



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

**Clinic Name:**

CCF/NF Program

**Affiliated Hospital:**

Cleveland Clinic Foundation

**Affiliated University or Institution:**

Cleveland Clinic Lerner College of Medicine

**Clinic Address:**

Cleveland Clinic  
9500 Euclid Avenue  
Cleveland, OH 44195

**Clinic Director:**

A. David Rothner, MD

**Clinic Coordinator Name:**

Marge Zabukovec, RN

*\*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.

It is a clinic without walls. Patients are scheduled for a specialist in NF and an ophthalmologist. Further, appointments with other specialists and follow-up visits are then scheduled on an as needed basis. Routine follow-up visits are yearly.

## 2. CLINIC DIRECTOR and STAFF EXPERTISE

- a. CLINIC DIRECTOR: Please describe:
  - i. Your experience to date with NF care -  
**30 years of NF/patient care**
  - ii. Your past and current association with NF clinical trials  
**See below**
  - iii. Your past and current association with other clinical trials e.g. oncology trials  
**See below**
- 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. **See Dr. Cohen's CV**
  - ii. Your NF-related clinical and scientific publications. Include Journal, Citation and Title. **See attached**
- c. Who are the key staff in your NF clinic facility? Provide Name; Title; Degree/Qualifications; Role in Clinic. **See attached**
- d. Who within this core staff currently coordinates NF patient services? Describe this individual's NF clinic related duties. **Dr. Rothner and Mrs. Zabukovec**
- 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. Cohen- O.P.G.**

A. David Rothner, MD has been the main point person for Neurofibromatosis at the Cleveland Clinic for more than twenty years. He is ably assisted by Dr. Bruce H. Cohen, who is a pediatric neurologist/neuro-oncologist and has been involved in multiple chemotherapy and NF -targeted protocols. Dr. Manikum Moodley has joined our group and will be part of the group of three that directs the clinic. The CVs of all of these individuals is attached. All of us have had extensive experience in the caring for patients with NF type 1, NF type 2 and segmental NF for greater than 20 years each.

Dr. Bruce H. Cohen has been involved in clinical trials utilizing chemotherapy for patients with NF. His CV is attached.

He has been involved in numerous oncology trials for other neoplastic disorders. See his attached CV.

The following pages demonstrate publications and any task related to NF by two of the three directors.

All of us are involved in clinical research as it relates to NF. My recent activities involve echocardiographic findings in patients with NF type 1. Chest deformities in patients with NF type 1. Cerebrovascular abnormalities in patients with NF type 1 and a review of our patients with segmental NF.

### 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.

**See 4B**

- 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).

| SPECIALTY                                      | DOCTOR  | CLINIC ADDRESS   | PHONE  | EMAIL (if available)                                  |
|--|---|--|--|---|
| Genetics                                       | Marvin D. Natowicz<br>Rocio Moran                     | 9500 Euclid Avenue,<br>Cleveland, Ohio 44195                             | 216-445-3735<br>216-444-2200                 | natowim@ccf.org<br>moranr@ccf.org                     |
| Neurology                                      | A. David rothner<br>Bruce H. Cohen<br>Manikum Moodley | 9500 Euclid Avenue,<br>Cleveland, Ohio 44195, S71<br>Cleveland, OH 44195 | 216-444-5514<br>216-444-9182<br>216-444-3135 | Rothned@ccf.org<br>Cohenb2@ccf.org<br>moodlem@ccf.org |
| Orthopedics                                    | Robert T. Ballock and Staff                           | 9500 Euclid Avenue, A41<br>Cleveland, Ohio 44195                         | 216-444-5775                                 | balloccr@ccf.org                                      |
| Developmental pediatrics/learning disabilities | Michael Manos<br>Gerald Erenberg                      | 9500 Euclid Avenue,<br>S71Cleveland,                                     | 216-445-7574<br>216-444-2375                 | manosm@ccf.org<br>erenbeg@ccf.org                     |

