

New Hope for Chronic Illness and Health Disparity

My Journey to Learn about the Role of Emotional Trauma

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My name is Pat Rush. I have been an Internal Medicine physician for over 40 years. I am honored to share with you my experience.

This can be a challenging conversation with discussion of painful topics. But this is fundamentally a conversation of hope – because of the opportunity to get to the root causes of physical and emotional suffering.

I believe it is time to recognize that our approach to chronic illness - and our approach to Health Disparity - has been incomplete.

The major work of my career has been to **promote universal access** to high quality medical care –

- I spent 20 years in the Cook County Health System including 6 years as the Director of Cook County Hospital's Emergency Room
- Studied health economics while getting my MBA at the University of Chicago
- Became a national expert in care and financing of the Dual Eligible population - poor elderly and disabled – those patients having both Medicare & Medicaid
- And for 12 years I was appointed by the Illinois governor to serve as the only physician on the Illinois Medicaid Advisory council for coverage of home care and institutional care for the disabled and elderly.

When I started in the Cook County Hospital Emergency Room in 1980, the conventional wisdom was that the reason poor and minority patients had worse health outcomes and died younger was that they had no access to care and therefore diagnosis and treatment were delayed. Such a delay in care can have tragic outcomes.

But, in fact, many of the patients that I saw had been evaluated and treated soon after symptoms began. Yet despite receiving prompt and appropriate care, these patients' health outcomes were significantly worse than one would expect. I came to wonder, **is there another, deeper issue underlying Health Disparity?**

From 2000-08, I created a solo private medical practice here in Chicago – and over those 8 years, I completed in-depth interviews with over 500 patients.

Today – I want to **share with you 3 things**:

- What led me to create a different kind of primary care practice
 - The **ASTONISHING** relationship I found between patient experience and health
 - And lastly - new scientific findings – which can help us all create a new and better approach
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PART 1: WHY I CREATED A NEW APPROACH TO CHRONIC ILLNESS

During my years as a physician at Cook County and later in managed care and academia, I saw thousands of patients. What never made sense to me was how medical science looked at chronic illness – especially for patients with multiple combined illnesses or sudden onset of profound illness. I felt we didn't know what was really going on.

I also knew from my years as a health executive in big systems of care - where I had analyzed tens of thousands of patient care episodes from a Population Health perspective - that our methodology, our way of collecting data and analyzing data was missing something. Missing something BIG.

So in 2000 - with the support of my wonderful husband, I took a wild leap, quit my job as Associate Vice President at Rush Medical Center, and started over - creating a solo primary care practice in Oak Park. (I called the practice PRIMARY CARE PLUS.) When I opened the practice I had been a physician for 25 years. I knew from talking to my patients that chronic illness was somehow related to stress. Using today's terminology, I created a Trauma-Informed medical practice. But that's not what I called it then -- because like most physicians, I knew very little about Emotional Trauma.

I had been in academia for quite a while, so I thought: I need validated research tools. I put together a packet of assessments and questionnaires: I opened my practice and presented each new patient with my stack of questionnaires. Needless to say, the patients HATED the questionnaires. And when I reviewed the patient responses on the questionnaires, I really learned nothing new.

One of my first patients in my new practice was a woman I'll call "Karen*." Karen was a young woman with serious but unexplained medical problems eventually diagnosed with Lupus, a potentially fatal autoimmune disease.

In my first visit with Karen, I asked a standard medical question, "When did this problem start?"

She answered, "When I was 12. I was living with my grandmother."

I asked, "Were your parents around?"

She answered, "I never knew my father and my mother died of breast cancer when I was eleven."

I said, "Oh I'm so sorry."

Karen said, "That's not the bad part. My grandmother basically raised me and she died of cancer when I was 14."

My heart sunk. I was speechless. But my brain had a light bulb moment. I thought, "This has GOT to be related."

Soon after, I set the research Questionnaires aside and went to asking one question:

HOW WAS GROWING UP FOR YOU? MOSTLY OK or PRETTY STRESSFUL?

