

# FORWARD

The National Databank for Rheumatic Diseases



# About FORWARD

**45+** YEAR STUDY



**100+**  
CO-AUTHORS

**30+** PARTNER  
COLLABORATIONS



**277** CONDITIONS  
STUDIED

**75,000+** PATIENTS  
STUDIED



**1,000+**  
PEER-REVIEWED  
ARTICLES, PUBLIC-  
ATIONS, ABSTRACTS

**FORWARD-THE NATIONAL DATABANK FOR RHEUMATIC DISEASES** is a nonprofit long-term registry of patients with rheumatic diseases established in 1998 by Dr. Fred Wolfe. For over 20 years, FORWARD has represented the patient voice as one of the largest and longest running patient-reported research registries for rheumatic conditions.

**FORWARD COLLECTS DATA ON** rheumatic conditions directly from the people who have these conditions.

**FORWARD'S MISSION** is to advance knowledge about the

- + Causes
- + Outcomes
- + Costs
- + Treatments
- + Side Effects that are all related to rheumatic conditions.

**WE COMMUNICATE** our findings via publications, forums, meetings, and advisory panels to the rheumatology community:

- + Physicians
- + Health Care Professionals
- + Government Agencies
- + Patients, Caregivers, and Family
- + Corporations/Pharma

# Key Variables



**SOCIO-DEMOGRAPHICS**



**CLINICAL AND DISEASE ACTIVITY**



**MEDICATIONS**



**DIRECT/INDIRECT MEDICAL COSTS** (HOSPITALIZATIONS  
AND LOSS OF WORK/EMPLOYMENT)



**HEALTH-RELATED QUALITY OF LIFE SCORES**



**PHYSICAL FUNCTION**



**MEDICAL EVENTS**



**MORTALITY**



**PHYSICIAN CONFIRMED DIAGNOSES**

## DIAGNOSES

RHEUMATOID ARTHRITIS

PSORIATIC ARTHRITIS

LUPUS

ANKYLOSING SPONDYLITIS

FIBROMYALGIA

OSTEOARTHRITIS

AND MORE!

# FORWARD Connections

## Our Participants

**OUR REGISTRY IS BUILT** from the ground up. Patients are the heart of the registry, and FORWARD continues to recognize the value of the patient and their perspective on their disease and treatments. Over 75,000 participants have completed more than 1,000,000 questionnaires. With the help of our participants, we have produced over 1,000 peer-reviewed articles, publications, and abstracts for the rheumatology and health professional community.

## Our Physicians and Health Care Professionals

**HEALTH CARE PROVIDERS** who participate in the FORWARD registry strive to advance the understanding of rheumatic conditions. We recognize that various specialties may see patients with rheumatic diseases, which is why we invite all health care professionals to participate.

## Our Partnerships and Collaborations

**FORWARD COLLABORATES** with researchers worldwide and works with universities, organizations, and qualified investigators to improve our research and ultimately improve the care of patients.

- + University of Nebraska Medical Center: FORWARD Biobank/Research
- + University of Pennsylvania: FORWARD Spondyloarthritis Registry/Research
- + University of CA San Francisco: FORWARD Lupus Registry
- + University of CA San Diego: Mother to Baby/Pregnancy Registry
- + University of Alabama-Birmingham: CMS Linkage/Research
- + International Patient Registries
- + International Foundation for Autoimmune & Inflammatory Arthritis
- + Dupuytren Research Group: IDDB-Dupuytren Registry

# FORWARD Biobank

## Our Biobank

**FORWARD PROVIDES ACCESS TO**, storage for, and analysis of biological samples. Current samples can be used to address specific research questions, or additional samples can be obtained from FORWARD participants. Samples have been collected on various diagnoses including: rheumatoid arthritis, psoriatic arthritis, lupus, ankylosing spondylitis, fibromyalgia, osteoarthritis, and others.

### TYPES OF SAMPLES FOR EACH PATIENT

- + Whole blood (DNA stabilized)
- + Whole blood (RNA stabilized)
- + Serum
- + EDTA Plasma
- + Cryopreserved white blood cells

### BIOMARKERS ASSESSED FOR EACH PATIENT

- + CRP
- + RF
- + Anti-CCP

Contact: Kristin Wipfler, PhD, Biobank Director at [Kristin@ndb.org](mailto:Kristin@ndb.org) or 402.541.9357

# Research Services



## Safety Studies

**LARGE NUMBERS OF PATIENTS** with long term follow-up in this longitudinal population-based registry make the data ideal for safety studies. Reported outcomes of interest including, but not limited to, malignancies and hospitalizations are confirmed and validated with medical records. Additional data collection, including specialized questionnaires, sub-studies, and sample collection, is possible.



