# Starting a Cancer Genetics Clinic in a County Hospital

## The Dallas and Tarrant County Hospital Systems experience

**by Sara Pirzadeh, MS, CGC**

*In Brief*

Approximately 5 to 10 percent of cancers have a hereditary component, and hereditary cancer susceptibility has been observed in most races and ethnicities.[1,2] Due to limited access, however, cancer genetic counseling and testing services are historically underutilized in minority and underserved populations.

To improve access to these services in the Dallas and Fort Worth area, four cancer genetic counselors at UT Southwestern Medical Center, part of the University of Texas System, spearheaded a unique collaboration between their program and two county hospitals. UT Southwestern, a large academic medical center, contributed the cancer genetic counselors; the county hospitals contributed clinic space and support staff. Through this collaborative effort over the last 21 months, cancer genetic counseling services were provided for about 250 patients in the two county hospitals.

These cancer genetics clinics were opened without financial backing from the county hospitals. The goal: to identify the need for genetic counseling and testing services and, subsequently, to obtain permanent internal funding for the clinics. Here is our experience and the processes we used to provide cancer genetics services to underserved patients in our community.

Genetic testing for hereditary breast cancer has been available since *BRCA1* and *BRCA2*, the genes that cause hereditary breast and ovarian cancer syndrome (HBOC), were discovered in 1994 and 1995.[3] Females with *BRCA1* and/or *BRCA2* mutations have as high as a 40 to 87 percent lifetime risk of breast cancer and a 15 to 45 percent lifetime risk of ovarian cancer.[4,5] In addition, women with these mutations have a 40 to 60 percent lifetime risk for developing a second primary breast cancer.[6,7] Since that time, many additional hereditary cancer predisposition tests have become available, including Lynch syndrome or hereditary non-polyposis colorectal cancer (HNPCC). For patients diagnosed with Lynch syndrome, colorectal, uterine, and ovarian cancer, lifetime risks are elevated to as high as 80 percent, 40 to 60 percent, and 10 to 12 percent respectively.[8]

Genetic testing for hereditary cancer syndromes has become a standard of care option for appropriately selected patients.[9,10,11] Cancer genetic testing has also become standard of care for individuals at increased risk for a hereditary cancer syndrome.[9,12] Unfortunately, many individuals at risk for hereditary cancer do not have access to genetic testing services due to uninsured or underinsured status, limited financial resources, limited service availability, and affordability.[13]

### Getting Started

The UT Southwestern Cancer Genetics Program started in 1992 at the Dallas campus and has since expanded to seven satellite offices staffed by four cancer genetic counselors throughout the Dallas-Fort Worth area. To improve access to services for the county patient population, UT Southwestern Medical Center cancer genetic counselors set a goal of establishing cancer genetics services, including genetic counseling and testing, within both of our local county hospital systems—Parkland Memorial Hospital in Dallas County and John Peter Smith Hospital in Tarrant County.

Our first step was to identify key decision-makers at each site who would be responsible for green-lighting these new services. We initially contacted the cancer program administrators at both sites to discuss our idea for implementing a cancer genetics clinic and to outline the benefits to their cancer center and hospital. When making our case, we found it helpful to reference the National Cancer Institute's (NCI) requirements for an NCI-designated cancer center. NCI identifies a cancer genetics clinic as a core component of a comprehensive cancer program because these services allow affected families access to cancer prevention and early-detection methods.

To Parkland Memorial Hospital, we proposed a comprehensive cancer genetics clinic. We were able to obtain exam room space within Parkland Memorial Hospital's cancer center, which enabled us to see all Parkland Memorial Hospital cancer genetics referrals.

Due to logistics and lack of space at the John Peter Smith Hospital cancer center, we scaled back on services at this location. Obtaining exam room space in the John Peter Smith Hospital Center for Women, we started with a hereditary breast and ovarian cancer genetics clinic only. Since only women (and men with breast cancer) are seen at the Center for Women, it was a logical fit. We believed it was best to start with a scaled down genetics cancer clinic rather than to wait for space at the cancer center. Our hope was that this specific patient population would illustrate

the need for a more comprehensive cancer genetics program.

