



NF Clinic Network (NFCN) Application Form*

Clinic Name:

Neurofibromatosis Clinic

Affiliated Hospital:

New York-Presbyterian Hospital and St. Luke's/Roosevelt Hospital

Affiliated University or Institution:

Columbia University

Clinic Address:

New York-Presbyterian Hospital and St. Luke's/Roosevelt Hospital
3959 Broadway BHN-601A
New York, NY 10032

Clinic Director:

Wendy Chung, MD, Ph.D.

Clinic Coordinator Name:

Anita Shanmugham

**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.

We evaluate pediatric and adult NF patients in the Division of Clinical Genetics located on the 6th floor of the Children's Hospital of New York (CHONY). CHONY is the largest children's hospital in the tri-state region and has the benefit of dedicated services within the children's hospital as well as being physically contiguous with facilities for adults. Newly referred patients are scheduled for appointments within 24 hours of calling. The secretarial staff collect demographic information from patients and the indication for referral. For all of our cancer patients, a senior genetic

counselor is given the referral and personally speaks with the patient or family to collect additional information about the clinical situation, urgency of evaluation, family history, and needs for referral to multiple specialists. We have genetic counselors and secretarial staff whose native language is either English or Spanish and hospital provided or telephone translation is available for all other languages. New patients are mailed and asked to complete a medical questionnaire (in English or Spanish) prior to their appointment. Pertinent information including birth history and developmental history as well as results of evaluations by other specialists are summarized in the questionnaire. Medical records including pathology results, genetic testing results, and medical consultations are requested prior to the appointment. The patient's case is then reviewed in conference by the NF genetic team prior to the first appointment. At the first visit, a complete evaluation is performed including a review of the questionnaire, detailed medical and family history, and physical examination and discussion with one of the two attending clinical geneticists, Drs. Kwame Anyane-Yeboah or Dr. Wendy Chung. Dr. Anyane-Yeboah has been in clinical practice for over 25 years. Dr. Chung is a clinical and molecular geneticist and supervises the cancer genetic program. If necessary, genetic testing for NF1 or NF2 is performed during the initial visit. Genetic counseling is provided to discuss recurrence risks and reproductive options including pre-implantation diagnosis (PGD). All reproductive planning is coordinated centrally through the clinical genetics offices.

Depending on the needs of the patient and the clinical assessment after the initial visit, the genetic counselor coordinates any necessary imaging studies (MRI, CT, ultrasound, Xrays), audiologic testing, blood tests developmental assessments and referrals to NF specialists affiliated with our clinic. When possible, tests and visits with other specialists are coordinated for the same day to limit the number of visits to the medical center. Referrals are made most commonly to ENT, neurology, endocrinology, hematology, ophthalmology, developmental pediatricians and surgeons.

We provide a comprehensive consultation note to each physician caring for the patient and to the referring physician, to coordinate the patient's care. The genetic counselor coordinates annual routine follow up and annual surveillance testing and is available on an ad hoc basis to coordinate care when new issues arise.

2. CLINIC DIRECTOR and STAFF EXPERTISE

a. CLINIC DIRECTOR: Please describe:

i. Your experience to date with NF care

As director of the cancer genetics program, I follow approximately 2500 patients at increased risk of cancer and have specialized clinical care programs for von Hippel Lindau syndrome and Cowden syndrome that are recognized by patient support groups.

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

Currently there are 8 genetic counselors who could participate in the care of NF patients. With the Foundation's support we will consolidate all the NF patients with a single genetic counselor who will act as the NF clinical care coordinator. Currently counselors collect medical records from patients, provide genetic counseling, and coordinate referrals for patients for any necessary testing/referrals to specialists.

- 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.

Due to our strength in child neurology and in conjunction with the Neurological Institute at Columbia University, we have special expertise in the neurocognitive issues and learning disabilities and teams of pediatric psychologists, some affiliated with Columbia's Teacher's College, able to perform in depth psychological evaluations to assist patients with appropriate individual educational programs.

