



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

**Clinic Name:**

The Comprehensive Neurofibromatosis Clinic at New York Presbyterian/Weil Cornell

**Affiliated Hospital:**

New York Presbyterian Hospital  
Memorial Sloan Kettering Cancer Center

**Affiliated University or Institution:**

Weil Medical College of Cornell University  
Memorial Sloan-Kettering Cancer Center

**Clinic Address:**

The Comprehensive Neurofibromatosis Clinic at New York Presbyterian/Weil Cornell  
525 East 68<sup>th</sup> Street, Box 91  
New York, NY 10021

**Clinic Director:**

Kaleb Yohay, MD

**Clinic Coordinator Name:**

Kathleen Berentsen

*\*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.

Patients with neurofibromatosis types 1 and 2 and schwannomatosis require coordinated multidisciplinary care due to the complex natural history of these disorders. By combining the available resources of Weill Cornell/New York Presbyterian Hospital, The Hospital for Special Surgery and Memorial Sloan-Kettering Cancer Center we have a unique opportunity to create a true center of excellence for the care of these patients.

The neurofibromatosis clinic will be designed to provide comprehensive health care for adults and children with neurofibromatosis type 1, neurofibromatosis type 2 and schwannomatosis. The clinic will be held in several different venues. Twice-monthly clinic will be held at the Oxford clinic (428 East 72<sup>nd</sup> St) of Weill Cornell where patients will be seen by Dr. Kaleb Yohay (pediatric neurology) and/or a nurse practitioner and a genetic counselor. Dr. Jessica Davis (genetics) and Dr. Yasmin Khakoo (neuro-oncology MSKCC) will be available for consults at the time of the visit on an as needed basis. Twice-monthly the clinic will be held in New York Presbyterian Hospital outpatient clinic (Helmsley Tower, 505 East 70<sup>th</sup> St, 5<sup>th</sup> floor), where patients will be seen by Dr. Kaleb Yohay and/or a nurse practitioner, and a genetic counselor. Once a month, the clinic will be held in the Starr 6 clinic at 525 East 68<sup>th</sup> St. Patients seen in this venue will primarily be pre-and post surgical patients and will be seen by Dr. Kaleb Yohay and Dr. Mark Souweidane.

Dr. Mark Souweidane, Dr. Kaleb Yohay and Dr. Linda Heier (Neuroradiology) meet weekly to discuss case management and imaging results for all new patients or patients with new imaging. For all cases in which surgery, chemotherapy or radiation therapy is under consideration, patients are presented at the tumor board at MSKCC which provides an opportunity for multidisciplinary treatment planning.

A nurse practitioner (Jessica Lessing) and a genetic counselor (Kathleen Berentsen) have been hired to co-coordinate the clinic. Jointly they will be responsible for:

- 1) Prescreening and triage of all new patients prior to scheduling of appointments:
  - a) Collection of relevant medical materials including scans and records from outside hospitals;
  - b) Assisting in the scheduling of multiple appointments for new patients including consultations with multiple medical subspecialties;
  - c) Coordinating the appropriate review of the obtained materials prior to the appointment.
- 2) Coordinating care of established patients:
  - a) Scheduling and following up on the results of genetic testing;
  - b) Scheduling and following up on the results of imaging and other diagnostic testing;
  - c) Scheduling and following up on the results of additional consultations;
  - d) Scheduling follow-up appointments;
  - e) Responding to patient phone calls.
- 3) Establishment and maintenance of educational and support programs for patients and their families.
- 4) Establishment and maintenance of a clinical and research database as well as coordination of clinical trials.

Additional responsibilities of the genetic counselor will include attending all clinics and providing genetic counseling services to patients and their families during their appointments and providing genetic counseling services for inpatients at New York Presbyterian Hospital and Memorial Sloan-Kettering Cancer Center with neurofibromatosis. Additional responsibilities of the nurse practitioner will include attending all clinics and acting as a physician extender during clinics, assisting in obtaining histories and performing physical examinations, triaging urgent and non-urgent medical issues of an established patients, assisting with inpatient consultations.

The nurse practitioner will be responsible for interacting with the surgical services, providing support for Neurosurgery for NF patients requiring surgical intervention including:

- a) Arranging for OR time, ICU bed availability, and coordinating surgical admissions, including insurance pre-authorization;
- b) Working with families and patients to anticipate and coordinate surgical care and post-op rehabilitation;
- c) Coordinating multi-disciplinary care required for surgical clearance as well as post-operative needs.

