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### Letter from the Director

Dear Friends,

I am delighted to report that our friend and ALS Center of Excellence Board Member, **Scott L. Pranger**, has given us a **\$2 million gift**, the largest in the history of the Michigan Medicine ALS Clinic. To honor his tremendous generosity, we are renaming our clinic the **Pranger ALS Clinic**. Scott is passionate about fostering multidisciplinary care for ALS patients, while also having the foresight to see that research is the key to discovering new treatments for ALS. There are many other pieces of good news that I wish to share. Working with our physicians and scientists at Michigan Medicine, as well as our network of elite researchers worldwide, we have renamed our research program the **NeuroNetwork for Emerging Therapies**. What began 20 years ago with two physicians and a handful of scientists has grown to dozens of investigators from all parts of the globe, working in collaboration to achieve our goals of improving the lives of our patients. Please go to **www.mneuronet.org** to see the exciting projects that are currently in progress.

Our ALS Center of Excellence at Michigan Medicine is currently on a mission to repurpose an existing, FDA-approved drug to slow ALS progression. We have obtained the patent from Pfizer to investigate using the drug Tofacitinib (Xeljanz) in ALS. Our hope is that this drug, which works by modifying the immune system, will slow or stop the progression of the disease. Please see <a href="https://www.umich-als.org">www.umich-als.org</a> for further details.

For years we have been at the forefront of research that reveals that exposure to environmental pollutants, like pesticides and flame retardants, can increase the likelihood of ALS onset, and accelerate the rate of disease progression. This work is especially important in the state of Michigan, which has the highest prevalence of ALS in the United States. In the last year, our environmental research has received nationwide acclaim. We were featured in print (Detroit Free Press, MLive), over the airwaves (NPR/Michigan Radio), and on television (PBS Detroit and Grand Rapids), as well as numerous prominent scientific journals.

2020 has been a year with unprecedented challenges for our medical community. I could not be more proud of our physicians, scientists and worldwide collaborators, who are committed to solving the devastating effects of human disease. They are an inspiration.

ALS may have no cure or effective drug treatments, but we are on the path to solving this disease that afflicts 6,400 new patients in the U.S. each year. Thank you for joining us in this battle against ALS — one we plan on winning.

Eva L. Feldman, MD, PhD Russell N. DeJong Professor of Neurology Director, ALS Center of Excellence Director, NeuroNetwork for Emerging Therapies





The ALS Center of Excellence at Michigan Medicine and the University of Michigan ALS National Advisory Board are thrilled to have accepted a \$2 million gift from fellow Board Member and philanthropist Scott L. Pranger, in May of 2020, for the naming of the Multidisciplinary ALS Clinic. Henceforth the clinic shall be called the **Pranger ALS Clinic** at Michigan Medicine.

Scott's wife, Cathleen, was diagnosed with ALS in 2003, and was a patient at the ALS Clinic at Michigan Medicine for the 12 years of her disease. Cathleen passed away in 2015. "The cost of my wife's care was in excess of \$2 million over her life with ALS, which were costs the insurance companies did not cover. I want to be able to help other families with the care their loved ones truly need and deserve," said Scott.

Scott has been involved as one of our founding National Advisory Board Members since 2018, and has been very active in philanthropic activities in Western Michigan. Born in Shelby, Michigan, Scott has been a lifelong West Michigan resident. He currently lives in Spring Lake, Michigan, while enjoying winters in Arizona.

### "I want to be able to help other families with the care their loved ones truly need and deserve"

Scott became the first sales engineer and eventually vice president of sales at Kurdziel Industries in Norton Shores, Michigan. He founded his own company, EQI Ltd., a global manufacturing and logistics corporation, in 2004, and grew this company into a global powerhouse. Pranger sold his company in 2012 to devote more time to his family.

Scott's other philanthropic activities include establishing the Scott L. Pranger Central Michigan University Business Scholarship for students attending CMU, from which he graduated in 1983. This provides a four-year, full scholarship to a Shelby or Spring Lake, Michigan, student every year. Scott was chosen as the

CMU College of Business Administration 2015 Distinguished Alumni Award winner.

He is also a Board Member, and a recipient of the 2019 Bronze Leadership Award from Junior Achievement in Grand Rapids/ West Michigan, and provides leadership in their annual golf fundraising event. He has also been very active in West Michigan community affairs, and in faith-based causes around the world.

