



NF Clinic Network (NFCN) Application Form*

Clinic Name:

Cincinnati Neurofibromatosis Center

Affiliated Hospital:

Cincinnati Children's Hospital Medical Center

Affiliated University or Institution:

University of Cincinnati

Clinic Address:

Cincinnati Neurofibromatosis Center
CCHMC, Division of Human Genetics
333 Burnet Avenue, ML 4006
Cincinnati, OH 45229

Clinic Director:

Elizabeth K. Schorry, MD

Clinic Coordinator Name:

Anne Lovell, RN, MSN

**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 pediatric NF Clinic meets twice per month, in clinic space of the Div. of Human Genetics at Cincinnati Children's Hospital. It is a multidisciplinary clinic, attended by 3 geneticists, an orthopedic surgeon, a developmental pediatrician, social worker, and nurse coordinator. Patients are seen by each of the specialists as needed during the clinic visit. Each specialist gives their recommendations, and

a letter of group recommendations is compiled by the nurse coordinator and mailed to the family after the visit. About 20 patients are seen at each clinic.

A separate NF-Oncology clinic is held once per month in the Oncology Clinic for those children with NF1 who also have CNS tumors such as optic nerve glioma. Children are seen by their Oncologist, geneticist, and NF clinic nurse coordinator when they are coming for their regular follow-up visit with Oncology or for ongoing chemotherapy. A neurologist, psychologist, endocrinologist, physiatrist, and oncology social worker are also available at this clinic as needed.

Our Adult NF Clinic is held once per month across the street, in the Dept. of Internal Medicine and Pediatrics of the University of Cincinnati. It is attended by an Internist, a geneticist, and our NF nurse coordinator. Patients are evaluated by both physicians at this visit, and referrals are made to other specialists as needed. Patients may also receive their primary care, if desired, in this setting, through the internist, Dr. Caroline Mueller.

2. CLINIC DIRECTOR and STAFF EXPERTISE

a. CLINIC DIRECTOR: Please describe:

i. Your experience to date with NF care

I was involved in the formation of our NF clinic in Cincinnati in 1986 as a genetics fellow, and have been actively involved in the clinic and in seeing patients with NF1 and NF2 for the past 20 years. I have been director of the Cincinnati NF Center since 1993. I am currently a member of the CTF Clinical Care Advisory Board.

ii. Your past and current association with NF clinical trials

I have been a co-investigator in several NF clinical studies, including Dr. John Carey's study of natural history of tibial dysplasia in NF1 and Dr. David Viskochil's study of scoliosis in NF1 (both still ongoing) and have enrolled patients in multiple studies. Our center also participated in Dr. Korf's study of plexiform neurofibromas in NF1. Together with our oncologists, we have enrolled NF patients in several therapeutic trials for plexiform neurofibromas, including 10 patients enrolled in the Tipifarnib trial.

Our center is one of the 9 centers chosen to be in the NF Consortium funded by the DOD for drug trials for NF, and the first study of the consortium (Rapamycin for progressive plexiform neurofibromas in NF1) will be led by our center.

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

We work closely with Drs. John Perentesis and Brian Weiss of the Div. of Pediatric Oncology, and our patients have been enrolled in multiple clinical trials

through the COG, NCI and others, including the Tipifarnb trial for plexiform neurofibromas. There is a well-established Clinical Trials Program through the Div. of Pediatric Oncology which has experience with thousands of patients enrolled in Phase I and II clinical trials for pediatric tumors and malignancies.

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.

Source – U.S. Dept. of Defense

Title – Social and Emotional Functioning of Children with NF1 and their families:
A case controlled study.

Amount - \$1,042,037

Dates – 7/1/99 – 6/30/02

P.I. – Robert Noll, Ph.D.

