

Fall 2021 Newsletter

Path4ward Webinar

**Join us for a X4
Pharmaceutical Sponsored Webinar**

**Friday, September 10, 2021
3pm ET (US and Canada)**

Join us for an overview of the Path4Ward Program, including information about genetic counseling, how to access, and one patient's experience.

[Click here to register.](#)



COVID 19: Covid-19 infections in patients with severe chronic neutropenia & anti-body testing

David C. Dale, MD & Peter Newburger, MD

The Severe Chronic Neutropenia International Registry (SCNIR or Registry) maintains a database on the infectious complications and other serious health events for patients enrolled in the Registry. Since the epidemic began in February 2020, 15 patients with positive antibody tests have reported to our Seattle office about their illness and complications. Most of the cases occurred between February 2020 and February 2021, with the highest frequency in September to November 2020. The age range was broad, 2-62 years; the average was 29 years. There were 9 females and 8 males.

Symptoms of Covid 19 infection were very similar to other patients without neutropenia. Usually the illness began with fever or fatigue and headaches, resembling a common cold. More severe cases also had the loss of smell and taste, difficulty

Helpful Resources

Emergency Room Card
[English ER card \(PDF\)](#)
[Español ER tarjeta \(PDF\)](#)
Need another language,
[Contact us.](#)

[ANC Calculator](#)
[E-Cards: submit & send](#)
[SCNIR](#)

Information on types of neutropenia, management, and more at:

[National Neutropenia Network](#)

Savvy Survey

Savvy Cooperative has a survey for patients in the Severe Congenital Neutropenia community. They need to get perspectives from patients who would consider being part of a clinical trial. Note: survey will close after the maximum number of completions. Thanks!

[Click here to participate in this survey.](#)

Junior Ambassador

Applications due Aug 31

Our children have a rare opportunity to turn their Neutropenia journey into something positive. By becoming involved in community outreach, education and fundraising, our hope is that children with

breathing and symptoms of acute pneumonia. 12 patients were ill enough to go to the emergency room or urgent care center, only one was hospitalized and data is not available for 2 others. Examples are: twin sisters with severe congenital neutropenia, who were doing well on G-CSF treatment, return to college in August 2020. Both acquired Covid 19 infection with typical symptoms that were relatively mild and they recovered uneventfully except for a prolonged loss of taste and smell. Another young adult with severe congenital neutropenia on treatment with G-CSF for more than 7 years went off to college and then became involved with providing urgent care at an urban hospital. This was before the availability of the Covid 19 vaccines. He acquired Covid 19 infection and died quickly from pneumonia. This is the only known death in US patient with severe chronic neutropenia.

The SCNIR cooperates with a large European network to study the treatments and complications of chronic neutropenia. The European data is similar to the US data. The only death was in a patient with a serious heart abnormality. The US and Europe patients have continued their usual G-CSF treatment. There is also accumulating data on cancer patients undergoing chemotherapy were radiation therapy and receiving G-CSF. There is no suggestion that it worsened symptoms or outcomes. With the availability of the Covid 19 vaccines, the number of patients with infections has decreased dramatically.

Based on these observations I recommend:

- Covid 19 vaccination for all SCN patients and their families. Children should be vaccinated as soon as we learned the safety of the vaccine for children and and it is approved by the FDA.
- G-CSF treatment should continue as usual and not be interrupted for fear that neutrophils will make Covid 19 pneumonia worse.
- Practice prevention with facemask, social distancing, good hygiene including thorough handwashing and avoidance of crowded places.
- Patients with symptoms of Covid 19 should seek medical attention promptly. Go to urgent care/emergency care promptly; do not be afraid to contact your doctor or go to a hospital emergency.

Testing for antibodies to SARS-CoV2 (COVID-19) is useful for diagnostic testing, but not for determination of immunity to COVID-19 or response to vaccine. The tests vary quite a bit and may not detect some vaccine responses unless part of a research program tailored to the specific vaccine.

2021 Virtual Conference

The 2021 Neutropenia Virtual Conference was a time for individuals and families of all ages and all types of neutropenia to come to listen to experts, learn, and spend time together. Thank you to those who provided great content for the conference. Thank you to those who were able attend.

[Visit our website for conference materials.](#)

Neutropenia will discover an upside, if you will, to what they have been given in life. We hope that they will not only learn to advocate for themselves and others, but that they will also help to define the role Neutropenia will play in their lives instead of allowing their Neutropenia to define it for them. Additionally, we hope they will gain a sense of pride in making a difference in their Neutropenia community.

If you are interested in joining our Junior Ambassador program, please [visit our website and complete aa application](#) and send to Tanya, our Ambassador Coordinator. Applications are due August 31, 2021. Thank you and good luck.

Advocating for Health

Monisha Kandala has been assisting with vaccinations, the largest inoculation site in Dallas, Texas and has found it rewarding to educate others about the benefits. Monisha has been involved with the National Neutropenia Network for several years. She was a member of our Patient Support Committee and has also been involved in other individual projects. Monisha is working on advancing her career in health care.



The team at [National Neutropenia Network](#) wants to extend a hearty 'thank you' to all of our wonderful readers. You've helped make our community shine, and we want to keep that going! For more information on our mission and how you can help visit [our website](#).