## Patient Reported Outcomes

**EXTENSIVE PATIENT REPORTED MEASURES** are collected in this registry, and piloting and validation of new measures is possible as well.



## Patient Preference

**UNIQUE AND FOCUSED TOOLS** used to collect a patient's preferences regarding social factors, economic factors, healthcare utilization, and medication formulation allow FORWARD to answer questions about real-life circumstances.



## Effectiveness and Health Economic Analyses

**GIVEN THE HEALTHCARE UTILIZATION, OUTCOMES, AND ECONOMIC DATA** collected in the patient questionnaire, FORWARD has the ability to perform sophisticated effectiveness and economic analyses.



## Qualitative Research and Mixed Methods

**FORWARD IS TAKING ONE STEP FURTHER** to highlight the voice of patients with rheumatic diseases. We offer researchers and pharmaceutical companies the opportunity to explore how patients think and feel about their disease and treatments in the context of their lives.



## Specialized Studies

**FORWARD WELCOMES THE OPPORTUNITY** to collaborate on innovative study designs and collection tools. Some possible areas of focus include medication adherence, biobank and genetic studies, and building a larger cohort for a population of interest.

# FORWARD

## Data & Research

**FORWARD collects critical data for researchers to study and analyze to better understand the experience of individuals with rheumatic diseases.**

**THE FORWARD COMPREHENSIVE QUESTIONNAIRE** collects patient-reported disease and outcome data using validated measures. Diagnoses reported by patients are verified by physicians. The questionnaire is designed to provide a comprehensive, in-depth understanding of the patient's experience with their disease.

**CUSTOMIZATION:** Ask patients about what you want to know. FORWARD data covers a wide breadth of information related to the diagnosis and treatment of rheumatic diseases, comorbidities, side effects of treatments, and socio-economic measures. FORWARD can develop and include specific questions to meet your research needs.

**FLEXIBILITY:** Access to additional follow-up data. If your research project requires longitudinal data other than what is already available or additional follow-up with participants, FORWARD will assist you in continual tracking, analysis, and reporting necessary to answer your research question.

# FORWARD Personnel Resources to help.

## Leadership



**FRED WOLFE, MD**

-----  
Founder/Co-Director  
Wichita



**KALEB MICHAUD, PHD**

-----  
Co-Director  
Omaha



**REBECCA SCHUMACHER, BS**

-----  
Executive Director  
Wichita

## Operations and Patient Facing



**JACOB CLARKE, MD**

-----  
Community Liaison  
Wichita



**KRISTIN WIPFLER, PHD**

-----  
Biobank Director  
Omaha



**SUPPORT TEAM**

-----  
2 Programmers,  
10 Research Assistants  
Wichita



## Research and Analytics



**SOFIA PEDRO, MS**

-----  
Statistician  
Lisbon



**JOSHUA BAKER, MD, MSCE**

-----  
Assistant Professor of Medicine  
and Epidemiology  
University of Pennsylvania



**GULSEN OZEN, MD**

-----  
Pharmacoepi/CVD  
University of Nebraska  
Medical Center



**ALEXIS OGDIE, MD, MSCE**

-----  
Associate Professor of Medicine  
University of Pennsylvania



**YOMEI SHAW, PHD**

-----  
Mixed Methods  
East Lansing



**PATTI KATZ, PHD**

-----  
Professor in Residence  
University of California

# We Are FORWARD



As a team of researchers, patients, and healthcare providers, **WE ADVANCE SCIENTIFIC RESEARCH AND DISCOVERY** in rheumatology.



**WE ARE RELENTLESS** in searching for scientifically-based answers.



**WE HAVE DECADES OF EXPERIENCE** breaking boundaries and making an impact on the lives of the patients we serve.



**WE CHAMPION THE PATIENT VOICE.** Our data comes directly from the patient—the expert in their disease.



**WE SUPPORT THE NEXT GENERATION** of researchers and specialists so that one day, we can all enjoy a life free of affliction from rheumatic diseases.







# FORWARD

The National Databank for Rheumatic Diseases

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## How To Contact Us

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