



NF Clinic Network (NFCN) Application Form*

Clinic Name:

University of Oklahoma Children's Physicians

Affiliated Hospital:

University of Oklahoma Medical Center

Affiliated University or Institution:

University of Oklahoma Health Sciences Center

Clinic Address:

OU Children's Physicians Building
Room 2B 2418
940 NE 13th Street
Oklahoma City, OK 73104

Clinic Director:

John Mulvihill, 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.

The NF clinic is held in the general clinic space with appointment times reserved for patients with the diagnosis or those referred for initial evaluation. Those appointments are on Tuesday mornings and allow for individuals to have contact with other NF patients in the waiting area, if desired. It also allows for referrals to other specialists, as needed, within a short period of time. The other participating specialists do not physically

attend clinic, but are prepared to have patients referred on short notice when necessary. All patients are seen first by a genetic counselor, who obtains relevant history and determines the needs and concerns of the individual and family. The physician evaluates the patient and determines needed testing and follow up.

2. CLINIC DIRECTOR and STAFF EXPERTISE

a. CLINIC DIRECTOR: Please describe:

i. Your experience to date with NF care

Dr. John Mulvihill began seeing patients with NF in 1978 and has continued his interest to the present time. He spent 20 years at the NIH and participated in many clinical trials during that time. During his almost 30 years taking care of NF patients he has participated in the care of over 500 individuals and families.

ii. Your past and current association with NF clinical trials

The University of Oklahoma Genetics Laboratory, a CLIA- and CAP-certified service facility in a building adjacent to OU Medical Center, has conducted *NF1* genotyping on over 100 individuals, including members of the Borberg cohort in Denmark, under funding from the National Cancer Institute. Preliminary publication of the clinical validation of the assay in our hands included results on 94 individuals (Mulvihill 2004), in three groups: known affected, unaffected, and “problematic” (those with just one diagnostic criterion). Specificity is close to 95% in the patient group and only one “problematic” case had a mutation; his father was affected and the café-au-lait marks did not quite meet criteria, but he was young. No control had a mutation.

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

Childhood Cancer Survivor Study – began while at the NIH and expanded to a national collaborative study that continues today.

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.

Dates	Agency	Title
1976 – 1990	National Cancer Institute (intramural)	
1986 – 1989	National Neurofibromatosis Foundation	
1993 – 1995	US Army	Scientific Advisory Board Randomized Phase II Trail on Neurofibromatosis, Co investigator
1999 – 2006	National Cancer Institute	3/4 Century of Neurofibromatosis in Denmark by Genotype; PI
1998 – 2005	U S Army	Imaging of Plexiform Neurofibromas in Neurofibromatosis 1
2006 – 2009	US Army	Aging in Neurofibromatosis

