



# AUTO-IMMUNITY

**SPECIAL REPORT**

**2022**



## HELPING PATIENTS NAVIGATE THEIR AUTOIMMUNE JOURNEY

Dear Friends of the Autoimmunity Institute,

Too often when a patient develops an autoimmune disease, they end up spinning their wheels in search of a diagnosis. They see specialist after specialist. Just keeping track of their medical records—not to mention the toll that uncertainty takes—can leave a patient running on fumes.

Then they make a pit stop at the Autoimmunity Institute. A systemic disease can affect any part of the body or the mind. But with 17 specialties under one roof, every symptom is in our wheelhouse. While some providers practice “my way or the highway,” our diverse team of experts have created a truly collaborative environment, working together to design a holistic plan for every patient. Even when a case doesn’t quite fit within diagnostic criteria, as so often happens with these complex diseases, we are here to put every patient on the right track.

Our on-site, full-time research lab is where the rubber meets the road. We are racing to find better tools for diagnosis, monitoring, and treatment. We are racing to one day find a cure. We are racing to put patients living with autoimmunity back in the driver’s seat.

Joseph Ahearn, MD  
Chair

Linda Santelices, MS  
Director of Research

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## AUTO-IMMUNITY

Chronic disease care and fast cars may seem like an unlikely pair. So what's the connection between the Autoimmunity Institute and automobile racing? The answer is Michael Linn, Vice Chair of the Relapsing Polychondritis (RP) Foundation, Co-Founder of Race for RP, and philanthropist racing to conquer autoimmunity.



## A Q&A WITH MICHAEL LINN CHAMPION FOR AUTOIMMUNE CARE

### How did you get involved with the Autoimmunity Institute?

I got a call from what was formerly AARDA, now known as the Autoimmunity Association. Virginia Ladd had read an announcement about the launch of the AHN Autoimmunity Institute. Opening a dedicated center for autoimmune care had been a long-term objective, so when Virginia called me, I could barely understand her – she was that excited. I responded in kind. I told her if there was anything I could do to get involved, I'd get on a train or a plane that day. Eventually Dr. Joe Ahearn and I got in touch and agreed to meet. We both drove to AARDA outside of Detroit. Listening to him describe the mission of the Autoimmunity Institute was just fantastic. That was 2018.

### How did the Autoimmunity Institute get involved with automobile racing?

Sometime after that, AARDA had a meeting in Washington DC and we were invited along with Drs. Manzi and Ahearn. I brought my son with me. (I told him it would be a spring break trip, but he knew there was something going on in autoimmunity land.) My mom happened to be in town, too. The net of it is, everyone was invited to dinner – there was even a pending snowstorm – and yet there's all this action at the table, free-flowing, sincere. We just hit it off.

In the course of that meeting, I leaned over and told Dr. Ahearn that my brother-in-law is an amateur racer, and from time to time we have an opportunity to put decals on racecars. I asked if he would be interested in putting the AHN logo on a car, and he said yes. That fact that he made that decision on the spot? I said this guy has my attention! And with the creativity, time and energy that went into the Autoimmunity Institute, they deserved the attention.

### Why is automobile racing a productive space for raising disease awareness?

We had been promoting disease awareness this way with Race for RP. But there are so many more autoimmune diseases, so we decided to use AUTO-immunity as an umbrella to raise awareness for a broader group of patients. The drivers and teams opened the door to our primary awareness campaign. It's an international sport that has a near cult-following. There's an inherent team spirit to it. And the people who are involved are not afraid of a challenge. If you say to the average person, I want to climb Mount Everest, they think you're nuts. But if you say it to a known climber, they say, when do you want to go? Essentially we were adopted by the auto racers who were highly collaborative and immediately helpful.

### How is the Autoimmunity Institute like a full-service pit stop?

They're not leaving you alone. The patient arrives, there's a deep team with expertise, offering traditional and other medicine, and they're going to stick with you. And that, to me, is what full service means. It's not like a restaurant chain where you show up with your order in mind and money in hand. The providers here are going to help you navigate this journey, wherever you may be, and I think that's massively different than other institutions. There's a lot of thought that went into this beyond the science and the medical care. It was designed to be more like a Disney™ 5-star check-in process. Besides being a first-class, good looking place, I watched it work. There are very few people who could have pulled off what they've done here.



