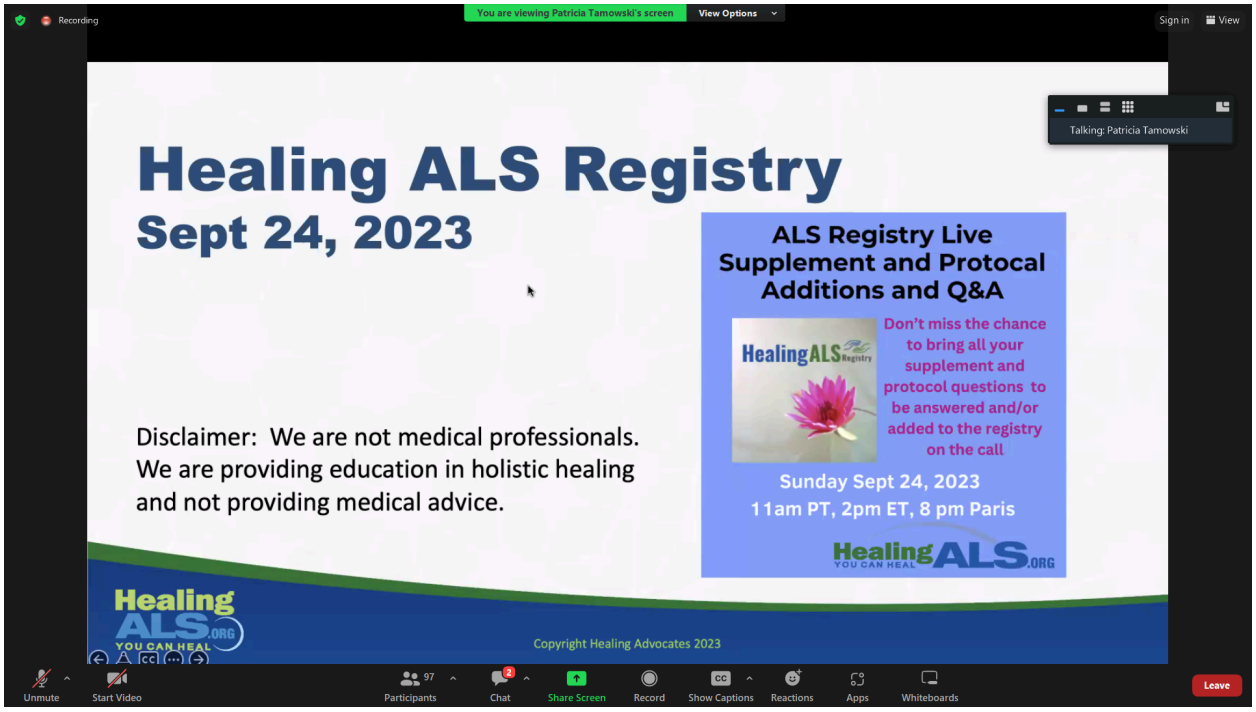
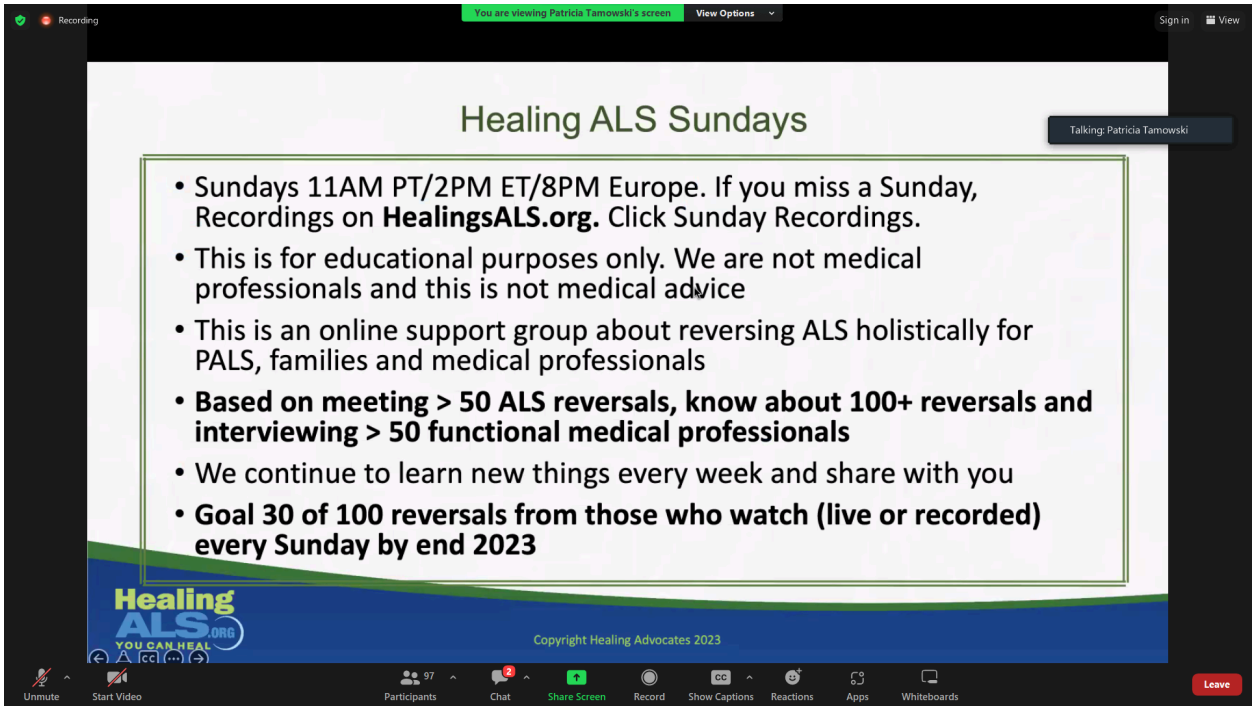
HealingALS.org Sunday Meeting Notes: Bring your questions about ALS Research, the ALS Registry, supplements and protocols
September 24, 2023

(I arrived late, so I missed the first 12 minutes or so of the meeting).

Freddy McClurkin was talking about flying his plane and what he has been doing to manage his ALS.

