



NF Clinic Network (NFCN) Application Form*

Clinic Name:

Neurocutaneous Disorders Program

Affiliated Hospital:

Children's Hospital Los Angeles

Affiliated University or Institution:

University of Southern California

Clinic Address:

4650 Sunset Boulevard, MS#82
Los Angeles, CA 90027

Clinic Director:

Tena Rosser, MD

Clinic Coordinator Name:

Kate Kelts, MS

**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 Neurocutaneous Disorders Program is a jointly run clinic by the Division of Child Neurology and the Division of Medical Genetics at Childrens Hospital Los Angeles (CHLA). The clinic meets every Friday morning from 8:30am-12pm. The current schedule allows us to see approximately 3-4 follow-up patients and 2-3 new patients per week. Five to 6 patients are scheduled per week. Each patient is seen by our medical geneticist (Dr. Randolph) and our neurologist (Dr. Rosser). All new patients are seen by our genetic counselor (Erin Baldwin) who takes a family history and draws a family tree. Our clinic coordinator (Cathy Goodhue) facilitates visits for families.

She organizes charts, medical records, test results and notes from other consultants prior to the clinic. She helps maintain the flow of patients through the clinic. She is also in charge of providing educational materials for families as well as discussing eligibility for any of our research studies.

2. CLINIC DIRECTOR and STAFF EXPERTISE

a. CLINIC DIRECTOR: Please describe:

i. Your experience to date with NF care

Dr. Tena Rosser has been caring for adults and children affected with Neurofibromatosis 1 and 2 for 6 years.

ii. Your past and current association with NF clinical trials

We are a current site for an NIH funded study: A Phase II Randomized, Cross-Over, Double-Blind, Placebo-Controlled Trial of the Farnesyltransferase Inhibitor R115777 in Pediatric Patients with Neurofibromatosis Type 1 and Progressive Plexiform Neurofibromas.

While at Children's National Medical Center (CNMC) in Washington, DC, Dr. Rosser was also the principal investigator on the multicenter study, PEG-interferon trial for progressive plexiform neurofibromas coordinated through the University of Pittsburgh.

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

Dr. Rosser is a co-investigator on several pediatric epilepsy drug clinical trials.

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.

We currently have no funded studies through the CHLA NF clinic.

While at CNMC, Dr. Rosser had the following grants:

1) Principal Investigator for Hippocampal Abnormalities in Children with Neurofibromatosis Type 1 from the George Washington University School of Medicine Gill Fellowship Award from 6/1/04-9/1/04 in the amount of \$1,200.

2) Co-Investigator for Early Identification of Cognitive Deficits in Children with Neurofibromatosis Type 1 from the United States Army, Department of Defense from 4/1/04-3/31/08 in the amount of approximately \$1 million.

3) Principal Investigator for Functional Magnetic Resonance Imaging in Children with Attention Deficit Hyperactivity Disorder and Neurofibromatosis Type 1: A Pilot Study from a CNMC Internal RAC Award from 1/1/04-1/1/05 in the amount of \$30,000.

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

Book Chapters

Rosser T, Packer RJ: Novel Therapeutic Approaches for Plexiform Neurofibromas in Neurofibromatosis Type 1. In: Curatolo P, Riva D (ed): Neurocutaneous Syndromes in Children. Montrouge, France: John Libby & Company Ltd., 2006

Journal Articles

Rosser T, Vezina G, Packer RJ: Cerebrovascular abnormalities in a population of children with neurofibromatosis type 1. *Neurology* 2005; 64:553-555.

Rosser T, Packer RJ: Neurocognitive Dysfunction in Children with Neurofibromatosis Type 1. *Current Neurology and Neuroscience Reports* 2003; 3:129-136.

Rosser T, Packer RJ: Intracranial Neoplasms in Children with Neurofibromatosis Type 1. *Journal of Child Neurology* 2002; 17(8):640-677.

Rosser T, Packer RJ: Neurofibromas in Children with Neurofibromatosis Type 1. *Journal of Child Neurology* 2002; 17(8):585-591.

Packer RJ, Rosser T: Therapy for Plexiform Neurofibromas in Children with Neurofibromatosis 1: An Overview. *Journal of Child Neurology* 2002; 17:638-641.

Abstracts

Rosser T, Janusz J, Kaplan L, Glezer L, Stizlein CA, Vaidya CJ: Neural basis of working memory in children with and without NF1 and ADHD: A functional MRI study, abstract. *Annals of Neurology* 2005; 58 (S9):S87.

Rosser T, Janusz J, Coble C, Gioia GA: Profiles of executive functioning, behavior and adaptive skills in children with

neurofibromatosis type 1, abstract. *Annals of Neurology* 2004; 56(S8):S127.