KYLE MARCELLI  
with a young fan

## FULL-SERVICE PIT-STOP

### Kyle Marcelli Professional Race Car Driver

"The Autoimmunity Institute is like a full-service pit-stop. When I come in the pits in a race, full-service stop means we're changing the driver in an endurance race, we're changing the tires, we're adding fuel, maybe making adjustments to the car, and then we're back in the race.

At the Autoimmunity Institute, it's the same thing. A patient can go there and not just see one specialist, but multiple specialists, and it's this central hub ultimately trying to find answers and cures. I thought it was really cool and exciting and positive and hopeful for patients.

It's amazing how once you're exposed to autoimmunity, you start seeing it everywhere. I'm racing for everyone who's involved or associated with an autoimmune disease, whether it's yourself, someone you know, a friend or a family member, or just a donor, a doctor, or a scientist. It's all of the above. Whether we win or we don't win, the people who are affected by it are a part of something bigger. If you're a patient at home, there are people who are trying to raise awareness or education, raise money, do research. It's a big picture thing. It involves more than the driver behind the wheel."

KRISTI ROSENBERRY, RN  
&  
CLARE CLIFTON, PA



## A WINNING TEAM

When a patient has a disease that doesn't always show up on standard tests, the path to diagnosis can be a long road. And yet their interactions with the healthcare system can feel cursory, like a drive-through. At the Autoimmunity Institute, we are patient advocates above all else: listening is at the heart of what we do. All of our team members are driven to improve the patient experience, and 10 of our providers were named **Top Doctors by Pittsburgh Magazine™** in 2022.



**Susan Manzi, MD, MPH - Rheumatology**  
*Director, Lupus Center of Excellence*  
*Chair, Medicine Institute*  
*Medical Director, Lupus Foundation of America*

"We understand that people aren't textbook cases and we don't dismiss people if they don't fit into a classic mold. We believe in shared decision making and welcoming patients to ask questions and be a part of the plan."



**Adam Dore, DO - Rheumatology**  
*Division Chief, Rheumatology*

"The providers at the Autoimmunity Institute leave no stone unturned! The collaboration amongst different specialties routinely discussing and managing difficult and out of the ordinary situations, and the transformational team along with the staff providing the extra support for patients, makes it an extraordinary place leading to specialized care unlike anywhere else in the country."



**Briana DiSilvio, MD - Pulmonary & Critical Care**  
*Director, Interstitial Lung Disease Clinic*  
*Director, Post-COVID-19 Recovery Clinic*  
*Pittsburgh Magazine™ "Rising Star"*

"At the Autoimmunity Institute, our providers and staff are focused on providing tailored comprehensive care to this complex population of patients while also engaging the support team. Helping patients and families comfortably navigate the health care system is just one way we try to lessen the burden of their disease."



**Jamil Alkhaddo, MD - Endocrinology**  
*Chief, Division of Endocrinology*  
*Diabetes Lead Specialist, Highmark Living Health*

"The collaboration and team support are an essential part of the Autoimmunity Institute's success and our ability to provide a higher level of care. The team provides education around nutrition, medications, and other important aspects of care that leave the physician's interaction with patients more productive."



**Sonia Manocha, MD - Rheumatology**





**Paul Lebovitz, MD - Gastroenterology**  
*Vice Chairman, Medicine Institute*

"I really believe that providers in the Autoimmunity Institute are the model of how we put the patient central in care. Their utilization of team-based and multidisciplinary care helps a patient diagnosed with a chronic disease not only understand and treat the disease, but also maintain a positive quality of life."



**Tanmayee Bichile, MD - Rheumatology**

"I consider myself lucky to work with the providers and the rest of the team at Autoimmunity Institute. Everyone is bringing their A game to work - it's a mix of different characteristics, but especially the compassion and tireless dedication to get patients with autoimmune diseases better is what makes this a great team!"