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Talking: Patricia Tamowski
Healing ALS Sundays
• Sundays 11AM PT/2PM ET/8PM Europe. If you miss a Sunday, Recordings on HealingsALS.org. Click Sunday Recordings.
• This is for educational purposes only. We are not medical professionals and this is not medical advice
• This is an online support group about reversing ALS holistically for PALS, families and medical professionals
• Based on meeting > 50 ALS reversals, know about 100+ reversals and interviewing > 50 functional medical professionals
• We continue to learn new things every week and share with you
• Goal 30 of 100 reversals from those who watch (live or recorded) every Sunday by end 2023
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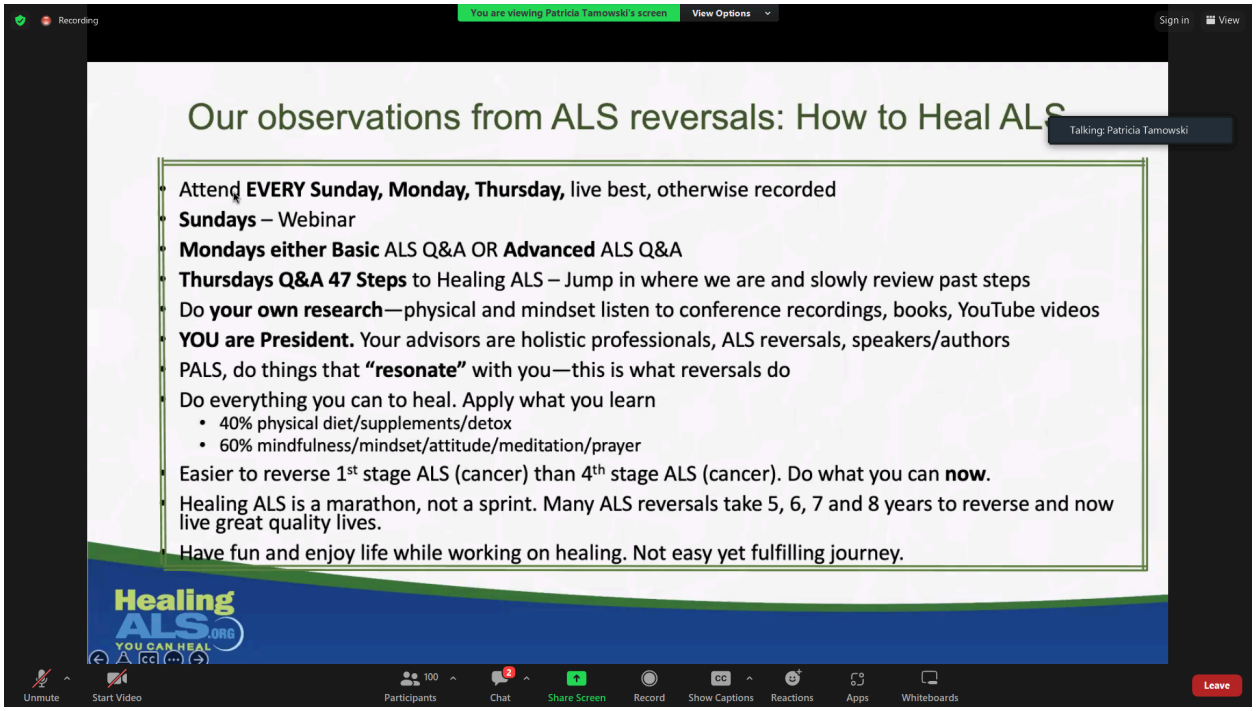
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Our observations from ALS reversals: How to Heal ALS
• Attend EVERY Sunday, Monday, Thursday, live best, otherwise recorded
• Sundays – Webinar
• Mondays either Basic ALS Q&A OR Advanced ALS Q&A
• Thursdays Q&A 47 Steps to Healing ALS – Jump in where we are and slowly review past steps
• Do your own research—physical and mindset listen to conference recordings, books, YouTube videos
• YOU are President. Your advisors are holistic professionals, ALS reversals, speakers/authors
• PALS, do things that "resonate" with you—this is what reversals do
• Do everything you can to heal. Apply what you learn
  • 40% physical diet/supplements/detox
  • 60% mindfulness/mindset/attitude/meditation/prayer
• Easier to reverse 1st stage ALS (cancer) than 4th stage ALS (cancer). Do what you can now.
