FALL 2021

# Arthritis Progress Report

News from the Russell/ Engleman Rheumatology Research Center





### The Patient Education Task Force

Christy Abele Terry Berkemeier Pamela Culp Karen Curtis Sharon McCarthy Susan O'Brien Janeen Tuitupou Freddie Wilkinson PJ Handeland, Executive Director, Russell/Engleman Rheumatology Research Center David Wofsy, MD, Director, R/ERRC

## Also in This Issue

- 2 PHILANTHROPY: Growing Research Center Accelerates the Search for Cures
- 3 RESEARCH: Transforming EHR Data into Safety and Quality Improvements
- 4 MESSAGE FROM THE DIRECTOR: Devotion to Others Defines a Difficult Year

David Wofsy, MD (right), introduces researcher Jonathan Graf, MD (left), in the webinar titled "The Virus, the Vaccine, and You." You can view the recording at tinyurl.com/virusvaccineyou.

## Patient Education

# The Power of Knowledge for Those with Rheumatologic Diseases

"As a patient and board member, I've felt lucky to hear our doctors and researchers speak, and I thought it would be amazing for others to have this information," says Christy Abele, chair of the patient education task force at the Russell/Engleman Rheumatology Research Center (R/ERRC) at UCSF. "Providing education is a way to help patients take better care of ourselves."

In December 2020, Abele and her colleagues began to transform this thinking into reality. Six months later, the group presented a timely webinar titled **"The Virus, the Vaccine, and You: An Update for People with Rheumatologic Diseases."** The program has garnered more than 550 combined views on YouTube to date, some live and some of the recording; such programs will be central elements of the UCSF Rheumatology Education Program.

### First, the Immediate Need

For people suffering from rheumatologic disease, the COVID-19 pandemic has generated questions and anxiety beyond what most of the world's population is already feeling. How might their condition affect their risks for contracting the disease or its severity if they do contract it? What are the risks and efficacy of the various vaccines?

With those concerns in mind, task force volunteers consulted with David Wofsy, MD, director of the R/ERRC, to choose the topic and speaker for its first webinar. They worked with groups like the Vasculitis Foundation, which publicized the webinar and posted a link at its website, to raise awareness about the event.

In the webinar, Wofsy introduced Jonathan Graf, MD, whose research focuses on cardiovascular risk in patients with rheumatoid arthritis (RA) and who has emerged as a leading expert on COVID-19 and the new vaccines. Graf walked viewers through what we know about the interaction among COVID-19, the vaccines and rheumatologic diseases. A lively, informed Q and A session followed. *Continued on page 2* 

### **Philanthropy**

# **Growing Research Center Accelerates the Search for Cures**

Whith the generous support of Terry Berkemeier and Lori Lerner, the UCSF Division of Rheumatology has established the UCSF Center for the Rheumatic Diseases. The center integrates clinical care with a comprehensive research program aimed at discovering the underlying causes of rheumatic diseases, developing and testing new therapies, exploring prevention strategies and, ideally, finding cures.

#### **Building on a Prior Program**

Lerner and Berkemeier – he is a rheumatoid arthritis (RA) patient – have long supported both the division and the Russell/Engleman Rheumatology Research Center (R/ERRC). Nearly a decade ago, they began funding the Breakthrough Program for Rheumatoid Arthritis Research (BPRAR), which targeted the high-risk, high-reward work of investigators willing to focus on the biology of RA.

Those efforts brought investigators from diverse fields into collaborations with faculty and trainees in the Division of Rheumatology, producing significant new insights into possible genetic and microbiological causes for RA. This led in turn to new National Institutes of Health (NIH) grants to continue the work, including career development awards that launched the careers of two young investigators who were subsequently recruited to the UCSF faculty to conduct RA research.

When Maria Dall'Era, MD, became chief of the UCSF Department of Medicine's Division of Rheumatology in 2020, she, Berkemeier and Lerner began exploring how to build on BPRAR's successes. Modeling the new center on the NIH structure, they created clinical centers as well as an intramural research program for work done by investigators within the division and an extramural research program for collaborations with, and grants awarded to, investigators from other UCSF programs.

While the center's initial work is focused on RA and lupus, "We will eventually expand our efforts to other rheumatic diseases, such as scleroderma, spondyloarthritis, vasculitis, osteoarthritis, Sjögren's, myositis and pediatric rheumatology," says Dall'Era.

The division's integrated clinical and research program in lupus exemplifies this approach. There, Dall'Era, Jinoos Yazdany, MD, MPH, and Patti Katz, PhD, lead the Centers for Disease Control and Prevention-funded California Lupus Epidemiology Study in which they develop and study a cohort of lupus patients throughout the San Francisco Bay Area. The work includes collecting blood and tissue samples to facilitate a variety of innovative analyses.

"These analyses will enable us to develop a better understanding of disease mechanisms, including the identification of novel pathways and targets for therapies," says Dall'Era. "Our center is building similar bridges from the clinic to the laboratory, creating a pathway to personalized medicine."

