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FSHD is a condition like this – “it is a ruthless disease”
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A rare neuromuscular disease took Tinja the ability to smile already as a child: “I don’t want to come off as rude”

Tinja, diagnosed with a rare neuromuscular disease as a little girl, can’t walk or smile. Getting a wheelchair in her teens was a relief.

When Tinja Toivonen, 28, from the city of Porvoo, was 5 years old, it was paid attention, that she could not keep up with other kids in a sport-focused preschool.

-There was a lot of physical activities, hiking, and all that kind of stuff. I ran slower than the others and there was something different in my balance too. I didn’t like climbing that much. I was a pretty cautious kid, Toivonen explains to MTV news.

According to Toivonen, no one knew what caused the cautiousness, but she believes “she had an idea in her body before it was on paper”.

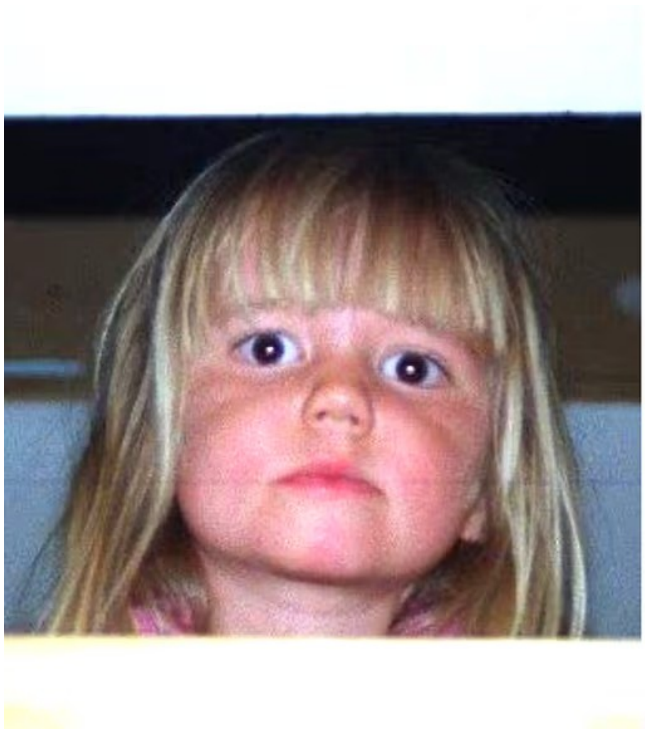
-I knew my muscular strength was probably not normal, she describes.

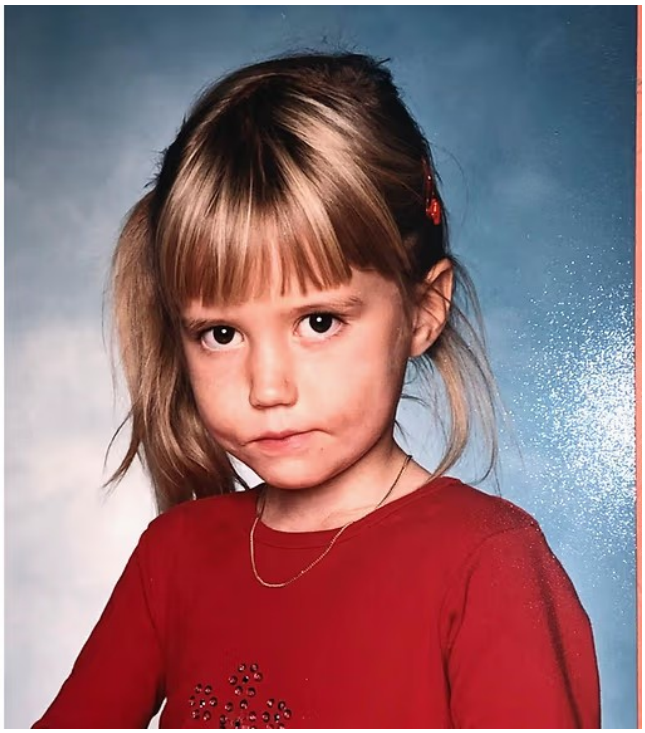
As the symptoms became more prominent, Tinja’s parents brought her to Lastenlinna children’s hospital in Helsinki where a doctor called Helena Pihko knew immediately it was a rare disease called FSHD, facioscapulohumeral muscular dystrophy.

