

IMPACT REPORT

JUNE 2020 – MAY 2021



Advocating on Behalf of Individuals with Neuroimmune Conditions



We have changed our name from **Foundation For Children With Neuroimmune Disorders** to **Neuroimmune Foundation** to reflect our commitment to individuals of all ages impacted by neuroimmune disorders and to reinforce the reality that PANS and PANDAS can impact adults.

The Neuroimmune Foundation is 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.



The Neuroimmune Foundation 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 infectious, post-infectious, and autoimmune encephalitis.

We aim to accomplish our goals by sponsoring high quality medical provider education, fundraising for research, and directly supporting families.



Thank you!

Dear Supporters,

When I think of the pain I've watched countless families endure over the years that led me to found Neuroimmune in the first place, and think of the faces of the beautiful, burdened children and young adults that have graced my inbox, and the desperate pleas from parents, I feel great sadness for what our community has collectively endured, but also tremendous hope for the future given what we've been able to accomplish together in the past three years.

The exponential growth in medical providers attending our educational events on PANS/PANDAS has exceeded our expectations and hopes. We know that for each provider who becomes educated on PANS/PANDAS, dozens of patients' lives will be positively impacted. Our ability to offer and market these programs is due entirely to the support from our community. We have made great strides in the past year that would not have been possible without the outpouring of support we've received from you.

Well over 1200 medical providers alone registered for this conference. Stanford, UCSF, Columbia, and Yale accounted for the majority of our speakers. AAP Chapters, Medical Societies, and medical colleges in multiple states have endorsed and shared the conference and our CME. Not once in planning, marketing, or engaging anyone did I hear the word "controversial." In fact, I did not hear anything but resounding affirmation that this information is not only worthy of being shared, but that physicians are truly excited to have the opportunity to become educated on these topics.

Gratitude is owed to many – from the very first advocates of PANS/PANDAS who laid the earliest groundwork, to the researchers and clinicians who faced criticism for daring to think outside of the box, to the parents wrecked with exhaustion who still took the time to reach out to their providers and share our educational events, to our biggest donors who have made much of our work possible, and to our littlest donors who have given what they were able to despite being stretched so thin. There is much more work yet to be done, but there is light at the end of this tunnel. To each of you who have played a part in bringing all of our families a little closer to that light, thank you. You have made a tremendous difference and we appreciate you.

Anna Conkey

Executive Director and Founder
Neuroimmune Foundation

www.neuroimmune.org

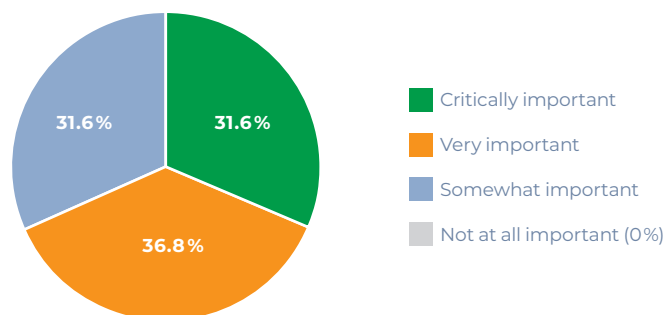
2020

Survey Data

From medical providers who attended our continuing medical education and Q&A events in the past year

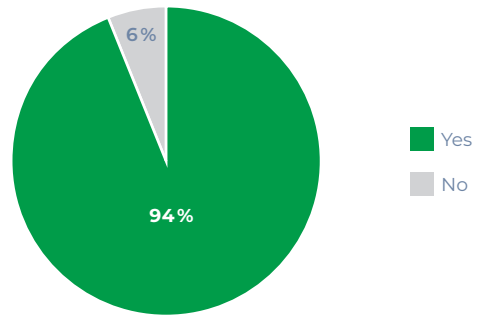
Via an email marketing campaign, we targeted 80,000 medical providers, offering them free access to our CME and Q&A events to support them in the diagnosis and treatment of patients with neuroimmune conditions including PANS/PANDAS.

How important is ongoing support from Neuroimmune via Q&As and CME to your ability to effectively diagnose and/or treat patients with these conditions?