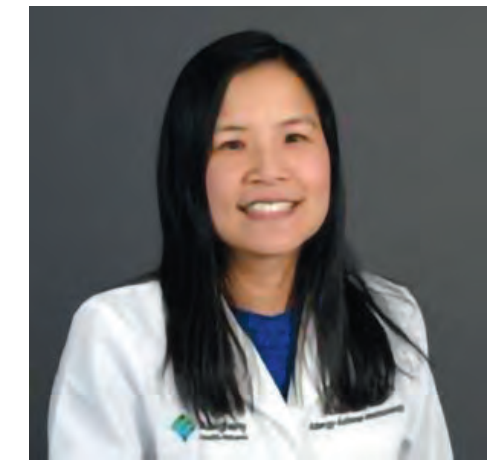
**Holly Lowther, MD - Rheumatology**

"I really think that our patients benefit greatly from the collaborative effort that occurs between providers and the team at the Autoimmunity Institute. We have been able to provide comprehensive support for our patients with the help of our Pharmacy, Nursing, Social Work, Dietary and Behavioral Health teams. As we work together, we are truly providing excellent health care."



**Alicia Kaplan, MD - Psychiatry**  
*Medical Director, Center for Adult Anxiety & OCD*

"The multidisciplinary approach truly benefits the patients in utilizing a biopsychosocial framework for overall wellness. I truly enjoy collaborating with the providers and staff in this welcoming center."



**Ellen Lu, MD - Allergy & Immunology**

CHRISTIAN GRANT, MD  
2022 Fellow

## FUELING THE FUTURE

The Rheumatology Fellowship program was established in 2018 with the launch of the Autoimmunity Institute. Our fellows have experienced multi-specialty, integrated team-based care from the very start. These exceptional trainees are embedded in our mission. Graduates of the program shape their future practices on the lessons learned within our walls, expanding our vision for coordinated care nationwide.

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**AQUILAH WEST**  
Medical Assistant

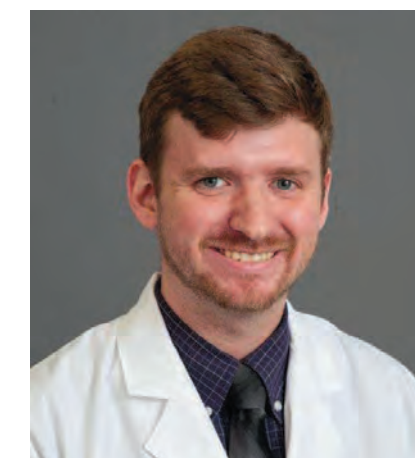


**MICHAEL LUCKE, MD**  
**RHEUMATOLOGY FELLOWSHIP**  
**PROGRAM DIRECTOR**

**What are you looking for when you recruit a fellow?**

**ML:** The types of doctors that are attracted to training here at AHN and the Autoimmunity Institute are comfortable assessing some of these complex rheumatologic cases that often need collaboration across different specialties. Often in rheumatology and autoimmunity, there is no single diagnostic test, and it's about taking all the pieces of a patient's history and examination, as well as some of the lab tests and imaging studies obtained, to reach that diagnosis. We look for those doctors who want to further their expertise through the complexity of cases seen here, as well as learn from the perspectives of multiple rheumatologists and specialists within the group.

Doctors who are going to be a good match and fit for our program are those who excel with some of the uncertainty in the diagnostic workup. Many fellows applying have accomplished significant research in rheumatology and other fields that have separated them from their peers—showing



**NICHOLAS WIEMER, DO**  
**FELLOW**

that they're looking not just at one patient in front of them, but trying to uncover some of the mysteries behind these illnesses.

**NW:** You could call it a puzzle aspect – you're presented with an interesting case and you're probably the fourth person to see this patient. You're the person that might be able to figure it out. And it's an ever-expanding field, with new treatment options, and our fellows find that really interesting.

