

# Retinitis pigmentosa — lonely disease recognized

By MARY CONNELLY

Take an empty cardboard roll from a box of wax paper or aluminum foil and hold it up to one eye. Close the other eye.

Try to walk around the living room peering through the tunnel of cardboard.

If you tripped on the coffee table in the center of the floor or bruised your knee against a chair, it was to be expected. Tunnelled-sight causes a loss of peripheral vision, the ability to see things away from the center line of sight.

**TUNNEL VISION** has the medical name of retinitis pigmentosa, abbreviated to RP. Approximately 100,000 Americans have the disease, according to national records.

RP is primarily a genetic disease in which the retina gradually deteriorates. The disease, in which the retina progressively loses its ability to transmit a visual picture to the brain, can lead to loss of vision at age one or two and may produce total blindness early in life.

"RP can strike anybody at any age. But if it strikes in the developmental years, it accelerates with body growth," said Martha Lawrence of Bloomfield Hills, founder and president of the Retinitis Pigmentosa Foundation of Michigan.

MRS. LAWRENCE, who uses a pseudonym for her family's sake, has a son with RP. He can shoot an arrow or throw a dart but playing baseball is outside his scope because his field of sight is narrowed.

The inability to see anything but objects straight ahead is the second of RP's most common symptoms. First is the development of night blindness.

"In the crib the child could not see a glass of water brought in to him in the night," Mrs. Lawrence said of her son.

Mrs. Lawrence said that many families have multiple incidences of the disease because it is carried genetically.

"The weight of the tragedies and the difficulties are multiplied," she commented.

One of every 80 persons carries the recessive RP gene.

Two gene-carriers can produce offspring with RP.

ALTHOUGH there are tests available to diagnose the eventual development of RP in a child, the National RP Foundation estimates that for 99 percent of RP patients there is no medical or surgical treatment which can stem the gradual deterioration of eyesight.

Research efforts are being carried on and most recently the Massachusetts Eye and Ear Infirmary and the Harvard Medical School in Boston developed a center for the study of RP.

Coupled with the research goals of the national foundation are efforts to educate and inform the public about the existence of the disease.

"I'VE MET people who have never breathed a word to anyone that they had RP because they think no one has ever heard of it," Mrs. Lawrence said.

She recalls her own feelings of being alone with the disease.

"It's a very lonely thing to be in," she said.

"We were told our son had RP when he was four-and-one-half-years old."

"For about five years we just lived with the situation as best we could."

"Two years ago I heard Arthur Godfrey say retinitis pigmentosa on a radio show. I was shocked. I had never heard anyone say it but my ophthalmologist."

THAT RADIO broadcast led to Mrs. Lawrence's discovery of the National RP Foundation and the establishment of a Michigan chapter in 1972.

The state organization has developed a network of 100 to 150 RP families in Michigan, Mrs. Lawrence said.

Some couples, she commented, are "back-door members."

"Because it is a genetic disease a lot of people are reluctant to identify publicly what they have," she explained.

Although almost a dozen families meet monthly to organize fund-raisers and share their problems, Mrs. Lawrence said emotional therapy is not the focus of the foundation.

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## Bicentennial director urges women to unify

By SANDY TESSLER

Joyce Garrett is widely known in her role as hostess for, and special friend of Detroit Mayor Coleman Young. She finds this role, which the Detroit news media have chosen to assign to her, absurd.

Ms. Garrett is an articulate woman with a long list of impressive credentials ranging from director of the Wayne County Office of Human Relations to the distinction of having been the first black female foreign officer. She recently was appointed to the prestigious position of director of Detroit's bicentennial Commission.

Ms. Garrett, as keynote speaker,

addressed a group of women assembled at Bloomfield Country Day School for Woman's Opportunity Day. She spoke hard words in soft tones. Her appeal boiled down to a simple call for unification.

"OPPORTUNITIES for women are limited in our society," she said. "We are victims of certain oppressive forces and we are an oppressed class. The very first fact with which we have to contend is that women are at the bottom economically."

Ms. Garrett noted that women with degrees earn on the average the same salaries as men with no more than an eighth grade education.

"I am a feminist in the sense that I do not perceive men as superiors," she said. "Personhood is what we're striving for—for everyone."

"The classic conservative role of a woman is that of someone who serves other people." "When," she asked, do we become ourselves?

"WE ARE IN the throes of social revolution concerning the roles of women in this culture," Ms. Garrett said.

How, then, will this revolution take place? How can women who desire "personhood" achieve their goal?

One of the greatest hopes lies in education of young people and re-education of those who influence the lives of the young, she said. High school counselors were

cited as among those who have perpetuated role assignments. For example, a girl with a high-scholarship and high aptitude is channeled into nursing, instead of medicine. It is up to mothers, too, to prevent sexist attitudes about various roles, she said.

NEXT, WOMEN must unite, through organizations such as National Organization of Women (NOW) putting aside prejudice and competitiveness.

"Women must deal with the fact that ours is a society which responds to organized power. Power and its utilization is going to make the difference in what happens with women in the future."

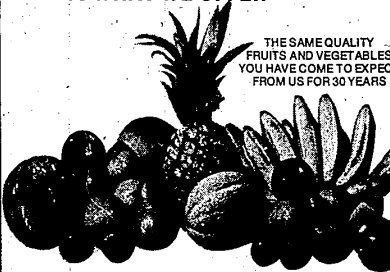
"Not until we are in a position to make our views heard in the public forum are we going to be able to make some really significant changes," Ms. Garrett said in a call for women to enter politics.

"WE MUST BECOME politicized. You are never significant alone. It is only through joining forces with other women that we can arrive at equity for women in this culture," Ms. Garrett said.

"We must understand that economics is a basic prerequisite for political aspirations. If we intend to be free human beings, women must begin by making an accurate assessment of where we are — as a group."


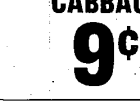

Men, asserted Ms. Garrett, have a monopoly on power and power is never given up willingly.

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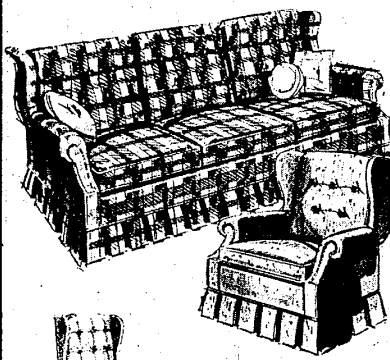
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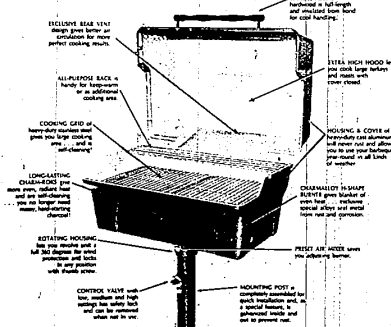
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