



Care Clinic Application | ASMD

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 ASMD patients:			
Average time for new patients to be seen:			
Specialists/consultants with expertise in managing patients with ASMD:			
<input type="checkbox"/> Cardiologist		<input type="checkbox"/> Neurologist	<input type="checkbox"/> Social Worker
<input type="checkbox"/> Gastroenterologist		<input type="checkbox"/> Psychiatrist	<input type="checkbox"/> Speech-Language Pathologist
<input type="checkbox"/> Genetic Counselor		<input type="checkbox"/> Pulmonologist	
<input type="checkbox"/> Hematologist		<input type="checkbox"/> Registered Dietitian Nutritionist	
Please list the name, title, and specialty of all providers who provide clinical care with ASMD patients below.			
Would like this information included in your listing? <input type="checkbox"/> Yes <input type="checkbox"/> No			
NAME:	TITLE:	SPECIALTY:	

Additional Information:

Do you provide any ASMD-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 ASMD?

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 ASMD into practice?

Yes No

Has your clinic conducted any recent Acid Sphingomyelinase Deficiency (ASMD) clinical research or supported an Expanded Access Program (EAP) for ASMD 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, Acid Sphingomyelinase Deficiency (ASMD), INPDR, or published ASMD guidelines visit nnpdf.org