



## **NF Clinic Network (NFCN) Application Form\***

**Clinic Name:**

NYU Medical Center NF Clinic

**Affiliated Hospital:**

NYU Medical Center

**Affiliated University or Institution:**

New York University

**Clinic Address:**

Hassenfield Clinic  
160 East 32<sup>nd</sup> Street, 2<sup>nd</sup> Floor (L3)  
New York, NY 10016

**Clinic Director:**

Jeffrey C. Allen, MD

**Clinic Coordinator Name:**

TBD

*\*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.

Programmatic Goals: NYU Medical Center has a long history of providing specialty care to patients with both NF 1 and NF-2. Our goal regarding response to this application from the CTF is to develop a more comprehensive, better organized program for pediatric and adult patients with both NF1 and NF2. To accomplish this, we propose forming a triage team to assess all new patients. This team will formulate an individualized treatment plan, supervise referrals to specialists and be available for follow-up evaluations. To accomplish this goal, we will endeavor to acquire institutional support, raise funds from both internal and external sources and hire a dedicated NF work force consisting of a family NP, attending physician (neurologist or geneticist), social worker, neuropsychologist, part time office manager and data manager.

Operating Procedure: New patients will be seen on a weekly basis in our NF Triage Clinic. After making initial contact, the patient and family will be asked to complete an extensive questionnaire including personal and family history and prior therapy. At their first encounter in our NF Triage clinic, the patient will be seen by the NP (presently Erin Hartnett, PNP) who will review the medical history and perform a general physical exam. Following obtaining informed consent, a blood sample may be requested for diagnostic testing and tissue banking. Thereafter, the attending neurologist (Jeffrey Allen, MD) or geneticist (John Pappas, MD) will perform a more focused examination based on the patient's chief complaints. All suspected NF2 patients will also be evaluated by a neurotologist and a neurosurgeon. The patient will have access to our patient library services and receive printed material relevant to their condition. Thereafter, the patient and family will be offered the opportunity to meet with the social worker and neuropsychologist. An

educational history will be obtained, especially regarding potential or previously diagnosed learning or behavioral deficits.

A multi-disciplinary team meeting will be held monthly to discuss all new patients and include members of the triage team, above, and physicians and other health care workers with expertise in the complications of NF1 and NF2. Regarding NF1 conditions, this could include representatives from the Child Study Center who specialize in learning and behavioral disorders, David Feldman, MD, an orthopedic surgeon with a longstanding commitment to the care of NF1 children, pediatric and neuro-oncologists such as Jeffrey Allen, Sharon Gardner and Matthias Karajannis, MD; plastic surgeons, and dermatologists. Regarding NF2, this will include J. Thomas Roland, Jr., MD, Director of Otology and Neurotology, Jeffrey Wisoff, MD and John Golfinos, MD, pediatric and adult neurosurgeons, audiologists, and ophthalmologists.

The family will return several weeks later to discuss the recommendations. Further diagnostic testing such as an MRI or hearing evaluation may be suggested and consultations will be arranged with the various subspecialists. Our current practice is to identify the optimum clinical resource on the medical campus and refer the patient there. For example, if the primary concern of an NF1 patient is an optic pathway glioma or learning disability or bone deformity, the patient's care will be best rendered in the appropriate specialty clinic. The ultimate goal would be to accrue a large enough NF population to justify bringing the specialists to the NF Clinic. Routine follow-up visits with the core NF Triage Team will be schedule at least annually, depending on the patient's needs.

As of May 2007, NYU Medical Center has made a commitment to support a dedicated NF2 Clinic under the direction of J. Thomas Roland, Jr., MD. The NF2 Clinic will be housed in the Faculty Practice Building at 550 First Avenue. NYU Medical Center will provide funding for a nurse practitioner. William Carroll, M.D., the Director of the Division of Pediatric Oncology, has generously offered space in the recently renovated pediatric oncology Hassenfeld Clinic for an NF Triage and Follow-up Clinic, including an office for the Clinic Coordinator. The Hassenfeld Clinic is located at 160 East 32<sup>nd</sup> Street, 3 blocks from NYU Medical Center. It currently provides multi-disciplinary care for children and young adults with neoplastic, hematological and various neurological disorders.

