



NF Clinic Network (NFCN) Application Form*

Clinic Name:

The Neurofibromatosis Center at Montefiore/Einstein

Affiliated Hospital:

Montefiore Medical Center
Children's Hospital at Montefiore (CHAM)

Affiliated University or Institution:

Albert Einstein College of Medicine

Clinic Address:

The Neurofibromatosis Center at Montefiore/Einstein
Division of Hematology/Oncology, CHAM
3415 Bainbridge Avenue
Bronx, NY 10467

Clinic Director:

Adam S. Levy, MD

Clinic Coordinator Name:

Tania Shiminski-Maher, RN, CPNP

**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 at Montefiore/Einstein consists of two key foci of activities: an extensive clinical program centered at the Children's Hospital at Montefiore and a basic science/translational research focus centered on the campus of the Albert Einstein College of Medicine. Linked by a common interest in the care and treatment of individuals with NF, these two foci interact through a centralized leadership, described below.

There are basically three entry routes into our clinical center. Most children with neurofibromatosis (NF) are referred to Dr Robert Marion, a pediatric geneticist who is Chief of the Division of Genetics in the Department of Pediatrics, or to one of his colleagues. The clinical geneticists evaluate the child's condition, confirm the diagnosis, perform appropriate testing, and refer the child to the appropriate affiliated specialists. Children who are seen by Dr. Marion and his staff will be entered into our database and Drs Abbott and Levy will be informed of their entry into the center. Occasionally, children will be referred directly to Drs. Abbott or Levy. These children, if not already evaluated by the clinical geneticists, will be referred to Dr Marion and his colleagues for a standard evaluation. Dr Marion will see these patients on a regular basis (every six months for younger children, yearly for older children and adults). Drs. Levy and Abbott will also see them on a yearly basis. Appointments by other specialists will be determined on an as need basis.

Members of the clinical team meet on a monthly basis to discuss patients seen during the previous 30 days. At these sessions, problems concerning the patients' management or care are raised, and discussions regarding treatment plans are developed and reviewed.

As noted above, the research arm of the Center is situated on the campus of the Albert Einstein College of Medicine. Through the generous support of the Betty and Sheldon Feinberg Supporting Foundation, a series of groundbreaking research projects are currently under way. These include:

Laboratory of Dr. Jean Hebert

The research in Dr. Hebert's laboratory focuses on the mechanisms of tumor genesis. The factors involved in regulating the proliferation of the tumor cells remain obscure. Clues to what those factors might be come from recent work on signaling pathways involving neurofibromin (the protein product of the NF1 gene). Research suggests that this protein normally acts to keep in check some of the cell's pathways that initiate growth and proliferation. Ongoing studies are aimed at understanding the role of these signaling pathways in regulating the normal and abnormal proliferation and differentiation of neural cells during development and in the adult.

Laboratory of Dr. Suzanne Zukin

Using animal models (fruit fly and mouse with introduced NF mutations), the investigators are attempting to develop novel therapeutic strategies to ameliorate the primary disease symptoms of neurofibromatosis and associated deficits in cognition and attention. Their goals with respect to NF1 include characterizing its role in intracellular signaling, synaptic plasticity and cognition in flies, mice and humans; identifying novel therapeutic targets for treatment; and implementing these treatment strategies. Utilizing a fruit fly model developed by investigator Sean McBride, disease models have been initiated in the fruit fly and will be translated to the mouse within the next two years.

Laboratory of Dr. Ganjam Kalpana

Dr. Kalpana's translational research work has attempted to develop a targeted therapy for rhabdoid tumors that includes AT/RT. The critical gene that is deleted in these tumors, *INI1*, was discovered by Dr. Kalpana in connection with HIV-1. Her lab has made strides in understanding its mechanism and has developed a potential therapeutic strategy for treatment of rhabdoid tumors. This treatment has been well received within Pediatric Oncology community.

Recently, it became clear that *INI1* is also a candidate gene for Schwannomatosis, a form of NF2. As a result, Dr. Kalpana has been invited by the CTF to apply for a drug development initiative pilot grant on Schwannomas; she was also invited to give a keynote address at the annual meeting of the CTF.