#### Philanthropy Needed to Create Infrastructure

Yet setting up a scientific infrastructure for gathering and storing well-annotated biospecimens and making them available to researchers is an expensive, labor-intensive process. Ongoing philanthropy is critical, and other donors are stepping up, enabling the division to begin building out all components of the center.



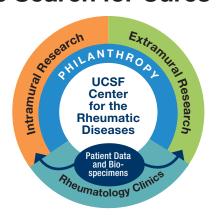
#### Continued from page 1

"It was effective, especially because Dr. Graf talks in ways that people can understand without oversimplifying the science," says Abele.

Joyce Kullman, executive director of the Vasculitis Foundation, heard from various attendees that they found the webinar "outstanding," and noted, "There is a critical need for accurate and timely information, and we appreciate the UCSF team hosting the webinar."

# Delivering an Ongoing Gift to the Community

After debriefing, the task force organized a second talk, **"Osteoarthritis: Current Treatments and What's Ahead for the Future,"** which took place November 3, 2021. Wofsy moderated, with short presentations by



This includes awarding of grants. The first intramural grants went to Judith Ashouri Sinha, MD, to study RA-causing T cells, and to Renuka Nayak, MD, PhD, to study the role of the microbiome in RA pathogenesis and treatment response. The first extramural grants went to researchers studying possible causes of skin and joint disease that are also implicated in RA and lupus, and to researchers studying a protein they suspect plays a role in suppressing autoimmune disease. An initial meeting with all of the researchers, Dall'Era and Associate Chief for Basic Research Julie Zikherman, MD, generated enormous enthusiasm.

"We hope initial successes will have a multiplier effect, making it easier to attract funding from other individuals, or institutions like UCSF or the NIH," says Berkemeier. "We know many rheumatology patients at UCSF are more than willing to roll up their sleeves and help."

"If not for Terry's doctors at UCSF, I don't know if his life or ours would be nearly as rich and full as they've been," says Lerner. "So to be behind research that could change people's lives – that's a big deal." ■

rheumatologist Krishna Chaganti, MD, MS, RhMSUS, and Thomas Link, MD, PhD, from the UCSF Department of Radiology and Biomedical Imaging, followed by a Q and A session.

"Because people can only absorb so much in a doctor visit, these talks provide another touch point with amazing doctors doing cutting-edge research," says Abele. "It's the center's responsibility to give our community this gift." ■

Research

# **Transforming EHR Data into Safety and Quality Improvements**

or all its miracles, medicine is often slow to move proven therapies and practices into everyday clinical settings. The relative rarity of most rheumatologic diseases makes it especially difficult to devise studies with

numbers large enough to drive practice change in this field.

Chief of Rheumatology at the San Francisco VA Health Care System (SFVAHCS) Gabriela Schmajuk, MD, MSc, is determined to speed the process by leveraging information hidden in electronic health record

(EHR) data. Much of her work in this area is housed at the UCSF Quality and Informatics Lab (QUIL), where Schmajuk and Jinoos Yazdany, MD, MPH, are the principal investigators.

"The EHR is an amazing tool for rheumatologists," says Schmajuk, noting that shared registries that EHR data populate are powerful resources for researchers. In addition, when fresh data from research and EHRs appear in easy-to-read dashboards, they can spur clinicians to action. Schmajuk is leading three important projects that exemplify the patient-centered advantages of this approach.

#### **Population Health Dashboards**

One project addresses the need for clinicians to quickly understand factors that could affect rheumatologic treatments. For example, immunosuppressant drugs can reactivate latent and potentially dangerous infections, including tuberculosis and hepatitis. When Schmajuk and her colleagues at the SFVAHCS found that across the United States, more than half of patients are missing at least one screening test for these infections, the researchers developed a secure, web-based dashboard to help clinicians quickly see which patients are missing pretreatment screening tests. In turn, physicians can prescribe antibiotics to prevent reactivating infections.

The team is building a similar dashboard that reports on dosing of hydroxychloroquine, which puts patients at greater risk for eye toxicity when administered at doses greater than 5 mg per kg per day. "We've found nearly 20 percent of patients across the U.S., including at the VA, were receiving higher than recommended doses," says Schmajuk. A pilot study of the dashboard cut the number of patients receiving higher than

> recommended doses to less than 10 percent in just six months.

#### Boosting Patient Self-Management

Dashboards driven by EHR data also hold enormous promise for improving patient self-management. At UCSF Health, Schmajuk and an engineering team –

with input from rheumatoid arthritis (RA) patients – have built a multilingual, patient-facing dashboard for use during a rheumatology clinic visit.

The dashboard is a graph with disease activity and pain scores illustrated on a timeline; it updates with data gathered during the visit. As illustrated at right, the clinician and patient then review the dashboard together to discuss a management plan going forward. The patient keeps a printout and has electronic access, so he or she can review it at home. A randomized trial will determine if the dashboard increases patients' confidence in their medication choices and whether patients and clinicians are more satisfied with their visits.