After receiving the support of the cancer program administrators at both locations, we turned our attention to physician buy-in. We solicited support from physicians who would likely be caring for the majority of our high-risk patients—breast surgeons, gynecological oncologists, and colorectal surgeons. Setting up meetings with key physicians, we talked about the services offered at the cancer genetics clinics and how to establish a pathway for continuity of care for these patients.

## Developing the Proposal

The next step was to write two formal proposals. The first proposal went to the Cancer Committees at Parkland Memorial Hospital and John Peter Smith Hospital. These committees establish the budget and initiate new program development at their respective locations. The second proposal went to the cancer program administrator at the UT Southwestern Cancer Center. In it, we asked for permission to establish cancer genetics clinics in the community and to waive the counseling fee for the county patients.

Our proposals included the following basic facts: 1) expected patient volume, 2) estimated number of mutation-positive patients, and 3) benefits and limitations of the cancer genetics clinic.

***Expected patient volume.*** To estimate the volume expected for the clinic at Parkland Memorial Hospital, we first obtained the number of cancer cases (per type) from their cancer registry from the previous year. We then extrapolated the volume based on our positive test rate at the UT Southwestern cancer genetics clinics. For breast cases, we also used mutation-positive test rate statistics from the testing laboratory.

At John Peter Smith Hospital, we were unable to obtain the cancer registry's data, so we adapted Tarrant County's reported cancer cases from the Texas Department of Health Cancer Registry Division. These reports were available online at the state's Department of Health website. We also obtained the county's estimated percentage of uninsured citizens and estimated number of cancer cases under age 50. Once we calculated that number, we extrapolated the volume using the same method we did for Parkland Memorial Hospital.

***Estimated mutation-positive patients.*** Once the clinic volumes were estimated, we used our mutation-positive percentages from the UT Southwestern cancer genetics clinics to estimate the mutation-positive rate in the county hospitals.

***Benefits of an onsite cancer genetics clinic.*** One major benefit for the county hospitals is the downstream revenue generated from mutation-positive patients. Patients identified with a cancer gene mutation have an elevated likelihood for different types of cancers for which preventative medical management measures are recommended. These preventative measures would likely produce downstream revenue for the hospital system, as referrals are made to in-house physicians and services.

For example, based on the incidence numbers from the previous year, we predicted that we would most likely see breast and colon cancer cases at the Parkland Memorial Hospital cancer genetics clinic. We expected to offer testing for the most common hereditary breast or colon cancer syndromes, including HBOC and Lynch syndrome. Preventative and prophylactic measures for the former include earlier and more frequent breast surveillance through mammograms and breast MRI, as well as prophylactic bilateral salpingo oophorectomy for appropriate patients.[6,9] Risk management recommendations for Lynch syndrome include annual colonoscopy and prophylactic total abdominal salpingo oophorectomy for appropriate patients.[7] These management recommendations clearly illustrate downstream revenue to cancer centers that offer these services.

Additionally, we have found that for every patient who is mutation-positive approximately four family members will be identified as mutation-positive. If these individuals are local residents, they may obtain preventative care at the institution, providing further revenue opportunities. Figure 1 illustrates an example of a patient seen in the Parkland Memorial Hospital cancer genetics clinic who tested positive for a *BRCA1* mutation. Her test result led to single-site testing for 14 other relatives. Six of the 14 were positive and established their care at Parkland Memorial Hospital to obtain the recommended surveillance.

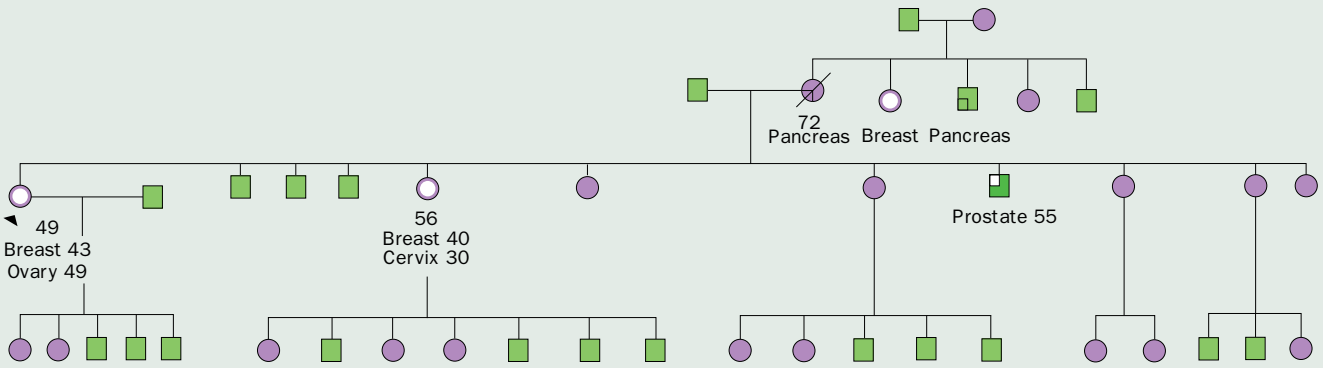
Another benefit to a cancer genetics clinic at the county hospital is the alleviation of transportation issues. Prior to establishing the clinic at John Peter Smith, we calculated that UT Southwestern-Fort Worth was losing about 50 percent of our John Peter Smith Hospital referrals because our UT Southwestern-Fort Worth cancer genetic clinic is not accessible by public transportation. Many of the patients referred did not have their own vehicles.