Dr. Kalpana is keenly interested in understanding the mechanism of *INI1* mediated tumorigenesis; she and her colleagues have developed a number of tools and reagents to conduct research in this front, including the development of an *INI1* knock-out model. In addition, the lab is interested in evaluated human samples.

Other research activities

The funding made available by the Feinberg Foundation has allowed us to develop a novel medical college- wide grant making competition, an attempt to encourage young researcher to develop additional NF-related projects. These projects will be aimed at the molecular basis of NF, the development of novel treatments for these disorders, and new efforts to elucidate the natural history of NF. As an example, through use of a

number of assessment batteries, Dr. Susan Rose, a behavioral neuroscientist, is interested in evaluating visuospatial deficits in children with NF1 by assessing abilities from several core domains (attention, processing speed, memory and executive functioning), pinpoint deficits within a domain and gain a more detailed picture of deficits by examining a number of distinct aspects of each ability, examine the extent to which core abilities underlie individual differences in visuospatial functioning, and to determine the extent to which ADHD is responsible for deficits seen in children with NF1.

Members of the research and clinical groups will meet together on a regular basis to discuss their work and share information. It is anticipated that with recognition of this program as a center, there will be greater integration of the research and clinical arms of the center.

2. CLINIC DIRECTOR and STAFF EXPERTISE

a. CLINIC DIRECTOR: Please describe:

Adam Levy, MD Director
Robert Marion, MD Co-Director
Rick Abbott, MD Co-Director

i. Your experience to date with NF care:

Our records show that in 2006, 79 separate patients with a primary diagnosis of NF were seen at Montefiore Medical Center. Since, in our experience, the primary diagnosis often does not reflect the underlying condition affecting the individual, it is reasonable to assume that, in fact, we cared for more than 100 individuals with this condition over the past year. And this is not a recent phenomenon. During his more than 25 years as a clinical geneticist, Dr. Marion has cared for hundreds of patients of all ages with NF; in the 1990s, he headed a multidisciplinary neurogenetics clinic at Blythedale Children's Hospital in Valhalla, New York, which included a pediatric neurologist, a pediatric ophthalmologist, a pediatric physiatrist, a social worker, and support staff. He has written about NF in textbooks and articles, and trained hundreds of professionals from an array of medical specialties to recognize the signs and symptoms of the conditions, and to make the diagnosis of neurofibromatosis type 1 (NF1) using the consensus clinical criteria.

An internationally known neurosurgeon specializing in disorders of the central and peripheral nervous system, Dr. Abbott's expertise in treating patients with neurofibromas is widely known, having been covered repeatedly in the media. At the present time, patients are referred to him from across the world, and he is known to perform operations in patients who are rejected for surgery elsewhere. Dr. Abbott has been involved in the development of techniques used in the surgical management of central and peripheral nervous system tumors. Many of the intraoperative neurophysiological procedures currently

used to both map the location of critical structures of the nervous system and to monitor their integrity during tumor resection have been developed through his collaboration with neurophysiologists from other leading institutions. The advanced intra-operative monitoring techniques used by Dr. Abbott allow more precise tumor resections while preserving function. He frequently works with other surgical specialists in a team to deal with complex surgical problems that cross subspecialty boundaries. He has developed a program for minimally invasive neurosurgery using small endoscopes to perform surgery within the nervous system. Dr. Abbott utilizes “Functional Neurosurgery” which enables him to deliver novel treatments to children and adults with injured nervous systems to improve function.

Dr. Levy’s experience with NF care has been as a pediatric oncologist specializing in patients with solid tumors and central nervous system tumors (curriculum vitae, attached). As such, his experience with NF patients is mainly based on the high incidence of neoplasms in children with NF. Dr. Levy has followed and treated many children with NF and brain tumors, and has enrolled many on Children’s Oncology Group (COG) trials for low-grade gliomas. Also, Dr. Levy has cared for several patients with malignant peripheral nerve sheath tumors. Dr. Levy has been consulted on many children with large plexiform neurofibromas and coordinated the complex care of these patients with the many sub-specialists needed to provide their scope of care.