FSHD is a hereditary and progressive neuromuscular disease, that leads to replacement of muscle fibers by either fat or connective tissue. The disease severity varies from mild symptoms all the way to severe disability.

The name of the disease is based on three typical symptoms in latin: face – facio, scapula – scapula and humerus – upper arm. However, typical symptoms are not limited only to these body parts.

According to the doctor, Toivonen’s symptoms were a textbook example of the disease.





Unfamiliar disease felt frightening

For her worried parents, getting a diagnosis was a relief in a way, though the disease was unfamiliar, strange and frightening.

-It was known already back then, that some neuromuscular diseases may shorten one’s life, and that was their primary fear. However, that fear turned out to be unnecessary as FSHD does not affect life expectancy.

-My parents were also offered peer support, but they did not find it that crucial as I was a healthy child in my own way.

Life was revolutionized by surgery

Toivonen’s symptoms got worse over time. When she was 14 years old, her spine was curved that seriously, it needed to be operated.

Simultaneuously, Toivonen found out, that she won’t walk anymore.

-In my teens, it was a shock. I was already struggling with being different from others, and losing the ability to walk felt insurmountable. Back then, walking ability felt like a remarkable sign of normal life. I did not know back then, what I now know, that own health is more important than faultless ability to function.

However, she understood, that the operation was inevitable. At the end of the deep curved spine, nerves were in compression and her legs used to get numb.

-And indeed, the operation relieved the situation, definitely, also in a cosmetic way. When I had been in a two-fold posture, clothes did not fit and coat zippers could not be closed.

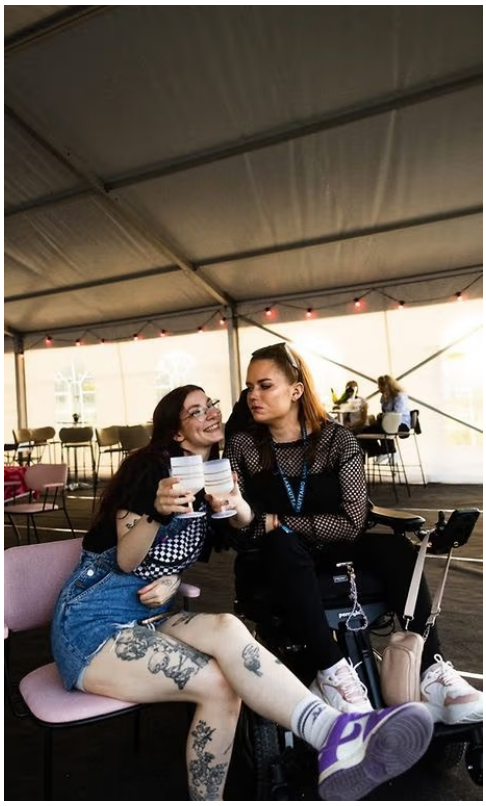
Grateful everyday

Toivonen says, she is still grateful for the surgery every day.

-But it was not easy. I was on an intensive care unit for five weeks, and the operation needed to be carried out twice. It was the summer of my confirmation school and I could not attend it with my friends, as I had that severe pain. Fortunately, I was able to do the tasks as homework and I was confirmed in the same summer eventually. Then my pain was present daily, but slowly, maybe in half a year, I recovered in a better condition. Since then, I have felt much better and comfortable in my own skin.

Toivonen says, losing the ability to walk was eventually a little price for the outcome.

-It is most important that you can feel comfortable, you have no pain in your back and your legs don’t get numb, that you have this kind of good overall feeling. Also, later, closer to adulthood, my scapular winging, typical to FSHD, was fixed by surgery in two operations. That reduced the pain caused by that kind of hypermobile scapulae.



Tinja Toivonen on the right with a friend of hers, Tia, on a festival.

“Smile a little”

One of the most significant effects of FSHD towards others is lack of ability to smile.

-Fear of getting misunderstood has been probably the most tricky part. I am a positive and human-centric person and I don’t want to come off as rude or unpleasant.

-There are also some issues with articulation due to weakness of facial muscles, but I am lucky in that way that I can communicate clearly.

Toivonen says, many people have taken it as their responsibility in a way to cheer her up. Sometimes, even in tragicomic ways.