**For a patient, what's the benefit of being treated by both experienced providers and current trainees?**

**NW:** Trainees, especially as we're getting close to taking boards, are about as fresh as you can get on the current literature and recommendations. On the other hand, someone who's been in the field for a long time has seen this before, has maybe seen this disease present in an unusual way before, and they are "out of the box" diagnosticians. So you have the more traditional text book knowledge and then some life experience that results in two different perspectives for the same patient.



### CARE PATHWAYS

The Autoimmunity Institute treats patients through Clinical Care Pathways: a coordinated, data-driven, and standards-based approach to managing chronic disease. Providers help patients with Inflammatory Bowel Disease, Rheumatoid Arthritis or Psoriatic Arthritis choose a treatment goal, usually remission. Disease activity is measured at each visit, and therapeutic adjustments are made every 1-3 months. Unlike a non-targeted approach, our Pathways decrease variability of care, improving clinical outcomes at lower cost.

PAIGE RUTTER, MS  
Senior Clinical Research Coordinator



## SHIFTING GEARS

The Autoimmunity Institute has a full-time, on-site research team racing to find better, faster ways to diagnose, monitor, and treat these complex diseases. One such physician researcher is Tarun Sharma, MD, a rheumatologist who leads the Rheumatoid Arthritis (RA) Care Pathway. Dr. Sharma is currently the principal investigator of a study which will help find the safest, most effective way to taper medication among patients with RA once their symptoms are under control.

ERIN FAIGHT  
Research Scientist



**TARUN SHARMA, MD**  
**DIRECTOR, RHEUMATOID ARTHRITIS CENTER OF EXCELLENCE**

**What is the background for this study?**

When we start a younger patient with RA on an immune suppressant treatment, one of their first questions when we write that prescription is, how long do I have to take this medication? And once they've been on it for a while and start to feel better, the next question they ask is, can I reduce or stop this medication now? Those are intuitive questions we face all the time. And when we surveyed patients about the use of biologics, they had a very high interest in tapering their medication.

**What will doctors be able to learn from it?**

First we performed an initial study through the Autoimmune Association Grant about different tapering strategies and which specific medications can be safely tapered—methotrexate, expensive biologics—and we found that methotrexate can be tapered with a very low risk of flare compared to biologics. We wanted to do a deeper dive into this particular finding, and that's what we're doing in with the AHN, Highmark Health, Penn State Clinical and Translational Science Institute Collaborative Grant: looking at different strategies of tapering methotrexate in stable, well-controlled RA. We would also survey patients and providers to see if they're interested in that strategy.

**What's the benefit of partnering with another research institution?**

There's a benefit any time you have heads coming together. We're partnering with senior investigators at Penn State, academic rheumatologists. This study is unique in the sense that with Penn State, we have different populations, not just larger populations. They have the central PA mix of demographics, and here we have the urban population in Pittsburgh. So when you have a larger population, the results become stronger, more reliable and more generalizable.

**How will this work potentially help patients with RA?**

Clinical care is great, because that's where we start to think about what we don't know in medical science. It's wonderful to impact the health of one patient at a time. The potential benefit of this work, and what draws me to research, is the opportunity to impact care of all patients with RA if our findings are significant. The largest impact of this study will be measuring the reduced medication use and the health outcomes of these patients, ultimately impacting clinical care by reducing risk of long-term immune suppression.



**LYNETTE MCCULLOUGH-KENNEY**  
Health Management Coordinator

## **GOING THE EXTRA MILE**

The Autoimmunity Institute is a destination for autoimmune care because our model is unique in the world. We've treated patients from 44 states and counting. When an out-of-state patient makes an appointment with us, the entire team goes the extra mile to make them feel welcome and at home.

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## A Q&A WITH AMANDA, AUTOIMMUNITY INSTITUTE PATIENT ST. CLAIRSVILE, OHIO

### How did you end up at the Autoimmunity Institute?

I started out testing positive some years ago with lupus. Before I knew it, Relapsing Polychondritis reared its ugly head. I was going to ENTs and ERs, but since it's a super rare disease, no one knew what it was. I went to an orthopedic surgeon who said my knee pain was just a little wear and tear. Another doctor told me there was nothing wrong with me. It's been a long road to get help.