The core group of the neurofibromatosis clinic (Dr. Kaleb Yohay, Dr. Jessica Davis, Dr. Mark Souweidane, the genetic counselor, and the nurse practitioner) will meet to discuss case management on a weekly basis. In addition, a larger monthly meeting is to be established for case management discussions in a larger group format including multiple consultant subspecialists.

## 2. CLINIC DIRECTOR and STAFF EXPERTISE

a. CLINIC DIRECTOR: Please describe:

i. Your experience to date with NF care

After completing my residency in pediatric neurology in 2002, my clinical practice became focused on neuro-oncology and neurofibromatosis. In conjunction with Dr. Alan Belzburg at Johns Hopkins Hospital I established and co-directed a new comprehensive neurofibromatosis clinic, providing multidisciplinary care for over 200 children and adults with NF1, NF2 and schwannomatosis. I ran that clinic until last summer (2006) when I moved from Johns Hopkins to Cornell University. Since my arrival here, I have been developing a new NF clinic, and continue to see children and adults with neurofibromatosis.

ii. Your past and current association with NF clinical trials

At Johns Hopkins through Dr. Robert Arceci we participated in the R115777 trial run by Dr. Widemann. We are not currently actively associated with any NF specific clinical trials (but hope soon to be.)

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

I personally am not currently involved in other clinical trials, however, as a group we have access to a large number of clinical trials including trials through the Children's Oncology Group, sarcoma and adult and pediatric brain tumor trials through MSKCC, etc. I would be happy to provide a complete list of specific trials if requested.

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.

The research I have done to date relates to NF only peripherally. My research has focused on two areas: 1) novel therapeutics for the treatment of gliomas via modulation of glutamate 2) radiation neuroprotection in the developing CNS. My work has been funded through the NINDS via a K12 (June 2002-June 2006, \$50,000/year) and through a private foundation, ABC2 (June 2003, \$100,000).

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

**Yohay, K**, Denckla, M. Neurofibromatosis and Tuberous Sclerosis. In: Child and Adolescent Neurology for Psychiatrists, edited by Audrey M. Walker, M.D., David Myland Kaufman, M.D., Gail E. Solomon, M.D., and Cynthia Pfeffer, M.D. 2007, In Press.

**Yohay, K.** The genetic and molecular pathogenesis of Neurofibromatosis Types 1 and 2. *Seminars in Pediatric Neurology*. 2006 Mar;13(1):21-6.

**Yohay, K.** Neurofibromatosis Types 1 and 2. *Neurologist*. 2006 Mar;12(2):86-93.

**Yohay, K.** Neurofibromatosis. In : *Treatment of Pediatric Neurologic Diseases*, 1st ed. Singer, H, Kossoff, E, Crawford, T, Hartman, A, ed. Taylor & Francis, USA 2005.

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

Clinic Director: Kaleb Yohay, MD. Assistant Professor, Pediatrics, Child Neurology;

Clinic Co-Director: Jessica Davis, MD. Associate Professor, Pediatrics, Genetics; Coordination and provision of genetic services

Clinic Co-Director: Mark Souweidane, MD. Associate Professor, Vice Chairman, Neurologic Surgery; Coordination and provision of surgical care

Clinic Co-coordinator: Kathleen Berentsen, MS, CGC. Genetic Counselor, NF Clinic.  
Clinic Co-coordinator: Jessica Lessing, RN CPNP. Nurse practitioner, NF Clinic and pediatric neurosurgery.

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

Currently, care is coordinated by the co-coordinators, Kathleen Berentsen and Jessica Lessing in conjunction with Dr. Kaleb Yohay, director of the clinic.

- 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.

Surgical treatment of pediatric brain and spinal cord tumors: Mark Souweidane

Sarcoma: Gary Schwartz and Robert Maki

Neuro-oncology (pediatric): Yasmin Khakoo, Ira Dunkel, Kaleb Yohay

Neuro-oncology (adult): Lisa DeAngelis

Scoliosis and Pseudarthrosis: Roger Widmann, Daniel Green and David Scher

Vestibular Schwannoma: Philip Stieg, Samuel Selesnick

Neurology: Kaleb Yohay

### 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.

Response to requests for appointments occurs within one business day. Patients are typically scheduled for within 4 to 6 weeks. However, patients with urgent needs are seen within one week. Patients are "triaged" by Dr. Kaleb Yohay.