The Hassenfeld Clinic offers a wide range of supportive care services such as child life, social services, financial advice, psychological counseling, clinical trials and database management and direct access to a clinical laboratory. The clinic provides office space for medical and nursing personnel with expertise in pediatric neurology, oncology and neuropsychology. Housed in contiguous space in the Pediatric Ambulatory Care Center are specialists in pediatric cardiology, urology, nephrology and GI. The majority of these specialists focus on the care of children and young adults. Different arrangements will be made for our adult NF1 patients. The availability of funds for a full time dedicated NF Clinic Coordinator would allow us to expand our services to the regional NF community, especially for adult patients with NF1.

### Cognitive and Behavior Programs

We will endeavor to expand our cognitive and behavioral services for NF1 children, utilizing the expertise of a clinical neuropsychologist at the Hassenfeld Clinic, Eduvigis Cruz-Arrieta, PhD and the extensive programs in the Child Study Center led by Glenn

Hirsch, MD. Additional assessment/interventions needed will also be made available through all available psychology departments and services at NYU Medical Center and its affiliates (e.g. Rusk Institute, Leonard Diller, PhD., Director), and via community-based referrals to neuropsychologists with expertise in this area (Charles Zaroff, PhD). While only a very small proportion of patients with NF-1 have serious cognitive deficits, a large proportion has more mild learning difficulties. It is estimated that between 25% and 50% of neurofibromatosis children will have a learning disability. If subtle neuro-developmental problems exist but remain undetected, NF1 children may potentially miss opportunities for educational assistance. Thus, early assessment in all NF1 children is indicated to assist families and schools with designing preventative and remedial educational strategies.

Attentional problems that meet criteria for a DSM IV diagnosis of attention deficit disorder are present in roughly 39% of children with NF1. This is a major risk factor for poor social functioning. Learning disabilities and attention problems negatively influence the development of skills needed for social success with other children. Adult NF1 patients often suffer from anxiety, depression, and suicidal ideation. These issues highlight the need for early detection and prevention.

Psychological adjustment and quality of life in NF1 children is affected by illness-related variables such as mild disfigurement to life threatening complications as well as the quality of their family relationships. Given the lay culture's distortion of what the condition is, many parents may experience unwarranted fears about the future of their child. Body image is often a major preoccupation of NF1 patients. Many patients with subcutaneous and plexiform neurofibroma growths experience embarrassment and social ostracism. It is extremely important for the medical team to incorporate periodic reviews of questions, concerns, and misconceptions regarding NF1.

Our goal is to promote healthy child development, behavior and psychological adjustment despite the stresses placed on children and families and the unpredictable nature of the condition. We will utilize the services of a team consisting of psychologists, social workers, psychiatrists and educational specialists, working in close coordination with the NF1 clinic's nurse practitioner(s). An initial developmental evaluation followed by periodical reviews of the child's home and school functioning, as per the following guidelines will be made available to the families:

- All children with NF1 will be assessed before they reach school age to allow early intervention in education where required;
- First recommended age of assessment: around age 4, or earlier if developmental delays are noted during routine pediatric check-ups;
- Follow up of those with learning delays as deemed appropriate by the psychological/educational services;
- Psychiatric screenings for children at risk for attention problems will be obtained, as low doses of medication have proven beneficial to NF1 children who also suffer from ADHD;
- Next assessments when the child is at school, at three to four yearly intervals.
- Affected NF1 children with normal assessments will be reassessed at the ages of 8 and 11 years;
- School performance will be monitored during periodic medical appointments.
- Children at 50% risk under the age of 5 with no clinical signs of being affected will not be assessed if there are no signs of learning difficulties.