|   |                                     |   |                              |                                    |
|---|-------------------------------------|---|------------------------------|------------------------------------|
|   |                                     | OH 44195  |                              |                                    |
| Ophthalmology                             | Elias Traboulsi<br>Andreas Marcotty | 9500 Euclid<br>Avenue, i32<br>Cleveland, Ohio<br>44195,<br>Cleveland, Ohio<br>44195 | 216-444-4363<br>216-831-0120 | traboue@ccf.org<br>marcota@ccf.org |
| Neurosurgery                              | Mark Luciano                        | 9500 Euclid<br>Avenue, S80<br>Cleveland, Ohio<br>44195                              | 216-444-5747                 | lucianm@ccf.org                    |
| Plastic surgery                           | Francis Papay                       | 9500 Euclid<br>Avenue, A60<br>Cleveland, Ohio<br>44195                              | 216-444-6905                 | papayf@ccf.org                     |
| Neurooncology                             | Bruce H. Cohen                      | 9500 Euclid<br>Avenue, R20<br>Cleveland, Ohio<br>44195                              | 216-444-9182                 | Cohenb2@ccf.org                    |
| Medical<br>Oncology/Radiation<br>Oncology | Tanya Tekautz<br>John Su            | 9500 Euclid<br>Avenue,<br>Cleveland, Ohio<br>44195                                  | 216-444-9532<br>216-444-5574 | tekautt@ccf.org<br>suj@ccf.org     |
| Endocrinology                             | Doug Rogers                         | 9500 Euclid<br>Avenue,<br>Cleveland, Ohio<br>44195                                  | 216-445-8048                 | rogersd@ccf.org                    |
| Audiology/ENT                             | Susan Forsythe<br>Keiko Hirose      | 9500 Euclid<br>Avenue,<br>Cleveland, Ohio<br>44195                                  | 216-444-5142<br>216-444-8586 | forsyts@ccf.org<br>hirosek@ccf.org |
| Radiology/<br>Neuroradiology              | Janet Reid<br>Paul Ruggieri         | 9500 Euclid<br>Avenue,<br>Cleveland, Ohio<br>44195                                  | 216-445-2999<br>216-445-7035 | reidj@ccf.org<br>ruggiep@ccf.org   |
| General<br>Surgery/Surgical<br>Oncology   | Oliver Soldes                       | 9500 Euclid<br>Avenue,<br>Cleveland, Ohio<br>44195                                  | 216-445-1588                 | soldeso@ccf.org                    |
| Dermatology                               | Allison Vidimos                     | 9500 Euclid<br>Avenue, A61<br>Cleveland, Ohio<br>44195                              | 216-444-3345                 | vidimoa@ccf.org                    |
| Cardiovascular<br>Disease                 | Larry Latson                        | 9500 Euclid<br>Avenue,<br>Cleveland, Ohio<br>44195                                  | 216-445-6532                 | latsonl@ccf.org                    |
| Oral and<br>Maxillofacial<br>Surgery      | Keiko Hirose and Staff              | 9500 Euclid<br>Avenue,<br>Cleveland, Ohio<br>44195                                  | 216-444-8586                 | hirosek@ccf.org                    |

|                   |              |   |              |                 |
|-------------------|--------------|---|--------------|-----------------|
| Behavioral Issues | Dunya Yaldoo | 9500 Euclid Avenue, S20<br>Cleveland, Ohio<br>44195 | 216-445-1279 | yaldood@ccf.org |
|-------------------|--------------|---|--------------|-----------------|

### ADULT CARE

| SPECIALTY                                      | DOCTOR                       | CLINIC ADDRESS                                       | PHONE                        | EMAIL (if available)              |
|--|------------------------------|--|------------------------------|-----------------------------------|
| Genetics                                       | Marvin Natowicz              | 9500 Euclid Avenue, S71<br>Cleveland, Ohio<br>44195  | 216-445-3735                 | natowim@ccf.org                   |
| Neurology                                      | Glen Stevens                 | 9500 Euclid Avenue, S90<br>Cleveland, Ohio<br>44195  | 216-445-1787                 | steveng@ccf.org                   |
| Orthopedics                                    | Kenneth Marks                | 9500 Euclid Avenue,<br>Cleveland, Ohio<br>44195      | 216-444-2637                 | marksk@ccf.org                    |
| Developmental pediatrics/learning disabilities | Neuropsychology Staff        | 9500 Euclid Avenue,<br>Cleveland, Ohio<br>44195      | 216-444-7748                 |                                   |
| Ophthalmology                                  | Gregory Kosmorsky            | 9500 Euclid Avenue, I-32<br>Cleveland, Ohio<br>44195 | 216-444-2855                 | kosmorg@ccf.org                   |
| Neurosurgery                                   | Gene Barnett<br>Joung Lee    | 9500 Euclid Avenue, R20<br>Cleveland, Ohio<br>44195  | 216-444-5381                 | barnetg@ccf.org                   |
| Plastic surgery                                | James Zins                   | 9500 Euclid Avenue, A60<br>Cleveland, Ohio<br>44195  | 216-444-6901                 | zinsj@ccf.org                     |
| Neurooncology                                  | Glen Stevens                 | 9500 Euclid Avenue, S90<br>Cleveland, Ohio<br>44195  | 216-445-1787                 | steveng@ccf.org                   |
| Medical Oncology/Radiation Oncology            | John Su                      | 9500 Euclid Avenue,<br>Cleveland, Ohio<br>44195      |                              | Suj@ccf.org                       |
| Endocrinology                                  | Robert Zimmerman             | 9500 Euclid Avenue,<br>Cleveland, Ohio<br>44195      | 216-444-9428                 | zimmerr@ccf.org                   |
| Audiology/ENT                                  | Gordon Hughes<br>Peter Weber | 9500 Euclid Avenue,                                  | 216-444-5375<br>216-444-6696 | hughesg@ccf.org<br>weberP@ccf.org |

