

Listing Information for NNPdf Care Clinics Webpage

| Name of Clinic: | | | |
|---|---|------------|--|
| City and State: | | | |
| Type of Clinic: | <input type="checkbox"/> Academic Center <input type="checkbox"/> Private Practice | | |
| Population Age: | <input type="checkbox"/> Pediatric <input type="checkbox"/> Adult <input type="checkbox"/> Both | | |
| Clinical Coordinator/Main Contact: | | | |
| Title: | | | |
| Email: | | Phone: | |
| Appointment Line: | | Website: | |
| Number of NPC patients: | | | |
| Average time for new patients to be seen: | | | |
| Specialists/consultants with expertise in managing patients with NPC: | | | |
| <input type="checkbox"/> Gastroenterologist <input type="checkbox"/> Neurologist <input type="checkbox"/> Registered Dietitian Nutritionist <input type="checkbox"/> Hematologist <input type="checkbox"/> Psychiatrist <input type="checkbox"/> Social Worker <input type="checkbox"/> Genetic Counselor <input type="checkbox"/> Pulmonologist <input type="checkbox"/> Speech-Language Pathologist | | | |
| Please list the name, title, and specialty of all providers who provide clinical care with NPC patients below. Would like this information included in your listing? <input type="checkbox"/> Yes <input type="checkbox"/> No | | | |
| NAME: | TITLE: | SPECIALTY: | |
| | | | |
| | | | |
| | | | |
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Additional Information:

Do you provide any NPC-specific educational materials to patients and their families, or direct them to specific websites for disease-related information?

☐ No ☐ Yes *If yes, please describe:*

Has a member of your clinic ever attended an NNPDF Family Support & Medical Conference or patient education and support webinar?

☐ No ☐ Yes *If yes, please describe:*

Has a member of your clinic ever presented at a scientific meeting on NPC?

☐ No ☐ Yes *If yes, please describe:*

Does your clinic participate in the International Niemann-Pick Disease Registry (INPDR)?

☐ Yes ☐ No

Does your clinic incorporate the International Niemann-Pick Disease Alliance (INPDA) published guidelines on the diagnosis and management of NPC into practice?

☐ Yes ☐ No

Has your clinic conducted any recent Niemann-Pick type C clinical research or supported an Expanded Access Program (EAP) for NPC patients?

☐ No ☐ Yes *If yes, please describe:*

Please submit your completed form via email to nnpdf@nnpdf.org

For more information on the National Niemann-Pick Disease Foundation, Niemann-Pick type C, INPDR, or published NPC guidelines visit nnpdf.org