Genetic counseling services can also help identify the appropriate individual to test in a family, as many times the most informative person to test is *not* the initial patient that obtains genetic counseling. For example, if the initial patient is unaffected and she has a relative with early-onset breast cancer, the relative would have a higher likelihood to carry a breast cancer gene mutation. This likelihood is based on the relative expressing one of the common features of a person with these gene mutations.

Finally, a comprehensive cancer genetics clinic adds a truly preventative component to a cancer center, moving the center closer to achieving the components of an NCI-

**Figure 1. Familial Genetic Testing for Patient Testing Positive for *BRAC1* Mutation**

A large Hispanic family was seen at our Parkland Memorial Hospital clinic. The initial proband was referred due to history of breast cancer diagnosed at age 43 and ovarian cancer diagnosed at age 49. A sister was diagnosed with breast cancer at age 40, and a brother was diagnosed with prostate cancer at age 55. Her mother and maternal uncle were diagnosed with pancreatic cancer, and a maternal aunt was diagnosed with breast cancer at an unknown age. The proband was found to have a *BRCA1* deletion via *BRCA* large rearrangement testing (BART). We were able to test 7 of 10 siblings at the Parkland Memorial Hospital clinic through the laboratory's financial assistance program, and 4 were positive. Four of the proband's nieces and nephews were also able to undergo single-site testing through the Parkland Memorial Hospital clinic as well. In total, the proband's positive result enabled us to define future cancer risk for 14 additional family members.




designated comprehensive cancer center.

***Limitations of an onsite cancer genetics clinic.*** In operating a cancer genetics program in a county hospital setting without a funding source, we faced some significant challenges. For example, financial limitations and lack of funding made it highly unlikely that we would be able to fund testing for the more rare hereditary cancer syndromes, such as Von Hippel-Lindau and Peutz-Jeghers syndromes. Also, some patients in the county hospital setting make slightly too much annual income to qualify for hardship funding or grant money, but not enough to be able to obtain genetic testing.

## Making the Presentation

The proposal to Parkland Memorial Hospital's Cancer Committee was presented by UT-Southwestern cancer genetic counselors with support from one of the hospital's breast surgeons. At the John Peter Smith Cancer Center, the cancer program administrator made the proposal to that hospital's Cancer Committee. She, too, received support from one of the hospital's breast surgeons. Both committees consented unanimously to the proposals.

When presenting the second proposal to the UT Southwestern Cancer Center, we focused on proving that our goals were compatible with the cancer center's strategic initiatives. Because UT Southwestern Cancer Center would be providing the genetic counseling time to the outreach clinics, it would have a major investment in the proposed program (i.e. giving up counselor time to go off-site and waiving some potential revenue). Specifically, we proposed that we would need two or three genetic counselors—depending on clinic volume—to staff the clinics once a month. From our experience, we estimated four hours of work per patient. Overall, we estimated at least 40 hours of genetic counselor time for each clinic per month. In our case, the UT Southwestern Cancer Center wanted to expand research opportunities with minority patients. The cancer center was also looking to introduce more outreach and educational activities into the community. In the end, both of these major initiatives aligned with the goals of the proposed cancer genetic clinics.