Together with a team of medical professionals who have expertise in managing and treating individuals with NF, the Director and Co-Directors of our Center are poised to take the next step in providing outstanding care to the people of the New York metropolitan area with NF.

ii. Your past and current association with NF clinical trials

Dr. Levy was the site Principal Investigator for a clinical trial of Methotrexate and Vinblastine for large plexiform neurofibromas. As an academic clinician he has been proactive about referring patients to the NIH and other centers for phase I clinical trials for plexiform neurofibromas and facilitated the care of patients enrolled on studies far away from home. Dr. Levy has enrolled many patients with NF and low-grade gliomas on COG trials.

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

Dr. Levy is the site Principal Investigator for the Children's Oncology Group at the Children's Hospital at Montefiore (CHAM). In this capacity, Dr. Levy oversees approximately 30 Institutional Review Board-approved clinical trials. Also through his COG affiliation, Dr. Levy is a member on the study committee for two COG national studies for children with brain tumors. The first study recently opened for enrollment through the COG. The other study is in development and Dr. Levy has been given responsibility for protocol authorship.

Dr. Levy has presented and co-authored the results of an international clinical trial for children with malignant brain tumors (see bibliography).

Dr. Levy is currently working with industry on a phase I study using a novel agent in pediatric patients with recurrent solid tumors. That protocol has been submitted for review and industry support.

- 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.

None
 - ii. Your NF-related clinical and scientific publications. Include Journal, Citation and Title.

PRESENTATIONS and PUBLICATIONS (by clinical staff):

1. Wisoff JH, Abbott IR, Epstein FJ: 1990. Surgical Management of Exophytic Chiasmatic-Hypothalamic Tumors in Childhood. *Journal of Neurosurgery* 73: 661-667.
2. Deletis V, Vodusek D, Abbott IR, Epstein FJ, Turndorf H: 1992. Intraoperative Monitoring of Dorsal Sacral Roots: Minimizing the Risk of Iatrogenic Micturition Disorders. *Neurosurgery* 30:72-75.
3. Abbott IR, Maher T, Wisoff JH, Epstein FJ: 1992. Intrinsic Tumors of the Medulla: Surgical Complications. *Pediatric Neurosurgery* 17:239-244.
4. Abbott IR: 1993. Tumors of the Medulla. In Haines SJ, Heros RC (Eds). *Surgery of the Brainstem: Neurosurgical Clinics of North America* 4:519-528.
5. Squires LA, Allen JC, Abbott R, Epstein FJ. 1994: Focal tectal tumors: management and prognosis. *Neurology*. 1994 May; 44(5):953-6.