Asking this question ("How was growing up for you?") is when the window opened and I began to see what was going on. The stories patients told me stunned me, shocked me, saddened me. The most powerful lessons of my medical career - lessons that changed my own brain - came from these conversations with patients.

I want to clarify here that this was not a randomized controlled study. This was my own pilot study.

I also want to clarify that all these patients were adults age 18 or older and part of the informed consent prior to a patient joining my practice was talking with them about my interest in chronic illness and stress.

* All of the cases discussed here are real, although the names are changed to preserve anonymity.

PART 2: HERE'S WHAT I FOUND WITH THE NEW APPROACH:

What was so amazing was that based on that one question ("How was growing up for you?"), the patients in my practice fell into 3 groups:

- 1) Younger patients (under age 50) - who answered that GROWING UP was MOSTLY OK.
These patients had mostly minor complaints and were in good health.
- 2) Patients older than 50 – who answered GROWING UP was MOSTLY OK - were also generally well but had more wear and tear of life.
- 3) Patients who answered GROWING UP was PRETTY STRESSFUL - all had complex chronic illness:

**My Patients who answered
"Growing Up was *Pretty Stressful*"**

All had serious, complex chronic illness:

- Lupus; Rheumatoid Arthritis
- Severe Obesity
- Type 1 - Juvenile Onset Diabetes
- Crohn's Disease and Ulcerative Colitis
- Multiple Sclerosis
- Young women with Breast Cancer
- Severe Chronic Pain, Fibromyalgia
- End Stage Kidney Disease on Dialysis
- End Stage Congestive Heart Failure
- And more

I thought: how did the most interesting patients in Chicago find their way to my little office in Oak Park? And then I realized that I had been seeing patients with this history my whole career. We all have. I didn't know – we don't know - how to SEE what is going on.

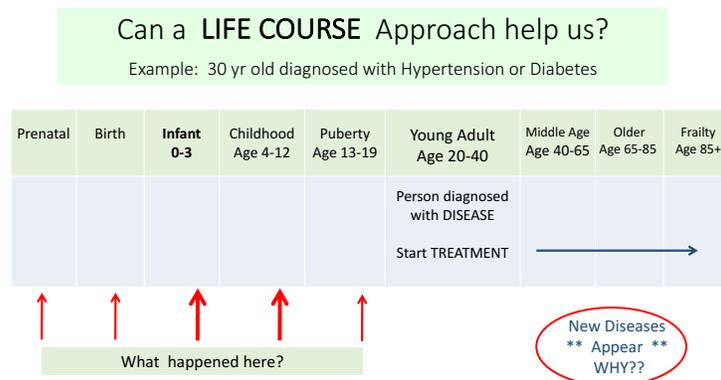
The **FIRST THING** I realized was that what we call *Past Medical History* (asking about diseases, surgeries, allergies, medications, etc.) is NOT really the history of the patient illness.

What we currently call *Past Medical History* is the history of the patient's interaction with the medical system. This is very different from the patient's life experience – and the complex physiologic pathway as a patient's experience changes their body's structure and function.

In learning to make sense of a patient's actual experience, I used what's called a "**life course**" perspective tracing a person's specific health path (history of experience, health and illness) - starting with conception and evolving through development and through their own unique experience over the lifespan.

Using a life course perspective, each "episode of illness" is not seen as a stand-alone event or stand-alone disease, but rather as the "state of system function" at that moment in a person's life. A life course perspective helps us as patients and providers to understand the context and trajectory of each person's experience and its impact on health.

With my new approach, I learned that all patient symptoms are clues to underlying physiologic balance or imbalance. To understand the onset and course of chronic illness – and to see opportunities for prevention and effective treatment - we must have the time and context to partner with patients to learn together about their experience and its impact on their health.



The **SECOND THING** I realized was that my physician training did not prepare me for what patients would tell me about their childhood and about their experience as adults. This was a humbling recognition after having been a physician for twenty-five years.