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

- Riccardi VM, **Mulvihill JJ** (Eds): *Neurofibromatosis (von Recklinghausen Disease): Genetics, Cell Biology, and Biochemistry. Advances in Neurology*, Volume 29. New York, Raven Press, pp 282, 1981.
- Stokes DC, **Mulvihill JJ**, Zinkham WH: Neurofibromatosis and leukemia. *Am J Dis Child* 132:321, 1978.
- McKeen EA, Bodurtha J, Meadows AT, Douglass EC, **Mulvihill JJ**: Rhabdomyosarcoma complicating multiple neurofibromatosis. *J Pediatr* 93:992-993, 1978.
- Hope DG, **Mulvihill JJ**: Malignancy in neurofibromatosis. In Riccardi VM, **Mulvihill JJ** (Eds): *Neurofibromatosis (von Recklinghausen Disease): Genetics, Cell Biology, and Biochemistry. Advances in Neurology*, Volume 29. New York, Raven Press, pp 33-56, 1981.
- Fitzpatrick TB, Eldridge R, Hall JG, Riccardi VM, Rubenstein AE, Miller RW, **Mulvihill JJ**, Knudson AG Jr, Bader JL: Problems in diagnosing neurofibromatosis. In Riccardi VM, **Mulvihill JJ** (Eds): *Neurofibromatosis (von Recklinghausen Disease): Genetics, Cell Biology, and Biochemistry. Advances in Neurology*, Volume 29. New York, Raven Press, pp 245-249, 1981.
- Kao YS, Kao-Shan CS, Knutsen T, Whang-Peng J, **Mulvihill JJ**: Neurofibromatosis: No chromosomal defect by prophase banding technique. *Cancer Genet Cytogenet* 13:281-282, 1984.
- Sørensen SA, **Mulvihill JJ**, Nielsen A: Malignancy in neurofibromatosis. In Müller H-J, Weber W (Eds): *Familial Cancer*. Basel, Karger, pp 119-120, 1985.
- Sørensen SA, **Mulvihill JJ**, Nielsen A: Long-term follow-up of von Recklinghausen neurofibromatosis: Survival and malignant neoplasms. *N Engl J Med* 314:1010-1015, 1986.
- Sørensen SA, **Mulvihill JJ**, Nielsen A: On the natural history of von Recklinghausen neurofibromatosis. In Rubenstein AE, Bunge RP, Housman DE (Eds): *Neurofibromatosis. Ann NY Acad Sci* 486:30-37, 1986.
- Mulvihill JJ**: Neurofibromatosis: A genetic epidemiologist's point of view. In Rubenstein AE, Bunge RP, Housman DE (Eds): *Neurofibromatosis, Ann NY Acad Sci* 486:38-44, 1986.
- Spence MA, Parry DM, Bader JL, Marazita ML, Bocian M, Funderburk SJ, **Mulvihill JJ**, Sparkes RS: Genetic linkage analysis of neurofibromatosis. In Rubenstein AE, Bunge RP, Housman DE (Eds): *Neurofibromatosis. Ann NY Acad Sci* 486: 287-292, 1986.
- Seizinger BR, Rouleau GA, Ozelius LJ, Lane AH, Faryniarz AG, Chao MV, Huson S, Korf BR, Parry DM, Pericak-Vance MA, Collins FS, Hobbs WJ, Falcone BG, Iannazzi JA, Roy JC, St. George-Hyslop PH, Tanzi RE, Bothwell MA, Upadhyaya M, Harper P, Goldstein AE, Hoover DL, Bader JL, Spence MA, **Mulvihill JJ**, Aylsworth AS, Vance JM, Rossenwasser GOD, Gaskell PC, Roses AD, Martuza RL, Breakefield XO, Gusella JF: Genetic linkage of von Recklinghausen neurofibromatosis to the nerve growth factor receptor gene. *Cell* 49:589-594, 1987.
- Mulvihill JJ**, Parry DM: Closing in on the gene for von Recklinghausen neurofibromatosis. *Genomics* 1:337-339, 1987.
- Seizinger BR, Rouleau GA, Lane AH, Farmer G, Ozelius LJ, Haines JL, Parry DM, Korf BR, Pericak-Vance MA, Faryniarz AG, Hobbs WJ, Iannazzi JA, Roy JC, Menon A, Bader JL, Spence MA, Chao MV, **Mulvihill JJ**, Roses AD, Martuza RL, Breakefield XO, Conneally PM, Gusella JF: Linkage analysis in von Recklinghausen neurofibromatosis (NF1) with DNA markers for chromosome 17. *Genomics* 1:346-348, 1987.
- Mulvihill JJ**: Neurofibromatosis: History, nomenclature, and natural history. *Neurofibromatosis* 1:124-131, 1988.
- Goldgar DE, Green P, Parry DM, **Mulvihill JJ**: Multipoint linkage analysis in neurofibromatosis type 1: An international collaboration. *Am J Hum Genet* 44:6-12, 1989.
- Seizinger BR, Farmer GE, Haines JL, Ozelius LJ, Anderson K, Korf BR, Parry D M, Pericak-Vance MA, **Mulvihill JJ**, Menon A, Hobbs WJ, Martuza RL, Gusella JF: Flanking markers for the gene causing von Recklinghausen neurofibromatosis (NF1). *Am J Hum Genet* 44:30-32, 1989.
- Eldridge R, Denckla MB, Bien E, Myers S, Kaiser-Kupfer M, Pikus A, Schlesinger S, Parry DM, Dambrosia J, Zasloff M, **Mulvihill JJ**: Neurofibromatosis 1 (von Recklinghausen's disease): Neurological and cognitive assessment with sibling controls. *Am J Dis Child* 143:833-837, 1989.
- Mulvihill JJ**: Overview of the problems and controversies. In Aylsworth A, Rubenstein AE (Eds): *Optic Gliomas in Neurofibromatosis (Conference Series Vol. 2)*. New York, National Neurofibromatosis Foundation, pp 15-22, 1989.

Mulvihill JJ, Parry DM, Sherman JL, Pikus A, Kaiser-Kupfer MI, Eldridge R: Neurofibromatosis 1 (Recklinghausen disease) and neurofibromatosis 2 (bilateral acoustic neurofibromatosis): An update. *Ann Intern Med* 113:39-52, 1990.

Mulvihill JJ: Introduction and history. In Rubenstein AE, Korf BR (Eds): *Neurofibromatosis: A Handbook for Patients, Families, and Health Care Professionals*. New York: National Neurofibromatosis Foundation, pp 1-12, 1990.