The supportive psychosocial interventions will aim to coordinate efforts with the medical, educational, and psychological/psychiatric teams available at our institutions. Liaisons with the child's community will be facilitated by the team's social worker and/or psychologist. Psychosocial interventions for behavioral, psychosocial adjustment or emotional regulation problems related NF1 and/or procedures related to its treatment will include both traditional and complementary therapies.

### Data Management

We do not have access to accurate statistics on the number of NF1 patients receiving care throughout NYU Medical Center or the annual accrual estimates of new patients. There is no central registry at NYU Medical Center related to the diagnosis of a genetic disorder. We will endeavor to hire a part time CRA to maintain a computer data base on all patients followed at the NF Clinic. The Neurology and Neurosurgery Departments have a very active NF2 practice that has been growing exponentially. A select clinical database has been maintained for the past 2 decades by the Pediatric Neuro-oncology Program under the direction of Jeffrey Allen, M.D and Jeena Mathew, CRA. This Program follows approximately 125 patients with NF1, over 50 of whom have either a primary CNS tumor or plexiform neurofibroma. This Program has accrued approximately 10-15 new patients per year. Other large NF1 programs at NYU Medical Center include Pediatric Orthopedics led by David Feldman, M.D., Clinical Genetics led by John Pappas, M.D. and Harry Ostrer, M.D., Pediatric Surgery led by Howard Ginsberg, M. D., Child Psychiatry led by Glenn Hirsh, M. D. and Pediatric Dermatology led by Seth Orlow, M. D.

### Clinical and Translational Research

An important goal of the NF1 Program will be the promotion of translational research leading to improved cognitive, behavioral, medical and surgical therapies addressing several of the key concerns affecting NF1 patients such as systemic and CNS tumors, learning disabilities and behavior disorders and the management of various orthopedic conditions. We have recently recruited a junior attending in pediatric oncology, Matthias Karajannis, M. D., who will bolster our translational research efforts and participate in the design of innovative NF-related clinical trials for both children and adults. There are a number of basic scientists at NYU Medical Center engaged in research projects germane to the molecular biology of NF1. We also collaborate with several clinical and laboratory investigators in the US and Canada and we maintain an extensive frozen tissue Brain Tumor Bank for research purposes.

### Current and Future Management of NF-2 Patients

The majority of NF-2 patients present in adolescence or young adulthood with progressive hearing loss due to unilateral or bilateral acoustic schwannomas (AS). However, there are also several more virulent presentations in early childhood. The incidence of NF2 (1/40-50,000) is less than 10% of that of NF1 (1/3,000) so there are far fewer patients. NYU Medical Center has had a long term interest in hearing preservation and restoration in NF2 patients and presently offers comprehensive care for a large number of NF2 patients in the newly designated NF2 Center headed by J. Thomas Roland, Jr., M.D. In addition to offering surgical expertise to safely remove AN's and other cranial nerve schwannomas, Dr. Roland and the team also evaluates each patient for either a cochlear and brainstem auditory implant. Several neurosurgeons such as, Jeffrey Wisoff, M.D. (pediatrics) and John Golfinos, M.D. (adult), have special interest and expertise in resecting the types of

CNS tumors commonly arising in NF-2 patients such as intramedullary spinal ependymomas, extramedullary, intradural spinal meningiomas and spinal schwannomas as well as intracranial cranial nerve tumors and meningiomas. Jeffrey Allen, M. D. is also provides neuro-oncologic care to a large cohort of NF-2 patients with a variety of primary CNS tumors. Vestibular evaluation and rehabilitation, facial nerve reanimation, peripheral nerve lesion treatment and hearing restoration are well known strengths of the NYU Medical Center.

The neurology skull base team has been taking a more aggressive surgical approach to small tumors with the goal of preserving hearing in the long run.