I found that emotional trauma can affect persons of all backgrounds - all races and ethnicities, all economic backgrounds, all genders:

- Suffering of painful emotions: fear, terror, rage, shame, despair – extending to emotional numbness, intrusive thoughts, and dissociation
- Childhood sexual assault. Of my patients with complex chronic illness, 50% of women and 25% of men reported sexual assault
- Separation from a parent; death of a parent or sibling; being forced into Foster Care
- Witnessing violence within the community and within their family

- Located 3 blocks from the Chicago West Side, my practice was also near a community of Eastern European refugees, bringing families who suffered in the Holocaust and Soviet era labor camps.
- I heard the pain and despair of patients who experienced the cruelty of the hatred and extreme discrimination of racism.

One of my patients was named Sandra* – a 54 y/o woman living on the West side of Chicago. Sandra had severe asthma, hypertension and coronary artery disease.

I became Sandra’s doctor because I had been the on-call doctor when Sandra was admitted to ICU for a severe asthma attack. When I first met her, Sandra had been admitted to the ICU and placed on a ventilator 3 times within one year for severe asthma. Her chances for survival were poor. Sandra had no primary care doctor and she agreed to come to my office in Oak Park.

Gradually Sandra and I untangled her experience. She was the victim of sexual assault as a child. I taught her how to do deep breathing and a simple meditation. Over 2 years, her health improved and we were able to gradually decrease some of the 12 meds she was prescribed. And over those 2 years, Sandra had no ER visits and no hospitalizations.

One day, I got a call from the ER that Sandra had been admitted to the ICU. I went to see her, and after she was stabilized and able to talk, I asked “Sandra, what happened?”

She said, the house my daughter was renting in Milwaukee had a fire and she is homeless.
 I said, “Oh I’m so sorry.”
 She said “I am so ANGRY. DCFS took my daughter’s 3 children away from her.
 My daughter is a good mother. DCFS would not have done this if we were white.
 This happened because we are black.”

I have no way of knowing what the facts were in the case of Sandra’s daughter. But there is reason to believe Sandra. Repeated studies show that black boys and girls, black men and women continue to be 3 times more likely than whites to be arrested or referred to court services for the same behavior as whites in the same situation.

Racism causes emotional trauma. And emotional trauma causes disease. The cruelty of discrimination causes emotional trauma - whether you are black or brown, gay or transgender, Muslim or Jew.

What my patients told me: Impact of Discrimination

- Never feeling safe
- Never feeling accepted; always feeling judged
- Expected to fail
- Never getting a fair chance

Could I (as a straight, white woman) REALLY understand?	Probably Not
Could I see the exquisite anguish at the unending injustice and corrosive fear?	YES

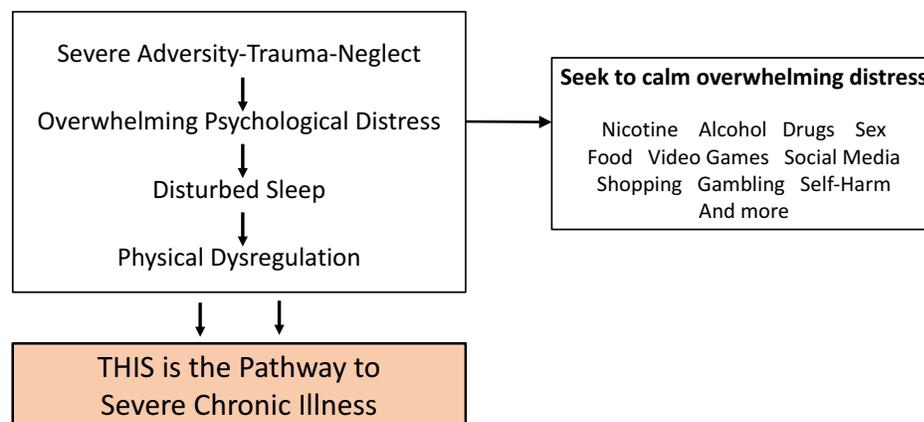
When I started hearing these stories, I realized that I did not know how to interview patients without re-traumatizing them. I quickly sought advice from Behavioral Health and eventually went for formal trauma counseling training. It took me 10 years to recognize my own secondary trauma (the trauma to my own spirit from hearing my patients’ stories) and to seek help for myself.

