



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

**Clinic Name:**

Cardinal Glennon Children's Hospital

**Affiliated Hospital:**

SAA

**Affiliated University or Institution:**

St. Louis University

**Clinic Address:**

Cardinal Glennon Children's Hospital  
1465 South Grand Avenue  
St. Louis, MO 63104

**Clinic Director:**

Thomas J. Geller, MD

**Clinic Coordinator Name:**

Lydia Johnson, RN, BSN

*\*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 clinic at Cardinal Glennon Hospital meets every 1st, 3<sup>rd</sup> and 5th Wednesday of the month from 8AM to Noon to provide multidisciplinary care to patients. Then from 12:00 to approximately 1PM we review each case with the team and generate a report to the referring physician and family through our nursing coordinator, outlining needs for investigative studies, additional therapies and plans for follow-up.

The NF clinic is truly multidisciplinary with physician attending providers from genetics, neurology, pediatrics, endocrinology, orthopedics, pediatric ophthalmology present concurrently, and seeing patients in the sequence suggested by our nursing coordinator. When required ENT, plastic surgery, and dermatology physician providers are immediately available on-site by consultation. Child psychologists are similarly available. There are generally 8 to 10 rooms available to permit providers the opportunity to see each patient independently, but also to allow families to see each specialist in turn giving an independent history, and to express problems or concerns.

Each child has a simple hearing and speech screen conducted by audiology at least at initial referral and subsequently according to established, published follow-up guidelines. Each child has at a minimum a screening complete ophthalmic exam upon referral. Follow-up visits are conducted according to the recommendations outlined for NF-1 and NF-2 in JAMA 1997. Referring physicians and parents receive a summary letter of the overall visit including pertinent comments and plans from each provider.

Reminder letters are sent out prior to follow-up visits several weeks before the next anticipated appointment.

## 2. CLINIC DIRECTOR and STAFF EXPERTISE

a. CLINIC DIRECTOR: Please describe:

i. Your experience to date with NF care

I am a board certified Child Neurologist who has been practicing for 19 years since fellowship. I have been director or co-director of the NF clinic since 1995. I have published a study of seizure type and semiology in NF-1 from the database that we maintained independently here, before a national database was available to us.

I have participated in the care of at least a thousand NF patients and am involved in the continued Neuro-oncologic management of numerous cases of progressive optic pathway tumors, low- grade and high-grade cerebral gliomas, spinal cord tumors, plexiform neurofibromas and complications due to therapies for these tumors. I co-direct the Neuro-oncology clinic at Cardinal Glennon Children's Hospital and participate fully in the COG sponsored trials available here. I have referred patients to other institutions including Washington University, St Jude's Medical center and others when we do not have an appropriate open protocol for that histologic tumor type.

I have managed numerous neurologic complications of NF-1 and NF-2 including chronic pain syndromes, peripheral mononeuropathies and plexopathies, myelopathies, epilepsy of various forms, migraine and non-migrainous headache, involuntary movement disorders, moya-moya disease.

ii. Your past and current association with NF clinical trials

I am presently conducting a trial of Transcranial Doppler Sonography as a screening tool for identifying subclinical cerebral vasculopathy in NF-1, through a protocol submitted to St Louis University's IRB.

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

As stated above I am an active member of the Children's Oncology Group and am on the protocol committees for the clinical trials regarding infant medulloblastoma, prevention of vincristine induced neuropathy, and am a participating member of the Neurology interest group.

I am the institutional principal investigator for a clinical trial of pharmacokinetics of hydromorphone in pediatric patients.

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.

I have a 10,000 \$ grant from the Fleur-de-Lis foundation for the Transcranial Doppler Screening study listed above.

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

Kulkantrakorn K, Geller TJ: Seizures in Neurofibromatosis 1. Pediatric Neurology. 1998;5:347-350.

Martin DS, Geller TJ, Falbo S, Pittman T. Exophytic Juvenile Pilocytic Astrocytomas of the Posterior Fossa. J Child Neurology;2000;15:262-265.

Geller TJ, Kotagal S. Spinal Cord Compression as the Initial Manifestation of Sarcomas in Childhood. Ann Neurology. 1994;(36)516

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

Thomas J Geller, MD Board Certified Child Neurologist,  
Director NF Clinic and Chief neurologist for NF Clinic

Gary Gottesman, MD, Director, Division of Medical Genetics  
Rick Martin, MD Division of Medical Genetics  
Petra Swidler, MD Division of Medical Genetics  
Kathy Morris, MSSW, Genetics Counselor  
Elizabeth Engel, MD, Director, Division of Pediatric Orthopedics'  
Bradley Davitt, MD, Division Director of Pediatric Ophthalmology  
Joel Nadler, PhD, Division of Child Psychology  
Lydia Johnson, RN, BSN Clinical Nurse

- d. Who within this core staff currently coordinates NF patient services?  
Lydia Johnson RN, BSN

Describe this individual's NF clinic related duties:

