



NNPDF is excited to partner with the Firefly Fund, Niemann-Pick Canada, the Ara Parseghian Medical Research Fund and AllStripes to create a research database that will power multiple NPC research studies. The first study will explore early diagnosis and intervention. We hope to use the data to advocate for adding NPC to newborn screening programs.

To move this research forward, we are looking for families of 40 sibling pairs with NPC willing to contribute their de-identified medical records. All data shared with researchers is de-identified, or anonymized, meaning no identifying information like name or phone number is shared.

Should you choose to participate, you'll be able to learn from the experiences of other families, receive research updates and access all your medical records in a secure AllStripes account. AllStripes does the work to collect all your medical records on your behalf, at no cost. Their goal is to remove the burden and expense of requesting these medical records on your own.

How it works



Sign up: Create your secure AllStripes account and review the research consent (takes about 10-20 minutes) at allstripes.com/npc



AllStripes gets to work: They do all the behind-the-scenes work to collect and process your records



Empower research: Track your contribution to research projects and receive updates on research outcomes

A note for legacy families

Families who have lost children to NPC can participate in this study. Contributing records on behalf of a loved one who has passed away can create a meaningful legacy and provide valuable information to improve the lives of patients and their families for generations to come.

When signing up for AllStripes, the support team may need additional documentation to obtain your loved one's medical records on your behalf. While exact documentation requirements will vary across the U.S., Canada and the U.K., in many cases a death certificate and/or a power of attorney or similar documentation is required.

We encourage those who are legally eligible and interested in donating their loved one's legacy medical records to begin the sign-up process, and upload the documentation if possible. The AllStripes team will reach out if any additional information is required. Questions can be directed to support@allstripes.com

To learn more or sign up, visit: allstripes.com/npc