Also I want to say that although patients could easily tell me if growing up was hard for them, few patients would tell me as a stranger what had actually happened to them. Some took 5 years as my patient before they would talk about what had happened.

The **THIRD** thing I realized was that **patients with childhood adversity had a COMMON PATTERN:**

- **FIRST**, the patient had experienced extreme trauma and emotional distress – often starting between the ages of 3 years and 12 years.
- **SECOND**, the child developed all kinds of physical and emotional symptoms (multisystem physiologic disruption) and was diagnosed with various diseases.
- **THIRD**, in response to their terrifying childhood experience, patients developed a profound sleep disturbance which became lifelong.
- **FOURTH**, I realized that behaviors we might call addictions (smoking, alcohol, prescription or street drugs, compulsive eating, gambling, etc.) could also be interpreted as creative coping mechanisms to calm the tremendous fear, anxiety – and rage - some of our patients have experienced - but which remains invisible to us as healthcare providers.

Consistent Pattern from Adversity



As healthcare providers, we have not been taught to see the signs and symptoms of fear and terror. Instead our medical training teaches us to focus on a particular organ system or disease. Specialization can create tunnel vision obscuring the big picture. Yet when we healthcare providers can let go of the old mindset, we can see that ALL patient symptoms, especially sleep disruption and addiction, are invaluable clues to overall physiologic picture.

The **FOURTH** major realization - and to me as a physician, the most interesting of all – was that about 25% of these adults with complex chronic illness had had a severe, prolonged illness as a child or young adolescent. Again, looking at the patient’s whole life course allowed me to see previously unidentified patterns.

These patients had a childhood illness characterized by:

- unexplained fever, abnormal blood count
- profound fatigue, altered mental status, perhaps confusion
- often prolonged time out of school.

About half of this subset of patients had been hospitalized with a diagnosis like meningitis or rheumatic fever. The other half had been treated at home with a diagnosis like chronic mono.

What was common in all of these patients was that the acute illness appeared to resolve – but 5-25 years later, the patient would suddenly present with a new unexplained serious illness, even organ failure.

One of many patients I saw with this pattern was Deborah*, age 35.

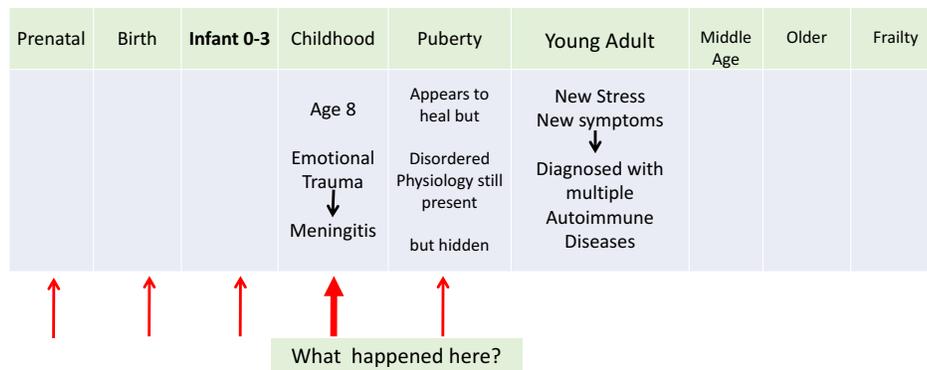
Deborah’s medical problems included headaches, red painful eyes, mood swings, infertility, disrupted sleep, and crampy abdominal pain.

After a comprehensive workup, Deborah was diagnosed with an autoimmune disease (Crohn’s inflammatory bowel disease) and uveitis (an inflammation of the connective tissues of the eyes). She was followed by 5 different medical specialists and took 6 daily medications.

