



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

**Clinic Name:**

Children's Memorial Hospital Neurofibromatosis Clinic

**Affiliated Hospital:**

Children's Memorial Hospital

**Affiliated University or Institution:**

Feinberg School of Medicine, Northwestern University

**Clinic Address:**

Division of Genetics, Birth Defects and Metabolism  
Box 59  
Children's Memorial Hospital  
2300 Children's Plaza  
Chicago, IL 60614

**Clinic Directors:**

Robert Listernick, MD and Joel Charrow, MD

**Clinic Coordinator Name:**

Michelle Gilats

*\*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 clinic is a multidisciplinary clinic which was established in 1985 and is staffed by a general academic pediatrician, geneticist, and pediatric ophthalmologist. It meets from 8:30-12:00 the first three Thursdays of each month. Urgent or emergent patients are seen on an ad hoc basis.

The clinic primarily cares for children on an ongoing basis from 0-21 years of age; adults are seen for a one-time consultation either to establish a diagnosis or to perform genetic or prenatal counseling. Each patient is seen by either the pediatrician or the geneticist, acting as the "primary care NF physician." Patients  $\leq 10$  years of age receive yearly eye exams; eye exams are performed less frequently thereafter. Once

the diagnosis of NF-1 is established, patients are seen yearly, unless specific medical issues indicate the need for more frequent visits.

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

a. **CLINIC DIRECTOR:** Please describe: **The 2 clinic co-directors- Robert Listernick, M.D. and Joel Charrow, M.D. share equally in the clinical, research, and administrative responsibilities. Dr. Listernick is in the Division of General Academic Pediatrics and Dr. Charrow is Head of the Division of Genetics, Birth Defects and Metabolism. Both physicians are in the Department of Pediatrics of Children's Memorial Hospital and the Feinberg School of Medicine, Northwestern University.**

i. **Your experience to date with NF care Drs. Listernick and Charrow founded the clinical program for children with NF at Children's Memorial Hospital in 1985, and have been continuously seeing patient with NF ever since. We have had extensive experience with and published numerous papers on optic pathway tumors. We have also contributed to numerous local, national, and international symposia related to NF, have organized and presented educational programs for physicians, and actively contributed to local patient organization activities.**

ii. **Your past and current association with NF clinical trials We have participated in the Dr. Korf's study on the natural history of plexiform neurofibromas and Dr. Viskochil's studies on tibial dysplasia. We have also enrolled multiple patients in the several existing NIH treatment trials of plexiform neurofibromas, including use of R115777 and pirfenidone.**

iii. **Your past and current association with other clinical trials e.g. oncology trials We work closely with Drs. Stewart Goldman and Tadanori Tomita who are co-directors of the Falk Brain Tumor Center of the Children's Memorial Hospital. Both have had extensive experience with clinical trials as part of the Children's Oncology Group and the Pediatric Brain Tumor Consortium. Our NF patients with brain tumors and other malignancies are regularly enrolled in ongoing clinical research protocols. Drs. Listernick and Charrow routinely attend both the Brain Tumor Board and Tumor Board of Children's Memorial Hospital in which treatment decisions of our patients are made in a multidisciplinary setting with input from all the involved subspecialists.**

**Dr. Charrow has had extensive experience with clinical trials of multiple enzyme replacement products for the treatment of lysosomal storage disorders, including Phase II, III and IV**

studies, and has published the results of these studies. He has also had extensive experience with natural history registries for these disorders, and has served for many years as a Regional Coordinator of the International Collaborative Gaucher Group Registry and the Fabry Disease Registry Advisory Board.

b. CLINIC DIRECTOR: Please provide information on:

- i. Present and past funding you have received for NF research. Include funding source, date received, amount and project description. **No funding to date.**
- ii. Your NF-related clinical and scientific publications. Include Journal, Citation and Title.
  1. Listerick R, Charrow J, Greenwald M, Esterly NB. Optic gliomas in children with neurofibromatosis-1. *J Pediatrics* 114:788-792, 1989
  2. Listerick R, Charrow J. Neurofibromatosis-1 in childhood. *J Pediatrics* 116:845-853, 1990
  3. Listerick R, Charrow J, Greenwald M. Emergence of optic pathway gliomas in children with neurofibromatosis-1 following normal neuroimaging studies. *J Pediatrics* 121:584-587, 1992
  4. Charrow J, Listerick R, Ward K. Autosomal dominant multiple cafe-au-lait spots and neurofibromatosis-1: evidence of non-linkage. *Am J Med Gen* 45:606-608, 1993
  5. Charrow J, Listerick R, Greenwald MJ, Das L, Radkowski MA. Carboplatin induced regression of an optic pathway tumor in a child with neurofibromatosis. *Med Ped Oncol* 21:680-684, 1993
  6. Listerick R, Charrow J, Greenwald MJ, Mets M. Optic pathway tumors in children with neurofibromatosis type-1: a longitudinal study. *J Pediatr* 1994;125:63-6
  7. Habiby R, Silverman BL, Listerick R, Charrow J. Precocious puberty in children with neurofibromatosis type 1. *J Pediatr* 126:364-7, 1995
  8. Listerick R, Darling C, Greenwald M, Strauss L, Charrow J. Optic pathway tumors in children: the effect of neurofibromatosis type 1 on clinical manifestations and natural history. *J Pediatr* 127:718-22, 1995
  9. Listerick R, Louis DN, Packer RJ, Guttman DH. Optic pathway gliomas in children with neurofibromatosis type 1: consensus statement from the NF-1 Optic Pathway Glioma Task Force. *Ann Neurol* 41: 143-9, 1997
  10. Listerick R, Charrow J, Guttman DH. Intracranial gliomas in neurofibromatosis type-1. *Am J Hum Gen* 89: 38-44, 1999
  11. Listerick R, Charrow J, Tomita T, Goldman S. Carboplatin therapy for optic pathway tumors in children with neurofibromatosis type 1. *J Neuroonc* 45:185-90, 2000