Percent effort – 5%

Role – Co-Investigator

(Project was cancelled after 1 year due to IRB conflicts)

Source – Shriner’s Hospitals Research Foundation

Title – Clinical Outcome Study: Multicenter study of tibial dysplasia in neurofibromatosis type 1 (NF1) patients

Dates – 1/1/2004 – 12/30/2007

Amount - \$170,000 per year

P.I. – John Carey, M.D., Univ. of Utah

Percent effort – 5%-8%

Role – Co-Investigator in multi-center study

Source – U.S. Dept. of Defense

Title – Cincinnati Neurofibromatosis Center Consortium Proposal

Dates – 1/1/06-12/31/06

Amount - \$30,000

Percent effort – 5%

Role – Principal Investigator

(One of 8 centers chosen nationwide to form a consortium for clinical trials for NF)

Source – NIH (R01)

Title – Spinal abnormalities in neurofibromatosis type 1

Dates – 3/1/06 – 2/28/10

P.I.- D. Viskochil, Univ. of Utah

Percent effort – 10%

Role – Co-investigator in multi-center study

Source – U.S. Dept. of Defense (CDMRP, NFRP)

Title – Neurofibromatosis Consortium

Dates – 6/1/07 – 5/31/12

Amount - \$6,000,000

P.I. – Jeannette Lee, University of Alabama

Percent Effort – 10%

Role – Local P.I. for 9 center consortium for drug trials for NF

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

1. E.K. Schorry, A.M. Lovell, A. Milatovich, H.M. Saal, "Ullrich-Turner syndrome and neurofibromatosis-1", *Amer. J. Med Genet.* 66: 423-425, 1996.
2. E.K. Schorry, A.H. Crawford, J.C. Egelhoff, A.M. Lovell, H.M. Saal, "Thoracic tumors in children with neurofibromatosis-1", *Amer. J. Med. Genet. (Neuropsych. Genet.)* 74: 533-537, 1997.
3. A.H. Crawford and E.K. Schorry, "Neurofibromatosis in children for the orthopaedist", *J. Amer. Acad. Ortho. Surg.*, 7(4):217-230, 1999.
4. D.A. Stevenson, P.H. Birch, J.M. Friedman, D.H. Viskochil, P. Balestrazzi, A. Buske, B.R. Korf, M. Niimura, E.K. Pivnick, E.K. Schorry, M.P. Short, R. Tenconi, J.H. Tongard, J.C. Carey, "Descriptive analysis of tibial pseudarthrosis in patients with neurofibromatosis 1", *Amer. J. Med. Genet.* 84:413-419, 1999.
5. N.S. Johnson, H.M. Saal, A.M. Lovell, E.K. Schorry "Social and emotional problems in children with neurofibromatosis type 1: Evidence and proposed interventions", *J. Pediatrics* 134(6):767-772, 1999.
6. Y. Tang, A. Lu, B.J. Aronow, E. Schorry, R. Hopkin, D. Gilbert, T. Glauser, A. Hershey, N. Richtand, M. Privitera, A. Dalvi, A. Sahay, J. Szaflarski, D. Ficker, N. Ratner, F.R. Sharp, "Human blood genomics: Distinct profiles for gender, age, and neurofibromatosis type 1", *Molecular Brain Research* 132(2):155-167, 2004.
7. C.R. Drake Sebold, A. Lovell, R. Hopkin, R. Noll, E. Schorry, "Perception of disease severity in adolescents diagnosed with neurofibromatosis type 1", *J. Adol. Health*, 35(4):297-304, 2004.
8. T. Yang, M. Schapiro, D. Franz, B. Patterson, F. Hickey, E.K. Schorry, R.J. Hopkin, T. Narayan, T.A. Glauser, D.L. Gilbert, A.D. Hershey, M. Wylie, F.R. Sharp, "Comparative blood expression profiling of tuberous sclerosis complex 2, neurofibromatosis and Down syndrome", *Annals of Neurology*, 56(6):808-14, 2004.

9. A.H. Crawford and E.K. Schorry, “Neurofibromatosis Update”, J. Ped. Orthopaedics 26(3):412-423, 2006.
10. A.H. Crawford, S. Parikh, E.K. Schorry, D. VonStein, “Symposium on the Immature Spine: The Immature Spine in Neurofibromatosis type 1”, J. Bone & Joint Surgery, in press, 2007.
11. R.B. Noll, J.Reiter-Purtill, B.D. Moore, E.K. Schorry, A. Lovell, K. Vannatta, C.A. Gerhardt, “Social, emotional and behavioral functioning of children with NF1”, AJMG, in press.