Rosser T, Cooney K, Packer RJ, Tiff C: Spectrum of Cerebrovascular Disease in a Population of Children with Neurofibromatosis Type 1, abstract. *Annals of Neurology* 2003; 54(S7):S139.

Rosser T, Cooney K, Packer RJ, Tiff C: ADHD and developmental Delay in a Population of Children with Neurofibromatosis type 1, abstract. *Annals of Neurology* 2002; 52(S3):S137.

Rosser T, Dubovsky E, Vezina LG, Cooney K, Packer RJ, Tiff C: Hippocampal abnormalities in a population of children with neurofibromatosis type 1, abstract. *Annals of Neurology* 2002; 52(S3):S137.

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

The clinic is co-directed by Dr. Tena Rosser (Division of Neurology) and dr. Linda Randolph (Division of Medical Genetics). All patients are seen by both physicians.

Cathy Goodhue CPNP is the clinic coordinator. She has 13 years of pediatric outpatient experience as a PNP. She facilitates referrals to specialists, consents patients to our database, educates families, and ensures that the clinic runs on schedule. As time allows, she is also involved in promoting our research studies.

Erin Baldwin MS is the genetic counselor. She see each new patient and obtains a family history as well as a detailed pedigree. She also participates in educating families about NF.

Judy Eloed LCSW is the social worker. She facilitates referrals to outside agencies, such as those for early childhood interventional services. She also provides counseling on an as needed basis and refers families to appropriate social services agencies for further assistance.

Various office support staff in the Division of Neurology and the Division of Medical Genetics are also involved. They schedule patients, obtain insurance authorizations and confirm appointments.

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

Cathy Goodhue CPNP coordinates the clinic. Prior to the Friday morning clinic, she organizes patient charts, obtains relevant test results and follows up on consultations performed since the last visit. She facilitates referrals to various subspecialists within CHLA. She follows up on insurance authorizations requested for testing and/or consultation visits. When necessary, she contacts

administration in various subspecialty clinics to improve coordination of care. She also consents patients for the internal clinic database and communicates with the IRB for all studies as time allows.

- 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.

None.

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.

Any patients with emergent issues are seen within 1-2 days, typically in Dr. Rosser's general neurology clinic. Visits for new patients with active issues are facilitated within 1-3 weeks depending on the level of urgency. New patients who are medically stable are typically seen within 2-3 months.

- 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	Linda Randolph MD	4650 Sunset Blvd MS 90	(323) 361-2178	lrandolph@chla.usc.edu
Neurology	Tena Rosser MD	4650 Sunset Blvd MS 82	(323) 361-2940	trosser@chla.usc.edu
Orthopedics	David Skaggs MD	4650 Sunset Blvd MS 69	(323) 361-2142	Dskaggs@chla.usc.edu
Developmental pediatrics/learning disabilities	Virdette Brumm PhD	4650 Sunset Blvd MS 82	(323) 361-2498	vbrumm@chla.usc.edu
Ophthalmology	Mark Borchert MD	4650 Sunset Blvd MS 88	(323) 361-4510	mborchert@chla.usc.edu
Neurosurgery	Mark Krieger MD	4650 Sunset Blvd MS 102	(323) 361-2169	mkrieger@chla.usc.edu
Plastic surgery	John Reinisch MD	4650 Sunset Blvd MS 96	(323) 361-4544	jreinisch@chla.usc.edu

Neurooncology	Jonathan Finlay MD	4650 Sunset Blvd MS 54	(323) 361-8147	jfinlay@chla.usc.edu
Medical Oncology/Radiation Oncology	Robert Lavey MD	4650 Sunset Blvd MS 54	(323) 361-2417	rlavey@chla.usc.edu
Endocrinology	Debra Jeandron MD	4650 Sunset Blvd MS 61	(323) 361-5915	djeandron@chla.usc.edu
Audiology/ENT	Kenneth Geller MD	4650 Sunset Blvd MS 58	(323) 361-2145	kgeller@chla.usc.edu
Radiology/Neuroradiology	Marvin Nelson MD Ashok Panigrahy MD	4650 Sunset Blvd MS 81	(323) 361-4572 (323) 361-5739	mdnelson@chla.usc.edu apanigrahy@chla.usc.edu
General Surgery/Surgical Oncology	James Stein MD	4650 Sunset Blvd MS 100	(323) 361-2491	jstein@chla.usc.edu
Dermatology	N/A			
Cardiovascular Disease	Mark Sklansky MD	4650 Sunset Blvd MS 34	(323) 361-2461	msklansky@chla.usc.edu
Oral and Maxillofacial Surgery	Mark Urata MD	4650 Sunset Blvd MS 96	(323) 361-7072	murata@chla.usc.edu
Behavioral Issues	Susan Turkel MD	4650 Sunset Blvd MS 82	(323) 361-5576	sturkel@chla.usc.edu