6. Robertson PL, Allen JC, Abbott IR, Miller DC, Fidel J, Epstein FJ: 1994. Cervicomedullary Tumors in Children: A distinct Subset of Brainstem Gliomas. *Neurology* 44:1798-1803
7. Abbott IR. Endoscopic resection of intraventricular tumors. International Society for Pediatric Neurosurgery. Santiago, Chili 1995
8. Morota N, Deletis V, Epstein FJ, Kofler M, Abbott R, Lee M, Ruskin K: 1995. Brain stem mapping: neurophysiological localization of motor nuclei on the floor of the fourth ventricle. *Neurosurgery* 37: 922-9
9. Jallo GI, Morota N, Abbott R: 1996. Introduction of second working portal for neuroendoscopy. A technical note. *Pediatr Neurosurg* 24: 56-60
10. Abbott R, Shiminski-Maher T, Epstein FJ: 1996 Intrinsic tumors of the medulla: Predicting outcome after surgery. *Pediatr Neurosurg* 25: 41-4
11. Abbott IR Mapping and monitoring in conus/cauda equina surgery. Conference on advances in neurophysiologic monitoring. New York 1997
12. Abbott IR. Intraoperative use of evoked potentials for mapping of eloquent neural tissue and monitoring of its function. International Society for Pediatric Neurosurgery. Melbourne, Australia 1998
13. Abbott R, Goh K: Brainstem gliomas. in Albright AL, Pollack IF, Adelson PD (eds): Principles and Practice of Pediatric Neurosurgery. Thieme, New York 1999
14. Kobrinsky N, Packer R, Boyett J, Stanley P, Shiminski-Maher T, Allen J, Garvin J, Stewart D, Finlay J: Etoposide with or without Mannitol for the Treatment of Recurrent or Primarily Unresponsive Brain Tumors. *Journal of Neuro-Oncology* 45:47-54 1999.
15. Abbott R: Brainstem gliomas in McLone D (ed) Pediatric Neurosurgery: Surgery of the Developing Nervous System, 4th ed. Saunders, 2001
16. Abbott IR. Evoked potentials in the operating room. Yonsei University Grand Rounds, Seoul Korea, May 2001
17. Roonprapunt C, Abbott R. 2002 Surgical treatment of brainstem gliomas in children. *Neurosurgery Quarterly* 12: 160-169
18. Levy, A. Chemotherapy Trial for Neurofibromatosis. Presented at New York Symposium for the national Neurofibromatosis Foundation, INC. Mount Sinai Hospital, New York (Nov 2002).
19. Shiminski-Maher T, Cullen P, Sansalone M. Childhood Brain and Spinal Cord Tumors: A Guide for Families, Friends and Caregivers. O'Reilly & Associates: Sepastopol, CA, 2002.
20. Jallo GI, Shiminski-Maher T, Velazquez L, Abbott R, Wisoff J, Epstein F. 2005 Recovery of lower cranial nerve function after surgery for medullary brainstem tumors. *Neurosurgery*. 2005;56(1):74-7; discussion 78.
21. Ray P, Jallo GI, Kim RY, Kim BS, Wilson S, Kothbauer K, Abbott R. 2005 Endoscopic third ventriculostomy for tumor-related hydrocephalus
22. Jallo G, Shiminski-Maher T, Velazquez L, Abbott R, Wisoff J, Epstein F: Recovery of Lower Cranial Nerve Function After Surgery for Medullary Brainstem Tumors. *Neurosurgery* 56:74-78 2005

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

Adam Levy, MD: Director, Pediatric Neuro-Oncology Program

Robert Marion, MD: Chief, Section of Genetics; Director,
Children's Evaluation and Rehabilitation Center.

Rick Abbott, MD: Professor of Neurological Surgery.

Tania Shiminski-Maher, MS, CPNP: Neurosurgery Nurse-
Practitioner.

Siobhan Neary, PNP: Pediatric Oncology Nurse Practitioner

Rigoberto Tomala, CSW: Social Worker

Arlene Rodriguez: Clinical Office Coordinator

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

Nurse practitioners are involved in patient care throughout a patient's experience. Nurse practitioners see patients with an attending physician and then coordinate the patient's services with our Office Coordinator.

- 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.

We have a coordinated Neuro-Oncology Clinic weekly at which Dr. Levy (Pediatric Neuro-Oncology), Dr. Abbott (Pediatric Neurosurgery), and Dr. Sogawa (Pediatric Neurology) see patients together with Nurse Practitioners that focus on patients with central nervous system tumors and solid tumors (Tania Shiminski-Maher and Siobhan Neary). This established clinic presents a strong framework in which to provide outstanding care to children with central nervous system neoplasms.

Dr. Richard Gorlick, Chief, Division of Pediatric Oncology, is an internationally recognized expert in solid tumors and specifically sarcomas. Dr. Gorlick is a clinician-scientist with a basic research interest in sarcomas and tumor sensitivity to chemotherapy. As such, his expertise establishes particular clinical strength in the care of patient with malignant nerve sheath tumors. Dr. Gorlick's basic science interest provides a platform for establishing pre-clinical evaluations of novel agents for neoplasms associated with NF.

Dr. Robert Marion, Chief of Genetics and Child Development, has a long-standing interest in neuro-genetics and has coordinated the clinical care and

provided genetic counseling for families affected by NF over the past three decades. The strength of the clinical genetics program at Montefiore is an outstanding resource for patients and families. The Children's Evaluation and Rehabilitation Center (CERC), which Dr Marion also directs, is one of the largest centers of its kind in the United States. The professional staff at the CERC provides more than 58,000 diagnostic, therapeutic and related services to about 8,000 children and their families annually, while training close to 1,000 professionals each year.

