



PANDAS NETWORK
ADVOCACY, SUPPORT & RESEARCH FOR PANDAS, PANS, AE

\$100K for PANDAS-PANS-AE Research of Immune Cells in Microbiome of Tonsil Tissue and Gut Microbiota

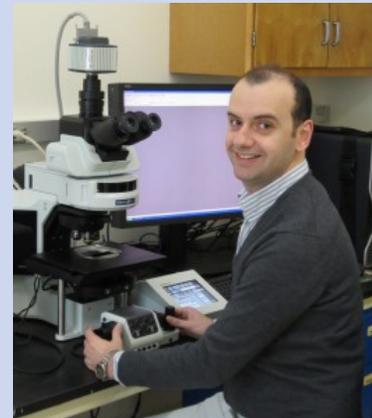
As we write this newsletter, we see and hear from many families on Facebook, Instagram and via email. Greater access to care is needed. We understand the strong fight we are all making to improve our children's lifetime outcome from PANDAS-PANS-AE. Know that our Board of Directors and each researcher and doctor involved is fighting hard. We work tirelessly with you for a CURE.



Dr. Earl Harley, MD
Otolaryngologist (ENT),
Georgetown University



**DR. PAWEL KIELA, DVM,
PHD**, Research Associate
Professor, Immunobiology
and Autoimmune Disease
Research



Dr. Dritan Agalliu, PHD
*Neuroscientist & Asst.
Professor of Pathology and
Cell Biology (in Neurology
and Pharmacology)*

PANDAS Network together with the Alex Manfull Memorial Fund are funding two new projects that will take place in 2020 with results to be published in 2021-2022.

Tonsil Microbiome

Dr. Earl Harley, ENT at Georgetown will collaborate with the Agalliu Lab on the analysis of tonsil tissues of 20 children with a strong streptococcal history. This study will be announced in Fall 2020 and will seek to find both immune markers and genetic factors. Both tissue and blood sera will be analyzed at the Columbia University, Agalliu Lab and Georgetown University Labs.

This will further identify the presence of key Th17 cells that impact PANDAS children. Cytokines/ chemokines in both tonsillar tissue and serum before and after tonsillectomy will be studied together with potential genetic markers such as ROR γ t discovered by Maryann Platt's, PhD candidate, Columbia Univ. It is suspected by earlier work by Dr. Agalliu, that human tonsils carry autoimmune cells that can *potentially adversely* impact

healing of children.

To understand how tonsil and blood sera of PANDAS children alter healthy immune function -

Watch Three Videos:

[2016 Journal of Clinical Investigation to learn of early tonsil research](#)

[PN Conference 2019: Maryann Platt, PhD candidate](#)

[PN Conference 2019: Dr. Earl Harley](#)

Gut Microbiome & Autoantibody Identification

PN and The Alex Manfull Memorial Fund are very pleased to announce that they have agreed to fund two studies to be conducted by Pawel R. Kiela, DVM, PhD at the University of Arizona in the Department of Pediatrics, Division of Pediatrics Gastroenterology and Nutrition. These studies will further the knowledge of the relationship between the gut microbiome and PANDAS and, hopefully, move us closer to developing a new diagnostic tool based for PANDAS, based on autoantibody screening.

In the first part of Study I, Dr. Kiela will complete the metagenomics analysis of the gut microbiota (begun in an earlier study) to, hopefully, identify “a unique but persistent microbial signature among [PANDAS] children.”

In the second part of Study I, germ-free mice will be “humanized” with gut microbiota from either healthy or PANDAS cases. Then both groups will be given repeatedly immunized intranasally with *Streptococcus pyogenes* (GAS-2W) to assess the role of gut microbiota in *S. pyogenes*-induced neuroinflammation.

In the third part of Study I, *Akkermansia muciphila* (one of the microbial species that most prominently decrease in PANDAS patients) will be orally administered to conventional mice that will be repeatedly immunized intranasally with *Streptococcus pyogenes* (GAS-2W) to induce neuroinflammation to observe whether *A. muciphila* can reduce or prevents the development of neuroinflammatory and behavioral symptoms.

In Study II, Dr. Kiela will narrow down the number of protein targets of auto-reactive antibodies identified in an earlier analysis of the sera from 13 patients with PANDAS and 9 patients with Autism Spectrum Disorder (ASD) to establish a “simpler” panel of proteins that will differentiate PANDAS patients from ASD patients. The sera of PANDAS patients, ASD patients and healthy (control) subjects will then be screened to determine the validity of the measure in diagnosing PANDAS.

BRINGING LIGHT INTO The DARK

3 Children, Three Families Change the Course of PANDAS-PANS-AE



Chuck and Renee Lumio of Pennsylvania, fundraisers for over 5 years, walks-a-thons, fundraisers & now! Casino Royale 2020

Dawn & Kiley Schmitt, of Pennsylvania, creators of the Pie Face Challenge

Michele Kleczkowski of Illinois. Designer for 7 years of Awareness Day Shirts

We are honoring *three families* for extraordinary effort in SUPPORT RESEARCH and COMMUNITY BUILDING for the families of PANDAS-PANS-AE. They each exemplify undaunted commitment to ridding the world of P/P/AE devastation.

Chuck and Renee Lumio were one of the first families identified by the NIMH in 2014 as having a young son with PANDAS. Collectively their efforts have raised over \$160,000. They have lead in fundraising efforts together with dedicated volunteers EACH YEAR for FIVE YEARS. March 28 is their second **CASINO ROYALE** with music, fun, auction, games of chance, gift baskets, festive food & wine at the beautiful [Rose Bank Winery](#) will bring in 400 families and sponsors. An entire community learns about P/P/AE. This year, again, the Agalliu Lab will discuss their research and scientific efforts. ([Take a look at some photos of last year's event.](#)) Also, they have mentored for many the creation of support groups in PA, and they have stuck with PN as we innovated with new consortium researchers. Thank you Chuck and Renee for being devoted leaders in your community even as your child has healed.

Michele Kleczkowski In 2012, Michele became the originator of the October Awareness ANNUAL T-SHIRT sale event listing names of children afflicted with this illness. She has collectively raised over \$37,000 and given every penny awareness and research throughout the U.S. Michele's son was diagnosed with PANDAS in 2011 after been misdiagnosed for several years. His brave struggle is well known by many of us and the lack of access to care has been fuel for legislative efforts nationwide. Thank you Michele for your relentless efforts and honoring children, name by name, on the famous t-shirts so many treasure.

Dawn and Kiley Schmitt initiated 2019's wonderful, fun! Pie-Face-Challenge that many of you participated in from Facebook and Instagram. Check out these links on [FB](#) and [INSTAGRAM](#). This was their FIRST YEAR and they raised \$50,000 all going to research together with one anonymous donor who matched their larger community effort. **KILEY**, a 6th grader in 2019, bravely and openly shared her story of looking for help with her illness ([see story attached](#)) and brought in other families as well - talking about the fight, the struggle, the lack of help and now ---- a path out of the dark to treatment. Watch their story on ABC news here. <https://6abc.com/society/would-you-take-a-pie-for-pans-/5691926/>

THIS IS A SHORT THANK YOU FOR HOURS AND HOURS of EFFORT FROM THESE REMARKABLE FAMILIES. Many other families, teachers, doctors and community persons including the news media work together to make these fundraising efforts happen. BLESSED IS THE MATCH - these families - that began the flame of inspiration for all of us. WE FIGHT FOR A CURE and build loving community along the way.....



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*Dedicated to improving the diagnosis and treatment of
children with PANDAS and PANS*

DONATE NOW

