

ANNUAL REPORT 2013



Rheumatology Research Foundation

Advancing Treatment | Finding Cures



PRESIDENT'S MESSAGE



The Rheumatology Research Foundation is entirely dedicated to its mission of advancing research and training to improve the health of people with rheumatic diseases. With more than 52 million adults in the U.S. impacted by the pain of arthritis and other rheumatic diseases, it is a lofty goal, but the path to fulfilling that mission is shining brighter than ever.

The Foundation continues to be the largest private funding source of rheumatology research and training programs in the United States. Since it was founded in 1985, the organization has committed more than \$107 million to its extensive awards and grants program – \$12.3 million of which was committed in fiscal year 2013. Through its awards and grants, the Foundation is introducing the best and brightest minds to rheumatology and furthering their education and training in the field. The Foundation is also investing in targeted research specifically focusing on particularly debilitating rheumatic diseases such as rheumatoid arthritis and similar types of inflammatory arthritis. The hope is that this research will lead to advances in treatment and, one day, cures.

The Foundation's work to advance treatment and find cures would not be possible without generous support from individuals, organizations and corporations. Over the past two years, their donations have been directly invested in *Journey to Cure: The Campaign to Advance Patient Care and Accelerate Discoveries*. The five-year, \$60 million campaign was launched in 2011. At the halfway point, *Journey to Cure* has already exceeded its benchmarks by raising 72 percent of the overall goal. Those contributions play an important role in continuing the Foundation's work. On average, 90 cents of every dollar donated to the Foundation is used to fund the awards and grants program.

Both the Foundation's work and its support are flourishing and will continue to do so. It has been an honor to serve the Rheumatology Research Foundation and as I pass the torch to the next leader, I know the organization will highlight the important roles that research, education and training play in treating rheumatic diseases. If we continue on this path, the Foundation will lead the way toward addressing the growing need for patients to have easy access to rheumatologists, as well as the latest treatments that will significantly improve their health.

David I. Daikh, MD, PhD

The Rheumatology Research Foundation would like to thank the volunteers who gave their time from July 1, 2012 through June 30, 2013 to serve as leaders for the organization:

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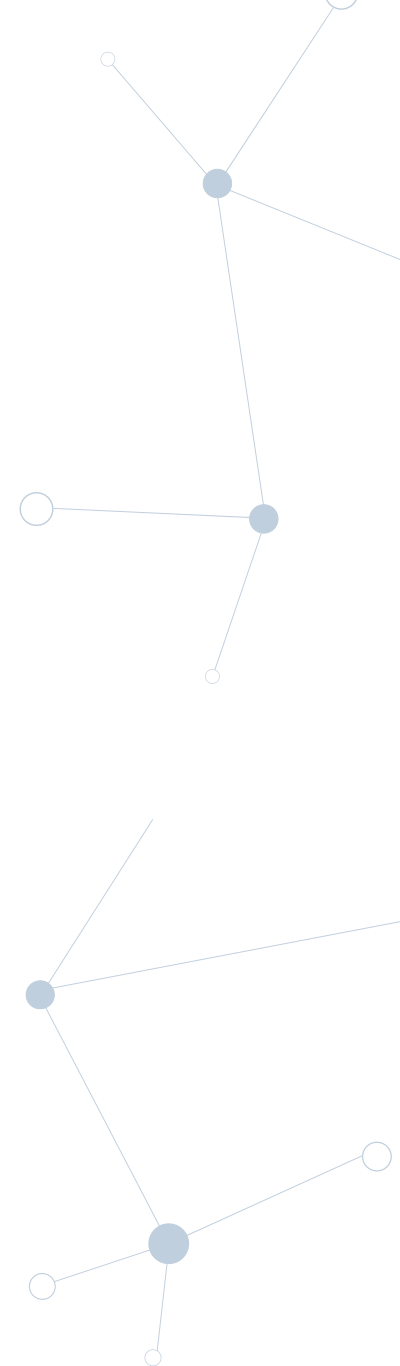
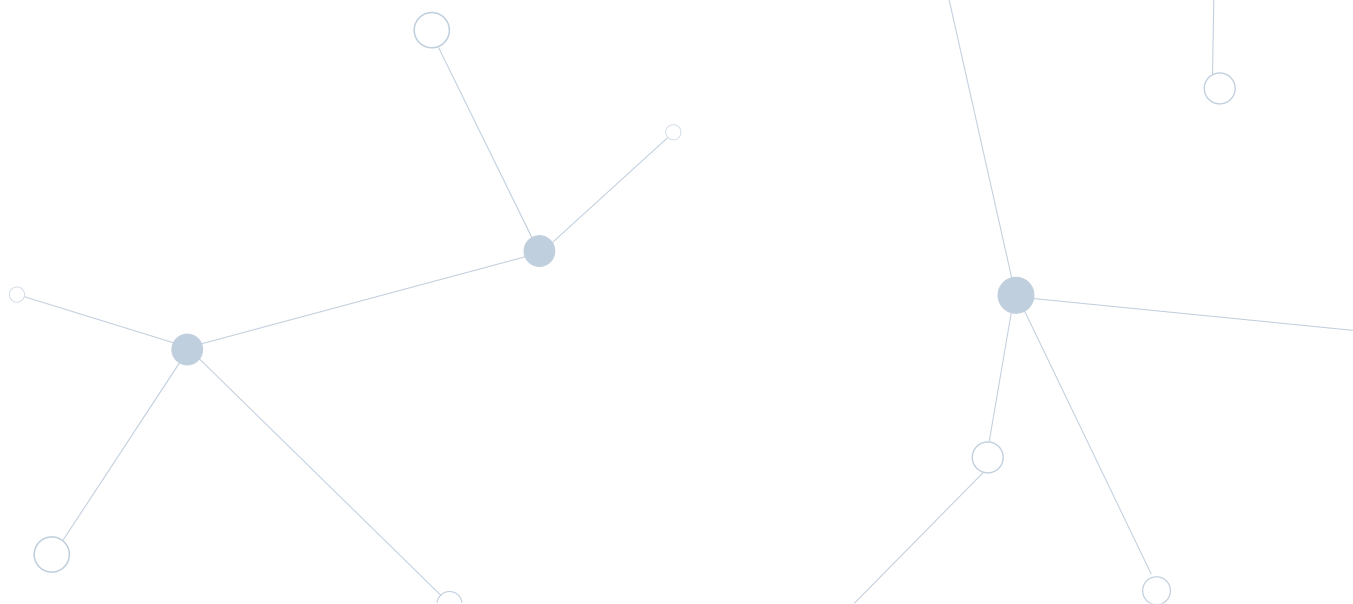




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FOUNDATION AWARDS AND GRANTS





FOUNDATION AWARDS AND GRANTS PROGRAM: **2013 IN REVIEW**



The Rheumatology Research Foundation's awards and grants program hit several major milestones in fiscal year 2013, making significant strides toward fulfilling the organization's mission of advancing research and training to improve the health of people with rheumatic diseases. First and foremost, the Foundation committed more than \$12 million, the most in its history, to the program. The funds are used to train and develop future rheumatology professionals, as well as nurture innovative and novel research ideas. The Foundation is on track to continue setting records with its award funding in upcoming years.

