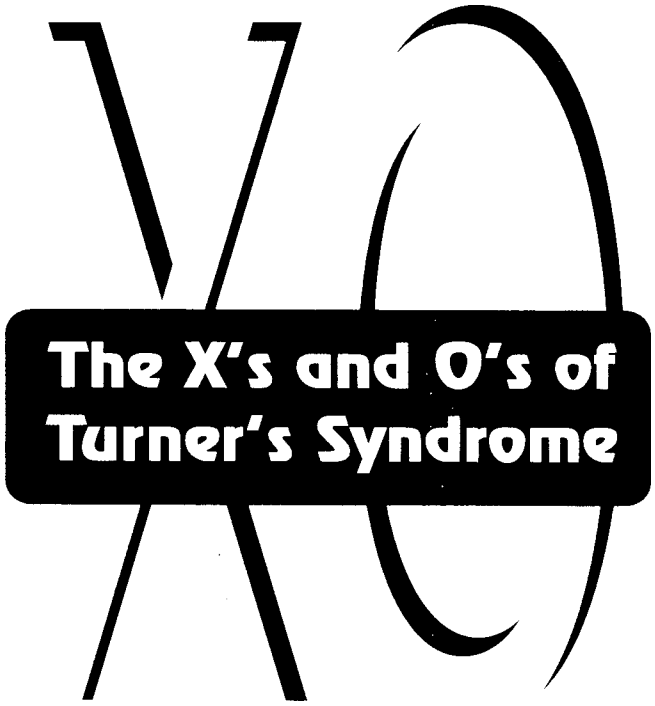

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Introduction

The Turner's Syndrome Society of Canada was formed to provide much needed services for those with Turner's Syndrome and their families. The Society held its inaugural meeting in 1981 with only 3 members present. It has since grown to include hundreds of members from all over the world.

People with disorders that are not common or well known often feel isolated. Our members have reported that they have benefited a great deal from the support provided by a common meeting ground where individuals with a like condition can share their anxieties, problems, concerns and possible solutions.

Information in this publication has been gathered from questionnaires and discussions with individuals with Turner's Syndrome. Members from Turner's Syndrome support groups also contributed. We felt that this approach would best represent the personal, day-to-day feelings of Turner's people and in this way reach out to those who want to know more about the disorder.

There have been many requests for an updated version of The X's *and O's of Turner's Syndrome.* This new edition includes some recent medical advances dealing with Turner's Syndrome. We hope that this booklet will go a long way toward providing a clear concise understanding of this condition.

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MEDICAL PERSPECTIVE

What Is Turner's Syndrome? How do women with Turner's Syndrome differ from other women who are short and/or cannot have children?

History

In 1938, Dr. Henry Turner, after whom the condition is named was the first to identify its characteristics and categorize them under one comrnon syndrome. Without knowing the underlying cause of the disorder, Dr Turner began treating these women with estrogen supplements. It wasn't until 1959 that Dr C. E. Ford discovered the chromosomal basis of the disorder and identified it as chromosomal ovarian dysgenesis ... Turner's Syndrome.

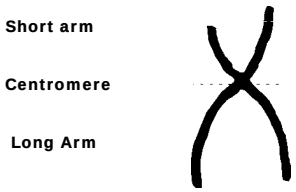
Turner's Syndrome

Turner's Syndrome is a disorder which affects 1 in 2,500 females It results in short stature (adult height is about 4'8"), the need to take hormones in order •c develop secondary sexual characteristics (breasts, menstruation and pubic and axillary hair), and infertllity. There is also a wide range of other physical associated with this condition. Please see page 12

Genetics

Chromosomes are thin, rod-like structures found in the nucleus of each cell. They are composed of two corresponding chromatlds that are joined by centromere. The strands of a chromosome branching out from the centromere are called arms. In an X chromosome the centromere divides the chromosome into long and short arms.

Chromosomes contain the genes which give each person his or her individua[l] characteristics Genes are molecular units located on the chromosomes, which determine hereditary traits such as blood type, eye colour, hair colour and height potential.



Humans normally have twenty-three pairs of chromosomes Including are pair of sex chromosomes.

A female's pair of sex chromosomes are represented by XX and a male's pair by XY. At conception, each parent contributes twenty-three of their total of 46 chromosomes. The female always contributes an X sex chromosome, whereas the male contributes either an X or a Y sex chromosome. The fertilized egg will thus have two X chromosomes (XX) and develop into a normal female fetus, or have an X and a Y chromosome (XY) and develop into a normal male fetus.

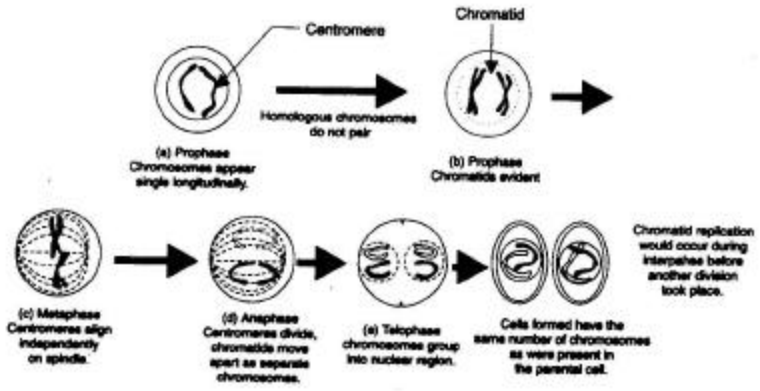
In Turner's Syndrome one of the X-chromosomes is missing entirely or is structurally altered in some or all of a woman's cells. As a result, height and sexual development are affected. Sex chromosomes play a major role in the development of reproductive tissues and organs. They are also thought to influence an individual's adult height. The loss of the X chromosome is a random occurrence during the formation of sex cells. Contributing parents have no control over the possibility of this occurrence, and therefore "blame" cannot be ascribed to either parent. There is no increased risk of future offspring having Turner's Syndrome.

The following statistics will help to place Turner's Syndrome in its proper perspective within the wide realm of congenital disorders. Congenital disorders are those with which one is born, and they can stem from genetic or chromosomal problems, or from environmental factors such as viruses or medication.

Three percent of all infants will be born with a major congenital disorder. About 60% of all spontaneous first trimester miscarriages (those that occur during the first three months of pregnancy) have a chromosome disorder. In about 20% of these miscarried fetuses Turner's Syndrome has been diagnosed. Only 2% of Turner's fetuses survive to full term. One possible explanation is that there is often a fluid build-up in the body tissues of the fetus, rendering it non-viable. Therefore, if you are reading this and you are a Turner's person, you are very fortunate! Consider yourself one of the "cream of the crop."

Cell Division

Each one of us begins as a single cell which is the united combination of two sex cells (egg and sperm). In order for us to develop into adult individuals, the single initial cell must duplicate itself many times over. As adults, we have literally trillions of cells in our bodies.

