



NF Clinic Network (NFCN) Application Form*

Clinic Name:

The Neurofibromatosis Center of New Jersey

Affiliated Hospital:

University Hospital

Affiliated University or Institution:

University of Medicine and Dentistry of New Jersey

Clinic Address:

Doctor's Office Center
Suite 8100
90 Bergen Street
Newark, NJ 07103-2499

Clinic Director:

Beth Pletcher, MD

Clinic Coordinator Name:

Kayon T. Williams, MS, CGC

**Note: Some non-public information has been removed from this application form.*



The Neurofibromatosis Clinic Network (NFCN)

FORM PART A: Affiliate Clinic Application

1. ABOUT YOUR NF CLINIC

a. Is your NF Clinic:

- Freestanding
- Hospital based
- In an academic center
- Other (please describe)

b. Describe overall your NF Clinic, when it meets and how it functions.

The Neurofibromatosis Center of New Jersey is housed in the Neurologic Institute of New Jersey in the Doctor's Office Center. University Hospital is a teaching hospital for the University of Medicine and Dentistry - New Jersey Medical School. Clinic days are on Mondays. Both pediatric and

adult patients are seen in our NF Center. The pediatric and adult patients are seen on alternating Mondays. During the clinic a neurology consultation occurs concomitantly with the general NF evaluation. We have both pediatric and adult UMDNJ neurologists who are committed to seeing our patients on a regular basis, during their NF appointments. An ABGC board certified genetic counselor is also active within the NF clinic, and is present on clinic days. The Neurofibromatosis Center of New Jersey follows over 400 patients in the tri-state area with NF (both NF1 and NF2), as well as patients with other neurogenetic conditions. As such, we are a very busy clinic and appointments are generally made approximately 3-4 months in advance; however, we are easily accessible to patients who need appointments more urgently. In addition, the clinic director and genetic counselor are directly available by telephone to all NF patients.

2. CLINIC DIRECTOR and STAFF EXPERTISE

a. CLINIC DIRECTOR: Please describe:

i. Your experience to date with NF care

→ Dr. Pletcher has been involved in the care of patients with neurofibromatosis and other neurogenetic conditions since completing her fellowship in human genetics at Yale University School of Medicine in 1987. Upon arrival at North Shore University Hospital in Manhasset Long Island, she put together a multidisciplinary team of specialists devoted to the care of patients with NF. In this center many children as well as adults were seen by Dr. Pletcher, a genetic counselor, one of the neurologists on staff, and an ophthalmologist familiar with NF. Other subspecialists were involved as needed. The center was devoted to patient support as well, with one of the social workers in the genetic center organizing and leading the local NF support group which held evening meetings around the area. When Dr. Pletcher came to New Jersey in 1993, she put together The Neurofibromatosis Center of New Jersey with the help of many other specialists and subspecialists on campus. The center has grown and thrived, with more than 450 individual patients seen since its inception, providing state of the art multidisciplinary care and management of patients.

ii. Your past and current association with NF clinical trials

→ While not an official site for clinical trials, over the years Dr. Pletcher has referred patients to various trials as indicated for treatment of optic nerve gliomas and plexiform neurofibromas.

iii. Your past and current association with other clinical trials e.g. oncology trials

→ As above.

b. CLINIC DIRECTOR: Please provide information on:

- i. Present and past funding you have received for NF research. Include funding source, date received, amount and project description.

→ No funding has been sought or provided for NF Center.

- ii. Your NF-related clinical and scientific publications. Include Journal, Citation and Title.

1. Dorschner MO, Sybert VP, Weaver M, Pletcher BA and Stephens K: "NF1 microdeletion breakpoints are clustered at flanking repetitive sequences", Human Molecular Genetics 9:35-46, 2000.
2. Pletcher BA: "Neurofibromatosis" Pediatrics: An Online Medical Reference. 1st Edition. St. Petersburg. *Emedicine Online Textbooks*. Eds. Steven Altschuler et al. 2000. Emedicine.com, Inc. (Chapter revised January 6, 2006)
3. Pletcher BA: "Neurofibromatosis, Type 1" Neurology: An Online Medical Reference. 1st Edition. St. Petersburg. *Emedicine Online Textbooks*. Eds. Nicholas Lorenzo et al. 2001. Emedicine.com, Inc. (Chapter revised January 4, 2006)
4. Pletcher BA: "Neurofibromatosis, Type 2" Neurology: An Online Medical Reference. 1st Edition. St. Petersburg. *Emedicine Online Textbooks*. Eds. Nicholas Lorenzo et al. 2001. Emedicine.com, Inc. (Chapter revised January 4, 2006)
5. Pletcher BA, Magee MI, Frohman LP, Wagner RS, DeRespini P, Kamin S and Chatkupt S: "Confirmation of decreased risk of optic glioma in African Americans with NF type I", American Journal of Human Genetics 59(4):A101, 1996.*
6. Committee on Genetics: "Health supervision for children with neurofibromatosis", Pediatrics 96(2):368-372, 1995.

c. Who are the key staff in your NF clinic facility?

