

# IMPACT REPORT

JUNE 2022 - MAY 2023

**Celebrating five years of clinician education,  
family support, and research funding**



**NEUROIMMUNE**  
FOUNDATION

**Advocating on behalf of individuals with neuroimmune conditions**



Dear Supporters,

In January 2018, Neuroimmune Foundation (at that point named Foundation for Children With Neuroimmune Disorders) received our IRS Letter of Determination, officially acknowledging the launch of our non-profit organization. The following month, we set up our Facebook and Twitter pages, and the month after that hosted Dr. Susan Swedo of the NIMH at multiple Wisconsin Grand Rounds events. Later that fall, as we set out to offer our first accredited CME webinars, we collaborated with many other advocates to mail 40,000 postcards to clinicians nationwide offering them free PANS/PANDAS CME. In the blink of an eye, with the support of our community, we'd educated over 5000 clinicians worldwide, launched a fellowship program at two major universities, provided funding for two major research studies, grown a clinician network in the hundreds, were invited to have our conference content featured in special issues of medical journals, and supported thousands of families! It's been a whirlwind five years, and thanks to the incredible help from many of you, we've accomplished so many goals and seen a genuine change in the medical landscape for families facing PANS/PANDAS.

In celebration of our fifth anniversary, we wanted to review the impact you've helped us have across the past five years. Our organization would be nothing without our amazing supporters. Thank you to those of you who have played a role, big or small, in lightening the load for PANS/PANDAS families!

Kindest Regards,

Anna Conkey

Executive Director and Founder  
Neuroimmune Foundation

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

## Mission & Vision

Neuroimmune Foundation (formerly The Foundation for Children with Neuroimmune Disorders) is a 501(c)(3) non-profit organization dedicated to improving outcomes for individuals with Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Syndrome Associated with Streptococcal Infections (PANDAS), as well as related immunepsychiatric conditions.

