

INTERESTED IN JOINING THE SEVERE CHRONIC NEUTROPENIA INTERNATIONAL REGISTRY AT BOSTON CHILDREN'S HOSPITAL?

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Why is the Severe Chronic Neutropenia International Registry (SCNIR) needed?

SCN is a rare condition, so information about SCN is scarce. More information is needed to improve the diagnosis and treatment of children and adults with SCN.

The SCNIR provides a way for any patient with SCN or a related condition to share their information, experiences, and samples with researchers working to find the best treatments for SCN.



What does the SCNIR do?



By studying medical records and biological samples from the same patients over time, the SCNIR works to enhance SCN diagnosis, improve treatment, and advance our understanding of risk factors for severe complications.

Samples for the SCNIR are collected when they are obtained for clinical care, so no extra visits or needle pokes are needed.

Who will have access to the SCNIR?

SCNIR databases are password-protected behind a firewall and can only be accessed by designated members of the SCNIR study team. Only de-identified data and samples are provided to qualified investigators who will study these to improve the lives of people with SCN.

Will my identity be shared?



Data and samples are de-identified for research. None of your personal information will be shared outside the study team.

How will sharing my samples and experiences help?

Your information and samples are critically important to advance knowledge about these rare conditions with the goal of finding a cure. Here are some examples of ongoing research made possible by the data and samples collected through the SCNIR:

- Determine the causes of SCN
- Guide recommendations for medical care to improve the health of people with SCN
- Understand the medical complications of SCN and their progression over time
- Develop strategies to monitor for and prevent complications such as leukemia
- Develop better therapies for SCN



How can I get involved?

If you would like to partner with the SCNIR in the quest for a cure for SCN, please reach out to our team either by calling 617-919-1574 or emailing SCNIR-dl@childrens.harvard.edu

EVERY PATIENT MAKES A DIFFERENCE!