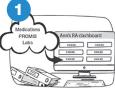
# Enhancing Quality Reporting and Research

The third project involves the Rheumatology Informatics System for Effectiveness (RISE), a Qualified Clinical Data Registry that the American College of Rheumatology developed. RISE aggregates de-identified data from the EHRs of more than 300 rheumatology practices across the U.S. to enhance quality reporting to the Centers for Medicare & Medicaid Services and serve as a resource for researchers.

The more than 2 million patients and 20 million rheumatology visits in the database make it possible for Schmajuk and her team to study very rare diseases, because the accumulated data comprises enough patients for researchers to make reliable inferences about practice patterns and epidemiology. One example: In the largest study of its kind in the U.S., Schmajuk's team examined 1,300 patients with Behcet's disease and found important differences between the U.S. population with this disease and those in other regions of the world.

Such insights validate Schmajuk's belief that EHR data generated in realworld clinical practice can help accelerate the development and use of evidencebased treatments – especially important in a field such as rheumatology, where there are so many rare diseases. She says, "Even if we can reduce the time between when an evidence-based practice is developed and when it is implemented to years instead of decades, we will have helped countless patients."

#### **RA Patient Dashboard**



Pre-visit data is autoloaded from EHR into Ann's RA dashboard.



During Ann's visit, Dr. Gomez updates EHR with data from her exam, such as swollen and tender joints. This data updates her dashboard.



Dr. Gomez launches Ann's dashboard from the RA Navigator in Epic.



Ann takes a printout of these options with her, which she can also access later through MyChart.



Dr. Gomez and Ann look at all of her data together and discuss progress, medications, treatment, lifestyle and goals.



Later, she references the printout when discussing her medication options with her sister.

Illustrations by UCSF SOMTech





First-Class Mail U.S. Postage **PAID** 

San Francisco, CA Permit No. 8285

Russell/Engleman Rheumatology Research Center 513 Parnassus Avenue, MSB, 847C San Francisco, CA 94117

ADDRESS SERVICE REQUESTED

### Message from the Director

# **Devotion to Others Defines a Difficult Year**

As this difficult year approaches its conclusion, I have found myself reflecting on how individuals and organizations prepare for the unexpected and on the qualities that sustain us through hard times.

We did not build the Russell/ Engleman Rheumatology Research Center (R/ERRC). It was conceived and built for us by people now gone – Rosalind Russell, Ephraim Engleman, Holly Smith, Wally Epstein, Ken Fye and countless others whom they inspired. None of them knew that a pandemic was coming, but they had the foresight to know that their successors would need their help. This year has proven how right they were and has shown that they continue to be partners in all that we do.

A few examples, among many, stand out. The center is proud of its role in recruiting and sustaining a faculty with the talent and selflessness to achieve the following: (1) creation of a global registry to track the impact of the pandemic on patients with rheumatic diseases and the implications with regard to treatment; (2) collaboration with Washington University in St. Louis to provide the first comprehensive prospective analysis of

the effects of immunosuppression on SARS-CoV-2 vaccine response; and (3) transformation of the clinical care operation to ensure continued, uninterrupted, safe medical care for our patients. At the same time, Division of Rheumatology faculty succeeded at a remarkable level in attracting National Institutes of Health (NIH) grants, including critical renewals for our training grant and our Precision Medicine (PREMIER) Center. With the help of R/ERRC, the division succeeded in recruiting two young investigators committed to studying rheumatoid arthritis and helping to build a comprehensive Center for the Rheumatic Diseases.

The central quality that stands out for me in reflecting on the division's success this year is that it is often devotion to others that carries one through a crisis. That devotion comes in many forms. It includes the devotion to provide care under challenging circumstances, the devotion to new knowledge, and devotion to the future – which, in a very real sense, is what R/ERRC is all about.

David Wofsy, MD Director, Russell/Engleman Rheumatology Research Center

*To support* the UCSF Division of Rheumatology, you may go directly to makeagift.ucsf.edu/rheumatology. Thank you.

The UCSF Foundation is a California nonprofit public benefit corporation organized and operated exclusively for the charitable purposes of the University of California, San Francisco. It is the policy of the University of California, San Francisco that a portion of every restricted gift be used to help pay for the facilities, infrastructure, and core administrative costs required to carry out the purpose of the gift. If you wish to be removed from patient-related fundraising communications, please complete our opt-out form at giving.ucsf.edu/optout. You may also contact UCSF at HIPAAOptOut@ucsf.edu, (888) 804-4722, or UCSF Box 0248, San Francisco, CA 94143.



Rheumatology Department of Medicine

# Arthritis Progress Report

Produced by the Russell/Engleman Rheumatology Research Center (R/ERRC) in the Department of Medicine at UC San Francisco.

**R/ERRC Director and Editor-in-Chief:** David Wofsy, MD

R/ERRC Executive Director and Managing Editor: PJ Handeland Writer: Andrew Schwartz Design: Laura Myers Design

## For more information

about our programs, please contact PJ Handeland, executive director of the Russell/Engleman Rheumatology Research Center, at patricia.handeland@ucsf.edu or (415) 722-8536.

© 2021 THE REGENTS OF THE UNIVERSITY OF CALIFORNIA