The awards and grants offered by the Foundation are made possible through generous donations from the rheumatology community, corporate supporters, as well as people impacted by rheumatic disease and their loved ones. During fiscal year 2013, the Foundation distributed its first funds raised through *Journey to Cure: The Campaign to Advance Patient Care and Accelerate Discoveries*. The goal of the five-year, \$60 million campaign is to ensure a pipeline of qualified rheumatologists and rheumatology health professionals move toward advancing patient care and accelerating targeted research that will lead to important breakthroughs and possible cures.

The *Journey to Cure* campaign builds on the success the Foundation had with its first campaign, *Within Our Reach: Finding a Cure for Rheumatoid Arthritis*. While fundraising for the *Within Our Reach* campaign has ended, the last stage of distributing those funds began in fiscal year 2013. For the first time in its history, the Foundation is supporting two clinical trials. The investigators leading the trials receive up to \$1 million each per year for three years from funds raised during the *Within Our Reach* campaign. The trials are focused on advancing treatments for patients with active RA and tapering therapy for people who have achieved remission.

The Foundation is proud of the many history-making moments it had during fiscal year 2013. They are examples of our efforts to ensure people impacted by rheumatic disease have the care and treatment they need. We will continue and expand that important work in the years to come.

Anne Davidson, MBBS, FRACP

Chair, Rheumatology Research Foundation Scientific Advisory Council

WITHIN OUR REACH **CLINICAL TRIALS**

In 2006, the Rheumatology Research Foundation launched *Within Our Reach: Finding a Cure for Rheumatoid Arthritis* – a \$30 million national campaign to fund cutting-edge research with a goal of finding a cure for RA. Through this campaign, the Foundation committed to funding the advancement of innovative RA research that is not being done elsewhere, which will impact medical breakthroughs in RA and other rheumatic diseases. To that end, the Foundation has developed a peer-reviewed research program comparable to the National Institutes of Health major grant funding that includes novel clinical trials focused on advancing treatments for patients with active RA and tapering therapy for patients in remission.



Jonathan Graf, MD

University of California, San Francisco
Adalimumab to Mitigate CV Risk in RA Patients with Well-Controlled Joint Disease

People with rheumatoid arthritis have systemic inflammation, meaning the disease can affect their arteries as well as their joints. It also means people with RA are at increased risk of developing cardiovascular disease, or CVD. However, standard RA therapy focuses on reducing only the effects of

inflammation on joints, and if a patient achieves low disease activity targets, the disease is considered well controlled. Suppressing the underlying systemic inflammation that, over time, may lead to life-threatening cardiovascular conditions like hardened arteries is not one of the therapeutic goals in RA, but increased heart disease risk is still a long-term concern.

With funding from a *Within Our Reach* grant, Jonathan Graf, MD, director of the Rheumatoid Arthritis Clinic at the University of California San Francisco Medical Center, is launching a clinical trial to determine if ramping up RA therapy can help control systemic inflammation and lessen CVD risk in RA patients whose disease is otherwise well controlled. The trial focuses on 60 RA patients who have achieved low disease activity on treatment with non-biologic, disease-modifying antirheumatic drugs, also known as DMARDs. One group of patients will add a tumor necrosis factor, or TNF, inhibitor drug. The other group will add a placebo. Dr. Graf's goal is to examine if adding the biologic improves three key factors that may contribute to increased cardiovascular disease risk in RA. These include improving function of the cells that line the interior

of blood vessels, reducing vascular inflammation and improving the function of HDL particles, which play a role in transporting cholesterol through the body's blood vessels. Dr. Graf and his team believe that adding the biologic may reduce the rate of CVD events in RA patients by 15 percent, which would help many people impacted by RA live longer, healthier lives.



Arthur Weinstein, MD, FACP, FRCP, MACR

MedStar Health Research Institute
Stopping Anti-TNF Agents in Rheumatoid Arthritis (STARA) Trial

While anti-tumor necrosis factor, or TNF, drugs are highly successful in treating rheumatoid arthritis symptoms and controlling disease activity, they are expensive and may increase infection risk.

Rheumatologist Arthur Weinstein, MD, is

investigating whether RA patients who have achieved clinical remission of their disease for at least six months can stop taking TNF inhibitors and maintain their low disease activity.

Supported by a *Within Our Reach* grant, the Stopping Anti-TNF Agents in Rheumatoid Arthritis (STARA) Trial is a 48-week clinical trial studying two groups of patients. All patients in the trial have achieved clinical RA remission for at least six months. They are also taking and will continue to take disease modifying antirheumatic drugs (DMARDs), such as methotrexate, leflunomide or hydroxychloroquine. However, one group will continue receiving their anti-TNF biologic medications while a second group will receive a placebo. Investigators will monitor both groups for clinical changes that indicate disease activity, as well as changes in physical function and imaging scans of the hands and wrists, in order to predict who is likely to relapse or maintain remission.

Dr. Weinstein and his colleagues believe that the RA patients who stop taking anti-TNF drugs will not relapse sooner than those who continue using these medications. If that is the case, patients would be able to stop using expensive drugs that increase their risk of infection. It would also lessen the probability that patients would be forced to find new treatments because they stop responding to their biologics.

The trial is a collaboration between the National Institute of Arthritis, Musculoskeletal and Skin Diseases (NIAMS) and multiple extramural academic and practice sites.

DISEASE TARGETED RESEARCH GRANTS



Award Spotlight: Disease Targeted Innovative Research Grant

To better understand how, why and when certain people develop rheumatoid arthritis, rheumatology researchers have to act as pioneering cartographers, mapping the journey from potential autoimmunity to early, active disease on the cellular level. In the past decade, these researchers have learned that certain RA-related autoantibodies may be found in the blood of people who do not develop RA symptoms for another five to 10 years.

Now, with support from the Foundation's Disease Targeted Research program, researcher V. Michael Holers, MD, is delving into how the individuals who have those RA-related autoantibodies in the blood, known as humoral autoimmunity, go on to develop active, clinically apparent RA and how that transition happens. Working at the University of Colorado Denver, Dr. Holers and his fellow investigators have identified a set of patients whose blood contains these antibodies that put them at risk for developing RA, as well as those who already have early disease. In the Studies of the Etiology of Rheumatoid Arthritis, or SERA, the investigators will specifically look at antibodies to anti-citrullinated proteins, or ACPAs, a new type of RA-related antigen discovered only 10 years ago.

One of the study's goals is to evaluate how ACPAs change when these individuals make the transition to developing early arthritis. Investigators will monitor changes in the levels of antibodies, what other antigens they react with, and what role these antibodies play in the unfolding process of the immune system injuring tissues in early RA. Through SERA, Dr. Holers and his colleagues aim to better understand how and why certain people transition from a state of autoimmunity without exhibiting any symptoms to developing clinically apparent RA. They also hope to further determine what changes in the body could predict the onset of the disease. These discoveries could give doctors the ability to identify which patients should be high-priority candidates for targeted therapies to control RA inflammation before it can do significant damage to joints and other tissues.

Disease Targeted Research Grants

Through its disease targeted research programs, the Rheumatology Research Foundation is committed to funding innovative research that will impact patient care. Outcomes from these grants will lead to new insights into the etiology, pathogenesis and treatment of rheumatoid arthritis and related autoinflammatory diseases.

