

FEATURES

Charney's vision is to help others who suffer from Turner's Syndrome problem she faced alone

PJ Todd
Years of taking daily doses of synthetic hormones—estrogen and androgen—kept Susan Charney's physical development fairly normal. But at 21, when her doctor warned her that without drugs she would not grow or menstruate, Susan became suspicious.

She was short, just four feet seven inches, and had always looked much younger than she was. "My doctor told me I needed the hormones to stimulate growth. He never told me there was something wrong with me."

Charney's desire to understand her situation took her on a tangled investigative journey. She consulted professionals, friends and read all the literature available. Her questions led to the realization that she was a victim of Turner's Syndrome—a genetic disorder affecting about one in every 3,500 children born—and that she was sterile.

"My parents had known the truth since I was ten, but didn't tell me. I was incredibly angry—at them, at my doctor. I've come through a tremendous amount of anger and now realize why my parents wanted to protect me and themselves too—they felt very guilty that they had in some way caused my condition." Susan has since discovered that neither parent is responsible.

Missing chromosomes

Turner's Syndrome is a women's chromosomal abnormality, medically referred to as *chromosomal ovarian dysgenesis* that occurs when females have 45 chromosomes instead of 46. This shortage results in missing genetic material that produces a number of characteristics.

TS babies are often shorter at

birth, they may have puffy hands and feet, webbed necks (an extra layer of skin), elbows that turn out slightly, low hairlines and they are generally sterile. The average height for a Turner's Syndrome woman is four feet seven inches. But because of the complex nature of cell division in

Every case different

the sex chromosome at conception, every woman afflicted with the condition has different characteristics. "We are all individuals and counselling has to reflect that reality."



Susan Charney, a Turner's Syndrome victim, is helping other women cope with the genetic disorder. Shown here hard at work in her clinic, located in the Behavioural Sciences Building

Charney is not one for self-pity or 'if only' indulgence. Instead she has dedicated herself to helping other TS women. With a \$15,000 grant from the Hospital For Sick Children Foundation she has established a Turner's Syndrome Clinic at York University (located in the Behavioural Sciences Building).

Symposium in March

She writes and mails a monthly newsletter and is involved in research. Charney

has also organized a one day seminar on Saturday, March 13. The Turner's Syndrome Symposium will feature four Toronto doctors who will discuss the genetic, endocrinological and cognitive aspects of TS. (Interested parties can call 667-3773.)

"We want to define the needs of the TS population and provide services to fulfill those needs," says Charney. She recognizes herself as a role model; both for the women she counsels and for the medical community. "This work can create a model for health services that people

classify us all. They categorize and label us. The pictures in those books are horrible."

While Susan admits the medical profession is better informed now than ten years ago, information is still generally limited to specialists.

"General practitioners know the term, but not much more

Doctors playing God

about it. They should know the signs and be able to recognize the disorder. Usually they don't have the time or the knowledge to advise women with TS.

"The big question doctors ask themselves is 'how much do they need to know'. How much they will tell the woman involved. Well I need to know. I want to know.

It's frightening that doctors won't tell. They are playing God. I think women can handle the information if it is presented properly—with sympathy and compassion."

Charney suggests that Turner's Syndrome is possibly the most difficult nondisfunctional disorder (in which chromosomes do not split properly) to deal with because it is the least severe.

"Our intelligence is not affected so we are totally aware of any unusual feature. Unlike victims of, say, Down's Syndrome, we are aware of every difference between us and others—no matter how small or insignificant."

She is optimistic about her work. She's seen about forty TS women since September and counselled twenty parents. "We talk about the implications of the condition, about our expectations, about being an adult in a young body. It is



symposium will provide an important information link.

difficult to talk, normally, about imperfections. We all try to cover them up."

Susan stresses the need for Turner's Syndrome women to interact and know they have a support system available to them. "It's an inhibiting topic because it involves our sexuality and our sensitivities. Women and girls come to me who have been teased about their height

Must deal with adoption

or are afraid to tell friends or boyfriends about their disorder.

Married women who are sterile must deal with their feelings about adoption."

Susan Charney has accepted that she will never be able to conceive—her body does not produce ovum—and she acknowledges "it was very rough at first, but I have accepted it.

"Our choice is taken away. Others can't have children but that doesn't make me feel better. You can, of course, come to terms with anything—and you have to do that to survive."

Gil White's Europe on 84¢ a Day is the ultimate European travelogue

Alt and Morowicz

Is Europe possible on 84¢ a Day? Gil White, a 24 year old student from St. Catharines, Ontario, knows that it's possible because he's done it.

White travelled to thirty countries in 115 days, at a cost of \$1,000, including return airfare and has written a book about it. It's the ultimate European travelogue for an el cheapo tourist, and it's now available at York U's bookstore. (Warning: it costs more than 84¢.)

White explains, "I wanted to show young people that a European holiday is affordable. You can minimize expenses and maximize enjoyment without sacrificing your health, sleep and integrity."

In a nutshell, Gil White advocates the "hitch-hike and mooch" approach to travel. He sets out his 27 tricks to the art of successful hitch-hiking, including such curios as the "New Wave" Switch-over and Yacht-hiking. According to White, as well as being a surprisingly fast and extremely cheap way to move from point A to point B, hitch-hiking is an exciting and adventurous way to meet people.

couple of nights with your new

found acquaintances. Knock on a few doors and offer your services as baby-sitter or dishwasher in exchange for free room and board. There's no harm in asking, White claims, but it requires a very keen sense of adventure.

The results are phenomenal, both in monetary and educational terms. Gil White has met people and done things which Butterfield Travel couldn't set up

for you in a million years. He has eaten dinner cross-legged on the floor in a Jordanian home, participated in university English classes in Rabat, Morocco, lived with a Yugoslavian peasant family, and very nearly caught a glimpse of the inside of a Turkish jail.

It's not as easy as it sounds. Despite White's assurances that European hitch-hiking is a safe and pleasurable adventure, it is difficult to accept without hard facts and statistics. He encountered no problems and it is no wonder looking at the strong, athletic, semi-pro tennis player on the book's cover.

Hitch-hiking can be a dangerous occupation, parti-

cularly for females. "Take the commonsense precautions," he says. "Look the driver over and expect the best." You take your chances, Gil. Most other people will take the train.

White's Europe is not for your typical sight-seer. When you depend on freebies for lifts, meals and accomodation, you have to be extremely mobile. Even the most solicitous of hosts may balk at the idea of a fifteen day non-paying houseguest. It's easy to mooch for one night, but don't over-stay your welcome.

White emphasizes that this way of travel is primarily for a young people who wants to experience Europe by getting to know the people. While certainly one extremely important aspect of travel, what of the 'traditional' Europe, the galleries, nightclubs, monuments, and cultural events? All this costs money, and it's rare that anyone, at any age, will want to sacrifice them.

White's book is an excellent guide to the do's and don'ts of hitch-hiking and a demonstrates a successful approach to cost-saving travel. If nothing else, Gil White has proved that it can be done. But as a complete travelogue, you pay your money and take your chances.