- 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	Jessica Davis	428 East 72 <sup>nd</sup> Street, Suite 100 New York, NY 10021	(212) 746-1496	jgdavis@med.cornell.edu
	Kenneth Offit	MSKCC 205 East 64 <sup>th</sup> Street New York, NY 10065	(212)434-5149	offitk@mskcc.org
Neurology	Kaleb Yohay	525 East 68th St. Box 91 New York, NY 10065	(212) 746-3278	Kay2003@med.cornell.edu
Orthopedics	Roger Widmann	Hospital for Special Surgery 535 East 70th St. New York, NY 10021	212.606.1325	widmannr@hss.edu
	Daniel Green	Hospital for Special Surgery 535 East 70th St. New York, NY 10021	212.606.1631	Greendw@HSS.EDU
	David Scher	Hospital for Special Surgery 535 East 70th St. New York, NY 10021	212.606.1253	scherd@hss.edu
	Boachie-Adjei, Oheneba	Hospital for Special Surgery 523 East 72 <sup>nd</sup> St. New York, NY 10021	212.606.1948	boachie@hss.edu
Developmental pediatrics/learning disabilities	Maureen Packard	525 East 68th St. Box 91 New York, NY 10065	212-746-3278	mpackard@med.cornell.edu
Ophthalmology	Richard Levy	520 East 70 <sup>th</sup> St. Starr Pavilion 8 <sup>th</sup> FL New York, NY 10021	212-746-2020	rll2003@med.cornell.edu

Neurosurgery	Mark Souweidane	520 East 70 <sup>th</sup> St. Starr Pavilion, Room 651, New York, NY 10021	212-746-2363	mmsouwei@med.cornell.edu
Plastic surgery	Jeffrey Ascherman	161 Fort Washington Ave Ste 607 New York, NY 10032	(212) 305-9612	jaa7@columbia.edu
Neuro-oncology	Yasmin Khakoo	MSKCC 205 East 64 <sup>th</sup> St. New York, NY 10065	212-639-8292	khakooy@mskcc.org
	Ira Dunkel	MSKCC 205 East 64 <sup>th</sup> St. New York, NY 10065	212-639-2153	dunkeli@mskcc.org
	Timothy Gershon	MSKCC 205 East 64 <sup>th</sup> St. New York, NY 10065	212-639-3449	gershont@mskcc.org
	Kaleb Yohay	525 East 68th St. Box 91 New York, NY 10065	212-746-3278	kay2003@med.cornell.edu
Medical Oncology/Radiation Oncology	Alexander Aledo	525 East 68th St. P-695 New York, NY 10021	212-746-3400	aaledo@med.cornell.edu
	Leonard Wexler	MSKCC 205 East 64th St. New York, NY 10065	212-639-7990	wexlerl@mskcc.org
	Suzanne Wolden	MSKCC 205 East 64th St. New York, NY 10065	212-639-5148	woldens@mskcc.org

Endocrinology	Charles Sklar	MSKCC 205 East 64th St. New York, NY 10065	212-639-8138	sklarc@mskcc.org
	Maria Vogiatzi	525 East 68th St. Box 103 New York, NY 10065	212-746-3462	mvogiatz@med.cornell.edu
Audiology/ENT	Robert Ward	525 East 68 <sup>th</sup> St. New York, NY 10065	(646)962-2224	rfw2001@med.cornell.edu
	Max April	525 East 68 <sup>th</sup> St. New York, NY 10065	(646)962-2225	Mma2005@med.cornell.edu
Radiology/ Neuroradiology	Linda Heier	525 East 68th St. New York, NY 10065	212-746-2581	laheier@med.cornell.edu
General Surgery/Surgical Oncology	Nitsana Spigland	525 East 68th St. New York, NY 10065	212-746-5399	naspigla@med.cornell.edu
	Michael LaQuaglia	MSKCC 205 East 64th St. New York, NY 10065	212-639-7002	laquaglm@mskcc.org
Dermatology	Horatio Wildman	525 East 68th St. New York, NY 10065	(646) 962-3376	hfw2001@med.cornell.edu
	Rochelle Scott	Hospital for Special Surgery 535 East 70th St. New York, NY 10021		
Cardiovascular Disease	Patrick Flynn	525 East 68th St. New York, NY 10065	(212) 746-3561	paflynn@med.cornell.edu
Dentistry	Abhinav Sinha	525 East 68th St. New York, NY 10065	(212)746-5119	abs2011@med.cornell.edu

Child Development	Jennifer Cross	525 East 68th St. N-1002 New York, NY 10065	212-746-3392	jfc2001@med.cornell.edu
	Purnima Valdez	525 East 68th St. N-1002 New York, NY 10065	(212)746-3392	puv2001@med.cornell.edu