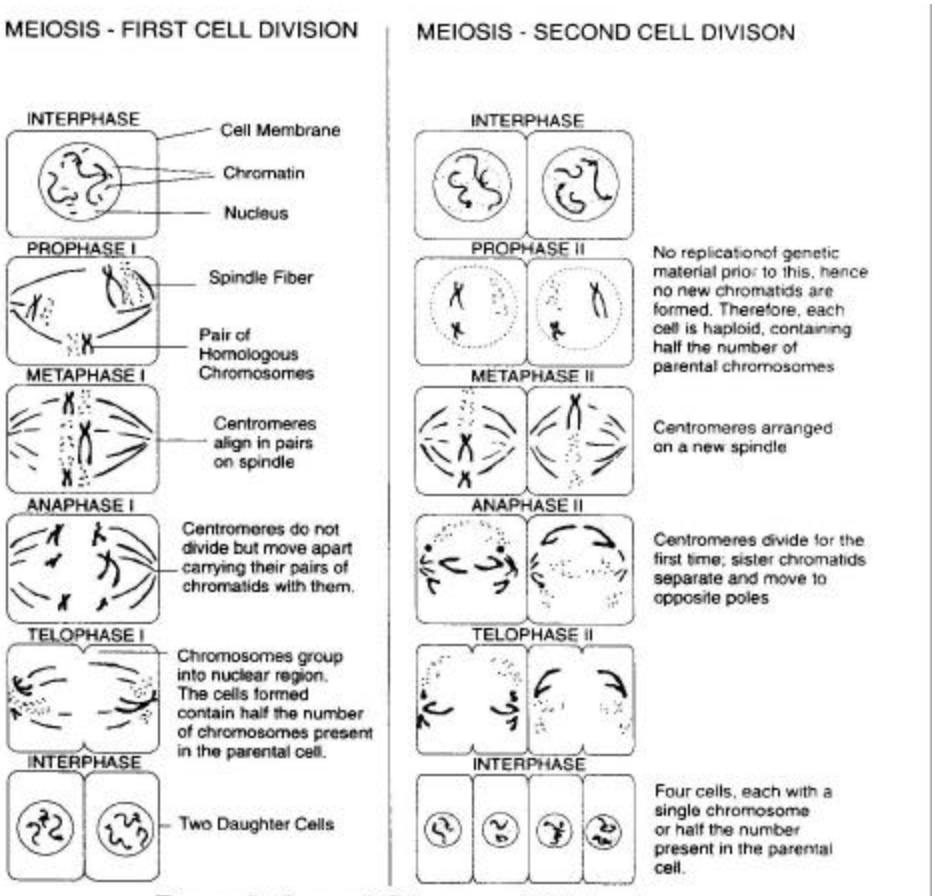


MITOSIS

The X's and O's of Turner's Syndrome 9

There are two types of cell division; meiosis and mitosis. In order to produce sperm and ova, cells undergo meiosis. Meiosis is a specialized cellular division process which occurs only in the sex cells. In meiosis, the chromosomes separate from one another once, but the cell body divides twice. The result is that the nucleus of the mature egg or sperm contains a reduced number of chromosomes The chromosomes in meiosis come together and cross over, exchanging genetic material. This is the basis for the statement that no two people are identical - except for identical twins. When sperm or eggs are formed, chromosomes break and re-join. It's the only way, in fact, that you can get this crossing over and exchange of genetic material. Please see following page. It is usually during this type of cell division that errors occur leading to Turner's Syndrome.

Mitosis is the process by which all other cells of the body divide . From the point of conception on, all cell divisions are mitotic, except when sperm or egg cells Is are formed; then they are meiotic. In a resting cell, the chromosomes are spread out; they are long, thin and separate.

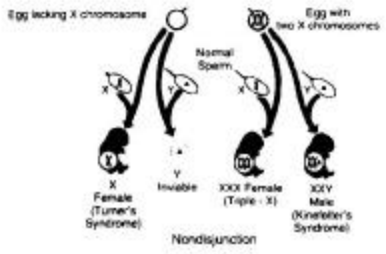


Description of Stages of Meiosis

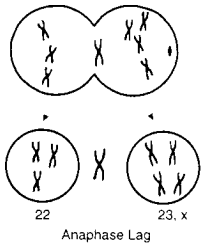
Courtesy of Sherman and Sherman, "Biology: A Human Approach"[5]

Errors in Cell Division Which May Cause Turner's Syndrome

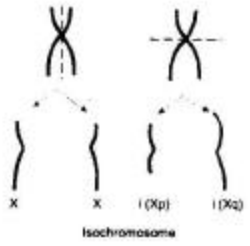
One of the errors that can occur in dividing cells is called nondisjunction. This occurs when a cell divides and one daughter cell receives an extra chromosome and the other daughter cell receives one less chromosome. This results in an error of chromosome number.



Another error that may occur is called anaphase lag. Anaphase is the cell division stage in which the chromosomes are being pulled off to the side by the spindles attached to the centromere. So in anaphase lag, one of the chromosomes, for some reason, is left, and when the cell divides, it is lost. This a mechanism which also can yield one fewer chromosome than normal.



Structural abnormalities can also occur. For example, when chromosomes divide transversely instead of longitudinally the result is called isochromosome. The result is that the short arm is joined by the centromere (isochromosome for the short arm). The long arm can also be joined by the centromere (isochromosome for the long arm). When this happens to the chromosome, the isochromosome for the short arm, which obviously must form, usually gets lost. But the isochromosome for the long arm tends to survive and show up in the cells.



Physical Characteristics

In addition to short stature, infertility, and the lack of secondary sexual characteristics, all of which are common to Turner's Syndrome, the following is a list of additional physical characteristics that have been detected in Turner's individuals. Most of these features are not exclusive to Turner's. It is sometimes difficult to determine if a physical characteristic attributed to Turner's is actually a result of the disorder itself, or the result of an independent inherited or environmental factor.

Nearly half of newborn Turner's girls have puffy hands and/or feet These problems usually disappear in a few weeks or months so parents should not be too anxious about this. There may also be relatively pronounced skin folds In the neck which also disappear rather quickly. In some cases where there is a broad neck or permanent skin folds (so-called webbing on both sides of the neck) these folds, if they continue to be present and cosmetically disturbing, can be surgically removed by a plastic surgeon.

Approximately half of all girls with Turner's Syndrome have problems during the first year of life with gulping and vomiting. In rare cases there may be a constriction of the connection between stomach and bowel.

Approximately 1 out of 10 girls with Turner's Syndrome is born with constriction of the aorta (main heart artery). This disorder, which is called coarctation of the aorta, is usually diagnosed during the first year of life or later in childhood. If the constriction is pronounced, it has to be surgically corrected This can be done with very little risk, and leads to completely normal cardiac function If the constriction is not present in the early childhood there is no risk that it will appear later in life.

It should be noted that Turner's individuals may not exhibit all of the listed features. Most of the features listed are not debilitating, and are mainly used as an aid to diagnosis.

STATISTICAL CLINICAL FINDINGS IN 100 PATIENTS WITH A CROSS-SECTION OF DIFFERENT TURNER'S SYNDROME KARYOTYPE:

Soft finger nails which turn up at the tips. 43
Low set ears. 48
Chronic middle ear infection (otitis media) 53
Constriction or narrowing of the aorta (Coarctation of the aorta) . . . 9
Wide carrying angle of the elbows (cubitus valgus) 55
Dysfunctions of the kidneys and urinary tract) 27
Folds of skin on inner edge of eye (epicanthal folds) 27
Gastrointestinal and other feeding problems (during infancy) 37
Heart murmur 43
Reduced thyroid function (hypothyroidism) 8
Low hairline. 54
Build-up of fluid in limbs during infancy (lymphedema) 36
Short-sightedness (myopia) 14
Other skeletal abnormalities 40
Droopy eyelids. 11
Renal abnormalities (structural abnormalities and dysfunction of the kidneys and urinary tract. 27
Broad chest with widely spaced nipples (Shield chest) 55
Webbed neck. 41

Other reported Findings in Turner's are:

- Diabetes mellitus
- Dry skin
- High blood pressure
- Formation of scar tissue (keloid formation)
- Small jaw (microgenia)
- Narrow high-arched palate (the top of the inside of the mouth)
- Pigmented moles
- Verbal/performance discrepancy

Diagnosis

Approximately one-third of Turner's individuals are diagnosed during the newborn period, one-third during childhood, and one-third during the late teens when it becomes apparent that they have failed to go through puberty.