-Once in a pub, I was talking to my friends, and an older lady came to me pulling my arm wanting me to dance with her, Toivonen said in an interview of Trendi magazine in 2022.

Some people might say I should smile more, that life is not that serious.

It upsets.

Toivonen says she compensates lack of smile by speaking in sunny way.

-You can hear smile and joy in one’s voice too. You can smile with eyes too. I hear often people saying that I am brisk as I work, and I am brisk as I live overall.

Toivonen says she is also really grateful for her power wheelchair.

-My muscular strength is that weak and my hands too, that it would be hard to move with a manual wheelchair. I can barely lift my hands on side and my feet are so weak I can move away from the chair but can’t take steps. Therefore, the power wheelchair has been a life revolutionizing tool. I can practice standing and maintain functioning ability of my feet with the power wheelchair. Thanks to it, I can live alone.

It is good to remind yourself of resting too

Toivonen is working as a second-generation entrepreneur in a work clothing company founded by her parents in Porvoo. At home, she has two cats.

An assistant helps her with heaviest duties in everyday life every now and then, but generally she manages everyday life quite independently.

-I work and my hobby is signing in a choir. I like music a lot and I play ukulele at home. I like also drawing, colouring and making handicrafts. I spend a lot of time with my friends and I like traveling. Also, I have collected some tattoos on my skin from several adventures.

-And also working takes a lot of time as an entrepreneur. I have a lot of responsibilities, and sometimes you have to remind yourself that you don’t have full resources. It is good to try to be

merciful to yourself with that. Though you are doing well independently, it is not a must to do all the same work and have the strength for that long, physical work day that your colleagues have.

Tinja Toivonen on her workplace with the company’s master pattern maker’s dog Luna, who tends to have a position as an “office dog”.

Toivonen goes to physiotherapy and aquatic therapy weekly.

-Sitting causes a lot of pressure on hamstrings, buttocks and back of the knees. If I had no physiotherapy or aquatic therapy, pain would be present a lot more. When you keep moving slowly and listen to your body, pain stays bearable.

Tinja Toivonen says she has collected some tattoos on her skin “from several adventures”.

New treatments are anticipated

There is no cure for FSHD – yet.

-The word yet has been added to the clause in the past few years. Earlier it was said, there is no treatment or drug, but now we are in an interesting situation in that sense, that abroad, mostly in the United States, there are around 20 companies working on treatments aiming at curing or relieving the symptoms of FSHD, Toivonen says.

Also, regeneration of muscle fibers is under research.

-Treatment of hereditary diseases may change probably already in the near future due to development of medicine. We are on the edge of a significant change. That is followed very closely here in Finland too.

According to Toivonen, drug development creates hopefulness to patients, though she knows there will be no miracles.

-I believe they could find such medicine that could slow or stop the disease progression, that could benefit for example, children and teens who are diagnosed. So, you would not need to struggle with progression of the disease for years, like many of us have to.

Important peers

Toivonen is involved as a secretary in a Finnish FSHD association, FSHD Finland, founded in 2024. She knows peer support is really important to all patients.

-People want to be heard, seen and understood and know that they are not alone with the disease and its symptoms, probably accompanied by fear as well.

-All kinds of horrific scenarios may come to your mind, if you don’t know, what you, your child or your loved one has. We try to be there for you.

Love as a dream

In her personal life, as a young woman, Toivonen is dreaming of love and professional success for instance. She hopes she will have the chance to see the world even more.

Her fears are related to progression of the disease.

-When you take it for granted that you can do with only a little help, it does not sound that nice if the disease progression will take, for example, capability of living independently away from you.

-I set my hope on drug development. If that could help slow disease progression. If you could freeze your condition to what it is now, the future would look quite bright. If you did not need to fear disease progression, that would be quite a good goal.

Toivonen descibes “fixing things is probably not always the best way to handle them”.

-I have always believed that you have to accept things as they are and do your best with the resources you have, and not always dream of something that does not exist.

FSHD is a condition like this – “it is a ruthless disease”

FSHD is a rare neuromuscular disease, that causes progressive degeneration of muscle fibers. World FSHD day is celebrated on June 20th by posting orange slice photos on social media.

FSHD, facioscapulohumeral muscular dystrophy, is a genetically complicated neuromuscular disease, that leads to progressive replacement of muscle fibers by fat or connective tissue. ALS, among others, belongs to the same group of diseases.