BOOK CHAPTERS

A.H. Crawford and E.K. Schorry, Neurofibromatosis. In Staheli and Song (ed) Pediatric Orthopaedic Secrets, chapter 88, 537-543 (2007).

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

Elizabeth K. Schorry, M.D., Assoc. Professor, Div. of Human Genetics
Role: Clinic director, geneticist.

Howard M. Saal, M.D., Professor, Div. of Human Genetics Role: Geneticist

Robert J. Hopkin, M.D. , Asst. Professor, Div. of Human Genetics Role: Geneticist

Alvin Crawford, M.D., Professor, Dept. of Pediatric Orthopaedics
Role: Orthopaedic surgeon; attends monthly NF clinics

John Perentesis, M.D., Professor, Director, Div. of Pediatric Oncology
Role: Oncologist; co-investigator in NF drug trials

Brian Weiss, M.D., Asst. Professor, Div. of Pediatric Oncology
Role: Oncologist; co-investigator in NF drug trials

Caroline Mueller, M.D., Assoc. Professor, Dept. of Internal Medicine/ Pediatrics,
University of Cincinnati. Role: Internist for Adult NF clinic.

Anne M. Lovell, RN, MSN, Advanced Practice Nurse, Coordinator of NF Clinic
activities

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

Anne Lovell, RN, MSN, is coordinator for NF patient services. She attends all NF clinics; orders and schedules recommended testing for patients; reviews all laboratory and radiology testing results with NF clinic physicians and transmits results to families; answers phone calls from families about NF-related issues; provides NF education and counseling to families and school professionals; and performs other NF clinic-related activities. She is the primary point of contact for families and patients with NF or suspected NF.

- 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 extensive experience in bone/ orthopaedic complications of NF1. Dr. Alvin Crawford, the Orthopaedic Surgeon for our clinic, has dedicated his extensive career to management of orthopaedic complications of NF1, particularly tibial dysplasia and scoliosis. Our center (Drs. Crawford and Schorry) is also participating in two funded natural history studies of bone complications in NF1.

Our center also has a strong interest in social/emotional dysfunction in NF1, as well as peer relationships. Dr. Schorry has pursued this interest with other outside co-investigators, including Drs. Bart Moore and Robert Noll.

Oncology and drug trials for pediatric tumors is another strength of our center, coordinated by Drs. Weiss and Perentesis.

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.

Our clinic is fortunate that we can schedule NF patients with a very short wait time for evaluation. All parent phone calls are returned within 24 hours. Most new patients being seen for evaluation for NF or suspected NF will usually be scheduled for an appointment with one of the geneticists within 2 weeks of initial contact. The multidisciplinary clinic is primarily for follow-up patients with an established diagnosis of NF1 or NF2, although occasionally new patients will be seen there if needed. Patients with acute problems will be seen by one of the geneticists as soon as possible, usually within several days. The nurse coordinator, in discussion with the Clinic Director, makes decisions regarding prioritization of patient visits.