We have developed extremely sensitive methods to diagnose copy number variations and have diagnosed patients with large deletions in NF1 using oligonucleotide array comparative genomic hybridization. We are particularly interested in this subset of patients with NF1 deletions and, with the development of a national NF1 registry, would like to better characterize these patients both in terms of molecular genetics and phenotypic manifestations.

We have extensive expertise in serving as the molecular genetics core for several multicenter studies including the pediatric heart network and the pediatric neuromuscular clinical research group. We would like to begin to establish a biorepository tied to our clinical database that could be used to molecularly characterize NF1 and NF2 mutations, determine modifiers of NF1 and NF2, bank longitudinal blood samples for future exploration of biomarkers, bank flash frozen tumor and control normal tissue for studies of gene expression and immunohistochemistry, and create NF cell lines that could be used for in vitro preclinical studies for future drug trials.

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 speak with a secretary within 24 hours of calling our office at which time demographic information and reason for referral are determined. If the patient is calling for a routine visit, the appointment is then immediately scheduled. If this is a new referral, a genetic counselor then calls the patient/family to determine the needs of the patient and discusses the case with an attending physician. For non-urgent appointments, the patient is seen within 4 weeks. For urgent appointments, the attending physician calls the patient/family and arranges all the necessary testing and referrals to specialists within the week. We also have a long-standing policy of providing genetic services to patients and accept Medicaid, Medicare and most insurance.

- 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	Dr. Wendy Chung	CHN 6-601A 3959 Broadway	212-305-6731	wkc15@columbia.edu
	Dr. Kwame Yeboa	CHN 6-601A 3959 Broadway	212-305-6731	ka8@columbia.edu
Neurology	Dr. Claudia Chiriboga	Harkness 552	212-305-8549	cac3@columbia.edu
Orthopedics	Dr. Joshua Hyman	CH8N	212-305-5475	Jh736@columbia.edu
Developmental pediatrics/learning disabilities	Dr. Harriet McGurk	PH5 East - Rm517	212-305-9862	hem2@columbia.edu
Ophthalmology	Dr. Steven Kane	Eye Institute	212-927-8722	sak6@columbia.edu
Neurosurgery	Dr. Neil Feldstein	Neurological Institute Unit 159	212-305-1396	naf6@columbia.edu
	Dr. Richard Anderson	Neurological Institute 2nd Floor, Room 213	212-305-0219	rca24@columbia.edu
Plastic surgery	Dr. Jeffrey Ascherman	161 Ft Washington Ave Atchley Pavilion- Rm 607	212-305-9612	jaa7@columbai.edu
Neurooncology	Dr. Casilda Balmaceda	710 W 168 St	212-305-4572	cb116@columbia.edu
Medical Oncology/Radiation Oncology	Dr. James Garvin	Irving Pavilion 7- 708	212-305-5872	jhg1@columbia.edu

Endocrinology	Dr. Sharon Oberfield	PH 5 East Room 520	212-305-6559	seo8@columbia.edu
Audiology/ENT	Dr. Joseph Haddad	Babies Hosp North 3959 Broadway Rm 501-N	212-305-6559	jh56@columbia.edu
	Dr. Eli Grunstein	Babies 506N	212-305-8933	eg582@columbia.edu
Radiology/ Neuroradiology	Dr. Carrie Ruzal-Shapiro	Dept Of Radiology BHN-3-331	212-305-3320	cbr1@columbia.edu
General Surgery/Surgical Oncology	Dr. Charles Stolar	BHN 2-212	212-305-2305	cjs3@columbia.edu
Dermatology	Dr. Maria Garzon	HIP 12 FI	212-305-9551	mcg2@columbia.edu
Cardiovascular Disease	Dr. Daphne Hsu	CHONY 221 North 3959 Broadway	212-342-1560	dh17@columbia.edu
Oral and Maxillofacial Surgery	Dr. Sidney Eisig	Physicians & Surgeons Dental Clinic	212-305-7626	sbe2002@columbia.edu
Behavioral Issues	Dr. Charles Kaufman	NYSPI-Unit 6 1051 Riverside Drive	914-238-7909	cak2@columbia.edu

