Three women tell: We are born without uterus

It has different causes, but the three women have one thing in common: They are born without uterus. Here they tell openly how it has affected their lives.

By Ingunn Saltbones 21 December 2015

There are a number of different forms of hormonal and deformities that can affect the genitals, uterus, ovaries and vagina.

VG has spoken with three women who were born without uterus.

Two of the women have the syndrome Mayer Rokitansky Küster Hauser Syndrome (MRKH). One of the women has Morris syndrome. It is very different states, and should not be confused. But common to them is that they are born without the uterus. (See also fact boxes at the end of the article.)

- Born with vagina depth 1-2 cm

Lise Gimre (37):

GIRL: Lise Gimre (37) feels still more as a girl than as a woman. - When I was diagnosed, I felt not as female as others. I did not get menstruation, it was difficult with sex, and I could not have children. I have not gone through puberty in the same way as others, says Lise Gimre. PHOTO: PRIVATE

It was a tough message to get that young, that she would never be able to have her own children, and that she was not like other women. Today Lise is running and MRKH organisation so that it will be easier for those who come after her.

Lise was diagnosed MRKH in 1995 and missed information and support for many years.

18 years later it was still as little information in Norwegian and she therefore started the NGO MRKH Norway in 2013.

As in most other with MRKH, which stands for Mayer Rokitansky Küster Hauser Syndrome, the condition was detected in Lise at 16-17 years old, when she did not start menstruating.

- I had gone in agony for two years. I was bearly making it at the school, and ended finally in the emergency room, where I had to go on a gynecological examination, which I had refused a while, says Lise.

Suspects something wrong

She had basically a suspicion that there was something wrong.

- I had a boyfriend and we had tried to have intercourse without success, she says.

It was discovered that the vagina was only 1-2 cm deep, and that she had only remnants of a uterus.

- The reason for the great pain was that the blood went into this rest of a uterus and piled up there. It Finally cracked , says Lise.

She was operated on, but chose to retain the ovaries not to come in menopause. She was also recommended expanding the vagina using dialtors (dildos in plastic) and not by surgery when there is a risk of scarring and that later it can collapse. - The vagina is stretchy, so it is possible to obtain a sheath with normal length by such spells, or intercourse, says Gimre.

INSUFFICIENT INFORMATION AND: Lise Gimre (37) experience that she has had littlte or no information and has started association MRKH Norway to help those who come after her to get information easier. Photo: PRIVATE

Gimre experienced that she got too little information and follow-up on how this should be treated when she was young.

- I chose the smallest dilator, was sent home, and did not hear from them anymore, says Lise.

- Actually, I should have been called in to control, and gotten a set of dilators in different sizes, and learned more about how to use them.

She had boyfriend at this time and could thus expand by means of intercourse.

- But it was a pain for many years, says Gimre.

Mental Influence

Today, she has a good sex life, but she wished she had gotten better follow up.

- As for many years it was painful to have intercourse, it puts itself in mental, and it's easy that it spans, says Gimre.

With this diagnosisthet sex hormones are not affected, they have the same emotions and desires as all other women, and the same ability to orgasm. They also have the usual ovulation, but the eggs and the blood is absorbed in the body and do not disappear in the form of a menstrual bleeding.

As she like others with MRKH have ovaries, she could, in principle, have a baby using surrogacy.

- It's not something I've considered. It is illegal in Norway, and is very expensive to do abroad.

Gimre have instead chosen to become foster parent along with her boyfriend.

- It has been a very nice way to get family, says Gimre.

But to get where she is today, has been a process.

- I felt as a girl when I was little. But when I was diagnosed, I felt not as female as others. I did not get menstruation,it was difficult with sex, and I could not have children. I have not gone through puberty in the same way as others, says Lise.

Even today she feels most like a girl and not as a woman.

- I do not feel that I have become a ripe woman, since the body have been left behind, says Lise.

HAVE FAMILY: Lise Gimre could since she has ovaries in principle have children by surrogacy. But Gimre have instead chosen to become foster parent along with her boyfriend. - It has been a very nice way to get family, says Gimre. PHOTO: PRIVATE

Lise heard no more from the hospital, until she was 25 year old, she got in touch to get an assessment of whether operation of the vagina was an opportunity for her.

- It was rejected, as they believed 8-6 cm sheath was enough. But then it was discovered that I should have been followed up for the longest time, she says. She has the impression that when they discover MRKH today they generally receive better information than what she did, but believes it is still not good enough.

