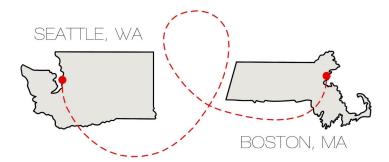
## THE SCNIR IS MOVING!



# Important Information from the Severe Chronic Neutropenia International Registry

The Severe Chronic Neutropenia International Registry (SCNIR) will now be located at Boston Children's Hospital! The Registry's new Directors are Dr. Akiko Shimamura and Dr. Peter Newburger; they will still be working closely with Dr. David Dale and Audrey Anna Bolyard in Seattle.

#### What Does This Mean for Me?

All clinical data previously collected when the SCNIR was in Seattle are being shared with SCNIR Boston. New clinical data and biological samples will now be sent to Boston Children's Hospital.

We need to re-consent you to the Boston Children's Hospital SCNIR protocol so that you can continue to share updates and samples. This consent discussion can be done remotely with an electronic form. If you are interested in re-consenting, please reach out to our team at SCNIR-dl@childrens.harvard.edu or 617-919-1574.

#### Who Is the Best Contact?

Karyn Brundige, who will be working closely with Audrey Anna Bolyard, is a pediatric nurse practitioner in the bone marrow failure and hematology programs at Boston Children's Hospital. Karyn is available to patients and families for clinical questions about neutropenia and the SCNIR. To contact Karyn, please email SCNIR-dl@childrens.harvard.edu

### Where Can I Receive Communication?

We are currently constructing a new SCNIR website to keep you informed of SCNIR updates and advances. The website will also include a link for you to send messages or questions to the SCNIR. You can visit our website here: www.scnir.org

If you have questions or wish to contact us for any reason, please call us at 617-919-1574 or email us at SCNIR-dl@childrens.harvard.edu

We look forward to continuing to work together to improve diagnosis, treatment, and health of people with severe chronic neutropenia!