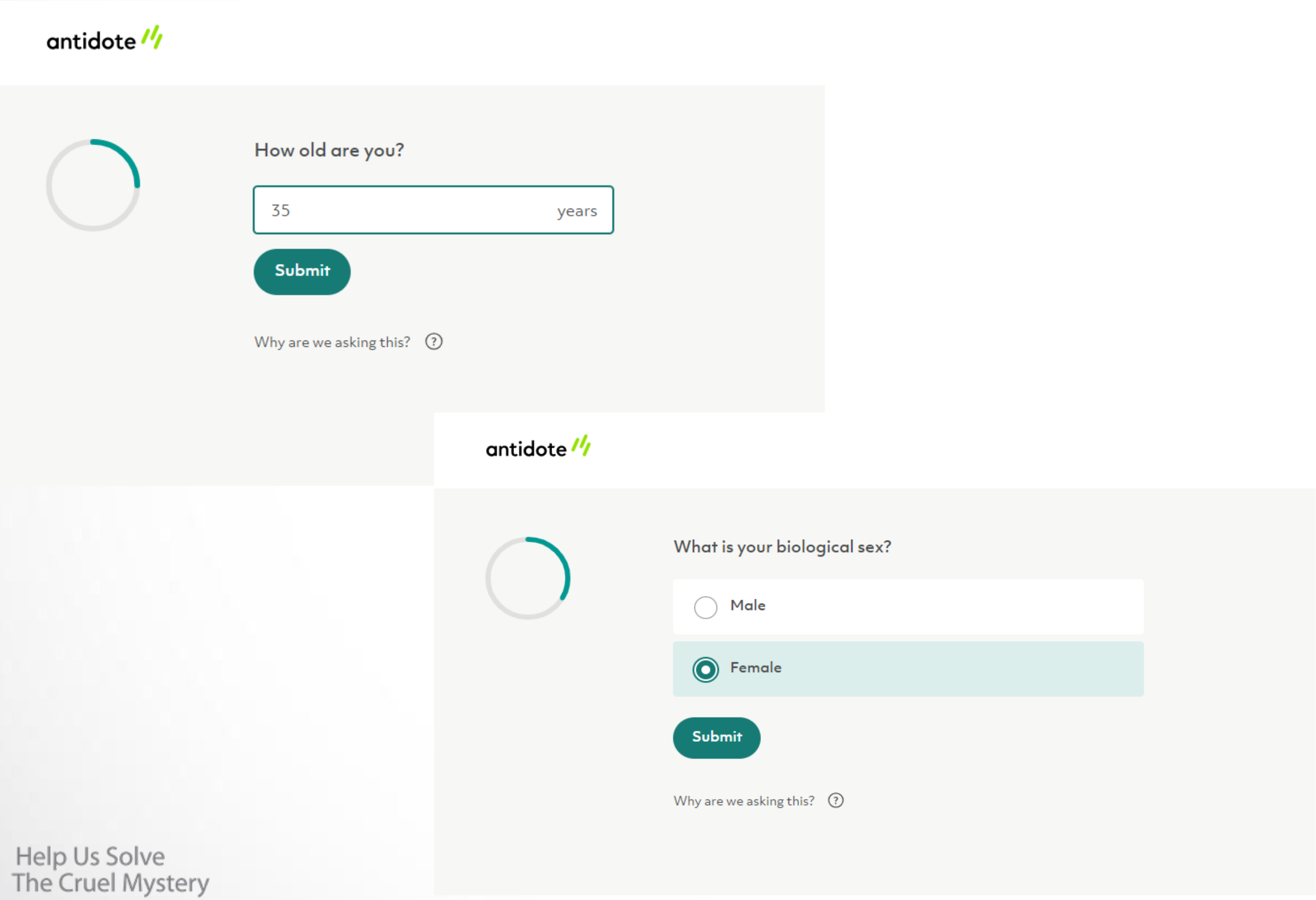

How old are you?

35 years

What is your biological sex?