• Healing ALS is a marathon, not a sprint. Many ALS reversals take 5, 6, 7 and 8 years to reverse and now live great quality lives.
• Have fun and enjoy life while working on healing. Not easy yet fulfilling journey.
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If you are new to HealingALS.org
Talking: Patricia Tamowski
1. Click Start Here on HealingALS.org!!!
2. Come Sundays, Mondays (basic ALS Q&A), & Thursdays
3. Overwhelm is normal at first. Baby steps.
HealingALS.ORG
YOU CAN HEAL
Sun June 11 Dr. Lee Cowden MD, ALS: Excess Saliva and Mucus Click HERE to register.
HOME OUR TEAM ALS REVERSALS EVENTS 47 STEPS ALS REGISTRY PRODUCTS RECORDINGS LOGIN DONATE
YOU CAN HEAL!
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FREE Course
47 Steps to Healing ALS
If you missed so far jump in where we are and catch up at your own pace.
HealingALS.org
Talking: Patricia Tamowski
47 Steps to Healing ALS
Based on dozens of ALS Reversals. We put together what they did in steps. Most steps will take a week, others longer. Goal: Do 47 steps in a year and finish incomplete steps in the second year.
Course Introduction:
47 STEPS TO HEALING ALS
Step 1: ALS Reversals Are Real
Step 2: ALS Reversal Science
Step 3: Your Team & Sunday Webinars
Step 4: ALS Registry
Sign Up Now!
Step 5: Clean Home
Step 6: Clean Air
Step 7: Clean Water
Step 8: Clean Mouth Dental Amalgams
Step 9: ALS Reversals, Clean Mind:
Step 10: Clean Food Part 1
Step 11: Clean Food Part 2
Step 12: Clean Electricity /EMFs
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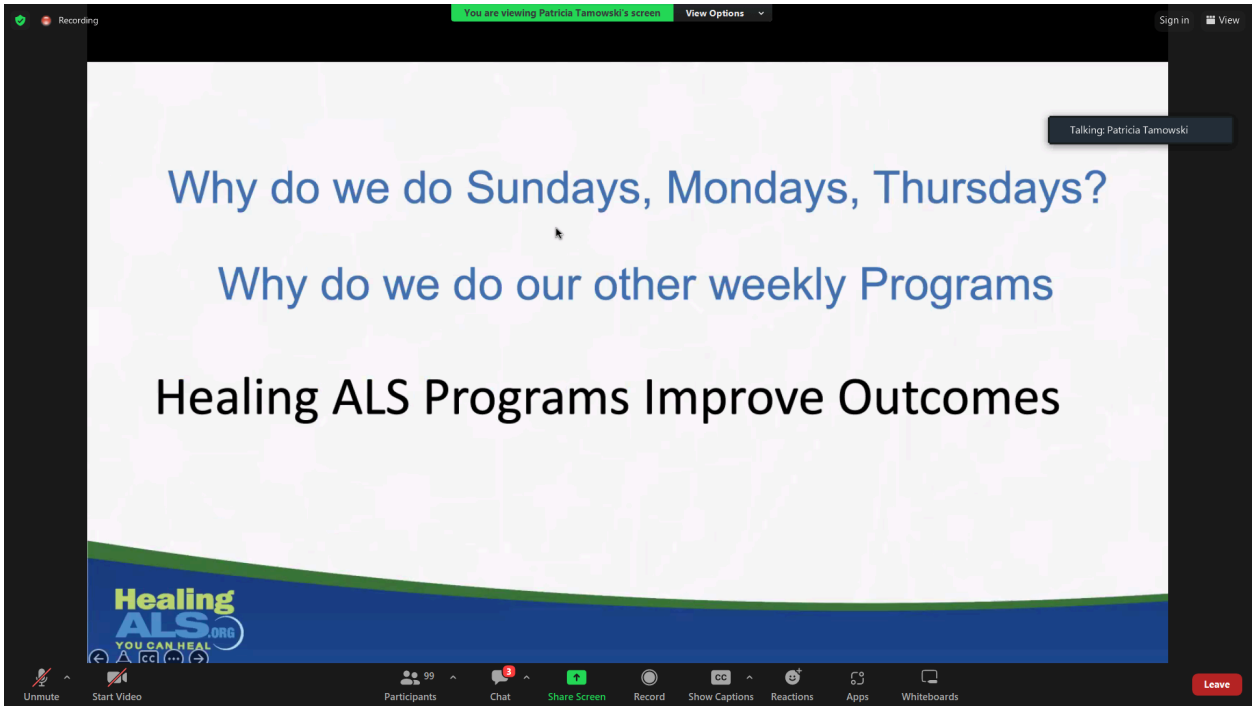
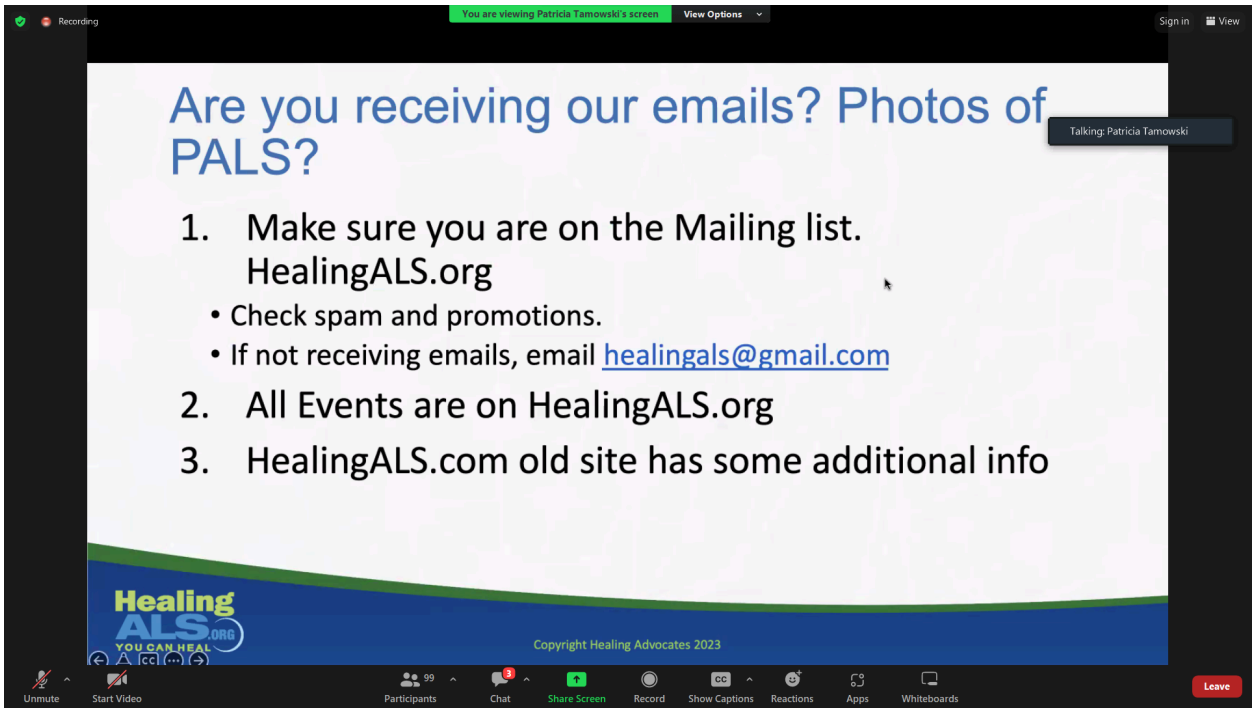
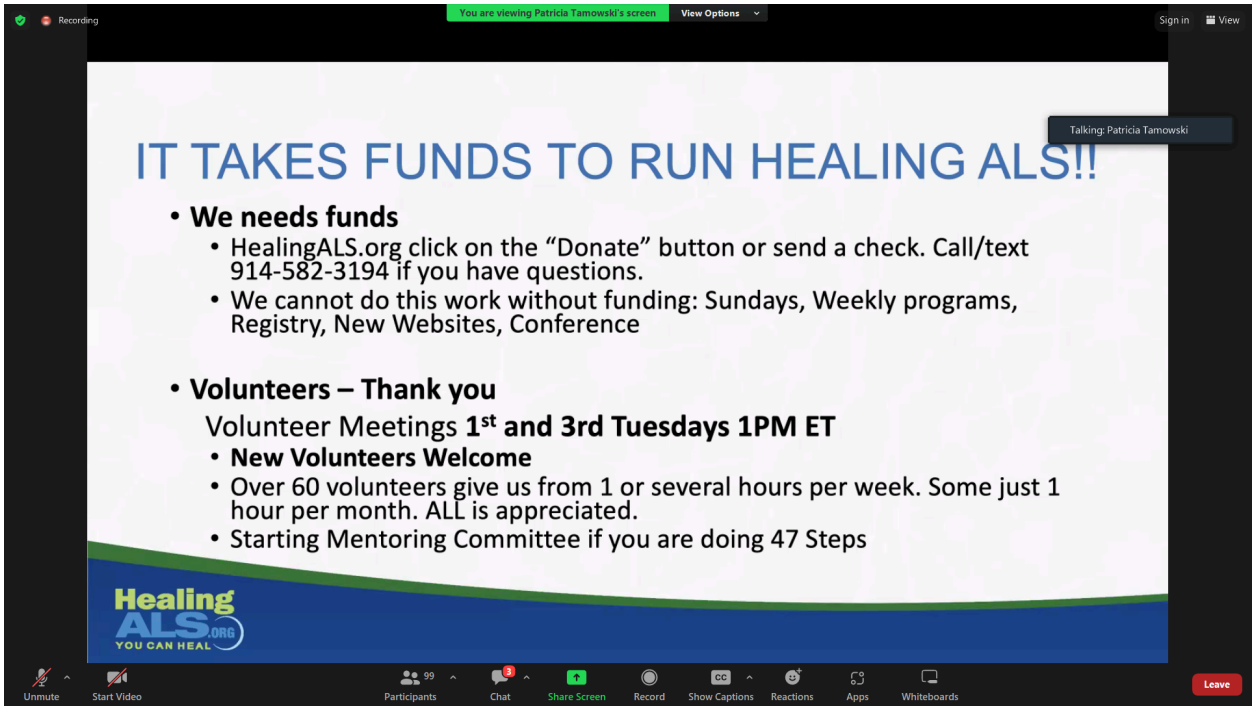


