



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

**Clinic Name:**

Neurofibromatosis Clinic

**Affiliated Hospital:**

Children's Hospital of Wisconsin

**Affiliated University or Institution:**

Medical College of Wisconsin

**Clinic Address:**

Children's Hospital of Wisconsin  
9000 West Wisconsin Avenue, MS 716  
Milwaukee, WI 53226

**Clinic Director:**

Pamela Trapani, MD

**Clinic Coordinator Name:**

Heather Radtke, 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): Our NF clinic is a hospital-based clinic staffed by faculty physicians of the Medical College of Wisconsin and staff from the Children's Hospital of Wisconsin.

b. Describe overall your NF Clinic, when it meets and how it functions.

Our NF clinic is held two times per month. The clinic is based in Genetics and we have a medical director and 3 genetic counselors who are case managers for individual patients. These 4 individuals meet once a month to discuss upcoming clinic patients and develop a plan for each patient's clinic visit including any evaluations needed (referrals, testing, etc). We have a multidisciplinary team (including Dermatology, Neurology, Physical Therapy, Occupational Therapy, Speech, Social Work and Child Psychology) who meet with patients during their clinic visits. We also refer to a variety of other specialists, including the specialties listed on page 5, as well as the Pain Clinic, GI clinic, Renal clinic and Neuropsychology clinics at Children's Hospital.

## 2. CLINIC DIRECTOR and STAFF EXPERTISE

a. CLINIC DIRECTOR: Please describe:

i. Your experience to date with NF care

*Pamela Trapane, MD began following NF patients during her genetics fellowship in 1999. She cared for a number of patients with NF1 in general genetics clinic while in the military (2001-2005). In October of 2005, she became program director of the Children's Hospital of Wisconsin NF clinic.*

ii. Your past and current association with NF clinical trials  
*None.*

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.

*Please see: 9. PUBLICATIONS and RESEARCH section b on page 9.*

ii. Your NF-related clinical and scientific publications. Include Journal, Citation and Title.  
*None to date.*

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

*Stefanie Dugan, MS, CGC, Genetic Counselor, Case Manager  
Heather Radtke, MS, CGC, Genetic Counselor, Case Manager  
Dania Stachiw-Hietpas, MS, Genetic Counselor, Case Manager  
Debbie Anderley, Medical Support Secretary, Intake, Scheduler*

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

*Currently, Heather Radtke is our "clinic coordinator".*

*Her current clinic coordinator role includes:*

- *Respond to patient and physician inquiries*
- *Triage and prioritize patient scheduling*
- *Compile the NF schedule and distribute to specialists*
- *Coordinate program development*

- 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 pediatric and surgical subspecialists with considerable experience with all of the above concerns.*

### 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.

*A patient or physician initially calls central scheduling to request an appointment and provide demographic and insurance information. This is entered in our computer system. The central scheduling department transfers the individual to the Genetics clinic secretary to schedule the appointment. If not immediately available, she contacts the family within 2-3 business days to schedule the appointment. Routine new appointments (non-urgent) are generally booked 3 months in advance. If there is a sense of urgency with the appointment, the secretary will discuss the situation with one of the NF genetic counselors. At that time, it is determined if a more emergent appointment is required. These special circumstances include both parental anxiety and/or medical urgency.*

- 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

*All pediatric specialists are located at Children's Hospital of Wisconsin, 9000 W. Wisconsin Avenue, Milwaukee, WI 53226 with internal mailing stations designated below\*. All phone numbers have the following prefix 414-266-XXXX.*

<b>SPECIALTY</b>	<b>DOCTOR</b>	<b>CLINIC ADDRESS *</b>	<b>PHONE</b>	<b>EMAIL (if available)</b>
Genetics	<i>Pamela Trapane, MD</i>	<i>MS 716</i>	<i>X3347</i>	
Neurology	<i>Richard Jacobson, MD, PhD Tamara Fennig, MS, RN, CPNP</i>	<i>C 540</i>	<i>X7545</i>	
Orthopedics	<i>John Thometz, MD</i>	<i>C 360</i>	<i>X7302</i>	
Developmental pediatrics/learning disabilities	<i>Kenneth Grizzle, PhD</i>	<i>MS 744</i>	<i>X2928</i>	
Ophthalmology	<i>Mark Ruttum, MD</i>	<i>MS 784</i>	<i>X2020</i>	
Neurosurgery	<i>Sean Lew, MD</i>	<i>C 310</i>	<i>X6435</i>	
Plastic surgery	<i>John Jensen, MD</i>	<i>C 340</i>	<i>X7525</i>	
Neurooncology	<i>Catherine Amlie-Lefond, MD</i>	<i>C 540</i>	<i>X7545</i>	
Medical Oncology/Radiation Oncology	<i>Sachin Jogonal, MD</i>	<i>MS 756</i>	<i>X2420</i>	
Endocrinology	<i>Ramin Alemzadeh, MD</i>	<i>C520</i>	<i>X6750</i>	
Audiology/ENT	<i>Stephen Conley, MD</i>	<i>MS 782</i>	<i>X6453</i>	
Radiology/Neuroradiology	<i>Brian Lundeen, MD</i>	<i>MS 721</i>	<i>X3110</i>	
General Surgery/Surgical Oncology	<i>Thomas Sato, MD</i>	<i>C 320</i>	<i>X6558</i>	
Dermatology	<i>Kristen Holland, MD</i>	<i>786F</i>	<i>X6430</i>	
Cardiovascular Disease	<i>Michael Earing, MD</i>	<i>MS 713</i>	<i>X2380</i>	
Oral and Maxillofacial Surgery	<i>Arlen Denny, MD</i>	<i>C 340</i>	<i>X2825</i>	
Behavioral Issues	<i>Kenneth Grizzle, MD</i>	<i>MS 744</i>	<i>X2928</i>	



