

## 2022 Neuroimmune Foundation Inflammatory Brain Disorders Conference Day 1 – Q&A

NOT INCLUDED: 7a-8a PST

Christianna Beebe 8:03 AM

Research read-outs seems to show at least 40% without "severe onset" - or perhaps only some symptoms are sudden - how is this explained?

Dr. Jennifer Frankovich 9:35 AM

For our program, we use the criteria of Sudden-onset of the majority of symptoms, but certainly we see that some kids have some mild symptoms before the abrupt deterioration. Sometimes classifying these kids can be challenging. For those kids who do not meet strict criteria, but have the flavor of PANS, we are still tracking them and studying them and in cases where we find evidence of inflammation and/or the child is refractory to standard psychiatric treatments, we have treated some of these kids with immunomodulation with varying responses (some respond beautifully, some have no response).

Jennifer Bahr 8:18 AM

Have you seen late onset of type 1 diabetes with PANS?

Neuroimmune Foundation 9:18 AM

Private answer

Thanks for your question.

Vikram Bhise 8:21 AM

Have the antibody findings been replicated in other labs?

Dr. Jennifer Frankovich 9:32 AM

Aoron Ring at Yale is using a different approach to try to understand the specific antigen that the cholinergic autoantobody is targeting. He has preliminary data I hope that he will present next year at this conference.

The Karololinska PANS group has found the same non-specific autoantibodies and low complements that we have found— published.

Thanks for your question.

Sarah Barnett 8:23 AM

Dr. Frankovich - In your PANS patients who later develop other autoimmune conditions, how are you seeing them respond to targeted treatment? Are you seeing PANS flares as the immune system is suppressed with the use of DMARDs or biologics?

Neuroimmune Foundation 10:48 AM

Private answer

Our apologies for not getting to your question.

Theresa Willett (You) 10:52 AM

In general, it does seem that treatment for the identified autoimmune/inflammatory disorder also improves the psychiatric symptoms, but not always dramatically. This is one reason we put great effort into identifying other treatable processes.

Theresa Willett (You) 10:57 AM

Forgot 1 more point: for a couple patients on more significant immunosuppression, there may be a point of diminishing return w recurrent infection such as sinus infection counteracting the improvements noted w the suppression, so less suppressive pathways are needed while the infection issues are addressed.

Wendy Edwards 8:24 AM

What about anti inflammatory effects of some of the antibiotics - don't they do MORE than just treat a possible hidden infectious trigger??

Neuroimmune Foundation 10:03 AM

Private answer

Thanks for your question.

Sonal Goswami 8:26 AM

in PANS do you recommend continuing antibiotics for 6 months?or longer?

Neuroimmune Foundation 10:48 AM

Private answer

Our apologies for not getting to your question.

Theresa Willett (You) 10:55 AM

I think Dr Frankovich touched on this live, and for patients with ARF/Sydenham Chorea, we may use long term anti-strep prophylaxis, and some patients with recurrent sinusitis will be on prophylactic antibiotics, but we do try to limit chronic use when possible.

Candida Fink 8:26 AM

For Dr. Frankovich - wondering if you have seen catatonia in any of your patients. One patient this year has had clear catatonia with a PANS presentation - another patient had features similar to catatonia within PANS

Neuroimmune Foundation 10:48 AM

Private answer

Thank you for your question.

Naema Qureshi 8:26 AM

in between flares are kids at their pre-PANS baseline?

Dr. Jennifer Frankovich 9:40 AM

Hi Naema- Many patients have residual OCD, anxiety, ADHD symptoms etc after they get to their new baseline. Some patients fully resolve all psychiatric symptoms. For all of our patients, our psychiatry/therapy team uses standard of care for treatment of these residual symptoms (SSRIs, CBT, ERP, etc). Even though these approaches do not work in the acute phase (ie. many of our patients are hypersensitive to meds during flare and have difficulty with CBT), but after they improve they can tolerate and make progress with these approaches.

Roxanne Allegretti 8:26 AM

How did you dose the steroid burst in flare up study you mentioned

Dr. Jennifer Frankovich 9:41 AM

Frankovich J, Swedo S, Murphy T, Dale R C, Agalliu D, Williams K, Daines M, Hornig M, Chugani H, Sanger T, Muscal E, Pasternack M, Cooperstock, et al. Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part II—Use of Immunomodulatory Therapies. *Journal of Child and Adolescent Psychopharmacology*, Vol. 27, No. 7, 574-593. September 2017. doi: 10.1089/cap.2016.0148

Vikram Bhise 8:27 AM

Many patients are being 'diagnosed' without evidence of OCD or eating restriction, usually in settings of behavioral regression alone. Do they represent a different disorder or an un/underrecognized aspect of PANS?

Dr. Jennifer Frankovich 9:44 AM

Hi Vikram- great question. We do not know yet if Sudden-onset Behavior Regression is related to PANS (Sudden onset OCD/Eating Restriction). We typically do not see these kids in clinic since they would not pass our clinic screening criteria. But if you are seeing

these patients and are collecting samples, we are happy to study them and see if they have overlapping immune markers.

Angela Tang 8:28 AM

Dr F: how soon do you need to give oral steroids in order to cut the duration of flare from 11.5 wks to 6.5 wks? Within a couple of days?

Dr. Jennifer Frankovich 9:48 AM

Hi Angela- For the study we only included cases who were treated within 10 days of flare-onset. But in clinical practice, we have given steroids later and often we see a clinically significant reduction in symptoms (after the steroid SE wear off). If the patient responds, but does not go back to their baseline, we will often do a second or third burst. Not all patients respond, but those who meet strict criteria often do.

Thanks for your question!

I also owe you an email!!! I am sorry I have been swamped/overwhelmed by email in the last few weeks. Lots of kids flaring since the masks have come off in schools!

Albina Zimany 8:33 AM

Dr. Frankovich- is there a clinical checklist that can be used to determine the likelihood of PANS vs primary psychiatric condition? Or should be primary looking for rapid onset, relapsing/ remitting illness? It seems as though looking for other autoimmune conditions is not as helpful, given that they are not present in most patients.

Neuroimmune Foundation 10:58 AM

Private answer

Our apologies for not getting to your question.

Lourdes Carolina Ceron-Canas 8:38 AM

We have been seeing a surge in PANS in our practice in Northeast florida.

Some entire families.

Can you give some outline of meds, we have used azithromycin with good results and nsaids, but less so steroids. Do you have specific or basic recommendations to set up a treatment plan.

Wait times to see rheumatologists are about 6 months.

I need to manage these patients asap and would so appreciate guidance.

Also, is there a current study (s) that I can refer some of these?

Dr. Jennifer Frankovich 9:52 AM

Thanks for your question and for seeing PANS patients in your practice. this disease is so hard to treat (even with a multi-D clinic). so I commend you for doing the work you are doing.

We also see a very high rate of siblings being affected and sometimes parents with more subtle symptoms. We hope to publish our experience with siblings soon.

Here is our publication page where you can find the treatment recommendations outlined. I hope these are helpful to you. Don't forget to look at the appendices!

<https://med.stanford.edu/pans/publications.html>

Margaret Ward 8:46 AM

What is VLA-4 ? What is the history behind it's discovery?

Neuroimmune Foundation 10:48 AM

Private answer

Our apologies for not getting to your question.

Stephen Gutu 8:47 AM

Dr Frankovich, which types of MRI /and or sequences would be beneficial to pursue during acute or flare presentation? PET scan, Quant MRI, SPECT, FLAIR or what would you suggest?