Dr. Abbott follows a large group of patients with a history of intramedullary spinal cord and brainstem gliomas, a type of tumor frequently seen in patients with both neurofibromatosis types I and II. Yearly he operates on 15 to 20 such tumors. He also has a long-standing interest in surgery on tumors of the peripheral nervous system. He operates on 5-8 such tumors yearly. He has a staff skilled in the use of intraoperative mapping and monitoring, techniques which greatly improve the safety of the surgery.

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.

Generally, patients are initially referred to the clinical genetics program for evaluation and diagnosis. Following the taking of intake information, an appointment with Dr. Marion or one of his colleagues is arranged within two weeks. At the time of this initial evaluation, the diagnosis of NF is either confirmed or ruled out. If NF is diagnosed, the patient is scheduled for an MRI of the brain and possibly the spine, referred to ophthalmology for full evaluation, and to other specialists listed below, as necessary. The diagnosis is discussed in depth, and the family is provided with written information about NF. Genetic counseling is also provided at this initial visit, other members of the family who appear to have some signs of NF may be examined, and, if necessary DNA based testing is offered.

Following completion of this initial evaluation, the patient and family are scheduled for follow-up, so that the findings of the ophthalmologist and other specialist and the results of the MRI can be reviewed with the family. If further evaluation is necessary, (i.e. if an abnormality is found on the MRI), this is arranged at this time as well. The follow-up visit is also an opportunity to review and reinforce information that was given during the first visit, including prognosis and genetic counseling. If no additional problems need to be addressed, the family will be given a follow-up appointment for six

months; if additional issues have been raised, follow-up is scheduled for an earlier date

Patients with newly diagnosed tumors have their calls returned the same day and are seen within a week - typically within a day or two. Patients previously seen by us and who have a new problem have their calls returned the same day and are scheduled for an appointment at the time of the returned call. Routine follow-up visits are scheduled by patients or families calling for appointments.

- 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).

The establishment of a named Neurofibromatosis Clinic at Montefiore Medical Center/Albert Einstein College of Medicine will essentially formalize a process that is already in place. The physicians listed below are use to working with one another to meet the challenging problems that typify the caseload of our medical center. The key specialties of Neurooncology, Medical Oncology, Radiation Oncology, Neurology, Neuroradiology, Neurosurgery, Pediatric Surgery and Pediatric Intensive Care meet on a weekly basis to discuss the patients under our mutual care. Other specialties regularly attend this conference when patients of interest to them are to be discussed. There is a well-established mechanism for the dissemination of information about patients to be discussed each week so that all interested parties are aware. In this manner we have coordinated the care of our oncology patients for the past 3 years. It is our intent to group all the neurofibromatosis patients into one of these meetings, a so-called *Clinic Board Meeting*. This will occur at a frequency that is warranted but no less than every month. This will allow for greater emphasis on the non-oncological issues facing these patients.

PEDIATRIC CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Robert Marion, MD Joy Samanich, MD Paul Levy, MD Alan Shanske, MD	Dept Pediatrics CHAM 111 E 210 th St Bronx, NY 10467	718 741-2323	rmarion@montefiore.org jsamanic@montefiore.org plevy@montefiore.org ashanske@montefiore.org
Neurology	Yoshimi Sogawa, MD	Dept Neurology, Montefiore Med Center 111 East 210th St	718 920-4311	ysogawa@montefiore.org