ADULT CARE N/A

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics				
Neurology				
Orthopedics				
Developmental pediatrics/learning disabilities				
Ophthalmology				
Neurosurgery				
Plastic surgery				

Neurooncology				
Medical Oncology/Radiation Oncology				
Endocrinology				
Audiology/ENT				
Radiology/Neuroradiology				
General Surgery/Surgical Oncology				
Dermatology				
Cardiovascular Disease				
Oral and Maxillofacial Surgery				
Behavioral Issues				

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	45	2	1	18
NUMBER OF <u>NEW</u> PATIENTS SEEN IN PAST 12 MONTHS	28	3	2	9
TOTAL	73	5	3	27

- 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 (%)_93%__ 18+ (%)_7%__

5. TRANSITIONING PEDIATRIC TO ADULT NF CARE

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

There is limited availability of local primary care physicians with experience in NF. There is one local adult neurologist who is familiar with NF. We also refer pediatric and adult patients with NF2 to the House Ear Institute.

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

Transitioning young adult patients to an adult facility is one of our greatest challenges as there is only one local adult neurologist familiar with NF. It is not always practical for patients to be seen at that institution. Also, where patients can be seen is also often dictated by their insurance company which further complicates continuity of 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.)

We participate in a weekly interdisciplinary neuro-oncology conference attended by neurology, neurosurgery, radiology, radiation oncology, neuro-oncology and medical genetics services. Films of all NF patients scanned the prior week are reviewed and discussed.

The CHLA NF clinic also hosted an educational seminar for families in September of 2006. The conference was co-sponsored by the CTF and NF Inc.

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 are a site for the NIH multicenter study - A Phase II Randomized, Cross-Over, Double-Blind, Placebo-Controlled Trial of the Farnesyltransferase Inhibitor R 115777 in Pediatric Patients with Neurofibromatosis type 1 and Progressive Plexiform Neurofibromas. However, to date, we have not had any patients who qualify.

Dr. Rosser will also be the study physician for the trial to Evaluate the Safety of Lovastatin in Adults with Neurofibromatosis Type 1 (NF1) coordinated through UCLA.

8. PATIENT REGISTRY

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

Yes No

If 'yes', please describe.

We attempt to consent each family during the office visit. We track clinical features, NF complications, physical exam findings, medical history, developmental history, family history, radiology results and genetic results.

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.

Book Chapters

Rosser T, Packer RJ: Novel Therapeutic Approaches for Plexiform Neurofibromas in Neurofibromatosis Type 1. In: Curatolo P, Riva D (ed): Neurocutaneous Syndromes in Children. Montrouge, France: John Libby & Company Ltd., 2006.

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

The current studies are open at our institution:

A Phase II Randomized, Cross-Over, Double-Blind, Placebo-Controlled Trial of the Farnesyltransferase Inhibitor R 115777 in Pediatric Patients with Neurofibromatosis type 1 and Progressive Plexiform Neurofibromas (Multicenter study coordinated through the NIH)

Clinical Outcome Study: Multicenter Study of Tibial Dysplasia in Neurofibromatosis Type 1 (NF1) Patients (Multicenter study coordinated through the University of Utah)

Clinical Outcome Study: Multicenter Study of Spinal Abnormalities in Neurofibromatosis Type 1 (NF1) Patients (Multicenter study coordinated through the University of Utah)

Quantitative Phenotyping and Genotype-Phenotype Correlations in Neurofibromatosis Type 1 (Multicenter study coordinated through the University of Alabama. The study is no longer enrolling patients and our final report has been submitted to IRB).

Trial to Evaluate the Safety of Lovastatin in Adults with Neurofibromatosis Type 1 (NF1) (Dr. Rosser is the study physician for this trial at UCLA)

Prospective Study of the Morbidity of Plexiform Neurofibromas in Individuals with Neurofibromatosis Type 1

Exploring Neural Networks in Children with Neurofibromatosis Type 1: A Functional MRI Study

Evaluation of the Morbidity of Neurofibromatosis Type 2

Neurocutaneous Disorders Database

10. PATIENT SUPPORT

Do you have an NF patient support group that meets in association with your NF Clinic? NO

If 'yes' provide details.

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

What resources would help you to do this?

Starting a support group is not feasible at this point in time. We have limited resources and our patient referral area is very large.

11. OTHER INFORMATION

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