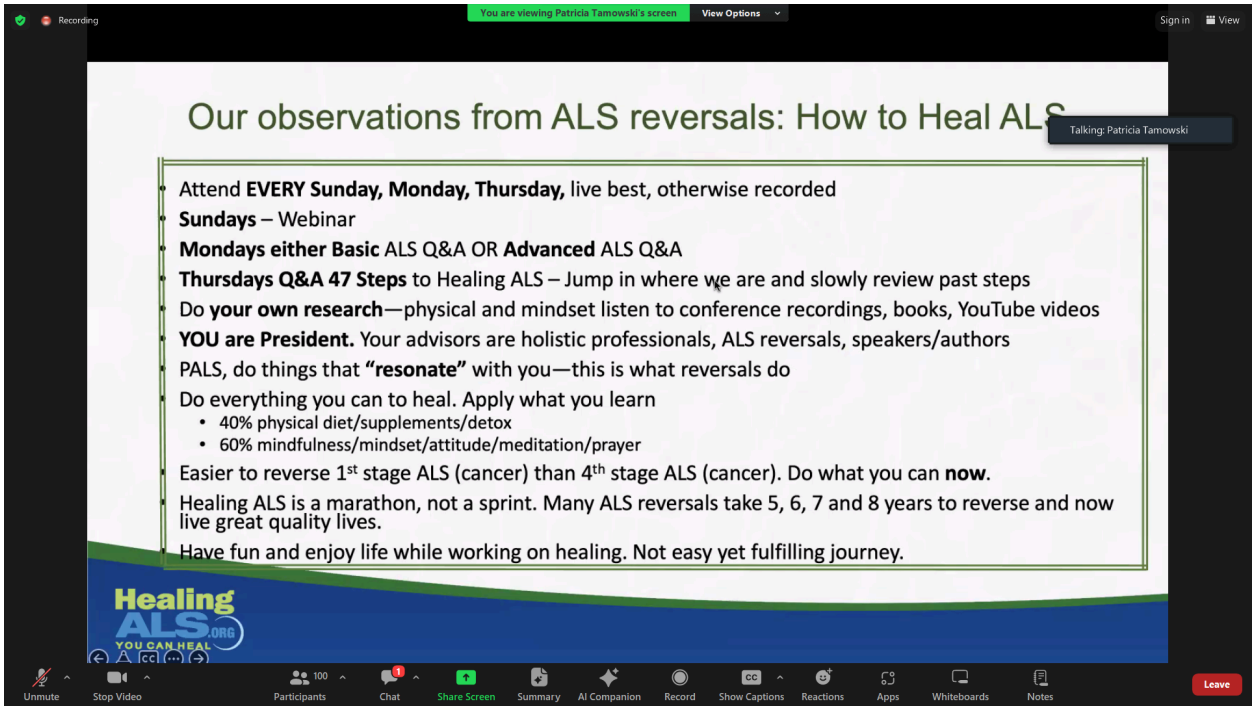
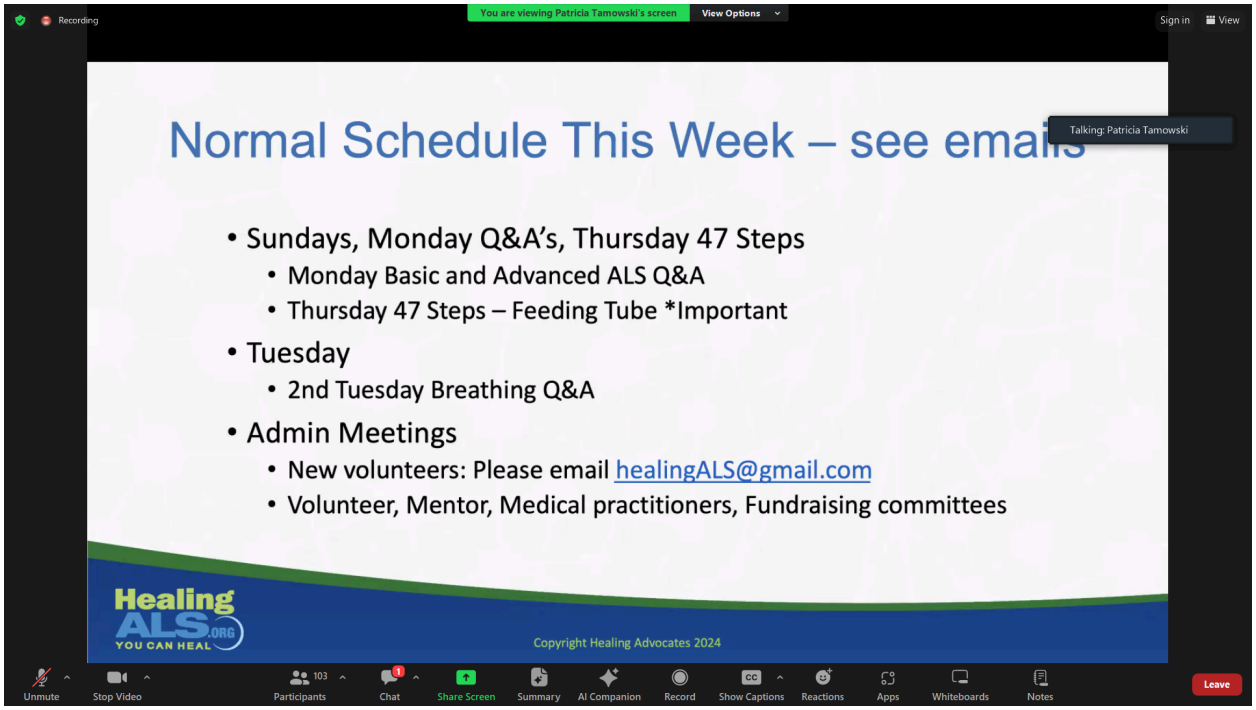
HealingALS.org Sunday Meeting Notes: How are your fellow Healing ALS PALS doing?
January 7, 2023

