



{PNRR}

ADVANCING PERIPHERAL NEUROPATHY RESEARCH

*the* PERIPHERAL  
NEUROPATHY

Research  
Registry



## Why is the Peripheral Neuropathy Research Registry (PNRR) needed?

The PNRR is the only biobank for peripheral neuropathy (PN). That makes it very valuable for research. Peripheral neuropathy is a complex disease that's not fully understood. Since the causes vary from patient to patient, there is no easy way to diagnose PN. The PNRR allows patients to be part of a unique and important research study. Its purpose is to identify demographic, genetic, environmental and other items that link the disease's development and outcomes. It also provides direct access to human DNA and biosamples for researchers.

## What is the PNRR?

The PNRR collects data and DNA samples from people diagnosed with one of four types of PN: diabetic, chemotherapy-induced, idiopathic (unknown), and HIV/AIDS associated neuropathies. Patients who enroll in this study are asked to provide biological samples and details about their medical history. The patients' samples are kept in a secure warehouse until they are needed for research. No personal information is given to researchers, to ensure patient confidentiality.

## Why was the biobank created?

The PNRR helps researchers learn more about peripheral neuropathy by learning more about the patients who have this disease. The biobank allows for research studies using human samples that are needed to improve the understanding of the causes of PN, as well as research that helps develop treatments and the search for cures.

The goals of the biobank are to give researchers information about lots of patients and to improve clinical studies and research.

*The key objectives of the PNRR are to:*

- » Understand the disease
- » Improve diagnosis of PN
- » Develop new effective treatments and therapies
- » Provide data for researchers and clinicians
- » Find cures for PN

When you participate in this research study, you help improve the lives of all PN patients by:

- » Increasing understanding of PN
- » Providing data to research treatments and cures
- » Speeding up new or promising treatments

## Who manages the PNRR?

The biobank is run by *the* Foundation for Peripheral Neuropathy (FPN). FPN is guided by a Scientific Advisory Board. The Board includes leaders in the medical, ethical, scientific and PN communities. This team makes sure the right data are being collected, and that the best research projects are using the samples.

## After I enroll, where does my information go?

All data and samples are securely held at Indiana University in Indianapolis, Ind., USA.

## Who can enroll?

People over the age of 18 who have been diagnosed with diabetic peripheral neuropathy or idiopathic peripheral neuropathy can enroll. If you're not currently a patient at one of our partner sites, but you want to enroll, contact the research coordinator nearest you. Enrolling in the Registry is voluntary. Choosing not to participate will not affect your medical care in any way.

## What are participants asked to do?

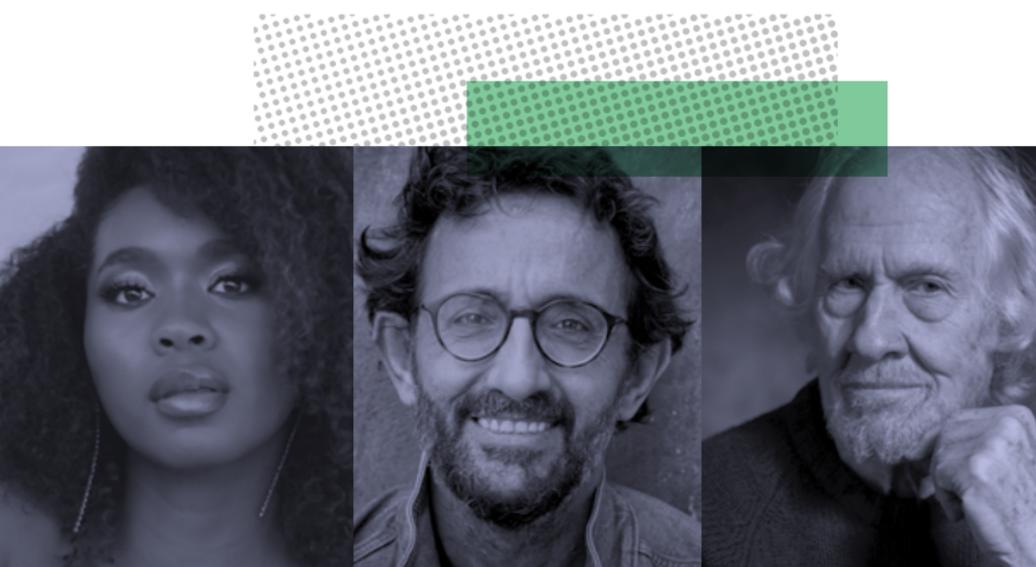
- » Review and sign the informed consent form
- » Complete a patient history questionnaire about your medical and family history
- » Donate a biological (blood) sample

## How many times must I be seen by the physician?

You must be willing to be seen by a neurologist at one of the participating consortium sites at least once.

## What happens after I complete my forms?

Once you choose to enroll, your doctor will complete a form about your neurological and physical exams. Your patient history, and the information from your neurological and physical exams, will be entered and securely stored in the biobank. You are free to decline or withdraw from the PNRB at any time.



## Is my personal information safe?

Yes! Once information is added to the PNRR, it is de-identified. That means any personal info, like names and addresses, are stored in a secure database separate from PN specific data. The PN data you provide will only be shared with approved research projects. Third parties will not be given access to the database, or your personal information. Data sent to third parties for research includes none of your personal identifying information.