Dr. Andrew Brotman, Senior VP of Ambulatory Care has been instrumental in helping Dr. Roland develop a model program for NF2 patients and in recently providing start-up funding for designated space and funds for the recruitment of a nurse practitioner. When this individual is recruited, we will strive to expand the multi-disciplinary care offered to NF-2 patients and their families to include genetic and psychological counseling, psychiatry for the rehabilitation of spinal cord injuries, long term planning for hearing preservation or restoration, instruction in lip reading and signing, access to cochlear and brainstem auditory implants, radiosurgery or resection of cranial nerve schwannomas and intracranial meningiomas and timely resection of the intramedullary spinal ependymomas. The Administration has also offered to hire a social worker with special interests and expertise in the assistance of patients who are either deaf or blind. This social worker currently runs an support group for NF2 patients. Plans are underway for an NF2 patient informational forum in October, 2007. Dr. Matthias Karajannis has been recruited to develop clinical trials to identify drugs which may cause stabilization or regression of NF-2 related tumors.

## **2. CLINIC DIRECTOR and STAFF EXPERTISE**

### **a. CLINIC DIRECTOR: Jeffrey C. Allen, M.D.**

#### **i. Your experience to date with NF care**

Dr. Jeffrey Allen is a board certified pediatric neurologist with special expertise and interest in neuro-oncology. He has led Pediatric Neuro-Oncology Programs in three institutions in Manhattan over the past 30 years: Memorial Sloan Kettering Cancer Center (1976-86); NYU Medical Center (1986-96); Institute for Neurology and Neurosurgery at Beth Israel Medical Center (1996-2004) and upon return to the NYU Medical Center (2004- present). Primary CNS and peripheral nerve neoplasms constitute a major cause of morbidity and mortality for NF1 and NF-2 patients. Dr. Allen has cared for over 200 patients with NF-1 and NF-2 related disorders at these institutions and he continues to follow most of these patients in his clinic. He also provides pediatric neurology care for over 50 NF-1 patients without any CNS or peripheral tumors. Professionally, he has served on the Clinical Research Committee of the NF Foundation in Manhattan from 2000-2003 led by Bruce Korf, M.D. He was a member of the Neurofibromatosis Research Programmatic Review Committee (2005-2006) supported by the Department of Defense. He has attended several NF Foundation supported symposia usually held in Aspen. His programs have been listed as a resource for NF patients on the NF and CTF websites for over 10 years.

**ii. Your past and current association with NF clinical trials**

Dr. Allen has participated in several NF1 and 2 clinical trials as a co-investigator for over 15 years. To highlight a few of these studies: 1. Pegylated alpha-interferon designed by Regina Jakacki, M.D. and sponsored by Schering Plough for NF1 related plexiform neurofibromas; 2. NF-2 natural history study (PI - William Slattery, M.D.) funded by the NIH; 3. Investigation of the incidence of clinical and subclinical signs of NF2 in several large NF-2 families, while serving in the PHS at the NINDS from 1970-72; and 4. Phase I/II clinical trial of perfenidone for progressive plexiform neurofibromas designed by Roger Packer, M.D. and sponsored by a pharmaceutical company from 2003-4. During an elective in Pediatric Neuro-oncology at NYU Medical Center in November, 2006, an adult neurology resident, Lindsey Lair, M.D., conducted a retrospective review of our clinical database of NF1 patients with multiple primary CNS tumors and presented a poster at the Academy of Neurology meeting in Boston this year (May, 2007).

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

Dr. Allen has been a major contributor to clinical trials development in pediatric neuro-oncology both at an institutional and cooperative group level. He served as the Head of the Brain Tumor Strategy Group for the Children's Cancer Group (CCG) from 1990-95. He was the PI of a large CCG phase II study using neoadjuvant chemotherapy and hyperfractionated craniospinal radiotherapy for children with high risk PNET (CCG 9931) which accrued 124 patients from 1997-2001. He is presently the PI of a recently opened (1/07) phase III trial in the Children's Oncology Group (COG) comparing "Standard radiotherapy alone vs. neoadjuvant chemotherapy followed by response dependent reduced radiotherapy for children with newly diagnosed CNS germinomas" (COG ACNS0232). Dr. Allen has published over 140 articles addressing various aspects of neuro-oncology. He has trained over 15 fellows in pediatric neuro-oncology, many of whom are leading Pediatric Neuro-oncology Programs in the US and Canada.

