



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

**Clinic Name:**

Henry Ford Genetics Clinic

**Affiliated Hospital:**

Henry Ford Hospital

**Affiliated University or Institution:**

N/A

**Clinic Address:**

Henry Ford Genetics Clinic  
3031 West Grand Boulevard, Suite 700  
Henry Ford Health System  
Detroit, MI 48202

**Clinic Director:**

Howard Feit, MD, Ph.D.

**Clinic Coordinator Name:**

Amy Decker, MS, CGC

*\*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.

Our NF clinic meets twice monthly. Clinic staff includes an adult neurologist (Dr. Feit), clinical geneticist (Dr. Roberson, pediatrician and geneticist) and genetic counselors. Patients are seen at their initial appointment by a genetic counselor, geneticist and neurologist. Patients seen in follow up are seen by the neurologist and/or the geneticist. Average wait time for an appointment is 1-2 weeks. Care is coordinated with other specialists within our system and externally if needed.

## 2. CLINIC DIRECTOR and STAFF EXPERTISE

### a. CLINIC DIRECTOR: Please describe:

#### i. Your experience to date with NF care

Dr. Feit has been associated with the NF Clinic at Henry Ford Hospital since 1986. Dr. Roberson assumed the role of seeing pediatric patients with NF after the death of Dr. Lester Weiss in 1998.

#### ii. Your past and current association with NF clinical trials

We have not conducted any NF trials at the HFH NF clinic. We have referred patients with optic glioma to the Cleveland Clinic for trials.

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

Dr. Feit has participated in numerous multiple sclerosis trials (see CV). The Oncology Department is affiliated with numerous trials and is noted particularly for brain tumor trials thru the Hermelin Brain Tumor Center.

### 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.

July, 1988 - June, 1989 DNA sampling a large Bermudan pedigree with NF-1. National Neurofibromatosis Society, \$6,000.

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

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

Provide Name; Title; Degree/Qualifications; Role in Clinic.

Jacquelyn Roberson, MD, FACMG Division Head Genetics Clinics, Clinical Geneticist (Peds) for 30 years.

Barry Wolf, MD, PhD, FACMG, Chair, Dept Medical Genetics, Clinical Geneticist (Peds) for 30 years.

Xia Wang, MD, PhD, FACMG, Clinical Geneticist (Adult)

Amy Decker, MS, CGC, Certified Genetic Counselor, Clinic Coordinator, Genetics Clinic

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

Amy Decker coordinates NF clinic scheduling, patient scheduling and facilitating patient referrals to the NF clinic. Dr. Feit facilitates and coordinates imaging and medical issues.

- 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.

Dr. Feit stays abreast of advances in NF research and clinical care by attending the NF Conference in Aspen (Park City 2007) every year. Recognition of patients with unusual manifestations of NF led to the identification of the multiple isolated neurofibroma phenotype based in part on two patients that were referred to Dr. Mia MacCollin (A clinical study of patients with multiple isolated neurofibromas. Blakley P, Louis DN, Short MP, MacCollin M, Jmed Genetics 2001; 38:485-8.

### 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 phone calls are typically returned within 1 business day. Average wait time for an appointment is 1-2 weeks; if urgent, then the patient will be accommodated on either the Genetics schedule or the Neurology schedule.

- 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	Barry Wolf, MD, PhD Jacquelyn Roberson, MD	3031 W. Grand Blvd NCO 7 Detroit, MI 48202	313-916-3188	Bwolf1@hfhs.org Jrobers1@hfhs.org
Neurology	Jules Constantinou, MD	24555 Haig Taylor, MI 48180	313-375-2170	jconsta1@hfhs.org
Orthopedics	Ira Zaltz	2799 W. Grand Blvd; K-12 Detroit, MI 48202	313-916-2013	izaltz1@hfhs.org
Developmental pediatrics/learning disabilities	Dr. Tisa Johnson	3031 W. Grand Blvd, NCO 8 Detroit, MI 48202	313-916-2600	Tjohnso2@hfhs.org
Ophthalmology	Brian Bachynski, MD Patrick Dennehy, MD	2799 W. Grand Blvd; K-10 Detroit, MI 48202	313-916-2020	bbachyn1@hfhs.org
Neurosurgery	Dr. Fred Junn Dr. Jack Rock	2799 W. Grand Blvd; K-11 Detroit, MI 48202	313-916-1094	jrock1@hfhs.org
Plastic surgery	Dr. Vigen Darian	2799 W. Grand Blvd; K-16 Detroit, MI 48202	313-916-2683	vdarian1@hfhs.org
Neurooncology	Dr. Tom Mikkelsen	2799 W. Grand Blvd; ER-3 Detroit, MI 48202	313-916-8688	tmikkel1@hfhs.org
Medical Oncology/Radiation Oncology	Dr. Samuel Ryu (Rad Onc) Dr. Thomas Doyle (Med Onc)	2799 W. Grand Blvd; GSBS Detroit, MI 48202	313-916-1027	sryu1@hfhs.org tdoyle1@hfhs.org
Endocrinology	Dr. Mahalakshmi Honasoge	6777 W. Maple Rd W. Bloomfield, MI 48323	248-661-7920	mhonaso1@hfhs.org
Audiology/ENT	Michael D. Seidman, MD., FACS	6777 W. Maple Rd W. Bloomfield, MI 48323	O:248-661-7211 F:248-661-6456	<a href="mailto:mseidma1@hfhs.org">mseidma1@hfhs.org</a>
Radiology/ Neuroradiology	Dr. Suresh Patel	2799 W. Grand Blvd; K-3 Detroit, MI 48202	313-916-1374	spatel@rad.hfh.edu
General Surgery/Surgical Oncology	Dr. David Nathanson	2799 W. Grand Blvd; K-8 Detroit, MI 48202	313-916-2917	dnathan1@hfhs.org
Dermatology	Dr. Tor Shwayder	3031 W. Grand Blvd NCO 8 Detroit, MI 48202	313-916-2161	tshwayd1@hfhs.org