I started searching on the internet and came across the Autoimmunity Institute. Once Dr. Manzi and Amanda Bembic started treating me, I was able to get the disease under control. I still have flares, but if I had not gone to the Autoimmunity Institute, I don't know what I would have done. The unknown was as scary as the pain.

### How was the the care you received here different?

At the height of my problems, a doctor sat with me for three minutes and then said, I'll see you in six months. That's not going to work—this is long-term. When you go to the Autoimmunity Institute, they listen to your symptoms. The first time going in, of course I was nervous. Would they be able to help me? But they're very educated. Dr. Manzi had experience in RP—it's really hard to find that. She has a really good bedside manner, she has compassion, she has passion for the job she does, and she treats us very well.

Sometimes you just get lost in paperwork, but here I actually felt like a patient instead of a number. From the receptionist who answers the phone, to the doctors, the assistants the nurses—it's been phenomenal. It was very efficient. They're very thorough—I'm impressed with that. The holistic treatment intertwines. I learned techniques like meditation, and nutrition based on what my body feels, not fads or trends. You're not going to find that any other place: your



rheumatologist and nutritionist and therapist all in one.

### What has it been like living with an autoimmune disease?

These autoimmune diseases change your whole life. It's like the monster under your bed as a kid. It's so sneaky. All of a sudden it shows up—not just in your mind but in your body. But it doesn't always show up on X-rays or a CT scan or an MRI. Sometimes when people can't see it, they basically say it's in your head. A lot of us patients go through that. It upsets us—and our caregivers, because they can't help us. I'll say it another way: when you have an autoimmune disease, the body is like a computer, but a little piece of code got rewritten. It still works, but it's glitchy. That little piece of code tells the body to attack itself.

If someone had said, hey, you're going to have this autoimmune disease and it's going to attack the cartilage in your ears, I wouldn't have believed them. This is an ornery disease.

It's such a lonely path. That's the reason why I participated in research. One it's so rare, and two, it's awful for other people to have to suffer. So why not all of us who've been diagnosed with it speak up and say something? The more information we can get out there the better, not just for the patients but for the medical field.

### Will you continue to travel out of state to receive care?

There's no question. When you find this kind of healthcare, you're going to do what you have to do to get there. The medication does help. And if my symptoms get bad, I go talk to the team and they make adjustments as needed. I have my days, because the disease does flare, but not as severely with the medication I'm taking. And the diet change has really helped. There are treatments and there's management, and that's why I'm thankful for AHN. They will get to the bottom of it. You might still have pain, and you still have the disease, but they're on your side.



## DRIVING DIVERSITY, EQUITY AND INCLUSION

Dear Friends of the Autoimmunity Institute,

2022 was an extremely exciting year for the Autoimmunity Institute as we realize our vision of focusing on diversity, equity and inclusion intentionally, courageously and openly. To meet this goal and foster an inclusive and safe environment with a sense of belonging for all staff, our team participated in four micro-sessions and one Inclusivity Reset session. These sessions were created by the Enterprise Equitable Health Institute (EEHI) team and led by Dr. Margaret Larkins-Pettigrew, Senior Vice President and chief clinical diversity officer.

This year's micro-sessions were intended to help staff understand how small actions and incremental change at the individual and team level can create and sustain an inclusive culture. Discussions focused on topics such as the 'Five Habits of Inclusion' (empower, support, cooperate, be open, be fair), the pain of exclusion, and understanding and managing conscious and unconscious bias during decision making. Staff also learned how to develop inclusive habits that can lead to meaningful conversations, engagement, and improved productivity in their work space.

During these meaningful dialogues, staff were engaged, provided feedback and comments, and shared their lived experiences. Many team members expressed how these discussions will improve social interactions with patients, family, friends, neighbors and strangers. As a woman of color, I am encouraged to pursue learning opportunities to establish understanding, increase knowledge, and create allies for all cultures. My hope is that what is learned in these sessions becomes contagious and spreads beyond the walls of the Autoimmunity Institute.