## Laying the Groundwork

Before establishing the cancer genetics clinics, we first had to answer several important questions:

- What are our biggest logistical concerns?
- What are the most effective methods to advertise our services to the county hospital and the community at-large?
- What will constitute our referral criteria?
- What are our resources for obtaining genetic testing for our patients?
- How do we educate patients about the purpose of our service to decrease no-show rates?
- What is the most effective method to monitor our progress and report back to the respective cancer center administration?

***Logistical concerns.*** Our most significant logistical concerns included consultation space, phlebotomy services, how to charge patient visits, chart documentation for each clinic, translation services, and patient scheduling.

At both sites of service, we obtained exam room space one morning per month. Both county hospitals agreed to waive laboratory charges for our patients; the cancer genetic

counselors would handle shipping the sample. All patients are charged the county hospital office visit co-pay for our consultation. At both sites, charts for cancer genetics clinic patients are pulled prior to the clinic day. Counselors put a brief progress note in the chart on the day of appointment, followed by formal dictation.

With patient scheduling, we decided that front desk staff and/or nursing staff from each cancer center would schedule their respective patients, thereby promoting the idea of the cancer genetics program being internally driven in the future. At both sites, the nurses or other cancer center staff pull the hospital chart for each patient scheduled at the cancer genetics clinic.

Parkland Memorial Hospital cancer genetics clinic staff sends patients a letter with the date and time for the consultation. If necessary, clinic staff will also schedule translation services. Appointment no-show rates have historically been higher at the county hospitals, so cancer genetic counselors follow up with a second letter (in English and Spanish), summarizing the purpose of the appointment and an informational DVD a week prior to the clinic visit. The DVD briefly discusses the purpose of genetic testing and how it could affect future medical management and family members. It is available in both English and Spanish. Cancer genetic counselors also place a reminder call to the patients the week of the clinic.

At John Peter Smith Hospital, patients are scheduled for their genetics appointment right after their visit with the breast surgeon or gynecologic oncologist. This appointment is followed up with the letter and informational DVD discussed above. Cancer genetic counselors call patients the week of their appointment to remind them of appointments, and to see if translation services need to be scheduled.

On the actual day of the clinic visit, cancer center staff inform the genetic counselor when a patient has checked in, but does not have any other responsibilities at the cancer genetics clinic.

***Referral criteria***. We adapted Medicare criteria for hereditary cancer testing as our referral guidelines. At least initially, we decided to limit referrals to cancer-affected patients, as they would typically be the most appropriate to test.

***Clinician education***. We used various methods to educate physicians at Parkland Memorial Hospital and John Peter Smith Hospital about our services and reasons for referral, including:

- Placing laminated referral guideline sheets in every clinic room for clinician use
- Setting up meetings with referring providers (medical oncologists, surgeons, radiation oncologists, gynecologic oncologists, colorectal clinicians and surgeons) to discuss our clinic
- Hosting in-services for residents and fellows to provide education on hereditary cancer syndromes
- Producing clinic advertisement flyers for placement in lounges and common areas in the cancer centers
- Putting cancer genetics clinic information on each cancer center's website
- Writing articles about cancer genetics and our cancer genetic clinic in each hospital's employee newsletter.

When new cancer genetics-related recommendations or guidelines are released, the cancer genetics counselors write a summary letter to clinicians in our area, with the pertinent information and a reminder about our clinic.

***Community education***. To educate the community about our new cancer genetics clinics, we write letters to possible referring providers outside of the county hospital. We pass out flyers at local cancer events like the annual Susan G. Komen race and National Ovarian Cancer Coalition walk. We also author cancer genetics articles for local affiliates of national nursing and other clinician organizations (i.e., Oncology Nursing Society), and encourage word-of-mouth advertising by discussing our clinics at cancer support groups and local tumor boards.

***Funding sources***. To help fund genetic testing for our clinic patients, we use a number of clinical and research laboratory tests. For example, we have used financial hardship genetic testing funds for HBOC, Lynch syndrome, and Familial Adenomatous Polyposis (*APC* and *MYH*) from a major clinical testing laboratory. The financial hardship program is a patient assistance program funded by the laboratory. We also enroll appropriate patients in Dr. Mary-Claire King's HBOC study.[14] Research genetic testing performed by Dr. Charis Eng's lab at the Cleveland Clinic has provided another route to obtain necessary genetic analysis for select patients. Her laboratory conducts several translational genetic research projects, and the studies listed below are among those we have used:[15-17]

- The PTEN study (Cowden syndrome, Bannayan-Riley-Ruvalcaba syndrome, and Proteus syndrome)
- Genetics of pheochromocytoma and paraganglioma (SDH gene testing)
- The unexplained hamartomatous and/or hyperplastic polyposis study (PTEN, BMPR1A, SMAD4, LKB1, Endoglin, and MYH gene testing).