		Bronx, NY 10467		
Orthopedics	David Geller, MD	Dept Orthopedics, Montefiore Med Center 111 East 210th St Bronx, NY 10467	718 920-2060	dgeller@montefiore.org
Developmental pediatrics/learning disabilities	Oscar Purugannan, MD	Dept Pediatrics CHAM 111 E 210 th St Bronx, NY 10467	718 430-8600	opurugga@ montefiore.org,
Ophthalmology	Judy Gurland, MD	Dept Ophthalmology Montefiore Med Center 111 East 210 Street Bronx, NY 10467	718-920-2020	jgurland@montefiore.org
Neurosurgery	Rick Abbott, MD James T. Goodrich, MD John Houten, MD Patrick Lasala, MD	Dept Neurosurgery, Montefiore Med Center 111 East 210th St Bronx, NY 10467	718 920-7400	rabbott@montefiore.org goodrich@acem.yu.edu jhouten@montefiore.org plasala@montefiore.org
Plastic surgery	David Staffenberg, MD	Div Plastic Surgery, Montefiore Med Center 111 East 210th St Bronx, NY 10467	718 920-4465	dstaffen@montefiore.org
Neurooncology/Medi cal Oncology	Adam Levy, MD	Div Hematology/ Oncology CHAM 111 E 210 th St Bronx, NY 10467	718 741-2342	adlevy@montefiore.org
Radiation Oncology	Marnee Spierer, MD	Dept Radiation Oncology, Montefiore Med Center 111 East 210th St Bronx, NY 10467	718 405-8550	mspiere@montefiore.org
Endocrinology	Morri Markowitz, MD	Div of Endocrinology CHAM 111 East 210 St Bronx, NY 10467	718-920-4664	mmarkowi@montefiore.org
Audiology/ENT	Sanjay Parikh, MD	Dept Otolaryngology, Montefiore Med Center 111 East 210th St Bronx, NY 10467	718 920-4646	sparikh@montefiore.org

General Surgery/Surgical Oncology	Christine Whyte, MD	Div Pediatric Surgery, CHAM 111 East 210th St Bronx, NY 10467	718 920-9200	cwhyte@montefiore.org
Dermatology	David Rosenstreich MD	3400 Bainbridge Ave Bronx, NY 10467	866-633-8255	drosenst@montefiore.org
Cardiovascular Disease	Samuel Weinstein, MD	Dept. of CT Surgery, Montefiore Med Center 3400 Bainbridge Avenue	718 920-7745	sweinste@montefiore.org

		Bronx, NY 10467		
Oral and Maxillofacial Surgery	Jairo Bastidas, DDS	Centennial Bldg, 2nd Flr., Montefiore Med Center 3332 Rochambeau Avenue Bronx, NY 10467	718 920-6266	jbastida@montefiore.org
Behavioral Issues	Blanche Benenson, MD	CHAM 111 East 210 Street Bronx, NY 10467	718-741-2500	bbenenso@montefiore.org

ADULT CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Robert Marion, MD Joy Samanich, MD Paul Levy, MD Alan Shanske, MD	Dept Pediatrics CHAM 111 E 210 th St Bronx, NY 10467	718 741-2323	rrmarion@montefiore.org jsamanic@montefiore.org plevy@montefiore.org ashanske@montefiore.org
Neurology	Yoshimi Sogawa, MD	Dept Neurology, Montefiore Med Center 111 East 210th St Bronx, NY 10467	718 920-4311	ysogawa@montefiore.org
Orthopedics	David Geller, MD	Dept Orthopedics, Montefiore Med Center 111 East 210th St Bronx, NY 10467	718 920-2060	dgeller@montefiore.org
Developmental pediatrics/learning disabilities	Alex Okun, MD	Dept Pediatrics CHAM 111 E 210 th St Bronx, NY 10467	718 405-8094	aokun@montefiore.org
Ophthalmology	Judy Gurland, MD	Dept of Ophthalmology Montefiore Med Center 111 East 210 St Bronx, NY 10467	718-920-2020	kgurland@montefiore.org

Plastic surgery	David Staffenberg, MD	Div Plastic Surgery, MONTEFIORE MED CENTER 111 East 210th St Bronx, NY 10467	718 920-4465	dstaffen@montefiore.org
Neurooncology	Adam Levy, MD	Div Hematology/ Oncology CHAM 111 E 210 th St	718 741-2342	adlevy@montefiore.org

