

# Announcing a New PSC Partners Initiative



## What is WIND?

WIND, Worldwide Integration of Natural History Databases, is a PSC Partners-led and sponsored initiative that will make valuable patient data available to researchers. This will give them a better understanding of the lived PSC experience.

The WIND database will serve as a central location where PSC natural history data is securely shared with PSC Partners and with the broader PSC research community. Medical centers from around the world will be invited to contribute clinician-reported natural history data.

Data will be integrated from existing databases in different countries, amplifying their power by facilitating consistent, comprehensive, and monitored data collection. This will ultimately support and accelerate drug development for PSC.

## Why is the natural history of a disease important?

*Natural history* refers to the usual course of a disease over time. When natural history is captured, patients are followed over time as their PSC progresses. With a patient's consent, important data, such as treatments, complications, and more, can be stored securely in a *natural history registry*.

Natural history studies are crucial to PSC research, and will one day enable us to get the right treatment to the right PSC patients at the right time.

## How is WIND different from a patient registry?

The main differences between a *natural history registry (or database)* and a *patient registry* are the types of data, and how the data is captured. The PSC Partners Patient

Registry is a *patient-reported registry*. A natural history registry includes systematic and regular collection of past or current data from medical records, imaging data, hospitalization records, and lab test results. The systematic capture of these health data over time is key to enabling the completion of *natural history studies*.

For more on the basics of natural history studies, please consider watching (or rewatching) the [recording of the ROADMAP Natural History 101](#).

## What are some of the main objectives of WIND?

WIND aims to contribute to development of biomarkers which may be used to demonstrate effectiveness of an investigational drug for PSC. A biomarker is a characteristic of the body that can be measured.<sup>1</sup> For example, blood tests or liver imaging may serve as biomarkers of treatment response. One reason clinical trials for PSC are challenging is because PSC currently lacks noninvasive biomarkers that are proven to correlate with disease progression.

In rare disease drug development, natural history data may provide an untreated external control group (instead of a group receiving a placebo) for late-stage clinical trials. The natural history data must meet stringent regulatory collection and monitoring requirements, as well as patient confidentiality and data security; WIND is being designed with this use of the data as an objective.

The WIND initiative also plans to collect various measures of quality-of-life simultaneously with physician-reported clinical data. This will support the study over time of PSC symptoms and quality-of-life during PSC progression.

## Who is involved in WIND? How can I join?

WIND is the inaugural project of the PSC Partners [International Collaborative Research Network \(ICRNetwork\)](#). The ICRNetwork is a place for anyone to volunteer and contribute to ongoing research efforts. The success of WIND relies on support from patients, caregivers, clinicians, and researchers.

To support drug development, PSC Partners is working with great urgency to establish formal partnerships with academic researchers and institutions, and we will keep PSC Partners Registry participants and the community updated on which sites are ready to enroll patients into the WIND cohort.

It is important to know that the goals of WIND can be accomplished by enrolling a few thousand dedicated PSC patients who are willing and able to follow-up regularly at

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<sup>1</sup> This short patient-friendly video from the FDA defines and describes biomarkers  
[What Are Biomarkers And Why Are They Important?](#)

dedicated research centers. Given the limited budget and numbers of patients and research centers needed to accomplish these goals, not all interested PSC patients will be able to join this initial cohort. An additional challenge is that many in our community do not live near participating research centers.

We value every PSC patient's voice. Regardless of whether you are able to join the WIND cohort, we encourage you to join the [PSC Partners Patient Registry](#), through which you can give priceless input and can support the WIND initiative and other PSC research studies. Through the Registry, PSC Partners may connect you to ongoing natural history registries, research studies, and clinical trials for PSC.

### Where can I learn more??

Excited to join the Registry and hear more about the plans for the WIND cohort? Attend the [March 23 ROADMAP webinar](#) and the [Annual PSC Partners Conference](#) from June 2-5, 2022 to learn more about the WIND initiative. Visit the WIND page of the PSC Partners website for more details.

Together in the fight, whatever it takes!