ADULT CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Dr. Wendy Chung	CHN 6-601A 3959 Broadway	212-305-6731	wkc15@columbia.edu
	Dr. Kwame Anyane-Yeboah	CHN 6-601A 3959 Broadway	212-305-6731	ka8@columbia.edu
Neurology	Dr. Michio Hirano	Neurology Dept, P&S 4-443 630 W 168 St	212-305-1048	mh29@columbia.edu
Orthopedics	Dr. Theodore Blaine	PH 11-1118	212-305-4037	tb211@columbia.edu
Developmental pediatrics/learning disabilities	N/A			
Ophthalmology	Dr. Stephen Tsang	Edward S. Harkness Eye Institute Research Addition 160 Fort Washington Avenue, Room 513	212-342-1189	sht2@columbia.edu
Neurosurgery	Dr. Michael Sisti	The Neurological	212-305-1728	mbs4@columbia.edu

	Dr. Peter Angevine	Inst Rm 414 Neurological Institute Spine Center, Room 510	212-305-1550	pda4@columbia.edu
Plastic surgery	Dr. Jeffrey Ascherman	161 Ft Washington Ave Atchley Pavilion- Rm 607	212-305-9612	jaa7@columbai.edu
Neurooncology	Dr. Steven Rosenfeld	Neurological Institute Mail Code: 2	212-305-2700	sr2327@columbia.edu
Medical Oncology/Radiation Oncology	Dr. Robert Taub	Irving Pav(Atchley Pav) 9 Flr	(212) 305-4076	rnt1@columbia.edu
Endocrinology	Dr. Thomas Jacobs	Atchley Pavillion Rm 210	(212) 305-5578	tpj1@columbia.edu
Audiology/ENT	Dr. Ian Storpor	HIP 7th floor	(212) 305-1906	iss9@columbia.edu
Radiology/ Neuroradiology	Dr. Robert DeLaPaz	Mhb-3-111- Neuro 177 Fort Washington Avenue	(212) 305-9820	rld17@columbia.edu
General Surgery/Surgical Oncology	Dr. Zachary Gleit	Allen Pavilion 3 Fe 3-170	(212) 305-0319	zlg1@columbia.edu
Dermatology	Dr. Julide Celebi	HIP12	(212)305-5293	jt165@columbia.edu
Cardiovascular Disease	Dr. Marlon Rosenbaum Dr. Deborah Gersony	Cardiology Atchley Pavilion 540 Presbyterian Hospital 3-347	212-305-6936 212-305-0629	msr5@columbia.edu drg5@columbia.edu
Oral and Maxillofacial Surgery	Dr. Sidney Eisig	Physicians & Surgeons Dental Clinic	212-305-7626	sbe2002@columbia.edu
Behavioral Issues	Dr. Laurence Greenhill	Nyspi-Unit 78	(212)305-6001	llg2@columbia.edu

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
NUMBER OF PATIENTS SEEN IN PAST 12 MONTHS	63	1	0	
NUMBER OF <u>NEW</u> PATIENTS SEEN IN PAST 12 MONTHS	44	0	0	
TOTAL	63	1	0	

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

Under 18 _____ 18+ _____ (give numbers - if data available)

OR estimate

Under 18 (%) 85% 18+ 15%

5. TRANSITIONING PEDIATRIC TO ADULT NF CARE

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

The clinical genetics and genetic counselors serving the children and adults are the same. Therefore, the clinical genetics unit provides the continuity of care as patients transition their care. We have specifically chosen pediatric and adult colleagues within each speciality that work well together, and when

necessary transfer copies of medical records, films, and test results from the pediatric to the adult counterpart. This concept is not unique to neurofibromatosis, and we have experience providing continuity of care for pediatric oncology, cystic fibrosis, congenital heart disease, and muscular dystrophy patients and have a large network of excellent clinicians within the NYPH-CUMC system that facilitate transition of care.

