Women and Autoimmune Diseases: Gender and Biological Perspectives

SUMMARY
by Dr. Mary Kay Flowers

On March 2, 2000 the American Autoimmune Related Diseases Association, Inc. (AARDA) and the Global Alliance for Women's Health (GAWH) sponsored a panel discussion entitled "Women and Autoimmune Diseases: Gender and Biological Perspectives". It was held at United Nations headquarters, New York, during the 44th session of the Commission on the Status of Women. Attending the panel, moderated by Virginia T. Ladd, President and Executive Director of AARDA and Dr. Elaine M. Wolfson, founding President of GAWH, were more than 80 representatives of over 55 NGOs from 15 countries. The Grace R. and Alan D. Marcus Foundation (Daniel Soba, Trustee) and the NGO Health Committee were additional sponsors. The program was made possible in part by unrestricted educational grants from Merck & Co., Inc. and Aventis Pharmaceuticals.

The speakers were Dr. Nafsiah Mboi, Director of the Department of Women's Health at the World Health Organization, Geneva; Dr. Noel Rose, researcher and a leading expert in autoimmunity from Johns Hopkins University School of Public Health; Kellie Martin, actress and spokesperson for AARDA; Dr. Denise Faustman, Associate Professor at Harvard Medical School and Director of the Immunobiology Laboratory at Massachusetts General Hospital; Professor Jean-Francois Bach, Head of Immunology Research Laboratories at Necker Hospital, Paris; and Dr. Vivian Pinn, Associate Director for Research on Women's Health at the National Institutes of Health, Washington, D.C.

There are some 80 autoimmune diseases which occur when the body's immune system, becoming misdirected, mistakenly recognizes the body's own proteins as foreign invaders and begins producing antibodies that attack healthy cells. Although individual autoimmune diseases are rare and not well-known, taken together, they are now the third largest category of diseases, after heart disease and cancer, in most industrialized countries. They are also a major women's health concern because between 75 and 90% of those who suffer from them are women. The diseases include lupus, rheumatoid arthritis, Graves' disease, scleroderma, type one or juvenile onset diabetes, pernicious anemia and multiple sclerosis.
In her opening remarks, Dr. Mboi congratulated AARDA and GAWH for organizing the panel. She observed that the panel must be one of the first discussions devoted to autoimmune diseases at this sort of international meeting. It exemplifies, she said, what is best about the work of the NGO community: NGOs identify and work on issues the rest of the UN hasn't taken up or has overlooked, and then sometimes gently, sometimes with force, introduce the new issue so everyone can move forward together. Along with increased life expectancy all over the world, Dr. Mboi pointed out that there has been a rise in noncommunicable diseases, both in developing countries and industrialized nations. While communicable diseases get much more public attention, autoimmune diseases also have a substantial influence on health and quality of life, especially for women. They can appear at any point in a woman's life cycle and they are likely to be chronic, manifesting themselves in progressive physical debilitation. This is not only important to women themselves, but their families and communities, as women all over the world are often the only home-based health care providers.

Because WHO is increasingly concerned with the number of years one can live in relatively good health, the organization is committed to supporting work not only on biotechnical aspects of autoimmune diseases, but also their negative impact on health, quality of life, and their cost to health systems. "The research and study which is needed may not be fashionable and it will surely be expensive, but women around the world will benefit," said Dr. Mboi.

Dr. Rose, a pioneer in autoimmune research, began by observing that even in this modern age of intensive medical research, individual autoimmune diseases are relatively unknown in the medical community. What is known after 40 years of research is that these diseases are women's diseases, they can cause other diseases, and they can affect any body site. They cluster in individuals and families, and have genetic predispositions and environmental triggers.

Traditionally, treatment of autoimmune diseases has been divided into specialty areas by the organs involved, Dr. Rose pointed out. These divisions plus poor communication among medical specialists have retarded research and understanding of the principles underlying the illnesses. Right now, treatment consists of administering anti-inflammatory, immunosuppressant and/or replacement drugs. For the future, Dr. Rose emphasized that scientists will need to find specific treatments for T-cells that attack the immune system, predictors of these diseases, the environmental triggers and how to avoid them, and early interventions and preventions.

Actress Kellie Martin, spokeswoman for AARDA, described how her sister died of lupus, which was diagnosed only after repeated trips to doctors, emergency
rooms and hospitals, and after the disease had caused dehydration and kidney failure. Ms. Martin would like to see clinics set up for early diagnosis, where specialists see patients, run tests, and share knowledge and information to diagnose the sometimes vague, seemingly unconnected symptoms characteristic of autoimmune diseases. In the meantime, she offered concrete advice to women who fall ill: keep a family medical history and a list of symptoms; don't stop with one or even two doctors, but get multiple opinions; and use health resources on the internet.

**Dr. Faustman**, speaking on "Gender and Genetics", stated that until about age 70, autoimmune diseases affect predominantly women. It has only recently been acknowledged that autoimmune diseases are important as underlying causes in more common illnesses such as heart disease, which is the leading killer of older women. They are also diseases in which morbidity, not mortality, is the primary concern. Dr. Faustman commented that autoimmune diseases are slow and chronic and people who have them don't die and get attention. Seventy-five percent of those affected by rheumatoid arthritis are women, and it has the decreased life expectancy of three-vessel coronary heart disease, is more severe in women, and causes disability in fifty percent of those afflicted within five years.

There are identifiable hormonal links which need further investigation, according to Dr. Faustman. The incidence of autoimmune disease peaks in women during menopause, with the exception of lupus, which affects women ages 15 to 25 years. When these diseases do occur early, women often go into remission during pregnancy, only to have the disease return once they deliver.

**Dr. Bach** observed that over the past four decades, as the world has seen a decrease in the rate of infectious diseases, there has been a corresponding rise in autoimmune and allergic diseases. While genetic predisposition and hormones play a part in autoimmune diseases, scientists have also found that where one lives also affects what type of autoimmune disease one gets. For example, the incidence of multiple sclerosis, Crohn's disease and type one diabetes are highest in Northern Europe but nearly disappear as one moves south to the equator. It has also been discovered that if a child moves by age 15, the risk for certain types of autoimmune disease changes. Thus, a child from near the equator who moves to Northern Europe is at higher risk for type one diabetes than a child who remains in his original environment.

Information on the risk in different areas of one country confirms that socioeconomic status affects the incidence of particular autoimmune diseases, according to Dr. Bach. Studies in Northern Ireland, where ethnicity and area of the world are constant, show that rates of some autoimmune diseases can vary
within a country. The poorer areas of Northern Ireland have lower incidence of diabetes, multiple sclerosis and allergic diseases than more economically advantaged areas. One exception is rheumatic fever, which is still rampant in poorer areas of the world, but is the only autoimmune disease for which there is a known cause and a cure: the illness is caused by a variety of streptococcus bacteria and is successfully treated with antibiotics.

Dr. Pinn said that autoimmune diseases are a priority at the National Institutes of Health in the United States for the 21st century, with a $30 million appropriation in 1999. She wants them now to become a global priority. To continue to affect policy making and funding levels requires that organizations such as AADRA and GAWH continue to work to expand the definition of women's health and health care beyond reproduction. The scientific and medical communities also need information and research sharing about the diseases themselves and how to prevent them, and outreach and educational programs for women, their families and health care givers. Early diagnosis, which Dr. Pinn notes can be as difficult as living with the disease itself, is essential. As the women who have autoimmune diseases can testify, they do not just affect the individuals who have them, but their families and communities.