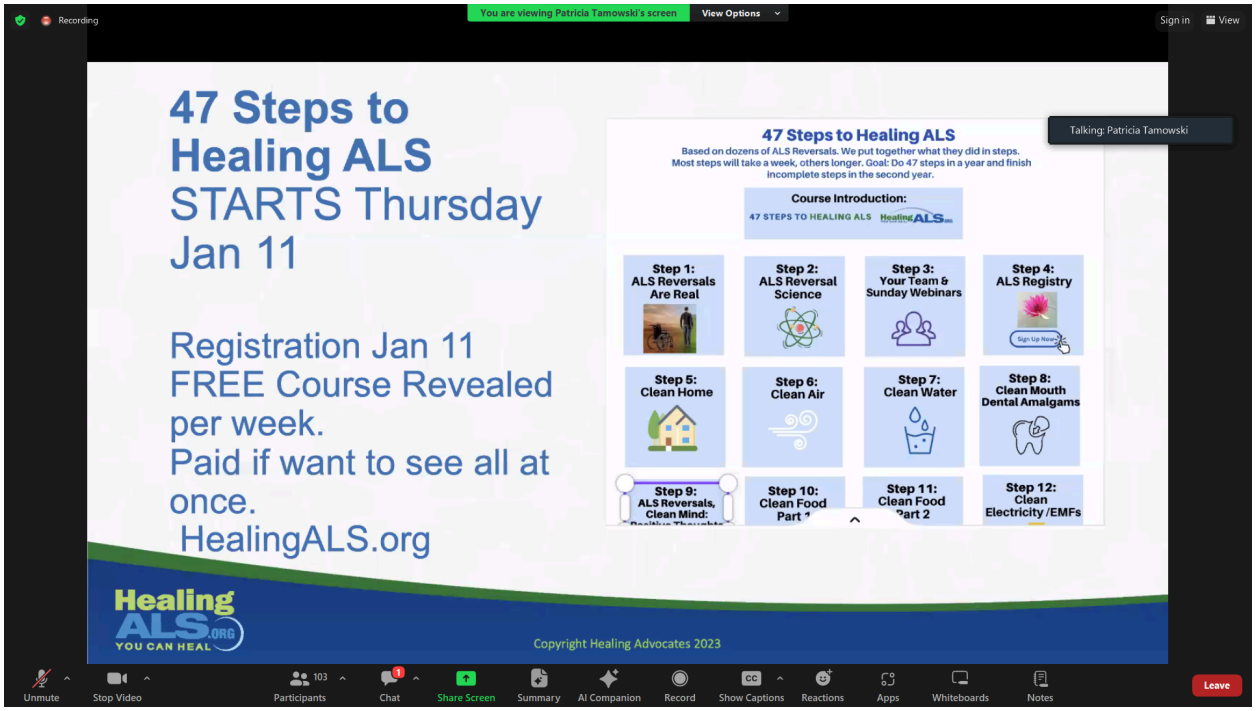
Scott began the meeting at 11:05am PT and welcomed everyone to the meeting. He explained our purpose and reminded everyone that we are not medical professionals nor are we offering medical advice; rather we share what others have done and are doing to slow, stop or reverse their ALS symptoms.



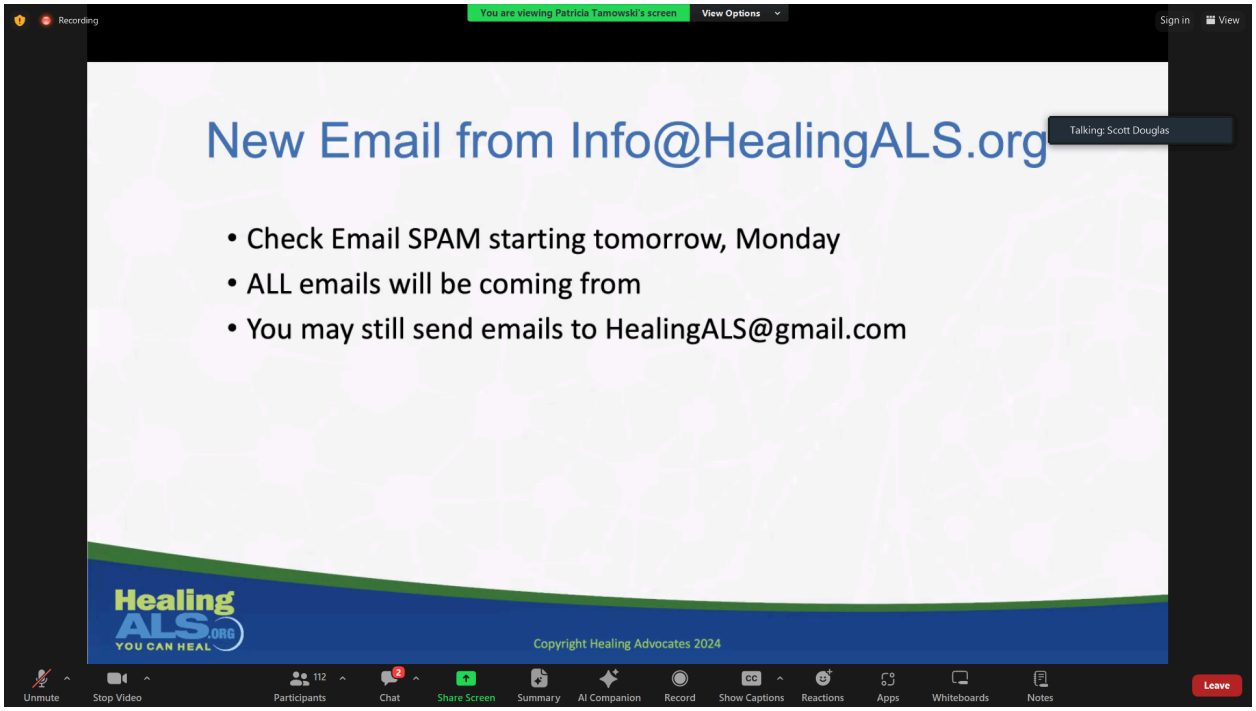

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Talking: Patricia Tamowski
Our observations from ALS reversals: How to Heal ALS
Attend EVERY Sunday, Monday, Thursday, live best, otherwise recorded
Sundays – Webinar
Mondays either Basic ALS Q&A OR Advanced ALS Q&A
Thursdays Q&A 47 Steps to Healing 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.
Healing ALS.ORG YOU CAN HEAL
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If you are new to HealingALS.org
1. Click Start Here on HealingALS.org!!!
2. Come Sundays, Mondays (basic ALS Q&A), & Thursdays
3. Overwhelm is normal at first. Baby steps.
Healing ALS.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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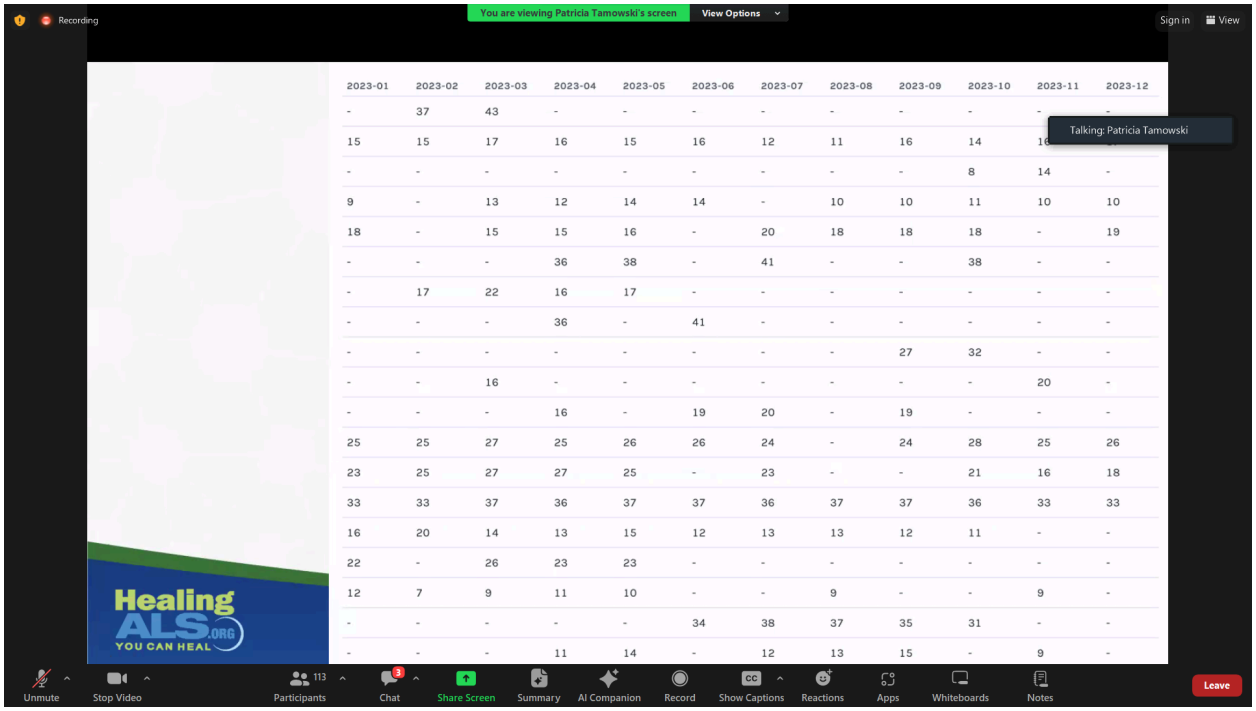