Jobs for information

- It depends on where you end up in the country, if you're lucky going to a doctor who know something about it, says Gimre.

She currently works for everyone to get good information when the diagnosis is made, and that the women themselves should be involved in determining when and what treatment they receive.

- They must be offered psychologist and sexologist, and when they get older get information about various ways to get children, says Lise.

Lise hopes her openness can help remove taboos.

- I have the impression that it is still taboo. Especially when you're young, and all her friends have got menstruation, she says.

For women with a different cultural background can be especially difficult.

- In cultures where having children is her main task, we have certainly seen cases that they are expelled from the family. In Norway it is fortunately great acceptance of childlessness, so you do not get such trauma as well, says Lise.

As head of the association, she follows also experiments with pregnancy after uterine transplant closely.

- I think it's really great that this becomes an opportunity. For me it is too late, but I hope it will be an opportunity for many of those who come after me, she says.

- Born woman, but with male genes

Linda Olsen (41)

WOMAN WITH XY: Linda Olsen (41) found that doctors were very concerned that she should not have to feel like something other than a girl. - They stressed that although I had no uterus or ovaries, I was girl. But I had never felt like anything else, says Linda. PHOTO: TOM EGIL JENSEN

She was born as a girl, with normally developed vagina but with testicles hidden in the abdominal cavity. She has Morris syndrome, which inherit genes are like those of a man, XY, but where they still are girls because the body does not respond to testosterone.

Through puberty Linda was a very active handball player.

- I figured that was why I had not got menstruation, says Linda.

But she was also bothered by the fact that she did not get pubic hair, which is also characteristic of the syndrome. And this was before it became fashionable to be clean-shaven.

- Because of handball I was much in public changing rooms and showers. I thought it was embarrassing not to be like everyone else, often waiting to shower when the others were finished, or sneaked along the wall. It was very difficult for me, she says.

When she was 17 years old it was discovered during a doctor's visit, she was not like everyone else.

- I will not forget the gynecological examination, luckily my mom with me. The doctor examined me thoroughly and I could see that she became more and more serious. She was quite white in the face, and said she did not find my uterus. I looked at mom that she has gone out and I realized that it was pretty serious, says Linda.

Blood tests (chromosome analysis) confirmed the diagnosis.

Testicles were operated out just before she was to fill 18 years old. She has since had to take estrogen supplements daily to drop menopausal symptoms.

- My first encounter with Rikshospitalet was overwhelming. There were very many people were involved in the investigations, and I realized that I was seen as a small sensation. There were many questions about whether I even managed to have intercourse. I have been fortunate and never had problems with this, but for many people with the same diagnosis may be required corrective surgery in the vagina to perform a normal sexual intercourse.

REMOVING taboo: Linda Olsen (41) wants to help remove taboos and shame associated with this and similar diagnoses. - I am very happy that my family has supported me and helped me to speak openly about it, without giving me some feeling that there is something that should be hidden. Here with her husband Espen Johnsen (41). Photo: TOM-EGIL JENSEN

For someone who had always been active, healthy and fit, it was scary to be admitted to hospital for surgery, she says.

- Anyway, I remember that I felt well taken care of, and that I got to have my mother there was a tremendous support. My biggest fear was that I would be seen as a victim and that friends and family would feel sorry for me. I was also afraid that I would become a "hot topic" among friends and acquaintances. I decided early on that I wanted to be open about my shortcomings and diagnosis. In retrospect, I see that this was more difficult than anticipated and there were a lot of rocks face outward and chaos of emotions inside, says Linda.

She also found that doctors were very concerned that she should not feel like anything other than a girl.

- Dream Figure for some

- They stressed that although I had not the uterus or ovaries, I was girl. But I then had never felt like anything else, says Linda.

On the contrary, she has always felt feminine.

- You are often tall and slender, narrow hips and get what for many women is a dream figure, she says.

Women with the syndrome often also have nice skin.

For Linda has issues around gender identity never been an issue. She has all the time both before and after the set diagnosis felt like 100 percent woman.

But she still experiences that she has received little and partly inaccurate information in healthcare. She also missed more supervision of qualified health personnel at the time the diagnosis was made.

- When you are 17-18 years old, one is above a vulnerable period in life where one goes from being young to being an adult, when you also face it to get such a diagnosis it can be good to have some help to sort feelings and thoughts on the topic. Then it is probably easier to accept their own situation to think ahead, says Linda.

- I got including the message that this was just something that occurs randomly in pregnancy. First as an adult it was confirmed that it was hereditary. My mother has the gene which has turned out AIS for me. For me it meant a lot to get that explanation, says Linda.