Assists in scheduling patient appointments  
Coordinates communication between NF Team members and patients/families  
Schedules patient tests in timely manner. Communicates with family regarding test appointments and test results as appropriate.  
Interviews/assesses patients during NF Clinic appt.  
Coordinates clinic post conference  
Oversees all new referrals and answers patient/family questions regarding appt  
Provide education regarding NF to patients/family members as appropriate  
Coordinate patient appts as needed with other specialists, ie endocrine, neurosurgery, pulmonology outside of direct clinic visit  
Assist in obtaining referrals to services required as needed  
Obtain/retrieve patient data as necessary for physician specialists  
Provide NF education to nursing staff

- 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 available some specific skills in cranial base tumors through our contacts with Dr Saleem Abdulrauf, a skull-base surgeon in the dept of Neurosurgery at St Louis University. He has special expertise with CP angle tumors of the posterior fossa in NF-2, and with tumors of the region of the sella and cavernous sinus encountered in the Neurofibromatoses. Dr Thomas Geller the director has some additional skills in chronic pain management as a member of the pediatric section of the American Pain Society and as a board member of the Missouri Pain Initiative. We have through our contacts with Dr Howard Place, MD special capabilities in pediatric orthopedic spine surgery. We have available through the

department of Psychology a certified Neuro-psychologist (Dr Sarah Wright) for specific assessment of neuropsychological syndromes that may occur in our NF-1 and NF-2 patients.

### 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.

Patient and/or physician phone calls regarding referral or scheduling a patient are returned by the secretary or nurse within 24 – 48 hours. The intake information is collected and the NF specialists assigned who should see the patient. New patients are scheduled within 2 – 4 weeks of the initial call/referral depending on any health issues they may have. Patient appointments are prioritized according to any NF related problems being experienced by the patient. All patients experiencing any acute symptoms possibly related to NF are seen at the next NF clinic. If the patient’s problem is more emergent than even this time would be appropriate, then the patient is scheduled with the direct provider/specialist immediately.

- b. Provide details of those specialists to whom (either within or outside our own clinic facility) your clinic refers NF patients for the following specialty care. **These should individuals familiar and experienced with consensus guidelines for care of individuals with NF** (Please provide information for PEDIATRIC CARE referrals in the first table and ADULT CARE in the second table).

PEDIATRIC CARE SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Gary Gottesman, MD, Petra Swindler, MD, Richard Martin, MD	1465 S Grand Ave, St Louis, MO 63104	314-577-5639	gottesgs@slu.edu
Neurology	Thomas J Geller, MD	1465 S Grand Ave, St Louis, MO, 63104	314-577-5338	gellertj@slu.edu
Orthopedics	Elizabeth Engel, MD	1465 S Grand Ave, St Louis, MO 63194	314-577-5646	Engelm2@slu.edu
Developmental pediatrics/learning disabilities	Dr Sarah Wright, PhD, Dr Joel Nadler, PhD, Dr Monica Ultmann, MD	Dept of psychology, 1465 S Grand Ave, St Louis, MO 63105	314-577-5609	Ultmanm2@slu.edu

Ophthalmology	Dr Bradley Davitt, MD	1465 S Grand Ave, St Louis, MO	314-577-5660	davittb@slu.edu
Neurosurgery	Dr Anne Flannery, MD	SAA	314-577-8795	flanneam@slu.edu
Plastic surgery	Dr Michael Carstens, MD	SAA	314-577-8793	mcarsten@slu.edu
Neurooncology	Dr Thomas J Geller, at the Bob Costas Cancer Clinic	SAA	314-268-4000	gellertj@slu.edu kguavain@slu.edu
Medical Oncology/Radiation Oncology	Dr Karen Guavain, MD, at the BobCostas Cancer Center	SAA	314-268-4000	kguavain@slu.edu
Endocrinology	Dr Sherida Tollefsen, MD and Dr David Dempsher, Dr Susan Meyers	SAA	314-577-5648	tollefs@slu.edu
Audiology/ENT		SAA	314-577-5383	
Radiology/Neuroradiology	Dr Atchawi Luisiri, MD, dept of Radiology	SAA	314-577-4105	luisirim@slu.edu
General Surgery/Surgical Oncology	Dr Martin Keller, MD	SAA	314-577-5629	kellerms@slu.edu
Dermatology	Dr Elaine Sigfried, MD	SAA	314-256-3433	
Cardiovascular Disease	Dr Sadeih Jureidini, MD	SAA	314-577--5600	
Oral and Maxillofacial Surgery	Dr John Stith, MD, dept of ENT	SAA	314-577-5675	stithja@slu.edu
Behavioral Issues	Dr Joel Nadler, dept of Psychology	SAA	314-577-5609	

## ADULT CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Dr Maulik Shah, dept of Medicine, St Louis University	West Pavilion Center, SLU , Rm 361, 3660 Vista Ave, St Louis, MO	314-268-7938	shahmr@slu.edu
Neurology	Dr Amy Rauchway, DO, Dept of Neurology SLU	1438 S Grand Ave, St Louis, MO	314-977-4865	rauchway@slu.edu