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Normal Schedule This Week – see emails
• Sundays, Monday Q&A's, Thursday 47 Steps
• Monday Basic and Advanced ALS Q&A
• Thursday 47 Steps – Feeding Tube *Important
• Tuesday
• 2nd Tuesday Breathing Q&A
• Admin Meetings
• New volunteers: Please email healingALS@gmail.com
• Volunteer, Mentor, Medical practitioners, Fundraising committees
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47 Steps to Healing ALS STARTS Thursday Jan 11
Registration Jan 11
FREE Course Revealed per week.
Paid if want to see all at once.
HealingALS.org
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
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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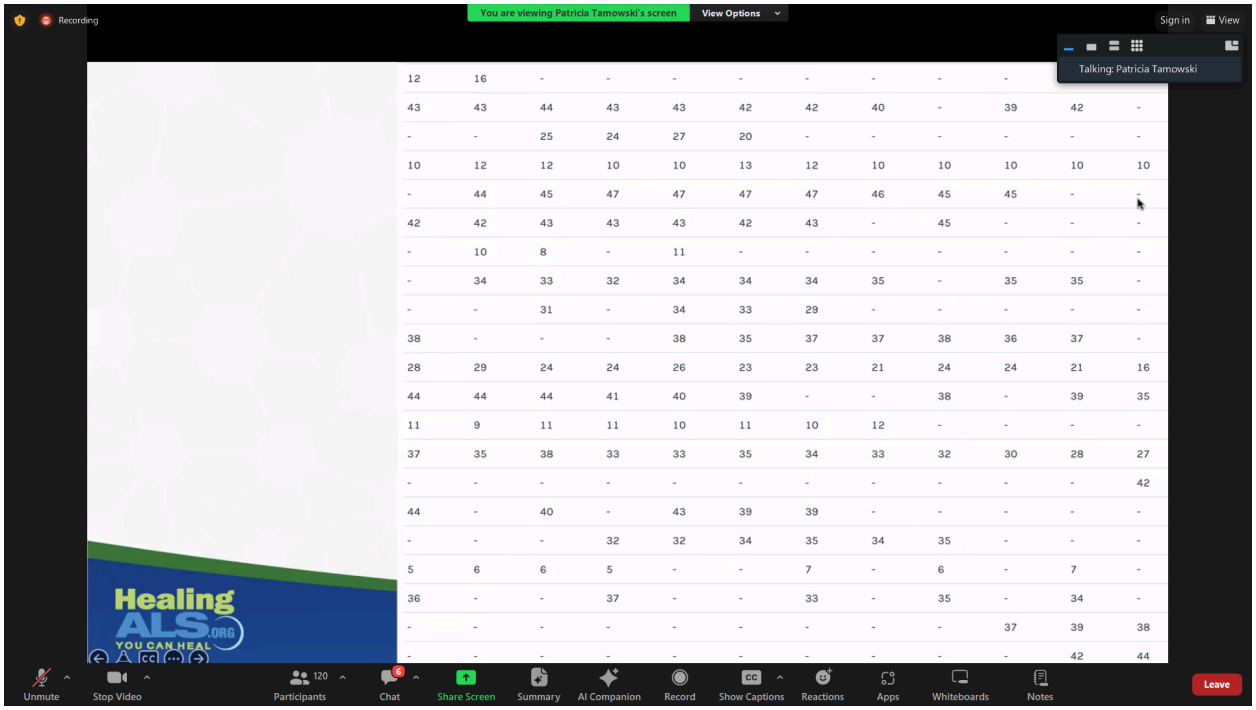

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Talking: Patricia Tamowski
Mentor Program 2024
• Applications Available Next week.
• Both Mentors and Mentees
• Mentors will be assigned partner Mentor if preferred
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Talking: Scott Douglas
New Email from Info@HealingALS.org
• Check Email SPAM starting tomorrow, Monday
• ALL emails will be coming from
• You may still send emails to HealingALS@gmail.com
Copyright Healing Advocates 2024
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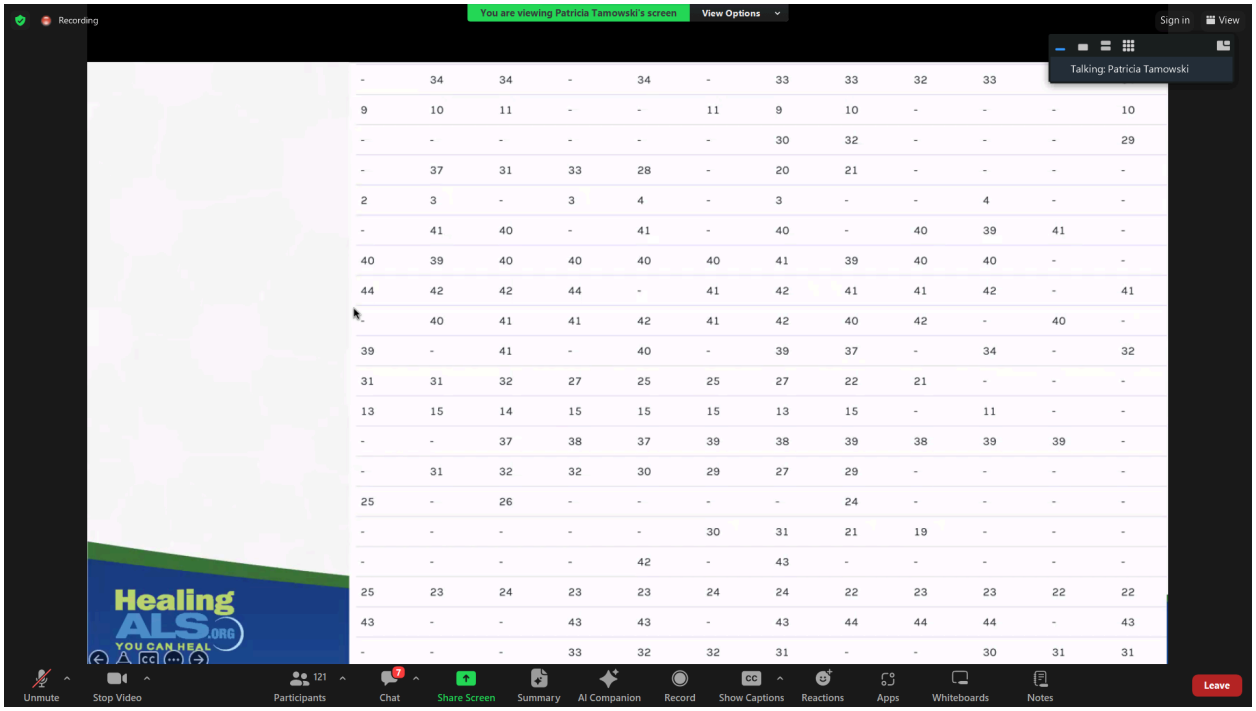