Neuroimmune Foundation 10:49 AM

Private answer

Our apologies for not getting to your question.

Stephen Gutu 8:48 AM

Why can't they approve these special MRI's to be done since there seems to be a direct correlation?

Neuroimmune Foundation 10:49 AM

Private answer

Our apologies for not getting to your question.

Tatjana Peskir 8:49 AM

can we have a link on this study with myeloid cells in the brain Dr Mellins is talking about

Neuroimmune Foundation 10:50 AM

Private answer

Our apologies for not getting to your question.

Angela Tang 8:54 AM

Dr Mellins: Very interesting findings re changes when PANS flares recover! Do you find the reverse changes when a child goes into a relapse?

Neuroimmune Foundation 10:50 AM

Private answer

Our apologies for not getting to your question.

Hai Jin Kim 8:59 AM

How about kids who meet PANS criteria, but not necessarily with sudden onset?

Neuroimmune Foundation 10:50 AM

Private answer

Our apologies for not getting to your question.

Henry Braa 8:59 AM

Is there a clinic or doctor that you know about that sees young adults with PANS that can't be seen by a pediatrician because of their age? In our case, this is in the San Francisco Bay Area. For example, are there any rheumatologist or ID docs at Stanford or UCSF that do this? Thanks

Neuroimmune Foundation 10:51 AM

Private answer

Our apologies for not getting to your question. I believe in the Bay Area Dr. Bella Chhedda may be an option.

Nathalie Paravicini 9:00 AM

How young can children who receive IVIG be?

Dr. Jennifer Frankovich 10:06 AM

I do not think there is a lower age limit for IVIG in kids. We have used IVIG in babies/toddlers for treatment of other diseases like Kawasaki Disease.

The youngest patient with PANS that we have given IVIG was 4 years old.

Thanks for your question.

Yuval Shafir 9:02 AM

What about epidemiology? Why Sydenham Chorea went down? Do you believe that the prevalence of PANS/PANDAS is increasing?

Dr. Jennifer Frankovich 10:00 AM

Hi Yuval.

Thanks for your question.

SC incidence/prevalence went down because there were public health efforts to screen all kids in schools (in the past each school had a nurse that would test kids for strep monthly or with outbreaks) and give penicillin. This effort was poorly documented but I believe this effort in Baltimore was published.

I do wonder if PANS/PANDAS reflects different strains and/or difference of the current immune-profiles (microbiome etc) of our population.

So much work to do!

Janet Cunningham 9:02 AM

Can you add the link for the azitromycin RCT study.

Dr. Jennifer Frankovich 9:55 AM

Murphy TK, Brennan EM, Johnco C, Parker-Athill EC, Miladinovic B, Storch EA, Lewin AB. A Double-Blind Randomized Placebo-Controlled Pilot Study of Azithromycin in Youth with Acute-Onset Obsessive-Compulsive Disorder. J Child Adolesc Psychopharmacol. 2017 Sep;27(7):640-651. doi: 10.1089/cap.2016.0190. Epub 2017 Mar 30. PMID: 28358599.

Malik Talha 9:03 AM

Are there currently any trials ongoing examining plasmapheresis in PANS / autoimmune encephalitis / regressive autism ?

Dr. Jennifer Frankovich 10:02 AM

I am not aware of PEX trials at this time.

Stefanie Magee 9:03 AM

Have there been any studies or observations with Low Dose Naltrexone for control of inflammation?

Dr. Jennifer Frankovich 10:03 AM

LDN experiences have been published in Inflammatory bowel disease, pain syndromes, and I think fatigue. Anecdotally, we do see coincident improvement in pain/fatigue/post-exertional crashes in patients after LDN introduction.

Lisa Donovan 9:03 AM

Role for N-acetylcysteine?

Dr. Jennifer Frankovich 10:06 AM

NAC has been shown to be helpful in OCD and related conditions, so we do use it in our PANS clinic.

Yuval Shafir 9:04 AM

Any cases of use of monoclonal antibodies aimed at components of the innate immune system?

Neuroimmune Foundation 10:51 AM

Private answer

Our apologies for not getting to your question.

Ann Maitland 9:04 AM

increased risk of PANS in patients with immunodeficiency- in the adaptive or innate immune compartments

Dr. Jennifer Frankovich 10:11 AM

Yes.. we do see this! We are hoping to publish this report soon. Thanks for your interest.

Tatjana Peskir 9:04 AM

in an IgA deficiency with PANS, do you use just IVIG or something else as well?

Neuroimmune Foundation 10:51 AM

Private answer

Our apologies for not getting to your question.

Jason Schiller 9:04 AM

All 14- and 15-membered macrolide antibiotics have a blocking of pro-inflammatory upregulation in microglia... Do you see one 14- / 145- membered macrolide antibiotic as more effective than another, azithromycin, tetracycline, minocycline, Erythromycin, Clarithromycin, Clarithromycin?

Dr. Jennifer Frankovich 10:13 AM

Hi Jason. It's hard to know based on our clinical data, but the RCT with Azith indicated that it was helpful. We are reluctant to use minocycline since we have seen this antibiotic trigger lupus, vasculitis, and other rheum disorders in children. WE have used Clarithromycin in a few patients, with response in one but unclear in the others.

Sonal Goswami 9:05 AM

Would be nice if PANS treatment recommendations are shared from the journal!

Neuroimmune Foundation 9:10 AM

I'm having trouble copying the link as Zoom won't allow it but if you google JCAP Treatment Guidelines PANS 2017, you'll see them.

Henry Braa 9:05 AM

Do you find IVIG works well for most vs. Rituximab treatment? Any recent update on best practice in PANS patients?

Neuroimmune Foundation 10:51 AM

Private answer

Our apologies for not getting to your question.

Janet Cunningham 9:05 AM

This just came out also regrading possible mechanisms:

<https://www.karger.com/Article/FullText/519874>

Neuroimmune Foundation 9:08 AM

Thank you for sharing.

Ann Maitland 9:06 AM

thoughts on "anti-inflammatory" properties of anti-microbial agents - azithomycin 3x weekly or daily doxyclyne?

Neuroimmune Foundation 10:51 AM

Private answer

Our apologies for not getting to your question.

Jacob Peterson 9:06 AM

Do we have affordable treatments (cheap if cash pay such as azithromycin), methotrexate, hydroxychloroquine, etc that have evidence of helping disease, although not definitive treatment.

Neuroimmune Foundation 10:58 AM

Private answer

Our apologies for not getting to your question.

Susan Manfull 9:08 AM

Do you assess for alexithymia (or the characteristics thereof such as diminished empathy and diminished ability to articulate feelings)?

Thank you!

Theresa Willett (You) 9:09 AM

Yes, some of our patients have very different social interactions when flaring vs resolved..

Erin Burns 9:08 AM

Can you speak to utility of Cunningham panel?

Neuroimmune Foundation 9:11 AM

We'll have a presentation on this tomorrow morning with Dr. Chandra Menedez.

Deanne McNulty 9:08 AM

Are you seeing that the crossover of diagnosis of ASD and PANS?

Theresa Willett (You) 9:11 AM

Some of our patients have been dx in their teens w ASD, though they have generally been noted to have had subtle symptoms pre-PANS onset.

Ann Maitland 9:09 AM

great article- thank you!

Jason Schiller 9:10 AM

Do you thin the micoglia seeking the basil ganglia is a function of CCL2 which is constitutively expressed in cholinergic neurons located there?

