Investing in the Future of Science

NPF-Funded Research Yields Over 6 Times Return

Thanks to generous support from our community, NPF invested $970,000 in research in 2013. The researchers awarded funding that year went on to receive awards from the National Institutes of Health (NIH) worth almost $7 million through 2019, representing more than a 6-fold return on the NPF investment.

Outcome tracking information is collected during a 5-year post-award survey.

Research For a Better Tomorrow

NPF funded $2.8 million in research grants and fellowships in 2019, a record amount of funding by the NPF.
Fiscal Year 2020-2024 Strategic Plan

NPF recently launched its new strategic plan, which will guide our priorities and efforts from July 1, 2019 to June 30, 2024. The new plan was developed by a committee of patients, caregivers, clinicians, researchers, nonprofit consultants, former industry executives and NPF staff and board members. In this, our most ambitious strategic plan yet, NPF highlights a continued focus on a life free of psoriatic disease and remains committed to finding a cure for psoriasis and psoriatic arthritis while supporting individuals to live longer and healthier lives. Over the next five years, NPF will focus on achieving three goals:

1. Lead collaborative, transformational research in psoriatic disease
2. Increase the lifespan and health of individuals living with psoriatic disease
3. Secure the human, technological and financial resources necessary to achieve NPF’s mission-related goals

The research team is planning the most robust endeavors we’ve ever taken in research. Our primary research goal is to lead collaborative, transformational research in psoriatic disease. Measurement of success for these goals will be tracked against milestones created to achieve the following:

Reduce to zero the burden of psoriasis by generating research resulting in higher numbers of patients in remission and identifying tools that extend remission periods, regularly analyzing and publishing NPF-generated data and integrating current psoriatic disease research in NPF resources for the community.
Reduce by 50 percent the time from when individuals living with psoriasis first exhibit symptoms of psoriatic arthritis until their diagnosis and develop a diagnostic test for psoriatic arthritis by funding Psoriatic Arthritis Diagnostic Test Grants during the first year of the 2020-2024 plan.

Establish a multi-institution, multi-disciplinary research team with the aim of identifying an intervention that will prevent the onset of psoriatic disease by developing a new grant mechanism – the Psoriasis Prevention Initiative (PPI).

Improve by two years the lifespan of individuals living with psoriatic disease and improve by 50 percent the quality of life of individuals with psoriatic disease by identifying a reliable, predictive model for the onset of psoriatic disease, the potential relationship to comorbid conditions and the best treatment practices for a cure.

PsA Diagnostic Test Grant

As part of our goal to accelerate discovery in psoriatic disease research and research-related initiatives within the NPF 2015-2019 Strategic Plan, we committed to elevating the organization’s efforts to address delays in diagnosing psoriatic arthritis.

In 2019, NPF introduced the PsA Diagnostic Test Grant. The grant aims to fund the development of a clinically applicable diagnostic test for psoriatic arthritis that may improve detection of PsA in a highly sensitive, specific and non-invasive manner. Such a diagnostic test would dramatically reduce the guesswork and the long delays in reaching a diagnosis and beginning treatment, reducing the risk of permanent joint damage and improving quality of life.

This grant program funded six first-year, proof-of-concept proposals that have the potential to achieve this goal within five years. An additional one-year extension has been awarded to all proposals.
Meet Our PsA Diagnostic Test Grant Awardees

Siba Raychaudhuri, M.D.
Professor, Rheumatology, Allergy, and Clinical Immunology
University of California, Davis

“The broader goal is to use PET/CT as an early diagnostic marker for PsA to help and prevent chronic disabilities in patients suffering from PsA. Preliminary data shows that this technology may be able to visualize and quantify molecular activity at small joints, peri-articular area including enthesis and to assess simultaneously the radiotracer dynamics across the entire body.”

Wilson Liao, M.D.
Professor, Dermatology
University of California, San Francisco

“Using a simple blood draw, we will use innovative single cell technology to perform unbiased deep profiling of the RNA transcriptome, proteome, and genome of peripheral blood cells in patients with PsA, psoriasis without PsA (PsO), and other rheumatic conditions. We will use bioinformatics to determine the most promising combination of markers of PsA leading to a diagnostic test.”