(missed slide)

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IT TAKES FUNDS TO RUN HEALING ALS!!
We needs funds
HealingALS.org click on the "Donate" button or send a check. Call/text 914-582-3194 if you have questions.
We cannot do this work without funding: Sundays, Weekly programs, Registry, New Websites, Conference
Volunteers – Thank you
Volunteer Meetings 1st and 3rd Tuesdays 1PM ET
New Volunteers Welcome
Over 60 volunteers give us from 1 or several hours per week. Some just 1 hour per month. ALL is appreciated.
Starting Mentoring Committee if you are doing 47 Steps
Healing ALS.ORG YOU CAN HEAL
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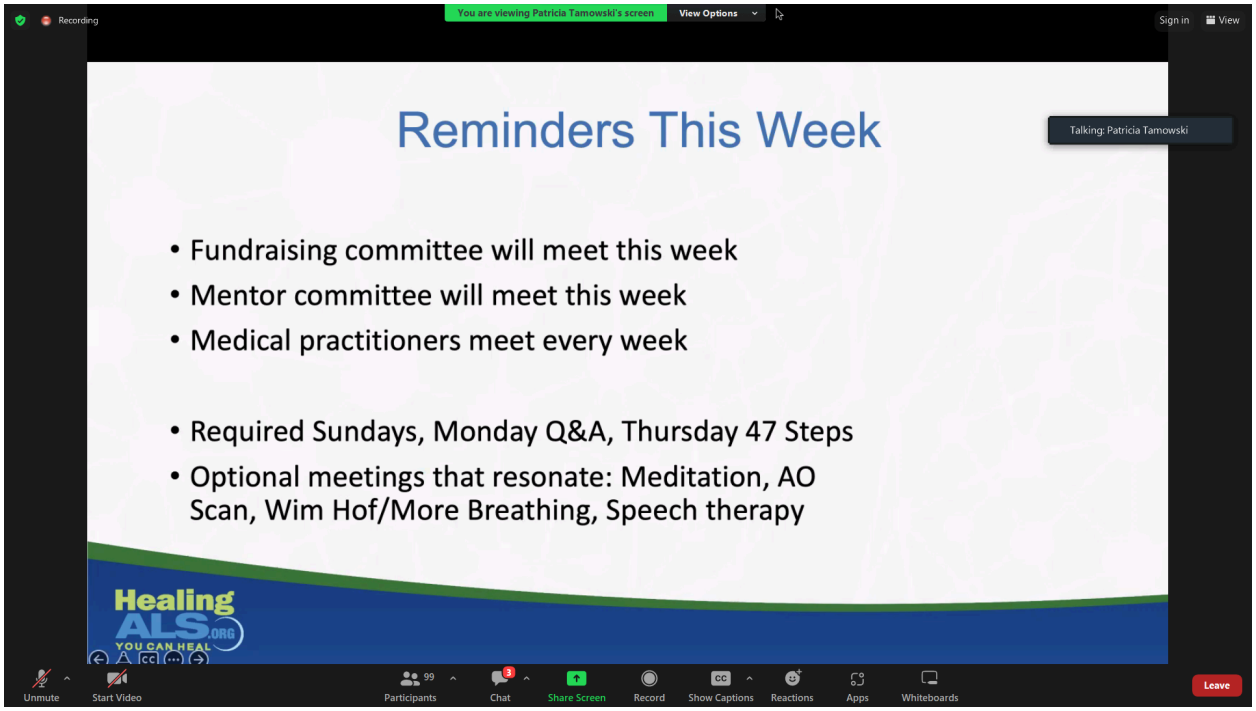
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Reminders This Week
Fundraising committee will meet this week
Mentor committee will meet this week
Medical practitioners meet every week
Required Sundays, Monday Q&A, Thursday 47 Steps
Optional meetings that resonate: Meditation, AO Scan, Wim Hof/More Breathing, Speech therapy
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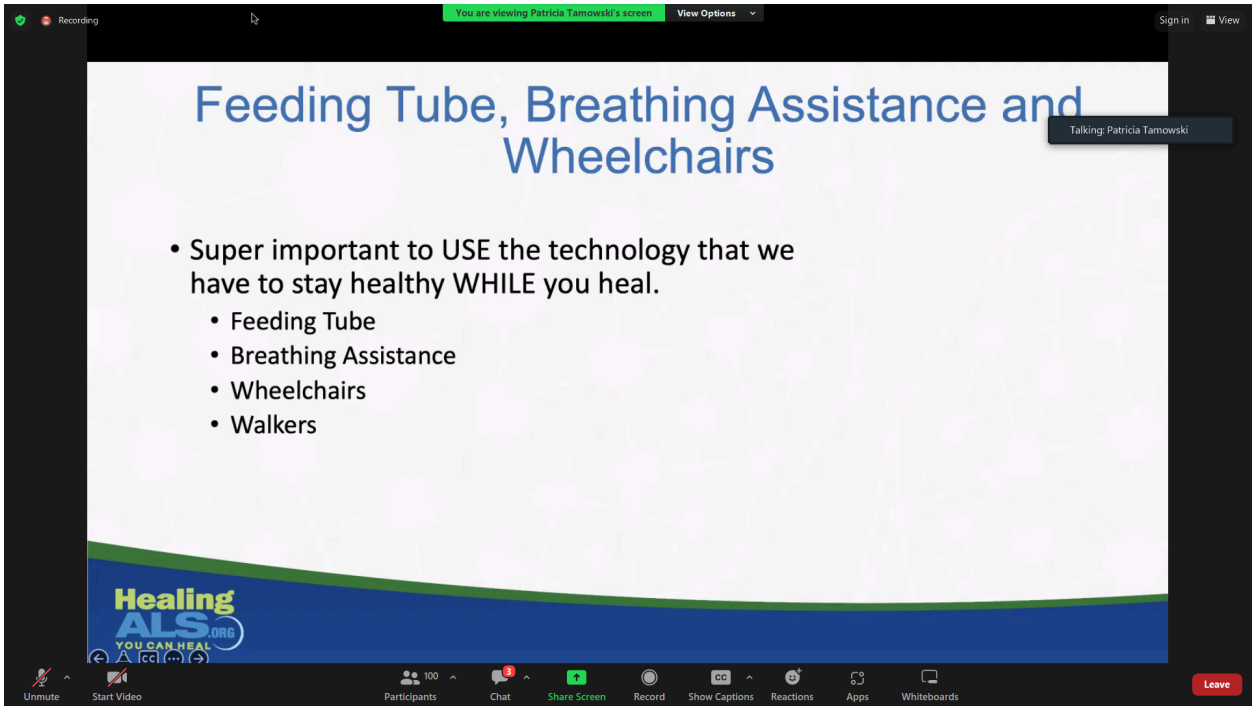
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Feeding Tube, Breathing Assistance and Wheelchairs
• Super important to USE the technology that we have to stay healthy WHILE you heal.
• Feeding Tube
• Breathing Assistance
• Wheelchairs
• Walkers
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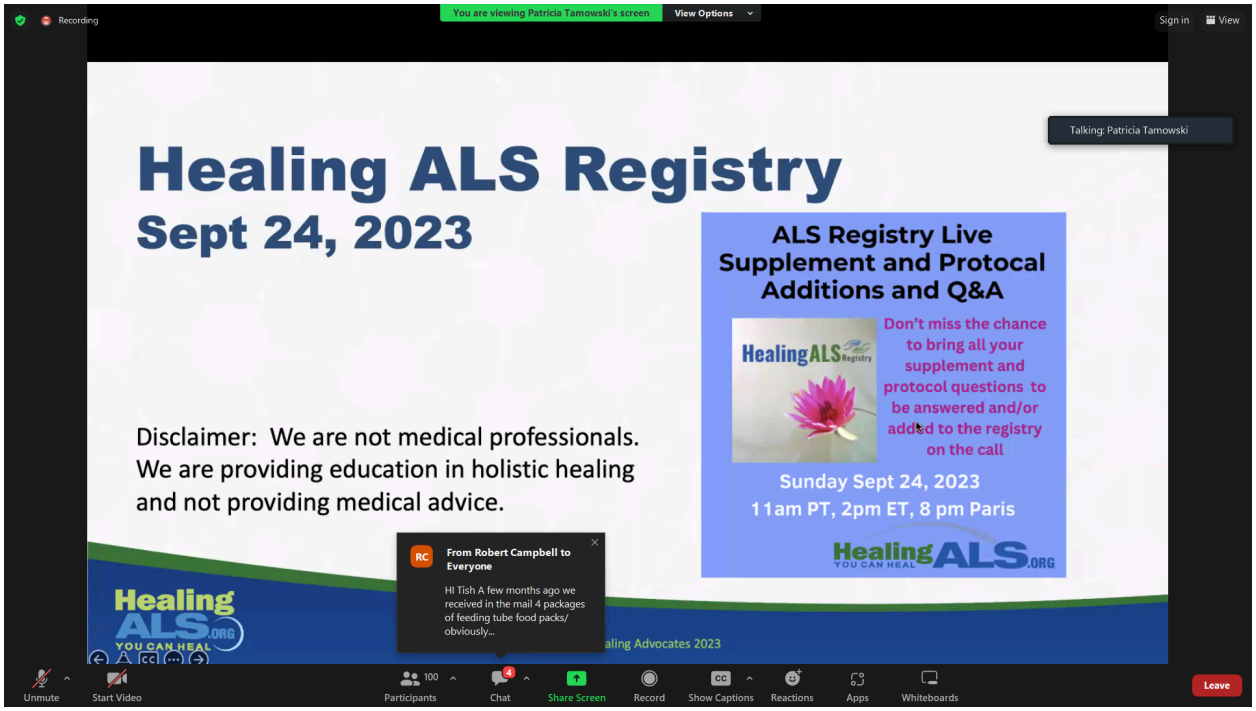
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Healing ALS Registry
Sept 24, 2023
ALS Registry Live Supplement and Protocal Additions and Q&A
HealingALS Registry
Don't miss the chance to bring all your supplement and protocol questions to be answered and/or added to the registry on the call
Sunday Sept 24, 2023
11am PT, 2pm ET, 8 pm Paris
HealingALS.ORG YOU CAN HEAL