Neuroimmune Foundation 10:51 AM

Private answer

Our apologies for not getting to your question.

Sonal Goswami 9:13 AM  
have you seen thyroid dx with pans kids?

Theresa Willett (You) 9:14 AM  
Yes, we have quite a few patients with hashimoto's antibodies, though most have not yet developed detectable thyroid dysfunction

Rosa Aurora Chavez 9:13 AM  
If they are not already included, could you please include in the treatment guidelines recommendations about how to treat flares more optimally in children that had considerably improvement after IVIg, and what would be the criteria to give or not another round of IVIg?

Diana Bastien 9:13 AM  
If a child has a neurodevelopmental disorder, such as autism, and you suspect PANS, is the sudden-onset, or sudden worsening of premorbid symptoms, what you will see? In autism, the child might already have ritualistic behavior, picky eating, etc.

Sonal Goswami 9:14 AM  
thank you for presenting this topic! I have tried to convince pediatrician and neurologist few times in my career with kids having PANS but as a child psychiatrist no one sees what you see!

Dr. Jennifer Frankovich 10:15 AM  
Private answer  
Thanks Sonal for advocating for these kids. If you are interested in this disease, we are looking to add a psychiatrist to our PANS staff! [jfranko@stanford.edu](mailto:jfranko@stanford.edu)

Anders Fasth 9:18 AM  
And we do not see any of Dr Yolken's slide either

Michelle Young 9:18 AM  
Is everyone still hearing the chirping? It's very hard to hear him

Judith Leventhal 9:19 AM  
Im getting sound muffled with feedback squeaking, Very difficult to understand.

Melissa Stutler 9:20 AM  
Plus, his mic volume is a bit low.

Tatjana Peskir 9:20 AM

A few years ago there was an article in the New York Times about two cases / one where schizophrenia was induced by a bone marrow transplant (affected sibling donation) or cured (bone marrow transplant for other cause). Would this approach be worth exploring for schizophrenia?

Neuroimmune Foundation 10:52 AM

Private answer

Our apologies for not getting to your question.

Stephanie Vidrine 9:21 AM

Thank you!

Jonathan Birnkrant 9:21 AM

Try lower volume

Teresa Kohlenberg 9:21 AM

Very grateful to moderator for taking the time to intervene on the sound quality!

Jonathan Birnkrant 9:22 AM

That is a feedback sound

Nathalie Paravicini 9:23 AM

thank you for the great work. worth waiting for

Michelle Shores 9:24 AM

I do not see the 2022 slides - neuroimmune.org - where do I find this site? I only see the 2021 slides.

Neuroimmune Foundation 9:26 AM

[neuroimmune.org/2022-slides/](https://neuroimmune.org/2022-slides/)

Archana Leon-Guerrero 9:26 AM

Would be great if these questions and comments will be available afterwards, as many links and resources have been posted here

Neuroimmune Foundation 9:27 AM

We will do our best though I'm not sure that Zoom has improved the functionality on this since last year.

Rajitha Avva 9:26 AM

Regarding the previous talk, are most child psychiatrists treating with antibiotics or do most child psychiatrists just watch for these symptoms and refer out when PANS/PANDAS is suspected?

Theresa Willett (You) 9:31 AM

We have seen both in patients referred to us. Some psychiatrists have been comfortable assessing and treating infections and some have not, so it is most helpful for patients when primary providers can work closely with their psychiatrists.

Monica German 9:31 AM

Are the presentations recorded?

Neuroimmune Foundation 9:32 AM

Yes, but CME is only available to live attendees.

Yuval Shafir 9:34 AM

Any comments on autism?

Dr. Jennifer Frankovich 10:20 AM

We are interested in learning whether the immune response we see in PANS overlaps with autism regressions. we are in the process of applying for a Brain Foundation Grant to study autism regressions.

Anecdotally, we have analyzed ssRNAseq in one patient with autism and a PANS-like deterioration and he did have brain homing monocytes that resembled our PANS cohort.

We follow about 15 patients with Autism and PANS like deteriorations and we have mixed responses with regards to response to immunomodulation— which may reflect that we aren't always using the right immunomodulators or that there are other neuro-pathways we are not helping. Some of these patients do seem to be responsive to PANS directed therapies.

Carla Cavanagh 9:34 AM

was a syllabus sent out for the actual scheduling of all presentations?

Theresa Willett (You) 9:36 AM

<https://neuroimmune.org/wp-content/uploads/2022/05/Neuroimmune-Conference-Agenda-2022-final3.pdf>

Archana Leon-Guerrero 9:35 AM

Maybe moderator or someone could compile a list of these links and send them to us later? Hard for participants to do while also trying to pay attention to the presentations.

Neuroimmune Foundation 9:38 AM

We will do our best to add them to the same page the slides are on following the conference.

Henry Braa 9:41 AM

Do you know of psychiatric presentation due to Bartonella infections?

How about with Babesiosis or Borreliosis?

Neuroimmune Foundation 10:52 AM

Private answer

This will be covered by Dr. Shannon Delaney tomorrow.

Michelle Shores 9:43 AM

Thank you!

Madhuri Devdhar 9:45 AM

How about onset of PANS following covid? can you please shed light on this.

Theresa Willett (You) 9:48 AM

We have seen some cases in our clinic, and other centers have as well.

Bryan Levey 9:52 AM

I know of people who developed neuropsychiatric symptoms following covid-19 infections without preceding anosmia. Would the lack of anosmia suggest they are separate events, and that covid wasn't, in these cases, the cause of the neuropsych symptoms?

Neuroimmune Foundation 10:53 AM

Private answer

Our apologies for not getting to your question.

Henry Braa 9:53 AM

Does it seem that there may be increase incidence of new dementia in patients who have had covid-19 infection? Has dementia been accelerated in patients after covid-19 infection?

Neuroimmune Foundation 10:53 AM

Private answer

Our apologies for not getting to your question.

Margaret Ward 9:53 AM

Has it been investigated whether SARS CoV2 could get into the brain through the eyes via the optic nerve? Considering eye related symptoms with omicron.

Neuroimmune Foundation 10:53 AM

Private answer

Our apologies for not getting to your question.

Madhuri Devdhar 9:54 AM

Is the treatment of PANS induced by Covid infection the same as other P

Dr. Jennifer Frankovich 10:23 AM

Most of the post-COVID neuropsych deteriorations that I have been involved in looked different than PANS but we do have a few kids (one at MGH) who did meet PANS criteria after COVID.

Monica German 9:55 AM

Will you email us the recordings?

Neuroimmune Foundation 9:57 AM

Yes

Madhuri Devdhar 9:55 AM

Is the treatment of PANS induced by Covid infection the same as other PANS? Or is there anything more specific with covid induced PANS like antivirals

Theresa Willett (You) 10:13 AM

So far we have attempted to treat these patients similarly, but risk for re-infection cannot be reduced with prophylactic antibiotics.

Anne-Marie Turnier 9:57 AM

Are there genetic vulnerabilities we can screen for to educate our patients who are having neuropsychiatric symptoms, such as family history of Alzheimer's (APOE4)? I have patients who are experiencing "brain fog" and part of their frustration is they want a more definitive answer regarding SARS2 being a precipitant vs the "We think this is due to the virus, but we're not sure and we aren't really sure how to manage it.'

Neuroimmune Foundation 10:54 AM

Private answer

Our apologies for not getting to your question.