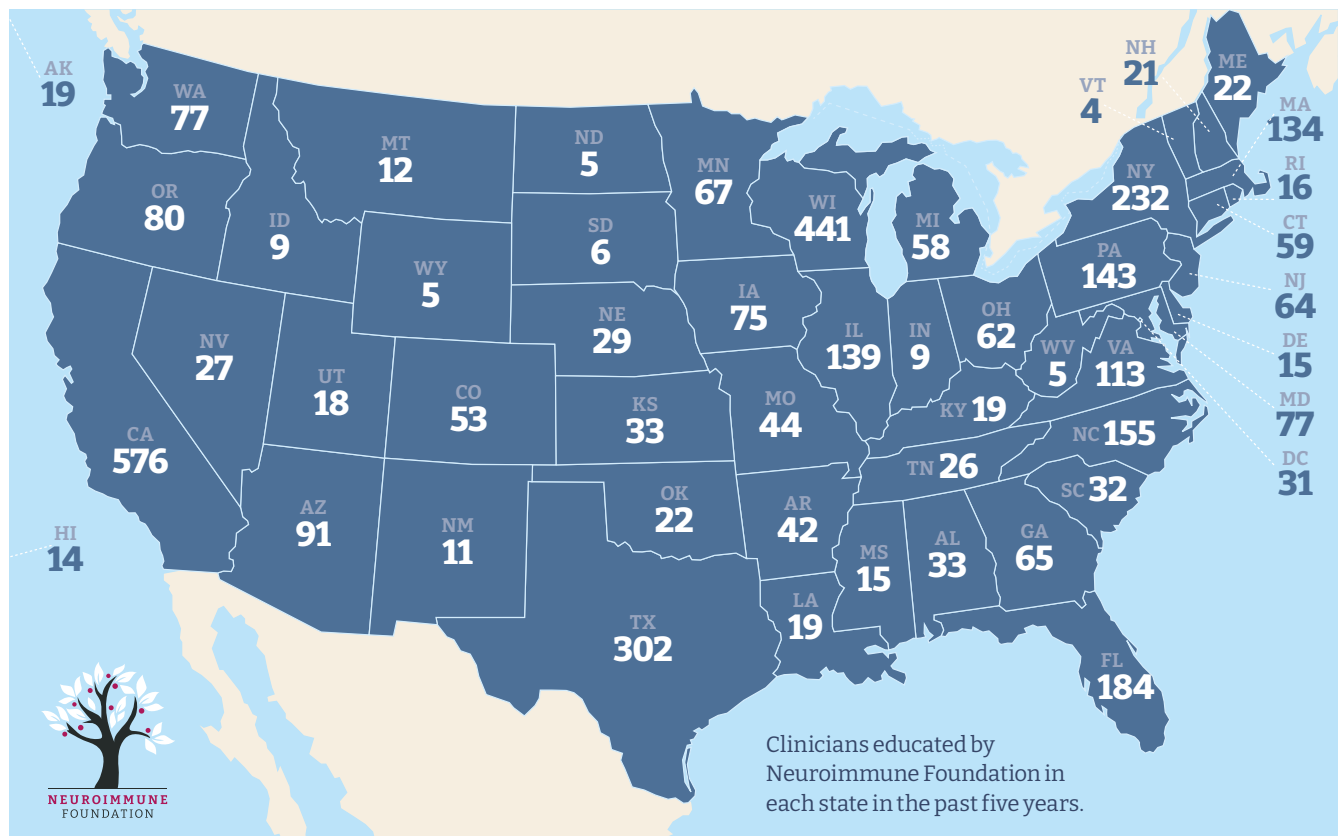


## We are dedicated to

- dramatically accelerating physician education of PANS, PANDAS, and encephalitis
- significantly improving outcomes for individuals impacted by these disorders through prompt diagnosis and insurance based care
- providing meaningful support to families during their darkest days
- catalyzing research at an unprecedented pace that will ultimately lead to lasting remission for all individuals impacted by these disorders

We aim to accomplish these goals by sponsoring accredited continuing medical education, fundraising for research and fellowships, and directly supporting families.

**Across the past five years, together we have educated nearly 4000 clinicians in the US and over 1000 outside of the US. Thank you for your support!**  
**Together, we are moving mountains.**



# 2018 – 2023

## Review of the Past Five Years

Accredited **65** credits of  
Continuing Medical Education

Sponsored  
**12 grand rounds events**  
at hospitals and institutions offering  
12 additional free CME credits

Educated

**5500+** clinicians

on PANS/PANDAS, most of them free  
of charge

**90%** of clinicians have rated the  
overall quality of the  
CME we've offered as **5/5**

Funded a  
**fellowship at UCSF**

Provided

PANS/PANDAS desk guides to

**7000** physicians

Donated

**\$ 210,000**

to PANS/PANDAS research at  
Stanford

Launched an

**Expert Consultation Panel**

for physicians to present complex  
PANS/PANDAS cases and have hosted  
11 physicians presenting 11 cases

About to publish (currently in  
peer review) a **Special Issue**

**on Inflammatory Brain**

**Disorders** in a medical journal

Funded a

**fellowship at Stanford**

Hosted dozens of

**Q&As with leading experts**

for families as well as clinicians

Over **500** clinicians  
have attended one of our **Q&As**

Organized a  
**critical meeting**  
with key National AAP decision  
makers and four top experts in the  
field of PANS/PANDAS

Advised by  
**17** of the **leading experts**  
in neuroimmunology and immuno-  
psychiatry in the world, who comprise  
our Scientific and Clinical Advisory  
Board

**20,000**

Number of families accessing **family support webinars**, participating in our **private support groups**, receiving **educational updates** from us

**750+**

**medical professionals**  
in our clinician network

Listed on **NIH's website** in  
autoimmune encephalitis and PANS  
categories and as collaborators with  
the **Stanford PANS Clinic  
Research Program**

**4000+**

**fee waivers/free admissions**  
to clinicians for CME events

Developed  
**groundbreaking new**  
**materials and PANS/  
PANDAS guides**  
for clinicians in partnership with  
Stanford

We were granted

**Guidestar's Platinum  
Seal of Transparency**

five years in a row — an honor held by  
under 1% of non-profit organizations  
and no other PANS/PANDAS  
organization