○ Male

● Female

- Enter your demographic information on the next few pages (age, biological sex,

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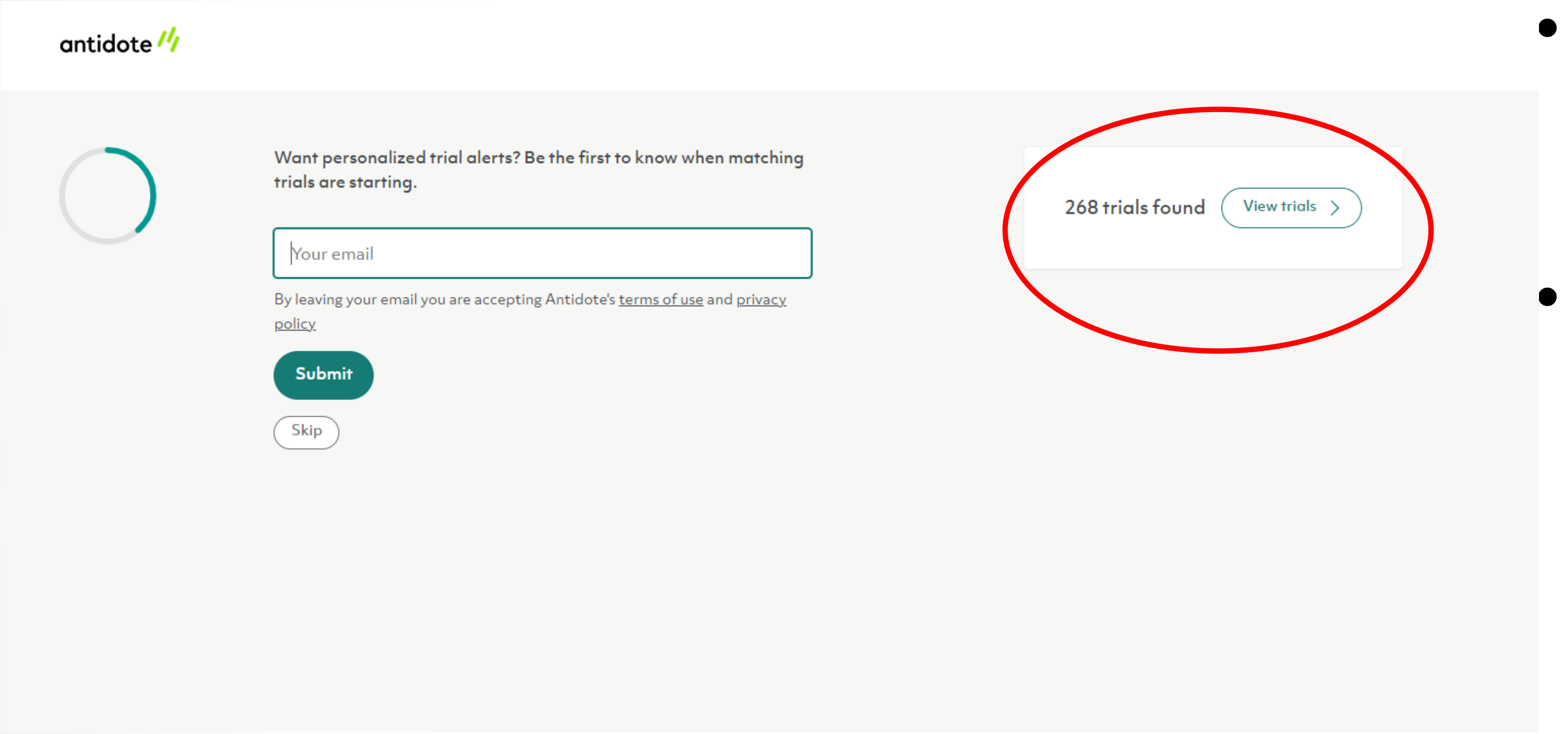

antidote

Want personalized trial alerts? Be the first to know when matching trials are starting.

Your email

By leaving your email you are accepting Antidote's terms of use and privacy policy

- You an enter your e-mail address to receive personalized trial alerts
- Click on View trials to see the trials in your area