Scott's commitment to our ALS Clinic, and to persons with ALS in the state of Michigan, and their caregivers, is deeply appreciated.

"Scott's gift to the ALS Clinic will allow us to continue our world-class care of ALS patients from Michigan. Much of the care in a multidisciplinary clinic is not reimbursed by insurance companies, and Scott's gift will allow outstanding multi-specialty care to ALS patients in perpetuity. His gift will truly propel our clinic, and research, into the future. He is a true friend, not only to our clinic, but to myself personally." – Dr. Feldman







<u>UMICH-ALS.ORG</u>

## Introducing the NeuroNetwork

"NeuroNetwork for Emerging Therapies" This is much more than just a name change. This year, we celebrate the 20th anniversary of the Feldman Research Program, formerly called the Program for Neurology Research and Discovery. As we look back, it's clear that we have accomplished so much in the last 20 years. We have furthered our understanding of the causes of neurological diseases through:

- New discoveries that advance our knowledge base
- Technological advancements that open new ways for us to think about, analyze and apply data-driven medicine
- Partnership with our patients who donate their samples and their time to help us better understand neurological disorders

Today, our work requires many diverse minds, medical disciplines and great institutions collaborating, creating, investigating and discovering to ultimately treat patients in new ways. Some say it takes a village. We say it takes a Network. So, as we begin a new decade, it seems like the perfect opportunity for us to change the name of our program to the NeuroNetwork for Emerging Therapies to better reflect our vision and goals for the future.

VISIT MNEURONET.ORG FOR MORE INFORMATION





NEURONETWORK'S
CURRENT ALS
GRANTS



Mapping the ALS Exposome to Gain New Insights Into Disease Risk and Pathogenesis (NIH, R01ES030049)

Metabolomic Signatures Linking ALS to Persistent Organic Pollutant Exposures (NIH, R01TS000289)

### **ALS Center Research**

### The Future Begins with Greater Understanding of ALS

#### **Identifying Environmental Causes of ALS and Genetic Associations**

The Midwest, and in particular, Michigan, has the highest prevalence of ALS in the United States. Our research, funded by the National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC), and the ALS Association, is demonstrating that patients with ALS have higher concentrations of environmental toxins in their blood compared to healthy individuals. Further, ALS patients with the highest levels of these pollutants progress at twice the rate of those ALS individuals

with the lowest levels. A person's genetics may also impact the rate of metabolism of these toxins. We are expanding our environmental research in Michigan, including examining the **effects of algae-blooms in our lakes** (Figure 1) as a potential source of toxins.

### Modifying the Immune System to Slow and Stop ALS

The immune system plays a complex but critical role in ALS. Our current focus is on natural killer (NK) cells, which specialize in killing diseased cells, including neurons. We see elevated levels of NK cells in the blood and spinal cords of ALS patients. When we eliminate NK cells in mice, ALS is slowed. Based on this work, our team is investigating the repurposing of an existing drug, Tofacitinib (Xeljanz), known to attack NK cells. We hold the patent on this drug for use in ALS, and hope to begin a human clinical trial within the next year.



Figure 1: Harmful algal blooms in Lake Erie and Lake St. Clair.

### Stopping the Spread of ALS

A promising treatment strategy for fighting ALS is interrupting its spread from nerve cell to nerve cell. Our scientists are focused on studying small "sacks" of biological material called exosomes. These exosomes are important because they can travel from one nerve cell to the next. We believe that targeting this exosomal "communication" is a promising therapeutic approach for ALS.

#### Transplanting Stem Cells to Slow ALS

Dr. Feldman is an international pioneer in the research of the **use of stem cells** (Figure 2) for potentially treating ALS. She is the principal investigator and director of the first-ever, FDA-approved human clinical trial in which stem cells are injected directly into the spinal cords of ALS patients. An analysis of Dr. Feldman's phase I and II clinical trials demonstrated promising findings and are paving the way for a larger, Phase III trial that focuses on the efficacy of this therapy.



Figure 2: Stem cells implanted into the brain

of an ALS patient.

Figure 3: Dr. Goutman accesses the frozen samples in the biorepository.