- 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 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	Elizabeth Schorry, M.D. Howard M. Saal, M.D. Robert J. Hopkin, M.D.	CCHMC, Div. of Human Genetics	513-636-4760	
Neurology	Mary Sutton, M.D.	CCHMC, Div. of Neurology	513-636-4222	
Orthopedics	Alvin Crawford, M.D.	Dept. of Pediatric Orthopaedics	513-636-4785	
Developmental pediatrics/learning disabilities	Nancy Lanphear, M.D. }+ others, clinical fellows Doug Ris, Ph.D. (Neuropsychology)	CCHMC, Div. of Developmental & Behav. Pediatrics	513-636-4688	
Ophthalmology	Constance West, M.D. and others	CCHMC, Div. of Pediatric Ophthalmology	513-636-4751	
Neurosurgery	Kerry Crone, M.D. Francesco Mangano, M.D. Karin Bierbrauer, M.D.	Dept. of Pediatric Neurosurgery, CCHMC	513-636-4726	
Plastic surgery	David Billmire, M.D.	CCHMC, Dept. of Plastic Surgery	513-636-7181	
Neurooncology	John Perentesis, M.D. Brian Weiss, M.D.	CCHMC, Div of Oncology	513-636-4266	
Medical Oncology/Radiation Oncology	Brian Weiss, M.D.	CCHMC, Div .of Oncology	513-636-4266	
Endocrinology	(multiple)	CCHMC, Div. of Endocrinology	513-636-4744	
Audiology/ENT	Charles Myer, M.D.	CCHMC, Dept. of Otolaryngology	513-636-4355	
Radiology/ Neuroradiology	Blaise Jones, M.D.	Dept. of Radiology/ Neuroradiology	513-636-4251	
General Surgery/Surgical Oncology	Bradley Warner, M.D.	CCHMC, Dept. of Pediatric Surgery	513-636-4371	
Dermatology	Anita Sheth, M.D.	CCHMC, Div. of Dermatology	513-636-4215	
Cardiovascular Disease	(multiple)	CCHMC, Div. of Pediatric Cardiology	513-636-4432	

Oral and Maxillofacial Surgery	Charles Myer, M.D.	CCHMC, Dept. of Otolaryngology	513-636-4355	
Behavioral Issues	(various)	CCHMC, Div. of Psychology	513-636-4688	

ADULT CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Elizabeth Schorry, M.D.	CCHMC, Div. of Human Genetics	513-636-4760	
Neurology	Joe Nicolas, M.D.	University Hospital, Dept. of Neurology	513-475-8730	
Orthopedics	Alvin Crawford, M.D.	Children's Hospital, Orthopaedics	513-636-4785	
Developmental pediatrics/learning disabilities	Tom Webb, M.D (transitional care).	CCHMC, Div. of Developmental and Behavioral Disabilities	513-636-4688	
Ophthalmology	University Ophthalmology	U.H. Medical Arts Bldg.	513-584-5461	
Neurosurgery	Ronald Warnick, M.D. Mayfield Neurosurgery	Mayfield Clinic	513-221-1100	
Plastic surgery	John Kitzmiller, M.D.	U.C., Div. of Plastic, Reconstructive, & Hand surgery	513-558-0984	
Neurooncology	Robert Albright, M.D.	The Christ Hospital Medical Bldg.	513-585-1210	
Medical Oncology/Radiation Oncology	The Barrett Cancer Center	University Hospital		
Endocrinology	U.H., Div. of Endocrinology	University Hospital		
Audiology/ENT	Miles Penzak, M.D.	University ENT	513-475-8400	
Radiology/Neuroradiology	University Radiology	University Hospital		
General Surgery/Surgical Oncology	Jay Johannigman, M.D.	University Hospital, Dept of Surgery	513-475-8787	

Dermatology	Hugh Gloster, M.D.	Montgomery Medical Bldg.	513-936-4561	
Cardiovascular Disease	University Hospital, Dept. of Cardiology	University Hospital		
Oral and Maxillofacial Surgery	University Hospital, Dept. of Otolaryngology	University Hospital		
Behavioral Issues	Central Psychiatry Clinic	University Hospital		

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	297	3	1	4
NUMBER OF <u>NEW</u> PATIENTS SEEN IN PAST 12 MONTHS	54	1	0	0
TOTAL	297	3	1	4

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

Under 18 245 18+ 52 (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?

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

All patients followed in the pediatric NF clinic (and all other adults with NF requesting evaluation) are eligible to be followed in the Adult NF Clinic, located at University Hospital (Hoxworth Building), located about 1 block from Children's Hospital. Most patients will be transitioned between 18 and 21 years of age, depending on their preferences. Some patients with significant orthopaedic complications (tibial dysplasia, pseudarthrosis, severe scoliosis) can continue to be followed by Dr. Crawford as adults in the pediatric NF clinic. The adult clinic is staffed by a geneticist (Dr. Schorry) and the same nurse coordinator from the pediatric clinic, providing significant continuity with professionals already familiar with many of the patients. Adult patients are seen jointly by Dr. Schorry and Dr. Caroline Mueller, who is board certified in Internal Medicine and Pediatrics, and is Director of the Internal Medicine/Pediatrics program at University Hospital. In addition to seeing adult patients once per month at the adult NF clinic, Dr. Mueller or her associates are available to provide primary care for some of the NF patients who do not have a primary care physician.