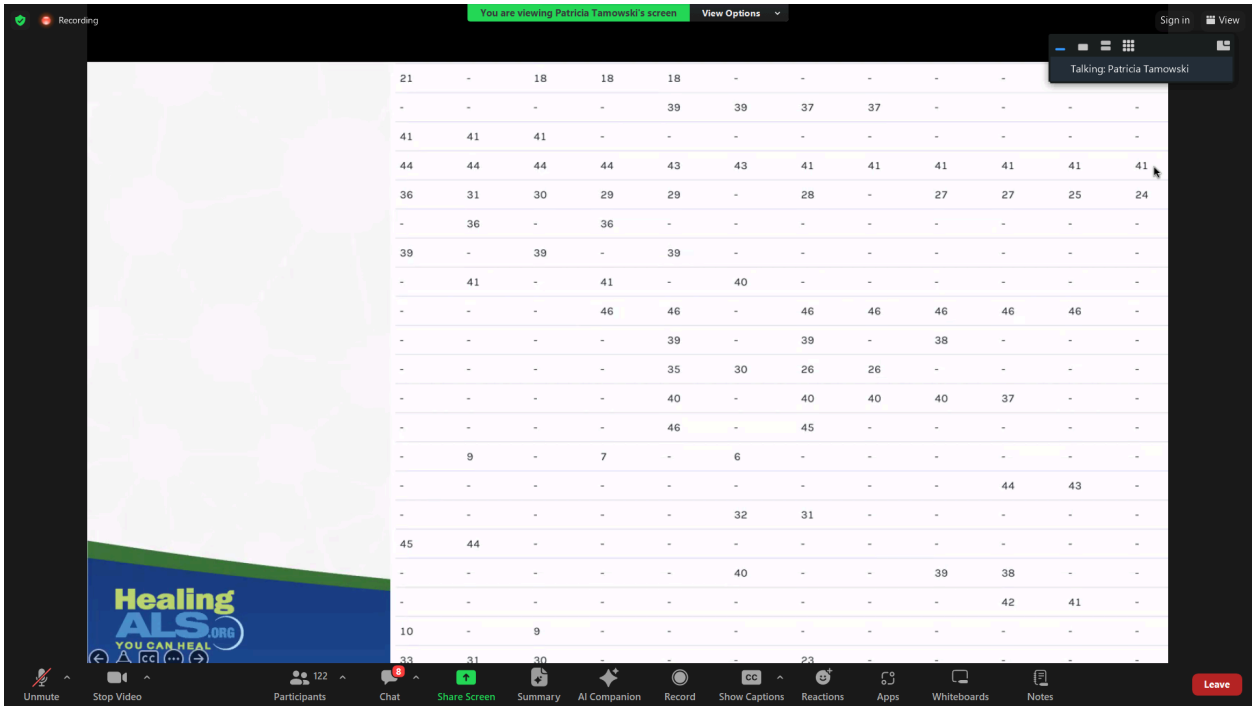
A chart from the Registry. These are all definitive ALS diagnoses and their ALSFRS scores over 2023.