Sandy Berenbaum, LCSW 9:58 AM

Dr. Yolken, You're presentation is excellent! Is it possible for me to contact you by e-mail? Sandy Berenbaum, LCSW, private practice, practice limited to children and families with vector-borne disease, PANS, CIRS (from mold)

Neuroimmune Foundation 10:54 AM

Private answer

Our apologies for not getting to your question.

Farshid Farrahi 10:00 AM

Dr. Yolken, is there any scientific feasibility to the theory that COVID-19 came from a lab outbreak?

Neuroimmune Foundation 10:54 AM

Private answer

Our apologies for not getting to your question.

Stephanie Vidrine 10:09 AM

I have a few patients with acute onset of OCD (doing PANS workups now), who had no discernable illness (of which parents were aware), just receipt of a vaccine dose with an appropriate immune response. Can you comment on whether you or others are seeing any interaction between (or a study that investigated) an onset of OCD (and/or possible PANS) with what would be a normal immune response to any vaccination (not just COVID vaccine)? (Just trying to make sure parents are not seeing vaccines as a "source" of psychiatric symptoms (e.g., the Autism vaccine mess) and be able to provide appropriate education and information.)

Dr. Jennifer Frankovich 10:29 AM

It is always hard to sort out coincidental vs causal inflammatory triggers like infections and vaccines. We generally do a comprehensive work up, but like you, we often do not

find an infection (likely the inflammatory trigger passes but the immune system stays activated for 3 months (on average) after it is triggered.

More often we see problems when both the vaccine and an infection are simultaneous... so we try to get our kids vaccinated in the summer when they are less likely to get infected (if they are not in camp!).

Melissa Wilder 10:09 AM

Could the cruciferous vegetables breakdown any gases in the gut which ultimately helps side effects such as nausea or GI side effects?

Neuroimmune Foundation 10:54 AM

Private answer

Our apologies for not getting to your question.

Karl Holtzer 10:15 AM

I'm honored to have been able to hear Dr Yolken lecture today. Quite the pioneer as the director of our nation's first pediatric research center devoted to linking mental illness with childhood viral infections. Bravo Dr Yolken!

Yuval Shafir 10:15 AM

Any comments about the ongoing increase in autism prevalence?

Neuroimmune Foundation 10:54 AM

Private answer

Our apologies for not getting to your question.

Ayanna Cooke-Chen 10:16 AM

From an evolutionary standpoint, is psychiatric illness beneficial to SARS/COVID 19?

Neuroimmune Foundation 10:54 AM

Private answer

Our apologies for not getting to your question.

Sonal Goswami 10:17 AM

Jennifer I would love to be involved! I will e mail you for more info.

Roxanne Allegretti 10:17 AM

Is there anything that helps the brain damage caused in people over 50 by COVID19?  
Asking for a friend...

Neuroimmune Foundation 10:55 AM

Private answer

Thank you for your question

Michelle Shuff 10:18 AM

How do patients enroll in the studies you mentioned for women exposed to COVID while pregnant?

Neuroimmune Foundation 10:55 AM

Private answer

Our apologies for not getting to your question.

Anahita Bunce 10:18 AM

As we consider viral causes of neuropsychiatric disorders, how can the medical community work to combat discrimination in insurance coverage? An example would be that many physician's disability insurances only cover 2 years if "psychiatric" versus other medical causes of longterm disability.

Neuroimmune Foundation 10:55 AM

Private answer

Thank you for your question.

Leslie Goransson 10:20 AM

what about long covid? can you comment on that as a neuropsychiatric consequence? treatment approaches?

Neuroimmune Foundation 11:00 AM

Private answer

Our apologies for not getting to your question.

Jenna Luu 10:24 AM

I'm already seeing a flood of patients with post covid cognitive dysfunction. What is the treatment? Stimulants? SSRI? SNRI? Anti-inflammatory?

Neuroimmune Foundation 10:56 AM

Private answer

Thank you for your question.

Lourdes Carolina Ceron-Canas 10:25 AM

Thank you so much for this amazing conference and all the speakers. Our patients will benefit greatly from this conference!

Neuroimmune Foundation 10:58 AM

Private answer

Thank you so much!

Tatjana Peskir 10:26 AM

I have seen relapse of my PANS free child after covid. Do you see many such cases? The re-onset was very chaotic with symptoms she previously had showing up in a very disorganized manner, some days only some, some days all of them, severity of symptoms also varying very much. IN our case reintroduction of monthly IVIG is on the way to resolving the relapse.

Theresa Willett (You) 10:39 AM

We have seen some patients relapse w COVID and Flu. The antivirals are pretty limited in access and duration, so IVIg seems like a good anti-inflammatory option without significant immunosuppression. Glad to hear it was helpful for your child!

Melissa Stutler 10:26 AM

Is anyone studying a correlation between PANS and narcissism?

Dr. Jennifer Frankovich 10:33 AM

Such an interesting question. We did have had a few patients who we thought had a very significant personality disorder, but after treating with immunomodulation we have seen their personalities transform. One kid in particular had no empathy and we really thought he had an underlying personality disorder (before PANS) but after steroid pulsing and treating arthritis, now he is a warm, kind, loving, empathetic and generous young man!

Kristen Brashares 10:30 AM

New study on Gulf War Illness:

<https://www.utsouthwestern.edu/newsroom/articles/year-2022/sarin-nerve-gas-gulf-war-illness.html>

Sophia Zervos Kamchis 10:30 AM

Have you seen any cases of PANDAS patients relapsing later severely with viral infection eg covid? Would antivirals help manage these symptoms?

Dr. Jennifer Frankovich 10:34 AM

most of our PANS patients do not relapse with the COVID vaccine or illness. But we have had a few.

Anahita Bunce 10:30 AM

Any studies suggesting viral causes of ADHD?

Neuroimmune Foundation 11:00 AM

Private answer

Our apologies for not getting to your question.

Lisa Drummond 10:31 AM

Thank you for this conference, the engaging, interesting, informative presentations, and research!

Nathalie Paravicini 10:33 AM

the info on sulphorafanes was particularly interesting for the current discussion, also may be more accessible, safe with many other positive benefits

Neuroimmune Foundation 10:58 AM

Thank you for your comment.

Rana Rand 10:57 AM

How can we learn more from Dr. Bergquist after today's talk?

Neuroimmune Foundation 11:23 AM

Private answer

Our apologies for not getting to your question.

Henry Braa 10:58 AM

Are there any known cases or suspected cases of CFS/ME caused by or associated with any types of vaccinations?

Neuroimmune Foundation 11:24 AM

Private answer

Thank you for your question.

David Traver 11:05 AM

Study by Singh et al for autism is helpful.

Neuroimmune Foundation 11:06 AM  
Thank you

David Traver 11:07 AM  
Combination of sulforaphane (robust titrated doses), CBD and LDN has offered encouraging benefit.

Neuroimmune Foundation 11:07 AM  
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Rana Rand 11:08 AM  
Can we see this study reference again?

Neuroimmune Foundation 11:24 AM  
Private answer  
Our apologies for not getting to your question.

Tempe Chen, MD 11:11 AM  
Will chat transcript be available later to attendees? There is some very good content here as well as resources.

Neuroimmune Foundation 11:16 AM  
Last year, there was not a function in Zoom to export chat however, we will try again this year.

Anahita Bunce 11:11 AM  
Dr. Bergquist, any waxing and waning of CFS patients. Related to autoantibodies? Any postmortem brain pathology?