Orthopedics	Dr Howard Place, MD	Desloge tower 7 <sup>th</sup> floor, SLU Medical center , 3600 Vista Ave, St Louis, MO	314-577-8850	place@slu.edu
Developmental pediatrics/learning disabilities	NA			
Ophthalmology	Dr Sophia Chung, MD, Anheuser Busch Eye Institute, SLU	1755 S Grand Ave, St Louis MO	314-256-3237	chungsm@slu.edu
Neurosurgery	Dr Saleem Abdulrauf, MD and Dr Richard Bucholz, MD	Desloge towers , 3 <sup>rd</sup> floor, 3600 Vista Ave, St Louis ,MO	314- 577-8849	abdulrsi@slu.edu
Plastic surgery	Dr Christian Paletta, MD	Desloge tower 3 <sup>rd</sup> floor, 3600 Vista Ave, St Louis MO	314-577-8793	palette@slu.edu
Neurooncology	Dr John Richart, MD	West pavilion Cancer Center, 3600 Vista Ave, St Louis ,MO	314-577-8854	richartj@slu.edu
Medical Oncology/Radiation Oncology	John Richart, MD	SAA	SAA	SAA
Endocrinology	Sherida Tollefson, MD	1465 S Grand Ave, St Louis, MO	314-577-5648	tollefs@slu.edu
Audiology/ENT	Anthony Mikulec, MD	Desloge tower 3 <sup>rd</sup> floor , 3600 Vista Ave, St Louis Mo 63105	314-577-8887	mikuleca@slu.edu
Radiology/ Neuroradiology	Anis Sami Nassif, MD	Desloge tower 2 <sup>nd</sup> floor, 3600	314-268-5782	nassifa@slu.edu

		Vista Ave, St Louis MO		
General Surgery/Surgical Oncology	Robert Johnson, MD	Desloge towers 3 <sup>rd</sup> floor, 3600 Vista Ave, St Louis MO	314-577-8352	johnsorg@slu.edu
Dermatology	Scott Fosko, MD	1755 S Grand Ave St Louis, MO	314-256-3433	Foskom2@slu.edu
Cardiovascular Disease	Arthur Labovitz, MD	Desloge tower 13 <sup>th</sup> floor, 3600 Vista Ave, St Louis, MO	314-577-8890	labovitz@slu.edu
Oral and Maxillofacial Surgery	John Stith, MD	1465 S Grand Ave, St Louis, MO	314-577-5675	stithja@slu.edu
Behavioral Issues	Not provided			

**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	297	2	1	0
NUMBER OF <b><u>NEW</u></b> PATIENTS SEEN IN PAST 12 MONTHS	112	0	1	0
TOTAL				

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

Under 18 (%)\_90%\_\_

18+ (%)\_10%\_\_

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

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

We generally ask that patients consider seeing faculty at St Louis University who are familiar with the Neurofibromatoses. These include: from adult medicine and genetics Dr Malik Shah, MD, from Adult Neurology Dr Amy Rauchway, DO, from Neurosurgery Dr Saleem Abdulrauf, MD, and from dermatology Dr Elaine Siegfried, MD.

If an individual or family chooses to use local providers, we provide a specific letter from the NF clinic outlining the recommendations for longitudinal follow-up of the adult NF patient.

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

We frequently are asked to provide consultative services to pediatric and adult primary care physicians regarding NF-associated disorders, and will assist in determining what specialists through the University adult services that the individual needs to utilize, make appropriate referrals through the coordinating nurse and follow-up on the adult's care. We cannot continue to do all of the primary care follow up of these patients at this time.

## 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.)

After each clinic an internal care case management conference takes place with all the providing specialties present from 12:00 noon to 1 PM to go over each patient's needs.

Educational conferences have included Grand Rounds Pediatric conferences, Grand Rounds Adult Neurology conferences, combined Neurology/Genetics Journal clubs semi-annually.

## 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; See above 2i.

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 referred patients to the Plexiform Neurofibroma trials of Perfenidone at Washington University on several occasions in the last 2 years. In addition we have enrolled patients in the COG "Natural history study" of low grade gliomas in COG, with the inclusion of the treatment arm of randomized chemotherapy for progressive disease in the study. One patient with an intracranial plexiform neurofibroma was referred for the Gleevac study in development by Dr Wade Clapp at Indiana University.

## 8. PATIENT REGISTRY

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

Yes

No

If 'yes', please describe.

We previously maintained a database until 1999, when staff limitations restricted our capabilities to input all data from visits. We would like to apply to provide data to the present national NF 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.

See #2.b. ii listed above.

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

As stated above, we have received a small grant and submitted a protocol to the St Louis University IRB to study subclinical cerebral vasculopathy and Moyamoya in pediatric patients aged 6 to 21 years, utilizing Transcranial Doppler Sonography.

#### 10. PATIENT SUPPORT

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

Yes. On one occasion there was a local meeting of the CTF Foundation on Sept 24, 2007 at the St Louis Hilton with our representative clinicians and those of Washington University, St Louis Children's Hospital. We are hopeful that the Local CTF will continue to develop such venues and will be happy to participate in any and all educational ventures. We are particularly interested in education regarding NF for primary care physicians. We have provided such updates in Neurofibromatosis for primary pediatricians through the CME program at Cardinal Glennon Children's Hospital, particularly through Grand Rounds presentations.

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.