Mulvihill JJ: From phenotype to gene in preneoplastic Mendelian disorders: Example of neurofibromatosis 1 (Recklinghausen disease). In Berg K, Retterstøl N, Refsum S (Eds): *From Phenotype to Gene in Common Disorders*. Copenhagen, Munksgaard, pp 188-198, 1990.

Pollack IF, Shultz B, **Mulvihill JJ**: The management of brainstem gliomas in patients with neurofibromatosis 1. *Neurol* 46:1652-1660, 1996.

Pollack IF, **Mulvihill JJ**: Special issues in the management of gliomas in children with neurofibromatosis 1. *J Neurooncol* 28:257-268, 1996.

Pollack IF, **Mulvihill JJ**: Neurofibromatosis 1 and 2. *Brain Pathol* 7:823-836, 1997.

Pollack IF, **Mulvihill JJ**: Neurofibromatosis. In Albright AL, Pollack IF, Adelson PD (Eds): *Principles and Practice of Pediatric Neurosurgery*. New York, Thieme, pp 719-740, 1999.

- c. Who are the key staff in your NF clinic facility?
Provide Name; Title; Degree/Qualifications; Role in Clinic.

<u>Name</u>	<u>Degree(s)</u>	<u>Position</u>
Sabrina Young	RN, BSN	Clinic Manager
Mavia Hardiman	RN, BSN	Staff Infusion Nurse
Kim Fluker	LPN	Staff Nurse
Denise Reed		Medical Assistant
Christina Rackley		Lead Patient Service Rep
Bobbi Pratt		Lead Patient Service Rep
Teresa Hernandez		Patient Service Rep

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

All individuals are seen by a genetic counselor in addition to the clinic director. The genetic counselor coordinates patient care and those who participate in clinic are listed in the table below. All genetic counselors in Oklahoma are licensed to practice under a new state law (2006).

<u>NAME</u>	<u>POSITION</u>
Erica Cole, MS, LGC	Genetic Counselor
Susan Hassed, MS, CGC, LGC	Senior Genetic Counselor
Julie Keeth, MS, LGC	Genetic Counselor
Jessi Mester, MS	Genetic Counselor
Lori Williamson Dean, MS, CGC, LGC	Senior Genetic Counselor

- 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.

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.

New patients referred to rule out NF are scheduled in the first available new patient appointment, generally within two months. However, if there is an indication of particular concern: abnormal MRI, suspicious lesion, pain, etc., the individual will be given an appointment within the week. In that case, if the clinic director is unavailable another medical geneticist will cover. All referrals are triaged by a genetic counselor who determines if there is a need for an early appointment. Also, all available medical records are reviewed by a genetic counselor prior to the appointment in order to provide the most comprehensive service for the patient.

- 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).

A full range of specialists are available on the University of Oklahoma Health Sciences campus and they willingly accept referrals from the NF clinic. Specific specialists listed in the attached table. All clinicians belong to the same practice plan (OU Physician's Group), and have nearly identical rosters of credentialed payors, including Medicaid.

PEDIATRIC CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	John J. Mulvihill, MD	940 NE 13 th St 1B 1409 (Kids' Care 1)	405-271-2006	John-Mulvihill@ OUHSC.edu
Neurology	Julie Parke, MD	711 Stanton L Young Blvd, Suite 210	405-271-3635	Julie-Parke@ OUHSC.edu
Orthopedics	William Puffinbarger, MD	825 NE 10 th St Suite 1300	405-271-6667	William- Puffinbarger@OUHSC. Edu
Developmental pediatrics/learning disabilities	Thomas Lock, MD	1100 NE 13 th St Room 108	405-271-5700	Thomas- Lock@OUHSC.edu
Ophthalmology	Michael Siatkowski, MD	940 NE 13 th St (Kids' Care 7)	405-271-7887	Michael-Siatkowski@ OUHSC.edu
Neurosurgery	Timothy Mapstone, MD	1000 N Lincoln Blvd, Suite 400	405-271-4912	Timothy-Mapstone@ OUHSC.edu
Plastic surgery	Christian El Amm, MD	940 NE 13 th St, Room MRI 2000 (Kids' Care 7)	405-271-2006	Christian-ElAmm@ OUHSC.edu
Neurooncology	Rene McNail, MD	940 NE 13 th St, MRI 3000 (Kids' Care 10)	405-271-4412	Rene- McNAIL@OUHSC.edu
Medical Oncology/Radiation Oncology	Same as above	940 NE 13 th St, MRI 3000 (Kids' Care 10)	405-271-4412	
Endocrinology	Kenneth Copeland, MD	940 NE 13 th St, 1B 1409 (Kids' Care 1)		Kenneth-Copeland@ OUHSC.edu
Audiology/ENT	Paul Digoy, MD	825 NE 10 th St, Suite 4200	405-271-7559	Paul- Digoy@OUHSC.edu
Radiology/ Neuroradiology	Faridali Ramji, MD	1200 Everett Dr 1NP606	405-271-7725	Faridali-Ramji@ OUHSC.edu
General Surgery/Surgical Oncology	David Tuggle, MD	940 NE 13 th St 2B 2403 (Kid's Care 7)	405-271-5922	David- Tuggle@OUHSC.edu
Dermatology	Carlos Garcia, MD	619 NE 13 th St	405-271-6110	Carlos- Garcia@OUHSC.edu
Cardiovascular Disease	Kent Ward, MD	940 NE 13th St 3B 3311 (Kids' Care 9)	405-271-2006	Kent- Ward@OUHSC.edu
Oral and Maxillofacial Surgery	Kevin Smith, MD	DCS 200	405-271-4441	Kevin- Smith@OUHSC.edu
Behavioral Issues	Thomas Lock, MD	1100 NE 13 th St Room 108	405-271-5700	Thomas- Lock@OUHSC.edu

