

EVERY STORY MATTERS BE PART OF THE SOLUTION

Join the XP Registry

The XP Registry is a national research effort to learn more about **Xeroderma Pigmentosum (XP)**

Only Together Can Our Stories
Become Tomorrow's Discoveries –



Power is in One Registry.



WHY PARTICIPATE?



BUILD A REGISTRY

One registry to centralize information and to improve the understanding of XP. Together our stories are more powerful.



STRENGTHEN ADVOCACY

Data from the registry can help identify unmet needs and strengthen XP advocacy efforts.



SUPPORT RESEARCH

The registry strengthens our position to partner with researchers and provides collective data we can publish in journals.



EDUCATION FOR ALL

Collective knowledge in one registry will be a valuable resource within our XP community and for healthcare providers.



WHO CAN JOIN?

- ✓ Adults with XP who can provide their own consent
- ✓ Individuals of all ages diagnosed with XP
- ✓ Caregivers or legally authorized representatives of adults with XP who may need assistance
- ✓ Family members or other knowledgeable individuals of a deceased person with XP



WHAT IS INVOLVED?

- ✓ Participation is simple and can be done online.
- ✓ You will be asked to complete a survey about:
 - Medical Information
 - Sunprotective Behaviors
 - Financial Burden
 - Psychosocial/Quality of life
- ✓ Follow-up surveys may be invited periodically.
- ✓ Your participation is voluntary.
- ✓ You may stop the survey at any time.



ENROLL INTO THE REGISTRY

Or Learn More & Provide Support

Scan the QR code
or visit
thexpfoundation.org



Scan me!



WITH AN ULTRA RARE DISEASE ONLY WHEN
WE ALL COME TOGETHER CAN WE MAKE A
DIFFERENCE FOR US AND FOR THOSE TO
COME IN THE FUTURE.

EVERY STORY MATTERS!

Thank you for helping more XP research forward.



Your privacy is important. All data are kept secure and confidential. De-identified information may be shared with researchers, medical institutions, or pharmaceutical companies to advance XP research in accordance with ethical and legal standards.

thexpfoundation.org