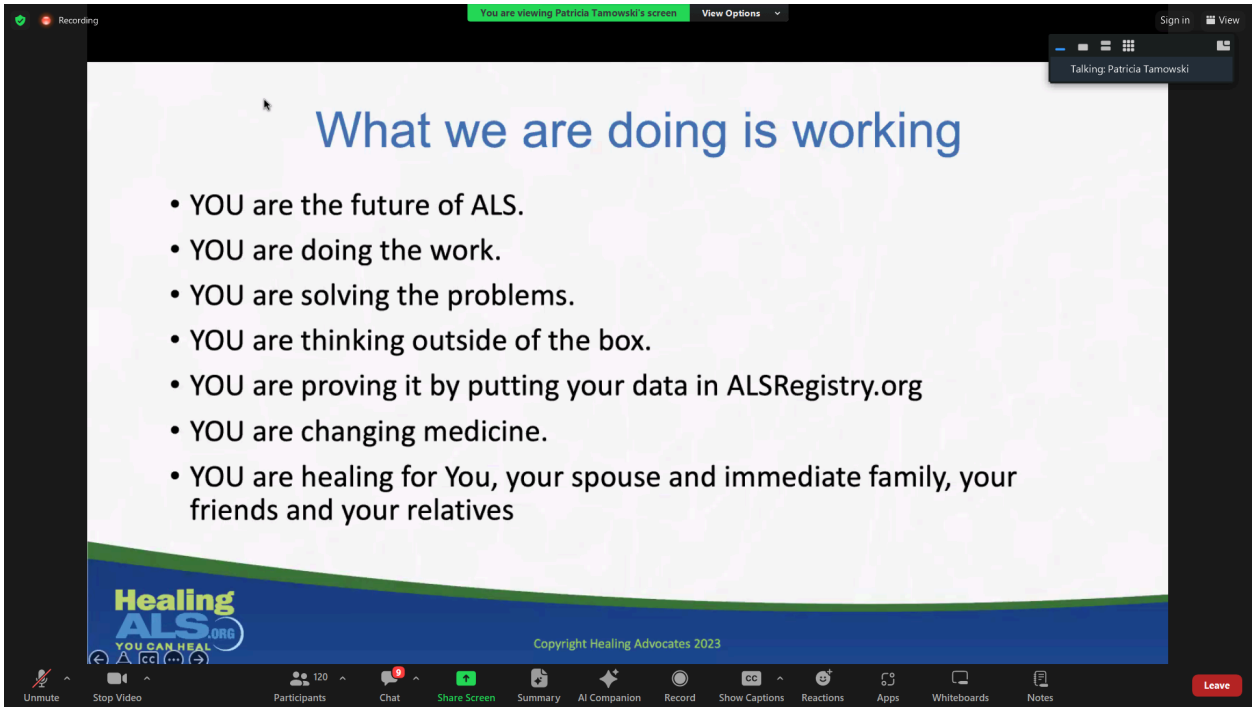


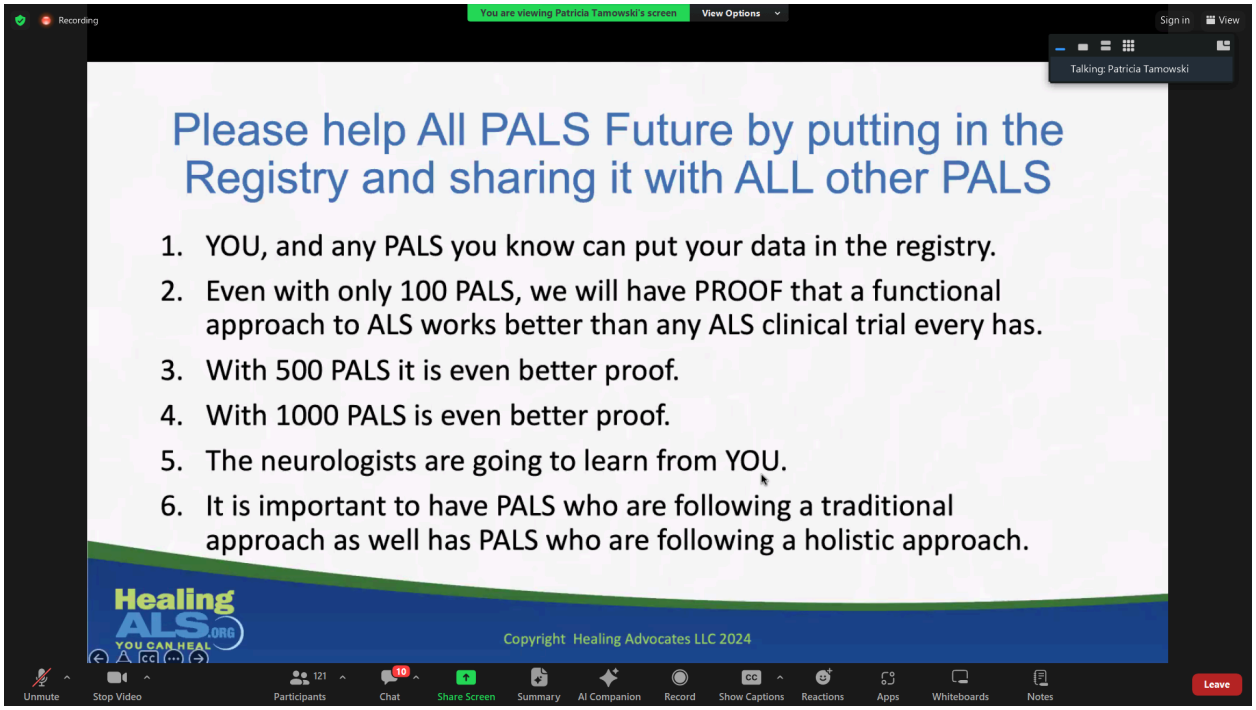
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10	12	12	10	10	13	12	10	10	10	10	10
-	44	45	47	47	47	47	46	45	45	-	-
42	42	43	43	43	42	43	-	45	-	-	-
-	10	8	-	11	-	-	-	-	-	-	-
-	34	33	32	34	34	34	35	-	35	35	-
-	-	31	-	34	33	29	-	-	-	-	-
38	-	-	-	38	35	37	37	38	36	37	-
28	29	24	24	26	23	23	21	24	24	21	16
44	44	44	41	40	39	-	-	38	-	39	35
11	9	11	11	10	11	10	12	-	-	-	-
37	35	38	33	33	35	34	33	32	30	28	27
-	-	-	-	-	-	-	-	-	-	-	42
44	-	40	-	43	39	39	-	-	-	-	-
-	-	-	32	32	34	35	34	35	-	-	-
5	6	6	5	-	-	7	-	6	-	7	-
36	-	-	37	-	-	33	-	35	-	34	-
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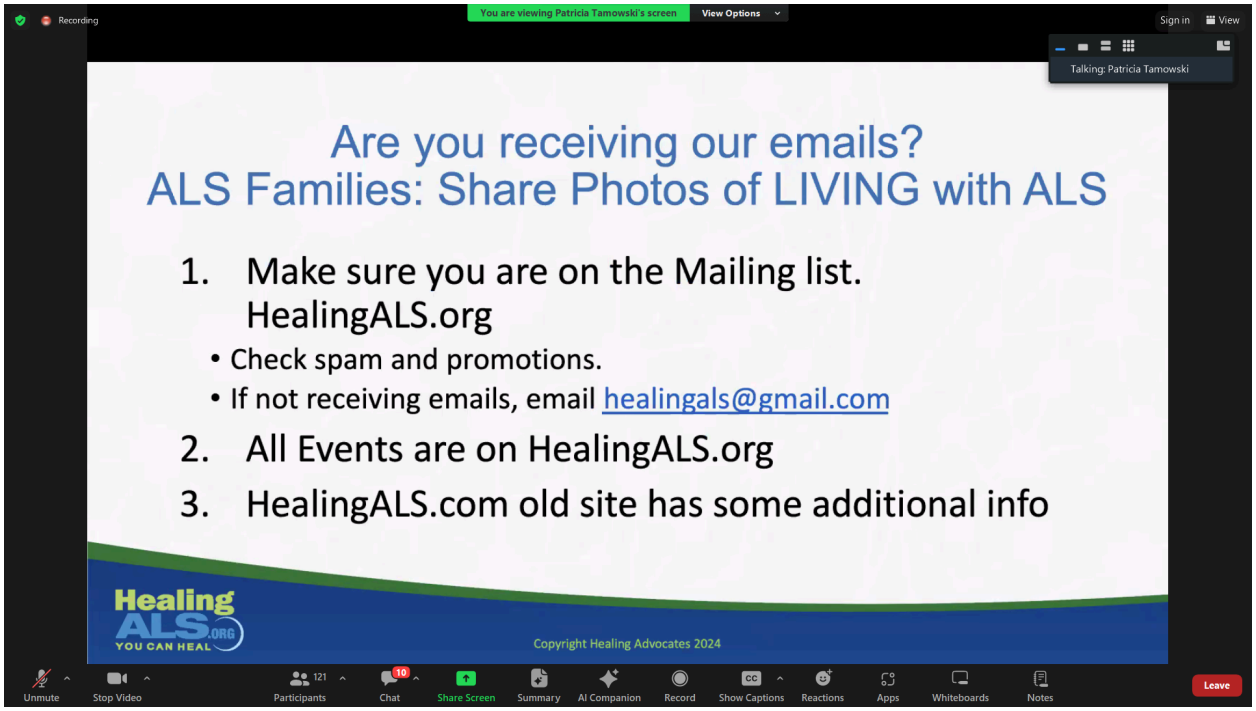


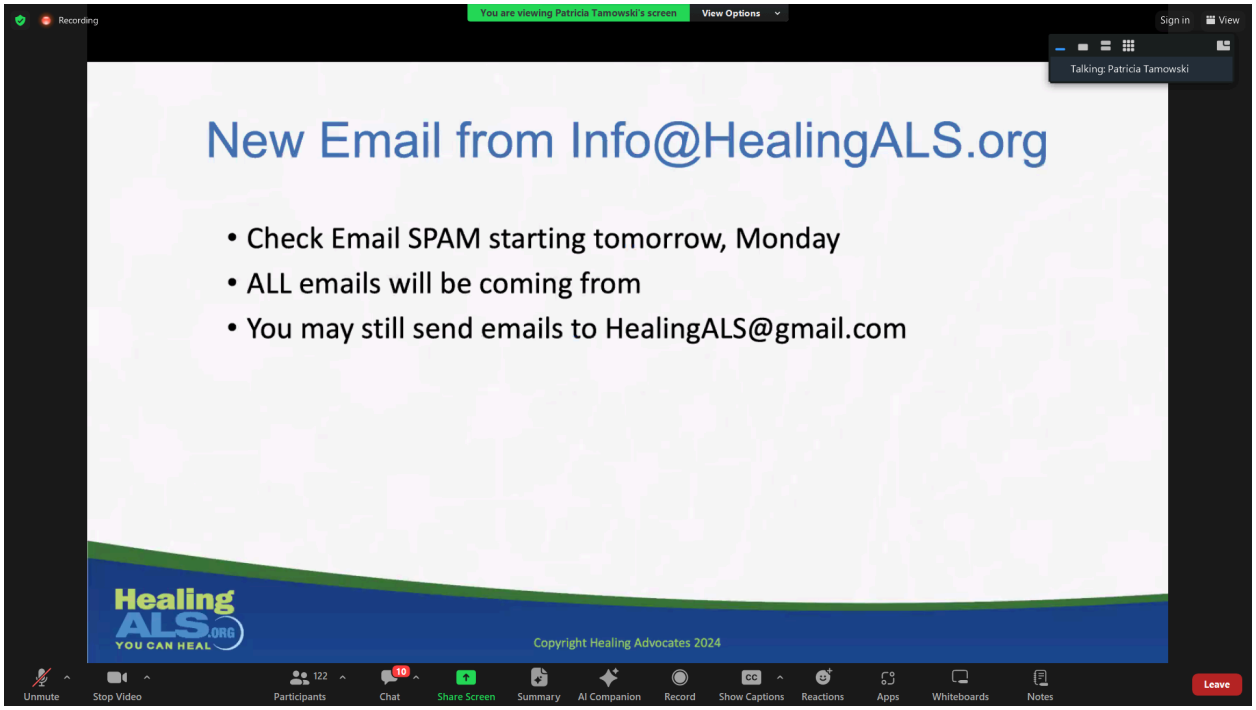
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44	42	42	44	-	41	42	41	41	42	-	41
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39	-	41	-	40	-	39	37	-	34	-	32
31	31	32	27	25	25	27	22	21	-	-	-
13	15	14	15	15	15	13	15	-	11	-	-
-	-	37	38	37	39	38	39	38	39	39	-
-	31	32	32	30	29	27	29	-	-	-	-
25	-	26	-	-	-	-	24	-	-	-	-
-	-	-	-	-	30	31	21	19	-	-	-
-	-	-	-	42	-	43	-	-	-	-	-
25	23	24	23	23	24	24	22	23	23	22	22
43	-	-	43	43	-	43	44	44	44	-	43
-	-	-	33	32	32	31	-	-	30	31	31