FSHD may cause muscular weakness in facial, scapular and humeral muscles as the name suggest and also in other parts of the body.

One’s smile might be asymmetrical or face expressionless, and it might be hard to lift hands over one’s head. Some patients get non-ambulant, and the disease may cause spine curvature.

FSHD may often begin in childhood, adolescence or early adulthood, but also significantly later. Disease severity varies a lot too.

There are no treatments yet for the disease, but there is still a lot of hope as FSHD research progresses at a swift pace, says chair of FSHD Finland, Lauri Pirinen.

According to him, there are more than 20 pharmaceutical companies that currently develop drugs for FSHD for stopping or slowing down the disease progression, and it is realistic that there would a treatment on the market in the near future. Also, regeneration of muscle fibers is under research currently.

“A ruthless disease”

Lauri Pirinen is a mildly affected FSHD patient. His symptoms started in adulthood.

-I could not have ever believed there would be such a reason behind my mild symptoms. Imagine that you visit a doctor just in case for having some issues with your scapular area, and then find out this is a typical first sign of such a disease, Pirinen says.

-It is a ruthless disease, there's no getting away from it, but it surprises me what you may learn to live with. I think I have got a lot out of this organizational work for counter balance and even more than that already by now, let alone if the disease can be cured one day. That would be so cool.

Pirinen says, FSHD Finland is actively involved in worldwide collaboration with other FSHD organizations as "invaluable support of research".

-This is a really solid community internationally. Although it hurt to find out having such a disease, else I would not have met these people and I would not be on this mission with them.

"We are living interesting times"

Chief Science Officer of the American organization FSHD Society, Dr. Lucienne Ronco says, the most advanced FSHD therapies could be submitted to the U.S. Food and Drug Administration, FDA for review around the year 2028.

-Once a drug is approved, it can reach patients in as little as a few days or as long as two years, depending on how prepared the manufacturer is to produce and distribute it at scale, Ronco describes in an email interview given to MTV News through FSHD Finland.

-The leading FSHD treatment currently in development is a three-part molecule of which sophisticated design requires careful manufacturing which may slow getting the treatment available on the market a little bit.
-While there is still uncertainty ahead, the progress made so far is encouraging for the FSHD community.

According to Ronco, we are living interesting times for FSHD patients overall, and there will be clinical breakthroughs expectedly.

She emphasizes that effective treatments for FSHD would benefit not just patients, but society as a whole.

-As the disease progresses, many patients are forced to retire early, struggle to keep up with work, and withdraw from their communities. This applies to patients' loved ones too, often taking on caregiving roles. It can take a toll on their own physical and mental health.

The medical burden is significant as well.
-Research shows that FSHD patients visit doctors more frequently than healthy individuals even in the early stages of the disease. As the disease progresses, managing it requires care from a growing number of different specialists and therapeutists.

-Treating FSHD more effectively would create a ripple effect of various benefits across patients, families, and the broader healthcare system.

An orange slice to replace a smile

World FSHD day is held on 20th June. The purpose of the day is to raise awareness of the disease. The day is celebrated by posting photos on social media with replacing a smile with an orange slice. The expression depicts one typical symptom of the disease, losing ability to smile. Besides, familiar landmarks all the way from Colosseum to Niagara falls are lighted up in orange.

FSHD in a nutshell

- FSHD, facioscapulohumeral muscular dystrophy is a rare, hereditary neuromuscular disease, that leads to deterioration of muscle fibers over time
- Symptoms begin most typically from facial and scapular muscles, but may start from any part of the body.
- Severity of the disease and appearance of symptoms across the body vary a lot even within families. Some patients develop milder symptoms whereas for others, it may lead to severe disability. Alteration of progressing and stable periods in disease progression is typical as well as asymmetry of symptoms.
- In Finland, there are supposedly a few hundred FSHD patients while there are roughly one million patients worldwide.
- Currently, there are no treatments for FSHD, but it does not affect life expectancy generally.
- For FSHD, two different mutations are known for causing the same disease, both eventually through DUX4 gene, which produces a protein that is toxic to muscles.
- The companies developing treatments for FSHD strive for reducing expression of the DUX4 gene in different ways, and the drug development is getting close to a breakthrough.
- World FSHD day is celebrated on June 20th for awareness and hence for better care.