Cardiovascular Disease	Dr. Michael Epstein	2799 W. Grand Blvd K13 Detroit, MI 48202	313-916-3121	mepstei1@hfhs.org
Oral and Maxillofacial Surgery	The University of Detroit-Mercy Faculty Dental Practice	4201 St. Antoine Detroit, MI 48201	313-494-6730	na
Behavioral Issues	Dr. Wiley Rasbury	Henry Ford Hospital One Ford Place-1 Detroit, MI 48202	313-874-6691	WRASBUR1@hfhs.org

## ADULT CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Xia Wang, MD, PhD	3031 W. Grand Blvd NCO 8 Detroit, MI 48202	313-916-3188	Xwang1@hfhs.org
Neurology	Dr. Howard Feit	6777 W. Maple Rd W. Bloomfield, MI 48323	313-661-2400	feit@neuro.hfh.edu
Orthopedics	Dr. Theodore Parsons  Dr. Stephen Bartol MD MBA	Henry Ford Hospital 2799 West Grand Blvd, CFP-103 Detroit, MI 48202	Ph: 313-916-3879 cell: 313-363-0007 clinical nurse coordinator is Yvette Hanker: 313-916-3661	tparson3@hfhs.org sbartol1@hfhs.org
Ophthalmology	Brian Bachynski, MD Patrick Dennehy, MD	2799 W. Grand Blvd; K-10 Detroit, MI 48202	313-916-2020	bbachyn1@hfhs.org
Neurosurgery	Dr. Fred Junn Dr. Jack Rock	2799 W. Grand Blvd; K-11 Detroit, MI 48202	313-916-1094	jrock1@hfhs.org
Plastic surgery	Dr. Vigen Darian	2799 W. Grand Blvd; K-16 Detroit, MI 48202	313-916-2683	vdarian1@hfhs.org
Neurooncology	Dr. Tom Mikkelsen	2799 W. Grand Blvd; ER-3 Detroit, MI 48202	313-916-8688	tmikkel1@hfhs.org
Medical Oncology/Radiation Oncology	Dr. Samuel Ryu (Rad Onc)  Dr. Thomas Doyle (Med Onc)	2799 W. Grand Blvd; GSBS Detroit, MI 48202	313-916-1027	sryu1@hfhs.org tdoyle1@hfhs.org
Endocrinology	Dr. Mahalakshmi Honasoge	6777 W. Maple W. Bloomfield, MI 48323	248-661-7920	mhonaso1@hfhs.org

Audiology/ENT	Michael D. Seidman, MD., FACS	6777 W. Maple W. Bloomfield, MI 48323	O:248-661-7211 F:248-661-6456	<a href="mailto:mseidma1@hfhs.org">mseidma1@hfhs.org</a>
Radiology/ Neuroradiology	Dr. Suresh Patel	2799 W. Grand Blvd; K-3 Detroit, MI 48202	313-916-1374	spatel@rad.hfhs.edu
General Surgery/Surgical Oncology	Dr. David Nathanson	2799 W. Grand Blvd; K-8 Detroit, MI 48202	313-916-2917	dnathan1@hfhs.org
Dermatology	Dr. Tor Shwayder	3031 W. Grand Blvd NCO 8 Detroit, MI 48202	313-916-2161	tshwayd1@hfhs.org
Cardiovascular Disease	Dr. Stephen Smith	2799 W. Grand Blvd, K6 Detroit, MI 48202	313-916-3189	Ssmith7@hfhs.org
Oral and Maxillofacial Surgery	The University of Detroit- Mercy Faculty Dental Practice	4201 St. Antoine Detroit, MI 48201	313-494-6730	na
Behavioral Issues	Dr. Wiley Rasbury	Henry Ford Hospital One Ford Place-1 Detroit, MI 48202	313-874-6691	WRASBUR1@hfhs.org

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	58	2	0	0
NUMBER OF <b>NEW</b> PATIENTS SEEN IN PAST 12 MONTHS	19	0	0	0
TOTAL	58	2	0	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 43                      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?

YES

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

Patients under 18 who have been followed by Dr. Roberson are transferred to Dr. Feit. Henry Ford Hospital maintains an extensive computerized medical record system so that all previous information is immediately available.

The only major barrier to transitioning to adult care is insurance issues. Social work is available to help in obtaining insurance through Medicaid, etc.

**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.)

The tumor cases are reviewed by the relevant tumor boards (Brain Tumor Board and Spine Tumor Board) under the direction of Dr. Tom Mikkelsen. An example of a recent review is attached.

**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.

**Treatment of optic glioma with platinum derivatives: two patients referred to the Cleveland Clinic**

## 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.

**Recognition of patients with unusual manifestations of NF led to the identification of the multiple isolated neurofibroma phenotype based in part on two patients from our NF clinic that were referred to Dr. Mia MacCollin (A clinical study of patients with multiple isolated neurofibromas. Blakley P, Louis DN, Short MP, MacCollin M, Jmed Genetics 2001; 38:485-8.**

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

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? There is a Michigan Chapter of the CFT. We would be happy to be associated with this support group. I have emailed the chapter president to discuss ways we could work together.

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.