

# START THE CONVERSATION: PRURIGO NODULARIS

If you're living with prurigo nodularis (PN), the lack of information available can be frustrating. PN is an often misunderstood, relentless disease. However, it's also rare, which means that many people may not understand just how overwhelming it can be.

You should know that **PN is real and it's not "just in your head."** Although the cause of prurigo nodularis is not fully understood, evolving research suggests an abnormal relationship between the skin, nervous system, and immune system can lead to chronic inflammation and relentless itch. This results in signs and symptoms you see and feel. These discoveries may change the way PN is understood and managed. Until then, you should work with a specialist who understands PN and share as much information as you can. Use this guide to help gather the details of your experience with PN and any questions you want to ask your doctor. Giving your doctor an accurate and complete understanding of your experience will help you both develop a plan together.

## SHARE YOUR PN EXPERIENCE WITH YOUR DOCTOR

Fill out this section **before your appointment**, making sure to capture the physical and emotional impacts PN has on your life.



*Remember to take photos of what your bumps look like between appointments since their appearance and features can change over time.*

PN has affected my ability to get a good night's sleep \_\_\_\_\_ days in the last week.

These are my most severe signs and symptoms: CHECK all that apply.

☐ Itching ☐ Pain/Burning/Stinging ☐ Bumps ☐ Bleeding ☐ Scarring ☐ Other: \_\_\_\_\_

I would describe the **itching** of PN as \_\_\_\_\_

This week, the severity of my itching was CIRCLE one.

1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10

(not at  
all severe)

(very  
severe)

I would describe the **pain/burning/stinging** of PN as \_\_\_\_\_

This week, the severity of my pain/burning/stinging was CIRCLE one.

1 — 2 — 3 — 4 — 5 — 6 — 7 — 8 — 9 — 10

(not at  
all severe)

(very  
severe)

Emotionally, PN negatively affects my life because of CHECK all that apply.

☐ Sadness ☐ Isolation ☐ Hopelessness ☐ Frustration ☐ Difficulty concentrating ☐ Other: \_\_\_\_\_

PN symptoms affect my quality of life CHECK one.

☐ Never ☐ Rarely ☐ Sometimes ☐ Frequently ☐ Almost always

## ASK YOUR DOCTOR ABOUT PN

With so little information available about PN, you may have a lot of questions. Now's your chance to get the answers! Use these prompts to start the conversation **during your appointment** and write your doctor's responses on the lines provided.



*Don't be afraid to speak up if you don't understand something or feel that your doctor isn't hearing you.*

What causes PN? \_\_\_\_\_

Why does PN cause these bumps on my skin? \_\_\_\_\_

Does PN come and go? \_\_\_\_\_

Additional questions: WRITE your questions here. \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## PLAN FOR A LIFE WITH PN

As a chronic condition, PN may never go away. **During your appointment**, work with your doctor to develop a care plan that you can use to help reduce the impact of PN. Remember to take notes in the spaces provided so that you can review them after your appointment.

What can I do to manage PN moving forward? \_\_\_\_\_

What can you suggest that may help my PN symptoms? \_\_\_\_\_

What, if any, are some things that I should avoid for my symptoms? \_\_\_\_\_

My hope for life with PN is: \_\_\_\_\_

Other notes: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



## DEVELOP A PLAN

**After your appointment**, review the answers you've written down and use them to develop a plan for managing your PN. Continue to take photos and record your symptoms using **this tracker**, as your PN may change over time. When you return to your doctor, you can come prepared to keep the conversation going with a discussion about your experience.