Neuroimmune Foundation 11:24 AM  
Private answer  
Thank you for your question.

Rana Rand 11:14 AM  
What do you find most helpful to improve symptoms and function in your patients with ME/CFS?

Neuroimmune Foundation 11:24 AM  
Private answer  
Our apologies for not getting to your question.

Stanley Naides 11:16 AM

Do paTIENTS With CFS/ME have variants inMITOCHONDRIAL DNA that may affect energy demands?

Neuroimmune Foundation 11:24 AM

Private answer

Our apologies for not getting to your question.

Valerie La Rosa 11:17 AM

You can also copy and paste it into a blank document of some kind, if that helps.

Neuroimmune Foundation 11:19 AM

Dr. Willett has been kind enough to do this for us! Thanks Dr. Willett!

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Rana Rand 10:57 AM

How can we learn more from Dr. Bergquist after today's talk?

Neuroimmune Foundation 11:23 AM

Private answer

Our apologies for not getting to your question.

Theresa Willett (You) 11:31 AM

For those interested in attending a conference focusing on autonomic illness, which has overlap w ME/CFS, there is an upcoming conference:

<https://www.dysautonomiainternational.org/page.php?ID=205> per Dysautonomia International, occurring in July 14-17,2022.

Julie Izatt 11:45 AM

I have found that bacillus subtilis could modulate the development pathways of th subsets. poly gamma glutamic acid promotes the development of th1 and th17 cells but inhibited the development of th2 cells and unregulated the expression of tbet and ror ty master genes while down regulating the level of gate 3 master gene. Do you think it's possible altering the microbiome with bacteria could work?

Neuroimmune Foundation 12:12 PM

Private answer

Our apologies for not getting to this question.

Rina Jaffe 11:09 AM

do patients with CFS have a higher chance of having long covid than the general population?

Neuroimmune Foundation 11:50 AM

Private answer

Our apologies for not getting to your question.

Robert Lowe 11:10 AM

Is there any overlap between your patients and patients with fibromyalgia?

Neuroimmune Foundation 11:50 AM

Private answer

Our apologies for not getting to your question.

Farshid Farrahi 11:13 AM

Do the antibodies which have been found in 20-30% of ME/CFS syndrome affect both the PNS and CNS muscarinic receptors?

Neuroimmune Foundation 11:50 AM

Private answer

Our apologies for not getting to your question.

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Angela Tang 11:46 AM

Dr Chen: Exciting work! Was the increase in antigen specific Treg activity long lasting?

Dr. Wanjun Chen 12:04 PM

good q, yes, this is what we hope for. we are now working on to keep them longer and functional ,

Terry Harville 11:47 AM

This approach with specific Treg generation could also be applied to the solid organ transplantation for tolerization.

Dr. Wanjun Chen 11:57 AM

yes.

Dan Camacho 11:46 AM

For this protocol, why is it necessary to induce apoptosis with antibodies if there are already so many cells undergoing apoptosis at baseline?

Dr. Wanjun Chen 12:10 PM

Private answer

Yes, this may be enough to maintaining homeostasis in normal people. however, in the case of autoimmune diseases and inflammation, at given any time, and location, the number of apoptotic cells may not be sufficient to trigger phagocytes to produce enough TGF- $\beta$  to creat

the immunoregulatory microenvironment. plus, as I mentioned, we have to clear up some "bad" cells in the system and empty some space for the newly generated cells.

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Jason Hyde 12:17 PM

Dr. Vasanaawala, what ultrasound criteria/methods are you using to confirm synovial thickening? Or are you just comparing to unaffected joints?

Dr. Shreyas Vasanaawala 12:19 PM

Thanks so much for this question. Mild synovial thickening is qualitative - in more moderate/severe cases the synovium will bulge in rounded fashion and extend beyond the line between the cortical bone on each side of the joint. So, to answer your question, it is not an assessment that is relative to other normal joints.

Annette Hulse 12:10 PM

For Dr. Vasanaawala, how can I refer patients to you for this kind of specific radiologic testing?

Dr. Shreyas Vasanaawala 12:23 PM

If you are not in our system, please fax request to (650) 724-2663. Our phone number is 650-497-8376

Achina Stein 12:21 PM

Will you be going over the treatment of PANS?

Neuroimmune Foundation 12:23 PM

We are working on a very in depth review of the treatment guidelines for PANS. This CME will be available this summer.

Stephanie Braun 12:25 PM

I know at Stanford you have access to US that can detect subtle joint findings. What imaging do you recommend to evaluate if you do not have access to this level of US?

Dr. Shreyas Vasanaawala 12:29 PM

MRI works very well. Our group strongly prefers contrast enhanced MRI, but many institutions perform without intravenous contrast

Nathalie Paravicini 12:28 PM

If we send for imaging, will the radiologists evaluating the imaging report on this? Or do we need to ask for them to look for it?

Dr. Shreyas Vasanaawala 12:31 PM

For MRI, yes - very standard. For US, it depends on whether the radiology group is already doing them. If not, you may have to ask explicitly the first few times.

Angela Tang 12:28 PM

Are community radiologists knowledgeable enough to make diagnosis of enthesitis?

Dr. Shreyas Vasanaawala 12:32 PM

On MRI, it is very clear. On US, the findings can be somewhat more challenging.

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### **Possible missed answers:**

*Tatjana Peskir 12:04 PM*

*Would ERA be visible on x ray?*

*Annette Hulse 12:10 PM*

*For Dr. Vasanaawala, how can I refer patients to you for this kind of specific radiologic testing?*

*Peter Klinger 12:13 PM*

*I had 10 yr old pt yesterday with ongoing aching pain behind his both knees that he has complained of over 2+ years. No tenderness elicited when palpating joint and tendon insertion sites. No redness, swelling noted. And he denies other joints involved. I did find that he met PANS criteria. How might I work this up?*

*Stanley Naides 12:14 PM*

*Did these arthritis patients have testing for rheumatoid arthritis, CCP, 14-3-3eta? ANA?*

*Henry Braa 12:19 PM*

*Do you see cervical spine signs and symptoms associated with PANS? ?Cervical spine instability that could sometimes cause POTS/autonomic dysfunction (that could be intermittent)?*

*Stephanie Braun 12:25 PM*

*I know at Stanford you have access to US that can detect subtle joint findings. What imaging do you recommend to evaluate if you do not have access to this level of US? Dr. Shreyas Vasanaawala is typing an answer...*

*Nathalie Paravicini 12:28 PM*

*IF we send for imaging, will the radiologists evaluating the imaging report on this? Or do we need to ask for them to look for it?*

*Angela Tang 12:28 PM*

*Are community radiologists knowledgeable enough to make diagnosis of enthesitis?*

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1230-1p missed new questions

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Sarah Barnett 12:20 PM

Is there any data suggesting that earlier or more aggressive treatment of PANS prevented the later development of these comorbid inflammatory arthritis diseases?

Dr. Jennifer Frankovich 1:08 PM

this study is on my TO DO list, but right now, I do not know the answer to your question! sorry!

Melissa Stutler 12:20 PM

Are you seeing any Costochondritis in the PANS patients?

Dr. Jennifer Frankovich 1:08 PM

Yes! We have seen this and it may be a manifestation of ERA.

Henry Braa 12:21 PM

How about acquired kyphosis or scoliosis in PANS patients?