A medical practitioner may suspect that a female has Turner's Syndrome due to the presence of physical features associated with the disorder (see previous page). A further and conclusive diagnosis can be made only by karyotyping (chromosomal analysis)- a precise means of identifying chromosome complement. Karyotyping involves several steps.

First, a blood sample is taken so that the chromosomes of the blood cells can be studied, although other tissue cells can be used with equal results. Cell dlvision is then stimulated in a controlled laboratory environment. The chromosomes are examined during cell division at the stage when they are most distinguishable. The chromosomes are counted and then by means of a photographic enlargement are further examined for structural abnormalities. This is done by arranging the chromosomes in a systematic order to construct a karyotype.

Classification

Monosomy (Classic)

This classic form of Turner's Syndrome is represented by the karyotype 45.X meaning that all cells are missing an X-chromosome. This group generally exhibits more of the physical features (see page 12) than those who fall under other categories of the Turner's Syndrome population. The incidence of monosomy Turner's is about 50%.

Isochromosome

Normally, a chromosome divides longitudinally, but in the case of an isochromosome it divides transversely. The result is a loss of all or a portion of one of the chromosome arms and the genetic material contained therein.

Two normal X-chromosomes are necessary for proper sexual development The term "isochromosome" in reference to an Xchromosome with normal long arm karyotype 46,i(Xq), means that the short arm of the chromosome is missing and the long arm is duplicated. Women with this isochromosome are not likely to differ in appearance from monosomy individuals. However they do have a slightly lower frequency of neck webbing and cardiovascular defects.

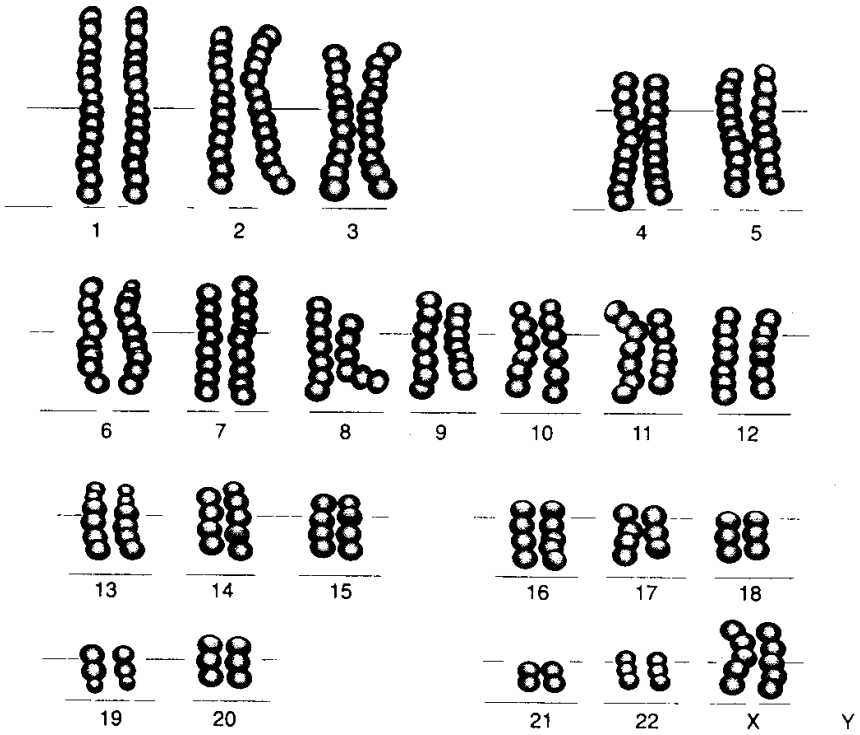
Isochromosomes account for a total of 12-20% of all Turner's cases.

Mosaicism

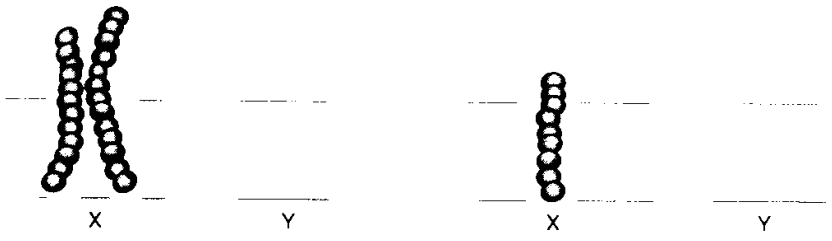
When either the chromosome number or structure differs in different cells of an organism, the condition is described as chromosomal mosaicism

One example of mosaicism in a Turner's individual is represented by the karyotype 45,X/ 46,XX. In this variation only some of the cells are missing the second chromosome. These individuals tend to exhibit the fewest number of physical characteristics associated with Turner's. Up to 20% of this group are capable of menstruation, and there have been one hundred known pregnancies reported from women with this type of mosaicism. Those who do menstruate usually experience early menopause, beginning in the late twenties or early thirties.

Cellular combinations differ in mosaicism. For example, an individual may have some cells that are missing an entire X-chromosome, as well as some that are isochromosome, eg. 45,X/46,X,i(Xq). Thirty to forty percent of all Turner's Syndrome patients are mosaics.



Normal Female Karyotype
46, xx



Ishochromosome
46, xi (xq)

Classic Turner's Syndrome
45, xo

■ short arm is missing and long arm is duplicated

Treatment

Hormone Therapy

Should I take estrogen?"

Normal pubertal and sexual development depends on the production of the hormones estrogen from the functioning ovary, and androgen from the adrenal gland, above the kidneys. Estrogen stimulates the growth of breasts and ultimately induces menstruation. It is also important for maintaining the structural integrity of the bones. Not only does it help prevent osteoporosis but it also lessens the risk, of hardening of the arteries in later years.

Because the majority of women with Turner's Syndrome have absent or insufficient ovarian function, it will be necessary to undergo estrogen replacement therapy.

When a Turner's woman reaches the age at which most women are entering menopause (late 40's), a physician will decide whether estrogen medication is advisable. However it is generally believed that these women should not discontinue hormonal treatment and that each woman is different with a unique set of factors inherent to her particular physiology. Risk factors considered when determining the continuance or termination of estrogen treatment are: obesity, heart problems, and smoking.

The ovary produces another hormone called progesterone. This hormone is essential in preparing the uterus for pregnancy and in sustaining pregnancy Women normally produce progesterone so it is important to include this hormone as part of your treatment. Abnormalities in the uterus may arise from taking estrogen alone. Progesterone helps prevent these abnormalities.

Androgen Therapy

Androgens are "masculinizing hormones" and are responsible for the normal appearance of underarm and pubic hair and for the spots and pimples typical of adolescence. They also contribute to the spurt in linear growth that occurs in early and mid puberty.

In many medical centres, low-dose androgen therapy has been given to Turner's patients at approximately 12 years of age in an attempt to mimic the growth spurt of puberty, but without causing excessive masculinization (muscular development, growth of facial hair, etc.). Although some success has been claimed there is a general consensus that such treatment does not result in significant improvement in final adult stature. Androgen therapy may result in attainment of final height at an earlier age, which for some children may be psychologically beneficial.

Human Growth Hormone (hGH)

Perhaps by the time the next issue of this book is printed, it will contain a definite statement about the therapeutic role of hGH in children with Turner's Syndrome. At present, preliminary studies using synthetic hGH are of approximately two years' duration. The experience thus far has been fairly positive, with improvement in growth rate during hGH therapy and without obvious side effects. Time, (perhaps five or even ten years) will tell whether such improvement is sustained, and whether there is a major im pact in final adult stature. At the moment, trials in the use of hGH are still in the experimental stage. The potential for side-effects and long-term benefit has yet to be ascertained. Cost is also another major factor.