12. Listernick R, Mancini AJ, Charrow J. Segmental neurofibromatosis in childhood. *Am J Med Gen* 121A:132-135, 2003
13. King A, Listernick R, Charrow J, Piersall L, Gutmann DH. Optic pathway tumors in neurofibromatosis type 1: the effect of presenting symptoms on outcome. *Am J Med Gen* 122A:95-99, 2003
14. Listernick R, Charrow J. Knowledge without truth: screening for complications of Neurofibromatosis type 1 in childhood. *Am J Med Gen* 127A:221-223, 2004
15. Listernick R, Ferner RE, Piersall L, Sharif S, Gutmann DH, Charrow J. Late-onset optic pathway tumors in children with neurofibromatosis 1. *Neurology* 63:1944-46, 2004
16. Listernick R, Charrow J. Neurofibromatosis-1 in childhood. *Adv Derm* 20:75-115, 2004
17. Lasky JB, Charrow J, Sandu M, Goldman S, Listernick R. Orbital optic pathway tumors in children with neurofibromatosis type-1. *JAAPOS* 10:534-539, 2006
18. Listernick R, Ferner RE, Liu G, Gutmann DH. Optic Pathway Gliomas in Neurofibromatosis-1: Controversies and Recommendations. *Ann Neurol* 61:189-198, 2007

- c. Who are the key staff in your NF clinic facility?  
Provide Name; Title; Degree/Qualifications; Role in Clinic.  
**Robert Listernick, M.D. Co-Director, general academic pediatrician**  
**Joel Charrow, M.D., Co-Director, geneticist**  
**Janice Lasky Zeid, M.D., pediatric ophthalmologist**  
**Stewart Goldman, M.D., pediatric neurooncologist**  
**Michelle Gilats, M.S., Clinical Coordinator, genetic counselor (part-time)**
- d. Who within this core staff currently coordinates NF patient services?  
Describe this individual's NF clinic related duties. **Michelle Gilats is the part-time Clinic Coordinator and performs this function.**
- 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 an interest and extensive experience in the diagnosis and management of optic pathway tumors in children with NF-1. We have published extensively on this subject and routinely receive referrals, both national and international, of patients with this problem.**

### 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. **Appointments are**

scheduled when the patient or parent first calls. Usually, an appointment can be scheduled within 6 weeks of the initial contact if there are no urgent problems. Urgent or emergent requests for an appointment are reviewed immediately by the clinic physicians. Such patients are seen within 48 hours of the contact by Dr. Listernick. This is a common occurrence in patients with newly diagnosed brain tumors. After the appointment is scheduled the patient or parent is called by the Clinic Coordinator (a genetic counselor) to obtain the medical and family history and to describe what will happen at the visit.

- 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).

**PEDIATRIC CARE**

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Joel Charrow, M.D.	Children's Memorial Hospital	773-880-4462	jcharrow@northwestern.edu
Neurology	Gesina Keating, M.D.	CMH	773-880-4352	gkeating@childrensmemorial.org
Orthopedics	John Sarwark, M.D.	CMH	773-327-1270	jsarwark@ childrensmemorial.org
Developmental pediatrics/learning disabilities	Frank Zelko, PhD	CMH	773-880-4874	fzelko@northwestern.edu
Ophthalmology	Janice Lasky Zeid, M.D.	CMH	773-880-4021	jzeid@childrensmemorial.org
Neurosurgery	Tadanori Tomita, M.D.	CMH	773-880-4373	ttomita@childrensmemorial.org
Plastic surgery	Bruce Bauer, M.D.	CMH	773-327-2440	bbauer@northwestern.edu
Neurooncology	Stewart Goldman, M.D.	CMH	773-880-3270	sgoldman@childrensmemorial.org