### Maintaining Our ALS Biorepository

A biorepository is a "bank" of stored biological samples (blood, urine, hair) that our ALS patients donate for research. Our ALS Center of Excellence maintains one of the largest ALS biorepositories in the country. We store these samples in a "deep freeze" (Figure 3) so that they can be used at U-M and shared with other universities, in perpetuity, for ALS research nationwide.

The Role of Natural Killer Cells in ALS (NIH, R21NS102960) ALS Gene and Environment Interactions (ALSA, 20-IIA-532)

Identifying NK Cells as Therapeutic Targets in ALS (ALSA, 20-IIA-431) ASSOCIATION

## In the Community

Part of our mission at the ALS Center of Excellence at Michigan Medicine is to educate and advocate for ALS in our community. Dr. Feldman, Dr. Goutman, and the rest of our team have been honored guests at Michigan Athletics events and have served as medical experts for media. Below are a few of our 2019 highlights:



The University of Michigan basketball team's alumni celebrated the hiring of Head Coach Juwan Howard at the inaugural "Hoops Fight ALS" fundraiser. Drs. Goutman and Feldman thanked Coach Howard for his program's support.



Honoring the memory of former player and ALS patient Scott Matzka at the fourth annual "Ice ALS" University of Michigan hockey game, Drs. Goutman and Feldman stood at center ice with Scott's children, Owen and Reese.



PBS Host Shelley Irwin spoke with Dr. Feldman, Sherry Schuen & Catie Matzka. PBS Grand Rapids and Detroit also aired a second 30-minute ALS special.



Cynthia Canty of NPR/Michigan Radio interviewed Dr. Goutman about the impact that Michigan's environment has on ALS patients.

### **Detroit Free Press**

PART OF THE USA TODAY NETWORK

The Detroit Free Press featured Dr. Feldman, Dr. Goutman, Rob and Lisa Cotton (pictured below) in "Michigan's Manufacturing Legacy May Be Affecting Our Health, Environment." The front-page story detailed Rob's journey as a person with ALS.





# PESTICIDE EXPOSURE CONTRIBUTES TO FASTER ALS PROGRESSION

Michigan has one of the highest rates of ALS in the country. Why? The answer may lie in the fact that Michigan is both an industrial and agricultural state. Drs. Feldman and Goutman examined how the environment impacts ALS development and progression.

7,430 Impressions on Twitter 18,200 Reached on Facebook



### **CLICK TO WATCH**

Dr. Feldman explains why the pollutants in Michigan rivers and lakes may be related to the onset and progression of ALS. Learn why patients participate in ALS research, meet our scientists and take a virtual tour of our laboratory.

## Meet Our Physicians



**Dr. Eva L. Feldman**Director,
ALS Center of Excellence

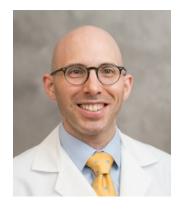
Eva L. Feldman, M.D., Ph.D., is the Russell N. DeJong Professor of Neurology at Michigan Medicine. A renowned neurologist and neuroscientist, she has

devoted her career to understanding neurological disorders and developing new treatments. Dr. Feldman earned her medical and doctoral degrees at U-M and completed her neurology residency at Johns Hopkins Hospital. She joined the U-M faculty in 1988.

Dr. Feldman has more than 30 years of continuous funding from the National Institutes of Health for her research on neurological disorders. She is a principal investigator on the first two U.S. Food and Drug Administration-approved stem cell transplant clinical trials for ALS. She is also supported by the Centers for Disease Control and Prevention for her groundbreaking work on identifying environmental pollutants as a contributing cause of ALS.

Dr. Feldman was the inaugural director of the A. Alfred Taubman Medical Research Institute at U-M. She is a member of the National Academy of Medicine. In 2019, she received the Michigan Medicine Alumni Society's Distinguished Achievement Award.

CLICK FOR MORE



Dr. Stephen Goutman
Associate Director,
ALS Center of Excellence
Director,
Pranger ALS Clinic

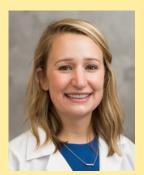
Stephen Goutman, M.D., M.S., is an Associate Professor of Neurology at Michigan Medicine. After graduating from Johns

Hopkins University, Dr. Goutman completed his medical degree at the University of Chicago Pritzker School of Medicine and his neurology residency and neuromuscular fellowship at Cleveland Clinic. He received a Master's of Science in clinical research design and statistical analysis at the University of Michigan.

