



NF Clinic Network (NFCN) Application Form*

Clinic Name:

USF Regional Genetics Program

Affiliated Hospital:

Tampa General Hospital, All Children's Hospital

Affiliated University or Institution:

University of South Florida

Clinic Address:

13101 Bruce B. Downs Boulevard
Tampa, FL 33612

17 Davis Boulevard, Suite 308
Tampa, FL 33606

880 Sixth Street South
St. Petersburg, FL 33701

Clinic Director:

Judith Ranells, 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.

Pediatric NF patients are served through our genetics clinic in Tampa 2 full days per week in an academic clinic setting and clinic at All Children's Hospital 3 days per week. Children who receive medical services through the state program for indigent children with chronic medical difficulties (Children's Medical Services) are also served through satellite clinics in Lakeland, Sarasota, St. Petersburg and Fort Myers. The patients are seen in a clinic setting and genetics is one component of their

comprehensive care. We have an adult genetic clinic in Tampa one full day every two months where adult patients with NF receive services.

2. CLINIC DIRECTOR and STAFF EXPERTISE

a. CLINIC DIRECTOR: Please describe:

- i. Your experience to date with NF care
Board certified in Pediatrics and Medical Genetics. Practicing clinician since 1982. Attends annual NF symposia held in conjunction with the annual ASHG meeting. Invited lecturer at statewide annual CTF (NFFF) conferences. Providing services to NF patients at USF for 16 years together with Dr. Boris Kousseff, former Chief of Genetics at USF, who had a special interest in NF and related disorders and was a member of the advisory board for the state NFFF chapter.
- ii. Your past and current association with NF clinical trials
To my knowledge there have been no trials available in Florida, would refer these patients to the NF Foundation for additional information.
- iii. Your past and current association with other clinical trials e.g. oncology trials
None.

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 outside funding
- ii. Your NF-related clinical and scientific publications. Include Journal, Citation and Title.
Galan-Gomez, E., Sutphen, R., Ranells, J., Kousseff, B.G.: Jadassohn nevus phakomatosis and neurofibromatosis type 2. Poster presentation, David W. Smith Workshop, Wesley Chapel, FL, August 1994.

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

Provide Name; Title; Degree/Qualifications; Role in Clinic.
*Eloise J. Prijoles, M.D./Clinical Geneticist
Tuya Pal, M.D./Clinical Geneticist*

*Melissa Loscalzo, M.D./ Clinical Geneticist
Pat Newkirk, M.S., C.G.C./Genetic Counselor
Terry Ferlita, M.S., C.G.C./Genetic Counselor
Troy Becker, M.S., C.G.C./Genetic Counselor
Liz Appel/ Clinic Coordinator
Julie Stann/Administrative Assistant*

- d. Who within this core staff currently coordinates NF patient services? Describe this individual's NF clinic related duties.
*Pat Newkirk, M.S., C.G.C. and Troy Becker, M.S., C.G.C. coordinate care for pediatric patients on an individual basis – referring to specialists as necessary, setting up testing as needed and providing support services and information as needed.
Terry Ferlita, M.S., C.G.C. coordinates care for adult patients on an individual basis – referring to specialists as necessary, setting up testing as needed and providing support services and information as needed.*
- 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.
No area of special expertise

3. PATIENT SCHEDULING and REFERRALS

- a. Provide the details of the 'typical' timeframe in which patients receive a response to a request for scheduling, are actually scheduled for an appointment, how patients are prioritized, etc.
The USF Regional Genetics Program has centralized scheduling through the USF medical clinics with dedicated schedulers for the genetics clinic. Patients are given the next available appointment and the patients are usually seen within 1-3 months. Procedures at All Children's Hospital are similar. Patients or referring physicians who request an immediate appointment are reviewed by the physician and worked into the schedule. Patients who are pregnant and need to be seen quickly can be seen in the academic office for genetic counseling.
- b. Provide details of those specialists to whom (either within or outside your 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	Dr. Judith Ranells Dr. Eloise Prijoles Dr. Tuya Pal Dr. Melissa Loscalzo	13101 Bruce B. Downs Blvd. Tampa FL 33612 880 6 th St. South, St. Petersburg, FL, 33701	813-974-2583 727-767-2687	
Neurology	Dr. Maria Gieron-Korthals	13101 Bruce B Downs Blvd Tampa FL 33612	813-259-8717	
Orthopedics	Dr. Scott Beck Dr. Cara Novick Dr. Dennis Grogan Dr. Harry Kim	All Children's Hosp 880 6 th St. S. St. Pete 33701 Shriner's Hospital for Children 12502 Pine Drive, Tampa, FL 33612	727-767-4133 813-972-2250	
Developmental pediatrics/learning disabilities	Dr. Carol Lilly Dr. Mary Pavan	12901 Bruce B. Downs Blvd. TampaFL All Children's Hospital	813-974-0602	
Ophthalmology	Dr. Jeffrey Hess Dr. Linda Nakanishi	All Children's Hosp USF Eye Institute	727-767-4393 813-974-4864	
Neurosurgery	Dr. Bruce Storrs	All Children's Hosp	727-767-8181	
Plastic surgery	Dr. Michael Gallant	1515 22 nd Av. St. Pete, FL 33704	727-822-0665	
Neurooncology	Dr. Jerry Barbosa	All Children's Hospital 880 6 th St. S., St. Pete, FL 33701	727-767-4175	
Medical Oncology/Radiation Oncology	Dr. Irmel Ayala	All Childrens Hosp 880 6 th St. S. St. Pete 33701	727-767-4176	
Endocrinology	Dr. Dorothy Shulman	12901 Bruce B. Downs Blvd., Tampa, FL	813-974-2583	
Audiology/ENT	Dr. James Endicott	555 4 th Ave. S. St. Petersburg, FL 33701	727-551-0800	
Radiology/ Neuroradiology	Dr. John Barnes	1033 Dr MLK Jr ST N, Ste 108 St. Pete 33701	727-767-4755	
General Surgery/Surgical Oncology	Dr. Andre Hebra	ACH, 880 6 th St. S., St. Petersburg 33701	727-767-4170	