Ananta Paine, Ph.D.
Research Assistant Professor, Department of Medicine, Allergy/Immunology and Rheumatology
University of Rochester

“The focus of this proposal is to validate our findings with additional samples, in blood, skin and bone marrow, to examine if any of the molecules identified in our study serve as clinical PsA biomarkers for the presence of disease or to predict psoriasis patients at risk to develop PsA.”
Vinod Chandran, M.B., B.S., M.D., D.M., Ph.D.
Associate Professor, Department of Medicine, Rheumatology
University Health Network, University of Toronto
“Our preliminary data strongly suggests that a successful diagnostic algorithm for PsA will need to combine clinical parameters with integrated, multi-omic markers (genes, proteins, metabolites) into a diagnostic signature. This will improve patient-centered care and optimize disease outcomes through earlier and more effective management.”

Jose Scher, M.D.
Assistant Professor, Department of Medicine Director, Psoriatic Arthritis Center
New York University School of Medicine
“We will utilize a novel high throughput sequencing technology to study individual immune cells with unprecedented resolution from the skin, blood and joints of patients with PsO, those with very early PsA and in a group of people with PsO at much higher risk for developing PsA. This approach will allow us to focus on molecular changes in the immune cells during disease progression and enable us to identify biomarkers for early diagnosis.”

Bingjian Feng, Ph.D.
Research Assistant Professor, Dermatology
University of Utah
“This study employs a multi-omic and multi-platform approach to identify plasma biomarkers in psoriasis patients with blood samples collected prior to PsA onset. These tools will comprehensively integrate multiple predictors including clinical phenotypes, genetic variants and proteomic biomarkers. This will improve our ability to identify PsA at an earlier stage and improve the quality-of-life of PsA patients by chemoprevention or early treatment.”
Where Do We Go From Here?

For the 2020 grant cycle, NPF introduced another pivotal grant mechanism addressing the first pillar of our strategic plan (to lead collaborative, transformative research): the Psoriasis Prevention Initiative. NPF plans to invest an estimated $6.5 million over the next five years to establish the PPI. Preventing the onset of disease, relapse or the related comorbidities would overcome many of the obstacles that continue to challenge patients and health care providers and significantly improve the lives of those affected by psoriatic disease.

Three applications were selected for funding during the first year of the program, with a competitive renewal award to one grantee for Year 2 funding. Renewal funding for years 3-5 are contingent upon continued demonstration of progress.

Corrona Psoriasis Registry

As part of our strategic plan goal to increase the lifespans and health of individuals living with psoriatic disease, the NPF partners with Corrona, LLC, the leading sponsor of registries in autoimmune and immune-mediated diseases. The Corrona Psoriasis Registry utilizes patient data routinely collected approximately every six months during patients’ visits to their dermatologist and tracks the journey for at least eight years. The information collected is utilized by researchers to compare the safety and effectiveness of psoriasis treatments, study diseases associated with psoriasis, and better understand the natural history of the disease. At the present time, over 10,000 patients with psoriatic disease have enrolled in the registry.

Patient Centered Research

The Power of the Annual Survey

The NPF Annual Survey underwent an extensive renovation this year that lead to an almost seven-fold increase in response rate from previous years. The survey was conducted utilizing a random sample of individuals from the NPF’s constituent database using both online and telephone interviews.

A novel inclusion in the survey this year was the addition of the Psoriasis Epidemiology Screening Tool (PEST screener), a validated tool to screen for PsA. Participants whose PEST scores ≥ 3 were prompted to follow up with a rheumatologist regarding potential psoriatic arthritis. These data will be included in a report related to health expectancy and lifespan prognosis for individuals living with psoriatic disease, a goal of our strategic plan.

A summary of conclusions can be found in the following page.

For more information about the National Psoriasis Foundation Annual Survey, please reach out to research@psoriasis.org.
Conclusions

60% of participants report psoriatic arthritis at an unacceptable disease level

Barriers to care are highly prevalent
• 64% experience some barrier to treatment

28% of people with psoriasis should consult with a rheumatologist, based upon PEST score
• 68% of individuals with psoriasis only whose PEST score indicates they should consult a rheumatologist have never seen a rheumatologist

Cost of treatment is most common barrier to treatment (38.2%)

Depression rates are higher than the general population
• Psoriatic disease: 20.8%
• General population: 8.1%

Individuals with psoriasis disease have an average of 3 comorbidities

The three most prevalent comorbidities are:
• High blood pressure: 38%
• Anxiety: 34%
• Depression: 32%

There is an unmet mental health need in psoriatic disease community
• 34% with depression based on PHQ-9 are undiagnosed
The National Psoriasis Foundation provides you with the help you need to best manage your psoriasis or psoriatic arthritis, while promoting research to find a cure.

research@psoriasis.org