PILOT RESEARCH GRANTS

These projects are designed to provide seed funds to scientists with novel ideas. The intent is to allow investigators to gather preliminary data to determine whether a greater investment is needed in their research idea. Recipients receive funding for one year up to \$75,000.



Joseph E. Craft, MD
Yale University School of Medicine
A Novel B Cell Marker and Therapeutic Target in Rheumatoid Arthritis



Mariana J. Kaplan, MD
University of Michigan
Neutrophil Extracellular Traps in the Pathogenesis of Rheumatoid Arthritis



Yukiko Kimura, MD
Hackensack University Medical Center
Development of Standardized Consensus Treatment Plans for Polyarticular JIA



Judith A. Smith, MD, PhD
University of Wisconsin-Madison
Excess IL-23 Production in Ankylosing Spondylitis and Related Arthritides

INNOVATIVE RESEARCH GRANTS

These projects provide funds to scientists who need to conduct additional testing on promising research ideas that are supported by preliminary data. Recipients receive funding for two years up to \$400,000 total.



Bryce A. Binstadt, MD, PhD
University of Minnesota
Targeting Endothelial Injury in Inflammatory Arthritis



Michael B. Brenner, MD
Brigham and Women's Hospital
Synovial Fibroblast Phenotypes after Activation By TNF/IL-17



Lindsey A. Criswell, MD, MPH
University of California, San Francisco
DNA Methylation Profiling in Rheumatoid Arthritis



Leonard Dragone, MD, PhD
University of Colorado Denver
The Role of APCs in Pregnancy Induced Arthritis Amelioration



Gary S. Firestein, MD
University of California, San Diego
DNA Methylome Signature in Rheumatoid Arthritis



Liana Fraenkel, MD, MPH
Yale University School of Medicine
Improving the Delivery of Care Using a Theory-Based Decision Support Tool



Jon T. Giles, MD, MPH
Columbia University
Adipose Tissue Inflammation in Rheumatoid Arthritis: Associations with Disease Characteristics, Cardiometabolic Risk Factors and Atherosclerosis



V. Michael Holers, MD
University of Colorado Denver
*Pathogenic Humoral
Autoimmunity in the Transition
to Clinically Apparent
Rheumatoid Arthritis*



Chuanju Liu, PhD
New York University
School of Medicine
*Progranulin: A Novel TNFR
Ligand and a Drug Target in
Inflammatory Arthritis*



John D. Mountz, MD, PhD
University of Alabama
at Birmingham
*Optimal Approach to Block
M1 Macrophages/Th17
Inflammation in Rheumatoid
Arthritis*



Gregg J. Silverman, MD
New York University
School of Medicine
*Anti-Citrullinated Protein B Cells
and RA Pathogenesis*



Allen C. Steere, MD
Massachusetts General Hospital
*Innovative Approach for
Identifying Infectious Agents
and Autoantigens in RA*



Teresa Tarrant, MD
University of North Carolina
at Chapel Hill
*Validating GPSM3 as a Key
Regulator of Monocyte-driven
Inflammatory Arthritis*



Arthur Weiss, MD, PhD
University of California,
San Francisco
*Identifying Antigen-Specific T cells
in Mouse and Human Arthritis*

CAREER DEVELOPMENT **RESEARCH AWARDS**

Award Spotlight: Scientist Development Award



The Scientist Development Award not only helps rheumatology professionals establish themselves as investigators; it also supports vital research into the cause, prevention and treatment of rheumatic diseases. One young investigator who received the award says it is helping her build her career, as well as funding research that will lead to a better understanding of scleroderma. Zsuzsanna McMahan, MD, MHS, joined the faculty at Johns Hopkins University as an Assistant Professor of Medicine when she received the Rheumatology Research Foundation's Scientist Development Award. She says she wouldn't have been able to join faculty at this level without the award.

With the funding, Dr. McMahan is working under established investigators on a research project to better understand scleroderma, which causes a thickening of the skin and/or tissues of certain internal organs. In scleroderma, most patients make antibodies that bind to specific cellular proteins. Patients tend to have certain symptoms based on the proteins to which the antibodies bind. For example, patients that have antibodies that bind to the protein topoisomerase-1 are at a significantly increased risk of lung disease. On the other hand, patients whose antibodies bind to the protein centromere have a significantly increased risk of having high blood pressure in the blood vessels between the heart and the lungs. However, the proteins that the antibodies target aren't specific to the tissue being affected. In fact, those proteins are thought to be present in all human cells. So, it's still not clear why scleroderma patients have complications in specific tissues, like the heart or lungs, when the antibodies are binding to proteins that are prevalent in all human tissues. Through her research, Dr. McMahan is trying to determine if the tissue being damaged plays a role in determining how the immune system responds to these proteins. She believes her research could lead to a better understanding of how the disease disrupts normal functions, which would help rheumatologists better diagnose it and provide patients more effective, targeted treatments.

“THE FOUNDATION, FOR ME, HAS BEEN MY LIFELINE. IT HAS REALLY MADE IT POSSIBLE TO PURSUE MY RESEARCH INTERESTS, BEGIN A CAREER IN ACADEMIC MEDICINE AND CONTRIBUTE TO RHEUMATOLOGY AS A WHOLE, ULTIMATELY HOPEFULLY IMPROVING THE LIVES OF PATIENTS.”

—Zsuzsanna McMahan, MD, MHS

SCIENTIST DEVELOPMENT AWARD

This award encourages physicians and health professionals without significant research experience to consider careers in biomedical or clinical research by supporting a structured research training program in arthritis and rheumatic disease. Recipients receive up to three years of funding and up to a total of \$225,000 for their research project.



Scott W. Canna, MD
The Children's Hospital of Philadelphia
IL-10 as a critical regulator of TLR9-induced MAS



Soumya D. Chakravarty, MD, PhD
Hospital for Special Surgery
Notch Signaling in a Murine Model of Inflammatory Arthritis



M. Kristen Demoruelle, MD
University of Colorado Denver
Biomarkers of Lung Autoimmunity in Preclinical RA



Evelyn Hsieh, MD, MPH
Yale University School of Medicine
Osteoporosis among HIV-Infected Individuals in China



Shaun Jackson, MD, PhD
Seattle Children's Hospital/University of Washington
B Cell Mediated Atherosclerosis in Autoimmune Disease



Jason S. Knight, MD, PhD
University of Michigan
Role of NET Formation in Models of Lupus Vascular Damage



Zsuzsanna H. McMahan, MD
Johns Hopkins University
Novel Scleroderma Autoantigens in Vascular Progenitors



Smita Rao, PT, PhD
New York University School of Medicine
Pain Sensitization in 1st Metatarsophalangeal Osteoarthritis



Jody Riskowski, PhD
Hebrew Senior Life
Foot Pain Relations in Movement & Socioeconomic Position



Shawn Rose, MD, PhD
Northwestern University
A Novel Mouse Model of Atherosclerosis in Inflammatory Arthritis



Joshua Jon Stefanik, PhD, MSPT
Boston University School of Medicine
Identifying Patellofemoral OA by Pain Site and Activities

INVESTIGATOR AWARD

This award supports basic science, translational and clinical investigators engaged in research relevant to rheumatic diseases for the period between the completion of post-doctoral fellowship training and establishment as an independent investigator. Recipients receive up to three years of funding and up to a total of \$375,000 for their research project.