|   |                               |  |                              |                                    |
|---|-------------------------------|--|------------------------------|------------------------------------|
|   |                               | Cleveland, Ohio<br>44195                               |                              |                                    |
| Radiology/<br>Neuroradiology            | Michael Modic<br>Paul Ruggeri | 9500 Euclid<br>Avenue, P34<br>Cleveland, Ohio<br>44195 | 216-444-9308<br>216          | Modicm1@ccf.org<br>ruggiep@ccf.org |
| General<br>Surgery/Surgical<br>Oncology | John Fung<br>Marc Shapiro     | 9500 Euclid<br>Avenue,<br>Cleveland, Ohio<br>44195     | 216-444-3778<br>216-445-2067 | fungj@ccf.org<br>shapirm@ccf.org   |
| Dermatology                             | Allison Vidimos               | 9500 Euclid<br>Avenue,<br>Cleveland, Ohio<br>44195     |                              | Vidimoa@ccf.org                    |
| Cardiovascular<br>Disease               | Bruce Lytle                   | 9500 Euclid<br>Avenue, F25<br>Cleveland, Ohio<br>44195 | 216-444-6962                 | lytleb@ccf.org                     |
| Oral and<br>Maxillofacial<br>Surgery    | Marshall Strome               | 9500 Euclid<br>Avenue,<br>Cleveland, Ohio<br>44195     | 216-444-6686                 | stromem@ccf.org                    |
| Behavioral Issues                       | George Tesar                  | 9500 Euclid<br>Avenue, P57<br>Cleveland, Ohio<br>44195 | 216-445-6224                 | tesarg@ccf.org                     |

**4. NUMBER OF NF PATIENTS YOUR CLINIC SEES**

a. How many NF PATIENTS did you see in the past 12 months?

The NF clinic functions as a clinic without walls. New patients are generally seen by one of the three pediatric neurologists active in this activity or the adult neuro-oncologist active in this program. Patients are generally pre-scheduled for the initial visit as well as a visit with either our pediatric ophthalmologist or adult neuro-ophthalmologist. The coordination of these activities take place on an Ad Hoc basis and I would estimate that anywhere from 4-10 hours per week are dedicated to seeing patients with NF.

b. How many of these were NEW patients to your clinic?

We have an excellent scheduling system. All visits are computerized. All appointment secretaries can make appointments for all physicians at the clinic when a call comes in regarding a patient with NF. That patient is scheduled for either myself, Dr. Cohen or Dr. Moodley. There is a second visit the same day scheduled with a pediatric ophthalmologist or neuro-ophthalmologist. At that initial visit it is decided as to whether additional studies are needed. If so they are put into the computer, the patient moves to the front desk and all appointments are scheduled immediately. The patient does not have to make any further calls. Should we receive information that there is an urgent issue such as impending loss of vision, a growing mass etc. that patient can be

accommodated within 24 hours during the regular week or by the pediatric neurologist on call during the weekend.