Both her mother and sister were checked.

- My sister has not been inherited gene, so this stops with me in our family, says Linda.

When she was younger, it was hard for her to know that she could not get biological children.

- It also led to that I quickly dumped boyfriends. I thought I was doing them a favor, because I felt sorry for him that would end up with me. I knew I could never give them their own children, says Linda. This was also to protect myself. It was easier to dump than being dumped, she says.

Knowing that she could never have children, she desided as pretty young and single that she wanted to adopt.

FAMILY: Without both ovaries and the uterus it is not possible to get bilogival children, but Linda Olsen (41) and man Espen Johnsen (41) is happy adoptive parents. - In retrospect, I feel that everything has been for the best. We are agreed that so lovely kids we had not managed to create on our own, Linda laughs. Photo: TOM-EGIL JENSEN

She applied and got in line for adoption when she was 30 years old. Coincidences made that this was the same time that the wait to get adopt from China even became longer.

She was therefore not blessed with the first child until 5 years ago. She have also found the man in her life, Espen Johnsen (41). One year after she had her first child, they were married, and they got a foster child that they recently did adopt.

- In retrospect, I feel that everything has been for the best. We have agreed that so lovely kids we would not have managed to create on our own, Linda laughs.

She has also been a part of a birth.

- I have a very good relationship with my little sister and was lucky enough to take part in her first childbirth. It was strong and a great experience, and it also made sure I have something to compare with when friends share experiences around this.

So this might be a tip to other childless, whether or not they have a sister, so they may have a friend who will share this experience with them, says Linda.

Linda wants to help remove taboos and shame associated with this and similar diagnoses.

- I am very happy that my family has supported me and helped me to speak openly about it, without giving any feeling that there is something that should be hidden. Often parents feel shame over having children with Morris, and think they have done something wrong during pregnancy. But that's not the case.

- We're going to grow up and be proud of who we are, whether we have the womb or not. The most important thing is to accept their situation and find solutions for themselves and those they love concludes Linda.

- I'm intersex, will not be either male or female

Gunn (21):

FREE: Gunn (21) points out that not everyone feels like a boy or girl. - I am committed to breaking down this gender. In MRKH Association is most concerned with getting a womb, and to enhance their femininity. It's fine for those who want it, but it can also be a pressure for us who do not want it. Photo: JANNE MØLLER-HANSEN

In her teens started violent menstruation-like abdominal pain, but she got no bleeding. Having been rejected by doctors in two years that it was only delayed menstruation, she was diagnosed MRKH at age 16.

She is like others with this diagnosis born without womb, and without vaginal depth. In the process that came in health care, she felt compelled to be more feminine than she is.

- They operated my vagina without informing me beforehand, when I thought they were only examining me, she says.

She thinks many doctors convey that to be a full woman it is important to have intercourse with a man.

- I see them as very oldfashion, she said.

Because of her experiences gender identity has become a sore subject.

- I find that all doctors and specialists I've had contact with assume that "of course would you like to be a woman," and we will help you. They have not given me leeway to find out who I am, she says.

Gunn wants to be defined as intersex.

- I am committed to breaking down this gender. In MRKH Association most girls are concerned with getting a womb, and to enhance their femininity. It's fine for those who want it but it can also be a pressure for us who do not want it.

- It may be that one does not feel like either sex at all, she says.

Gunn thinks everything where chromosomes, hormones, genitals and reproductive organs don’t follow the "book" for ordinary women and men, can be defined as intersex.

NOT FOLLOWING THE BOOK: Gunn (21) believes many male doctors have a very old-fashioned view that in order to be defined as full-fledged woman must be able to have intercourse with a man. Photo: JANNE MØLLER-HANSEN

Gunn also tells about traumatic experiences in the face of ignorant health workers.

- Before the diagnosis was made with MRI, I found that they were trying to crack what they thought was a thick hymen, then they realized that it was my vagina that was so short, she says.

When she was diagnosed, she was sent straight back to school, says Gunn.

- They thought I coped so good, that I could go straight back to school. In reality I was so put out, and got so much difficulty, that she did not managed to complete high school, she says.

Gunn also says that she repeatedly tried to get psychological help, without getting it.

She has spent time figuring out who she is, also when it comes to who she is attracted.

- I define myself today as pansexual, ie one that attracted all kind, she says.

Today she is an apprentice, and has a male lover.

- We've been together for two years, and he knew about the diagnosis before he was with me. We love each other as the people we are, says Gunn.