		Bronx, NY 10467		
Medical Oncology/Radiation Oncology	Schlom Kalnicki, MD	Center for Radiation Therapy 1625 Poplar Street, 1st Floor Bronx, NY 10461	718 405-8550	skalnick@montefiore.org
Endocrinology	Morri Markowitz, MD	Children's Hosp at Montefiore 111 E 210 St Bronx, NY 10467	718-920-4664	mmarkowi@montefiore.org
Audiology/ENT	Richard Smith, MD	Dept Otolaryngology, Montefiore Med Center 111 East 210th St Bronx, NY 10467	718 920-4267	rsmith@montefiore.org
Radiology/Neuroradiology	Jacqueline Bello, MD	Dept Radiology, Montefiore Med Center 111 East 210th St Bronx, NY 10467	718 920-4118	abello@montefiore.org
General Surgery/Surgical Oncology	Ronald Kaleya, MD	Professor and Vice-Chairman Dept Surgery 3400 Bainbridge Ave Bronx, NY 10467	718 920-8116 718 798-1883 (fax)	rkaleya@montefiore.org
Dermatology	Dr. David Rosenstreich	3400 Bainbridge Ave Bronx, NY 10467	866-633-8255	drosenst@montefiore.org
Cardiovascular Disease	Samuel Weinstein, MD	Dept. of CT Surgery, Montefiore Med Center 3400 Bainbridge Avenue Bronx, NY 10467	718 920-7745	sweinste@montefiore.org
Oral and Maxillofacial Surgery	Jairo Bastidas, DDS	Centennial Bldg, 2nd Flr., Montefiore Med Center 3332 Rochambeau Avenue Bronx, NY 10467	718 920-6266	jbastida@montefiore.org
Behavioral Issues	Blanche Benenson, MD	Children's Hosp at Montefiore 111 E 210 St Bronx, NY 10467	718-920-2500	bbenenso@montefiore.org

4. NUMBER OF NF PATIENTS YOUR CLINIC SEES
RATHER THAN LIST INDIVIDUALLY, I SUGGEST WE POOL THESE PATIENTS SO THAT WE PROVIDE CUMULATIVE (INSTITUTIONAL) EXPERIENCE

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

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

Approximately 51

Insert numbers below

	NF1	NF2	SCHWANNOMATOSIS	OTHER
NUMBER OF PATIENTS SEEN IN PAST 12 MONTHS	66	8	1	
NUMBER OF <u>NEW</u> PATIENTS SEEN IN PAST 12 MONTHS	49	2		
TOTAL	66	8	1	

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

estimate

Under 18 65% 18+ 35%

5. TRANSITIONING PEDIATRIC TO ADULT NF CARE

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

Most members of team continue to see patients as they become adults. This is certainly the case for clinical geneticists, oncologists, most medical specialists and for surgeons (with the exception of our pediatric surgeons). Consequently, the same group meeting where children are discussed will be used to discuss management issues for our adult patients.

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

Nurse practitioners in the Neurosurgical office and Hematology/Oncology office and a case manager in the Genetics Office helps to coordinate patient's appointments, and

assures that follow-up occurs with Ms. Maher coordinating the efforts of the groups to insure that our patients care needs are met. She will attend all Clinic Board meetings and all Neurooncology Clinic meetings as well as maintain close communication with the case coordinator in the Genetics Office. Ideally a dedicated clinic coordinator will assume this responsibility in the future if funding is made available.

All the specialists listed in section 3 see patients in the Montefiore Medical Center thus the distances our patients have to travel is minimized. Follow up from the various specialists seeing these patients will occur at the Clinics Board Meeting.

Professional staff that are members of the team will meet on a periodic basis to discuss the functioning of the center. They will be apprised of Clinic Board Meetings and expected to attend. Periodic seminars to discuss and solve clinical problems will occur.

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.)

A Tumor Board meets weekly. There is always representation by the hematology/oncology service, neurosurgical service, radiation oncology service, radiology and neuroradiology service, pathology and neuropathology service, general surgical service, and orthopedic service. NF patients are currently aggregated and parties of the Center are notified when the NF cases will be reviewed. New patients requiring therapeutic intervention are brought before the board on an ASAP basis. Here too, parties of the Center are notified of these pending discussions.