Beatrix Bartok, MD
University of California, San Diego
Phosphoinositide-3 kinase: A key regulator of synoviocytes function in RA



Rumey C. Ishizawar, MD, PhD
Brigham and Women's Hospital
Rheumatoid Arthritis Risk Genes in CD4 and T cell Biology



Jennifer King, MD
University of California, Los Angeles
Tissue Dendritic Cell Regulation in Organ Inflammation



Kaleb Michaud, PhD
University of Nebraska Medical Center
Mortality due to Rheumatoid Arthritis and Treatments



Michael Waterfield, MD, PhD
University of California, San Francisco
Novel Aire-Interacting Proteins in Central Tolerance



Maida Wong, MD
University of California, Los Angeles
T cell Tolerance in SLE via PD-1/PDL-1 Pathway

BRIDGE FUNDING AWARD

This award provides up to \$75,000 for one year of support to budding investigators as they revise outstanding applications for federal funding. Through this bridge funding award, the Rheumatology Research Foundation and the Arthritis Foundation hope to ensure these young faculty members have the highest likelihood of achieving success in obtaining future National Institutes of Health awards. Funding is made possible in part through the generous financial support of the Arthritis Foundation.



Jennifer L. Barton, MD
University of California, San Francisco

CAREER DEVELOPMENT SUPPLEMENT IN GERIATRIC MEDICINE

This award supports academicians focused on gerontology and the geriatric aspects of rheumatology during the early stages of their research career. This supplemental award is funded for two years at \$25,000 to support career development in conjunction with an R03 from the National Institute of Aging as part of the GEMSSTAR program. Funding for this award is made possible in part through the financial support of the Association of Specialty Professors.



Una E. Makris, MD
University of Texas Southwestern Medical Center
Understanding the Impact of Restricting Back Pain in Community-Living Older Persons

EDUCATION AND TRAINING **AWARDS**



Award Spotlight: Clinician Scholar Educator Award

The Clinician Scholar Educator Award recognizes educators who are dedicated to enhancing education in rheumatic diseases and attracting the best trainees to rheumatology. Susan Kroop, MD, is using the Clinician Scholar

Educator Award she received from the Rheumatology Research Foundation to meet those goals with her project titled “Rheumatology 101: Ambulatory Curriculum Development.” Dr. Kroop is developing a novel rheumatology curriculum for medical residents that will make them better able to recognize rheumatic diseases and also increase their interest in rheumatology as a subspecialty.

The curriculum will use simulated patient encounters to improve residents’ knowledge of rheumatic diseases, physical exam skills and clinical reasoning used to order and interpret rheumatologic laboratory tests. Dr. Kroop believes the curriculum will also improve the attitudes residents have toward rheumatology and encourage them to consider a subspecialty in the field. If the curriculum is successful, it will help internists better recognize rheumatic diseases meaning patients could get access to the treatments they need quicker. It may also help steer doctors toward completing a fellowship in rheumatology, giving people impacted by rheumatic disease increased access to a specialist who can provide the best possible treatments.

CLINICIAN SCHOLAR EDUCATOR AWARD

This award recognizes and supports rheumatologists who are dedicated to providing a high-quality clinical educational experience to future rheumatologists. Recipients receive up to three years of funding and up to a total of \$180,000 for their project.



Megan L. Curran, MD
Ann & Robert H. Lurie
Children’s Memorial Hospital
of Chicago
*E-Support for Pediatric
Residency Rheumatology
Teaching*



Susan F. Kroop, MD
Vanderbilt University
Medical Center
*Rheumatology 101: Ambulatory-
Based Curriculum Development*

AMGEN FELLOWSHIP TRAINING AWARD

This award helps to ensure that a highly trained workforce is available to provide competent clinical care to those affected by rheumatic disease. The award is funded for one year at \$25,000 to support the salary of one trainee during his or her clinical year of training. Funding for this award is made possible through the financial support of Amgen, Inc.

Stanley P. Ballou, MD
MetroHealth Medical Center

Bryce A. Binstadt, MD, PhD
University of Minnesota

Richard Brasington, MD, FACP
Washington University School of Medicine

Amy C. Cannella, MD
University of Nebraska Medical Center

Lisa Criscione-Schreiber, MD
Duke University School of Medicine

Anne Davidson, MBBS, FRACP
Feinstein Institute for Medical Research

Chris T. Derk, MD, MS
University of Pennsylvania

Howard A. Fuchs, MD
Vanderbilt University Medical Center

John I. Gomez, MD
Baylor College of Medicine

Samina Q. Hayat, MD
Louisiana State University Health
Sciences Center Shreveport

Simon M. Helfgott, MD
Brigham and Women’s Hospital

Jennifer L. Huggins, MD
Cincinnati Children’s Hospital Medical Center

Beth L. Jonas, MD
University of North Carolina at Chapel Hill

Robert A. Kalish, MD
Tufts Medical Center

Richard M. Keating, MD
The University of Chicago

Tzielan C. Lee, MD
Stanford University School of Medicine

Bonita S. Libman, MD
University of Vermont

Kristine M. Lohr, MD, MS
University of Kentucky

Carlos J. Lozada, MD
University of Miami

Vikas Majithia, MD
University of Mississippi Medical Center

Rory M. Marks, MBBS, FRACP
University of Michigan Health Systems

Michael H. Pillinger, MD
NYU Hospital for Joint Diseases

Philip Seo, MD, MHS
Johns Hopkins University

David D. Sherry, MD
The Children's Hospital of Philadelphia

Virginia D. Steen, MD
Georgetown University

Anne M. Stevens, MD, PhD
Seattle Children's Hospital

Katherine K. Temprano, MD
Saint Louis University

Robert Terkeltaub, MD
VA Medical Center

Sterling G. West, MD
University of Colorado School of Medicine

PAULA DE MERIEUX FELLOWSHIP TRAINING AWARD

This award ensures that a diverse and highly trained workforce is available to provide clinical care to patients with rheumatic disease. This award is funded for one year at \$25,000 to support the salary of a fellow who is an underrepresented minority or a woman. Funding for this award is made through an endowment established by the Paula de Merieux, MD estate.

Edward Dwyer, MD
Columbia University

TRAINING PROGRAM DEVELOPMENT AWARD

The purpose of this award is to help ensure that a diverse and highly-trained workforce is available to provide competent clinical care to those affected by rheumatic diseases. The Foundation supports two awards for one year at

\$50,000 each. These awards are designed to specifically address three objectives, listed below in priority order:

- 1. Creating a new fellow position, preferably one that was previously ACGME-accredited but was unfilled due to lack of sufficient fellow salary funding.*
- 2. Increasing the number of underrepresented minority* trainees.*
- 3. Providing a slot committed to trainees with a high likelihood of pursuing an academic rheumatology career.*

Ernest Brahn, MD
University of California, Los Angeles

Christopher Collins, MD
Washington Hospital Center

LAWREN H. DALTROY FELLOWSHIP IN PATIENT-CLINICIAN COMMUNICATION

The purpose of this award is to improve patient-clinician interactions and communications. The award is funded for one year at \$7,000. Funding for this award is made possible by an endowment established by Rheuminations, Inc.