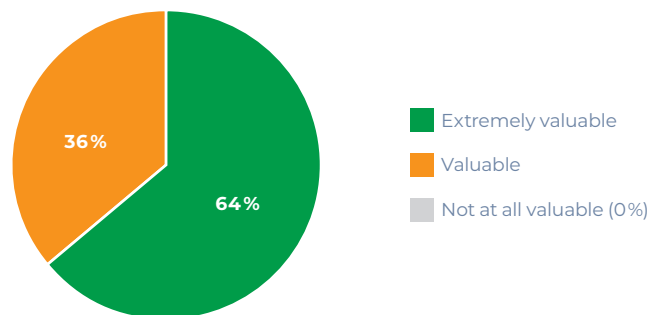


To ensure that our educational activities are having the intended impact, we followed up with medical providers who had attended CME and Q&A events in order to find out the impact our programs had on their medical practices, and ultimately their patients. We are pleased to report that medical providers have found these programs highly valuable to their practices.

Has Neuroimmune's CME or Q&A assisted in your treatment plan for one or more patients?



How valuable are our programs to enhancing your confidence diagnosing and treating PANS and other neuroimmune conditions?



2020

The Impact of Our Programs in the Past Twelve Months

Our social media posts

reached over **1 million** people in a
single month and over **3 million**
in the past 12 months.

We awarded Stanford

\$100k

for research to study a novel drug
for PANS.

Featured top experts in PANS/
PANDAS for monthly Q&As that
targeted

80,000

medical professionals

offering them the tools and support
to diagnose and treat patients
effectively.

We have offered free support
on a monthly basis to over

16,000

individuals and families
featuring expert physicians,
therapists, etc. via webinars, a private
FB group, Q&As, phone calls, and
emails.

We were granted

Guidestar's Platinum Seal of Transparency

an honor held by under 1% of non-
profit organizations and no other
PANS/PANDAS organizations for the
third year in a row.

In the past 12 months,
we have
educated 1991
medical providers
through a CME accredited
educational event (conference
or on-demand).

We established a **Scientific and
Clinical Advisory board** with
13 experts
in the field of neuroimmunology.

Our
33 chapters
around the nation and world have
been on hold due to COVID-19 but we
look forward to resuming them.

On-demand CME access with six
additional speakers available
through 2022 for all medical
providers free of charge reached over
1000 providers.

Our organization was
**added to the
NIMH's website**
as a resource for patients with
PANS, PANDAS, and encephalitis.

Executive Director, Anna Conkey
published an article on PANS and
COVID-19 that was picked up by
Apple News and **Yahoo.**

2021

Inflammatory Brain Disorders Conference Impact

Thanks to the generosity of our community and sponsors, we were able to effectively market the Inflammatory Brain Disorders Conference to physicians and other medical providers around the United States free of charge. This led to an excellent turnout and was the single most attended PANS/PANDAS educational event in history!

The first day of the conference focused greatly on advances in research related to PANS and PANDAS and the second day highlighted the clinical aspects of diagnosis and treatment. Provider feedback through Continuing Medical Education evaluations was exceptionally positive and confirmed the event exceeded our educational objectives.

Featured

20 speakers

from Yale, UCSF, Stanford, Columbia and more.

Over

1200
medical professionals
in attendance.

Marketed to

80,000

pediatric & adult physicians
through a series of 8 emails offering
free admission.

Reached

30,000

additional medical providers
through a second email campaign.

Granted

free admission

to all medical doctors
in the US.

Shared over

100 posts

about the events in FB groups
for medical providers.

Offered free admission to over

5000

medical providers
via fax.

Physicians from over

30 countries

and all 50 states in the US
in attendance.

Promoted by Stanford
University, Medical College of
Wisconsin, countless hospital
systems, and several state chapters
of the AAP.

Overall quality
of the event was rated

5/5

by greater than 90 % of medical
professionals.

2021

Inflammatory Brain Disorders Conference

Comments from the Physicians

“Excellent and impressive conference!”

Dr. Shannon Delaney, MD
Neuropsychiatrist, Columbia University Irving Medical Center
Assistant Clinical Professor, Columbia University, New York

“Very informative. High quality excellent speakers. Perfect balance between science and clinical at this conference.”

Kiran Belani, MD
Pediatric Infectious Disease, Children's Hospitals and Clinics of Minnesota
Assistant Clinical Professor, Pediatrics, University of Minnesota

“Historically, Sydenham's chorea has provided a demonstration of the impact of post-infectious immune reactions on CNS function. This conference was an exciting update of scientific progress in dissecting the mechanism of these disorders.”

Nancy Kuntz, MD, FAAN
Attending Neurologist, Ann & Robert H. Lurie Children's Hospital of Chicago, Illinois Medical Director, Mazza Foundation Neuromuscular Disorders Program

“Excellent conference. I found the speakers to be very informative and knowledgeable about their various areas of expertise.”

