

Immunology Update

Spring 2019

FROM THE JOHNS HOPKINS ADULT PRIMARY IMMUNODEFICIENCY CENTER OF EXCELLENCE

MESSAGE FROM THE DIRECTOR



April is Adult Primary Immunodeficiency (PI) Awareness month. A year ago this month, we held a fantastic event in Georgetown hosted by Tara Sakraida Parker and her husband Richard Parker to celebrate the launch of the Adult Primary Immunodeficiency Center of Excellence and to raise awareness of this heartbreaking disease. Heartbreaking because so many suffer in silence, undiagnosed and untreated. Since last April, we have been actively fundraising for the Center, and we are deeply grateful to all who have supported our efforts. Because of your generosity, we have achieved several critical milestones (see *Recent Milestones*).

None of this would be possible without you and your philanthropic support. Thank you! We have accomplished much and we have far to go, including the funding of a new laboratory, described later in this update. In this month of awareness-raising, I ask you to talk to your family, friends, and anyone who walks this journey with you to share with them how this disease impacts you, and ask them to consider taking action today toward conquering immune system diseases by supporting our Center. 70% to 90% of those living with PI remain undiagnosed: Help us diagnose, treat and find a cure for those thousands who suffer but remain untreated.

Warm regards,
 Antoine Azar

AROUND THE GLOBE

Dr. Azar's global education calendar can be found below.

February 2019	Rochester, NY	University of Rochester
March 2019	San Francisco, CA	American Academy of Allergy, Asthma and Immunology
April 2019	Baltimore, MD	Johns Hopkins School of Medicine Annual Rheumatology Symposium
April 2019	Atlanta, GA	Clinical Immunology Society Meeting
June 2019	National Harbor, MD	Immune Deficiency Foundation National Meeting

ANTOINE AZAR, M.D.
 Director, Johns Hopkins Adult Primary Immunodeficiency Center

DAWN BORST, RN
 Nurse, Johns Hopkins Adult Primary Immunodeficiency Center

KRISTIN BROWN, CRNP
 Nurse Practitioner, Johns Hopkins Adult Primary Immunodeficiency Center



OUR MISSION

To diagnose, treat, and cure Primary Immunodeficiency in adults.

<https://www.hopkinsmedicine.org/allergy/adult-primary-immunodeficiency-center.html>

RECENT MILESTONES

CENTER MILESTONES

SECURED NURSE DAWN BORST AS DEDICATED CENTER STAFF. Dawn has gained extensive expertise in the day-to-day management of patients with these complex disorders. She manages each step of care, starting long before the patient arrives, coordinating lab work, organizing specific medical records, and working with insurance companies. Importantly, Dawn helps with patients' education and monitoring, and setting up treatment and infusions.

ADDED NURSE PRACTITIONER KRISTIN BROWN. Kristin has many years of inpatient and outpatient care and will play a very active role in the Center, evaluating patients and increasing access to care.

INCREASED COLLABORATIONS WITH OTHER DEPARTMENTS within Hopkins such as the Vasculitis Center and the Departments of Rheumatology and Nephrology. Many of the most intransigent cases in these disease areas have been found to be associated with underlying immune system deficiencies. Our multidisciplinary approach aims to help patients achieve earlier diagnosis and improved healing.

SECURED NEW LABORATORY SPACE. The research mission of the Adult PI Center of Excellence is critical if we are to lead the way in discovering therapies that improve health and help people with Adult PI live more robust lives. Securing lab space is a significant milestone in the life of the Center!

IN THE NEWS

Breakthrough Magazine, 2018 Holiday Edition

<https://www.hopkinscim.org/breakthrough/holiday-2018/investing-in-genius/>

WATCH DR. AZAR

<https://www.hopkinscim.org/intiatives/about=pi/whats-new>

BreakOut

1. Dr. Azar’s research has helped pave the way for a significant change in the way some treatment centers treat patients with COPD. In many cases where COPD patients have frequent exacerbations of their disease, an underlying immune disorder may be the culprit. By analyzing the immune system of these patients, doctors can better determine who might be good candidates to receive immune therapy to help reduce COPD exacerbations and worsening of lung function.