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What we are doing is working
• YOU are the future of ALS.
• YOU are doing the work.
• YOU are solving the problems.
• YOU are thinking outside of the box.
• YOU are proving it by putting your data in ALSRegistry.org
• YOU are changing medicine.
• YOU are healing for You, your spouse and immediate family, your friends and your relatives
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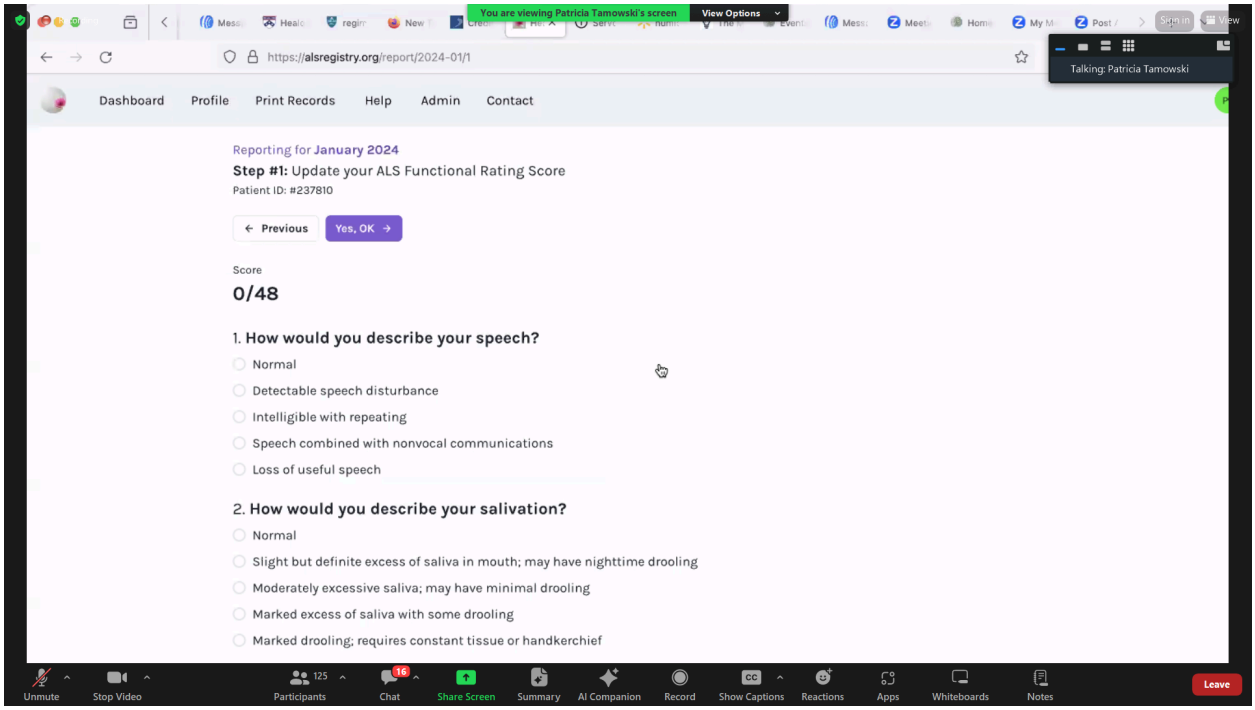

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Talking: Patricia Tamowski
Please help All PALS Future by putting in the Registry and sharing it with ALL other PALS
1. YOU, and any PALS you know can put your data in the registry.
2. Even with only 100 PALS, we will have PROOF that a functional approach to ALS works better than any ALS clinical trial every has.
3. With 500 PALS it is even better proof.
4. With 1000 PALS is even better proof.
5. The neurologists are going to learn from YOU.
6. It is important to have PALS who are following a traditional approach as well has PALS who are following a holistic approach.
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Are you receiving our emails?
ALS Families: Share Photos of LIVING with ALS
1. Make sure you are on the Mailing list. HealingALS.org
• Check spam and promotions.
• If not receiving emails, email healingals@gmail.com
2. All Events are on HealingALS.org
3. HealingALS.com old site has some additional info
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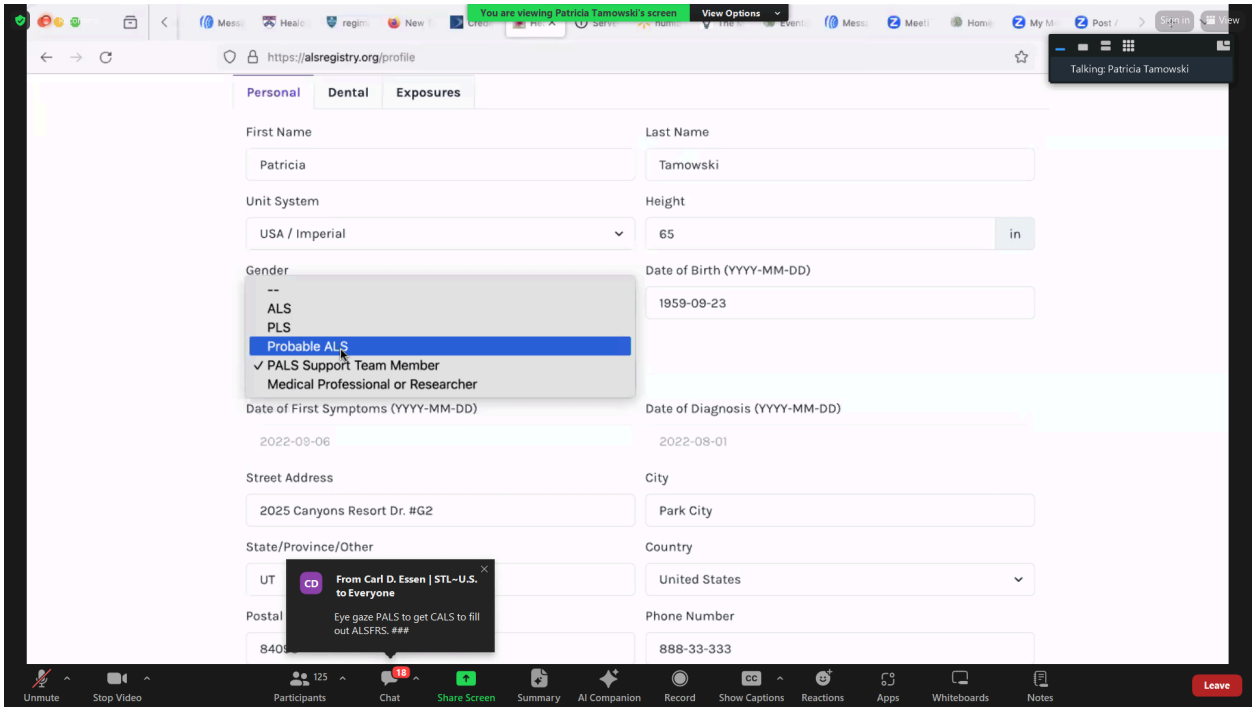