For more information regarding the use of estrogen, androgens and human growth hormone in the management of Turner's Syndrome, please contact your local chapter of the Turner's Syndrome Society or your doctor.

Donor Eggs

Thanks to pioneering research in the area of donor eggs, premature ovarian failure, early menopause, or lack of ovaries (such as in Turner's Syndrome) are no longer considered absolute infertility conditions.

The process of egg transplants involves retrieving eggs (ova) from a donor and implanting them into the uterus of a recipient who is incapable of producing her own eggs but can carry a pregnancy through to completion, e.g. a Turner's individual.

In order for this treatment to be successful, several problems had to be solved. One difficulty was in duplicating the normal development of the endometrium (lining of the uterus) during pregnancy, enabling it to support an embryo. This was done using estrogen and progesterone hormone therapy so the fetus could be implanted in the endometrium to initiate pregnancy. It was also necessary to synchronize the hormonal cycles of the donor and recipient. The optimal time to transfer embryos to the uterus was then carefully considered.

At the time of printing, this procedure is still not widely available. If it were, and you were considering it, one question you might ask could be "Would I want an anonymous donor or would I prefer a donor to be someone that I know?"

SOCIAL, PSYCHOLOGICAL AND EMOTIONAL PERSPECTIVES

Included in this publication is a needs survey that deals with relevant issues Some of these include disclosure and concerns about short stature, infertility and lack of secondary sexual characteristics. Please refer to the needs survey at tine end of this section for greater detail on these issues.

Disclosure

Sharing Information

Only you can decide whether or not to tell someone that you have Turner's Syndrome. If you feel that a person is mature and can deal with it, then you should tell him/her. I think you will find out, as 1 did, that it is not as bad as you might have thought. 1 believe the majority of people will not reject you for this reason They may even appreciate your honesty.

1 had this secret and I couldn't let anyone know. And I'm sure that affected me. The more I felt like I had a deep, dark secret, the more inadequate I felt."

Whom should you tell about having Turner's Syndrome? How much should you divulge? By its very nature Turner's Syndrome sometime seems hard to talk about. Sexuality and physical differences are generally "taboo" subjects

Should siblings be told? They are often curious and have questions that may need to be answered. If left unanswered, unnecessary tension within the family may result.

In most cases your parents will be told that you have Turner's Syndrome But there have been cases in which only the daughter was informed. If this happens support may be gained by confiding in your parents.

There seems to be two approaches toward disclosing personal information about Turner's Syndrome to someone with whom you are romantically involved The first is to raise the issue near the beginning of the relationship. "I want to talk about Turner's at the beginning so that if he's going to say good-bye, I won't be wasting my time!" The other approach is to wait until you feel you have developed a bond of trust; that you are at a point in the relationship where he knows and cares about you as an individual, and won't be frightened.

Trust your own judgement. To whom and how much you divulge depends or your own needs and personality. Disclosure to the right person at the right time can be helpful, be they an aunt, an uncle, a cousin or a friend.

"I find that the more the person knows me the less threatening this whole problem seems. They don't think of me as someone with a problem they know me as a person."

Getting Information

It is extremely important that parents get as much information about Turner's Syndrome as early as possible. This will help to promote independence and avoid overprotecting the daughter and/or treating her as younger than her chronological age. Parents will also be better able to inform their daughters about the disorder and answer any questions they might have in a calm and accepting manner. Different ages (of individuals with Turner's Syndrome) present different problems. When you're a young child, you may be concerned about classmates teasing you. As an adult, infertility may be of great concern. Turner's individuals must be allowed to feel and express their emotions involved with finding out about, or coping with, their having Turner's. Statements such as, "Don't be sad," or "Don't get upset" do not make someone feel better. Rather, they negate the individual's right to feel, and express emotions.

It is very important that girls with Turner's Syndrome be given correct and full information about their condition. To do otherwise might lead to unnecessary worry. Often the patient's speculation about her condition is worse than the actual reality. Turner's girls told about their condition at age 18-20 years (or later) often expressed regret and bitterness at not getting this information earlier. They feel that this would have saved them much anxiety and many worries concerning their short stature and late puberty. Getting information about Turner's Syndrome helps these individuals to accept their disorder and to be more open about it.

Turner's women often need medical treatment and sometimes appear younger than their years. As a result, people may treat them as being younger and more fragile than they actually are. In order to promote Independence Tur[n]er s individuals should be treated and given tasks according their chronological age Those with Turner's Syndrome also have a responsibility to behave in a mann[er] appropriate to their age.

Beware of the Self-Fulfilling Prophecy

While there are similarities among Turner's individuals, it is best to avoid labelling or stereotyping this population. Labelling is necessary in diagnosis and treatment but that is where it should stop. When we look at textbooks we often see photographs showing Turner's individuals standing nude with their eyes covered beside measuring tapes. These representations are purely clinical and while the photographs are necessary as learning aids, without a broad understanding of Turner's Syndrome, they can lead to stereotyping and misconceptions.

Misconceptions about Turner's continue to be found even in the most recent textbook editions. One such error is a reference to all Turner's women as being mentally retarded. It is obvious and well documented that this is not true. Clinical studies have shown that the incidence of mental retardation among Turner's individuals is about the same as it is in the rest of the population.

A syndrome is a collection of characteristics associated with a particular condition. Unfortunately, the word *syndrome* is sometimes misunderstood by the general public. As soon as people hear the word *syndrome,* they conjure up exaggerated notions of something terrible

Amongst the Turner's population, there is the ever-present danger of the "self-fulfilling prophecy." Believing something to be true about yourself often influences the way others perceive you. This may cause an imagined problem to come true in reality, even if it did not exist to begin with. You believe it to be true, thus the "self-fulfilling prophecy" comes true.

Turner’s women often need medical treatment and sometimes appear younger than their years. As a result, people may treat them as being younger or more fragile than they actually are. In order to promote independence Turner’s individuals should be treated and given tasks according to their chronological age. Those with Turner’s Syndrome also have a responsibility to behave in a manner appropriate to their age.

Height and Self-Image

For girls, being short frequently means being cute. but never beautiful fu A *s" girl cannot be willowy, slender, gorgeous or sophisticated Long is lovely :- = big is beautiful. A short girl can be petite. peppy. cuddly, also pudgy plump and chunky All our ads on T V say so."*

One of the major complaints that Turner's Syndrome individuals have about being short is the feeling that they are not taken seriously by their families employers. There is a tendency amongst Turner's women see themselves as "little girls," even in adult years. Generally, "little girls" do not have meaningful, adult relationships with the opposite sex. "Little girls" have to be looked after and little girls" are dependent on others. Continuing to

think of yourself as a “little girl' may make it difficult to work toward what you really want. It is unrealistic to expect others not to think of you as a "little girl" if you always see yourself in this manner.

Take a good hard look at yourself. This is always the first step to ward improving self-image. You contribute to the way others see you Begin by constructing and examining a list of characteristics for yourself such as the one which follows. This list is a summary of the views presented by members o* a Turner's Syndrome support group following discussions about reactions to being treated as younger than they are.

Qualities I Think an Adult Should Possess:

The ability to:

- listen to others
- be assertive
- express feelings and needs in a clear marine'
- take responsibility
- know one's own needs and capabilities
- understand the value of patience
- be sensitive to the needs of others

Childish Characteristics That Should Be Examined

- manipulative tendencies
- whiny voices
- over-dependency
- difficulty expressing one's needs and desires in a tactful manner
- concern with self and how things affect only oneself • irresponsibility

It is important to accept and cope with the fact that you are shorter than average. While it is important to realize that there are problems associated with being short, short stature does have its redeeming qualities as well.