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

As the care coordinators for many of the NF patients, we transition patients from pediatric to adult specialists between the ages of 18-25. We assess the clinical needs of the patient and with the assistance of their current specialists refer the patient to adult specialists. We gather the necessary medical records and ensure that the new adult medical team has the annual summary reports of the patient's care as well as relevant records from the corresponding pediatric specialist.

Because Morgan Stanley Children's Hospital is part of the New York-Presbyterian Hospital, our pediatric and adult physicians practice within the same medical center and share hospital information systems, increasing the convenience for our NF families who have come to CHONY for most of their lives.

For adult women patients, we have a team of maternal fetal medicine specialists available to manage any high risk pregnancies. We also have OB/GYNs available for routine gynecologic issues.

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 case conferences each Monday during which all the clinical geneticists, residents, fellows, and genetic counselors review and manage cases. Each week we have three conferences: didactic lectures for trainees, laboratory diagnostic review, and lecture series. Although the above conferences are not focused solely on NF, they serve a useful forum to discuss NF patients and get input from multiple clinicians.

We have ad hoc case management conferences and multidisciplinary family meetings to discuss difficult cases that require care coordination between services or for which there are multiple choices for management that require careful consideration by the patient/family. For less complex issues that simply require coordination between services, all of the clinicians communicate extremely effectively by email identifying patients only by medical record numbers and initials.

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.

8. PATIENT REGISTRY

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

Yes No

If 'yes', please describe.

We have a database of patient names, date of birth, gender, address, telephone number, referring physician, diagnosis and dates of visit.

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

Yes No

We would be willing to transfer either de-identified data or identified data if patients sign a release after we have received permission from the Columbia Institutional Review Board.

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.

N/A

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

We have developed robust methods to characterize genomic copy number variants and have developed a targeted oligonucleotide array for comparative genomic hybridization capable of detecting and defining deletions causing NF1. We are interested in using this technique to genetically characterize additional patients with deletions of NF1 or to test what percentage of patients with a clinical diagnosis of NF1 without mutations detected by sequencing have deletions of NF1.

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
What resources would help you to do this?

We currently do not have a NF patient support group. However, we would be interested in starting such a group and have a similar support group for our von Hippel Lindau program after which we would model the NF support group and would likely have meeting for patients (stratified by age) and families. We would have some educational sessions provided by physicians, sessions on resources available provided by the clinical coordinator, and sessions on how to deal with chronic medical issues and wellness provided by social workers.

11. OTHER INFORMATION

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

Columbia University has an In Vitro Fertilization Program located in the Center for Women's Reproductive Care. The program has an interdisciplinary team in which we are intimately involved in facilitating the use of pre-implantation genetic diagnosis when appropriate. We assist with providing the necessary molecular genetic diagnosis to allow for development of the necessary PGD assay, work closely with Dr. Mark Hughes to transfer the molecular assays to the PGD laboratory, coordinate evaluation and consultation with Dr. Mark Sauer in our IVF center, and coordinate confirmation of the PGD with prenatal testing.

Our Division of Clinical Genetics staff strives to provide ongoing care for patients with genetic conditions, coordinate multidisciplinary care for patients and be more sensitive and responsive to the issues facing patients' families and support network.

Being recognized as a NFCN Affiliate Clinic and having the opportunity to collaborate with other NFCN Affiliate Clinics nationwide, we will ensure that each of our NF patients receives the highest level of quality care by helping them access resources related to their condition and identify research studies for which they qualify, to understand their condition better, and provide additional therapeutic options. We believe in providing the care for today and the cure for tomorrow.