*Insert numbers below*

|  | NF1          | NF2        | SCHWANNOMATOSIS | OTHER        |
|--|--------------|------------|-----------------|--------------|
| NUMBER OF PATIENTS SEEN IN PAST 12 MONTHS            | 1200 visits  | 20 Est.    | 2-5 (est.)      | 2-3 (est)    |
| NUMBER OF <u>NEW</u> PATIENTS SEEN IN PAST 12 MONTHS | 80-100       | 6-8 (est.) | 2 (est.)        | 10-15 (est.) |
| TOTAL  | ~1200 visits | ~25        | ~5              | ~20          |

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 (%)60 18+ (%)40

There have been no major changes in the makeup of the individuals who see patients with NF during the past year. At the present time as our NF clinic is being re-formatted, if for example there is a group of five pediatric orthopedists, we are attempting to identify those that have a major interest in this area or are willing to develop a major interest in this area. As soon as our coordinator is appointed we will begin meeting quarterly with all integral members of the NF Center.

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

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

All who become 18-21.

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

## 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 pediatric neurology program at the Cleveland Clinic Foundation consist of 14 board certified Pediatric Neurologists. As patients become 18 and or complete high school, they are transitioned to the adult service. There is absolutely no problem with this as we have 50 adult neurologists. They are usually transferred to the care of Dr. Glen Stephens, adult neurologist/neuro-oncologist who follows our NF patients. There are no difficulties encountered in this process as the computer system that makes appointments is uniform to all physicians and can be easily accessed by any appointment secretary at the clinic. Dr. Cohen does not refer his patients to the adult doctors, as he care for both children and adults with NF type I and NF type 2.

The curriculum regarding NF is already in place. Yearly lectures are given to the pediatric residents, neurology residents and neurosurgery residents regarding NF. In addition, but not on a regular basis, conferences are scheduled in pediatric grand rounds, neurology grand rounds and pediatric neurology grand rounds and neurosurgery grand rounds. From time to time presentations are made in ophthalmology, orthopedics, internal medicine, genetics and otolaryngology.

As our coordinator assumes his/her position we will be proactive in presenting these conferences both in our educational program as well as the educational program of the ten (10) hospitals that are part of our system and the six regional medical centers that are associated with our system. In addition we will be proactive in contacting other hospitals to make these presentations so that word of our reformatted NF clinic becomes more widely disseminated across the state and nationally.

## 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.

See Curriculum Vitae of Dr. Bruch H. Cohen

## 8. PATIENT REGISTRY

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

Yes   No

If 'yes', please describe.

The system at the Cleveland Clinic allows us to enter the code for NF type 1, NF type 2 or NF other and receive all Cleveland Clinic patient numbers and names that were seen during a specific period of time. In this way, when we undertake clinical research we are able to access all NF patients seen in a given year or over a given period of time. As our new coordinator comes on board we hope to offer the services of the NF clinic to patients not seen by our core group. In addition we will offer those patients the opportunity to have their first agreed relative seen and evaluated for NF. When our coordinator comes on board one of the obligations will be to enter this data into the international NF registry and this will be one of their prime responsibilities.

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

Yes  No

**When we have a coordinator**

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 attached.

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

Neuro-oncology-O.P.G. Dr. Cohen

NF-Cardiac/Vascular/Skeletal -Drs. Rothner and Moodley

## 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? -Yes

What resources would help you to do this?

We would supply marketing /professional personnel and meeting space.

A list of some of the projects that we have carried out over the years and during the past year regarding NF. Most of the publications and presentations are clinical.

At the present time we have NF related research ongoing in chest deformities, cerebrovascular abnormalities, segmental NF, and cardiac and vascular abnormalities of NF. In addition, Dr. Cohen is an active participant in clinical trials. He also has a particular interest in optic pathway gliomas.

## 11. OTHER INFORMATION

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

Enclosed please find the proposal we have submitted to the Chairman of our Neuroscience program here at the Cleveland Clinic detailing our planned approach to our renewed efforts in the area of NF. In addition, Dr. Manikum Moodley has made an innovation trip to visit Dr. Bruce Korf at Birmingham Alabama to see how his clinic operates and what types of research are being done there. I have taken a similar trip to Dr. David Guttman at Washington University in St. Louis. The experience gained from our innovation trips to Birmingham and St. Louis opens our minds to new ideas in every direction and simultaneously expands the horizons of one's thinking about how best we can develop a NF Center at the Cleveland Clinic that will provide optimal

multidisciplinary care for all patients with NF. To accomplish the above one needs commitment, a special interest and passion and above all effective communication between the multidisciplinary team who all have a significant interest in NF. We believe we at the Cleveland Clinic have the necessary ingredients to set our NF center apart from the others in providing excellence in clinical care, education and research.