If possible, we confirm mutation-positive tests conducted by a research laboratory through a Clinical Laboratory Improvement Amendments (CLIA)-certified clinical laboratory. This type of confirmation is recommended since research laboratories are typically not under the same strict CLIA regulation requirements as clinical laboratories.

At Parkland Memorial Hospital, we were able to enroll appropriate patients in a study conducted at another local hospital where *BRCA* testing was done as part of the protocol. We were able to use existing hospital contracts with reference labs to cover Lynch syndrome germline and tumor testing for some patients. We also wrote a grant proposal to the NCI that was funded for a Von Hippel-Lindau (VHL) study that would cover VHL testing for appropriate patients.

For the John Peter Smith Hospital clinic, we wrote a grant proposal to the Tarrant County affiliate of Susan G. Komen for the Cure to fund genetic testing for *BRCA1/BRCA2*, Li-Fraumeni syndrome (p53), and clinical Cowden syndrome (PTEN) testing for appropriate uninsured and underinsured patients in Tarrant County. The total amount requested was specifically allocated for genetic testing costs, including single-site testing for unaffected family members.

***Methods to monitor progress***. To track our patients at both clinic sites, we designed a database where we record: 1) all patient demographic information and data, 2) the management strategies used, and 3) the name of the physician patients are referred to if the patient was mutation-positive. We also track the number of at-risk family members that undergo testing for their known familial

mutation. Cancer genetics counselors submit quarterly updates and annual reports to both sites, which summarize our activities and patient statistics. Cancer genetics counselors are careful to highlight cases where genetic testing and the recommended medical management truly reduced risk or prevented cancer. Conversely, we also document cases where the limitations of the clinic were detrimental to the patient or her relatives. Here is an example of this situation:

*Mrs. X came in for genetic counseling with her sister, Mrs. Y, who was just diagnosed with breast cancer at the age of 42. The family had a striking history of breast and ovarian cancer that is characteristic of hereditary breast and ovarian cancer syndrome or HBOC. Mrs. Y's personal and family history met most private insurance companies and Medicare criteria for* BRCA *gene testing. Mrs. Y has the county hospital plan which does not cover the cost of genetic testing.*

*We applied for financial assistance for Mrs. Y and were turned down because the patient made approximately $200 over the financial criteria cut-off for the year. We explained to Mrs. Y that although we suspect that she has a hereditary cancer, we could not do the genetic testing for her or her sister, Mrs. X.*

*Mrs. X returned to our clinic 6 months later with the diagnosis of ovarian cancer. We were then able to do the genetic testing for Mrs. X through private funding since she now had a cancer diagnosis and met financial criteria. Mrs. X was found to have a* BRCA *gene mutation and subsequently Mrs. Y also was determined to have the same mutation.*

*The hospital is now paying for Mrs. X's treatment of ovarian cancer. Had the hospital funded the testing on Mrs. Y six months earlier, Mrs. X would have known she was high-risk for ovarian cancer and would have been referred to gynecologic oncology for evaluation.*

## Lessons Learned

We found funding to be the most significant hurdle to implementing a cancer genetics clinic at a country hospital. When financial backing for genetic testing of indigent patients does not exist, other methods must be identified. The lesson we have learned is to look to local patient advocacy groups for grant or funding opportunities, particularly the groups that may run local fundraising events. In our experience, most local groups will keep the raised funds in the local community, and many will want to sponsor a worthwhile project such as cancer genetics testing. Another helpful tip is to use existing hospital contracts with large reference labs to obtain access to specialized genetic tests. Many of the genetic tests are performed at smaller laboratories that are not covered under insurance plans. When we funneled genetic testing through large reference laboratories that contract with UT Southwestern or the county hospitals, it opened access to more testing for patients. For those patients with insurance who are seen at these institutions and assuming the genetic test is a covered benefit under the patient's insurance plan, we optimize the chances that our patients can obtain the testing they need by collaborating with the larger reference laboratories.