Provide Name; Title; Degree/Qualifications; Role in Clinic.

Beth A. Pletcher; Co-Director; MD, FAAP, FACMG; Clinical Geneticist, Pediatrician

Stephen S. Kamin; Co-Director; MD; Adult Neurology

Allen H. Maniker; Co-Director; MD; Neurosurgery, Specialist in peripheral nerve surgery.

Kayon T. Williams; Genetic Counselor & Clinic Coordinator; MS, CGC; Genetic Counselor.

Nicole Burns; Scheduling & Clinic Coordinator; Scheduler.

- d. Who within this core staff currently coordinates NF patient services? Describe this individual's NF clinic related duties.

→ Kayon Williams provides clinical genetic counseling for the NF Center and acts as a liaison for patient and family concerns and follow-up.

→ Nicole Burns schedules patient appointments.

- e. Describe any areas of NF care in which your clinic has particular expertise (e.g. optic glioma, vestibular schwannoma, bone manifestations, learning disabilities etc.) and the clinic staff that provide this care.

→ Our neuroophthalmologists, ophthalmologists, neurologists, neurosurgeons, orthopedists, otolaryngologists and other providers are familiar with the special medical needs of patients with NF because of our vast experience caring for these patients. This is truly a team effort, with patients now being seen in the Neurological Institute of New Jersey in the Doctor's Office Center and with the addition of Co-Directors, Dr. Allen Maniker from Neurosurgery and Dr. Stephen Kamin from Neurology. Most of the patients seen in the NF Center are evaluated by both the geneticist (Dr. Pletcher) and one of the neurologists (Dr. Kamin for adults and Dr. Hayes-Rosen for children and teens). New patients are seen and evaluated by our genetic counselor, Ms. Kayon Williams, MS, CGC.

Dr. Paul Langer is an expert in oculoplastics and has cared for many of our patients with periorbital plexiform neurofibromas over the years.

Dr. Larry Frohman and Dr. Roger Turbin in neuroophthalmology provide ongoing subspecialty care for our NF patients, with an excellent retinal service available on an as needed basis. Dr.

Rudolph Wagner provides pediatric ophthalmology expertise; he has seen the vast majority of our pediatric NF patients over the years.

Dr. Robert Heary and Dr. Sanjeev Sabharwal are our adult spinal surgeon and pediatric orthopedist respectively; they have operated on many of our NF patients with progressive scoliosis and kyphoscoliosis in the past 10 years. They are well aware of the unique bony issues encountered by patients with NF and are able to adjust their surgical approaches accordingly.

Dr. Joseph Benevenia and Dr. Francis Patterson are two of our orthopedic oncologists who continue to ably care for our NF patients with pseudarthrosis and other bony lesions. Recent surgeries have included resection of MPNSTs and debulking of large plexiform neurofibromas.

Dr. Soly Baredes, Chief of Head and Neck Surgery, has extensive experience with skull base surgery and has cared for quite a few of our NF patients.

Dr. Mark Granick and Dr. Samuel Rhee from plastic surgery have been very involved in resecting cosmetically problematic neurofibromas as well.

Pediatric patients with brain tumors or optic nerve gliomas are referred for chemotherapy to other centers with pediatric expertise, but they are able to receive radiation therapy here at our center. Adult patients with CNS lesions can receive all of their oncology care here onsite.

Our experienced pediatric and adult neurosurgeons are able to address any NF patient needs. A number of patients with NF2 have had resection of vestibular schwannomas through both traditional surgical approaches as well as with stereotactic radiosurgery over the years. Other neurosurgeons in our center have special expertise in resection of spinal cord tumors with excellent outcomes for many NF patients.

Our pediatric neurologist, Dr. Caroline Hayes-Rosen, has expertise in developmental issues as well, and provides advice to parents on EIP evaluations and school issues including child study team evaluations. She also will prescribe medications such as psychostimulants as indicated with very close follow-up with parents to assess efficacy and tolerability.

Child development specialists and psychiatrists are available as needed for patients, although often psychiatric services may require referral to a local center for ongoing therapy.