Things I Like About Being Short

- I can wear high heels
- I can fit into almost any place
- people don't find me threatening
- I'm usually in the centre of pictures
- I can lie down in the bathtub
- regular sized beds or couches are comfortable to lie on

Things I Dislike About Being Short

- drinking fountains are too high
- bars on buses are so hard to reach
- hanging coats on coat racks is annoying
- watering hanging plants is a nuisance
- trying to see over heads at the movies or the theatre is difficult
- feeling lost in a crowd and trying to find someone else in a crowd are problems
- the expense and inconvenience of always having to alter new clothes is frustrating

Not everyone thinks about his/her size all the time. Try this exercise: Think about what situations make you aware of your short stature. When do you forget about being short?

There is substantial information to support the fact that short people are stereotyped. Insensitive comments such as, "How old are you?", How tall are you? "Why are you so short when the rest of your family is tall?", "What's the weather like down there?", "You don't have far to fall," often succeed in further alienating short people.

A feeling of having to try harder was expressed by many Turner's women "When you look young, when you're short, when you're taken less seriously and when you're taken for being less capable than you are, you have to try doubly hard in school, on the job, and with friends, in order to prove yourself."

The feeling of being separated and singled out due to short physical stature is not uncommon. The advertising world contributes to these feelings of inadequacy by portraying the ideal woman as a tall and slim beauty Advertising such as this is impossible to avoid. It bombards us everywhere, everyday. In reality, small can certainly be beautiful.

Individuals with Turner's Syndrome are governed by the same genetic laws as the rest of the population. Therefore, genetic background for height still exerts an influence so that Turner's girls with tall parents tend to be taller.

Presently, the average height of a normal female is slightly less than 5 5 for the Turner's population the average height is 4'8" inches. This is the height of a normal 11 year old.

How can we overcome this problem and achieve social adjustment and self-acceptance? By growing - mentally and emotionally. Stature has more than one dimension.

Occupations

Turner's individuals have reported that their height has affected the type of employment that they have been able to secure. As with the rest of the population it is important to set realistic work goals, and naturally there will be individuals who are professionals, blue collar workers, clerks, and even some who are unemployed.

The following is a list of some of the positions held by Turner's Syndrome individuals:

Animal Attendant
Day Care Worker
Genetic Counsellor
Hairdresser
Lawyer
Library Technician
Make-up Artist
Music Teacher
Nurse
Psychiatrist
Receptionist
Respiratory Technologist
Social Worker
Teacher
Translator
Upholsterer
Paediatrician

These professions are quite varied. It has been stated that Turner's individuals tend to choose nurturing professions - for example, teaching or paediatric nursing. While this may hold true for some, it is certainly not an absolute. One hypothesis regarding the choice of the caring professions purports that this kind of work gives those without children the chance to nurture others.

Physical stature may limit possible employment opportunities. Today, however, there are very few jobs a short person cannot do Being short can also prove to be an asset. One young woman, a teacher, points out that her physical stature is beneficial to her work because her students tend to relate to her more closely.

In the final analysis, Turner's Syndrome does not determine your job future. You do.

Femininity and Sexuality

Femininity is largely a state of mind, incorporating an adult image of oneself and a very real sense of satisfaction about one s womanhood. Having Turner's Syndrome does not mean that you are less of a female or less feminine. There's no reason that Turner's females cannot achieve fulfilling and satisfying sexual relationships. Turner's women are fully capable of having an orgasm.

Some feel that because their physiology has developed differently they will rejected by potential romantic partners. "I am afraid that anyone I m involved with romantically will eventually throw me over for someone physically more beautiful and that in the end I'll always lose out. " This is a common fear despite the fact that every woman is physically unique. Estrogen replacement therapy helps Turner's women develop figures similar to other women.

The way in which one views oneself in terms of sexuality and femininity will inevitably be communicated to others. What kind of signals do you give? Fears of not being able to have satisfying sexual relations and relationships are unsubstantiated. Like femininity, your sexuality is so much more a state of mind than merely a reflection of your anatomy.

Infertility

The one physiological factor that most Turner's women have In common is infertility. Infertility, be it permanent or short-term, is defined as " ... the inability to conceive after a year or more of sexual relationships without contraception." It is evident that Turner's individuals are not unique in this regard. Ten to fifteen percent of all North American couples suffer from infertility. In any gathering of twenty women, chances are that one or two of them have not been able to have children, or have fewer children than they want.

There are a variety of reasons for female infertility, the most common being blockage of the Fallopian tubes, hormonal disorders, and failure to ovulate. Infertility related to Turner's Syndrome stems from incomplete development of the ovaries, resulting in the failure to produce ova (egg cells).

It is often remarked with reference to infertility that "it's not so awful There are lots of people who choose not to have children." These comments do not provide consolation for those who desire children. Regardless of the supposed liberal mores of our present-day society, we are still largely socialized into viewing marriage and children as our most natural and desired goals. These values are very hard to change Furthermore, the most painful aspect of infertility is the loss of choice as to whether or not to have children of your own. Not having this choice may seem to be a violation of natural rights.

Some women have a difficult time dealing with their infertility The knowledge that there are others with the same condition may provide comfort.

On a positive note, Turner's people know they can t have children and they know why. To them, infertility is not a sudden shock which under other circumstances might cause enormous tension within a marriage. Neither do they suffer the agonies of fertility testing and the almost endless uncertainty waiting for possible fertile periods.

Pregnancy

While we have been clear to point out that infertility is an almost inevitable result of Turner's Syndrome, it should be indicated that out of the thousands of Turner's women some pregnancies have been reported. However, these instances are rare (only 100 such cases) and not surprisingly they have almost always occurred in mosaics.

Cathy (pseudonym) is 4'8" and is not aware of having any other medical problems commonly associated with Turner's Syndrome. At age 16, Cathy discovered that she had Turner's (mosaic) and was told that she would not be able to bear children. Three years later, Cathy had an even greater shock when she discovered that she was pregnant. She was not married at the time and was advised by her parents to have an abortion. But Cathy felt strongly about keeping the child. "I wasn't supposed to get pregnant in the first place. What if I was to have an abortion? There might have come a time when I wanted to get married, settle down and have a family. If I was unable to have children at that time, I would have had to look back and know that a few years earlier I could have had a baby."

Cathy had an amniocentesis at 17 weeks' gestation to ensure that her pregnancy was continuing normally. This procedure involves the extraction of sample of amniotic fluid which contains cells shed by the fetus. Amniocentesis is a pre-natal procedure employed to detect genetic disorders. Cathy was indeed lucky to have given birth to a normal, healthy baby since there is a 50% chance of spontaneous abortion and a high incidence of genetic problems (33%) in the offspring of Turner's mothers.

Cathy was hospitalized for six weeks prior to delivery and for another week after she gave birth. This was because there was concern that the developing fetus would complicate the normal functioning of her respirator system. Delivery was performed by Caesarean section.

Presently Cathy is married and her daughter, Tracy, is now ten years old. Cathy is very happy with her decision, and Tracy is beautiful and healthy. Cathy and her husband are currently trying to have more children, but thus far Cathy has not conceived. Cathy feels that the only difference between herself and a "normal" female is her height.

Adoption

For those who are not as fortunate as Cathy, the possibility of adoption s a viable alternative.

In Canada, there are two standard adoption routes to follow - public adoptions through adoption agencies, and private adoptions There are two categories of public adoption. The first is the infant - toddler section The second category accounts for "special needs" children who are usually school age and older. A few basic adoption stipulations apply to each category The first is that there can be no more than a forty-year age span between the oldest parent and the child. Secondly, there must be a medical reason why at least one of the parents cannot have children of his/her own and this claim must be supported by proof of fertility tests. Only childless couples and couples with one child with be considered for an infant adoption.