Gunn feel that there is too great a pressure to be a certain way in today's society.

PRESS: Gunn (21) fights against what she believes is far too much sex and gender pressures in today's society. Photo: JANNE MØLLER-HANSEN

- I also got the feeling at school that if you do not have a vagina then there is something wrong with you. I also find that it has been made a little like that if you do not have sex, so no one will be with you, she says.

Although it for her is quite possible to have intercourse today, she believes the focus of the community is completely wrong.

- There is too great a sexual harassment and gender pressures in today's society, she says enthusiastically.

- Firstly sex is much more than intercourse, it's very much else one can do. Secondly, sex is not a necessity, it is something you do if you bothered or want. We need a much greater tolerance for what is normal, says Gunn.

- Great that women are open

- It's really great that women talk openly about these rare disorders, and that it is formed a patient organization, says Agnete Lund, chief physician at Haukeland University Hospital. Lund says that she really has missed a patient organization.

- Although not everyone wants to seek union, this makes it possible for women to contact others in the same situation. It is very useful, especially for those who have just been diagnosed, says Lund.

Lund points out that the association can also be a pressure group in order to fight for more resources for monitoring and treatment of these conditions. For there are serious diagnoses to get, she emphasizes.

- On one side is the woman well, and there are no dangerous disease. Meanwhile time assimilating the situation they are in, they are not normal, that it becomes difficult to have children, says Lund.

One of the nation's foremost experts on these rare disorders, Mette Haase Moen, gynecologist at St. Olav's Hospital and professor emerita from NTNU, has 35 years experience in the field.

According to Moen for most people who are diagnosed MRKH there is a mixture of emotions.

- Mentally it is very varying: Despair with suicidal thoughts, resignation, but encouragement when she gets boyfriend and discovers that she can have a normal life, says Moen.

EMOTIONS: Professor emerita at NTNU and gynecologist at St. Olav Hospitalt, Mette Haase Moen says that in a relationship, it can also bring partners closer together in this challenge. Photo: KAJA Bruskeland

Relationship to therapy is that for other women and couples.

- A grief over a lost opportunity, desperation to get treatment, and joy when it succeeds either with its own biological child or adopted child, says Moen.

Also the women know about their infertility from an early age, so it comes as no shock when planning pregnancy.

- Partners are informed generally about the state at a time when the relationship is stable and I have the impression that it goes well. It may also bring the couple closer together in this challenge, says Moen.

Follow-up over time

Lunds experience is that women need to be followed up over time.

- Although what we can perform of treatment is finished, it can take a long time before the various reactions and issues comes up for women. They should therefore be offered follow-up over several years, and it happens probably not for everyone today, says Lund.

At St. Olav's Hospital, girls get offers of help from a psychologist or psychiatrist.

- Half wish, and half would not. There is no point making a big psychological problem out of it, if there is not, stressing Moen.

But it is not always a systematic plan, which provides for such an offer to anyone, says Lund.

- Resource centers for these conditions should ideally be able to provide a comprehensive follow-up with psychologist and sexologist, says Lund.

Gunn (21) tells about her encounter with a lack of expertise in health care, which led to that she witnessed an attempt to perforate what health worker thought where the hymen, but that was Gunns congenital short sheath.

- It is a problem for all patients with rare diseases, it may be difficult for clinicians to make accurate diagnoses and the evaluation and treatment may be affected by it. Therefore, it may be useful to gather expertise on rare conditions at few hospitals, says Lund.

SAD: Chief Agnethe Lund at Haukeland University Lund think it is sad that some people find that they have gained both inadequate and inaccurate information in the face of health care. Photo: PRIVATE

According to Lund doctors have been better at this in recent years.

- But there has not been any systematic, and that we must work for. It is better for all patients with rare diseases if a doctor can say: "I have treated more like you, you are not alone, and this we shall help you with," says Lund.

Lund also think it is sad that some people find that they have gained both inadequate and inaccurate information in the face of health care.

- It is my impression from patients I spoke with that those who have been treated previously could be met in a better way. Now, knowledge has become much larger, and I hope this gets better for the future, says Lund.

Important competence

Moen believes both the two conditions are so rare, that it should not be expected that all doctors have the expertise needed to treat these women.

- But it is important that we have centers in the country where they have expertise. There we have in Trondheim, Bergen and Oslo, says Moen.

Moen also underlines the importance of the information provided must be repeated and adapted to new phases of life for the woman and innovations in the field.