As part of my evaluation, I asked: “How was growing up for you?” Deborah reported that when she was 8 years old, her younger brother was killed in a freak school accident. She said, “the happiness was gone from our family. It was like we were made out of cardboard.” After her brother’s death, she was sent to live with relatives. Four months later, she returned home to her parents. One month after returning home, Deborah developed fever, stiff neck, confusion and vomiting. She was hospitalized for 3 weeks with meningitis. “I was never the same,” she said.

My evaluation: Deborah had a **major neuroinflammatory episode** at age 8 after emotional trauma. The physiologic impact of this episode was misunderstood by the clinical team. And therefore, the opportunity to prevent further illness was missed.

Link between Childhood Adversity & later Chronic Disease
 Example: 35 yr old diagnosed with autoimmune disease



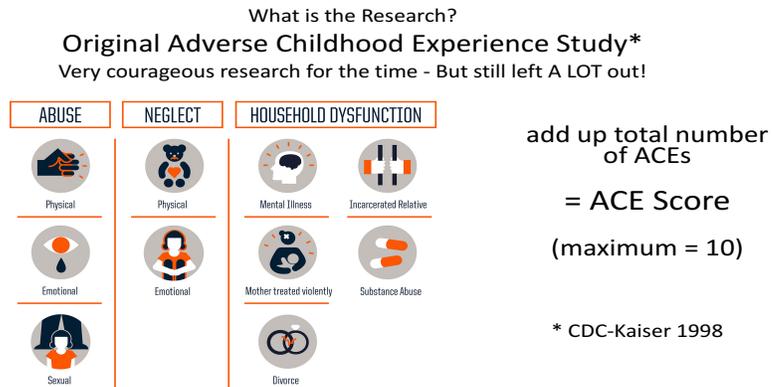
To all of us (the patient, the family, the physician), these episodes appeared unrelated. But once I learned how to take a detailed history of patient experience, I began to see the same pattern over and over. I realized that the initial patient illness, in response to emotional trauma, represented some type of neurologic disruption with inflammation, causing a profound reordering of the patient’s physiology.

As the child (or adolescent) appeared to heal from initial illness, those changes became quiescent (hidden) until a new major challenge occurred (perhaps hormonal changes of puberty or a pregnancy or another profound emotional distress). With the new stress, the patient’s underlying (but hidden) physiologic instability unraveled into a new pattern - which physicians diagnose as a new disease.

To my knowledge, this pattern (although I believe is a common pathway to severe chronic illness) has never been reported in the medical literature.

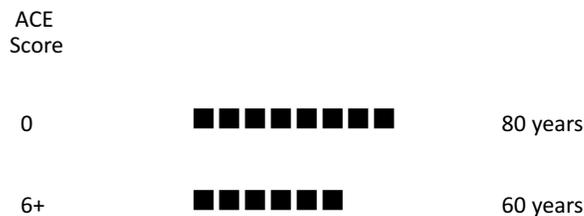
Part 3: NEW RESEARCH ABOUT EXPERIENCE, THE BRAIN AND HEALTH

The inspiration for much of the current interest in trauma was the CDC-Kaiser Permanente landmark 1998 research - the Adverse Childhood Experiences (ACEs) study (by V Felitti, Anda, et. al.).



This visionary research demonstrated that Adverse Childhood Experiences result in up to 600% increased risk of serious chronic illness and 400% increased risk of addiction. Most profound of all, having 6 or more adverse childhood experiences can shorten the average lifespan by 20 years. As physicians, how can we explain that?

ACE Score (# of Adverse Childhood Experiences) and Life Expectancy



The original ACEs study has been replicated over a hundred times by researchers throughout the world. Yet – now 20 years later - there is still NO coordinated research by medical science to look for the mechanisms involved. What is going on?

Certainly there are many obstacles to medicine adopting a Trauma Informed approach including:

- the continued false separation of physical and mental health,
- the lack of provider training to hear and respond to painful trauma histories - and lack of systems to protect providers from secondary trauma and burnout,
- and the structure and reimbursement of our healthcare delivery system which limits the amount of time a provider has with a patient and reinforces fragmentation of care.