Julie A. Unk, DNP
Washington University School of Medicine

PEDIATRIC VISITING PROFESSORSHIP

This award provides educational opportunities for medical students and residents in institutions where no established pediatric rheumatology expertise currently exists. Each visiting professor receives an honorarium and reimbursement for expenses. Funding for this award is made possible through an endowment provided by Amgen, Inc.

AnneMarie Brescia, MD
Visited Cooper University Hospital

Elizabeth Chalom, MD
Visited Richmond University Medical Center

Melissa E. Elder, MD, PhD
Visited Miami Children's Hospital

Philip J. Hashkes, MD, MSc
Visited Mt. Sinai Hospital Medical Center

Philip Kahn, MD
Visited University of Arizona

Katherine Marzan, MD
Visited White Memorial Medical Center

Lakshmi Nandini Moorthy, MD, MS
Visited Central Iowa-Blank Children's Hospital

James J. Nocton, MD
Visited John H. Stroger, Jr. Hospital

Sampath Prahalad, MD, MSc
Visited Mercer University

Kelly Rouster-Stevens, MD
Visited Southern Illinois University

Larry Vogler, MD
Visited Morehouse School of Medicine

Robert W. Warren, MD, PhD, MPH
Visited University of Kansas – Wichita

**For purposes of this pilot program, "underrepresented minority within rheumatology" shall mean black, Hispanic or Native American (American Indians, Alaska natives and native Hawaiians).*

PRECEPTORSHIPS



Award Spotlight: Medical Student Clinical Preceptorship

The Rheumatology Research Foundation is building interest in rheumatology by giving students the opportunity to experience the field firsthand. Through preceptorships, students and residents work with a

mentor to learn more about clinical or research work within rheumatology. For one student, her preceptorship has already changed how she views the field.

With her Medical Student Clinical Preceptorship, Melanie Schow worked with Robert Janson, MD, for four weeks. During that time, she went with Dr. Janson to outpatient rheumatology clinics at several hospitals in the Denver, Colorado area. She also attended lectures on various topics, including rheumatic diseases, tests and examinations, and treatments. Now that she has completed her preceptorship, Schow says it made a significant difference on how she views rheumatology. “I had wonderful mentors and really enjoyed the subspecialty of rheumatology,” she explains. “I will consider subspecializing in rheumatology much more seriously than I would have before this experience.” If Schow does choose to go into rheumatology, she will not be alone. Nearly half of doctors who completed Foundation preceptorships choose rheumatology as their subspecialty.

HEALTH PROFESSIONAL RESEARCH PRECEPTORSHIP

This award introduces students to rheumatology-related health care by supporting full-time research by a graduate student in the area of rheumatic diseases. Students receive a stipend, as well as reimbursable travel funds to attend the annual meeting.

Hans H. Kim

Preceptor: Andras Perl, MD, PhD
Upstate Medical University

Edward Doherty

Preceptor: Andras Perl, MD, PhD
Upstate Medical University

Miguel-Angel Gutierrez*

Preceptor: Ram Raj Singh, MD
University of California, Los Angeles

Andrew J. Kittelson

Preceptor: Jennifer E. Stevens-Lapsley, MPT, PhD
University of Colorado Denver

Katherine Milette

Preceptor: Brett D. Thombs, PhD
McGill University

Kasim S. Ortiz

Preceptor: Diane Kamen, MD, MSCR
Medical University of South Carolina

Priti Prasad

Preceptor: Ram Raj Singh, MD
University of California, Los Angeles

Cynthia Tran

Preceptor: Ram Raj Singh, MD
University of California, Los Angeles

**Funding for this research was made possible by a grant from the Sjögren's Syndrome Foundation.*

MEDICAL STUDENT CLINICAL PRECEPTORSHIP

This award introduces students to the specialty of rheumatology by supporting a full-time clinical opportunity. Students receive a stipend as well as reimbursable travel funds to attend the annual meeting.

Khush S. Aujla

Preceptor: Vikas Majithia, MD
University of Mississippi Medical Center

Michelle Breda, BSc

Preceptor: Sharon L. Kolasinski, MD
The Cooper Health System

Lucinda Guerra

Preceptor: Rochella A. Ostrowski, MD
Loyola University Chicago

Oluwafunmilayo Ogunremi

Preceptor: Joel M. Hirsh, MD
Denver Health and Hospital Authority

Victor Liou

Preceptor: Katherine K. Temprano, MD
Saint Louis University

Marika Raff

Preceptor: W. Joseph McCune, MD
University of Michigan

Anthony Sawyer, BSPH

Preceptor: Seetha Monrad, MD
University of Michigan

Melanie Schow

Preceptor: Robert W. Janson, MD
Biomedical Research Foundation of Colorado

Andrew C. Seymore

Preceptor: Diane Kamen, MD, MSCR
Medical University of South Carolina

Matthew J. Zuber

Preceptor: Charles L. Ludivico, MD
East Penn Rheumatology Associates

MEDICAL STUDENT RESEARCH PRECEPTORSHIP

This award introduces students to the specialty of rheumatology by supporting a full-time research experience. Students receive a stipend and reimbursable travel funds to attend the annual meeting.

Luke M. Barr

Preceptor: Rosalind Ramsey-Goldman, MD
Northwestern University

Laura Chiel

Preceptor: Robert P. Sundel, MD
Boston Children's Hospital

Kyle Dempsey

Preceptor: Jeffrey N. Katz, MD, MSc
Brigham and Women's Hospital

Emily Ferrell

Preceptor: Sampath Prahalad, MD, MSc
Emory University

Elena Gonzalez

Preceptor: Trine Jorgensen, PhD, MSc
Cleveland Clinic

Margo Toney

Preceptor: Diane Kamen, MD, MSCR
Medical University of South Carolina

Margaret Ivanov

Preceptor: Sally Pullman-Mooar, MD
Philadelphia Veterans Hospital

Josué José Vergara Juárez

Preceptor: Juanita Romero Diaz, MD
Instituto Nacional de Ciencias Médicas y
Nutrición Salvador Zubirán

Kevin M. McElligott

Preceptor: Natasha M. Ruth, MD, MS
Medical University of South Carolina

Samantha J. Minkin

Preceptor: Diane Kamen, MD, MSCR
Medical University of South Carolina

Kelly Brier San Miguel

Preceptor: Natasha M. Ruth, MD, MS
Medical University of South Carolina

Alexandra Wiese

Preceptor: Dinesh Khanna, MD, MSc
University of Michigan

EPHRAIM P. ENGLEMAN ENDOWED RESIDENT RESEARCH PRECEPTORSHIP

This award introduces residents to the specialty of rheumatology by supporting a full-time mentored research experience. This award is funded for one year at \$15,000. Funding for this award is made possible through the Ephraim P. Engleman Endowment.

Eric J. Allenspach, MD, PhD

Preceptor: David J. Rawlings, MD
Seattle Children's Hospital

RESIDENT RESEARCH PRECEPTORSHIP

This award introduces residents to the specialty of rheumatology by supporting a full-time mentored research experience. This award is funded for one year at \$15,000

Pui Y. Lee, MD, PhD

Preceptor: Peter Nigrovic, MD
Boston Children's Hospital

Meghan M. Scheibe, MD

Preceptor: Jinoos Yazdany, MD, MPH
University of California, San Francisco

Zheni Stavre, MD

Preceptor: Ellen M. Gravallese, MD
University of Massachusetts Medical School

HEALTH PROFESSIONAL ONLINE EDUCATION GRANT

The purpose of this award is to increase the knowledge and skills of rheumatology health professionals to meet the needs of a growing rheumatology patient population. This award is funded for one year up to \$1,500 to support registration costs to complete either the

Fundamentals of Rheumatology Course or the Advanced Rheumatology Course.