Dr. Goutman's area of expertise is ALS/Lou Gehrig's Disease where his focus is delivering comprehensive and compassionate care. As the Pranger ALS Clinic Director, he leads a team of providers that care for persons with ALS and their families.

Dr. Goutman's research is focused on identifying the causes of ALS and leveraging that knowledge to develop new treatments.

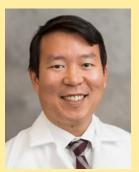
**CLICK FOR MORE** 



**Dr. Mary Schmidt**Physical Medicine and
Rehabilitation Physician

Mary Schmidt, D.O., is a Clinical Lecturer of Physical Medicine and Rehabilitation at Michigan Medicine. She obtained her medical degree from Michigan

State University. She completed her residency training in physical medicine & rehabilitation at the University of Pittsburgh Medical Center, where she was also chief resident. Dr. Schmidt's clinical responsibilities include outpatient practice focusing on ALS, adult muscular dystrophy, hereditary neuropathy, and other neuromuscular conditions. CLICK FOR MORE



**Dr. Philip Choi** Pulmonologist

Philip Choi, M.D., is an Assistant Professor of Pulmonary & Critical Care Medicine at Michigan Medicine, where he is Medical Director of the Assisted

Ventilation Clinic. He earned his medical degree from the Mount Sinai School of Medicine, completed his internal medicine residency at Brown University, and his fellowship in pulmonology and critical care medicine at Duke University. His area of interest is patients with chronic respiratory failure, especially in neuromuscular diseases such as ALS. CLICK FOR MORE



# Pranger ALS Clinic

<u>The Pranger ALS Clinic team</u> is dedicated to helping patients, their families, and caregivers overcome the many challenges posed by ALS. Each team member exhibits a different area of expertise to the ALS journey, including:

- Respiratory therapist assists with breathing difficulties.
- Physical therapist helps patients maintain and improve mobility.
- Occupational therapist provides instruction on daily tasks, such as dressing and feeding.
- Seating and mobility specialist provides rehabilitation equipment, including power wheelchairs.
- Speech therapist helps with speaking and swallowing.
- Dietitian teaches patients proper nutrition.
- Social worker ensures patients and families understand available resources.

### Partnering with Patients in Research

- Research coordinators provide patients with the opportunity to take part in research.
- By participating in surveys and studies, patients provide crucial data to researchers regarding quality of life, disease mechanisms, and disease progression.
- Data collected by patient participation drive the innovative research at the core of the ALS Center of Excellence's mission.

## Opportunities for Impact

Our most stunning successes have always stemmed from philanthropic partnerships with those who care most about our work. Perhaps you are grateful that a physician made your friend's or relative's journey with ALS more peaceful and comfortable. Perhaps you dream of helping uncover the mysteries of neurological diseases so that future generations need not worry about ALS.

Your generosity can help create the future we all envision - a future free of ALS. It can fuel the most promising discoveries, equip the most advanced laboratories, and support the best physicians and scientists. It can lead to more effective treatments and cures. It can improve lives - here and around the world.

Please join the ALS Center of Excellence at Michigan Medicine as we move confidently to create new knowledge, train future neurologists and neuroscientists, enhance care, and ultimately find better treatments for ALS, thereby making an impact that will be felt for generations. The future of ALS treatment begins now.

ALS Center of Excellence at Michigan Medicine Campaign Priorities:

### A NAMING GIFT FOR THE NEURONETWORK FOR EMERGING THERAPIES

For a gift of \$10 million or more, the NeuroNetwork for Emerging Therapies, which includes the research unit of the ALS Center of Excellence, will be named in your honor. This transformational gift would have a wide-ranging and profound impact on the scope and depth of research performed in the NeuroNetwork laboratory. A gift of this magnitude would create an endowment which would provide funding and support for numerous world-class scientists who are using cutting-edge technologies to investigate neurological diseases such as ALS.

#### NAMED EMERGING SCHOLAR FUNDS

For a gift of \$150,000-200,000, an emerging scholar fund will be established and named in your honor. Supporting our next generation of young scientists is pivotal. Assisting these future leaders in research may allow important life-saving discoveries in the causes and treatment of ALS.

#### NAMED INTERNSHIPS

For a gift of **\$50,000** or more, you will support research opportunities for medical students, research fellowships, or internships in collaborative scientific education.