Dr. Jennifer Frankovich 1:10 PM

We see this but we don't yet know if the rate is higher than the baseline pediatric population. I will add this to the list of studies to do!

Angela Tang 12:23 PM

do joint symptoms typically improve when PANS improves or is the arthritis independent? Is there a correlation between PANS severity and likelihood of extra-neurologic manifestations like arthritis, Behcets, IBD, thyroiditis?

Dr. Jennifer Frankovich 1:11 PM

We have seen both.... PANS and arthritis improve together. But we do have cases of patients whose PANS went into remission but the arthritis is still active.

Nicole Rice 12:25 PM

Do you recommend baseline ultrasounds of pans patients and of what joints if they do not have pain on presentation?

Dr. Jennifer Frankovich 1:15 PM

Hi Nicole. Since most centers (even excellent Children's Hospitals) do not have a trained MSK ultrasound team... thus, it is not possible that all patients with PANS get this evaluation at onset. We are lucky to have such a team at Stanford, but this is rare. I think for other centers, clinicians will have to rely on the history and physical exam.

Gretchen Brantley 12:25 PM

Can you please share the list of screening tools that you use in your clinic? What thyroid tests, etc? Thank you and so grateful to the work your clinic is doing for PANS/PANDAS!

Dr. Jennifer Frankovich 1:18 PM

Hi Gretchen- we are developing a database which will include all the questionnaires, labs, etc with the PPN and we would love to invite you and other PANS groups to participate. We hope that this system will help clinicians and patients.

In the meantime, a preliminary list of labs we get is in this publication.

Chang K\*, Frankovich J\*, Cooperstock M, Cunningham M, Latimer E, Murphy T, Pasternack M, Thienemann M, Williams K, Walter J, Swedo S. Clinical Evaluation of Youth with Pediatric Acute-Onset Neuropsychiatric Syndrome (PANS): Recommendations from the 2013 PANS Consensus Conference. Journal of Child and Adolescent Psychopharmacology, Vol. 25, No. 1, February 2015: 3-13. PMID: 25325534

Maria Hellman 12:26 PM

We met 2 different families with siblings not meeting PANS-criteria but with some more discrete neuropsychiatric symptoms that also answer on NSAIDs or antibiotics. One of those siblings also has spine-ache with confirmed inflammatory activity with Mrt. Should we focus more on siblings? Treat eventhough PANS-criteria are not fully met if PANS in the family?

Dr. Jennifer Frankovich 1:20 PM

Hi Maria

We do try to evaluate all of our PANS siblings and we do treat if we detect an inflammatory syndrome. But if the sib does not have signs of inflammation, but have a psychiatric disorder, we often use standard of care for the psych symptoms— but if they suddenly deteriorate, then we do treat like a pans case.

Jill Littrell 12:27 PM

Do you check for a mutation in AIRE, which is associated with a loss of negative selection of T cells in the thymus?

Dr. Jennifer Frankovich 1:21 PM

We have checked in about 50 cases, but found none. However, we are now doing exome sequencing in all our cases, so we will see if we find it! Thanks!

Sarah McAllister Ulbricht 12:27 PM

With the patients you are describing, were they aggressively treated for their PANS at initial presentation and STILL developed the arthritis or was their PANS not treated and THEN they developed further autoimmune issues?

Dr. Jennifer Frankovich 1:23 PM

Hi Sarah. It is a mix. Some of the kids had PANS for years before they came to us and showed up in our clinic with PANS + AI dz or arthritis. But we have even had kids, who

we thought that we treated well (and pans went into remission) and they still got arthritis!!!

Robert Paul 12:29 PM

By "treating" the pans (for us, azithromycin, ibuprofen, anti histamine) is the arthritis risk reduced. In our daughter we saw improvement in ankle pain when she came out of flare. Can we still get her ankle assessed despite the the pain having reduced.

Dr. Jennifer Frankovich 1:24 PM

early episodes of arthritis are likely post-infectious and can self-resolve or resolve with mild antiinflammatories including NSAIDs and Azith. We often treat even in the early stages to try to prevent relapses in PANS and arthritis. But there is no "correct path".

Ann Maitland 12:30 PM

any thoughts of preventive strategies after patients have been shown to be at risk for these arthritides, autoimmune disorders?

Dr. Jennifer Frankovich 1:24 PM

Plaquenil

Terry Harville 12:32 PM

In children B27CREG and B51 symptoms can be indistinguishable, until older. We also see with B35. We consider these spondyloarthropathy until Behcet's more obvious. Thanks for your presentation!!!

Dr. Jennifer Frankovich 1:30 PM

Hi Terry- this is so interesting. Thank you for this comment. It sounds like you are an expert in HLA/rheum disorders. Can I reach out to you and ask questions? I am at [jfranko@stanford.edu](mailto:jfranko@stanford.edu). Thanks for your interest in neuroinflammatory diseases.

Bryan Levey 12:33 PM

The problem I anticipate is that, even though we have rheumatologists in this area, most practice in a children's hospital where they believe PANS either is "controversial" or where they say frankly that they don't believe it exists. So to whom do we turn for help when our PANS patients develop arthritic symptoms?

Dr. Jennifer Frankovich 1:35 PM

This is a real problem plaguing many clinicians/pans families. There is no good path for many of these patients. We are trying to prove this is a real disease and we hope that eventually more clinical centers will recognize pans.

I think the best thing to do is counsel the family to not bring up PANS and focus on the joint symptoms... hopefully the family won't be discriminated against due to behavior/psych symptoms in the medical chart or displayed in the rheum office. PANS patients are definitely marginalized and discriminated against. so sad.

Tasha Ellis 12:34 PM

When you see intermittent or migrating joint pain in a PANS flare, is this symptom different than the chronic arthritis you are seeing in 25% of your cohort?

Dr. Jennifer Frankovich 1:40 PM

If the patient has migrating joint pain, I would be suspicious for a post-strep syndrome (acute rheumatic fever, Sydenham chorea, which can look like PANS with subtle signs of chorea- milkmaid grip, wormian or darting tongue, etc.

If the patient has intermittent pain, it may be post-infectious episodes or arthritis or pain dysregulation (which is common in PANS) or perhaps it is chronic arthritis but the patient only complains intermittently (which we have seen).

Our patients have so many symptoms, including pain amplification and under-reporting of pain that we usually have to get imaging to understand whether arthritis is present in these less clear cases.

Henry Braa 12:34 PM

Do you know any rheumatologist that would see a patient who is a young adult with PANS and spine and other joint pain likely due to this type of condition? Pediatric specialist won't see young adults and adult medicine rheumatologist won't see PANS patients with these conditions, so patients that are older than 18 yoa can be in a type of limbo in every way.

Dr. Jennifer Frankovich 1:44 PM

Hi Henry, This is truly an unfortunate situation (tragic for patients).

I would counsel the patient/family to see an adult rheumatologist but only reveal/discuss the joint/spine symptoms and not ask for "PANS care". Rheumatologists will almost universally say "I don't treat pans" but they are happy to evaluate and treat arthritis.

Madhuri Devdhar 12:55 PM

for patients with PANS being treated with IVIG, is HD IVIG 2 g/kg the only dose which offers immunomodulatory effect or has there been any data on using lower doses?

Dr. Jennifer Frankovich 1:46 PM

Hi Madhuri

For our larger patients, we cut off the dose at 70 g total so that the mg/kg is often less than 2/kg.

For our patients with frequent relapses and the diagnosis of CVID, we use 400 mg weekly SQ. But this dose does not treat the PANS illness. But it does help prevent infections we can trigger pans relapses.