Private adoption is another possibility. These adoptions are generally a matter of luck - being in the right place at the right time. Usually, a private adoption is arranged by a doctor who knows of a woman who is willing to give up her newborn child. The natural mother must sign legal consent for her baby to be adopted following delivery of the child. After the signing she has 21 days in which to rescind her decision. From there the case is passed on to a licensed agency where the adoption will be finalized through a lawyer. Private social workers, licensed through the Ministry of Community and Social Services (in Ontario) will then visit the home of the adoptive parents to determine their reliability and aptitude. Private adoption procedures usually take a total of six months, provided that immediate medical or legal problems do not arise.

Survey

The following are the results of a survey conducted by the Turner's Syndrome Society in 1985. This survey was conducted in order to find out how people felt about important issues. How would you answer these questions? Where do you stand on these issues:

Conclusions

There were many more respondents in the 26-30 age group than in the other age groups. Please keep this in mind when studying the results.

The majority of respondents indicated that they lived at home with their parents up to the age of 25. The percentage of Turner's people who get married is much lower than the percentage of those who stay single. Also Turner's individuals tend to get married at a later age than the rest of the population. The survey results in this category are in agreement with similar studies.

We asked respondents to indicate their occupation. In this category, the word *skilled* refers to work that has required special training of more than a few weeks duration. It involves either formal course work, apprenticeship, or both. *Professional* refers to an occupation that requires a degree at the post-secondary school level. There was good news; very few Turner's people were unemployed!

The highest percentage of respondents in the occupation category was from students. After that, the divisions were about the same for unskilled manual or clerical, skilled manual or clerical and professional service, Of those in the professional category, there were five nurses, three teachers, three library technicians and two social workers. Other professions represented were psychiatrist, genetic counsellor and laboratory technician.

When questioned about the type of medical information in which they were most interested, the 10-15 age group wanted to know more about genetic aspects, causes of Turner's Syndrome and up-dated research information, in that order. In the 16-20 age group, up-dated research information headed the list. All other factors except "psychological" seemed to hold equal weight. In the 21-25 age group most felt up-dated research information and intellectual aspects were of the greatest importance. The same held true for the 26-30 and the 31-35 age groups. In the 36 and over group, most wanted to know more about genetic aspects and related medical problems. When the results were taken overall, up-dated research information was most important.

"Psychological aspects" was not an item on the survey. IF someone listed it in the "others" column, it was note and tabulated. Therefore, it cannot be assumed (as shown in the results) that there is little interest in it

Short stature seemed to be the greatest concern of people in the 20-30 age group Infertility was a great concern across the board. We were surprised that infertility was the greatest concern in the 10-15 age group. Lack of secondary sexual characteristics bothered people most in their mid 20's. As one got older, disclosure became less of a concern An interesting fact was that it became important again for those over 35

A good portion of our survey dealt with disclosure We found out that the majority of people (52%) wished to be told that they had Turner's Syndrome earlier than they were told. Almost as many (47%) felt that they were told at the right age Only one person wanted to be told at a later age than she was told.

Ninety percent of those told between the ages of 9 and 11 felt that they were told at the right age. Of those told between 11 and 15, about half said that they wanted to be told at the age they were told and the other half wanted to be told earlier. Of those told over the age of 16, almost all wanted be told earlier. From these observations, we can conclude that the ages most people wanted to be told that they have Turner's Syndrome were between 9 and 11 (before puberty) As the age that one is told (that she has Turner's Syndrome) increases there seems to be a tendency to prefer to want to be told all at once

A sizeable percentage (34%) of the respondents first told a friend that they have Turner's Syndrome This tendency was apparent in every age group ~ Therefore, it seems that support offered by one's friends is very important

Another section of our survey covered various aspects of relationships Most respondents felt having Turner's Syndrome had no effect on their girlfriends Of those who reported some effect, most felt "different, shy, fearful or inadequate Almost exactly the same results as reported for girlfriends were reported with boyfriends.

A large percentage (60%) reported that having Turner's Syndrome had no effect on their relationship with their mothers. Of those who reported an effect most said that their mothers "were overprotective, promoted dependency or treated them as younger than their age." Again, the results for relationships with fathers were almost the same as for mothers.

Total number of respondents 87

Age groups	10-15		16-20		21-25		26-30		31-35		over 36		Total	
Number/ percentage	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Number of respondents by age group														
% of total	13	15	14	16	15	17	26	30	11	13	8	9	87	100
Marital Status														
Single	13	100	13	93	14	93	20	77	5	45	2	25	67	77
Married	0	0	0	0	1	7	4	15	5	45	5	63	15	17
Separated	0	0	0	0	0	0	0	0	1	9	0	0	1	1
Engaged	0	0	1	7	0	0	1	4	0	0	0	0	2	2
Divorced	0	0	0	0	0	0	1	4	0	0	1	13	2	2
Who do you live with?														
Parent(s)	10	77	14	100	11	73	10	38	3	27	0	0	48	55
Friend(s)	0	0	0	0	1	7	2	8	0	0	0	0	3	3
By yourself	1	8	0	0	2	13	9	35	3	27	3	38	18	21
Romantic partner	0	0	0	0	0	0	0	0	0	0	0	0	0	0
School residence	2	15	0	0	0	0	1	4	0	0	0	0	3	3
Spouse	0	0	0	0	1	7	4	15	5	45	5	63	15	17
At what age did you move away from your parents' home?														
	2		20		16		3		1		0		42	
Do you drive?	1	8	6	43	9	69	18	69	10	91	5	63	49	58
Present occupation:														
Unemployed	0	0	0	0	2	13	0	0	0	0	1	13	3	4
Student	8	100	7	64	5	31	2	9	0	0	0	0	22	29
Unskilled manual or clerical	0	0	1	9	2	13	6	26	2	22	1	13	12	16
Unskilled service	0	0	1	9	2	13	0	0	0	0	1	13	4	5
Skilled manual or clerical	0	0	1	9	3	19	4	17	2	22	4	50	14	19
Skilled service	0	0	1	9	1	6	1	4	0	0	0	0	3	4
Professional non-service	0	0	0	0	0	0	4	17	1	11	0	0	5	7
Professional service	0	0	0	0	1	6	6	26	4	44	1	13	12	16

Age groups Number / percentage	10-15		16-20		21-25		26-30		31-35		over 36		Total	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Medical Information														
What following symptoms of Turner's Syndrome do you have?														
Heart problems	7	54	2	14	4	27	3	12	2	18	2	25	20	23
High blood pressure	5	38	1	7	4	27	5	19	2	18	3	38	20	23
Keloid healing	2	15	2	14	1	7	5	19	4	36	1	13	15	17
Diabetes mellitus	0	0	0	0	0	0	0	0	1	9	1	13	2	2
Thyroid problems	1	8	3	31	4	27	5	19	2	18	4	50	19	22
Kidney & renal problems	4	31	0	0	3	20	2	8	3	27	0	0	12	14
Dry skin	7	54	8	57	7	47	23	88	10	91	7	88	62	71
Pigmented moles	10	77	10	71	10	67	20	77	4	36	5	63	59	68
Puffy hands	7	54	5	36	6	40	7	27	1	9	0	0	26	30
Puffy feet	7	54	6	43	4	27	10	38	3	27	1	13	31	36
Webbed neck	7	54	3	21	6	40	6	23	4	36	3	38	29	33
Skeletal deformity	3	23	3	21	1	7	4	15	4	36	2	25	17	20
Eye problems	5	38	5	36	6	40	7	27	3	27	3	38	29	33
Ear problems	6	46	9	64	6	40	11	42	3	27	3	38	38	44
What areas of medical information do you want to know more about?														
Treatment	4	31	6	3	9	60	12	46	5	45	4	50	40	46
Updated research information	6	46	12	86	12	80	18	69	9	82	7	88	54	74
Related medical problems	4	31	7	50	9	60	12	46	7	64	7	88	46	53
Genetic aspects	8	62	7	50	6	40	9	35	5	45	1	13	36	41
Cause of Turner's Syndrome	6	46	7	50	8	53	7	27	5	45	2	25	35	40
Intellectual aspects	3	23	7	50	12	80	14	54	9	82	4	50	49	56
Psychological aspects	1	8	1	7	0	0	4	15	1	9	2	25	9	10
Concerns which of these items bothers you the most?														
Short stature	1	8	2	14	6	40	5	19	3	27	0	0	17	20
Infertility	6	46	7	50	7	47	13	50	7	64	2	25	42	48
Lack of secondary sexual characteristics	1	8	2	14	2	13	8	31	1	9	1	13	15	17
Disclosure	4	31	5	36	3	20	4	15	0	0	3	38	19	22
People's comments about height	4	31	5	36	0	0	2	8	3	27	1	13	15	17