The Autoimmunity Institute will continue to foster an inclusive and safe environment with a sense of belonging for all with more micro-sessions planned for 2023.



Nicole Wilson, MS  
Associate Director of Bioinformatics,  
Medicine Institute Research Program  
Equity Officer, MIRP & AHNRI



NICOLE WILSON, MS  
Associate Director of Bioinformatics

## RACE WITH US

Join us in our race to defeat autoimmunity. Whether you are a patient, provider, caregiver, champion, or even just like fast cars, our partners help us pick up speed on the road to opportunity.



Michael Linn, Vice Chair of the Relapsing Polychondritis Foundation, Co-Founder of Race for RP; Louis Colmache, Head of Motorsport of FNA; Dr. Susan Manzi; Matteo Torre, President and CEO of FNA; Dr. Joseph Ahearn; and David Bammert, Director/President, Relapsing Polychondritis Foundation and Race for RP



## Language accessibility and nondiscrimination

Allegheny Health Network (AHN) complies with applicable federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex in its health programs and services. In order to treat individuals in a nondiscriminatory manner, AHN provides free communication aids and language assistance services.

### Spanish

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 412-359-3131.

### Chinese

注意：如果您使用繁體中文，您可以免費獲得語言援助服務。請致電 412-359-3131。

### Vietnamese

CHÚ Ý: Nếu bạn nói Tiếng Việt, có các dịch vụ hỗ trợ ngôn ngữ miễn phí dành cho bạn. Gọi số 412-359-3131.

### Russian

ВНИМАНИЕ: Если вы говорите на русском языке, то вам доступны бесплатные услуги перевода. Звоните 412-359-3131.

### Pennsylvania Dutch

Wann du Deitsch schwetzscht, kannscht du mitaus Koschte ebber gricke, ass dihr helft mit die englisch Schprooch. Ruf selli Nummer uff: call 412-359-3131.

### Korean

주의: 한국어를 사용하시는 경우, 언어 지원 서비스를 무료로 이용하실 수 있습니다. 번으로 전화해 주십시오. 412-359-3131.

### Italian

ATTENZIONE: In caso la lingua parlata sia l'italiano, sono disponibili servizi di assistenza linguistica gratuiti. Chiamare il numero 412-359-3131.

### Arabic

ملحوظة: إذا كنت تتحدث اذكر اللغة، فإن خدمات المساعدة اللغوية تتوفر لك بالمجان. اتصل برقم 412-359-3131.

### French

ATTENTION: Si vous parlez français, des services d'aide linguistique vous sont proposés gratuitement. Appelez le 412-359-3131.

### German

ACHTUNG: Wenn Sie Deutsch sprechen, stehen Ihnen kostenlos sprachliche Hilfsdienstleistungen zur Verfügung. Rufnummer: 412-359-3131.

### Gujarati

સુચના: જો તમે ગુજરાતી બોલતા હો, તો નિશ્ચલક ભાષા સહાય સેવાઓ તમારા માટે ઉપલબ્ધ છે. ફોન કરો 412-359-3131.

### Polish

UWAGA: Jeżeli mówisz po polsku, możesz skorzystać z bezpłatnej pomocy językowej. Zadzwoń pod numer 412-359-3131.

### French Creole

ATANSYON: Si w pale Kreyòl Ayisyen, gen sèvis èd pou lang ki disponib gratis pou ou. Rele 412-359-3131.

### Mon-Khmer

ប្រយ័ត្ន៖ ប្រសិនបើអ្នកនិយាយភាសាខ្មែរ, ស្តីអំពីជំនួយផ្លូវភាសា ជាយមិនគិតលុយនូវ គំរាចមានសារប្រយ័ត្ន។ ចូរ ទូរស័ព្ទ 412-359-3131.

### Portuguese

ATENÇÃO: Se fala português, encontram-se disponíveis serviços linguísticos, grátis. Ligue para 412-359-3131.

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