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Henry Braa 1:03 PM

Do you ever see “stiff mam” patients with perhaps paradoxical hyper mobility at the cervical spine level, rather than neck registry, but yet have rigidity at the lower spine and other parts of the body? Also kyphosis and acquired scoliosis in a young adult?

Dr. Sean Pittock 1:10 PM

yes-you can get predominant axial neck rigidity-more common in African Americans-electrophysiological studies and biomarker studies would be important in making a diagnosis

Alanna Yee 1:04 PM

If GAD65 is thought to involve significant T cell-driven autoimmunity, would that suggest that Cytoxin would be an appropriate therapy to arrest disease activity? Has the Mayo Clinic offered this for many GAD65+ autoimmune patients and what have the results been?

Dr. Sean Pittock 1:13 PM

excellent question-yes we do use for patients with rapidly progressive encephalitis, ataxia and those that have SPS that do not respond to IVIG/rituximab-results are variable but likelihood of response is <20%

Margaret Ward 1:17 PM

What triggers the production of GAD 65 Antibodies?

Dr. Sean Pittock 1:35 PM

great question: multifactoria-genetics plays a role as type 1 DM runs in families-environmental and possibly infectious triggers also play a role. We really don't have a good handlw on what triggers most autoimmune conditions

thanks

Sean

Alanna Yee 1:18 PM

Does the Mayo Clinic have any plans to develop testing for antibodies against dopamine receptor D1 and D2L, anti-lysoganglioside GM1, and anti-tubulin?

Dr. Sean Pittock 1:23 PM

thanks you-these are on a long list of development projects-we have a huge program of projects in development-currently we are validating the septins, novel discoveries and comprehensive cytokine and chemokine platform assays  
many thanks

Adeline Goss 1:19 PM

How frequently do you see normal IgG Index and OCB in SPS?

Dr. Sean Pittock 1:21 PM

In the majority of patients

Sonal Goswami 1:22 PM

do u recommend to check GAD65 in a patient with type 1 DM to find out risk for stiff syndrome/sz?

Dr. Sean Pittock 1:36 PM

Yes-I think it is helpful to know if the DM is autoimmune and type1vs type 2. risk of SPS in DM is tiny and thus I would not check unless indicated clinically

Melissa Meyer 1:27 PM

I was diagnosed with stiff person syndrome (GAD level 106), I know you mentioned a stem cell transplant that was effective for around 3 years. If this treatment becoming more common?

Dr. Sean Pittock 1:28 PM

it is a reasonable treatment to consider if all else has failed. The most important thing is to make sure the diagnosis is correct.

Regards

Alanna Yee 1:26 PM

Is GAD65 included if PNEFS is ordered?

Dr. Sean Pittock 1:31 PM

yes-it is included in both serum and CSf test

Melissa Meyer 1:27 PM

I was diagnosed with stiff person syndrome (GAD level 106), I know you mentioned a stem cell transplant that was effective for around 3 years. If this treatment becoming more common?

Dr. Sean Pittock 1:28 PM

it is a reasonable treatment to consider if all else has failed. The most important thing is to make sure the diagnosis is correct.

Regards

Sylvia Fogel 1:22 PM

Curious about overlap between stiff person syndrome and the diagnosis of "catatonia" in psychiatry. Also have patients dxed with catatonia been worked up at the Mayo Center

Dr. Sean Pittock 1:33 PM

good question-we have the largest Autoimmune Neurology Clinic in the World with 7 trained autoimmune specialists-we have seen just about every possible presentation for autopimmune disorders. Catatonia may be misdiagnosed as SPS-and vica versa-but they are different conditions requiring different treatment approaches

thanks for your question

Melissa Stutler 1:27 PM

Bartonella patients report similar symptoms, especially the neck rigidity and muscle spasms. Have you faced such patients in your practice?

Neuroimmune Foundation 1:34 PM  
Dr. Delaney will probably be able to address his tomorrow.

Taylor Bean 1:24 PM  
Can someone please confirm that not all presentations are available for download. I asked this question in the morning and was told all were found on this link <https://neuroimmune.org/2022-slides/> however I cannot find some of the slides. I would like to have them if possible!

Neuroimmune Foundation 1:32 PM  
Private answer  
Not all slides are available. Many presenters are sharing unpublished data so these will not be available. All that will be are on the website currently.

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Sonal Goswami 1:53 PM  
what is the age that DBS is approved for OCD  
Dr. Sameer Sheth 2:00 PM  
Adults, typically >21

Nicole Burkette Ikebata 1:53 PM  
are you accepting new patients for your trials?  
Dr. Sameer Sheth 2:01 PM  
OCD trial is almost over, but we're hoping to have a new one in a year or so. Depression trial still recruiting. You can email me (Sameer.Sheth@bcm.edu) and also look us up on [clinicaltrials.gov](https://clinicaltrials.gov).

Hasan Abdallah 1:54 PM  
any application for PTSD patients  
Dr. Sameer Sheth 1:59 PM  
West LA VA and UCLA have a study. Active area of research.  
Jamie Candelaria-Greene 1:56 PM  
Thanks for the very hopeful presentation!

Sonal Goswami 1:54 PM  
how do we refer patients?  
Dr. Sameer Sheth 2:00 PM  
Emailing me is probably easiest: [sameer.sheth@bcm.edu](mailto:sameer.sheth@bcm.edu). We have a multi-disciplinary committee perform the evals, as I mentioned, including Dr. Goodman (Psychiatry) and Dr. Storch (Psychology).

Pieter Fourie 1:55 PM

How about treating disruptive mood dysregulation such as one would find in excessive demand avoidance with DBS?

Dr. Sameer Sheth 2:02 PM

Not exactly sure, but it may be a challenge if outside the bounds of typical inclusion/excl criteria of a depression trial.

Priscilla Hidalgo 1:57 PM

How possible would it be for pts to eventually dc DBS after being stable, less say 1-2 years?  
Thnx

Dr. Sameer Sheth 2:03 PM

It's rare (have not seen it myself) that patients would eventually "outgrow" the need for DBS. This is true of depression, but also true for movement d/o like tremor, PD.

Archana Leon-Guerrero 1:58 PM

As a psychiatrist, I really appreciate the neurosurgeon's passion for parity between "mental health" and "medical health" issues. Certainly it is an artificial distinction.

Dr. Sameer Sheth 2:04 PM

Exactly! Lots of work to do. We just had a commentary accepted (today) at Nature Med on this topic. Please search in a month or so, and it should be out. Or email me and I would be happy to send you once we have a proof/link. [Sameer.Sheth@bcm.edu](mailto:Sameer.Sheth@bcm.edu)

Henry Braa 1:58 PM

Do you actually consider patients with refractory pans ocd for this d s?

Dr. Sameer Sheth 2:04 PM

Good question. I would have to defer to Dr. Goodman for that one.

---

David Traver 2:28 PM

specific anti -TNF agents may exert different levels of efficacy against depression?

David Traver 2:28 PM

<https://www.dermatologytimes.com/view/psoriasis-treatment-may-combat-accompanying-depression>

**unanswered:**

Christianna Beebe 2:34 PM

Herbalists will report that tumeric (normally good for inflammation) can cause dopamine surges which is not good for many kids with PANS

Sonal Goswami 2:26 PM  
any use of turmeric in depressed people?