Disclaimer: We are not medical professionals. We are providing education in holistic healing and not providing medical advice.
From Robert Campbell to Everyone
HI Tish A few months ago we received in the mail 4 packages of feeding tube food packs/ obviously...
aling Advocates 2023
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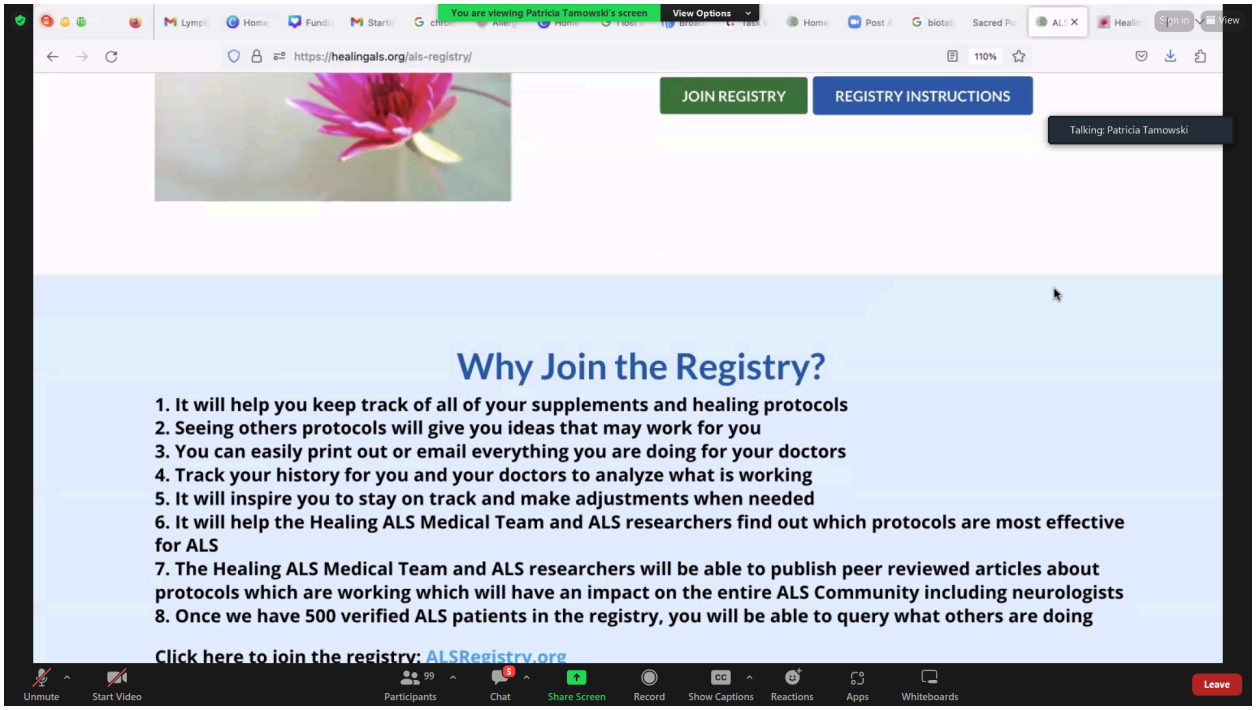
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https://healingals.org/als-registry/
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JOIN REGISTRY
REGISTRY INSTRUCTIONS
Talking: Patricia Tamowski
Why Join the Registry?
1. It will help you keep track of all of your supplements and healing protocols
2. Seeing others protocols will give you ideas that may work for you
3. You can easily print out or email everything you are doing for your doctors
4. Track your history for you and your doctors to analyze what is working
5. It will inspire you to stay on track and make adjustments when needed
6. It will help the Healing ALS Medical Team and ALS researchers find out which protocols are most effective for ALS
7. The Healing ALS Medical Team and ALS researchers will be able to publish peer reviewed articles about protocols which are working which will have an impact on the entire ALS Community including neurologists
8. Once we have 500 verified ALS patients in the registry, you will be able to query what others are doing
Click here to join the registry: ALSRegistry.org
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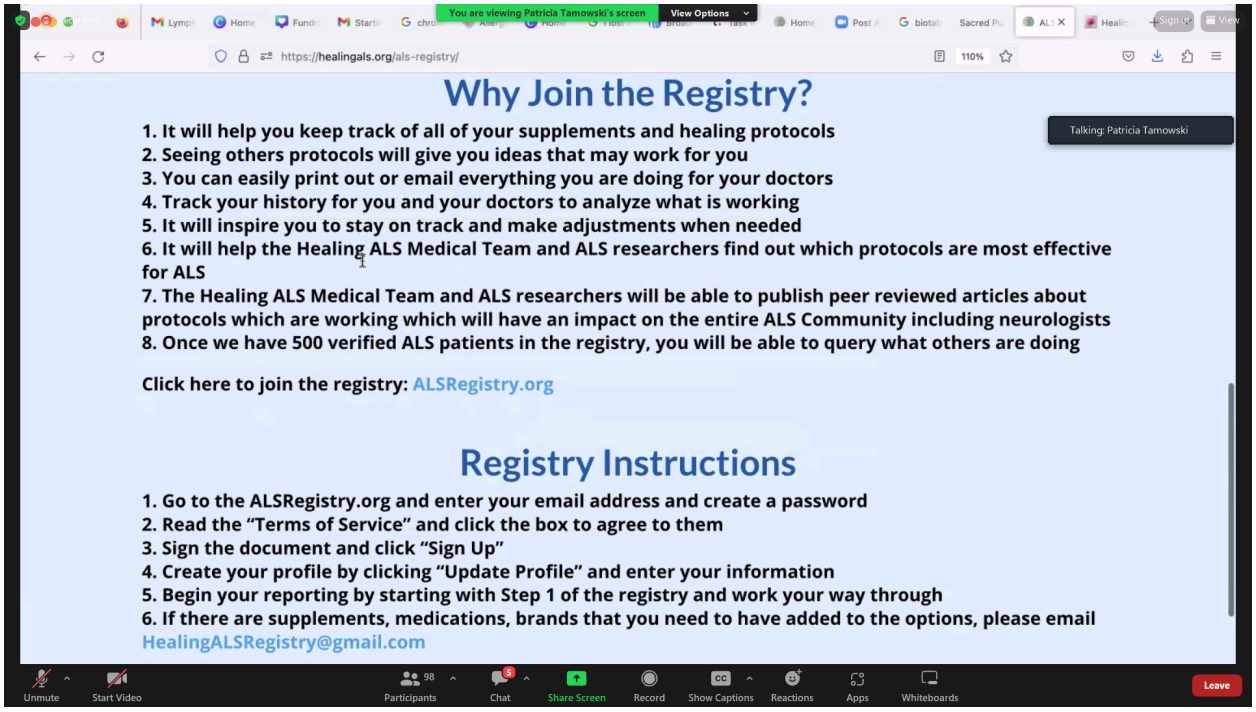
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8. Once we have 500 verified ALS patients in the registry, you will be able to query what others are doing
Click here to join the registry: ALSRegistry.org
Registry Instructions
1. Go to the ALSRegistry.org and enter your email address and create a password
2. Read the "Terms of Service" and click the box to agree to them