1. Can we see these numbers on our page in the registry? Yes, go to your print option on your page. “Print records"

2. Where do I find these numbers? EMG? No. These are ALSFRS scores. (you can fill out an FRS survey in the Registry)



3. If you aren't a confirmed ALS patient, can you still fill out the registry? Yes, you can. In your profile, you can choose which type of diagnosis fits you.

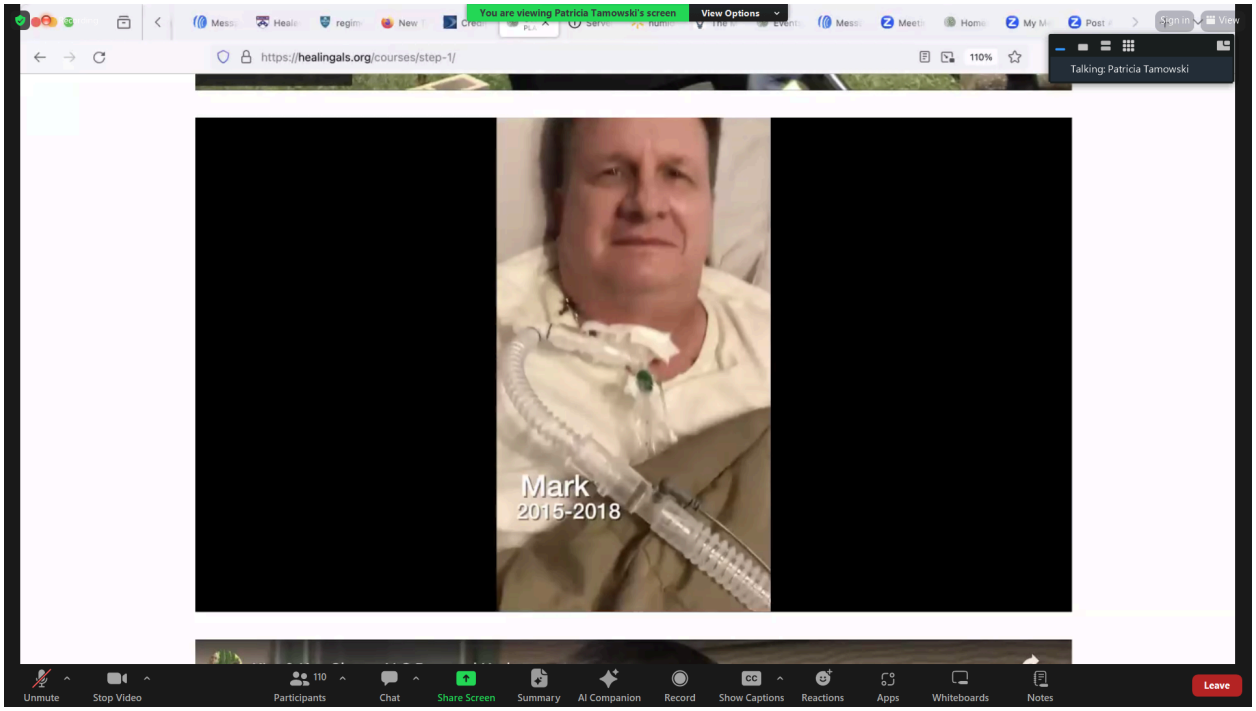


4. Do I need to see my doctor to get an ALSFRS survey? No. You can do it at home on the HealingALS Registry.

5. Have any of the reversals stayed on the drugs given by doctors along with all their other supplements? No. None of the drugs work, and they all have side effects.

6. Can we see others' data, especially those who are doing well? Yes, eventually, but we need more data to help confirm that what we are doing is working. We want to maintain anonymity, but with so few people doing the registry, we can't have that yet.

7. Is there anything that has helped with lung function? Does anyone have feedback on this? Not that it will help, but something to try? Watch the Mark Manchester video!



8. We are told to do research, google things and a zillion different things come up. Seems everybody is doing different supplements, how do you figure this out? Start with the Boot Camps and the 47 Steps. There are some basic supplements that most PALS in this group take.

Tish invited everyone to the breakout rooms to continue the conversation. Scott began his goodbye's at 12:36 pm PT.

NO SUNDAY MEETING NEXT SUNDAY!!! MLK Day!

Respectfully submitted,
Jim Getka

Chat thread for today up until 12:30pm PT:

Ataklti Medhin 11:06 AM
Happy new year everyone

Chris Kemp to Everyone 11:10 AM
Greetings from a Sunny Monday morning in New Zealand 🇳🇿

Scott Douglas to Everyone 11:14 AM
Tish's Number: (914) 582-3194

Kristen Bowlin to Everyone 11:16 AM
Happy New Year to all!! ✨🙌

ALEXANDRA STEINICKE to Everyone 11:22 AM
Can we see this number in our registry

Anu Ahmed to Everyone 11:25 AM
on the emg report, what number should I look at to compare with the numbers on the screen?

Ingela Sundberg to Everyone 11:30 AM
Pls explain the number system
What's the scale and how does it work
In. My country we don't have it

Karen Ose to Everyone 11:32 AM
If you are not a confirmed case do you want the information entered?

Carl D. Essen | STL~U.S. to Everyone 11:38 AM
Hi Ingela , what country are you located at , the #'s are called FRSALS Score , you can find online in google search , so if you have a 48 score you do NOT show signs of ALS , score is made up of 12 items . ###

Thomas Rossini to Everyone 11:39 AM
I don't see my doctor every month so how do I get my ALSFRS?

Sandra Hartman to Everyone 11:17 AM
Going up is a good thing?

John Andic 11:18 AM
Yes

Sue McCartan 11:39 AM

👍🏼

Carl D. Essen | STL~U.S. to Everyone 11:40 AM
The ALSFRS can be done by yourself . ###

Jose Pinto to Everyone 11:40 AM
It can also be difficult for PALS on eye gaze to fill out forms

Thomas Rossini to Everyone 11:41 AM
Have any of the reversals stayed on the drugs given by doctors along with all their other supplements

Ingela Sundberg to Everyone 11:42 AM
Thanks for info

Carl D. Essen | STL~U.S. to Everyone 11:44 AM
Eye gaze PALS to get CALS to fill out ALSFRS. ###

Thomas Rossini to Everyone 11:46 AM
Thank you

Nupur Bhatnagar to Everyone 11:47 AM
can we see others data specially who are doing well

Robert Campbell to Everyone 11:47 AM
Why do I have to start over each month with the mindset /emotional /psychological part?Shouldn't I just be able to update it?