**Honored**

by Stanford University's Immune  
Behavioral Health Clinic in a  
publication about Neuroimmune  
Foundation's partnership with  
Stanford

Exhibited at

**National Conference of  
State Legislatures**

educating on PANS/PANDAS,  
the challenges families face, and  
potential policies to address these  
issues

**70+** countries  
represented/accessing CME

# 2023

## Inflammatory Brain Disorders Conference

### Comments from the Medical Providers

*The Inflammatory Brain Disorders Conference 2023 was (again) the most educational and effective conference I have ever attended in my 43 years as a physician! International experts presented 16 lectures over the course of two days, delivering major gems every hour to facilitate the diagnosis and treatment of tough psychiatric and neurologic neuroinflammatory conditions. A cumulative tsunami paradigm shift for psychiatry is in the works; inflammatory brain disorders will be the rule, rather than the exception. My accolades to all the panel of experts who shared their latest research and efforts. Thank you!*

**Martin T. Jensen, MD, Adult, Adolescent, & Child Psychiatry, Laguna Niguel, CA**

*Wonderful conference! First time I attended this conference. Neuroinflammatory diseases are not a large part of my practice as a pediatric rheumatologist- at least I thought so before the conference. Given the expanding scope of diseases related to neuroinflammation, my preconceived notions have been challenged- in a good way! Each presentation was given by an obvious thought leader and the results presented were all cutting edge. Cannot wait until next year.*

**Daniel Lovell, MD, MPH, Pediatric Rheumatologist, Cincinnati, OH**

*Rigorous, wide-ranging, two-day conference by international faculty providing cutting edge genetic and clinical insights furthering the rapidly increasing knowledge about auto-immune mediated syndromes. Crisp presentations, excellent slides, and clinical movie clips combined with meticulous attention to the duration of the presentations. Information was presented on the autoimmune manifestations of Long Covid-19, PANS, PANDAS, postural orthostatic tachycardia syndrome (POTS), psychoses, seizure disorders and tick-borne illnesses alongside presentations on the Gut Microbiome and porosity of the blood brain barrier. Commercial-free. Well worth the tuition. My first Inflammatory Brain Disorders Conference. Planning on next year.*

**John Esterhai, MD, Orthopedic Surgeon, Spring House, PA**

*When I go to a conference, I feel that I have gotten my money's worth if at least 10% of what I learn is new. In this course, the new information was at least 60% and what I did know was expanded significantly. This has increased my understanding and sensitivity to the possibility of an immune disorder in patients I have seen over the years. There are several patients in my current practice who will be re-evaluated for the possibility of something I did not know to look for before.*

**Lee Solomon, MD, Psychiatry, Chattanooga, TN**

*This is a fantastic conference. I love the virtual format and access, and the wealth of research and information is tremendous. It's interesting and exciting to hear what's going on at the cutting edge of research and think about the implications of that on practical treatment and outcomes.*

**S.M. Thompson, MD, Pathologist, Westlake, OH**

*I have attended the conference for 3 years because I need to know what's happening in this field. Keeping up on what we know and what we don't know - but are learning more about - is critical in my work as a child psychiatrist. I have encountered several patients with significant neuroinflammatory concerns that were initially*



*treated as primarily psychiatric – and I credit this conference for my evolving skill set in this area. I highly recommend this conference to my psychiatry and neurology colleagues.*

**Candida Fink, MD, Board Certified Child, Adolescent, and General Psychiatry, Rochelle, NY**

*As a pediatrician and mother of two children with PANDAS, I am so happy that the neuroimmune conference exists to further physician education in advancements made in the field of neuro-inflammatory disorders. As our understanding of these conditions continues to evolve, it is SO important that primary care physicians are aware of these disorders and feel confident in at least considering the diagnosis and initiating management/referral when patients present with an acute change in behavior. I believe the conference provides solid scientific evidence to support this growing field and highly recommend that ALL physicians involved in ANY type of patient care attend the conference to increase their under-*

*standing of the important role that inflammation and the immune system plays in behavior and other psychiatric symptom development.*