BUT I have come to believe that the **#1 barrier preventing medicine from understanding and addressing the role of emotional trauma in health is the conceptual framework of our medical science.**

From my 40 years as a physician and healthcare executive, I believe that virtually all physicians and healthcare systems are compassionate and truly committed to excellence, yearning to improve access to effective therapies. But given the way medical science currently understands the body and thinks about disease, we physicians and scientists are trapped - trapped in an obsolete and ineffective paradigm.

For centuries, child abuse has been recognized as having a profound negative impact on emotional, physical and social well-being. Yet the idea that experience could actually disrupt the body's physiologic processes (the embodiment of experience) continues to be viewed very skeptically by modern medicine.

FORTUNATELY, core research through NIH and by scientists around the world is beginning to build a new science of health.

Science is coming to a fundamental change in perspective of how the body works.

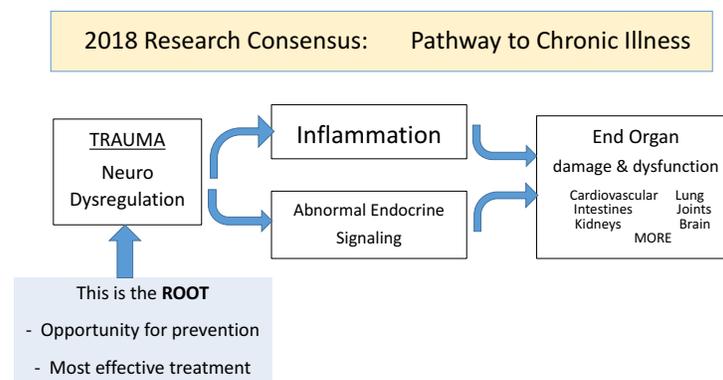
Science now sees the body as a deeply interconnected system that maintains function and structure through "signaling." The brain sends and receives signals (messages) and sends messages throughout the body. When the brain is disrupted – for example by emotional trauma – the brain signals to the body are changed – and can cause tissue and organ dysfunction.

Also, the explosive growth of neuroscience has provided new concepts and technologies to understand the brain and the "signal crosstalk" between the brain and the body.

In contrast to this large body of well accepted research, our current specialty-focused medical system largely ignores the critical question of communication (signaling) throughout the body and tends to treat the body as a set of stand-alone organ systems.

Lastly, there is strong evidence that processes behind many chronic illnesses (even asthma, hypertension, obesity, coronary artery disease, depression) – actually start in the brain through a process called neuroinflammation. [I will come back to this at the end, when I share new research published in Lancet.]

A major mechanism of disease appears to be that traumatic emotional experience, through excitation of the deep brain - overwhelms regulation (modulation) within the brain and autonomic nervous system, leading to abnormal signaling and tissue inflammation.

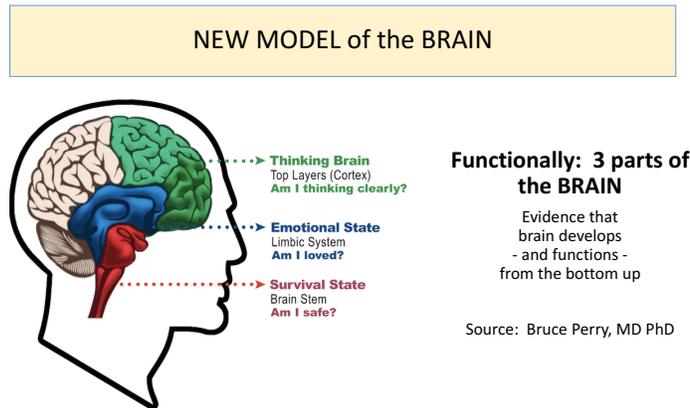


IN CLOSING, I want to summarize these concepts – and point you to new research that shows medical researchers are beginning to think differently:

- Scientists now appreciate that a person's experience is NOT peripheral to the cause and course of disease, but actually a critical factor.
- As many researchers have suspected, inflammation is a common pathway for many diseases.
- And the **experience of emotional trauma is a common pathway** to neuroinflammation and chronic illness.

