Promoting the Rights and Safety of Research Participants
An Interview with Research Subject Advocate Cathleen Acres

Cathleen A. Acres, R.N., M.A., recently met with Focus to discuss her role as a Research Subject Advocate (RSA) at the Medical Center’s General Clinical Research Center (GCRC).

A member of the Division of Medical Ethics since 2001, Ms. Acres, along with RSA Juan C. Cordero, M.D., works with investigators and GCRC staff to promote the safety and rights of research participants at the GCRC and oversees appropriate approval of GCRC’s active protocols in this capacity. The following is an edited version of Ms. Acres’ conversation with Focus.

What is the General Clinical Research Center (GCRC)?

The NIH-supported Weill Cornell General Clinical Research Center was founded in 1961. Like the other 80-odd Centers in the country, it provides resources, infrastructure and staff for investigators who are engaged in patient-oriented clinical research. The Center currently provides support for quite a wide range of human subject studies including those related to hematology-oncology, infectious diseases, endocrinology, transplant surgery, neurobiology, behavior and gene transfer. In addition, the Center is also involved in fetal research and research on aging.

Recent Department Site Visits

Site visits offer external checks and balances that ensure our educational programs and outreach clinics maintain the highest standards set out by accrediting agencies and that our research is competitive and innovative enough to obtain and maintain funding. The following is a recap of our recent site visits:

• Feb. 2004: Division of Prevention and Health Behavior undergoes extensive NIDA site visit to renew funding for its NIDA-funded center grant.
• May 2004: ACGME conducts site visit of the Residency in Addiction Psychiatry to review its accreditation—a standard procedure for all ACGME-accredited programs.
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The ethical aspect of medicine is an ever-present consideration no matter what country physicians are practicing in. With the opening of its Qatar campus, the Medical College faced the unique challenge of adapting to the American version of its Medical Ethics curriculum to suit a predominantly Mid- dle Eastern student body. Preparing students to their individual cultures and traditions to deal with the human side of medicine. This will allow them to render a real service to future patients in the region.

At the end of the course, students had a very integrative vision of the nucleus of moral conflict found in medicine," said Dr. del Pozo. "For me, this was a refreshing experience because I had the opportunity to go back to the basics of medical ethics issues. However, the most fulfilling part was watching the students’ growth and maturation. It was fascinating to see how much students changed over the two months I taught this course. Their discussions and reactions to the readings became more and more accurate and insightful. This transformation is epitomized by a student who commented on Kafka’s masterpiece The Metamorphosis: 'When I first read the book, I thought it was a piece of poorly written fiction. But after the discussion, I understood that it deals with how families are affected by one member’s illness.'"

Dr. del Pozo will be in Qatar for at least three years. During that time he will implement the complete second- and third-year Medical Ethics curriculum, as well as gain a greater understanding of the local laws and traditions that will affect students once they become practicing physicians. Dr. del Pozo will also help implement institutional requirements to make them work with the information that you are so theoretical that it can be difficult to put into practice. Dr. del Pozo has led a summer course exposed students to the humanistic issues they will face as doctors. A different thematic area was covered each week: Biology and Nature, the Patient, the Family, the Doctor, the Hospital and other Healthcare Systems, Resource Allocation in Healthcare, and the Law and Medicine.

It's exciting to know that the work you're doing has a direct impact on healthcare delivery. Mr. Bailey said. "This is rewarding and educational to work on a project from the early stages to the very end – to know what's going on at every stage," said Ms. Do. "This will be especially important for me as I look to becoming a P.L. [principal investigator] one day."

Dr. Austrian joined the EAPC as director in 1991. She developed an internship program, which is now the top choice for social work students from the University of Vermont for their third-year placement. "Having six to eight students placed here each year makes an incredible difference because we’re able to treat clients on a longer-term basis than we could on our own." The EAPC has two full-time counselors and treats approximately 600 individuals per year. "It is a privilege to serve this initial cohort of staff members, but many don’t even know what we offer," said Dr. Austrian. "This is something I’d like to see change. I want to get the word out about the EAPC and see even more employees utilizing our services."

The Employee Development Center was created after members of the EAPC were approached by various outside organizations who heard about the Consortium and were interested in having the EAPC provide those same services to their employees. Dr. Diaz, who was one of the original EAPC counselors, was named director of the EAPC and has held that position for 20 years. Among its many programs, the EAPC offers marital and substance abuse counseling, childcare/elder care planning in Life Points programs, organizational development, management training, help with legal and financial issues, and alternative wellness programs.

A member of the Department since July 2003, Mary Koshy, M.P.A., works with Dr. Huerta on a Bioterrorism Task Orders and U.S. Health Systems Epidemic Response capacity grant. She is also involved in a project with Dr. Hupert and Maryelena Vargas, R.N., that examines the role of treatment variations in different Ebola response scenarios. "This study is very interesting because I am using TSI, the Hospital’s clinical and cost accounting databases, to examine treatment patterns," said Ms. Koshy. Originally a senior financial analyst at the Hospital, Ms. Koshy became interested in outcomes and increasing quality using TSI. In her current role, she is working on improving the well-being of EDC’s beneficiaries and the EDC’s 68-plus pool of clients ranges from leading New York City corporations to non-profit organizations like the Wildlife Conservation Society, which runs the Bronx Zoo.

"I love my job because we work with such a diverse group of clients and I never know what sort of issues I’ll be handling when I walk in the door each day," said Dr. Diaz. EDC Senior Counselor Nawam Bailey, M.S., one of four counselors on staff, has been on board for seven years. Born in Trinidad, Mr. Bailey is fluent in French and Japanese. He has lived in Japan, where he was employed as a translator and teacher. Mr. Bailey’s multi-cultural background and his experience studying international social welfare policy as an intern at the United Nations, give him a unique insight into the problems of the EDC’s many international clients. A proponent of alternative wellness programs, Mr. Bailey has led programs in office yoga, healthy eating and alternative healing. Day-to-day, he focuses on counseling clients, while also supervising the interns and directing the in-services for staff members.

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The Outcomes Division’s research centers on determining ways to increase the efficiency and effectiveness of healthcare delivery. Many of our successful faculty researchers work closely with skilled research data specialists who provide an important service to the research team: outcomes data collection, analysis and modeling. Computer programs such as Excel, Access, SAS and DataPro are some of the most commonly used tools for data modeling and analysis.

Kristof Neukermans, who joined the Department in December 2002 with Drs. Nathaniel Hupert and Bruce Schackman. Mr. Neukermans earned his degree in molecular biology and also studied economics – it was the most well-rounded education he could get. "A Ph.D. was so theoretical that it can be difficult to put into practice. Mr. Neukermans uses U.S. historical data and data collected from trials currently being conducted in Haiti. For Dr. Schackman’s syllabus project, Mr. Neukermans uses the legal and ethical aspects of the EDC’s many international clients. A proponent of alternative wellness programs, Mr. Bailey has led programs in office yoga, healthy eating and alternative healing. Day-to-day, he focuses on counseling clients, while also supervising the interns and directing the in-services for staff members.

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