Linda Doberstein, MD
Pediatric Director, Medical Psychiatric Program
Hasbro Children's Hospital, Rhode Island

“I found that the selection of speakers to be incredibly balanced. Not only was the growing 'hot off the press' basic science behind autoimmune brain disorders discussed and done so with the attention to detail that it so deserves, but tips for the general practitioner were given for those practitioners who are just getting their feet wet with diagnosing and treating patients with these conditions. The primary responsibility of all clinicians is to be able to recognize common historical patterns, observe physical findings, and come up with a treatment plan. This conference provided that insight. I cannot recommend this conference more highly.”

Karl Holtzer MD, MS, IFMCP
University of Pittsburgh Medical Center, Pennsylvania

“Thank you. It was a pleasure to learn from these experts.”

Vidya Raj, MD
Assistant Professor, Psychiatry
Vanderbilt University School of Medicine, Tennessee

“The conference was an eye opener for me. As a pediatric Neurologist in a busy hospital-based practice, I have always been uneasy about the patients with abrupt onset of mental illness or movement disorder. Now I heard at least some objective evidence about auto-immunity. I hope that the better testing became commercially available, so we do not need to treat empirically and fight with insurance companies.”

Tatyana Dubrovsky MD
Pediatric Neurologist, Joe Di Maggio Children's Hospital, Florida

“I was astounded by the amount of scientifically based data presented on encephalopathy, COVID and PANS/PANDAS at this conference. I thought all of the presenters at this conference did an excellent job explaining the pathophysiology involved in the various conditions that were highlighted in this conference.”

Urszula Kotlow, MD
Pediatric Psychiatrist, CPAE Clinic, Banner Desert Medical Center, Arizona

“The conference was excellent, including some cutting-edge research. I am very impressed.”

Dr. Lanping Yu, MD

Clinical Assistant Professor of Virginia Commonwealth University, Pediatrics, Virginia

“I feel more confident as THE consultant on many of these cases due to expanded knowledge I have acquired via this resource. Excellent presentations with fantastic evidence-based information. I hope to be involved in more conferences. Thanks to all!”

Sandra Lawrence, MD, FACR

Pediatric Rheumatology, Florida

“The neuroimmune conference transformed my thinking about the relationship between infection, neurobiology and psychiatric disorders. I learned so much.”

Melissa Aguirre, MD

Pediatrician, California

“This was an outstanding conference. I plan to attend annually, especially important since this is a very actively researched, rapidly evolving field. Clinical applications have profound life altering effects upon patients and their families, and we all owe it to them to be as current in our understanding and practices as possible. Thank you to all involved in putting this together. Well done! I am grateful.”

Deborah „Gaya“ Milling, MD

Psychiatrist, South Carolina

“This conference was very well done. Anna orchestrated an exceptionally high-powered group. This was as good as any conference I have ever attended including national and international professional meetings. Pierre, as always asked relevant questions and is the ultimate professional. Keep up the great work!”

R. Craig Platenberg, MD

Neuroradiologist, Virginia

“Speakers on day one were particularly compelling. Prior to attending the conference, I was intrigued by the notion of PANDAS/PANS, but mostly skeptical as to whether it was real. After the evidence presented on day 1 of the conference, I am convinced that this entity genuinely exists — and excited to get a number of patients connected for appropriate investigations and treatment.”

Dr. Michelle Snyderman, MD

Development and Behavioral Pediatrician, Wisconsin

“This is the most comprehensive, well-organized, and current information on all topics I have encountered in such a long time. I plan to attend every conference moving forward. Thank you for such well-presented information. Armed with several screenshots of slides, I have already contacted several patients to complete a more thorough history for a more complete treatment plan. So grateful.”

Maria Del Sol, MD

Child and Adolescent Psychiatrist, Florida

“This was a great symposium that all physicians/practitioners should be educated about, those topics are easily left less discussed among physicians, and the whole day it was an amazing gathering of brilliant people. Thank you!”

Gabriela Mihalache, MD

Pediatrician, Florida

“This conference had the highest scientific quality and rigor, and all the presenters and discussants were outstanding. The contribution of the foundation for children with neuroimmune disorders to society is incommensurable.”

Rosa Aurora Chavez, MD, PhD, FABP, Washington, DC

“This was a conference with fantastic collaborators and speakers. As a physician I felt that it was clinically oriented and cutting edge. It was incredibly useful to gain knowledge in a field like neuroimmunology where so little is known.”