**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.**

Dr. Allen's Pediatric Neuro- oncology Program was reimbursed for patients entered on several clinical trials such as the pegylated alpha interferon (Schering Plough) and NF-2 Natural History Study (NIH).

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

Kanter WR, Eldridge R, Fabricant R, Allen JC, Koerber T. Central neurofibromatosis with bilateral acoustic neuroma: genetic, clinical and biochemical distinctions from peripheral neurofibromatosis. Neurology 1980; 30(8):851-859.

Packer RJ, Ater J, Allen J, Phillips P, Geyer R, Nicholson HS, et al. Carboplatin and vincristine chemotherapy for children with newly diagnosed progressive low-grade gliomas. *J Neurosurg* 1997; 86(5):747-754.

Allen JC. Initial management of children with hypothalamic and thalamic tumors and the modifying role of neurofibromatosis-1. *Pediatr Neurosurg* 2000; 32(3):154-162.

Gururangan S, Fisher M, Allen J, Herndon J, Quinn J, Reardon D, Vredenburg J, Desjardins A, Phillips P, Watral M, Drauser J, Friedman A and H Friedman. (2007). Temozolomide in children with progressive low-grade glioma. Neuro-oncol 9(2): 161-8.

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

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

Dr. William Carroll, Director of the Division of Pediatric Hematology/Oncology has had a long term interest in fostering clinical and basic research in NF1. He has chaired the DOD Grant Review Panel for the past 3 years and will do it again this year. He also heads the ALL Steering Committee for COG. He has helped recruit Matthias Karajannis, MD who will promote translational research activity in NF at NYU Medical Center. J. Thomas Roland, Jr, M.D. has a major career commitment to the clinical challenges of NF2. Not only does he resect base of skull schwannomas in a timely fashion, in an effort to spare hearing loss, he also directs the Cochlear Implant Program at NYU. The NYU Neurotology team, consisting of Dr. Roland, Dr. Anil Lalwani and Dr. Pamela Roehm, have extensive experience with the care of the NF2 patients. They are also involved in institutional-based laboratory research focusing on in vitro and animal tumor models relevant to NF2 as well as evaluated of new auditory prostheses. Sharon Gardner, MD is a national leader in protocols that intensify chemotherapy for infants with a variety of CNS tumors. John Pappas and Harry Ostrer have extensive clinic experience the clinical and laboratory diagnosis of the NF disorders. Members of the Child Study Team such as Glenn Hirsh, MD and allied neuropsychologists such as Eduvigis Cruz, PhD are highly regarded for their expertise in behavior disorders such as ADHD and learning disabilities.

d. **Who within this core staff currently coordinates NF patient services?**

Describe this individual's NF clinic related duties.

There is no separate treatment team for NF patients presently. NF patients are treated the same as other patients with similar medical conditions.

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.**

NYU has a variety of specialists with expertise in many health areas critical for both NF1 and NF2 patients. To share several highlights, the Division of Pediatric Neurosurgery, consisting of Drs. Jeffrey Wisoff, Howard Weiner and David Harter has a long traditional of excellence in the neurosurgical management of CNS and

PNS tumors that commonly arise in NF1 and 2 patients. The Pediatric Neuro-oncology team consisting of Drs. Jeffrey Allen, Sharon Gardner and Matthias Karajannis has extensive expertise in the conduct of clinical trials in a variety of neural tumors. The Division of Pediatric Orthopedics lead by Dr. David Feldman has a special interest in the orthopedic manifestations of NF-1 patients and Dr. Feldman was recently honored by the CTF at this year's annual meeting. NYU Medical Center has just authorized the creation of an NF-2 Center led by Dr. John Roland who with other team members has a long history of providing surgical and hearing restorative care for NF-2 patients. The Child Study Center is committed to identify and ameliorate the complex behavioral and learning difficulties facing NF-1 children. All these and other specialty services can be better mobilized for an NF patient population by the Clinic Coordinator. NYU Medical Center also provides high quality ancillary services in rehabilitation, neuroradiology and neuropathology.