3. Sign the document and click "Sign Up"
4. Create your profile by clicking "Update Profile" and enter your information
5. Begin your reporting by starting with Step 1 of the registry and work your way through
6. If there are supplements, medications, brands that you need to have added to the options, please email HealingALSRegistry@gmail.com
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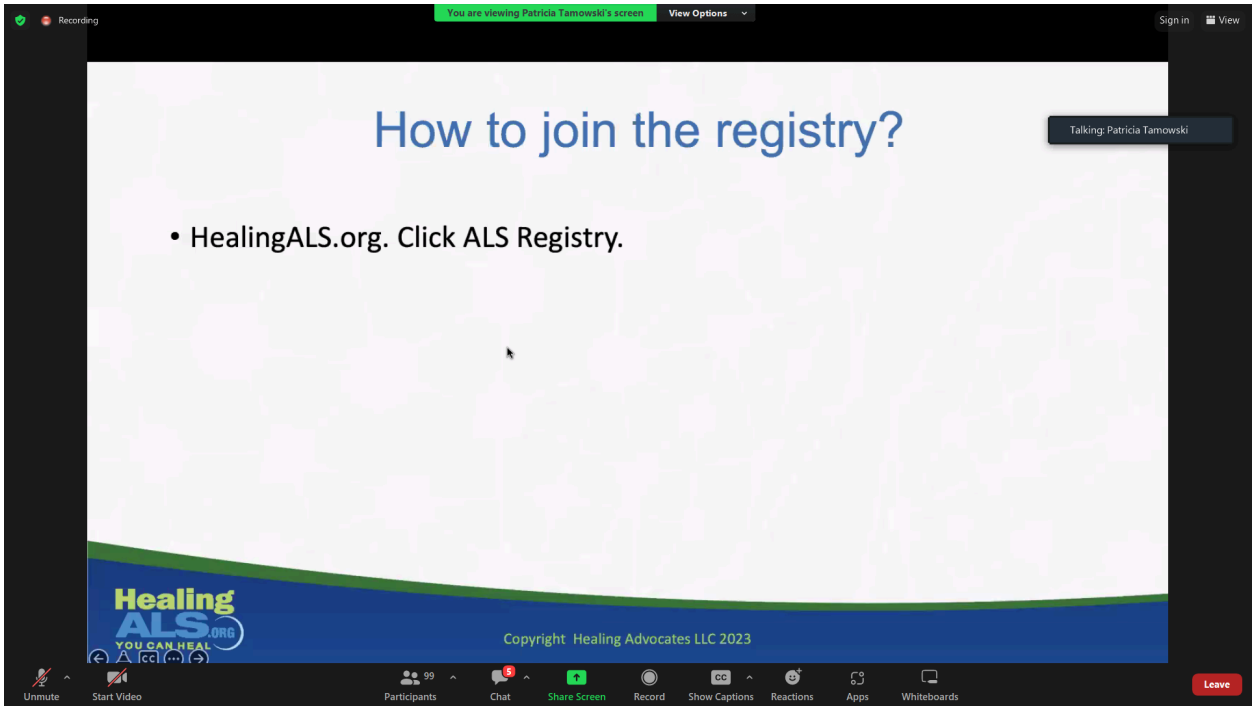
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How to join the registry?
Talking: Patricia Tamowski
• HealingALS.org. Click ALS Registry.
Healing ALS.ORG YOU CAN HEAL
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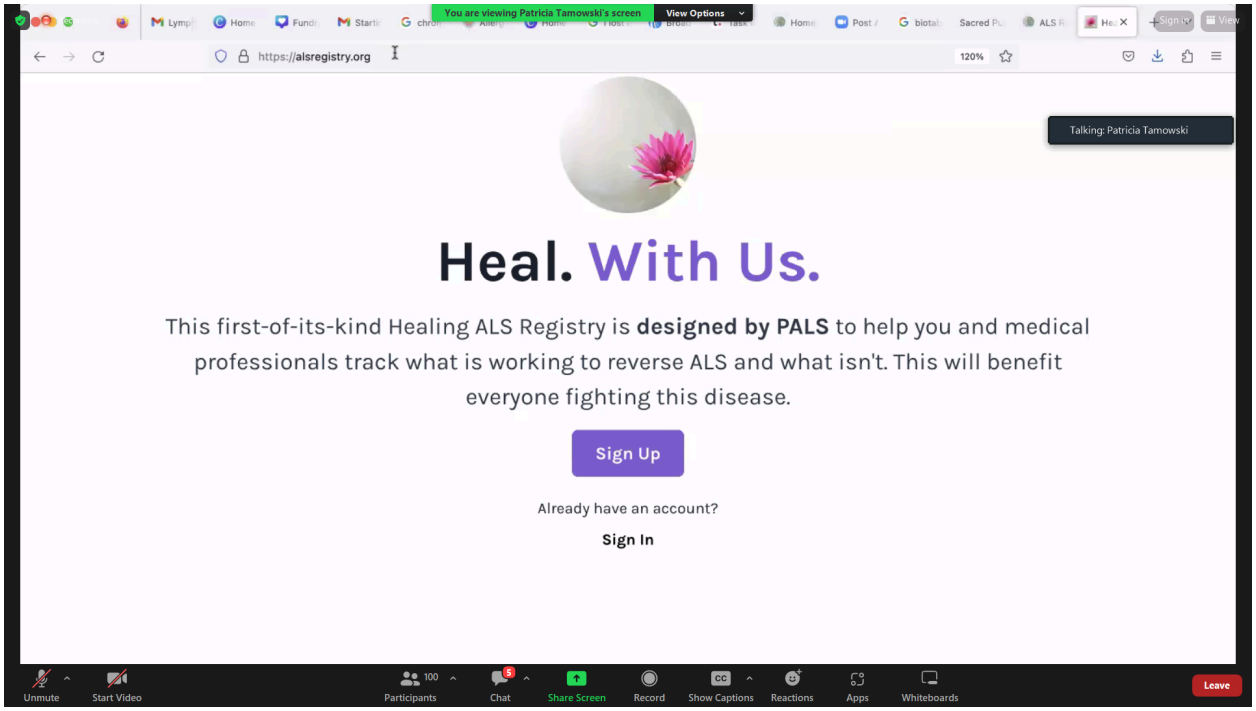
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https://alsregistry.org
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Talking: Patricia Tamowski
Heal. With Us.
This first-of-its-kind Healing ALS Registry is designed by PALS to help you and medical professionals track what is working to reverse ALS and what isn't. This will benefit everyone fighting this disease.
Sign Up
Already have an account?
Sign In
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Where we are in the registry?
Talking: Patricia Tamowski
• Over 650 PALS and CALS have joined
• Over 500 PALS have joined
• Over 100 PALS are putting their information in each month
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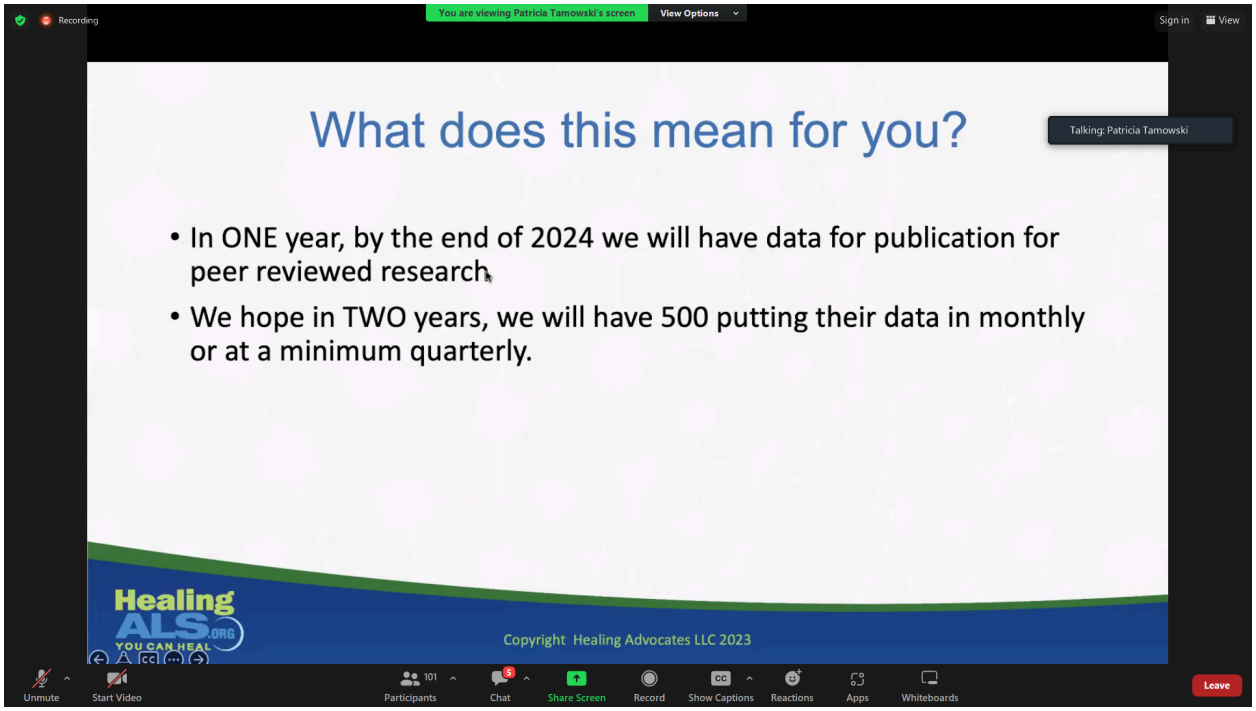
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What does this mean for you?
Talking: Patricia Tamowski
• In ONE year, by the end of 2024 we will have data for publication for peer reviewed research
• We hope in TWO years, we will have 500 putting their data in monthly or at a minimum quarterly.
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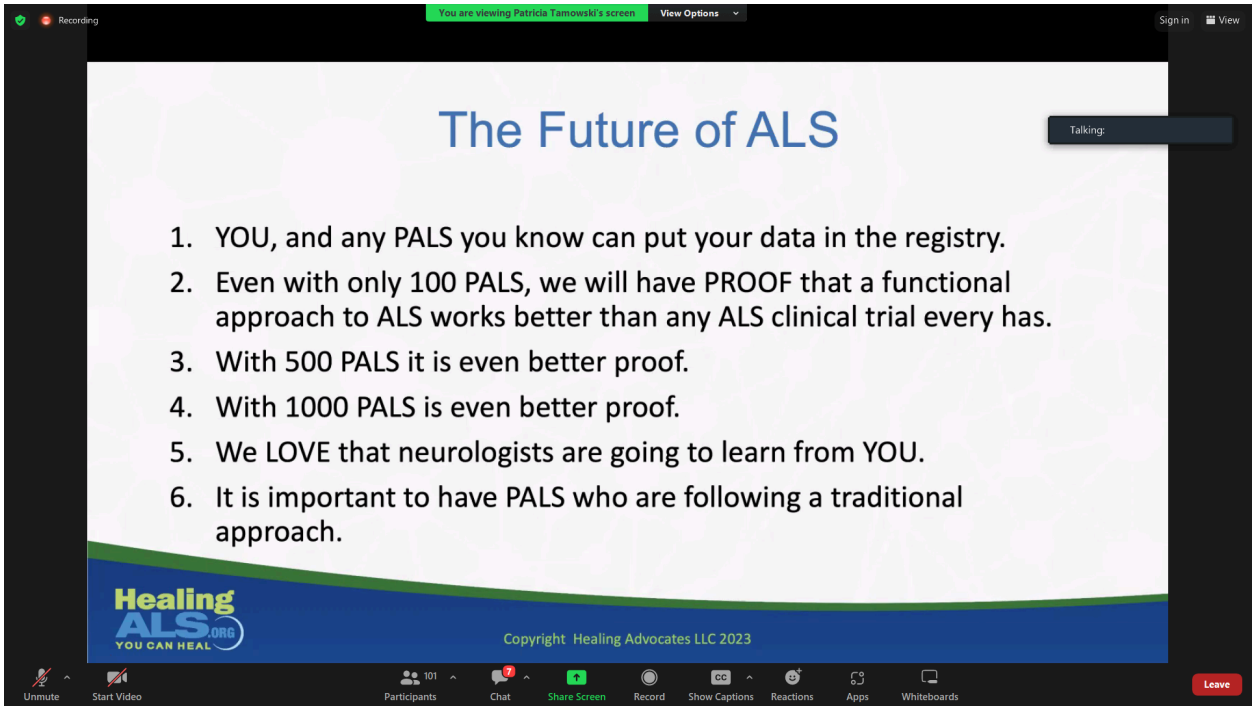