The Children's Hospital Division of Developmental and Behavioral Pediatrics also has a transition care program to assist patients with developmental disabilities to transition from pediatric to adult medical care. Some of our NF patients have participated in this program.

Limitations of our program are that the Adult Clinic is able to see fewer numbers of patients due to the smaller numbers of physicians involved. We do not have as much multi-disciplinary involvement with the other specialists at University Hospital, and communication between physicians is not as ideal as it is at Children's Hospital as we are located in separate facilities.

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 participating physicians and nurse coordinator meet at the end of each clinic and discuss their recommendations. A formal report is generated by each physician, and the nurse coordinator writes a list of recommendations which is sent to the families.

Neuroradiology conferences are held monthly (or weekly if needed) and are attended by multiple staff from genetics, oncology, and a neuroradiologist. MRI scans and other imaging of NF1 patients with CNS abnormalities are reviewed by

the group, and the group makes a joint decision regarding management of each patient.

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.

Tipifarnib trial for progressive plexiform neurofibromas: 10 patients referred

Natural history of tibial dysplasia in nf1: 41 patients enrolled

Natural history of spinal deformities in NF1: 9 patients enrolled

8. PATIENT REGISTRY

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

Yes No

If 'yes', please describe.

We have a large Access database of over 850 NF patients. Data includes demographic, family history, all NF complications, and laboratory and radiology 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.

Y. Tang, A. Lu, B.J. Aronow, E. Schorry, R. Hopkin, D. Gilbert, T. Glauser, A. Hershey, N. Richtand, M. Privitera, A. Dalvi, A. Sahay, J. Szaflarski, D. Ficker, N. Ratner, F.R. Sharp, "Human blood genomics: Distinct profiles for gender, age, and neurofibromatosis type 1", *Molecular Brain Research* 132(2):155-167, 2004.

C.R. Drake Sebold, A. Lovell, R. Hopkin, R. Noll, E. Schorry, "Perception of disease severity in adolescents diagnosed with neurofibromatosis type 1", *J. Adol. Health*, 35(4):297-304, 2004.

T. Yang, M. Schapiro, D. Franz, B. Patterson, F. Hickey, E.K. Schorry, R.J. Hopkin, T. Narayan, T.A. Glauser, D.L. Gilbert, A.D. Hershey, M. Wylie, F.R. Sharp, "Comparative blood expression profiling of tuberous sclerosis complex 2, neurofibromatosis and Down syndrome", *Annals of Neurology*, 56(6):808-14, 2004.

A.H. Crawford and E.K. Schorry, "Neurofibromatosis Update", *J. Ped. Orthopaedics* 26(3):412-423, 2006.

A.H. Crawford, S. Parikh, E.K. Schorry, D. VonStein, "Symposium on the Immature Spine: The Immature Spine in Neurofibromatosis type 1", *J. Bone & Joint Surgery*, in press, 2007.

R.B. Noll, J. Reiter-Purtill, B.D. Moore, E.K. Schorry, A. Lovell, K. Vannatta, C.A. Gerhardt, "Social, emotional and behavioral functioning of children with NF1", *AJMG*, in press.

Crawford AH, Schorry EK: Neurofibromatosis in Children: The Role of the Orthopaedist. *JAAOS* 7(4):217-230, 1999 (July/August).

Durrani AA, Crawford AH, Choudhury Sn, Saifuddin A, Morley TR: Modulation of Spinal Deformities in Patients with NF Type I. *Spine* 25(1) 69-75, January 2000.

Roush TF, Crawford AH, Berlin RE: Tension pneumothorax as a complication of VATS for anterior correction of idiopathic scoliosis in an adolescent female. *SPINE* 26(4):448-450, 2001.

Crawford AH: "Practice of Pediatric Orthopaedics. IN: Spine and Pelvis. Ed. Lynn Staheli. Chapter 8, pp. 159-182, May 2001.