### 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.

The timing of the appointments is based, in part, on the perceived medical urgency of the medical concern. We ordinarily can see new patients within 2-4 weeks of the initial phone contact but urgent problems will be done within 24-48 hours.

- 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 be 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).

Refer to table.

## PEDIATRIC CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Harry Ostrer	Medical Science Building 1 136 550 1 <sup>st</sup> Ave NY, NY 10016	212-263-7596	ostreh01@popmail.med.nyu.edu
	John Pappas		212-263-5746	pappaj01@popmail.med.nyu.edu
Neurology	Jeffrey Allen	160 E. 32 <sup>nd</sup> St, 2 <sup>nd</sup> Fl, Hassenfeld Children's Center NY, NY 10016	212-263-9907	Jeffrey.allen@nyumc.org
Orthopedics	David Feldman	NYU Hospital for Joint Diseases 4th 413 301 E. 17th St NY, NY 10003		David.feldman@nyumc.org
Developmental pediatrics/learning disabilities	Glenn Hirsch	Child Study Center 577 1st Ave NY, NY 10016	212-263-8704 212-263-8678	hirschg01@popmail.med.nyu.edu
Ophthalmology	Mark Steele		212-981-9800	steelm01@popmail.med.nyu.edu
Neurosurgery	Jeffrey Wisoff David Harter Howard Weiner John Golfinos Stephen Russell	317 E. 34 <sup>th</sup> St 10 <sup>th</sup> Floor NY, NY 10016	212-263-6419	Jhw1@popmail.med.nyu.edu harted01@popmail.med.nyu.edu weineh01@popmail.med.nyu.edu golfij01@popmail.med.nyu.edu russes01@popmail.med.nyu.edu
Plastic surgery	Joseph McCarthy	Tisch Hosp, 1 148 550 First Avenue NY, NY 10016	212-628-4420 212-263-5208	mccarj01@popmail.med.nyu.edu
Neuro-oncology	Jeffrey Allen	160 E. 32 <sup>nd</sup> St, 2 <sup>nd</sup> Fl, Hassenfeld Children's Center NY, NY 10016	212-263-9907	Jeffrey.allen@nyumc.org
Medical Oncology/Radiation Oncology	Sharon Gardner Matthias Karajannis	160 E. 32 <sup>nd</sup> St, 2 <sup>nd</sup> Fl, Hassenfeld Children's Center NY, NY 10016	212-263-9913 (SG) 212-263-9959 (MK)	Sharon.gardner@nyumc.org Matthias.karajannis@nyumc.org
	Ash Narayana		212 731-5003 (AN)	Ashwatha.Narayana@nyumc.org
Endocrinology	Ralph David	Schwartz Health Care Center 3 3A 530 First Avenue NY, NY 10016	212-263-6462	davidr01@popmail.med.nyu.edu
Audiology/Neurotology  Cochlear Implant/ABI Center	J. Thomas Roland Jr Anil Lalwani Pamela Roehm	Skirball Institute 8th Floor Suite 8S 550 First Avenue NY, NY 10016 660 First Ave. 7 <sup>th</sup> Fl New York	212-263-5565 (JR) 212-263-6344 (AL) 212-263-6344 (PR)	john.roland@nyumc.org anil.lalwani@nyumc.org roehmp01@popmail.med.nyu.edu
Radiology/ Neuroradiology	Ed Knopp	Schwartz Health Care Center C C-39 (Basement) 530 1 <sup>st</sup> Ave NY, NY 10016	212-263-7195 212-263-8723	edmond.knopp@nyumc.org