## ADULT CARE

SPECIALTY	DOCTOR	CLINIC ADDRESS	PHONE	EMAIL (if available)
Genetics	Jessica Davis	428 East 72 <sup>nd</sup> Street, Suite 100 New York, NY 10021	(212) 746-1496	jgdavis@med.cornell.edu
	Kenneth Offit	MSKCC 205 East 64 <sup>th</sup> Street New York, NY 10065	(212)434-5149	offitk@mskcc.org
Neurology	Kaleb Yohay	525 East 68th St. Box 91 New York, NY 10065	(212) 746-3278	Kay2003@med.cornell.edu
Orthopedics	Oheneba Boachie-Adjei	Hospital for Special Surgery 523 East 72nd St. New York, NY 10021	212.606.1948	boachie@hss.edu
	Edward Athanasian	MSKCC 205 East 64 <sup>th</sup> Street New York, NY 10065	212-639-8673	athanase@mskcc.org
Developmental pediatrics/learning disabilities	NA			
Ophthalmology	Christopher Starr	520 East 70th St. Starr Pavilion 8 <sup>th</sup> Fl. New York 10021, NY 10021	212-746-2020	cestarr@nyp.org
	Richard Levy	520 East 70 <sup>th</sup> St. Starr Pavilion 8 <sup>th</sup> FL New York, NY 10021	212-746-2020	rll2003@med.cornell.edu
Neurosurgery	Philip Stieg	525 East 68th St, Box 99 New York, NY 10065	212-746-4684	pes2008@med.cornell.edu
	Mark Bilsky	MSKCC 205 East 64th St. New York, NY 10065	212-639-8526	bilskym@mskcc.org
	Mark Souweidane	520 East 70 <sup>th</sup> St. Starr Pavilion, Room 651, New York, NY 10021	212-746-2363	mmsouwei@med.cornell.edu

Plastic surgery	Jeffrey Ascherman	161 Fort Washington Ave Ste 607 New York, NY 10032	(212) 305-9612	jaa7@columbia.edu
Neuro-oncology	Lisa DeAngelis	MSKCC 205 East 64th Street New York, NY 10065	212-639-7123	deangell@mskcc.org
	Suzanne Pannullo	525 East 68th St, Box 99 New York, NY 10065	212-746-2438	scp2002@med.cornell.edu
Medical Oncology/Radiation Oncology	Gary Schwartz	MSKCC 205 East 64th St. New York, NY 10065	646-497-9053	schwartzg@mskcc.org
	Robert Maki	MSKCC 205 East 64th St. New York, NY 10065	212-639-5720	maker@mskcc.org
	Kaled Alektiar	MSKCC 205 East 64th St. New York, NY 10065	212-639-7981	alektiak@mskcc.org
Endocrinology	Richard Bockman	Hospital for Special Surgery 535 East 70th Street New York, New York 10021	212.606.1458	bockmanr@hss.edu
Audiology/ENT	Samuel Selesnick	1305 York Avenue 5 <sup>th</sup> Floor New York, NY 10021	646-962-3277	shselesn@med.cornell.edu
	David Kutler	525 East 68 <sup>th</sup> St. New York, NY 10065	646-962-4323	dik2002@med.cornell.edu
Radiology/ Neuroradiology	Linda Heier	525 East 68th Street New York, NY 10065	212-746-2581	laheier@med.cornell.edu
General Surgery/Surgical Oncology	Samuel Singer	MSKCC 205 East 64th Street New York, NY 10065	646-497-9072	singers@mskcc.org

Dermatology	Horatio Wildman	525 East 68th Street New York, NY 10065	(646) 962-3376	hfw2001@med.cornell.edu
	Richard Granstein	525 East 68th Street New York, NY 10065	646-962-3376	rdgranst@med.cornell.edu
Cardiovascular Disease	Jones, Erica	525 East 68th Street New York, NY 10065	(212) 821-0821	ecjones@med.cornell.edu
Oral and Maxillofacial Surgery	David Behrman	525 East 68th Street New York, NY 10065	212-746-5175	dabehrm@med.cornell.edu
	Joel Friedman	525 East 68th Street New York, NY 10065	212-746-5175	friedmj@med.cornell.edu
Dentistry	Marsha Rubin	525 East 68th Street New York, NY 10065	212-746-5115	Mer2009@med.cornell.edu

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

- a. How many NF PATIENTS did you see in the past 12 months? 55 (Since November 2006)
- b. How many of these were **NEW** patients to your clinic? 38 (Since November 2006)

*Insert numbers below*

	NF1	NF2	SCHWANNOMATOSIS	OTHER
NUMBER OF PATIENTS SEEN IN PAST 12 MONTHS	42	6	1	6
NUMBER OF <b><u>NEW</u></b> PATIENTS SEEN IN PAST 12 MONTHS	38	5	0	0
TOTAL	55			

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

Under 18\_42 (76%)\_\_\_\_\_ 18+ \_13\_(24%)\_\_\_\_\_ (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?