Crawford AH: Video-Assisted Thoracoscopy (VATS) for Spinal Problems in Children: Minimally Invasive Surgery of the Spine. *Living Longer Health Courier* (Newsletter, ProScan Imaging). August 17, 2001.

Crawford AH, Kumar K: Role of "Bovie" in Spinal Surgery – A Historical and Analytical Perspective. *Spine* 27(9):1000-1006, 2002.

Crawford AH, Lieverman IH, Regan JJ: Contemporary Management of Spinal Disorders. *Audio-Digest Orthopaedics* 25(6), June 2002.

Parikh SN, Crawford AH: Orthopaedic Implications in the Management of Pediatric Vertebral and spinal Tumors: A Retrospective Review. *Spine* 28(20):2390-6, 2003.

Mehlman CT, Al-Sayyad MJ, Crawford AH. Effectiveness of Spinal Release and Halo-Femoral Traction in the Management of severe Spinal Deformity. *JPO* 24(6):667-673, 2004.

Herrera-Soto JA, Crawford AH, Loveless EA. Ossifying subperiosteal hematoma associated with neurofibromatosis type 1. Diagnostic hesitations: A case report and literature review. *JPOB* (accepted for publication), 2004.

Weiss B, Bollag G, Shannon KM. Hyperactive Ras as a therapeutic target in neurofibromatosis type 1. *Am J Med Genet* 1999, 89:14-22.

Weiss B and Shannon K. "Mouse Models as a Platform for Performing Pre-clinical Therapeutic Trials". *Current Opinion in Genetics & Development* 1:84-9, 2003.

Weiss B, Vora A, Huberty J, Price D, and Matthay K. "Secondary myelodysplastic syndrome and leukemia following ¹³¹I-MIBG therapy in relapsed neuroblastoma". *Journal of Pediatric Hematology Oncology* 25(7): 543-7, 2003.

Weiss B and Shannon K. Preliminary Examples of Preclinical Trials, in *Mouse Models of Cancer*, ed. Eric Holland. Wiley-Liss, 2004.

Weiss B, Lee D, Aiyagari A, Feldmann A, and Shannon K. "Myeloproliferation due to Ras activation in wild type and *Nf1* mutant mice treated with mycophenolate mofetil" in preparation.

BOOK CHAPTERS

A.H. Crawford and E.K. Schorry, Neurofibromatosis. In Staheli and Song (ed) Pediatric Orthopaedic Secrets, chapter 88, in press (2007).

Crawford AH, Al-Sayyad MJ: Miscellaneous Conditions of the Cervical Spine; Neurofibromatosis, Juvenile Rheumatoid Arthritis, and Rickets. IN: The Cervical Spine, 4th Edition. Clark CR (Ed). Lippincott, Williams & Wilkins, Philadelphia. Chapter 36, pp. 481-507, 2005.

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

Our NF Center is heavily involved in NF research, both clinical and basic science. Drs. Schorry and Crawford are participants in two natural history studies of bone disease in NF1 (tibial dysplasia and scoliosis). Drs. Schorry, Weiss, and Perentesis are members of the NF Consortium funded by the DOD, and are directly involved in all the clinical trials which will be forthcoming from that center. Please see list above for funded grant projects. In addition, our center interacts closely with Nancy Ratner, Ph.D., who performs basic science research on NF1 cell biology in the Div. of Experimental Hematology. We have a joint clinical/ basic science project with her lab to study markers of tumor burden in patients with plexiform neurofibromas.

10. PATIENT SUPPORT

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

If 'yes' provide details.

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

What resources would help you to do this?

We have had a very active NNFF chapter in the past (Ohio Chapter, led by Dolores Goldfinger). However, after the retirement of Mrs. Goldfinger, our support group has floundered somewhat. We currently have a small support group for parents of young children with NF1, and several parents have recently expressed interest in making a stronger group. We would very much appreciate input from the CTF to help energize our support group. We are planning a one-day symposium for parents and professionals in Spring of 2008 (funded by a local family), and this will hopefully be a time to re-energize the support group.

11. OTHER INFORMATION

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