Margaret Ward 2:26 PM  
I'm curious as to whether the omega 3 fatty acid were purified and checked for toxicants and contaminants as many fish oil samples have pcb's and other contaminants

Nick Stull 2:27 PM  
Dr. Raison, thank you for great information. Could Vitamin D reduce inflammation, and if so, is that a possible additional benefit to the estimated increase in brain serotonin? Thank you

David Traver 2:28 PM  
specific anti -TNF agents may exert different levels of efficacy against depression?

David Traver 2:28 PM  
Cite below:

Priscilla Hidalgo 2:28 PM  
Are we at that point that we need to routinely check CRP levels?

Amy Frey Miller 2:29 PM  
You said effexor in your list with the SSRIs and it is an SNRI - do you know actually which way it falls? If it is more adrenergic and falls more toward inflammatory response or like the SSRIs?

Monica German 2:31 PM  
I am wondering about the role of microbiome- inflammation- depression

David Traver 2:31 PM  
What is your experience with LDN and CBD combination for depression?

Meegan Lipman 2:31 PM  
Any evidence re: relationship btwn CRP and response to other mood stabilizers / antipsychotics?

Monica German 2:31 PM  
CRP is always high in my obese patients

Melissa Stutler 2:31 PM  
Could you please repeat the medication options for high versus low CRP? markers. Wellbutrin, for example, for high and what classes were the low?

Rachel Vinkey 2:31 PM  
Did Hashimotos show same effect re. depression type & R as other auto-immune diseases mentioned?

Henry Braa 2:32 PM

I am sorry if you have already answered this, but have you don't similar observations with respect to inflammation in severe OCD, and perhaps PANS-based OCD? Thanks.

Rebecca Hirsch 2:32 PM

Do you think getting a CRP for depression workup is useful for most people to guide drug choice? If it's high go noradrenergic, if WNL SSRI? And what about SNRIs compared to Wellbutrin?

Jenna Luu 2:32 PM

Obese patients also have chronically elevated CRP. But not all are depressed. Any thoughts?

Romeo Mariano 2:32 PM

You should look at the work of Jaak Panksepp and combine it with psychoneuroimmunology to understand the differences in response to different antidepressants or interventions for depression.

Orawan Gardner 2:33 PM

Why lurasidone vs. other SGAs for inflammatory subgroup?

Lisa Drummond 2:33 PM

Dr. Raison-Thank you for your presentation. What are your thoughts on pharmacogenetic testing prior to initiation of therapy for depression with SSRIs and other psychotropic medications?

Farshid Farrahi 2:33 PM

fascinating presentation, Dr. Raison! Thank you very much for your research as well.

Christianna Beebe 2:34 PM

Herbalists will report that tumeric (normally good for inflammation) can cause dopamine surges which is not good for many kids with PANS

Sarah Berkson 2:34 PM

You said how the lurasidone data included child and adolescent subjects. Which other anti-inflammatory interventions have been studied in children and adolescents and what have they found? Is CRP of 5 a meaningful cutoff across different ages?

Henry Braa 2:34 PM

Also, I want to clarify that when we speak of "inflammation" it could be manifested in different marker's right? That is CRP and/or ESR don't have to be elevated, but rather cytokines could be elevated, etc. Right? I guess the definition of inflammation has expanded over the decades, right?

Sonal Goswami 2:35 PM

thanks  
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Henry Braa 2:54 PM

Dr. Wilson, have you studied patients with PANS to find what organisms may have caused infection in these patients with PANS or POTS or tick-borne diseases, etc?

Henry Braa 2:56 PM

Or just simply a picture of neuroencephalopathy of unknown etiology that could be PANS but difficult to diagnose?

Henry Braa 3:01 PM

How do you feel about the Cunningham Panel used to help with diagnosing or evaluating patients that likely have PANS? Too many do not give it enough credit but it is useful, I feel.

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Melissa Stutler 2:31 PM

Could you please repeat the medication options for high versus low CRP? markers. Wellbutrin, for example, for high and what classes were the low?

Neuroimmune Foundation 3:17 PM

Private answer

Apologies we were unable to get to your question.

TheresaWillett (You) 3:19 PM

I believe his main differentiation was SRI vs dopaminergic/adrenergic agents, with the latter being more helpful for patients with identified inflammation + depression.

Jon Ahrendsen 3:38 PM

The name of the drug again?

Dr. Sarkis Mazmanian 3:44 PM

AST-120

Kristie Waln 3:36 PM

How do we find information about trial? Phase 2.

TheresaWillett (You) 3:37 PM

I believe he referenced <https://www.theautismstudy.com>

D. Dawn Motyka 3:38 PM

I am wondering about long term micronutrient deficiencies from a habitual binder. Need to watch for this in future study designs

Dr. Sarkis Mazmanian 3:45 PM

Yes, the drug absorbs amino acids, so is given 1 hour after a meal

Jon Ahrendsen 3:38 PM

The name of the drug again?

Dr. Sarkis Mazmanian 3:44 PM

AST-120

Pieter Fourie 3:40 PM

May I be able to get more information regarding AB-2004 please?

Dr. Sarkis Mazmanian 3:44 PM

theautismstudy.com

David Traver 3:30 PM

Looking for possible correlative significance in light of Sid Feingold's work...

Dr. Sarkis Mazmanian 3:45 PM

Sid was my hero

Sylvia Fogel 3:39 PM

Fabulous presentation and amazing work. Can you comment on fecal transplant as a way to shift levels of GI biomarkers.

Dr. Sarkis Mazmanian 3:46 PM

Early studies in FMT have shown promise, but we need placebo controls, just as in our trial

David Sherry 3:41 PM

How about fecal transplant?

Dr. Sarkis Mazmanian 3:46 PM

FMT has shown early promise, but more work is needed

---

Farshid Farrahi 3:13 PM

what are examples of co-metabolites which might be implicated psychiatrically?

Tarah Kruger 3:24 PM

Any research on the impact of microplastics on microbiome?

Julie Izatt 3:27 PM

My daughter with AE has responded extensively well to Bacillus subtilis, have you studied this bacteria and how it regulates naive cd4 cells or any other work? Thanks

David Traver 3:28 PM

4-EP is postulated to be formed via the fermentative action by Clostridia. Did you observe this in your studies? Does your work have any interface with McFabe and Clostridia and propionate levels?

David Traver 3:30 PM

Looking for possible correlative significance in light of Sid Feingold's work...

Ashok Srinivasan 3:31 PM

Given myelination defects, could 4-EP be a cofactor along with EBV in MS?

Henry Braa 3:33 PM

What is the name of the charcoal that you used from Japan?

Henry Braa 3:38 PM

Would you consider OCD and PANDAS patients for your trials since many have autism like behaviors, etc? Thanks.

D. Dawn Motyka 3:38 PM

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Jennifer Hubbard 3:38 PM

That was amazing! The gut brain connection validation is so appreciated

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Angela Ng 3:39 PM

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Sylvia Fogel 3:39 PM

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Monica German 3:39 PM

Can you please repeat what was the type of charcoal used?

Pieter Fourie 3:40 PM

May I be able to get more information regarding AB-2004 please?

David Traver 3:41 PM

Kynurenate? Glial activation?

David Sherry 3:41 PM

How about fecal transplant?

David Traver 3:42 PM

Thanks for the great presentation!

Sonia Carlson 3:42 PM

Do fecal transplants help?

Lisa Drummond 3:43 PM  
Thank you!

Deborah Milling 3:43 PM  
Deep gratitude!