Medical Oncology/Radiation Oncology	Stewart Goldman, M.D. and Maryanne Marymount, M.D.	CMH Northwestern Memorial Hospital	773-880-3270 312-926-2520	sgoldman@childrensmemorial.org  mmarymon@nmh.org
Endocrinology	Reema Habiby, M.D.	CMH	773-327-7740	rhabiby@childrensmemorial.org
Audiology/ENT	Nancy Young, M.D.	CMH	773-880-3020	n-young@northwestern.edu
Radiology/Neuroradiology	Cynthia Rigsby, M.D. (body imaging) John Curran, M.D. (neuroradiology)	CMH	773-880-3540 773-880-3541	jcurran@childrensmemorial.org
General Surgery/Surgical Oncology	Marleta Reynolds, M.D.	CMH	773-880-4292	mreynolds@childrensmemorial.org
Dermatology	Anthony Mancini, M.D.	CMH	773-327-3446	amancini@northwestern.edu
Cardiovascular Disease	Barbara Deal, M.D.	CMH	773-880-4553	bdeal@childrensmemorial.org
Oral and Maxillofacial Surgery	Bruce Bauer, M.D.	CMH	773-327-2440	bbauer@northwestern.edu
Behavioral Issues	John Lavigne, PhD	CMH	773-880-4824	jlavigne@northwestern.edu

## ADULT PATIENTS

Adults are seen for one-time consultations to establish a diagnosis, provide genetic counseling, or offer guidance on specific medical complications. We start transitioning patients to an adult facility sometime between their 18<sup>th</sup> and 21<sup>st</sup> birthday depending upon the specifics of the patient. In general, we have referred them to either an adult neurologist who has an interest in NF-1 (Scott Heller, M.D., 312-908-4878, Northwestern Memorial Hospital, s-heller@northwestern.edu) or to the Neurofibromatosis Clinic at the University of Chicago run by James Tonsgard, M.D.

### 4. NUMBER OF NF PATIENTS YOUR CLINIC SEES

- a. How many NF PATIENTS did you see in the past 12 months? **Over the last 12 months, we have seen 229 patients with NF-1, 64 patients with the diagnosis of “multiple café-au-lait spots,” 1 patient with**

NF-2, 11 patients with segmental NF, and 2 patients with other related diagnoses.

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

*Insert numbers below*

	NF1	NF2	SCHWANNOMATOSIS	OTHER (Segmental NF, multiple CALS, etc)
NUMBER OF <b>RETURN</b> PATIENTS SEEN IN PAST 12 MONTHS	183	0	0	21
NUMBER OF <b>NEW</b> PATIENTS SEEN IN PAST 12 MONTHS	46	1	0	56
TOTAL	229	1	0	77

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 (%) **97%** 18+ (%) **3%**

##### **5. TRANSITIONING PEDIATRIC TO ADULT NF CARE**

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

**We start transitioning patients to an adult facility sometime between their 18<sup>th</sup> and 21<sup>st</sup> birthday depending upon the specifics of the patient. In general, we have referred them to either an adult neurologist who has an interest in NF-1 (Scott Heller, M.D., 312-908-4878, Northwestern Memorial Hospital, s-heller@northwestern.edu) or to the Neurofibromatosis Clinic at the University of Chicago run by James Tonsgard, M.D.**

Explain how continuity of care is accomplished. Describe those partnering clinics with which you coordinate services, and explain any limitations: **All records are forwarded to the new physician's office. If there are any ongoing clinical issues, direct phone contact and an up-to-date summary letter is ensured.**

## 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.) **Drs. Charrow and Listernick discuss each patient during the clinic session with input from Dr. Zeid if there are any ophthalmologic issues. We often examine patients together if there are unusual or questionable physical findings. Patients with brain tumors or progressive plexiform neurofibromas who are on a clinical trial protocol are discussed at the weekly multidisciplinary Brain Tumor Board. Similarly, NF1 patients with malignancies are discussed at the weekly Tumor Board of the Division of Oncology.**

## 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. **We have enrolled numerous patients on Pediatric Oncology Group brain tumor treatment protocols. We have participated in the Dr. Korf's study on the natural history of plexiform neurofibromas and Dr. Viskochil's studies on tibial dysplasia. We have also enrolled multiple patients in the several existing NIH treatment trials of plexiform neurofibromas, including use of R115777 and pifrenidone.**

## 8. PATIENT REGISTRY

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

Yes  No

If 'yes', please describe. **Since 1990, information regarding patient demographics and NF-1 manifestations has been kept in a centralized database.**

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

Yes  No

If 'no', explain your limitations.

**9. PUBLICATIONS and RESEARCH (IF APPLICABLE)**

a. Please list any relevant NF publications from your clinic in the past 5 years. Include Journal, Citation and Title. **Please see reference list provided in section 2bii.**

b. Please provide information on NF-related research ongoing in your clinic or performed by personnel affiliated with your clinic. **We continue to enroll patients in the above clinical protocols. Dr. Listernick is one of the organizers of the Satellite Meeting on Optic Pathway Gliomas that was part of the 2007 CTF annual research meeting in Park city, Utah. It is hoped that a fundable multicenter clinical research trial will be an outcome of this meeting.**

**10. PATIENT SUPPORT**

Do you have an NF patient support group that meets in association with your NF Clinic? **No, but we would be interested in exploring the possibility of starting such a group. We would probably need funding for administrative support as well as some part-time salary support for a group facilitator such as a social worker.**

If 'yes' provide details.

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

What resources would help you to do this?

**11. OTHER INFORMATION**

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