2. NEW LABORATORY SPACE! A critical component of the Adult Primary Immunodeficiency Center of Excellence will be our ability to build a significant biorepository of DNA and other biologic samples and clinical data. This “big data” repository will help us better to classify which kinds of treatments work most effectively on patients with certain patterns

of symptoms or genetic markers. Additionally, very few laboratories in the western hemisphere process the unique tests that are necessary to diagnose PI. Our goal is to have all necessary testing available on site to create convenience and timely results for our patients. We have the space, but we need the following equipment to operate the lab.

ITEM	COST
Biological Hood (for research bench)	\$10,000
-80°C Freezer (for biological samples)	\$8,000
Centrifuge	\$6,000
Incubator	\$8,000
Other Small Equipment (pipettes, etc.)	\$6,000
Lab Technician (salary + benefits)	\$40,000 ANNUAL
Additional Lab Supplies (assay kits)	\$20,000 ANNUAL

IF YOU WOULD LIKE TO SUPPORT DR. AZAR’S NEW LAB,
 PLEASE CALL MONICA BUTTA AT
 410-550-9881 OR E-MAIL MBUTTA2@JHMI.EDU

PATIENT PERSPECTIVES

“A BAD COLD THAT DID NOT COMPLETELY END LED TO A CYCLE OF SEVERE SINUS INFECTIONS AND CHEST CONGESTION. AN UNCONTROLLABLE COUGH RESULTED IN TWO LATE NIGHT TRIPS TO THE ER. A SERIES OF SPECIALISTS AND TESTS OVER A 2 1/2 YEAR PERIOD FOUND NEITHER A CAUSE NOR A CURE WHILE MY LUNG FUNCTION CONTINUED TO BE SERIOUSLY COMPROMISED. MY FIRST VISIT WITH DR. AZAR RESULTED IN A 5-6 HOUR SERIES OF TESTS. HIS SUBSEQUENT ANALYSIS OF NOT ONLY THESE TESTS BUT RESULTS FROM PRIOR TESTS QUICKLY LED TO A TREATMENT PLAN THAT REDUCED SYMPTOMS AND RESTORED MY HEALTH. DR. AZAR’S COMPREHENSIVE INVESTIGATION INCLUDED GOING BENEATH SUMMARIES OF TEST RESULTS TO PERSONALLY ANALYZE THE ORIGINAL DATA AND TO CONSULT WITH MY PRIOR SPECIALISTS. HIS COMMITMENT TO THIS INTERDISCIPLINARY APPROACH AND WILLINGNESS TO SPEND AS MUCH TIME AS NEEDED RESULTED IN AN EXCELLENT OUTCOME IN A RELATIVELY SHORT TIME.”

- JARRETTSVILLE, MD

“OVER THE COURSE OF MY CAREER, I HAVE FELT THE PAIN, THE ANXIETY, AND IN SOME CASES THE DESPERATION, OF PEOPLE WHO HAVE SPENT YEARS COPING WITH ILLNESS, BOUNCING FROM DOCTOR TO DOCTOR WITH NO DIAGNOSIS OR CURE, FEELING UNHEARD AND UNSEEN. MY PATIENTS ARE THE REASON I GET UP IN THE MORNING.”

- DR. ANTOINE AZAR

“I AM HEARING IMPAIRED IN MY LEFT EAR AND RECENTLY RECEIVED A DIAGNOSIS THAT I’M LOSING HEARING IN MY RIGHT EAR. THIRTY YEARS AGO, THE ONLY PROTOCOL AVAILABLE TO ME WAS STEROIDS. TODAY, DR. AZAR IS USING IVIG IMMUNOGLOBULIN INFUSIONS TO MITIGATE THE HEARING LOSS IN MY RIGHT EAR AND PREVENT DEAFNESS. DR. AZAR IS A CREATIVE PROBLEM-SOLVER WHO PERSEVERES UNTIL ALL OPTIONS HAVE BEEN EXPLORED. FOR HIM AND THE PI CENTER, I AM TRULY GRATEFUL.”

- GEORGETOWN, DC

You can be a partner in our mission to care for those with immune disorders. If you would like to learn more about the Center’s needs and how you can support the Adult Primary Immunodeficiency Center, please contact Monica M. Butta at mbutta2@jhmi.edu or 410-550-9881.