Monica Richey, MSN, ANP-BC, GNP, BSN

Hospital for Special Surgery

Annual Meeting Awards

STUDENT ACHIEVEMENT AWARD

This award recognizes medical and graduate students for significant work in the field of rheumatology by providing an opportunity for students to attend the annual meeting. Recipients receive an award of \$750 and reimbursement for travel expenses to the annual meeting.

Samir Chabra

University of Illinois at Chicago

Marshall Davis, MPH

University of Nebraska Medical Center

Galina Grigoriev

Columbia College of Physicians and Surgeons

Sarah Kim

UCLA David Geffen School of Medicine

Paige Luneburg

University of Maryland School of Medicine

Vandana Vedanarayanan

University of Mississippi Medical Center

Michelle Yau, MPH

University of Maryland

MEDICAL AND PEDIATRIC RESIDENT RESEARCH AWARD

This award is designed to motivate residents to pursue subspecialty training in rheumatology by providing the opportunity to experience rheumatology first-hand at the annual meeting. Recipients receive an award of \$750 and reimbursement for travel expenses to the annual meeting.

Lauren Minor, MD

Emory University

PEDIATRIC RESEARCH AWARD

This award promotes scholarship in the field of pediatric rheumatology and recognizes outstanding abstracts with an award of \$1,000 and reimbursement for travel expenses to the annual meeting. Funding for this award is made possible through an endowment provided by Amgen, Inc.

Scott Canna, MD

Children's Hospital of Philadelphia

Eveline Wu, MD

Duke University Medical Center

MARSHALL J. SCHIFF, MD, MEMORIAL FELLOW RESEARCH AWARD

This award is designed to recognize outstanding scholarship in the field of rheumatology and provide fellows-in-training who are authors or co-authors of abstracts submitted to the annual meeting an opportunity to attend the meeting to present their abstract. Recipients receive an award of \$1,500 and reimbursement for travel expenses to the annual meeting. Funding for this award is made possible through an endowment from the Marshall J. Schiff family.

Kristine A. Kuhn, MD, PhD

Washington University School of Medicine

Ada Man, MD

Boston University

RHEUMATOLOGY RESEARCH FOUNDATION MEMORIAL LECTURESHIPS

Endowed lectureships support rheumatology research and honor the lives of four outstanding physicians.

Edmund L. Dubois, MD Memorial Lectureship

Presented by: Genevieve Law, MD

Oscar S. Gluck, MD Memorial Lectureship

Presented by: Ellen M. Gravalles, MD

Paul Klemperer, MD Memorial Lectureship

Presented by: Thomas A. Medsger, Jr., MD

**Rheumatology Research Foundation Memorial
Lectureship, In Honor of Dr. Edward D. Harris, Jr.**
Presented by: Gary S. Firestein, MD