Q & A

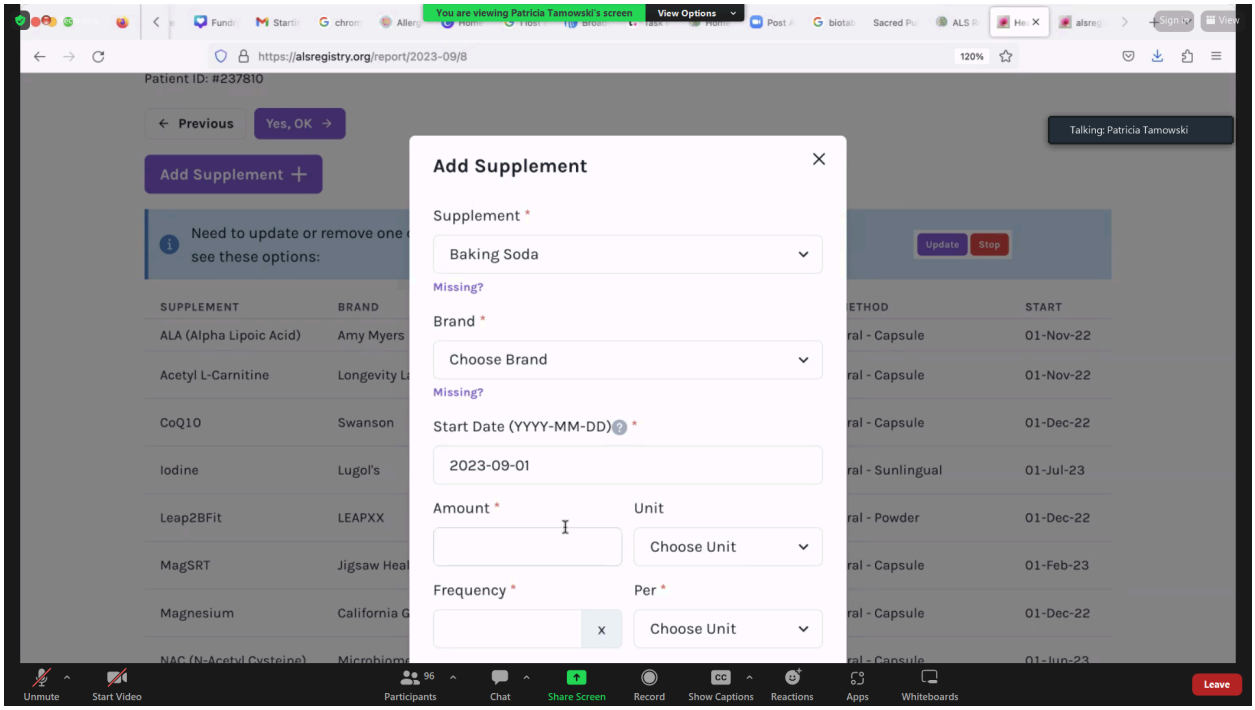
1. magnesium intake recommendation ,,and amount daily if taking 4-5 types , what is the best way to alternate them.? Bring that question into the meeting on Monday Q & A (with Dr Cowden?)

2. What does Freddie M. take? Once the Registry has the funds and we have the time, we can get protocols like Freddie's in the Registry. This has been a 10 year process for Freddie, and he's not done yet.

3. Is it feasible to advertise the Resistry so more pALS join? Yes, we can advertise in the newsletter, on Facebook and Instagram. pALS and cALS should share the Registry info with their friends on social media, too.

4. When should I enter my heart rate in the Registry? Anytime that is best for you

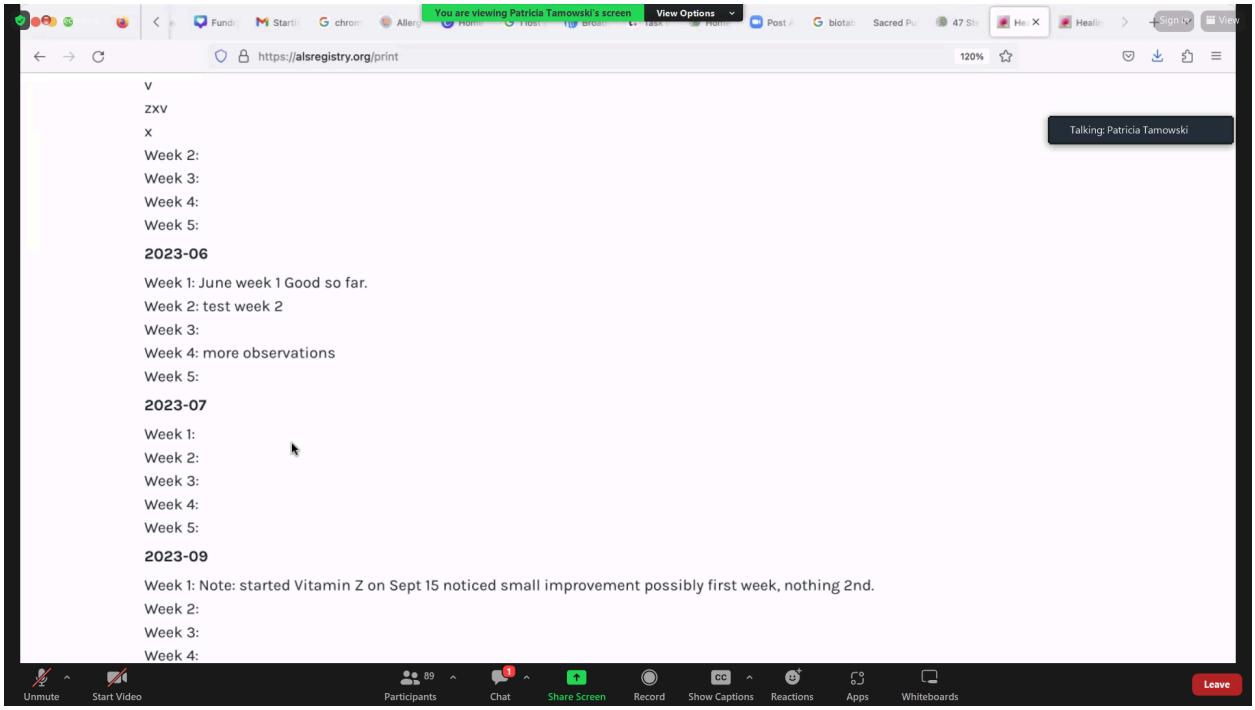
5. If you start a new med/supplement on the 15th of the month, but you don't enter it in the next month, will that mess up the data?



Enter the supplement start date on the first of the month after you started taking it. Eventually, we will be able to allow you to enter a date prior to the month you are on, but for now, go with the first of the month. (You can also make a note of things like this in the journal area where you describe what happened each week)

6. Is it ok to share your logo with others who might be interested in this group? Yes, as long as it is not attached to misinformation. Send an email to Healingals.org with your information and the purpose of your request.

7. A pALS did an SOT and found many benefits. Tish commented that we should be careful with SOT's because many (80%?) pALS have come back from an SOT and got worse. SOT's are #36 in the 47 Steps, so it may be that we need to do many other things first.



8. What about an MRI with contrast? Is it safe? Dr. Cowden recommends a functional MRI test rather than one with contrast. The functional one can provide more information, according to Dr. Cowden. Gadolinium contrast is contraindicated in ALS patients. It can take 6 months or more to get it out of your system.

9. Are there any bulbar onset pALS who lost their voice and got their voice back? Freddie McClurkin, Dr. Joyce, Kim Cherry, and more.

10. Can we use the Hi-Tech machine or an ozone machine without a HERTSMI test? Heather prefers having the test results so you can compare before and after you start using the Hi-Tech.

11. When should one go on hospice? Hospice is for dying. They often give you morphine, but that suppresses your breathing and immune system. If you get hospice for caregiving and refuse the drugs, you may get kicked out of hospice if you don't die. The group can provide a letter for your medical care team so tha tthey know not to say anything to promote your death.

12. Has anyone used Lyme Stop for Lyme? Bring that question to the Monday Q & A but try to share the ingredients beforehand, because Dr. C may not be familiar with it.

Tish made three Breakout Rooms: Physical Protocols, Mental Protocols and the Registry.

The meeting ended at 12:44 pm PT. Scott gave his goodbyes.

Respectfully Submitted,

Jim Getka

Here's the full Chat Box thread:

Joseph Chavez 11:11 AM
magnesium intake recommendation ,,and amount daily if taking 4-5 types , what is the best way to alternate them.?

Carl D. Essen | STL~U.S. to Everyone 11:19 AM
Believe Freddie rides his bike like 50 miles a day now . ###

carole thomas to Everyone 11:20 AM
Could you type out what Freddy takes, please?

Carl D. Essen | STL~U.S. to Everyone 11:22 AM
I am in STL and Freddie is in MCI or JM , you have to get info from him , understand he follows a program every day . ###

Robert Campbell to Everyone 11:27 AM
HI Tish A few months ago we received in the mail 4 packages of feeding tube food packs/ obviously sent to us by mistake for somebody named Scott Davidson? What to do with it? We don't need it plus it has a limited shelf life....