One lesson we learned in the proposal process to UT Southwestern Cancer Center was to parlay our idea into an opportunity to achieve the cancer center's goals, even if their objectives might not be directly related to our immediate purpose. For example, as discussed previously, one major goal for the UT Southwestern Cancer Center is to enroll more minority patients in the UT Southwestern Cancer Biorepository for Research Studies. We addressed this objective in our proposal and discussed the access to minority patients that would be achieved by our cancer genetic clinics, including the ability to offer enrollment in the biorepository. Since then, we have been able to show that most of the minority county clinic patients consented to enrollment.

## Future Considerations

Currently, the John Peter Smith cancer genetics clinic is housed in a setting that is meant only for women's health. Due to the location of the clinic, we cannot see men for genetic consultation unless they have a diagnosis of breast cancer. Obviously, this logistical concern makes it difficult to expand our genetics program at John Peter Smith Hospital. To truly make the cancer genetics program comprehensive in nature, our goal is to establish a cancer genetics clinic in the John Peter Smith Cancer Center.

We also would like to make cancer genetics an integral part of the curriculum for residents and fellows at both Parkland Memorial Hospital and John Peter Smith Hospital, since many of the graduates may stay within the institution after their training.

Finally, given the higher rates of medical staff turnover in the county hospital system, cancer genetics counselors must pursue continuous educational efforts aimed at cancer center clinicians.

## A Success Story

The Parkland Memorial Hospital and John Peter Smith cancer genetics clinics have been operational since January 2008. Table 1, page 43, shows 2008 data from both sites, as well as a comparison to 2008 data from the cancer genetics clinics at UT Southwestern Cancer Center. Of note, the mutation-positive rate in our county clinics is comparable or higher to the UT Southwestern cancer genetics clinics. The *BRCA* positive rates at the county clinics (Parkland Memorial Hospital: 21 percent; John Peter Smith Hospital: 16 percent) are equal or higher than the reported national positive rate of approximately 16 percent.[18] These data show that the most appropriate patients are being referred for cancer genetics testing, and that our educational efforts seem to have been helpful.

Table 2, page 43, illustrates the number of county cancer genetics clinic patients that took preventative measures based on testing results. We wrote a second Tarrant County Komen grant for 2009 based on our patient data from 2008, and we were awarded additional money for hereditary breast cancer testing in Tarrant County. When we calculated our total patient volume for all UT Southwestern Cancer Center genetics clinic sites in 2008, the county hospital clinics comprised about 10 percent of our total volume.

In the end, our main goal was to have each county hospital system internally fund a comprehensive cancer genetics clinic—both counseling and testing. Due to the success of our unfunded clinics, both Parkland Memorial Hospital and John Peter Smith Cancer Center administra-

**Table 1. 2008 Genetic Testing Statistics for UT-Southwestern,[1] Parkland Memorial Hospital, and John Peter Smith Hospital[2] Cancer Genetics Clinics**

| 2008 Statistics | UT Southwestern | Parkland Memorial Hospital | John Peter Smith Hospital |
|---|---|---|---|
| Number of patients seen | 831 | 105 | 58 |
| Number of patients tested | 562 (68%) | 77 (73%) | 51 (88%) |
| Number of abnormal results | 134/562 (24%) | 27/77 (35%) | 8/51 (16%)[2] |
| No test due to lack of funding | N/A | 25/105 (27%) | N/A, due to Komen grant |

[1]At UT Southwestern cancer genetics clinic, most patients are privately insured.
[2]Patients at John Peter Smith Hospital cancer genetic clinic underwent *BRCA* testing only.

**Table 2. 2008 Statistics on Prophylactic Surgeries Completed Due to Positive *BRCA* Results and Referrals for High-risk Breast Follow-up in County Clinic**

| 2008 Statistics | Parkland Memorial Hospital Cancer Genetics Clinic | John Peter Smith Hospital Cancer Genetics Clinic |
|---|---|---|
| Number of prophylactic mastectomies due to genetic test result | 2 | 4 |
| Number of prophylactic oophorectomies due to genetic test result | 7 | 7 |
| Number of patients referred to breast surgeon for high-risk follow-up | 11 | 6 |

tions have put a comprehensive cancer genetics clinic into budget consideration for the 2010 fiscal year.

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