ONGOING SUPPORT

SCIENTIST DEVELOPMENT AWARD

Urmila Bajpai, MD, PhD

University of California, San Francisco

Anna R. Broder, MD, MSc

Albert Einstein College of Medicine

Lisa A. Davis, MD

University of Colorado Denver

Angelica K. Gierut, MD

Northwestern University

Peter C. Grayson, MD, MSc

Boston University School of Medicine

Michelle J. Kahlenberg, MD, PhD

University of Michigan

Alfred H. Kim, MD, PhD

Washington University School of Medicine

Sang T. Kim, MD

Yale University School of Medicine

Melissa A. Lerman, MD, PhD

The Children's Hospital of Philadelphia

Rebecca L. Manno, MD, MHS

Johns Hopkins University

Jessica L. Maxwell, PT, DPT, MS

Boston University

Uyen Sa Nguyen, DSc, MPH

Boston University

Elizabeth Salt, PhD, ARNP

University of Kentucky

Miriam A. Shelef, MD, PhD

University of Wisconsin – Madison

Ernest Vina, MD, MS

University of Chicago

Zejin Zhu, MD, PhD

University of California, Los Angeles

INVESTIGATOR AWARD

Mara L. Becker, MD

Children's Mercy Hospital

Aimee Hersh, MD

University of Utah

Tamiko Katsumoto, MD

University of California, San Francisco

Erika Noss, MD, PhD

Brigham and Woman's Hospital

Alexis R. Ogdie-Beatty, MD

University of Pennsylvania

Amr H. Sawalha, MD

University of Michigan

Daniel K. White, PT, ScD

Boston University

CLINICIAN SCHOLAR EDUCATOR AWARD

Juliet Aizer, MD, MPH

Hospital for Special Surgery

Michal J. Cidon, MD

Lucile Packard Children's
Hospital/Stanford University

Lisa Criscione-Schrieber, MD

Duke University

Eugene Kissin, MD

Boston University

Seetha Monrad, MD

University of Michigan

David Sherry, MD

Children's Hospital of Philadelphia

Rodney Tehrani, MD

Loyola University Medical Center

WITHIN OUR REACH - CLINICAL PRACTICE RESEARCH GRANT

Ted R. Mikuls, MD, MSPH

Nebraska Medical Center

WITHIN OUR REACH - TRANSLATIONAL RESEARCH GRANT

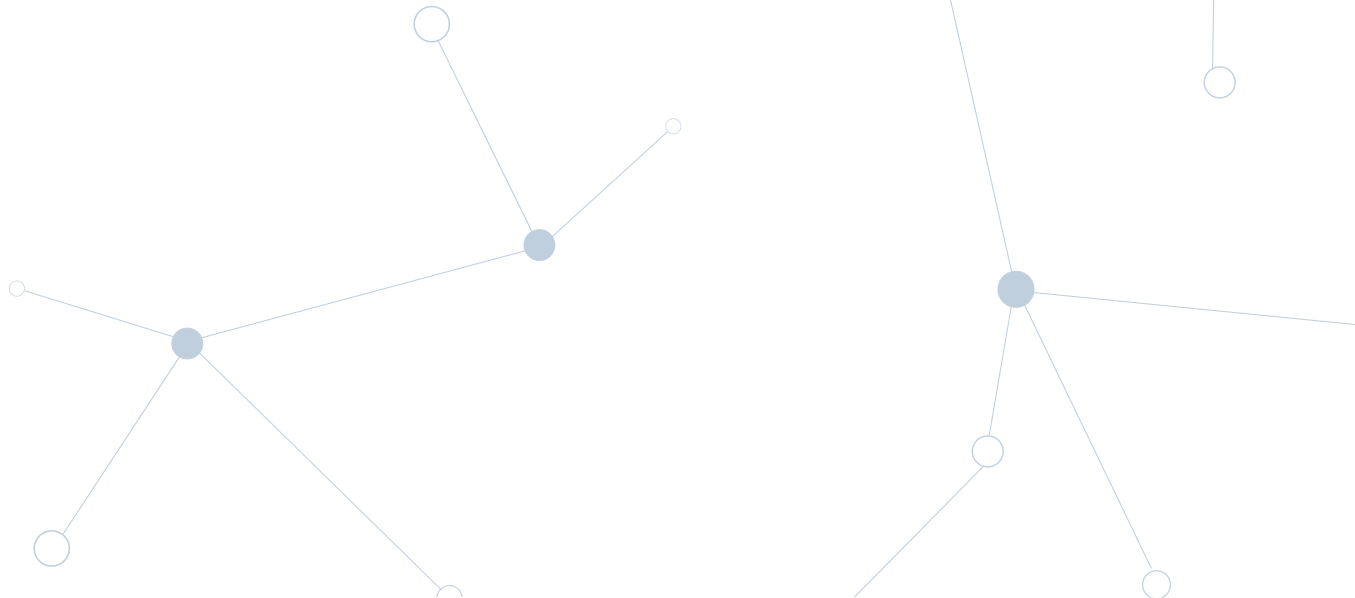
Joan M. Bathon, MD

Columbia University

Daniel L. Mueller, MD

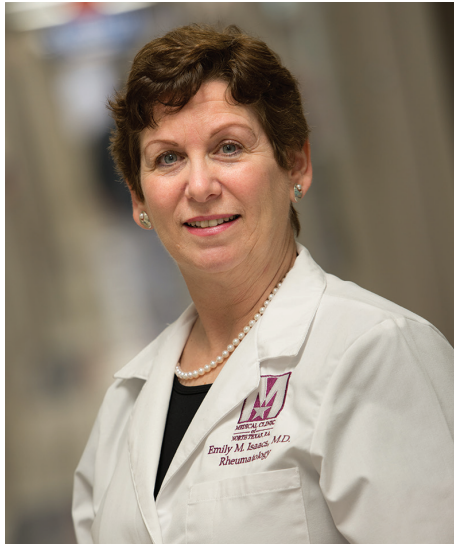
University of Minnesota

FOUNDATION FINANCIALS



Journey to Cure

THE CAMPAIGN TO
ADVANCE PATIENT CARE AND ACCELERATE DISCOVERIES

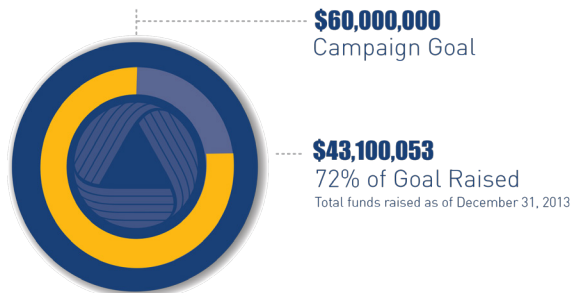


As the largest private funding source of rheumatology research and training programs in the United States and since its founding in 1985, the Foundation has provided more than 2,000 awards and grants to students, residents, fellows, physicians and health professionals – an investment totaling more than \$100 million.

In 2011, the Rheumatology Research Foundation launched *Journey to Cure: The Campaign to Advance Patient Care and Accelerate Discoveries*. The goal of the five-year campaign is to raise \$60 million that is directly invested in ensuring a pipeline of qualified rheumatologists and rheumatology health professionals move toward advancing patient care and accelerating targeted research that will lead to important breakthroughs and possible cures. The Foundation is dedicated to stewarding campaign donations effectively and efficiently. On average, 90 cents of every dollar donated to the Foundation is used to fund its extensive awards and grants program.

By the end of 2013, the *Journey to Cure* campaign was well ahead of schedule. At the halfway point, the Foundation has already raised more than \$43 million, 72 percent of the campaign's goal. The current success of the campaign is only possible because of the broad-based support it has received from the rheumatology community, corporate donors, as well as people impacted by rheumatic disease.

The Foundation will continue to build on its generous support in order to push for the advancements that will improve patient care and accelerate the discovery of important breakthroughs. As my term as chair of the Development Advisory Council ends, I truly believe that the Foundation is on the path to continued growth and success for many years to come.



 **Rheumatology Research Foundation**
Advancing Treatment | Finding Cures

Emily Isaacs MD

Emily M. Isaacs, MD

Chair, Rheumatology Research Foundation Development Advisory Council 2012-2013

GIVING BACK TO END A DAUGHTER'S PAIN

The Russell family clockwise from bottom left: Steve, Stephanie, Nicole, Courtney and Debbie



Steve Russell's voice breaks with emotion as he talks about a remarkable moment in his daughter's life. "The first time she ran that cross country meet three months after being in the hospital was an amazing thing," he says. At least half of the competitors had already finished the race, but Steve and his wife Debbie were waiting for their daughter, Courtney. "Then she crossed the finish line, and Debbie and I are sitting on the finish line just crying, tears running down our faces." Just three months before that touching moment, at the age of 16, Courtney had spent four days in the hospital. She was diagnosed with systemic juvenile idiopathic arthritis, or SJIA.

It all started nearly a year before that cross country meet. As Courtney's sophomore year in high school was getting into full swing, she started getting sick. She had a fever, a rash, joint pain and a sore throat. After a few days, her parents took her to the doctor. The doctor told them it looked like a parvovirus infection and it would clear up on its own. In a few weeks, Courtney's symptoms did clear up, but just a couple months later they were back. This time she also had hives that would come and go. "That lasted for months," Debbie explains, "sometimes so severe on her hands that her hands would swell so she couldn't even close them." Courtney was taking pain-

killers, anti-inflammatory drugs and allergy medication, but nothing was helping.

This went on for about nine months. It was a difficult time for Courtney and the family. Courtney spent almost the entire school year in pain. "It got so bad that she couldn't roll over at night without being in extreme pain, getting from the bed to go the bathroom was extraordinary," Steve says. "To watch your child go through something like this is painful beyond words." Still, Courtney kept up with her studies and even continued playing competitive volleyball through the end of the season. The Russells say through it all, they learned just how tough kids are. "It was incredible how resilient and optimistic she was through this whole process, what she would deal with just to get through the school day," Debbie proudly explains. Still, they wanted answers. She says, "It was gut-wrenching to just not know what was wrong with her and that we couldn't do anything to help her."

Eventually, two doctors suggested the Russells see a rheumatologist. Both gave the same reason. "They're brilliant at solving puzzles, solving the unknown. That's who you need to see," Steve explains. So they pushed

"It was gut-wrenching to just not know what was wrong with her and that we couldn't do anything to help her."

their pediatrician to send them to a rheumatologist. Unfortunately, Courtney got worse very quickly, so Steve and Debbie took her to the Ann & Robert H. Lurie Children's Hospital of Chicago. She was there for four days. During that time, the Russells met rheumatologist Marisa Klein-Gitelman, MD, who took the lead on Courtney's case. Steve and Debbie say they knew she was the right doctor for them because of her extensive experience and her ability to connect with the whole family. In just a few days, Dr. Klein-Gitelman had Courtney's diagnosis, sJIA with possible complications from macrophage activation syndrome, or MAS. MAS is a potentially life-threatening complication common with rheumatic diseases that causes a massive systemic inflammatory response.

After being admitted to the hospital, Courtney was forced to pull out of school shortly before finals. She started treatment right away with daily shots. Within weeks, Courtney was back on her feet. She finished her sophomore year over the summer. Then, she was running in that cross country meet, being greeted at the finish line by her crying parents. "I always laugh because everyone in the audience was probably like, 'they're not very happy because their daughter didn't do well,'" Steve says, "but we just couldn't contain ourselves." Today, she's a senior in high school, still running cross country and getting ready to go to college.