Anuja Vyas, MD, FACOG, Texas



“This was a conference with fantastic collaborators and speakers. As a physician I felt that it was clinically oriented and cutting edge. It was incredibly useful to gain knowledge in a field like neuroimmunology where so little is known.”

Anuja Vyas, MD, FACOG, Texas

“As a clinical psychiatrist, it is crucial that I understand the potential origins of psychiatric symptoms. This conference gave insight into infectious and immune mechanisms for Neuropsychiatric symptoms that I found truly valuable. The speakers were of top quality.” Matthew Bernstein, MD Psychiatrist, Massachusetts “I was so appreciative of the depth and breadth of quality information, both research and clinical, offered at the Neuroimmunology Conference. The information presented will help me in my clinical Pediatric Neurology practice to provide the most up-to-date care for children and teens with autoimmune encephalitis, PANS and PANDAS. There is so much misinformation about these diagnoses in lay literature and within the medical community. Hearing directly from physician leaders and researchers in the field was invaluable.”

Nevada Reed, MD
Child Neurologist, Ohio

“I felt this was an excellent educational event – to both basic research going on and clinical practice patterns. The speakers were very knowledgeable and mostly fabulous communicators about complex topics. Thank you very much – I look forward to future events. The multidisciplinary approach was perfect.”

Dr. Candida Fink, MD
Child and Adolescent Psychiatrist, New York

“I found the conference both scientifically interesting and clinically very useful – presenters were excellent. It was very interesting to hear about both cutting-edge research and from a variety of clinical experts who were able to shed light on different aspects of the PANS/ PANDAS presentation, and offer practical guidance for treatment.”

Donna Kirchoff, MD, FAAP
Developmental and Behavioral Pediatrician, Oregon

“I was totally impressed with the lectures. It was interesting to learn about the research studies in the ‘bench science research labs” but as a practicing clinician those items were not as valuable to me. I told one fellow watcher of the event by text. “This is very cutting edge research, it will be 10 years before they teach this in medical school.” Dr. Andrew Baumel’s presentation was absolutely golden. That should be required viewing for “boots on the ground” pediatricians and family medicine physicians who have to deal with PANDAS/PANS, and for those who are not even aware of the diagnostic entity of PANDAS/PANS.”

Dr. Jon Ahrendsen, MD
Family Medicine Specialist Adjunct Clinical Assistant
Professor, University of Iowa

“It was far superior to most information about PANS/PANDAS.”

Christina Hift, MD, Infectious Disease, Pediatric Rheumatology, Consultant Pediatric Rheumatology
Mount Sinai Beth Israel Medical Center, New York

“I am much more aware of the complexity and pervasiveness of these disorders, but at the same time feel that I have been given tools and encouragement to offer support for them as a physician.”

Patty DiBlasio, MD, MPH
Functional Medicine, New York

“This was incredible. Day one was a home run, especially. I knew we had more company in recent years in terms of people treating and researching. It was good to see their faces and hear their perspectives. Thank you Anna and Pierre from the bottom of my heart.”

Angela Tang, MD
Internal Medicine, California

“Increased my fluency with these topics. Better able to share this information and educate others. I thought this was a very effective line up of presenters.”

Dr. Peter Klinger, MD
Assistant Professor, Psychiatry and Pediatrics
University of Arizona College of Medicine

“The presenters should be commended for the clarity provided on such a complex subject. It takes a great deal of skill, experience and common sense to distill and present such a murky subject as PANS/PANDAS in a clear fashion. A magnificent job well done.”

Michael Buch, MD, California

“This course is a must for family practitioners and pediatricians- so often this connection, from infection to PANS/PANDAS, is not even on the practitioner’s radar and is missed due to lack of awareness.”

Janine K Rimland, MD
Family Practice Physician, Pennsylvania

“I intend to be more thorough in evaluating pediatric patients with primarily psychiatric complaints who are admitted to my service as a pediatric hospitalist and be ready to assist with the treatment of patients with autoimmune encephalitis. Excellent conference, thank you!”

Destiny Gmelch, MD, Pediatrician, Oregon

“Great conference with terrific speakers. I really enjoyed the variety of medical specialties and learned a lot about the vast amount of research being done.”

Robin Blitz, MD
Medical Director, Special Needs Initiative /
Complex Health Solutions

“Excellent topics. I also really appreciated the ease of registration, the online/web format facilitating discussions with the presenter, and the quick turnaround time for the CME credits and web recordings. Very professionally done!”

Dr. Safi Shareef, MD
Pediatric Neurologist, Texas

“This conference helped provide me information and guidance on how to look for certain neuro-inflammatory conditions and how to treat them. This was a very informative lecture series!”