General Surgery/Surgical Oncology	Howard Ginsburg	Faculty Practice Tower 10 W 530 First Avenue NY, NY 10016	212-263-7391	ginsbh01@popmail.med.nyu.edu
Dermatology	Seth Orlow	Tisch Hospital 1 H-100 550 First Ave NY, NY 10016	212-263-5889	orlows01@popmail.med.nyu.edu
Cardiovascular Disease	Marcelo Auslender	160 E. 32 <sup>nd</sup> St. 2 <sup>nd</sup> Floor NY, NY 10016	212-263-5940	auslem01@popmail.med.nyu.edu
Oral and Maxillofacial Surgery	Joseph McCarthy	Tisch Hosp, 1 148 550 First Avenue NY, NY 10016	212-628-4420 212-263-5208	mccarj01@popmail.med.nyu.edu
Behavioral Issues	Eduvigis Cruz-Arrieta	160 E. 32 <sup>nd</sup> St, 2 <sup>nd</sup> Fl, Hassenfeld Children's Center NY, NY 10016	212-263-9925	eduvigis.cruz-arrieta@nyumc.org

## ADULT CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Same as above			
Neurology	Same			
Orthopedics	Same			
Developmental pediatrics/learning disabilities	Same			
Ophthalmology	Same			
Neurosurgery	John Golfinos Anthony Frempong	Faculty Practice Tower 8 8R 530 First Avenue New York 10016	212-263-2950	golfig01@popmail. med.nyu.edu
Plastic surgery	Same			
Neuro-Oncology	Michael Gruber	Skirball Institute 540 First Avenue NY, NY 10016	212-731-5577	michael.gruber@ nyumc.org
Medical Oncology/Radiation Oncology	Ash Narayana Anna Pavlick	Clinical Cancer Center 160 East 34th St NY, NY 10016	212 731-5003 (AN) 212-731-5431 (AP)	Ashwatha. Narayana@ nyumc.org anna.pavlick@ nyumc.org
Endocrinology	TBN			
Audiology/ENT	Same			
Radiology/ Neuroradiology	Same			
General Surgery/Surgical Oncology	Howard Ginsburg Elliot Newman	Faculty Practice Tower 10 W 530 First Avenue NY, NY 10016	212-263-7391	ginsbh01@popmail. med.nyu.edu
Dermatology	Same			
Cardiovascular Disease	TBN			
Oral and Maxillofacial Surgery	Joseph McCarthy	Tisch Hosp, 1 148 550 First Avenue NY, NY 10016	212-628-4420 212-263-5208	mccarj01@popmail. med.nyu.edu
Behavioral Issues	Glenn Hirsch	Child Study Center 577 1st Ave. NY, NY 10016	212-263-8704 212-263-8678	hirscg01@popmail. med.nyu.edu

4. NUMBER OF NF PATIENTS YOUR CLINIC SEES (Dr. Jeffrey Allen):

a. How many NF PATIENTS did you see in the past 12 months? 100

b. How many of these were NEW patients to your clinic? 15

	NF1	NF2	SCHWANNOMATOSIS	OTHER
NUMBER OF PATIENTS SEEN AT NYU MEDICAL CENTER IN PAST 12 MONTHS	750	40	0	0
NUMBER OF <u>NEW</u> PATIENTS SEEN AT NYU MEDICAL CENTER IN PAST 12 MONTHS	36	13	0	0
TOTAL	786	53	0	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 (%):	18+ (%):
NF1 (70%)	NF1 (30%)
NF2 (5%)	NF2 (95%)

5. TRANSITIONING PEDIATRIC TO ADULT NF CARE

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

The same medical team usually follows the patients as long as they wish.

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

Comprehensive center without distinction between adults and children, the same specialists handle the NF1 and NF2 patients.

## 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.)

Not presently in place.

## 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.                      N/A

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.