Rate the following subjects as you experienced them in school

	Very Difficult		Average		Easy		Very Easy		Total
	#	%	#	%	#	%	#	%	Total
Spelling	4	5	24	29	29	35	22	26	84
English grammar	2	2	30	36	31	37	10	12	83
English literature	2	2	33	41	21	26	14	17	81
Mathematics	11	13	23	26	24	27	3	3	87
Foreign languages	5	6	21	24	29	33	8	9	87
History	0	0	34	39	31	36	5	6	87
Geography	2	2	40	46	24	28	3	3	87
Biology 5 6 10 11 23				26	24	28	8	9	87
Chemistry 10 11 17 20 20				23	10	11	3	3	87
Physics 11 13 19 22 18				21	5	6	2	2	87
General science 4 5 14 16 29				33	23	26	8	9	87
Physical education 11 13 28 32 28				32	8	9	7	8	87
Art 12 14 23 26 25				28	10	11	5	6	87

Disclosure

Who told you that you had Turner's Syndrome?	#	%
Parent(s)	26	30
Health professional	53	61
Both of above together	6	7
Parent(s) and other relative	1	1
Other relative	1	1
Did you feel that this was the right person?		
Yes	78	90
No	9	10
If not, who would you rather have had tell you?		
Parent	3	50
Health professional	2	33
Other	1	17

Do you feel that the person who told you was the right person?

	Right Person			
	No		Yes	
Who told you?	#	%	#	%
Parent(s)	2	8	24	92
Health Professional	5	9	48	91
Both of above together	1	17	5	83
Parent(s) &other relative	0	0	1	1 00
Other relative	1	100	0	0

Percentages in this category are of the total of those told by parents, etc.

A1 what age did you find out that you have Turner's Syndrome?

Birth-5	1	1
6-10	21	25
11-15	36	43
16-20	20	24
21-25	4	5
Over 25	2	2

At what age do you think you should have been told?

Earlier than told	31	52
Same as told	28	47
Later than told	1	2

For those who were told in the following age brackets that they have Turner's Syndrome, how many wanted to be told earlier, the same, or later than they were told?

	Wanted to be told					
	Earlier		Same		Later	
Age told	#	%	#	%	#	%
6-10	1	14	5	72	1	14
11-15	1	10	9	90	0	0
12-15	13	52	12	48	0	0
16-20	11	85	2	15	0	0
21-25	4	100	0	0	0	0
Over 25	1	100	0	0	0	0
Total	31	51	28	47	1	2

How were you told that you have Turner's Syndrome?	#	%
All at once	59	69
Bits & pieces	27	31

How would you like to have been told?

All at once	60	77
Bits & pieces	18	23

How many wanted to be told in the way they were told?

Percentages are of total No. of people told all at once or in bits & pieces.

General-all respondents	Wanted to be told: All at once #	All at once %	Bits 8 pieces #	Bits 8 pieces %
All at once	50	96	2	4
Bits & pieces	10	38	16	62
Age told				
6-8				
All at once	1	13	0	0
Bits & pieces	4	50	3	38
9-11				
All at once	10	67	1	7
Bits & Pieces	1	7	3	20
12-15				
All at once	22	71	1	3
Bits & pieces	3	10	5	16
16-20				
All at once	15	83	0	0
Bits & pieces	1	6	2	11
21-25				
All at once	1	25	0	0
Bits & pieces	2	50	1	25
Over 25				
All at once	1	100	0	0
Bits & pieces	0	0	0	0

Have you told anyone you have Turner's Syndrome?

	Yes #	Yes %	No #	No %
10-15	11	85	2	15
16-20	12	86	2	14
21-25	13	93	1	7
26-30	23	88	3	12
31-35	10	91	1	9
over 35	7	88	1	13

If so, who was the first person you told?

	10-15 •	10-15 %	16-20 #	16-20 %	21-25 #	21-25 %	26-30 #	26-30 %	31-35 #	31-35 %	over 36 #	over 36 %	Total #	Total %
Parent(s)	0	0	1	9	2	15	2	10	1	10	1	14	7	10
Sibling(s)	1	13	0	0	0	0	2	10	1	10	1	14	5	7
Other relative	1	13	2	18	0	0	4	19	1	10	1	14	9	13
Friend	5	63	6	55	7	54	11	52	4	40	1	14	34	49
Boyfriend/husband	0	0	1	9	2	15	0	0	2	20	2	29	7	10
Classmates	1	13	0	0	0	0	0	0	0	0	0	0	1	1
Teacher, doctor or other professional	0	0	1	9	0	0	2	10	1	10	0	0	4	6
Others	0	0	0	0	0	0	0	0	0	0	1	14	1	1

Relationships

	10 – 15		16 – 20		21 – 25		26 – 30		31 – 35		Over 35		Total	
	#	%	#	%	#	%	#	%	#	%	#	%	#	%
Girlfriends														
No effect	10	83	10	83	11	79	17	71	2	18	4	57	54	68
Special intimacy (from disclosure)	0	0	0	0	2	14	1	4	0	0	0	0	3	4
Felt different or was excluded but this was overcome with time, age or disclosure	0	0	0	0	0	0	2	8	1	9	0	0	3	4
Perceived self as being treated differently in negative way	0	0	1	8	0	0	1	4	1	9	0	0	3	4
Fell different, shy, fearful or inadequate	1	8	0	0	1	7	3	13	5	45	2	29	12	15
Unclassifiable negative effect	1	8	1	8	0	0	0	0	2	18	1	14	5	6
Boyfriends														
No effect	7	70	5	42	5	38	9	53	1	10	2	25	29	41
Special intimacy (from disclosure)	0	0	0	0	0	0	0	0	1	10	0	0	1	1
Felt different or was excluded but this was overcome with time, age or disclosure	0	0	1	8	1	8	0	0	2	20	2	25	6	9
Perceived self as being treated differently in negative way	0	0	4	33	1	8	1	6	1	10	0	0	7	10
Fell different, shy, fearful or inadequate	1	10	0	0	4	31	5	29	1	10	3	38	14	20
Unclassifiable negative effect	0	0	1	8	0	0	1	6	1	10	1	3	4	6
No friends or serious continuing difficulties in relations	2	20	1	8	2	15	1	6	3	30	0	0	9	13
Mother														
No effect	10	100	10	83	7	54	15	63	2	18	2	29	46	60
Special closeness or Positive relationship	0	0	0	0	1	8	2	8	0	0	0	0	3	4
Felt or was treated differently but this was overcome	0	0	0	0	0	0	0	0	1	9	1	14	2	3
Mother felt guilty	0	0	0	0	1	8	1	4	2	18	1	14	5	6
Felt lack of closeness	0	0	0	0	0	0	0	0	0	0	1	14	1	1
Mother overprotective, or promoted dependency, or treated them as younger than age	0	0	2	17	2	15	5	21	4	36	1	14	14	18
Mother pushed for normalcy or compensatory skills or achievement	0	0	0	0	1	8	1	4	0	0	1	14	3	4
Treated differently (unspecified)	0	0	0	0	1	8	0	0	2	18	0	0	3	4
Father														
No effect	9	90	12	100	9	69	16	70	3	30	4	57	53	71
Special closeness or Positive relationship	0	0	0	0	0	0	2	9	0	0	0	0	2	3
Father felt guilty	0	0	0	0	1	8	0	0	0	0	0	0	1	1
Felt lack of closeness	0	0	0	0	0	0	0	0	0	0	1	14	1	1
Father overprotective, or promoted dependency, or treated them as younger than age	1	10	0	0	2	15	4	17	3	30	1	14	11	15
Father pushed for normalcy or compensatory skills or achievement	0	0	0	0	1	8	1	4	0	0	0	0	2	8
Treated differently (unspecified)	0	0	0	0	0	0	0	0	4	40	1	14	5	7