Dr. Rita C. Silva-Leu, DO
Psychiatry, California

“I am greatly appreciative of the opportunity to learn about the latest research and clinical practices in neuroimmune conditions, which we are learning more about every day. It is incredibly important that providers across disciplines are exposed to this information so that they can recognize neuroimmune illnesses early in their course and provide the best outcomes for patients and their families. This is an exciting time in the history of psychiatry, as I believe this research will revolutionize my field and my own personal practice by the end of my career.”

Tara Richardson, MD
Diplomate, American Board of Psychiatry and Neurology,
Kansas

“Thank you so much for putting this conference together! This is such important work and I learned much from the great research and presentations! I’m looking forward to the next event.”

Jillian Shellabarger, MD
Child and Adolescent Psychiatrist, Ohio

“I intend to inform my colleagues including my fellows about this activity and hopefully they will participate in the future activities.”

Dr. Sulaiman Mohammed Almayouf
Pediatric Rheumatologist, Saudi Arabia

“It was great! Amazing that it was free! Thanks so much!!”

Paula McEvoy, MD
Pediatrician, Massachusetts

“This was a fabulously interesting, cutting edge conference. Thank you.”

S. Michael Thompson, MD
Clinical Pathologist, Ohio

“Excellent research and useful clinical information for front line pediatrician. Learned a lot! Thank you very much.”

Bin Sung, MD, FAAP
Pediatrician, Texas

“Presentations are excellent and very informative”

Loida Reyes, MD
Psychiatrist, New York

“This conference will greatly enhance care of a small cohort of my patient population in a community mental health care setting; it will do the same for the care I provide in a first episode psychosis clinic setting.”

Tonya Lawrence, MD
Medical Director, Child and Adolescent Psychiatry,
Pennsylvania

“I really enjoyed this conference, especially the talks relating to general pediatrics.”

Christiana Morganti, MD
Pediatrician, Pennsylvania

“Truly an excellent educational conference.”

Rosalie Greenberg, MD
Child Psychiatry, New Jersey

“I plan to evaluate and treat most of my patients for NI PANS and PANDAS instead of referring out. I will be able to do a better job at both of these tasks. Thank you for this opportunity!!”

Stacey Luetmer, MD
Family Medicine, Minnesota

“Great Conference! Learned a ton! Thank you so much for putting this together!”

Kerry Newman, MD
Pediatrician, California

“Thank you so much to the sponsors for making this available for free to all providers. I am hoping that really helps to increase the awareness regarding this as well as the treatment. I am sorry that COVID-19 happened but I am excited about the awareness it is promoting regarding infectious neuropsychiatric disorders and post-infectious neuropsychiatric disorders. I am thankful to all the researchers and clinicians involved in this work!”

Vicki Copeland, MD

“This was a fascinating set of lectures. I am pleased to have joined and in fact I will be seeing a teen soon who may meet the criteria for PANS will be using this knowledge very soon.”

Victoria Crescenzi, MD
Developmental and Behavioral Pediatrician, Washington

“Well organized. Informative. Kept my interest throughout. And thank you.”

Linda Arzola, MD
Psychiatrist, New York

“The coverage for this conference was quite comprehensive.”

Jeffrey Lichtman, MD

“I deeply appreciate this conference. It has been extremely educational.”

Rebecca Pate, MD
Psychiatrist, Tennessee

“This was a wonderful series of lectures which built on each other. I learned so much and have already applied what I learned to my practice.”

Rachel Workman, MD
Pediatrician, Colorado

“The rising tide of evidence stemming from both the peer-reviewed literature, clinical observations and feedback from medical colleagues makes this conference imperative for professionals who will encounter individuals affected by these conditions. The conference offered the opportunity to become exposed to the requisite basic science, and it progressed to the clinical interface, a course with which medical professionals are familiar. The necessity of this conference cannot be overemphasized. Colleagues across a wide range of disciplines including pediatrics, head and neck surgery, psychiatry and the attendant subspecialties are seeing these patients, and they are appealing for help. My personal gratitude to the organizers of this conference, but my deepest thanks is for the parents who struggle to make their voices heard. No greater service can be offered than to provide help to those who need it the most.”

David Traver, MD, FAAP
Pediatrician, California



All images from shutterstock.com

Neuroimmune Foundation

neuroimmune.org

info@neuroimmune.org

P.O. Box 25

Colgate, WI 53017

EIN #82-3128162



www.neuroimmune.org