Freddie McClurkin to Everyone 11:27 AM
This has been a 10 year process for me and I still have a long way to go. I am very thankful. We can all do it!!!

Colleen Corbett to Everyone 11:45 AM
Thanks for sharing Freddie. We appreciate your hard work and willingness to share.

Marian Earnest to Everyone 11:47 AM
Trish, is it possible to advertise for PALS to join the Registry?

Jim McDonald to Everyone 11:48 AM
I have a question on the registry, specifically, when should we be reporting our heart rate, O2 saturation, blood pressure? I usually take mine at the end of my morning meditation.

Cony Rodriguez to Everyone 11:49 AM
With energy testing supplements might change in the current month
How do you register that

Derek Roberts to Everyone 11:52 AM
I have been taking Relyvrio for 5 months but can't bear the taste. Does anybody take sodium butyrate and Tudca instead of the Relyvrio?

(Note)
Most PALS separately take the Tudca and Sodium Phenylbutyrate without the side effects and stomach pains they get from Relyvrio.

(Hi Risk)
Relyvrio - Side Effects, Interactions, Uses, Dosage, Warnings

kathleen crosby to Everyone 11:53 AM
There is no option in the sleep question that matches Mike. he sleeps 11 or 12 hours no naps

marion to Everyone 11:56 AM
Just a quick question my number has stayed the same is that good or bad
On the registry

Sarojini Bose to Everyone 11:45 AM
My lungs are getting better

Lisa Bean 11:57 AM
That's awesome! 👏🏽. Do you attribute this improvement to anything in particular?

Cynthia Baptiste to Everyone 11:58 AM
Is it okay if I can figure out how to copy your logo, print it with your info (website) and give it to interested people at the support group of PALS??

Sarojini Bose to Everyone 11:59 AM

My diarrhea stopped with akkermansia.
I sleep better
I need to work on mucus

Dusty Lavalley to Everyone 11:59 AM
For the first time ever I took a supplement and I saw improvement to gate speech and function. It is advertised as a joint and muscle supplement to help with arthritis and pain. Any idea why it is helping me? It is however slowing my bowel and disrupting my sleep.

Effective natural anti-inflammatory com-pounds.
• Lubricates Joints, Tendons, Ligaments and Muscles.
• Immune system modulator designed to be effective against Autoimmune disorders such as Rheumatoid Arthritis.
Relieves Fibromyalgia

Main Ingredients: _Aloe Powder, Ukpa, Bos-wellia, Una de Gato, Devils Claw Roots, Anyunsin Bark, Guaicum Resin Powder, Moringa Oleifera Wild Lettuce

Robert Campbell to Everyone 11:56 AM
My GI doc recommended the low FODMAP diet for me. Still in the first stage and it has already helped. IS anyone else out there doing low Fodmap and what are your thoughts on its usefulness safety for PALS

Mireia Marcos Marcos 11:59 AM
Hi Robert I did a low FODMAP diet a year ago for a month, then I went to paleo and later keto. I felt it was ok to do it, and I felt more energy afterwards

Elizabeth Pacheco to Everyone 11:59 AM
I meant for mold testing.

Brandon Lloyd to Everyone 12:00 PM
comment - science is benefited by consistency. ideal to measure bp, heart rate , etc. near the same time of day, or after 5 min rest.

Gabriel Tapia to Everyone 12:04 PM
I've been out of touch for a while but want to plug back in. I've been treating Lyme since February and just did my 4th treatment of SOT and I actually feel some improvements. Gaining strength in my legs and breathing is a lot better. No more wheezing when I lay down for bedtime. I still take a series of supplements.

You to Everyone 12:04 PM
Regarding entering a new supplement or change from the prior month, You can also make a note of things like this in the journal area where you describe what happened each week. At least, then, it is recorded there.

carole thomas to Everyone 12:07 PM
I cannot get into the registry. I did sign in and complete the initial month and I believe one other month. Since then, I cannot get into the site. I thought I would reregister and my email address is already in the database and I am told I cannot register. Change my password. When I try to change the password, I do, but then it will not work.

Elizabeth Pacheco to Everyone 11:53 AM
Ready to start cleaning my home from toxins. What is the name of the company to send it to?

Heather Plude 12:09 PM
heatherplude@gmail.com

Patricia Tamowski to Everyone 12:09 PM
HERTSMI cloth test. Mycometrics.com $150. 1 dry unscented Swiffer cloth. Take 8-10 samples, 1-2 samples in each
room (top of door frames, picture frames, places you never dust), put in a ziplock bag, mail in with a Chain of Custody document.

If positive NEVER do mold remediation, instead get a handyman to fix any active leaks and get a Hi-Tech machine. HealingALS.org/Products for 10%. Any questions email HeatherPlude@gmail.com.

Elizabeth Pacheco to Everyone 12:10 PM
Thank you Heather!

Cynthia Baptiste to Everyone 12:11 PM
BaptisteC@aol.com

Judah Sherwin to Everyone 11:57 AM
Does anyone know anything about contrast MRI's? The doctor has ordered an MRI with contrast dye. I have heard that some people report adverse effects from the dye but they can tell a lot more from the MRI with it. We are trying to decide whether to do it or not if anyone has any experience or other insight on this. Thank you

Derek Roberts 12:05 PM
Gadolinium is a common contrast used for MRI's. My wife had several of these in the past 2 years and recently tested for metal toxicity and was very high in gadolinium. She is now doing a detox protocol to get rid of it.

Katrin Kaalep 12:11 PM
I had 6 month lasting allergy reactions. Testing for heavy-metals shows high level in thallium. It takes a year to get it normal.

Monica Zhang to Everyone 12:11 PM
can we just use a Hi-Tech machine or ozone machine without taking a mold test?

Brandon Lloyd to Everyone 12:15 PM
Can't find the post re SOT treatment...Did you test positive for Lyme, and if so, what test did you use. great news you are gaining strength.

Colleen Corbett to Everyone 12:13 PM
Byron gained weight two weeks in a row. Even though I didn't think he was getting enough calories. Celebrating!

Lisa Bean 12:17 PM
@Colleen Corbett it sounds like Byron may actually be absorbing more of what he is consuming. Good for him!!!🎉🎉🎉

Gabriel Tapia to Everyone 12:17 PM
Ye

Susan DiLembo to Everyone 12:20 PM
What are SOT's

Margo Long to Everyone 12:25 PM
Do you know of anyone that has Bulbar ALS and has mostly lost their voice if they were later to eventually regain the ability to get some back?

carole thomas to Everyone 12:28 PM
Hurray. I got in… to the site…this was the first time I got another window in my email to change the password. Thank you. This has been a very long issue! Has been

Lisa DeLong to Everyone 12:28 PM
it will be a best seller Heather.....soon

Gabriel Tapia to Everyone 12:30 PM
Supportive Oligonucleotide Therapy

kathleen crosby to Everyone 12:31 PM
It takes a long time to add my supplements because they aren't on the list.. Can I fill out most of the registry and come back another day to add more?

Carl D. Essen | STL~U.S. to Everyone 12:31 PM
Arlene got her voice back , coming back as your natural voice before ALS . ###

Monica Zhang to Everyone 12:32 PM
What's your take on hospice?

Elliott & Marilyn Sheffield to Everyone 12:33 PM
Is it beneficial to do ozone saunas?

Carl D. Essen | STL~U.S. to Everyone 12:35 PM
On hospice in Medicare you do not get power chair bipartisan ect . ###

Monica Zhang to Everyone 12:35 PM
okay; good advice. Is that letter on healingals website?

Margo Long to Everyone 12:35 PM
Is the Positive Letter on the web site?

Carl D. Essen | STL~U.S. to Everyone 12:36 PM
We were on hospice for only 3 days and had to get off to go to ALS clinic
You have to order the power chair at team Gleason and the game is ALA association try to get their donating vendor to get you to get a power chair to keep team Gleason out of the loop . ###

marion to Everyone 12:38 PM
NASAL RINSE ON PHYSICAL STRATEGY

Carl D. Essen | STL~U.S. to Everyone 12:39 PM
ALA is ALS . ###

Cony Rodriguez to Everyone 12:39 PM

They don’t tell you your options when they are assessing your personal wheelchair. The person who took measures decided what to order
I knew after that standup was possible
And rear or center axle which affects how and where you can ride

Monica Zhang to Everyone 12:40 PM
I heard good and bad things about Lymestop
extremely expensive.

Carl D. Essen | STL~U.S. to Everyone 12:41 PM
Another power chair problem is they get you a chair that might not fit into your van . ###

Sue McCartan to Everyone 12:41 PM
TU God Bless to All!

Leena Sinha 12:42 PM
Thank you 🙏🏽