Anu Ahmed to Everyone 11:50 AM
What about the drug Relyvrio?

Robel haile to Everyone 11:51 AM
Appreciate all the work you guys do for us 🙏😌❤️
(Btw I fill my registry with an eye gaze and I don’t mind. The least I can do 😉)

You to Sue McCartan (Direct Message) 11:51 AM
Sue, are you taking just sodium Butyrate, or Sodium Phenylbutyrate?

Anu Ahmed to Everyone 11:51 AM
Hi Sue, you're looking so fab!! Thank you for sharing your story. Would you mind telling us how long you've had it for?

Chris Kemp to Everyone 11:52 AM

I only started in November last year , shall I know to re-start with the first step on the 11th so I am inclined with the course , or just keep working through at my pace ?

ALEXANDRA STEINICKE to Everyone 11:52 AM
My Neurologist told me to skip the drugs and trials at ALS clinic they don't help and cause more harm with no benefit

Jose Pinto to Everyone 11:49 AM
I'm the only English speaker at home in a Spanish speaking country, so eye gaze it is

Gabriela Tabarés Martinez 11:50 AM
Hola José, ¿de dónde eres?

Jose Pinto 11:52 AM
Colombia

Gabriela Tabarés Martinez 11:53 AM
Ay! En españa yo
Saludos!

Jose Pinto 11:54 AM
Bendiciones

Janet Caldwell to Everyone 11:51 AM
What is the 2nd supplement you mentioned with TUDCA?

Pawan Deol 11:53 AM
Sodium Phenylbutyrate (or Calcium Magnesium Butyrate).

You 11:55 AM
There is regular Butyrate that is a supplement that is easy to get. Phenylbutyrate may be more challenging to obtain. I asked Sue to clarify which one she takes. I tried the regular Butyrate, but didn't like the results. I have to look into it more.

Michael Kolesar to Everyone 11:55 AM
Will the steps from #33 to be completed? I never got the homework from last year.

Patricia Tamowski to Everyone 11:56 AM
healingals@gmail.com

Sharon Degen to Everyone 11:56 AM
My husband has taken Riluzole since Diagnosis in 2018, but had no adverse symptoms, as far as I know, but who knows!? Can I contact you Sue! Sharon in UK

Cynthia Baptiste to Everyone 11:56 AM
Can you get there if you're a CALS?

Jeff Ligon to Everyone 11:56 AM
I went off Riluzole also because of high liver enzyme tests (a sign of liver damage) and it took 7 months for my liver enzyme blood tests to return back to normal levels.

Joan MacLeod to Everyone 11:58 AM
Where does Sue get her organic Tudca and butyrate from?

Mike Shive to Everyone 11:58 AM
I mentioned to Tish that I saw a recommended functional medicine doctor and you have to be wealthy to follow his protocol. Seems they along with dentists (pull root canals, amalgam work) could discount for ALS

Karen Ose 12:00 PM
What is the name of the doctor

You to Everyone 12:00 PM
Sue, if you are taking sodium Phenylbutyrate, where are you getting it from? I can only find Sodium Butyrate as a supplement.

Sue McCartan to You (Direct Message) 12:02 PM
yes mine is just butyrate

ALEXANDRA STEINICKE to Everyone 12:02 PM
Peter Masny MD Arroyo Grande California, Also a new functional medicine Neuro clinic just opened in2023 Santa Monica Brain Health Clinic

Sandra Hartman to Everyone 12:03 PM
Sodium phenylbutyrate has anyone done thru IV infusions, would infusions be better

Karen Ose to Everyone 12:04 PM
Working ahead wouldn't work because the modules aren't ready.

Kristen Bowlin to Everyone 12:05 PM
Thank you both for all of your hard work and dedication! 🙏

Karen Ose to Everyone 12:09 PM
Liver enzymes are AST and ALT

Julie Calderwood to Everyone 12:10 PM
It may be helpful to remind us and everyone else how to get on the What's App. Thank you.

Nupur Bhatnagar to Everyone 12:10 PM
Milk Thistle is supposed to be good for liver

Patricia Tamowski to Everyone 12:14 PM
HopeDr.org

Cynthia Baptiste to Everyone 11:52 AM
Is there anything that has helped with lung function? Does anyone have feedback on this? Not that it will help, but something to try????

Marian Earnest 12:05 PM
I nebulize with Glutathione (PF) Solution 200 mg/ml inhalation. Add 1 ml to the nebulizer cup and breathe in vapor once daily.

Marian Earnest 12:07 PM
The Glutathione I use is a compound formula.

Cynthia Baptiste 12:14 PM
Thank you soooooo much!!!!!

Kevin New 12:15 PM
What was the treatment that Dr. Joyce did in Germany?

Nupur Bhatnagar 12:21 PM
@Marian Earnest Where do you get it?

Cynthia Baptiste 12:25 PM
Yes, where did you get the right glutathione to use in a nebulizer?

Marian Earnest 12:29 PM
@Nupur Bhatnagar my naturopath ordered it from a compounding pharmacy.

Sandra Hartman to Everyone 12:19 PM
We are told to do research, google things and a zillion different things come up. Seems everybody is doing different supplements, how do you figure this out?

Betsy Thomason to Everyone 12:20 PM
How to strengthen your breathing: Learn the BreatheOUtDynamic system for drug free management of anxiety, fear, pain, and stress as well as for relaxation and strength—to maximize your abilities EFFICIENTLY. Betsy Thomason coaches you through this. See info on healingals.org

Karen Ose to Everyone 12:21 PM
I suggest that you add one supplement at a time.

Lisa Bean to Everyone 12:22 PM
Have you been gathering statistics on the PALS who have passed away and have you identified any trends of things that we should avoid or should do to prevent avoidable negative outcomes?

Sharon Degen to Everyone 12:24 PM
great question Lisa!

Michael Kolesar to Everyone 12:24 PM
Do you know how one could go about changing their respiratory therapy company?

Lisa DeLong to Everyone 12:26 PM
can we get a list of potential bi pap settings for ALS if our respiratory is not familiar with ALS

Nupur Bhatnagar to Everyone 12:07 PM
Bodybio has excellent sodium butyrate

Sue McCartan 12:12 PM
👍🏻

Fadi Ramadan 12:13 PM
I'd love to find a good naturopath in orange county, ca

Cynthia Baptiste 12:27 PM
Is there one in Augusta, Ga.?

Kevin New to Everyone 12:28 PM
What was the treatment that Dr. Joyce did in Germany?

Sharon Degen to Everyone 12:28 PM
Can I add something!?

Anu Ahmed to Everyone 12:28 PM
What about stem cell therapy - does it help reduce progression?

Cynthia Baptiste to Everyone 12:29 PM
My husband was in ICU with pneumonia & sepsis the 2nd week in Dec. They informed us that they would be in at 6:00s.m. to get him to amputate his legs. NO!!!!!!!

Sharon Degen 12:29 PM
God Bless Mark Manchester!