**Kortney West, MD, Pediatrician, Wyomissing, PA**

*You are the best. Every year I am amazed at the range and quality of speakers!*

**Angela Tang, MD, Internal Medicine, Torrance, CA**

*Thank you for this excellent conference. I have attended for several years and have gained more understanding of neuropsychiatric conditions each year.*

**Destiny Gmelch, MD, Pediatrician, Springfield, OR**

*I truly loved this conference; the presenters, their research, their ability to answer our questions, and their passion for healing. This conference was by far one of the best conferences I have ever attended. The presenters were, for the most part, the actual researchers who not only comprehended their topics extremely well, but who*



**Physician education changes everything.**

*passionately apply their knowledgeable results in clinical settings to improve the lives of people who struggle emotionally and physically. This is what medicine is supposed to do--to figure out what the underlying issues are and to try to reverse the pathology that is causing the problems in those who have been seriously affected. I feel so frustrated that currently many are still having to take treatments that we know do not work, or we are made to wait and wait to utilize therapies proven to help many.*

**Sharon A. Collins, MD, Pediatrician, Cedar Rapids, IA**

*Fascinating conference – frontier of medicine. I imagine one day many “psychiatric disorders” will be recognized as stemming from significant immune dysregulation.*

**Kimberly Fullerton Nelson, MD, Family Medicine, Eureka, CA**

*As a pediatrician, I feel I am more prepared to recognize these conditions and refer to appropriate specialists. The conference gave me a much better understanding of inflammatory brain conditions.*

**Wayne Narucki, MD, Pediatrician, Rutherford, NJ**

*Thank you so much for another amazing conference! The research and presentations were cutting edge and fascinating. I always appreciate Dr. Frankovich's presentations, and I especially found the presentation on gut microbiome, gut brain axis and neuroinflammation to be interesting and encouraging. What an amazing opportunity for*

*researchers and clinicians to connect and share their research on inflammatory brain disorders!*

**Lisa Drummond, BSN, RN, MSN, Pediatrics, Madison, WI**

*The conference was well organized, the speakers were leaders in the field, and the topics discussed were relevant to my practice as a psychiatrist who needs to be informed about neuroimmune factors in diagnosing and treating patients who present with a variety of mental status changes and psychiatric symptoms.*

**Mary T. Mandell, MD, DFAPA, Psychiatrist, Southern Pines, NC**

*Amazing information on latest neuroimmune research. Exciting research helping explain underlying etiology of some psychiatric symptoms/clinical presentations. This research is so needed to better serve patients.*

**Carina Quezada Adan, MD, Pediatrician, Santa Rosa, CA**

*WOW! A fantastic conference with incredibly smart professionals! Very heavy on basic science and research, which makes me feel much more confident as I approach these issues in the clinic. Thanks for putting this together. It was very informative and very impressive.*

**Charles Sprague, MD, Pediatrician, Omaha, NE**

*This conference was such a helpful combination of both current research and clinically relevant information. Thanks for organizing!*

**Donna Kirchoff, MD, FAAP, Developmental and Behavioral**



## On the horizon!



Neuroimmune Foundation is happy to announce that together with several generous donors, we have funded the first year of a fellowship at UCSF. The fellow selected by UCSF, Dr. Greer Waldrop, will be starting July 2023 and will be using the Neuroinflammatory Diseases Cohort at UCSF (currently >2500 patients) to identify shared clinical features and outcomes related factors in this large cohort of patients with encephalitis, meningitis, and post-infectious neuroinflammation. This cohort has been under collection at UCSF for ten years since it was started by Dr. Michael Wilson and Dr. Joseph DeRisi, and it includes many groups of patients with autoimmune encephalitis, infectious meningoencephalitis, paraneoplastic neurologic disorders, and post-infectious neuroinflammation. This cohort includes many sub-cohorts of patients with specific underlying disorders that predispose to neuroinflammation (e.g., Lupus or tumors leading to paraneoplastic inflammation). Dr. Waldrop will utilize her extensive epidemiologic and clinical expertise to identify features critically associated with outcomes, responses to therapy, and underlying etiology. Dr. Waldrop's goal is to become a clinical researcher in the epidemiology of unusual neuroinflammatory diseases. A special thank you to our donors, Carrie and Jed Nussbaum, Jim Penney and LauraLeigh Young, Mary and Travis Blalock, and The Louisa Adelynn Johnson Fund for Complex Disease ([www.tlajfundforcomplexdisease.com](http://www.tlajfundforcomplexdisease.com)).



