

Ferre Institute, Inc.

Ferre Institute is a non-profit organization devoted to quality services in genetic and reproductive health.

Established 1974.

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New York State Division of the Budget

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Thank you for giving me the opportunity to tell you about the community based genetic counseling program of Ferre Institute and its critical role in the Mohawk Valley. I am a genetic counselor and the Executive Director of the Ferre Institute. Ferre Institute (Ferre) was founded in Utica NY in 1974 as a not-for-profit 501(c)(3) organization dedicated to providing exemplary genetic services to all. This was a novel idea. Ferre took the lead and today, through its community-based genetic counseling services, its genetic counselors provide the most current and balanced genetic information to more than 15,000 families facing complex medical conditions in the Mohawk Valley, Southern Tier and the North Country.

Community-based genetic counseling brings new genetic research to individuals of all ages and their families, regardless of their ability to pay, in the very communities where they live, working with their own medical

www.Ferre.org

www.FerreAnnualReport.org

www.CommunityGenetics.org

www.MohawkValleyGene.org

www.GeneticHelpDesk.com

www.HeartGenes.org

www.NYSGeneticCounselors.org

www.PregnancyRiskNetwork.org

www.InfertilityEducation.org

www.PrideAndJoyFamilies.org

providers. Ferre's community-based genetic counseling services is the only such program in New York State. It has received national attention. With support from New York State, Ferre's community genetic counseling program can bring genetics to more families in Central New York and, through replication, elsewhere in the state.

Ferre Institute is asking New York State to invest \$100,000 in new funds to support 1) an expansion of Ferre's community-based-genetic counseling services throughout the Mohawk Valley and 2) the expanded operation of its pilot initiative "Mohawk Valley Gene" which is an online and phone "genetic help desk" for physicians and other health professionals.

Certainly, I do not have to tell you about health care today, rising health care costs, unnecessary testing and disparities in access to care. Genetics offers solutions. The completion of the Human Genome Project has introduced a major shift underfoot in daily medical practice. New genetic advances offer unique opportunities to identify health risks pre-symptomatically. That means, a genetic test may predict if one specific person may be at risk for heart disease, breast cancer, diabetes, hypertension or dementia. Their medical care can then be tailored for that risk which improves care and less expensive. Pharmacogenetics examines how each of responds to prescription drugs based on our genetic make up, can improve patient response to medications, identify those most likely to work and protect against adverse effects of medications and consequent hospitalizations. Again, the health care is better and costs less.

Genetic discoveries are reported every day. The challenge, however, is how to get the most current information to health care professionals and their patients, how to help them make use of genetic tests and how to apply the test results to patient care. Currently, there are over 1300 clinical genetic tests available. National health leaders have recognized that there is a wide gap between the advances in the science of genes and the genetic knowledge base of many physicians, nurse practitioners and other health professionals. This knowledge gap is serious and alone contributes to unequal access to genetic information and treatment options. Genetic counselors close that gap.

Genetic counselors are specially trained to bring the advancing science of genetics and its health applications to physicians, nurse practitioners and other health professionals. We guide individuals, health professionals and communities through the unfolding era of genomics. Our profession emerged in the 1970's. I have practiced for 30 years. As a genetic counselor we assist individuals and often their families to help them understand the aspects of their health concerns could be related to genetic make up. We analyses family trees and clinical histories. We determine whether a known gene fits that person medical history, and if so, coordinate testing, if it 1) is clinically available and 2) if the person desires testing. We then interpret all this information for the person and their physician in the community.

Ferre's community-based genetics offers an immediate and creative solution to the disparity of genetic information and medicine in the Mohawk Valley. With community-

based genetics, Ferre's genetic counselors bring information about genetics, genetic tests and test results to individuals and their families in the communities where they live and work. In addition, community genetics gives access to genetic counseling through existing health care systems where individuals seek care. Ferre brings genetics to the people - in a way patients and physicians can use it.

Ferre Institute has been a leader in the effort to bring the Human Genome Project into medical practice. Ferre's first-hand, front-line experience has led us to develop innovative ways to bring genetics to Upstate New York. Our community-based genetic counseling brings current and responsible genetic information and testing to New York State residents. Our counselors have helped patients and their doctors to use new gene tests for breast and colon cancers. Ferre's new "Heart and Gene Program," the only such program in Upstate New York, brings specialized cardiovascular genetic risk assessment to families and gives them the opportunity to prevent heart disease. To assure that Ferre can continue its community-based genetics services, extend those services to more families and physicians in more communities and develop new genetic information and counseling service models which can give families and physicians in the Mohawk Valley full access to the advances of genetic science and access the best, most cost-effective health care, Ferre Institute needs financial assistance from New York State.