3. PATIENT SCHEDULING and REFERRALS

- a. Provide the details of the 'typical' timeframe in which patients receive a response to a request for scheduling, are actually scheduled for an appointment, how patients are prioritized, etc.

→ Patients are contacted with an appointment date within 24-48 hours of appointment request. The average appointment is booked approximately 2-3 months in advance. Patients with pressing medical concerns are reviewed with Dr. Pletcher and scheduled appropriately.

- b. Provide details of those specialists to whom (either within or outside our own clinic facility) your clinic refers NF patients for the following specialty care. **These should individuals familiar and experienced with consensus guidelines for care of individuals with NF** (Please provide information for PEDIATRIC CARE referrals in the first table and ADULT CARE in the second table).

PEDIATRIC CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Beth A. Pletcher, MD Kayon Williams, MS, Genetic Counselor	90 Bergen St, Suite 5400, Newark, NJ	(973) 972-3300	pletchba@umdnj.edu williakt@umdnj.edu
Neurology	Caroline Hayes-Rosen, MD	90 Bergen St, Suite 8100, Newark, NJ	(973) 972-2550	hayesrca@umdnj.edu
Orthopedics	S. Sabharwal, MD	90 Bergen St, Suite 7300, Newark, NJ	(973) 972-0246	sabharsa@umdnj.edu
Developmental pediatrics/learning disabilities	Caroline Hayes-Rosen, MD	90 Bergen St, Suite 8100, Newark, NJ	(973) 972-2550	hayesrca@umdnj.edu
Ophthalmology	R. Wagner, MD	90 Bergen St, Suite 6100, Newark, NJ	(973)972-2065	wagnerrrs@umdnj.edu
Neurosurgery	P. Carmel, MD J. Catrambone, MD	90 Bergen St, Suite 8100, Newark, NJ	(973) 972-2550 (973)972-1164	carmel@umdnj.edu catramje@umdnj.edu
Plastic surgery	P. Langer, MD	90 Bergen St, Suite 6100, Newark, NJ	(973) 972-2065	planger@umdnj.edu
Neurooncology				

Medical Oncology/Radiation Oncology				
Endocrinology				
Audiology/ENT	H. Quraishi, MD	90 Bergen St, Suite 8100, Newark, NJ	(973) 972-8906	quraisha@umdnj.edu
Radiology/Neuroradiology				
General Surgery/Surgical Oncology	A. Maniker, MD	90 Bergen St, Suite 8100, Newark, NJ	(973) 972-2908	maniker@umdnj.edu
Dermatology	L. Stolman, MD	290 S. Livingston Ave. Livingston, NJ 07039	(973) 740-0101	
Cardiovascular Disease				
Oral and Maxillofacial Surgery	S. Baredes, MD E. Cohen, MD	90 Bergen St, Suite 8100, Newark, NJ	(973) 972-4588	baredeso@umdnj.edu
	R. Turbin, MD	90 Bergen St, Suite 6100, Newark, NJ	(973) 972-2209	turbinre@umdnj.edu
Behavioral Issues	Caroline Hayes-Rosen, MD	90 Bergen St, Suite 8100, Newark, NJ	(973) 972-2550	hayesrca@umdnj.edu

ADULT CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Beth A. Pletcher, MD Kayon Williams, MS	90 Bergen St, Suite 5400, Newark, NJ	(973) 972-3300	pletchba@umdnj.edu williakt@umdnj.edu
Neurology	Stephen S. Kamin, MD (Adult)	90 Bergen St, Suite 8100, Newark, NJ	(973) 972-2550	kamin@umdnj.edu
Orthopedics				

Developmental pediatrics/learning disabilities				
Ophthalmology	R. Turbin, MD L. Frohmann, MD	90 Bergen St, Suite 6100, Newark, NJ	(973) 972-2209	turbinre@umdnj.edu
Neurosurgery	A. Maniker, MD	90 Bergen St, Suite 8100, Newark, NJ	(973) 972-2908	manider@umdnj.edu
	R. Turbin, MD	90 Bergen St, Suite 6100, Newark, NJ	(973) 972-2209	turbinre@umdnj.edu
Plastic surgery	P. Langer, MD	90 Bergen St, Suite 6100, Newark, NJ	(973) 972-2035	planger@umdnj.edu
Neurooncology				
Medical Oncology/Radiation Oncology				
Endocrinology				
Audiology/ENT				
Radiology/Neuroradiology				
General Surgery/Surgical Oncology	S. Baredes, MD	90 Bergen St, Suite 8100, Newark, NJ	(973) 972-4588	baredeso@umdnj.edu
Dermatology	L. Stolman, MD	290 S. Livingston Ave. Livingston, NJ 07039	(973) 740-0101	
Cardiovascular Disease				
Oral and Maxillofacial Surgery	S. Baredes, MD	90 Bergen St, Suite 8100, Newark, NJ	(973) 972-4588	baredeso@umdnj.edu
	E. Cohen, MD			
Behavioral Issues				

