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## Summary of Donations

We've received a total of \$95,000 in donations since October 2008. In February 2009 we gave \$50,000 to Dr. Marc Ladanyi's team at Memorial Sloan Kettering Cancer Center. In June we gave \$30,000 to Dr. Mario Capecchi's team at the University of Utah Medical School. Both Dr. Ladanyi's and



From left to right: Asu Okyay, Christine Bustany, Dr. Ito, Dr. Ladanyi, Laufey Bustany

Dr. Capecchi's work are critically important in a field where very few scientists devote their time to Synovial sarcoma research. We will continue to support their research, which has advanced the field's knowledge of this disease, and has led them to believe that a cure is possible within 5-7 years.

**From August 2006 to date, the friends of Paul Nabil have donated a total of \$200,000 to Synovial sarcoma research.**

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## Meeting with Distinguished Professor Dr. Mario R. Capecchi and Dr. Malay Haldar at The ECCLES Institute of Human Genetics, University of Utah

Last March, Laufey and Ted Bustany went to Salt Lake City to meet with Dr. Mario Capecchi—recipient of the Nobel Prize for Physiology and Medicine in 2007—and his co-investigator Dr. Malay Haldar.

Laufey writes:

*We began the meeting with a private discussion with Dr. Capecchi, where he explained to us his special interest in cancer, and sarcomas in particular, because they occur early in life and are simpler to understand than carcinomas that occur later in life when other issues may interfere and make it difficult to separate the cause and the effect of the cancer from other disorders.*

*Dr. Capecchi is currently researching three different types of sarcomas: Synovial, Alveolar Rhabdomyo, and Ewing's sarcomas. All three occur in young people. What they have in common is a translocation in the chromosomes of one gene, which is a different gene for each of these diseases and which produce different products that cause the disease. In the case of Synovial sarcoma it is SYT SSX1, SSX2, SSX4—monophasic or biphasic. It is the only cancer that has that gene. Dr. Capecchi believes that monophasic and biphasic are the same product, just at a different stage in its progression of disease—monophasic in its earlier and less aggressive stage, biphasic in its latter and more aggressive stage.*

*Dr. Capecchi explained that mutations occur all the time, but usually the body has a way to repair itself. In the case of Synovial sarcoma, Dr. Haldar's research indicates that once the translocation has taken place, there is something in the environment that sustains it and keeps the cells multiplying and causing the cancer. The fact that Synovial sarcoma is most often located close to joints indicates that there is something in the surrounding fluid/tissue that feeds it.*

*Dr. Capecchi went into further detail about Dr. Haldar's research and explained how he had been successful in producing mice with human Synovial sarcoma. This led to his first finding that the development of the disease takes place in the myoblasts (underdeveloped muscle cells), as opposed to younger cells in an earlier stage of development which get aborted when affected by the disease and fully developed muscles cells do not become cancerous but develop myopathy. Using mice in this research represents a significant leap forward. However, it is very costly and Dr. Capecchi is currently looking for a way to extract the protein he is studying and cultivate it in a petri dish to save money.*

*Following our discussion with Dr. Capecchi, Dr. Haldar gave a slide presentation on his latest research which was published in the April 15, 2009 issue of Cancer Research and was on the front cover of the magazine. This research indicates that Synovial sarcoma does not develop exclusively in myoblasts, but can also show up at random in a variety of other types of cells.*

*Ted and I are very pleased to have gotten to know the people whose important research the PNB Fund is supporting and look forward to following their progress.*

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## **Second Annual Fundraising Event: October 2008**

Last year's event was a huge success. Over 70 people ages 2 and up participated in a 5k Run/Walk in Central Park. Later that evening about 90 people attended the fundraising dinner at the Cornell Club in NYC. The occasion gave people a chance to catch up with old friends and make new ones. Dr. Marc Ladanyi and Dr. Ito of Memorial Sloan Kettering Cancer Center (MSKCC) were the guests of honor. Dr. Ladanyi is a pathologist who has devoted over twenty years of his life to Synovial sarcoma research and is Chief of the Molecular Diagnostics Service at MSKCC. Dr. Ito, a Fellow at MSKCC and a co-researcher with Dr. Ladanyi, is testing a promising drug target for Synovial sarcoma.

In his keynote speech, Dr. Ladanyi shared his interest in studying Synovial sarcoma and talked about why he believed more money should be directed towards this, and other research of the so-called "orphan" diseases instead of, for example, breast cancer that attracts many more donations. As he explained, research progresses slowly and it depends more on having good and devoted scientists with a steady supply of funds rather than an overflow of money.

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## **Upcoming Events**

On Saturday, October 17, 2009, the PNB Fund will hold its third annual fundraising event—a 5k Run/Walk in Central Park, meeting place by 67<sup>th</sup> Street and CPW at 9AM, followed by a benefit lunch at Pasha restaurant, a few blocks from the Park, at noon. For more info, email [pnbfund@gmail.com](mailto:pnbfund@gmail.com).

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## **How to Donate**

Option 1: Write a check to The Paul Nabil Bustany Memorial Fund for Synovial Sarcoma Research. Send your check to: 15 Footes Lane, Morristown, NJ, 07960.

Option 2: Donate online by visiting our website [www.pnbustanyfund.org](http://www.pnbustanyfund.org).

The PNB Fund is a 501(c)(3) nonprofit organization. All donations are completely tax deductible.

**The purpose of the PNB Fund is to raise money for basic scientific research on Synovial sarcoma. The PNB Fund is entirely run by volunteers and all donations go directly to Synovial sarcoma research. Thank you for your support.**