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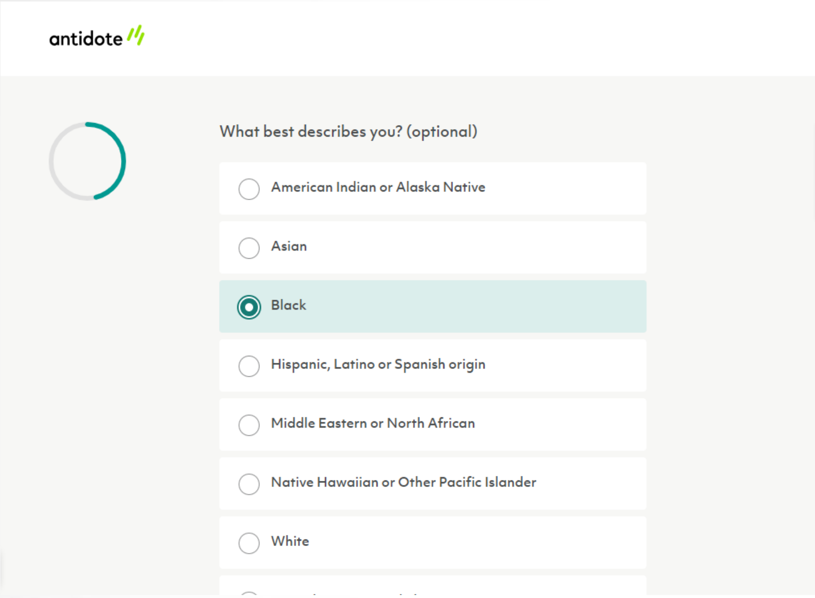
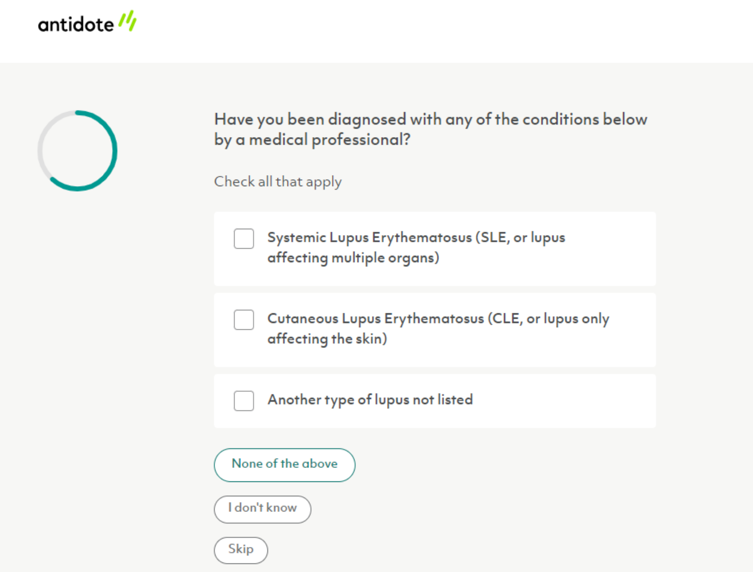
How to Use Antidote.me

- Continue to answer more questions for a more personalized list of trials



What best describes you? (optional)

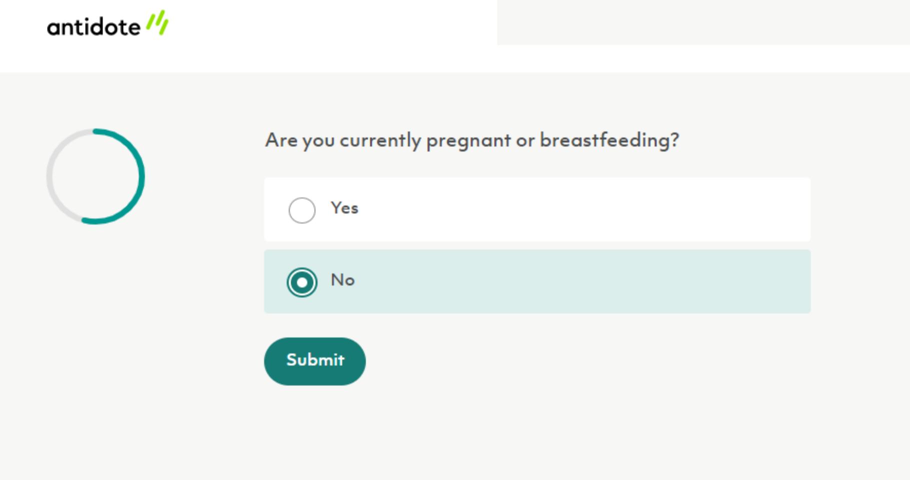
○ American Indian or Alaska Native
○ Asian
● Black
○ Hispanic, Latino or Spanish origin
○ Middle Eastern or North African
○ Native Hawaiian or Other Pacific Islander
○ White



Have you been diagnosed with any of the conditions below by a medical professional?