- The first time they get the information, it is usually 16 years, and this needs to be repeated later. For example, you now also need information about uterine transplant for those with MRHK. It is something that opens up as a possibility after the first experiments have been successful, says Moen.

Lund believes attempts with uterus transplantation is very exciting, but there is far to go before this becomes available treatment.

- It is a big operation, both for the woman and for the one donor. There is also a danger for the child. The four children born to now, all born prematurely, says Lund.

Lise (37) and Linda (41) find themselves entirely as women. But Gunn (21) wants to be defined as intersex.

- Interest medically there is nothing to suggest that those with MRKH is nothing but women. But everyone must get to define their own gender identity, and no one should be forced to be one or the other, says Lund.

No one should be treated without consent.

- One does not nees a sheath to be a woman, she says.

For other women with MRKH experienced it important to emphasize their femininity.

Moen stressed that there is no reason why women with MRKH should not see themselves as a woman completely.

- They are entirely women, she says.

Catwalk-body

It is more complex in women with Morris syndrome, which is as tall as if they were boys. But they are in sum more feminine than most other women. They simply cannot get male traits as more hair growth, even if administered testosterone, underlines Moen.

- I would guess that women with Morris is overrepresented on the catwalk. They have a perfect body for a revue, is tall and slender, with some broad shoulders and narrow hips, says Moen.

Moen assume that problems related to gender identity in general may be greater for those born with Morris syndrome. And says it's very important that they be informed correctly.

- But I've only had 3-4 cases during my 40 years as a gynecologist, and I therefore can not generalize on the basis of such small numbers, says Moen.

Common for women with MRKH and Morris syndrome is that they are born with small vaginal depth, in addition to that they lack the uterus.

Previously, women had surgery to create a vagina longer, or they have extended vagina using dildos in plastic. They operated a risk that the vagina coincides if they are in a period of not having intercourse, and therefore it has primarily been recommended to expand the vagina using spells.

Recent research and experience from St. Olav's Hospital, has shown that for most people it works best to expand the vagina by having sex with intercourse.

- After a few months with a regular sex life with intercourse, has vagina depth often become normal, with a 8-10 cm, says Moen.

This is experienced by patients as a more comfortable way to expand the vagina than having to block out with poles several times a day for half a year, adding to Moen.

Facts MRHK (Mayer Rokitansky Küster Hauser syndrome)

■ Are women with chromosomes XX and have ovaries with eggs and normal hormone production. Has normal hairs, and normal female appearance.

■ However, a missing uterus or womb undeveloped construction, and generally lacking vagina, or that there is a small pit. That is, they have no depth of the vagina, or very little depth, maximum one pair cm

■ This can be extended by means of surgery, bulging using spells (called dilation), or by intercourse. New research shows that to expand by starting a normal sex life and having intercourse perceived as the best method. Then you can get one normal vaginal length in a matter of months.

■ The syndrome often detected at age 16 because of a missed period.

■ Women with MRKH can get biological children using surrogate mother. Globally, there are now also many cases of successful uterine transplants, and this could become more common in the future.

■ The syndrome is caused by a fault developing in utero, and so far it is not known hereditary. Affects 1 in 5,000 births girls. Ie 5-6 girls a year in Norway.

SOURCES: MRKH Norway, Mette Haase Moen.

Facts Morris syndrome:

■ genetically boys, with chromosomes XY. However, because the receptor for the male sex hormone testosterone does not work, they develop for girls. Also called "androgen insensitivity syndrome."

■ Detected usually not by birth then they look like normal girls. The outer parts of the genitals is common, and they usually have vaginal, but often less vaginal depth than usual - 3-4 cm, the normally ca. 10 cm

■ Detected often at age 16 because of a missed period.

■ Women with Morris has not ovaries and uterus not, and can not obtain biological children. Nor will the pubic or underarm hair. They have however testis located in the abdominal cavity or hernia in

the groin. These testes produce enough testosterone is converted into estrogen, that women are normally developed breasts.

■ The women get the length they would have in a man, and are often tall and slender with narrow hips and broad shoulders.

■ Around 18 years of age operated testicles out because of cancer risks. The women come when menopausal and must take estrogen supplements until they are approximately 50 years.

■ Due to a genetic hereditary trait mother. Half of the sons will get the gene and thus develop into girls. Half of the girls will carry the gene further (like her mother).

■ Are very rare and occurs in 1 out of 50,000 births, there will in Norway say less than one case per year.

SOURCES: MRKH Norway, Mette Haase Moen

For more information visit mrkhnorge.org