I want to draw your attention to four key areas of research:

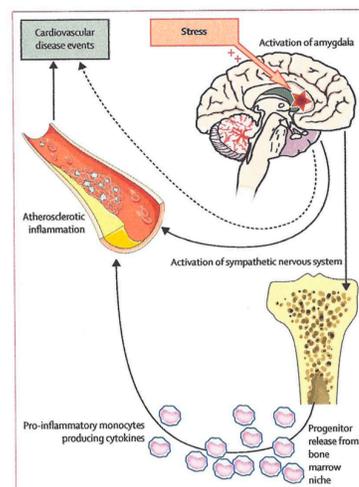
1. **Work of Bruce Perry, MD PhD at the Child Trauma Academy.** www.childtrauma.org
 Dr. Perry is a child psychiatrist who has developed a new, deeper approach to understand child mental health and development. Perry and colleagues identified a developmental sequence – showing that the development of the brainstem is first, then midbrain/emotional center, and then thinking brain (cortex).



Using this developmental assessment, Perry and colleagues are able to develop an individualized therapeutic plan – to support the child or adolescent in development of those missing milestones of brain development. This Neuro-Sequential Model provides hope for children, adolescents, and young adults previously considered beyond help.

2. **“Relation between resting amygdalar activity and cardiovascular events”** by Tawakol and colleagues. A study from Harvard Systems Biology, published in *Lancet*, January 2017. 293 subjects, average age 55 years old, with no known heart or vascular disease had total body PET scans. Patients were followed for up to 5 years. 22 of the patients had a heart attack during those 5 years.

All of the patients who had heart attacks were among the patients with abnormal scans – although the disease then was silent. The Harvard researchers found that the heart disease had started in the deep brain (the amygdala, the fear center). Their hypothesis is that the abnormal signals from the brain caused inflammation in the bone marrow and then blood vessels, resulting in atherosclerosis and a heart attack.



Physiologic Mechanism:

for example:
Hypertension and Heart Disease

are result of complex chain of events

Tawakol, et.al. *Lancet*
 January 11, 2017

Harvard Division of Systems Biology

3. **“Everyday discrimination” research by David Williams, PhD MPH** from Harvard
Everyday discrimination is the constant, eroding experience of being treated with less courtesy or respect, receiving poorer service, being threatened or harassed, encountering people who act as if they are afraid of you or think you are not honest, and so on. More than 750 medical studies demonstrate that a person’s experience of everyday discrimination can contribute to premature birth, low birth weight, poor birth outcomes, higher rates of diabetes, obesity, and other illnesses.

4. **“Heterogeneity in Blood Pressure Transitions Over the Life Course”** by Hardy and colleagues.
Published in JAMA Cardiology, April 2017. This study was done by researchers from North Carolina, Northwestern here in Chicago, and Minnesota. They tracked blood pressure readings in 17,000 people. High blood pressure (hypertension) is the first step in the body’s path to diabetes, heart disease, kidney failure and stroke. Researchers found that young black men, aged 15-25 years had twice the risk of hypertension compared to white youth. The transition from normal blood pressure to hypertension in black youth started at age 8.

Many research articles have shown that hypertension is the result of inflammation of the blood vessels. As outlined in the Harvard study, we also know that the inflammation starts with over-stimulation of the deep brain from fear. That black boys are developing hypertension at age 8 tells us that black boys are living in fear.

As physicians and scientists, can we continue to say we don’t know where hypertension, heart disease, and other chronic illness comes from? Health Disparity? Or can we learn more and change our perspective? and get to work.

It is time for us to take courageous action. We need to eliminate the root causes and focus on primary prevention of disease. If we want our children to do well...be healthy...if we want our schools to be calm and organized, we need to put into action what science tells us. People need to feel safe. They need to feel loved before they can be healthy and think clearly. We need to provide real support for at-risk families.

This is such an exciting time for medical science. Tremendous opportunity – and hope - awaits us and our patients.

THANK YOU.