ADULT CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	John J. Mulvihill, MD	940 NE 13 th St 1B 1409	405-271-2006	John-Mulvihill@ OUHSC.edu
Neurology	James Couch, MD	711 Stanton L Young Blvd, Suite 210	405-271-3635	James- Couch@OUHSC.edu
Orthopedics	Joseph Davey	825 NE 10 th St Room 108	405-271-6667	
Developmental pediatrics/learning disabilities	N/A			
Ophthalmology	Michael Siatkowski, MD	940 NE 13 th St (Kids' Care 7)	405-271-7887	Michael-Siatkowski@ OUHSC.edu
Neurosurgery	Mary K. Gumerlock, MD	1000 N. Lincoln Blvd, Suite 400	405-271-4912	Mary- Gumerlock@OUHSC.edu
Plastic surgery	Christian El Amm, MD	940 NE 13 th St, Room MRI 2000 (Kids' Care 7)	405-271-2006	Christian-ElAmm@ OUHSC.edu
Neurooncology				
Medical Oncology/Radiation Oncology	Terence Herman, MD	825 NE 13 th St, Suite 1430	405-271-3016	
Endocrinology	Timothy Lyons, MD	825 NE 10 th St, Suite 4300	405-271-8478	
Audiology/ENT	James Saunders, MD			
Radiology/ Neuroradiology	Donald Wilson, MD	1200 Everett Dr, 1NP606	405-271-5138	
General Surgery/Surgical Oncology	Russell Postier, MD	825 NE 10 th St, Suite 5200	405-271-7867	
Dermatology	Carlos Garcia, MD	619 NE 13 th St	405-271-6110	Carlos- Garcia@OUHSC.edu
Cardiovascular Disease	Kent Ward, MD	940 NE 13 th St 3B 3311 (Kids' Care 9)	405-271-2006	Kent- Ward@OUHSC.edu
Oral and Maxillofacial Surgery	Kevin Smith, MD	DCS 200	405-271-4441	Kevin- Smith@OUHSC.edu
Behavioral Issues	Thomas Lock, MD	1100 NE 13 th St Room 108	405-271-5700	Thomas- Lock@OUHSC.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	38	1	0	
NUMBER OF <u>NEW</u> PATIENTS SEEN IN PAST 12 MONTHS	16	0	0	
TOTAL	38	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 32 18+ 7 (give numbers - if data available)

OR estimate

Under 18 (%) 18+ (%)

5. TRANSITIONING PEDIATRIC TO ADULT NF CARE

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

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

This clinic continues to follow patients into adulthood and accepts new patients who are adults. As part of a University Medical Group, there are a full range of specialists, both general specialists and Pediatric sub-specialists. All those in the practice plan accept patients from others in the group.

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 monthly complicated case conference is underdevelopment. The majority of those who have agreed to participate in the clinic have, at the same time, agreed to participate in the case conference.

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.

Patients from this clinic participated in the NF1 gene study to determine the efficacy of gene testing for NF1 in the OUHSC molecular genetics laboratory.

8. PATIENT REGISTRY

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

Yes No

If 'yes', please describe.

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.

Sørensen S, Oettinger M, Fenger K, Olsen JH, Nielsen L, Mulvihill JJ: A six decade follow-up of a nationwide cohort of neurofibromatosis in Denmark: Mortality and cancer. Am Coll Med Genet Ann Meeting, March, 2005; A7.

2000-2003 Member, Integration Panel of DOD U S Army Research Program on Neurofibromatosis

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

Please refer to the studies listed under the clinic director in section 2.

10. PATIENT SUPPORT

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

If 'yes' provide details.

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

What resources would help you to do this?

There is not a support group in conjunction with the clinic, but there is an active group in the Oklahoma City area. We participated in this support group.

11. OTHER INFORMATION

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