Dr. Allen has referred NF1 patients to the NIH to participate in several clinic trials such as perfenidone and RAS inhibitors (Brigitte Weidman). NF1 patients are currently eligible for various institutional and COG clinical trials for recurrent or progressive primary brain tumors and approximately 5 NF1 patients have participated in these trials over the past 3 years.

## 8. PATIENT REGISTRY

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

Yes                      No

If 'yes', please describe.

We utilize a proprietary software package, Oncolog, to enter demographic and treatment and follow-up information on all pediatric neuro-oncology patients, including those with NF1 and NF2.

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

Yes

No

\* With appropriate measures to insure HIPPA compliance.

If 'no', explain your limitations. N/A

## 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.

Dr. Roland's Team has published on ABI results, cranial nerve presentation in larger tumor removal, complications of tumor removal, outcomes after cochlear implantation and management of hearing in NF2 patients. There is also ongoing research on the auditory midbrain implant and the auditory brainstem implant, hearing preservation strategies and complications of radiation thereapy in the NF2 patient.

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

We participate in a phase II anti-angiogenesis clinical trial composed by Dr. Mark Kieran of Children's Hospital in Boston consisting of metronomic daily therapy with various combinations of 5 oral medications (thalidomide, fenofibrate, Celebrex, etoposide and cyclophosphamide). We have enrolled 3 patients with NF patients.

## 10. PATIENT SUPPORT

Do you have an NF patient support group that meets in association with your NF Clinic? If 'yes' provide details.

Yes. The League for the Hard of Hearing sponsors a quarterly NF2 support group with cart support and with guest speakers. Plans are underway to move this meeting to the NYU Medical Center, as well as to provide more extensive patient educational support. Patient educational brochures have been created and are in the final stages of review. We also have a number of support groups for our oncology patients to which the NF patients are invited to attend.

If 'no', are you interested in starting such a group? N/A  
What resources would help you to do this? N/A

## 11. OTHER INFORMATION

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

A fundamental aim of the NYU NF program is to develop novel diagnostic and treatment strategies to prevent and treat the associated complications of these diseases. Dr. William L. Carroll, Chief of the Division of Pediatric Hematology Oncology and Deputy Director of the NYU Cancer Institute, has endorsed the development of an NF research and treatment program since his arrival on the NYU campus five years ago. The first step in this process was the recruitment of Dr. Allen and the re-building of the Pediatric Neuro-oncology Program. A robust program is currently underway and therefore this is an opportune time to launch the NF program. Dr. Carroll has been a participant in the Department of Defense's NF Program for many years and has chaired the Study Section on four occasions (including this year). As a physician scientist, his laboratory is focused on understanding the biology of childhood tumors including leukemia, brain tumors and neuroblastoma. He is head of the Children's Oncology Group's ALL Committee and therefore has considerable experience in the design and execution of clinical protocols. The Division is composed of additional internationally-known leaders in their respective fields: Dr. Francine Blei (Vascular Anomalies), Dr. Elizabeth Raetz (Leukemia, Phase I Studies/New Drug Development), Dr. Sharon Gardner (Brain Tumors, Stem Cell Transplantation) and Dr. Margaret Karpatkin (Laboratory Hematology).

NYU Medical Center has a number of scientists who conduct collaborative research relevant to the known genetic and cellular aberrations that occur in NF1 and NF2 including Drs. Mark Phillips, Angel Pellicer, and Dafna Bar-Sagi. All focus on understanding regulation of the ras pathway and the development of inhibitors for use in cancer treatment. Dr. Gordon Fishell's laboratory is examining the origin of neural stem cells and cancer stem cells while Dr. Moses Chao is focused on understanding the role of neural growth and differentiation factors and their receptors in normal development and in disease, including cancer. Lastly, Dr. Allen has had a long-standing collaboration with Drs. David Zagzag and Elizabeth Newcomb who study the molecular biology of brain tumors. These translational efforts are aided by a dedicated clinical trials office at Hassenfeld that includes three clinical research associates and a dedicated Brain Tumor Tissue Bank that is housed in Dr. Zagzag's laboratory.