## How confidential is this database?

Confidentiality about patients will be strictly maintained. The database is stored at Indiana University, in the department of Medical and Molecular Genetics. The group has over 30 years of experience in maintaining data registries. They have a state-of-the-art security system to maintain patient confidentiality. They are accredited by the Association of Accreditation of Human Research Protection Program Inc., a governing body that evaluates databases to make sure they meet rigorous standards for quality and protection.



# PNRR Partnering Consortium Sites

For more information on enrollment, contact the research study coordinator at the nearest participating site.

## Icahn School of Medicine at Mount Sinai

Neurology Department

1468 Madison Ave., Annenberg Building, Room 2-40

New York, NY 10024 | 📞 212-241-0784

## Johns Hopkins University

Clinic: 601 N. Caroline St., 5th Flr.

Baltimore, MD 21287 | 📞 410-614-4188

## Northwestern University

Peripheral Neuropathy Clinic

259 E. Erie St., 19th Flr.

Chicago, IL 60611 | 📞 312-695-7950

## University of Kansas Medical Center

Neurology Department

3599 Rainbow Blvd.

Kansas City, KS 66103 | 📞 913-945-9932

## University of Michigan

Department of Neurology

1500 E. Medical Center Dr.

1914 Taubman Center SPC 5316

Ann Arbor, MI 48109 | 📞 734-936-9010

## University of Utah

Department of Neurology

175 N. Medical Dr., 5th Flr.

Salt Lake City, UT 84132 | 📞 801-585-2741

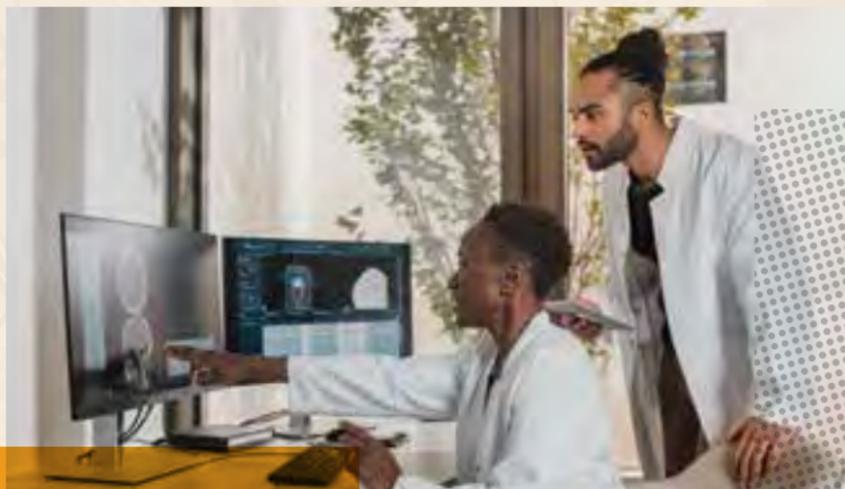
## Washington University School of Medicine in St. Louis

Department of Neurology

660 S. Euclid Ave., Box 8111

St. Louis, MO 63110 | 📞 314-362-6981

# FOR RESEARCHERS



## What is the PNRR?

The Peripheral Neuropathy Research Registry (PNRR) grants researchers direct access to data and biospecimens from over 2500 patients with predominantly axonal sensory polyneuropathies. DNA, plasma and serum samples are available to further discoveries about the pathology and etiology of this condition and increased characterization of the phenotypes and genotypes of patients with the disorder. The PNRR facilitates both the basic and clinical research studies needed for an improved understanding of the causes and development of PN.

The PNRR is a standardized collection of data and samples of individuals diagnosed with diabetic, idiopathic, chemotherapy-induced and HIV/AIDS associated neuropathies. It includes detailed information about medical, genetic, social and family history, all in an anonymized dataset.

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Ultimately, the *goal* is that this research will result in improved diagnosis, treatments, prevention and possibly *cures* for the disorder.

**AHMET HÖKE, MD, PHD**  
Professor of Neurology and Neuroscience  
Johns Hopkins University

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## How is research conducted?

De-identified data and biosamples (blood, plasma and serum) from participating consortium sites are aggregated into the biobank. PNRR dissemination procedures for the purpose of providing clinical data and biological specimens to investigators for basic and clinical research requires the researcher to submit a research application to *the* Foundation *for* Peripheral Neuropathy. FPN will submit all applications to the PNRR Scientific Advisory Board to review and approve prior to any dissemination of clinical information or biological specimens to researchers.



## How can I get samples for my research?

Submit your application online at [bit.ly/4o7d5KP](https://bit.ly/4o7d5KP) and it will be reviewed by the PNRR Scientific Advisory Board.

## What research is using PNRR data?

For more information about the biobank's research studies and progress to date, visit [FoundationForPN.org/current-research](https://FoundationForPN.org/current-research).

For a list of publications on the PNRR, go to [FoundationForPN.org/current-pnrr-publications](https://FoundationForPN.org/current-pnrr-publications).

“The cooperative nature of the formation of this registry is what makes it truly important. With the collaboration of the consortium members, we now have a standardized method of patient examination that will greatly reduce variability in our clinical studies and research. Ultimately, the goal is that this research will result in improved diagnosis, treatments, prevention and possibly cures for the disorder.”

### **Ahmet Höke, MD, PhD**

PNRR Lead Principal Investigator and FPN Scientific Advisory Board member, Professor of Neurology and Neuroscience, Johns Hopkins University