The Stanford Fellowship has been funded for a two-year period and will begin as soon as a suitable candidate is selected!

**Neuroimmune Foundation**

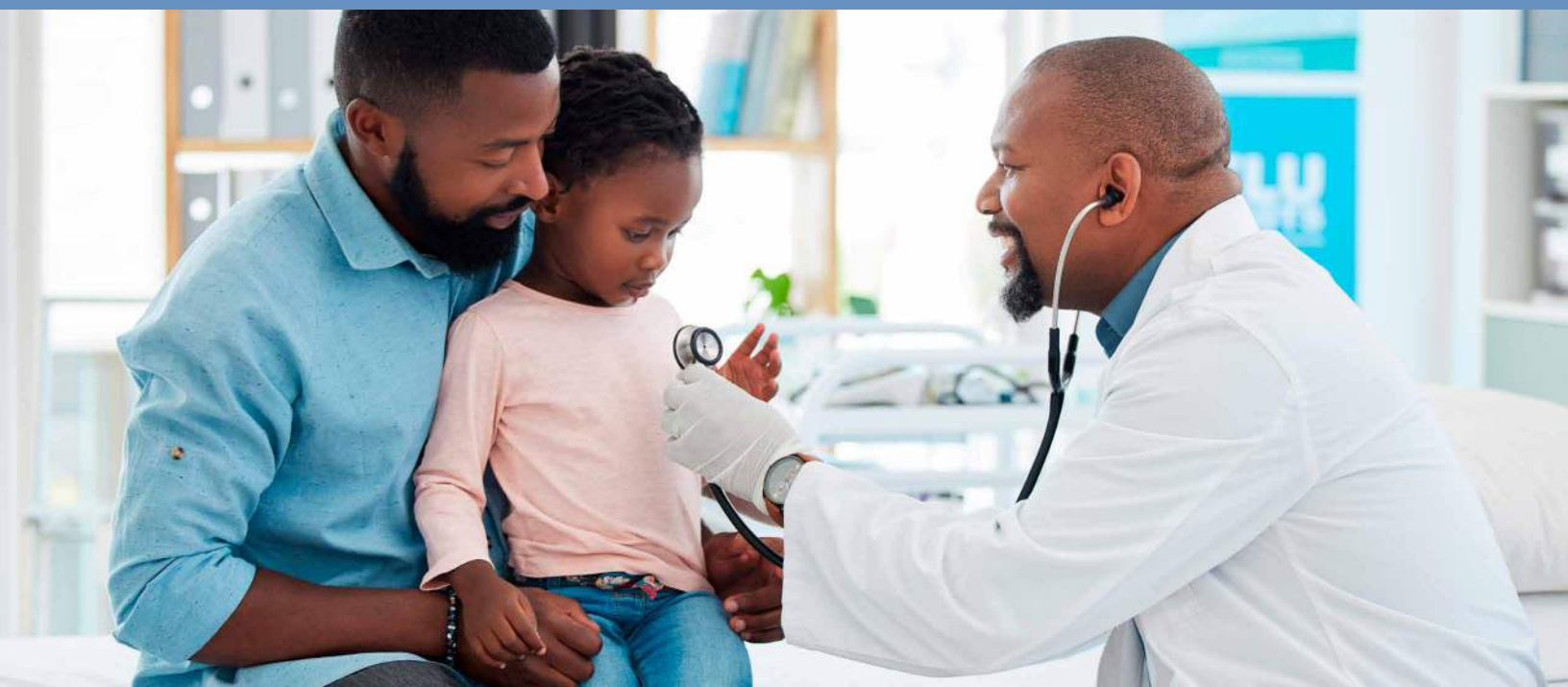
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