4. NUMBER OF NF PATIENTS YOUR CLINIC SEES

- a. How many NF PATIENTS did you see in the past 12 months?
- b. How many of these were **NEW** patients to your clinic?

Insert numbers below

	NF1	NF2	SCHWANNOMATOSIS	OTHER (neurologic)
NUMBER OF (follow-up) PATIENTS SEEN IN PAST 12 MONTHS	37	3	0	3
NUMBER OF NEW PATIENTS SEEN IN PAST 12 MONTHS	48	3	0	1
TOTAL	85	6	0	4

c. Overall what proportion of patients seen in the past year were (give finite numbers if these are available, or estimate percentage):

Under 18 = 63 18+ = 32 (give numbers - if data available)

OR estimate

Under 18 (%) 18+ (%)

5. TRANSITIONING PEDIATRIC TO ADULT NF CARE

How does your clinic facilitate continuity of care for patients transiting from pediatric to adult care?

→ Both pediatric and adult subspecialists are members of the NF care team.

Explain how continuity of care is accomplished. Describe those partnering clinics with which you coordinate services, and explain any limitations:

→ We have a single chart in which all reports are kept from various specialists as well as any imaging studies and outside reports.

6. INTERNAL CONFERENCES

Provide details on internal conferences in your institution which are related to NF patient care in your clinic (e.g. NF Clinic case management conference, etc.)

→ We have weekly conferences on Friday afternoon to discuss interesting cases.

7. CLINICAL TRIALS

Our clinic is willing and able to provide our NF patients with information on, and to facilitate their participation in, clinical trials for which NF patients are eligible (check box)

Yes No

If 'no', briefly describe why.

Do you currently refer patients to clinical trials?

Yes No

If 'yes', provide details of current clinical trial protocols in which you currently or have had patients involved in the past 5 years.

→ The plexiform neurofibroma treatment trial has been discussed with 5 patients; however, those patients did not meet inclusion criteria.

8. PATIENT REGISTRY

Do you currently have an NF specific patient database/registry?

Yes No

If 'yes', please describe.

→ We have a patient log which consists of thorough patient information including demographics and a list of medical problems. A formal problem list is maintained for patients with more involved medical problems.

Would you be willing to transfer this data to a centralized CTF NF Database?

Yes No

If 'no', explain your limitations.

9. PUBLICATIONS and RESEARCH (IF APPLICABLE)

- a. Please list any relevant NF publications from your clinic in the past 5 years. Include Journal, Citation and Title.

Pletcher BA: "Neurofibromatosis" Pediatrics: An Online Medical Reference. 1st Edition. St. Petersburg. *Emedicine Online Textbooks*. Eds. Steven Altschuler et al. 2000. Emedicine.com, Inc. (Chapter revised January 6, 2006)

Pletcher BA: "Neurofibromatosis, Type 1" Neurology: An Online Medical Reference. 1st Edition. St. Petersburg. *Emedicine Online Textbooks*. Eds. Nicholas Lorenzo et al. 2001. Emedicine.com, Inc. (Chapter revised January 4, 2006)

Pletcher BA: "Neurofibromatosis, Type 2" Neurology: An Online Medical Reference. 1st Edition. St. Petersburg. *Emedicine Online Textbooks*. Eds. Nicholas Lorenzo et al. 2001. Emedicine.com, Inc. (Chapter revised January 4, 2006)

- b. Please provide information on NF-related research ongoing in your clinic or performed by personnel affiliated with your clinic.

→ We are discussing with our radiology department the possibility of starting a project to examine functional MRI in patients with mental retardation.

10. PATIENT SUPPORT

Do you have an NF patient support group that meets in association with your NF Clinic?

→ No.

If 'yes' provide details.

If 'no', are you interested in starting such a group?

→ Yes. If there is sufficient desire expressed by our patient population.

What resources would help you to do this?

→ Financial support would be helpful to pay for mailings, marketing and maintenance of the group.

11. OTHER INFORMATION

Please provide any additional information that is pertinent to your request to join the CTF NF Clinic Network.