Check all that apply

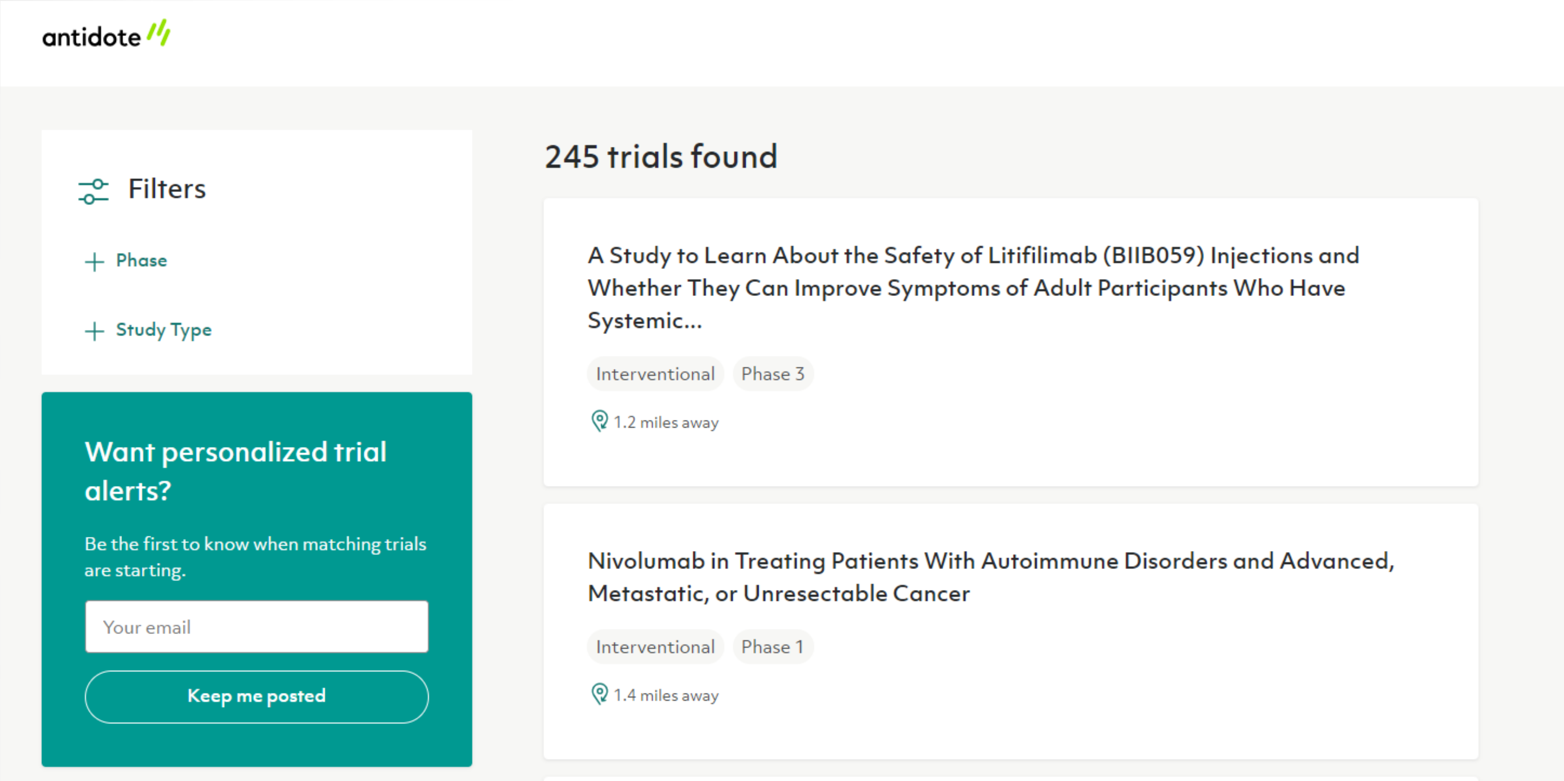
☐ Systemic Lupus Erythematosus (SLE, or lupus affecting multiple organs)
☐ Cutaneous Lupus Erythematosus (CLE, or lupus only affecting the skin)
☐ Another type of lupus not listed



Are you currently pregnant or breastfeeding?

○ Yes
● No

How to Use Antidote.me



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245 trials found

A Study to Learn About the Safety of Litifilimab (BIIB059) Injections and Whether They Can Improve Symptoms of Adult Participants Who Have Systemic...

Interventional Phase 3

1.2 miles away

Nivolumab in Treating Patients With Autoimmune Disorders and Advanced, Metastatic, or Unresectable Cancer

Interventional Phase 1

1.4 miles away

- Click on the trial you are interested in to see more information

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Understanding Eligibility Criteria

- Read through **inclusion** and **exclusion** criteria carefully
  - Age, Gender, Specific Lupus Diagnosis, and Prior Treatments
- Reach out to trial coordinators to ask questions

Talking to Your Doctor About Clinical Trials

- Discuss any trials that you are interested in participating in.
- Ask how the trial fits with your current treatment plan.
- Understand potential risks and benefits.
- Ask questions!

Informed Consent and Safety

- Know your **rights** as a participant (voluntary participation)
- Trials are regulated for safety, but some risks may exist

For More Information or Resources:
registrycoordinator@lupus.org

Any Questions?

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Time for Feedback

Complete the Feedback Survey

https://lupus.qualtrics.com/jfe/form/SV_0c92CwAEqBJWIfQ

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Thank You!