Genetic counseling is an up-front investment that will realize better health at less cost. But, genetic counseling costs as well as saves money. Genetic counselors are experts, trained in a unique assessment of risk and exponentially increasing body of knowledge

about genes and their application to health and disease. Genetic counseling takes time. For example, the availability of colon cancer predisposition genes allows for risk assessment and genetic testing in high risk families to determine who should have frequent screening and who can follow standard guidelines. This again tailors surveillance and manages costs. This multi-layered process for one person takes on the average 7 hours of research, analysis, explanation and documentation. For a family, it takes double that.

The demand for services is growing - growing beyond Ferre's resources. Of the 25 genetic service programs in New York State, Ferre Institute's community-based services reach the largest geographic region of the state. It fields requests from communities far beyond its geographic region.

Yet, resources for genetic counseling are very limited in New York State. In fact, although the demand for genetic counseling services has grown, the state has not increased funding. This 20 year flat funding has actually meant reduced funding because costs have increased.

Ferre's genetic counseling program now relies on health insurance reimbursements, direct patient payments based on a sliding fee scale that follows federal guidelines, foundation grants, contributions and state funds. These resources are not adequate to meet the current demand for Ferre's counseling services - especially as we attempt to respond to the referrals from throughout the Mohawk Valley and its surrounding communities. We

have worked diligently to stretch our funds to provide the most to many. We have, however, reached the limit of our capacity and, to do more, we need additional resources.

An investment of state dollars in Ferre Institute and its genetic counseling program for central New York will be public dollars well spent. It will help Ferre fulfill the promise of the Human Genome Project and community-based genetics for individuals and their families and for the state too. That promise includes earlier diagnosis and treatment of, for example, colon cancer. It includes reduced rates of chronic disease such as diabetes. It includes personalized medicine which will identify preventive strategies for better health and lifestyle modifications based on individual genetic make-up and environment. That promise includes reduced health care costs from early, individualized treatment plans and lower rates of chronic disease. Investment in genetic counseling will provide a platform for reducing cost of health care in the coming years and concurrently, reduce pain and suffering of individuals. These promises are real; they are today. And, there will be more tomorrow. New York State has an opportunity to help its citizens and itself.

Ferre Institute, therefore, requests \$100,000 in new funds for FY 2008-2009 for its community-based genetics program. With these additional dollars, Ferre can

- 1) counsel more families about genetics, genetic tests and test results,
- 2) educate more medical professionals - especially primary and family care practitioners - about genetics and thereby integrate the genetics into primary health care which must be its future. A new, key initiative in this effort is "Mohawk Valley Gene." This is an

online/phone "genetic help desk" which puts genetic advances at the finger tips of all health professionals in our region; and

3) extend its public education programs to communities throughout the Mohawk Valley and its neighbors.

Community-based genetics at Ferre Institute can assure universal access to genetic science and medicine, integrate genetics into primary health care and establish the infrastructure for professional and public conversation about policies and practice in the genomics era. Public dollars will support and strengthen Ferre's program in the Mohawk Valley, Southern Tier and North Country. I urge New York State to invest in Ferre Institute's genetics counseling program. It is an investment in health care of the future.

Thank you for the opportunity to speak with you today.

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Luba Djurdjinovic, MS

Luba Djurdjinovic, MS is the Executive Director of Ferre Institute, Inc., a non-profit organization that provides services in genetics and reproductive health. She is also Director of its Genetic Counseling Programs. She is a practicing genetic counselor with clinical interests in issues of infertility, familial cancer histories and most recently, cardiovascular genetics. Luba is credited for developing a unique genetic service delivery model and has promoted its adoption. In her 28 years of practice, she has been active in many state and national genetic professional organizations. She is the past president of the National Society of Genetic Counselors and a recipient of its National Achievement Award. Presently, Luba is co-chair of the NYS Genetic Counselors Group that represents all NYS genetic counselors. Luba has been a principle investigator on several projects with the National Human Genome Research Institute (Human Genome Project). She has provided public and professional education. In 2000, Luba completed 19 years on the adjunct faculty at the School Social Work in Syracuse, New York. In 2005, she received special recognition from the Alliance of Genetics Supports (an international organization representing genetic support groups). Luba is an author in a leading textbook for genetic counseling students and lectures extensively.

Murray L. Nusbaum, MD

Murray Nusbaum is the founder and Medical Director of Ferre Institute Inc. He is the Medical Advisor to the American College of Obstetricians and Gynecologist (ACOG) for New York State. He spent many years in the private practice of reproductive medicine and infertility before becoming Professor of Obstetrics and Gynecology at Upstate Medical Center in Syracuse. He is credited for the promotion of concurrent evaluation of infertile couples. In addition, his clinical work has resulted in a unique research database that has been central to numerous papers and congressional reports on the practice of infertility. In 2004, he was honored with a Lifetime Achievement Award from District II (New York State) ACOG.

Dr. Nusbaum has advocated for the integration of genetic discussions in clinical practice for 30 years. He is a frequent lecturer to professional and community groups about the importance of genetics in our daily lives. In addition, he has been involved in enhancement of ob-gyn services in rural counties of New York State with an emphasis on the Mohawk Valley and the "North Country".