With the establishment of CTF Affiliate Clinic status it is our intent to group these patients into one or more meetings a month to insure maximal participation of all interested parties and to facilitate the inclusion of aspects of the patients care needs that are non-oncological.

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)

X Yes

No

Faye Safavi, CRA is the Clinical Trials Manager for The Division of Pediatric Hematology-Oncology. Ms. Safavi and her staff coordinate nearly 30 Children's Oncology Group clinical trials and nearly 10 other institution investigator-initiated or industry-sponsored studies. The mechanism to provide the oversight for clinical trials is available and successfully active.

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.

Patients at CHAM have been enrolled on a variety of clinical trials through the COG, industry-sponsored drug trials, and investigator-initiated studies. The range have studies available at Montefiore include tumor-/tissue-banking studies, novel therapeutics, Phase I, II, and III clinical trials and studies of the psychosocial impact of cancer on children and their families. Clinical trial enrollment and development is a clear focus of this institution and expansion of clinical trials to include more NF-related clinical trials is supported by the hospital administration and relevant Department Chairs.

8. PATIENT REGISTRY

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

Yes No

We do maintain a database of children with tumors within their nervous system. We are moving ahead with the development of a database/registry. This will hopefully be accomplished in order to facilitate both clinical trials and basic science research. Currently, we are seeking philanthropic support for this endeavor.

If 'yes', please describe.

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

X 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.

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

Abbott – Ongoing research in the use of neurophysiologic monitoring to improve the safety of removal of tumors within the central and peripheral nervous system. Chart review of long-term outcomes of children undergoing aggressive surgical management of intramedullary spinal cord tumors.

10. PATIENT SUPPORT

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

If 'yes' provide details.

No

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

We would be willing to canvas our patients to get a sense of need. Previous experience with support groups have been initially fruitful but interest then died. In theory we are very supportive of this, but have been discouraged in practice.

What resources would help you to do this?

Funds for a psychologist or social worker.

11. OTHER INFORMATION

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

The Children's Hospital at Montefiore (CHAM) is one of the most technologically advanced hospitals for children in the world. Staffed by the nationally renowned faculty of the Albert Einstein College of Medicine, our pediatric specialists and caregivers are ranked among the best in the nation.

Along with our outstanding medical care, CHAM's unique integration of architecture, technology, education and inspiration is designed to engage children in a voyage of discovery and learning that can last a lifetime.

From family centered care that focuses on the whole child, to the bedside computers that can transport them to NASA's space station and beyond, we've created a hospital that brings healing, education and new possibilities to children – a model for children's hospitals in the 21st century.

Despite a population that approximates that of Philadelphia, the Bronx has only one comprehensive tertiary care hospital for the estimated 400,000 children in its service area. CHAM is the only medical center in the area that provides the multi-disciplinary care needed for children with complex medical problems like NF. In addition to providing state-of-the-art care, CHAM offers unique expertise in caring for a diverse socio-economic patient population. Conveniently located in the North Bronx, patients from Westchester County, Long Island, Brooklyn, Queens, Manhattan and beyond consider the Children's Hospital their resource for the specialized care they need.

CHAM is a free-standing building attached to the greater Montefiore Medical Center, thereby facilitating the care of transitioning adult patients and allowing CHAM's professionals the opportunity to interface with colleagues who care for adults. The new environment created by the establishment of CHAM and the modernization of medical center has allowed for the rapid growth of our neurooncology program and the nurturing of our team approach. The establishment of a dedicated neurofibromatosis program is a natural progression of this effort.

Our core group of medical professionals is extremely interested in participating in a network dedicated to the dissemination of quality information and outstanding care to families with members having NF. CHAM, Montefiore Medical Center and the Albert Einstein College of Medicine provide a collaborative environment in which health care providers can rely on colleagues who demand the highest care and support for patients, and research, both clinical and basic science, can lead to improvements in the lives of these patients.

We are excited to be given the opportunity to work with the Children's Tumor Foundation and trust that it can be a mutually beneficial partnership that will allow us all to accomplish our mission of caring for patients and families affected by NF.