Dermatology	Dr. Philip Shenefelt	12901 Bruce B. Downs Blvd	813-974-2920	
Cardiovascular Disease	Dr. James Huhta	All Children's Hospital	727-553-1251	
Oral and Maxillofacial Surgery	Dr. Pat Ricalde	304 S. MacDill Ave. Tampa, FL 33609	813-870-6000	
Behavioral Issues	Dr. Jeffrey Alvaro	ACH 880 6 th St. S. St. Pete 33701	727-767-8477	

ADULT CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Dr. Judith Ranells, Dr. Eloise Prijoles	17 Davis Blvd. Tampa, FL 33606	813-259-8772	
Neurology	Dr. Rossitza Chichkova	12901 Bruce B Downs Blvd. Tampa 33613	813-974-4115	
Orthopedics	Dr. David Leffers	13601 Bruce B. Downs Blvd. Suite 121 Tampa FL 33613	813-396-9422	
Developmental pediatrics/learning disabilities	Dr. Arthur Rosenblatt	3515 E. Fletcher Av., Tampa, FL 33613	813-974-8900	
Ophthalmology	Dr. Roger Gstalder	USF Eye Inst.	813-974-4864	
Neurosurgery	Dr. Thomas Freeman	4 Harborside Med. 4 Columbia Dr	813-974-5138	
Plastic surgery	Dr. Wayne Cruse	2 Columbia Dr Tampa FL 33606	813-844-7656	
Neuro-oncology	Dr. Steven Brem	12902 Magnolia Dr, Tampa, FL 33612	813-745-3980	
Medical Oncology/Radiation Oncology	H. Lee Moffitt Ca Ctr. & Research Institute	12902 Magnolia Dr, Tampa, FL 33612	813-745-3980	
Endocrinology	Dr. Anthony Morrison	12901 Bruce B Downs Blvd Tampa FL 33612	813-974-2271	
Audiology/ENT		12901 Bruce B		

	Dr. Thomas McCaffrey	Downs Blvd Tampa FL 33612	813-974-4683	
Radiology/ Neuroradiology	Dr. Sadie Aguila	12901 Magnolia Drive, Tampa, FL 33612	1-888-860-2778	
General Surgery/Surgical Oncology	Dr. Richard Karl	12901 Magnolia Drive, Tampa, FL 33612	813-972-8459	
Dermatology	Dr. Neil Fenske	12901 Bruce B Downs, Tampa, FL 33612	813-974-2201	
Cardiovascular Disease	Dr. Anne B. Curtis	12901 Bruce B. Downs Blvd. Tampa FL 33612	813-259-0600	
Oral and Maxillofacial Surgery	Terry Kelly, DMD	12901 Bruce B. Downs Blvd., Tampa FL 3612	813-974-4683	
Behavioral Issues	Dr. John Zak	3515 E Fletcher Av Tampa FL 33613	813-974-8900	

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	80	2	0	2 proteus
NUMBER OF <u>NEW</u> PATIENTS SEEN IN PAST 12 MONTHS	34	0	0	0
TOTAL	80	2	0	2 Proteus

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

Under 18__67__ 18+ __15__ (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?

Patients are transitioned to the USF Adult Genetics Clinic for follow up, which is at a different physical location but is staffed by the same health care professionals. The various pediatric subspecialists will make referrals to adult providers at the appropriate time.

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

Adult patients are seen every 1 to 2 years or on an as needed basis in the Adult Clinic and care is coordinated with a full range of specialists available in the University or community. One limitation may be that the specialists are physically not all in the same location, so patients will usually have to travel to different offices for their care.

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.) *No NF conferences at the current time*

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)

XYes 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.

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.

N/A

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

N/A

10. PATIENT SUPPORT

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

If 'yes' provide details. *The Florida Chapter of the National Neurofibromatosis Foundation meets annually in Tampa or St. Petersburg, FL. Currently, there is no other regular group meeting.*

If 'no', are you interested in starting such a group? *There is interest in a local support group according to the local contact person.*

What resources would help you to do this? We could help organize the meeting, locate meeting space and help provide speakers for the group.

11. OTHER INFORMATION

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

A neurologist specializing in pain management, Dr. Maria Carmen-Wilson, has also treated our NF patients .

Hillsborough and Pinellas Counties are the 4th and 5th largest counties in Florida according the 2000 census. The Regional Genetics Program at USF serves one-third of the state. The opportunity to join the CTF NF Clinic Network would provide valuable resources and coordinated care for a large population in West Central Florida.