4) *Assisting the family in finding adult resources and family support.*

*These tasks are performed by many individuals, including the program director, genetic counselor and social worker. The social worker also provides the family with a Transition Program packet.*

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

*We have developed a close collaboration with Dr. Hendrikus Krouwer, neuro-oncologist at Medical College of Wisconsin who manages the care of adults with NF1, NF2 and other related disorders. We transition our patients to his clinic between the ages of 18 and 24 years of age. Stefanie Dugan, MS, one of our genetic counselors, regularly staffs Dr. Krouwer's clinic.*

Challenges that we have overcome with this system is:

*The main challenge with our transition program is that the medical records and radiology films are at 2 different institutions. To handle this, the genetic counselor has the family sign a record of release to forward all pertinent records to Dr. Krouwer.*

## 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.)

*NF Staffing - 2-3 hours once a month; program director and genetic counselors; review each patient's medical history and anticipate their specific needs for upcoming clinics to formulate a plan of care. We also discuss a variety of other topics such as current advances, breakthroughs, clinical trials and recent publications.*

*Radiology Rounds - 1 hour conference once a month; genetics staff meets with radiologist; review all NF films and discuss case with the radiologist to develop surveillance recommendations and plan of care for each patient.*

*NF Meetings - 1 hour once a month; genetic counselors; problem-solve solutions to improve clinic flow, patient care and comprehensiveness of the clinic.*

*Case Conference - 1 hour twice a month; genetics department, including 3 medical geneticists, 10 genetic counselors, cytogeneticist and biochemical*

*geneticist; review challenging NF cases with our peers to solicit input on diagnostic, counseling and medical management dilemmas.*

## 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)

X Yes  No

Do you currently refer patients to clinical trials?

X 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 had one patient participate in the PEG-Interferon protocol with Brigitte Widemann, MD of the NIH in 2005. Unfortunately, our patient developed hepatic toxicity and needed to withdraw from the trial.*

## 8. PATIENT REGISTRY

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

X Yes  No

If 'yes', please describe.

*Our program director keeps a database of all patients that have been seen in our NF clinic since 2005. We also have a centralized hospital database that lists individuals who have been evaluated in our NF clinic. We have long been interested in expanding our database to capture clinical features and natural history information and look forward to working with CTF to accomplish this.*

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

X Yes  No

## 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.

**Neurofibromatosis Type I in Genetic Counseling Practice: Recommendations of the National Society of Genetic Counselors.** HB Radtke, CD Sebold, C Allison, J Larsen-Haidle, G Schneider, *Journal of Genetic Counseling*, in press, accepted 3/07.

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

*Associations Between Headache Experiences and Individual and Family Functioning in Adolescents with Neurofibromatosis-1, Children's Research Institute Grant in collaboration with Molly Garwood, PhD of the Jane B. Pettit Pain and Palliative Care Center at Medical College of Wisconsin, began in May 2007.*

*Early Indicators of Emotional, Learning, and Cognitive Difficulties in Neurofibromatosis-1, University of Wisconsin Milwaukee Research Growth Initiative Grant in collaboration with Bonnie Klein Tasman, PhD of the Psychology department at the University of Wisconsin Milwaukee. Grant is pending final approval.*

## 10. PATIENT SUPPORT

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

Yes. \*

*\* We work in close collaboration with Elaine Pankow and the Wisconsin Chapter of the CTF. We have planned and conducted medical symposiums with the chapter and we inform our patients and families about CTF and CTF events. In addition, they helped create an NF bulletin board for our clinic.*

## 11. OTHER INFORMATION

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

*Our NF clinic was started in 1987 and is the only designated NF clinic in the state of Wisconsin that provides a comprehensive, multidisciplinary approach to the diagnosis and management of NF1, NF2 and TSC.*

*Currently, the NF clinic serves the medical needs of over 200 individuals, offering family-centered, child-focused care by a dedicated team of specialists.*

*Our referral area includes northern Illinois, Upper Peninsula Michigan and the entire state of Wisconsin. Other genetic centers in the state recognize our expertise and refer to our multidisciplinary clinic.*

*We also provide education on a variety of levels. Genetic counseling students from programs throughout the country rotate through our clinic, as well as medical students and residents from the Medical College of Wisconsin.*

*Our clinic notes are comprehensive and informative including not only the patient's relevant medical history and recommendations, but also general information about NF so that the primary care physician and referring specialists become more knowledgeable about NF. Furthermore, these notes are copied to the patient's family serving as a valuable reference/resource to facilitate their role as partners in their own healthcare decisions.*