All patients in the clinic are seen and followed by Dr. Kaleb Yohay, regardless of age. He is trained in neurology with special qualification in child neurology, and is experienced in the care of adults and children with NF. As such, with the assistance of

the clinic coordinator(s) he will continue to coordinate care during the transition from childhood to adulthood and will make appropriate referrals based on need and age.

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

Dr. Kaleb Yohay (in conjunction with the co-coordinators) acts as the point of contact for all patients in the NF clinic. Continuity between the various sub-specialties is facilitated by having a single provider familiar with all of the patients and all of the sub-specialists involved with the clinic. Additionally there are weekly patient care meetings among the core NF group (Drs. Yohay, Souweidane and Davis, and our co-coordinators). Also, a larger monthly meeting is to be established for case management discussions in a larger group format including multiple consultant sub-specialists to provide continuity and consensus. Of course, working among sub-specialists from three separate institutions poses some logistical problems including problems with providers accepting different types of insurance, timely transmittal of study results and transfer of records, etc. These hurdles have not proved to be insurmountable but do require a certain amount of tenacity and patience.

## 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 core group of the neurofibromatosis clinic (Dr. Kaleb Yohay, Dr. Jessica Davis, Dr. Mark Souweidane, the genetic counselor, and the nurse practitioner) will meet to discuss case management on a weekly basis. In addition, a larger monthly meeting is to be established for case management discussions in a larger group format including multiple consultant sub-specialists.

## 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

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.

Pirfenidone in Children and Young Adults with NF1 and Progressive Plexiform Neurofibromas. Roger Packer, CNMC

Tipifarnib (R115777) to Treat Children with NF1 and Progressive Plexiform Neurofibromas  
Dr. Brigitte Widemann, National Cancer Institute

Phase II Trial of Irinotecan plus Carboplatin, and Irinotecan Maintenance Therapy Integrated into the Upfront Therapy of Newly Diagnosed Patients with Intermediate- and High-Risk Rhabdomyosarcoma  
Dr. Leonard Wexler, MSKCC

## 8. PATIENT REGISTRY

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

Yes  No

If 'yes', please describe.

We are using the database provided by the Children's Tumor Foundation

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.

None.

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

None (yet...)

## 10. PATIENT SUPPORT

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

If 'yes' provide details.

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

What resources would help you to do this?

No, but we certainly plan to do so in the near future. I plan to do what he had begun at my clinic at Johns Hopkins. We set up a daylong educational symposium for patients and their families to learn about neurofibromatosis. The speakers included sub-specialists from neurology, oncology, radiology, radiation oncology, orthopedics, developmental pediatrics, etc. all of whom talked about the aspects of neurofibromatosis pertinent to their area of expertise. I would like to try to set up a similar symposium here. In addition, we plan to establish more regular, perhaps monthly, small group support meetings for patients and families. These beings would have both an educational component as well as an opportunity for families and patients to meet and share experiences. The educational component would consist of a rotating list of speakers drawn from our sub-specialists who could address a specific topic of relevance in their area of expertise.

For the larger symposium funds would have to be raised to support the event. In the previous session that I held funds were provided from a nominal registration fee (which paid for lunch and refreshments) and from a donor (a pharmaceutical company).

## 11. OTHER INFORMATION

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

As you have no doubt gathered from the information already provided, we are a brand new clinic, still very much in the formative stages of development. I believe we have a unique opportunity to create a truly outstanding center of excellence given the clinical and research resources at our disposal at New York Presbyterian Hospital, Weill Cornell Medical College, Memorial Sloan-Kettering Cancer Center and the Hospital for Special Surgery. In addition to our great depth of resources, I believe we offer enthusiasm, energy and dedication to the neurofibromatosis community. I hope that our relative newness will be seen as a positive attribute and an opportunity for the Children's Tumor Foundation to be involved with a clinic from the outset. I believe this is truly an exciting time to be involved in the field, and we look forward to establishing relationships with the NF community locally, nationally and internationally.

Please do not hesitate to contact us if there is any additional information that would be helpful.