#### NAMED ENDOWED PROFESSORSHIPS

For a gift of \$1-2.5 million, a professorship will be named in your honor. The recruitment and retention of world-class physicians and scientists is critical for the advancement of research and treatments for patients with ALS. Endowed professorships allow our faculty members to investigate new ideas because they provide a secure source of funding for their research and educational activities.

\$2.5 Million for Full Professorship

\$1 Million for Research Professorship

\$1 Million for Early Career Professorship

### NAMED ENDOWED RESEARCH FUNDS

For a gift of \$100,000 or more, a research fund will be established and named in your honor. In the early stages of many research endeavors, traditional sources of funding with government grants may not be available. Funds generated from endowments offer a vitally important source of support for cutting edge investigations.

For more information on giving, or to make your gift, please contact Michael Harders at the ALS Center of Excellence: (734) 763-1402 or miharder@umich.edu.

## Private philanthropic support allows for exploration and scientific creativity, which is essential for turning novel, high-risk concepts into rewarding new treatments.



### **SHERI MARK**

Sheri Mark currently serves as President of the ALS Center of Excellence National Advisory Board, and has been a member since the founding of the Board in 2018. She has also served on the Board of the ALS of Michigan. "I've known Dr. Feldman for over two decades, since my cousin got diagnosed with ALS at the age of 43. Working with Dr. Feldman to secure funding for ALS research and to change Michigan's stem cell laws has led to significant advances in understanding ALS and other neurodegenerative diseases. I'm proud to continue my support of Dr. Feldman and her team as a committed Advisory Board member and friend."



### LAUREN HENDEL

ALS Center of Excellence National Advisory Board member Lauren Hendel (BA UM-Ross School of Business Graduate 2019) served as President of a student organization at the University of Michigan called A Lot Stronger (ALS) Together. The money raised by her group was donated to our ALS Center of Excellence to support research and provide ALS patients with valet parking vouchers to be used during their visits to the Clinic. These vouchers were gifted in honor of the legacy of her father, Stu Hendel, who developed ALS and passed away during her senior year. "The Pranger ALS Clinic team is making great strides in the fight against ALS and I look forward to continuing to support their research and clinical care."



### CHRISTINA CLARK

"Recognized among her peers for outstanding research and clinical programs, Dr. Feldman has always sought innovative pathways to advance ALS, Alzheimer's, and diabetes research and therapies. This is why our family foundation placed a grant more than 20 years ago in Dr. Feldman's lab for early work in ALS stem cell research and why we recently funded continuing studies in a promising drug for ALS. Being a National Advisory Board member allows me to share the hope and confidence built over two decades of association with Dr. Feldman and the ALS Clinic."

### FEATURED EMERGING SCHOLAR: RESEARCH ASSISTANT PROFESSOR BENJAMIN MURDOCK, PHD

Dr. Murdock's goal is to understand the immune system's role in ALS, targeting how it will allow us to develop new therapies.

#### Credentials:

- BS, Microbiology, Immunology & Molecular Genetics, UCLA, 2003
- PhD, Immunology, University of Michigan, 2010
- Postdoctoral fellowship, University of Michigan



### The Future of ALS Treatment Begins with You

Our mission is to provide exceptional care and advance education, advocacy and original scientific discovery for persons with ALS and their families.



### ALS CENTER OF EXCELLENCE NATIONAL ADVISORY BOARD

Back: Lisa Rosenberg, Harold Burrell, Jr., Willard Holt III, Scott Pranger.

Middle: Hilary King, Jon Gerych, Doris Allen, John Scarbrough.

Front: Dr. Stephen Goutman, Sheri Mark, Dr. Eva L. Feldman, Christina Clark, Dr. Mike Ritter.

Not pictured: Dr. William Allen, David Forbes, Lauren Hendel, James Hiller, Dr. Brian Roth, Ari Weinzweig.

### ALS CENTER OF EXCELLENCE STAFF

Director, Eva L. Feldman, MD, PhD Russell N. DeJong Professor of Neurology

Associate Director, Stephen Goutman, MD, MS Clinical Associate Professor of Neurology

Managing Director, D. Michael Ritter, MD

Communications Director, Matt Trevor

Marketing & Communications, Shoshanna Fischhoff

Development Officer, Michael Harders

Consultant, Paula Morning