Experiences

We've included the following experiences to demonstrate the need for support and accurate information. We hope you enjoy them.

Yvonne is the co-founder of Turner's Syndrome and Friends, based in Edmonton. She is the mother of a 4-year-old Turner's girl, Angela

At sixteen weeks into her pregnancy, Yvonne underwent amniocentesis. This procedure is performed on pregnant women over the age of 35. Yvonne fell into this category. Five weeks after the test, Yvonne was contacted by her gynaecologist who informed her that the test results were ready. The doctor told her that there was something wrong with the fetus, but assured her that it was not Down's Syndrome. This happened on a Friday. She was told to bring her husband and to meet with the gynaecologist and a specialist on the following Monday. Since Yvonne wasn't told what was wrong, she worried all weekend. She told us, "That was the worst weekend my life." At work on Monday, Yvonne was so distraught that she couldn't even think of her work. In the doctor's office she was told that the diagnosis was Turner's Syndrome. She was given an explanation and the booklet, Good *Things Come in Small Packages.* However, Yvonne was so upset that she couldn't take in what was told to her. All she knew was that she had about two weeks to decide whether or not to have an abortion! She and her husband, Graham, went home and read the booklet "a million times:" they still didn't really understand what was happening to them, A geneticist visited them at home and Yvonne felt he helped them the most. He took the time to fully and compassionately explain to them exactly what they could expect. Yvonne said, "We decided to have the baby and it felt as if a great weight had been lifted from our shoulders." When she went back to her gynaecologist with the good news, this doctor informed her that it was quite possible that she would have a miscarriage. "It was like a slap in the face," said Yvonne.

Yvonne felt a great need to talk to her friends about what she was going through and doing so seemed to help her. Graham was supportive throughout the pregnancy. Finally, the big day arrived. While Yvonne was waiting in the hospital to deliver her baby, a nurse happened by who had heard that Yvonne had an amniocentesis. She wanted to know the results and when Yvonne said, "Turner's Syndrome," the nurse said, "Oh, one of those small people with the webbed necks." This started her crying over again. About three hours later, Yvonne gave birth to a beautiful baby girl. This experience was the impetus for Yvonne (along with Sara, a Turner's person) to start a Turner's group in Edmonton. Yvonne contacted her geneticist to try to obtain the names of others with Turner's Syndrome. This is how she met Sara. Meeting Sara helped alleviate many of Yvonne' fears for her daughter. Yvonne's daughter, Angela, is now 4 years old and is doing very well.

Yvonne's advice to other mothers carrying a Turner's child is, "Keep the child." She went on to explain that it is very important that parents be given proper information. Then they can make an intelligent choice. Old books paint a very gloomy picture of Turner's Syndrome, as they merely list the many possible symptoms that a Turner's person *might* exhibit. It is important to understand that not all Turner's individuals have all these symptoms.

Kathy is a Turner's woman who lives in Atlanta. Georgia She went through some truly difficult experiences but she has persevered and has become a better person for them. Kathy has a B.A. in early childhood education and a social work degree. Though single, she has adopted a baby girl.

I am 36 years old, the second oldest of eight chlldren (6 girls). Since my parents are short, my being small wasn't a concern. I had a lot of ear infections including some loss of hearing. I had my adenoids removed and at age 9 had surgery to correct a droopy eyelid. Unfortunately, this surgery was unsuccessful.

Growing up was not too difficult until I started going to junior high school. I was made fun of because of my size and my bad eye. This was the pits! I was always active. Dance classes, school clubs and working as a baby-sitter took up most of my time. At 15 I started working at the local hospital and at 18 I was hired as a nurse's aide.

By the time I was 18, I hadn't grown as much as I should have nor had I started to menstruate. I was quite worried and felt that I had to find out what was wrong with me. I went to a paediatrician and he admitted me to the hospital. This was the same hospital where I had been working. I was there for a week while tests were being conducted. I was then sent home with a prescription for hormones and wasn't told a thing. Neither my mother nor myself was ever given either the results of any of the tests or a diagnosis. Upon my return visit to the paediatrician. I was still given no information. The doctor started yelling at my mother. blaming her for my condition. This made her feel guilty, as if she had done something wrong. Although I've since explained to her that nothing she could have said or done would have changed anything, she still feels guilty.

Since I was still working at the hospital and could get no answer from any doctor, I decided to check out my own medical records. What I read there was "Turner's Syndrome." I did not know what this was, so I looked it up in some medical books. Boy, was that a mistake! It was horrible! I felt like I was in a nightmare only awake. These were old books, showing classic Turner's Syndrome women with webbed necks, bowed legs and looking obese The books stated that these women were mentally retarded and had to be institutionalized. I think I went into shock. I never said a word to my mother, my friends or any of my sisters I felt that it was my own terrible secret, with all the guilt and shame to go along with it.

Not long after this, we took *Turner's Syndrome* in psychology class in high school. There, for everyone to see in the textbook. was *Turner's Syndrome* complete with pictures. I wanted to die! I knew everyone was looking at me saying that I was one of those horrible creatures pictured in the book. Then I remembe[r] getting angry - at the doctors and the book companies They were all wrong. They were lying! Turner's Syndrome was not like what they described. I didn't t look th[a]t bad. I wasn't retarded. I thought, "How dare they say those things' What tie helped me the most was knowing who I was and that what they said wasn't t true

I still never said a word to anyone. I know I was supposed to be under a doctor's care, so when I moved out west, I sought the services of an endocrinologist I went to a big university hospital and was re-tested. The diagnosis of *Turn*[e]r's Syndrome was confirmed. The doctor took the time to talk to me and he expla[i]ned some of the facts. He told me that they now know that Turner's Syndrome is not like

Conclusion

Turner's Syndrome is one of the least severe of the chromosomal disorders. The emotional problems related to Turner's are not uncommon to many other women in the larger population. The fact that Turner's women can lead normal, healthy and productive lives despite physical and emotional difficulties is the main point of this publication. For this reason, we have taken every opportunity to stress this point.

Since its inception, the Turner's Syndrome Society of Canada has been successful in furthering study about Turner's Syndrome, informing the public about the nature of the disorder, and most importantly, helping Turner's women confront and overcome the social, psychological and emotional complications they have experienced.

Successful self-help support groups, such as the Turner's Syndrome Society, continue to aid Turner's individuals in overcoming problems associated with this disorder. With increased public awareness, the unnecessary boundaries separating the "labelled" population from the "norm" will gradually fall away. It is toward this goal that this booklet has been aimed.

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