But the journey didn't end there for the Russells. Dr. Klein-Gitelman told Steve and Debbie about the work being done by the Rheumatology Research Foundation. They wanted to get involved, so they helped organize a special event in April called "Coffee & Conversation," which brought together patients and fellow parents of

children with rheumatic diseases. They all heard from researcher V. Michael Holers, MD, about advances in research and treatment of inflammatory arthritis. They also learned how few rheumatologists are currently practicing, especially pediatric rheumatologists. "We became more aware how blessed we are to have the resources we have and how many people don't have these resources, don't have [pediatric] rheumatologists in their state... That was just mind-blowing to us," Steve explains. According to the American Board of Pediatrics, the organization that certifies pediatric rheumatologists, at the end of 2012, there were more than 280,000 children for every board-certified pediatric rheumatologist in the United States. Adding to the problem, the ABP reports that 10 states don't even have one pediatric rheumatologist. "To go through what we went through with Courtney with somebody so close was so, so hard," Steve says. "I can't fathom what it would be like going through something like that without a doctor that you trusted and counted on nearby."

The Russells agreed to take their support one step further, pledging to donate \$25,000 to the Foundation. "We are fortunate that we can help in some way," Debbie explains, "so we feel we want to and need to." Steve and Debbie both hope that through the Foundation, they can reach more medical students and encourage them to study rheumatology. They also believe in the research being supported by the Foundation. With his daughter in mind, Steve explains what motivated them, "just doing anything we can to find a cure so nobody has to go through this, so no kids have to go through this.... Courtney is probably going to deal with this for life. We'd love to think that the cure is around the corner, and we can help."



Courtney Russell is still running cross country. This picture was taken during a race at the beginning of September.

“WE ARE FORTUNATE THAT WE CAN HELP IN SOME WAY, SO WE FEEL WE WANT TO AND NEED TO.”



CORPORATE **ROUNDTABLE**

As a direct result of the support of Corporate Roundtable donors, the Foundation continues to increase funding for research and training.

Participation in the Corporate Roundtable is a direct investment toward helping to:

Ensure a highly trained workforce is available to provide competent clinical care to patients affected by rheumatic disease;

Develop the next generation of researchers dedicated to rheumatic disease;

Accelerate targeted inflammatory arthritis research.

The Foundation thanks the Corporate Roundtable donors for their exemplary support.

* Industry Roundtable members as of July 31, 2013

† Within Our Reach Partner Donor

x Multi-year commitment

Leadership (\$7,500,000 +) ^x



Pinnacle (\$5,000,000 +) ^x



Principal (\$2,500,000 +) ^x



Partner (\$1,000,000 +) ^x



Steward (\$25,000 +)

Antares Pharma, Inc.

Statements of Financial Position

June 30, 2013 and 2012

Assets

Cash and cash equivalents
Investments
Contributions and grants receivable, net
Prepaid expenses and other assets
Property and equipment, less accumulated depreciation
of \$62,600 and \$45,226 in 2013 and 2012, respectively

Total assets

Liabilities

Accounts payable

Net Assets:

Donor restricted:

Temporarily restricted
Permanently restricted

Other:

Designated by board for education and research awards
Unrestricted

Total net assets

Total liabilities and net assets

	2013	2012
	<u>\$ 14,279,043</u>	<u>\$ 14,136,005</u>
	38,709,309	35,945,546
	17,695,397	17,946,163
	17,450	25,492
	215,059	68,851
	<u>\$ 70,916,258</u>	<u>\$ 68,122,057</u>
	\$ 374,379	\$ 312,124
	36,842,513	34,999,458
	2,305,795	2,305,795
	24,412,241	22,831,651
	6,981,330	7,673,029
	<u>70,541,879</u>	<u>67,809,933</u>
	<u>\$ 70,916,258</u>	<u>\$ 68,122,057</u>

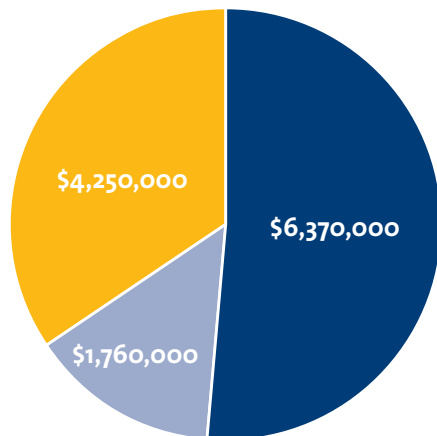
FINANCIALS /

ORGANIZATIONAL EFFICIENCY

Statements of Activities

For the years ended June 30, 2013 and 2012

FY 2013 Awards and Grants Funding



- Disease Targeted Research
- Recruitment, Education, and Specialized Clinical Training
- Academic Research Career Development

Changes in unrestricted net assets

Revenue:

	2013	2012
Gifts and grants	\$ 1,633,843	\$ 1,159,674
Investment and interest income	774,707	665,665
Net realized and unrealized gains (losses) on investments	2,194,273	(994,908)
Miscellaneous income	(14,216)	57,523
Net assets released from restriction	10,264,939	6,889,007
Total unrestricted revenues	14,853,546	7,776,961

Expenses:

Program services - research and education	12,182,322	8,031,395
Support services:		
Administrative	704,994	293,128
Fundraising	1,077,339	885,453
Total support services	1,782,333	1,178,581
Total expenses	13,964,655	9,209,976
Change in unrestricted net assets	888,891	(1,433,015)

Changes in temporarily restricted net assets:

Gifts and grants	11,325,622	17,199,854
Investment and interest income	200,521	193,225
Net realized and unrealized gains (losses) on investments	567,635	(263,872)
Net assets released from restriction	(10,264,939)	(6,889,007)
Miscellaneous income	14,216	-
Change in temporarily restricted net assets	1,843,055	10,240,200
Change in net assets	2,731,946	8,807,185

NET ASSETS AT BEGINNING OF YEAR

67,809,933 59,002,748

NET ASSETS AT END OF YEAR

\$ 70,541,879 \$ 67,809,933

FOUNDATION STAFF

FOUNDATION STAFF

Steven Echard, CAE, IOM
Executive Director

AWARDS & GRANTS:

Mary Wheatley
Senior Director, Research and Training

Amy Kane
Director, Core Programs

Eryn Marchiolo
Director, Targeted Research Programs

Damian Smalls
Senior Specialist

Ashley MacDermott
Coordinator

COMMUNICATIONS & MARKETING:

Alexa Newlin
Director

Tracy Johansson
Specialist

CORPORATE RELATIONS:

Amy B. Miller
Director

Nat Cabrera
Specialist

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Vice President

Samantha Rasnake
Regional Development Officer (NE)

Vacant
Regional Development Officer (W)

Vacant
Regional Development Officer (MW)

Vacant
Regional Development Officer (S)

Mary Roundtree
Director, Development Services

Lauren Landreth
Senior Specialist, Donor Stewardship & Events

Alysse Kong
Coordinator, Development Services

Andrea Sharper
Coordinator, Accounting and Development

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Colleen Merkel
Vice President

Erin Conner
Director, Treasury Accountant

Chasity Steverson
Senior Specialist

